# THE HEADACHE CHRONICLES

Katrine Skovsgaard
2025

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Front cover: Figure 1 *Chronicles*, Röhsska Museum of Design and Craft, Sweden (SE), 2023, photograph by Kristin Lidell.

Back cover: Figure 106 *Chronicles*, detail of Figure 1, Röhsska Museum of Design and Craft, SE, 2023, photograph by Kristin Lidell.

# THE HEADACHE CHRONICLES

## Sharing Chronic Headaches through a Contemporary Dialogical and Tactile Art Practice

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# DECLARATION

This thesis represents partial submission for the degree of Doctor of Philosophy at the Royal College of Art. I confirm that the work presented here is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

During the period of registered study in which this thesis was prepared, the author has not been registered for any other academic award or qualification. The material included in this thesis has not been submitted wholly or in part for any academic award or qualification other than that for which it is now submitted.

Katrine Skovsgaard
01/08/2025

*Like the northern lights in the night sky. Just this wild, unexpected flow of colours. And just that you can't predict where it's going to go next. Yeah, I feel like I think about pain in terms of vividness, whether it's vivid colours or vivid movement, which isn't all bad ... I don't think of pain as a demon or a monster. I can't think about living at war with myself like that. So, I try to think about its fluidity as a way to also think about the fact that I can navigate through it.*[1]

- Sonya Huber

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[1] Sonya Huber, Conversation with Katrine Skovsgaard on chronic headaches (recorded), 20 March 2023.

Figure 2 *Aura*, The Danish Art Workshops, Denmark (DK), 2024, photograph by Louise Uth Pedersen.

Figure 3 *Aura*, RCA Research Biennale, United Kingdom (UK), 2025.

# ABSTRACT

## THE HEADACHE CHRONICLES:

## Sharing Chronic Headaches through a Contemporary Dialogical and Tactile Art Practice

This practice-based doctoral project investigates how tactile and dialogical art can convey and share experiences of chronic headaches (CH), fostering conversations about CH within the public sphere. Through a contemporary art practice which includes work in textile, with sound, and through installation, this research explores an archive of visual migraine aura imagery, amplifies voices of individuals with CH, and studies touch as a means to communicate about CH. Based on these three components, this thesis transforms previously isolated chronicles of CH into *visible*, *audible*, and *tangible* forms.

CH affects many, yet it is seldom discussed in public forums, and our understanding of the phenomenon is limited. Medical research concentrates on the physical causes of pain, assessment and alleviation, with qualitative as well as quantitative studies often falling short in addressing the complexity and subjectivity of experiences of CH. Supplementing as well as challenging medical research findings, this project contributes to work in the critical medical humanities by emphasising the

importance of integrating diverse forms of knowledge and practices to deepen our understanding of health-related issues.

Drawing on my own experiences and on new knowledge generated through my conversations and workshops with individuals living with CH as well as with associated medical professionals, I develop and evaluate creatively descriptive methods to better comprehend and convey life with CH. Across three chapters, which focus on the three senses I identify as especially impacted by CH, *vision*, *voice* and *touch*, I explore these approaches to artmaking through visual, dialogue- and touch-centred artworks. This approach is set apart from and outside of clinical and therapeutic contexts. It offers a caring and critical perspective on existing hierarchies of knowledge by illustrating and giving voice to a diversity of experience presented by people living with CH and by associated professionals.

In the chapter VISION, I analyse and interact with the little-known archive, the Migraine Art Competition Collection, creating an art history for people with CH. By creating artworks inspired by this archive, and by adding tactile and auditory elements to these visual representations of CH, I allow audiences alternative ways to interact with CH. In the chapter VOICE, I reflect on the conversations I have conducted, how these have informed my artistic practice, and how and why I have synthesised personal narratives from these into sound installations and a choir piece. In the chapter TOUCH, I discuss how I bring the archive and the conversations to life by creating sculptural installations.

Engaging with CH through this sensory methodology revealed the complexity and vulnerability of dealing with these narratives while offering insights into the lives of those living with CH and influencing how it is expressed, perceived and navigated. Ultimately, this thesis suggests and demonstrates alternative ways to engage with pain and care through art and discusses ways of creating physical and mental space for vulnerability, reflection and communication.

Figure 4 *Aura*, RCA Research Biennial, UK, 2025, photograph by Chris Lee.

Figure 5 *Aura*, RCA Research Biennial, UK, 2025, photograph by Chris Lee.

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Unless otherwise stated, all artwork and photographs are by Katrine Skovsgaard, with the exception of artwork from the Migraine Art Competition. All photographs from the Migraine Art Competition are by the Wellcome Collection, except Figure 6, Figure 18 and Figure 27 photographed by Katrine Skovsgaard. When two figures or more occur on one page, the reading order is left to right, top to bottom.

# LIST OF ACCOMPANYING MATERIAL

Written thesis

Appendices

Exhibition of the following artworks:

- *Aura*
- *Chronicles*
- *Six Infinity*

Figure 6 Hand hovering over artwork from the archive, *Silhouette hand with flames*, the Migraine Art Competition, SA/MAR/139.

# ACKNOWLEDGEMENTS

I want to express my gratitude to my supervisors, Gemma Blackshaw and Mah Rana, for their unwavering support and trust throughout the years and for sharing their knowledge with me. I also appreciate the opportunity to join their academic circles, particularly by being invited to present at the Confabulations X Health and Care Conference.

I sincerely thank everyone who has generously shared their time and experiences of pain, as well as those who have met with me to discuss their work related to touch or pain. These include Anders Aarvik, Lene Baad-Hansen, Michael Banissy, Katerina Cerna, Hannah Clarkson, Kaitlin D'Avella, Peter Drummond, Peter Goadsby, Sonya Huber, Nadia Lesniarek, Melinda Nicola, Jes Olesen, Cameron O'Loan, Sophie Richings, Anke Samulowitz, Helena Backlund Wasling, and Joanna Zakrzewska.

Thank you, the Swedish Arts Council, IASPIS, Röhsska Museum of Design and Craft, and Konstepidemin, for inviting me to their residency in Gothenburg. Their generous support encompassed inspiring discussions, technical assistance, and delightful meals during my workshops, alongside a budget for my exhibition and collaboration with Rosanna Gunnarson. I particularly wish to thank Amanda Eriksson for her patience and excellent communication, Vanja Van Yurick Hermelin for organising and managing the events, and Maria Jansson and Kristin Lidell for their beautiful documentation throughout the

Figure 7 Embroidery, Röhsska Museum of Design and Craft, SE, 2023, photograph by Kristin Lidell.

exhibition. Collaborating with Rosanna Gunnarson to create *Six Infinity* was a fantastic experience. She guided me through the process, and I learned so much from her; it truly enhanced my skills. The choir that first performed *Six Infinity* with us was a joy to work with during this art-inspired musical piece, including Matilde Gimenez Bahl, Ludvig Broman, Margit Gabrielson, Axel Korsgren Norrby, Ingrid Öh, Ella Rudbäck, Ellen Tillberg, and Rasmus Johansson Wiborg.

I appreciate everyone who contributed to creating *Six Infinity* as an eight-channel installation. Sound engineer Joe Hirst expertly guided us through the entire process, while conductor Alexander Mackinder has been a reliable support and an energising collaborator through the many months we worked on the project. The choir delivering *Six Infinity* consisted of talented members: Anita Agarwal, Maria Vittoria Baggio, Hannah Fry, Andrew Morton, Ciaran O'Donovan, Vincent Pearce, George Salmon, Vicki Stilwell, Martina Telgmaa, Matthew Watts, and Ralph Williams.

I have had some fun and inspirational teaching opportunities throughout my doctoral research. Thank you to HDK-Valand—Academy of Art and Design for inviting me to lecture at the To Perform Body seminar, later to Cathryn Klasto for inviting me back to teach at the Contemporary Art and Health MA course, and most recently, Threadbare Collective for inviting me to do a workshop at Goldsmith CCA.

I would like to thank the technical staff at the Royal College of Art. Rosey Briggs-McCracken contributed significant academic insights, and Tim Olden was an excellent guide in sound editing and provided me with the best DIY solutions throughout my studies. When I expressed my desire for a tufting gun studio at the RCA, Debbie Stack and Rosamund Hanny listened and took action. Throughout, they have warmly welcomed me whenever I needed studio time. Initially, Anne-Sofie Staack taught me hand embroidery, and afterwards, Tom Costello patiently shared his expertise in embroidery software and machine operation.

I have gained invaluable insight from Camilla Groth at the University of South-Eastern Norway, and the entire group of Body-based Practices art practitioners has provided me with community, feedback, and a perspective on how practice-based doctoral research is disseminated and written in Scandinavia.

I have had the pleasure of being on some great residencies throughout the time I worked on this research. Curator Linda Rocco invited me to spend two months with her and a small group of artists in Ibiza, kindly supported by the Ses12naus Foundation. The experiments and research I conducted there with touch paved the way for how I now work. The Danish Arts Council has provided me with grants during my tufting residencies at The Danish Art Workshops. A variety of funding bodies have offered me economic support on this journey: Augustinus, Beckett, Christian & Ottilia Brorson, Danish Women’s Society, Helle & Arenth Jacobsen, Hielmstierne-Rosencroneske, Knud Højgaard, L.F. Foghts, Lizzi & Mogens Staal, Louis-Hansens, L. Zeuthen, Nancy Christensen, Ragnvald & Ida Blix, and William Demant. The RCA Conference Fund supported me in travelling to see Kustaa Saksi’s exhibition in Sweden.

Many other disability arts practitioners and communities continue to inspire me, even though I have not found space for them all in this doctoral thesis (see some of these in the bibliography). Some of these individuals have provided me with support in both significant and minor ways, and I find

community with them: Cassie Thornton started the Hologram, Gemma Blackshaw convened the Care(less) research group, Jonathan Boyd and Steve Brown convened the Material Engagement research group, and Emily Candela and Elaine Tierney convened the Sound@RCA research group, all of which I participated in.

Finally, I consider myself fortunate to be surrounded by generous and clever friends. Louise Uth Pedersen was always ready for a conversation about the art process and has captured stunning studio portraits of numerous sculptures and the photographic portraits included in this thesis. I am grateful for the extensive feedback sessions, the generous friendship of Hannah Clarkson and Charlie Hawksfield, and the sharp insights and editing expertise of Jack Fletcher and Nathan Newman. This thesis would neither be as engaging nor would my sense of belonging be as strong without the support and love of these individuals, along with many others who are among my nearest and dearest.

Thank you!

Figure 8 *Six Infinity*, Beaconsfield, UK, 2024.

# DEFINITIONS

## CHRONICLES, CHRONIC, CHRONOLOGICAL

According to the Oxford Dictionary, the noun chronicle is most frequently defined as a detailed and continuous register of events: “a factual written account of important or historical events in the order of their occurrence.” The verb chronicle is defined: “record (a series of events) in a factual and detailed way.”[2] By these definitions, my work here both chronicles the voices of people with CH and allows these individuals’ voices, narratives, and stories – their chronicles – to be heard.

The word closely connects to chronic, and both etymologically stem from the name of the ancient Greek god Chronos, who was the god of chronological time, or the march of time, as opposed to Kairos, the god of time in the sense of the appropriate time to do something or the significance of time. Chronos was called Saturn in Roman mythology, as depicted artist Francisco Goya’s painting of *Saturn Devouring his Son*.[3] Overcome by fear that one of his children would overthrow him and gain his throne, he consumed both of his children.

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[2] *Oxford Dictionary of English*, ed. by Angus Stevenson, Oxford Reference Online Premium (Oxford Univ. Press, 2010), doi:10.1093/acref/9780199571123.001.0001.

[3] Francisco Goya, *Saturn Devouring His Son*, 1823, Museo del Prado, Madrid.

## CRIP, CRIPPING AND CRIP THEORY

The noun crip, in the Oxford dictionary, is defined as an offensive term for a person living with a disability.[4] The terms I define here have previously been used by some as pejoratives but have been reclaimed by disability activist communities "to indicate people, relationships, and behaviours existing outside of bodymind norms within a given society, and connected by those experiences"[5] to create community and gesture towards a larger collective of experiences of persons with disabilities. As Professor of English and crip/queer theorist Robert McRuer also indicates in the quote below, in many ways, the reclaiming of crip mirrors the reclaiming of terms like queer. Associate professors focusing on disability studies Aimi Hamraie and Kelly Fritsch define crip in their *Crip Technoscience Manifesto* as ""crip," the non-compliant, anti-assimilationist position that disability is a desirable part of the world."[6]

Crip theory is a branch of queer disability theory popularised in Robert McRuer's book *Crip Theory: Cultural Signs of Queerness and Disability*.[7] Robert McRuer's starting point is that our culture's system of compulsory able-bodiedness produces disability and compulsory heterosexuality produces

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[4] Stevenson, *Oxford Dictionary of English*.

[5] *Crip Authorship: Disability as Method*, ed. by Mara Mills and Rebecca Sanchez (New York University Press, 2023), p. 8.

[6] Aimi Hamraie and Kelly Fritsch, 'Crip Technoscience Manifesto', *Catalyst: Feminism, Theory, Technoscience*, 5.1 (2019), pp. 1–33 (p. 2), doi:10.28968/cftt.v5i1.29607.

[7] Robert McRuer, *Crip Theory: Cultural Signs of Queerness and Disability*, Cultural Front (New York University Press, 2006).

queerness. Cripping something would mean to apply a disability justice lens to it and challenging the able-bodied perspective, while queering something is seeing something from a non-heterosexual, non-cisgender viewpoint, challenging heteronormativity. Queer theorist Eve Kosofsky Sedgwick states in *Tendencies* that the term queer has an “open mesh of possibilities, gaps, overlaps, dissonances and resonance, lapses and excesses of meaning when the constituent elements of anyone’s gender, of anyone’s sexuality aren’t made (or *can’t be* made) to signify monolithically.”[8]

Crip or sick time is a developing understanding of how people with disability of chronic illness experience time, how illness reorients time, and how normative and ableist expectations around time are part of the construction of disability.

These terms and ways of thinking offer a refreshing perspective on how heteronormativity and able-bodiedness push queer and crip experiences to be understood as non-normative: as a society, we treat these experiences as deviant, in actuality, they are widespread human experiences that should be understood as such. I come to this writing with an understanding that chronic pain is a non-normative experience and that if we were to accept pain as normative, we would have a considerably different language, culture and knowledge of it.

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[8] Eve Kosofsky Sedgwick, *Tendencies*, ed. by Michèle Aina Barale, Jonathan Goldberg, and Michael Moon, Series Q (Duke University Press, 1993), p. 8, doi:10.1515/9780822381860.

## DIALOGICAL, POLYVOCAL

I use dialogical – defined by the Oxford dictionary as something relating to or in the form of dialogue – to refer to my approach to conversation as a method to explore the experience of CH.[9] Throughout my research, I use dialogical questions to engage with audiences and dialogical ways of presenting works: recorded voices are heard in conversation, and audience members are invited to share their own experiences.

Polyvocality is a term that resists the idea that there can be only one account of reality. Even within each of us, there are numerous different stories and voices, and I found this especially true concerning the stories of CH I have encountered in my recorded conversations. To register this plurality of voices, I have named it polyvocality and used this term as an ethical and relational framework that celebrates individual voices within a larger network, allowing for a rich tapestry of chronicles and conversations. Polyvocality can critique hierarchical structures and call for a pluralistic approach to understanding experience. Professor of Political Philosophy Adriana Cavarero advocates a pluralistic perspective, delving into the depth of vocal expression, which she believes is more genuine than the written word. She stresses the importance of recognising varied voices and acknowledging different viewpoints.[10]

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[9] Stevenson, *Oxford Dictionary of English*.

[10] Adriana Cavarero, *For More than One Voice: Toward a Philosophy of Vocal Expression* (Stanford University Press, 2005).

I relate polyvocality in speech, to a mode of listening that composer, performer and Professor of Music Pauline Oliveros calls ‘quantum listening’, thinking about listening in an open and multifaceted way: “listening in as many ways as possible simultaneously – changing and being changed by the listening.“[11] Recognising the complexity of pain also highlights the significance of listening in many ways simultaneously and emphasises the importance of collective engagement. Author and Associate Professor of Creative Writing Sonya Huber poignantly described the way she listens for and connects to other people’s stories and the way that it lets her feel that she is not alone, even when she is not in a room with these people:

> I feel a need for constant contact with other people’s in-the-moment experience with pain because I really feel supported by that. I feel it, especially because it’s so invisible and it’s isolating. My pain is very triggered by the weather. And so, when there’s like a weather system, I think about all of us on the landscape experiencing it, all the pain people. And I feel it’s this sense of collectivity as opposed to my individual self. And I find that both terrible and beautiful at the same time.[12]

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[11] Pauline Oliveros and others, *Quantum Listening*, Terra Ignota (Ignota Books, 2022), p. 30.

[12] Huber, ‘Conversation with Katrine Skovsgaard on chronic headaches (recorded)’.

# NOTE TO THE READER

I have opted to implement a few unconventional approaches and standards for the written thesis of this doctoral project – the rationale for which I elaborate on here:

## APPENDICES

The appendices feature a glossary of medical terms, a short profile and characterisation of the people I have recorded conversations with, the sheet music for the choir piece *Six Infinity*, transcriptions of sound installations, and hyperlinks to sound installations, giving the option to listen or read. As they are lengthy, I have not included transcripts for my interviews.

## FULL NAMES

When referencing other people, whether scholars, artists, or individuals with whom I have had recorded conversations, I consistently use their full names every time I mention them, thereby attempting to even out hierarchies of knowledge and whose voice gets to be heard and have authority. The first time I mention a person, I generally include their title and credentials, and on further mentions, I include their full name.

Figure 9 *Six Infinity*, Röhsska Museum of Design and Craft, SE, 2023.

## PRONOUNS

I use the personal pronoun ‘I’ liberally. I am focusing on experience-based personal perception here, and therefore, my own body, my experiences, and my self are also important. I would like this thesis to read as intimately as possible within the constraints of a doctoral thesis.

## SUFFERING AND SIMILAR TERMS

I aim to avoid using words like *suffer* or *endure* in my writing. I have only used words like suffer and endure about living with pain in direct quotes, where the choice of words has come from the person speaking. Having experienced CH for more than a decade, I understand pain as the lens through which I see the world. Its presence is so familiar that I do not want to judge whether it is good or bad – it just *is*. The way I relate to people around me with pain is also through a neutral lens. To reflect this, I use wording such as experiencing or living with CH, persons or individuals with CH.

## FIGURES

Figures are largely included close to where they are written about in the thesis, and referred to in the main text. Images of my own artworks are interspersed throughout the thesis, and figure texts clarify their titles and contexts; because there are many photographs of these artworks, I have generally not included figure references to these, but a full list is included here:

*Aura* can be seen in Figures 2, 3, 4, 5, 11, 15, 66, 67, 70, 71, 72, 73, 75, 90, 91, 94 and 95.
*Chronicles* can be seen in Figures 1, 31, 45, 54, 56, 60, 76, 77, 92, 93, 98 and 106.
*Six Infinity* can be seen in Figures 8, 9, 34, 48, 50, 51, 52, 53, 54, 57 and 100.

Most Images from the Migraine Art Competition Collection are referenced, and can be seen in Figures 6, 10, 12, 13, 16, 17, 18, 19, 20, 21, 22, 23, 26, 27, 33, 44, 58, 61, 101, 102, 103, 104 and 105.

Figure 10 *Forbidden things and kitchen chaos*, the Migraine Art Competition, SA/MAR/316.

# INTRODUCTION

# INTRODUCING MY RESEARCH

Having a chronic health condition can involve complex challenges for the individual and their network, as well as in relation to the healthcare system. The healthcare system can sometimes include long wait times for treatment, a job system that prioritises productivity without regard for the individual's condition, medications with many unintended side effects, and a treatment framework where services are often few, fragmented, and characterised by staff turnover. Furthermore, there is often an expectation that experiencing pain is just a 'bad phase', suggesting that chronic pain, similar to acute pain, can be viewed as a temporary condition that one merely has to overcome. What about those who are not just in a difficult period? Those facing challenging and sometimes untreatable symptoms? Those who fall through the cracks and become revolving door patients in the medical system, tossed back and forth in a Kafkaesque environment where care and security often yield to bureaucracy, budgets or limitations in knowledge?[13] How might we meet each other outside of those systems, start approaching these misunderstandings about health in different ways and provide physical and mental spaces where we can expand our understandings? How can we have compassionate conversations where we listen to the voices of those in pain and add nuance to our understanding of each other?

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[13] A. Bahra and P. J. Goadsby, 'Diagnostic Delays and Mis-Management in Cluster Headache', *Acta Neurologica Scandinavica*, 109.3 (2004), pp. 175–179, doi:10.1046/j.1600-0404.2003.00237.x.

The Headache Chronicles is a doctoral thesis that chronicles stories of chronic headaches (abbreviated here as CH). As someone who has experienced CH for over a decade, I identify as chronically ill and in need of a type of care that has not been consistently forthcoming; visibility is central to this lack of care. Chronic pain is often invisible, and there are currently no biomarkers to validate the experiences of individuals with pain. Pain resists clinical categorisation: medical professionals often struggle to categorise pain clinically, as they must rely on patient testimonies, which are frequently undervalued.[14] When I first summoned the courage to share my experience of CH, many of my peers were young and unaffected by health issues, making it difficult for them to understand or sympathise with a pain that persisted despite professional efforts to alleviate it. My experience remained behind closed doors, and to onlookers, nothing appeared wrong with my otherwise strong, 'healthy' physique.

The invisible nature of chronic pain can be isolating, as it requires the person with pain to disclose it for it to be acknowledged. Chronic pain like this is generally complex to treat, and its hidden, unmeasurable nature can threaten one's social self and order. For example, because chronic pain is difficult to measure, the severity and longevity of symptoms are easily called into question by others. Because illness is socially perceived as something that can be 'fixed', with a treatment-adverse condition like CH, it can be challenging for those witnessing pain to acknowledge its ongoing nature and

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[14] Anne Whitehead and others, *The Edinburgh Companion to the Critical Medical Humanities*, Edinburgh Companions to Literature and the Humanities (Edinburgh University Press, 2022), p. 550, doi:10.1515/9781474400053.

easy for others to query how the person with pain may be approaching treatment. Not only is pain a lonely experience, but the very concept of pain is further scrutinised by those who do not experience it. Professor of Aesthetics Elaine Scarry argues: “To have great pain is to have certainty; to hear that another person has pain is to have doubt. (The doubt of other persons, here as elsewhere, amplifies the suffering of those already in pain).”[15] Visual artist and Associate Professor of History and Theory of Art Deborah Padfield, in her study of art as an expression of pain, concurs that chronic pain is “paradoxically the very thing arousing doubt in others, exacerbated by the limitations of language and the unequal hierarchies of knowledge and agency in many contexts.”[16] Author and Professor of English Maggie Nelson, in *Pathemata,* expresses concern that her pain makes her appear overly wordy. While compiling her symptoms and treatments: “not wanting to miss any details that might prove key, I allow the tapestry to widen.”[17] When visiting specialists, she unexpectedly encounters the doubt Elaine Scarry and Deborah Padfield describe: “no one wants to read this *pathemata*. People flick through it, then tuck it into the rear of my file, as if its principal message were that I am a logorrhoeic in need of management.”[18]

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[15] Elaine Scarry, *The Body in Pain: The Making and Unmaking of the World*, Oxford Paperback, First issued as paperback (Oxford Univ. Press, 1987).

[16] Deborah Padfield and others, ‘Images as Catalysts for Meaning-Making in Medical Pain Encounters: A Multidisciplinary Analysis’, *Medical Humanities*, 44.2 (2018), pp. 74–81, doi:10.1136/medhum-2017-011415.

[17] Maggie Nelson, *Pathemata, or, the Story of My Mouth* (Fern Press, 2025), p. 5.

[18] Nelson, *Pathemata, or, the Story of My Mouth*, p. 4.

In my art practice, I aim to address these unequal hierarchies and challenge the limitations of language about CH by engaging directly with my lived experiences of chronic pain and those of others. I aim to render otherwise invisible CH narratives and esoteric knowledge about pain in a way that is seen, heard, and felt publicly, making them accessible and sensory. I utilise a variety of tactile and dialogical art practices, including tapestry rugs, recorded conversations, sound, music, and installation art, to bring these invisible pain narratives to light and foster a sense of community around pain. I deliberately move away from study methods that adhere to an evidence-based medicine approach, which assumes that the use of art in healthcare contexts should be validated by hard scientific evidence in an attempt to manage uncertainty, and towards art-led research that embraces this uncertainty.[19] This shift in perspective enables me to explore art on its own terms and to consider how art can create opportunities for new conversations to emerge in everyday settings. Art often functions as an illustration or second thought in medical settings, but art is its own knowledge production and needs not be justified by evidence of its therapeutic effects. In their first chapter of the book *The Edinburgh Companion to the Critical Medical Humanities*, medical humanities researchers Professor Des Fitzgerald and Professor Felicity Callard write that,

> Scholars have begun to worry that the success of the medical humanities is tied up with being *useful* to biomedicine, that the medical humanities has been able to establish itself only by

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[19] Sheelagh Broderick, ‘Arts Practices in Unreasonable Doubt? Reflections on Understandings of Arts Practices in Healthcare Contexts’, *Arts & Health*, 3.2 (2011), pp. 95–109, doi:10.1080/17533015.2010.551716.

> appearing as the domain of pleasant (but more or less inconsequential) helpmeets – lurking hopefully, poetry books in hand, at the edges of the clinical encounter's primal scene.[20]

I believe art can contribute significantly to grounding the critical medical humanities. Strategies in art practice can broaden our understanding and provide critical perspectives, fostering new ways to think and talk about CH by publicising and politicising our bodies and personal experiences. The approach of arts-led research allows us to gain deeper insights into our perceptions of CH. Outside the medical sciences, which have a well-established vocabulary for discussing pain, it can be challenging to find a relational language that captures the specifics of pain and its impact on a person's life.

I explore how a contemporary art practice can provide a nuanced discourse on CH through the following questions:

- How can contemporary artworks foster conversations beyond diagnostic terminology related to CH?
- As an individual living with CH, how can I use my insights and experiences to create art that reshapes perceptions of CH?
- How can CH influence a contemporary art practice to develop and communicate narratives that broaden and enhance language to document CH?
- How can art shape the articulation and understanding of pain through making artwork from lived experience?

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[20] Whitehead and others, *The Edinburgh Companion to the Critical Medical Humanities*, p. 35.

In my art practice and writing, I aim to convey some of these specifics, adding nuance to the general discourse on what living with ongoing pain might entail.[21] I carry my own biases, so for this research, I have conducted recorded conversations where I incorporate voices either like or unlike mine to share the space and allow me to gain insights into different perspectives. Through writing and art practice, I aim to illuminate the diverse characters and perspectives of individuals experiencing CH and professionals in medicine, psychology, and art within clinical settings. Some of the individuals I have chosen to speak with are well-known today, with their research widely studied and their contributions to their fields firmly established in clinical practice. In contrast, the voices of those living with ongoing chronic pain are often overlooked, especially in medical contexts, with their perspectives generally granted less authority than those of professionals. This is also mirrored and evident in how we communicate with friends and family about chronic pain. We often reflect the diagnostic language we have acquired in communicating with medical professionals rather than sharing our own lived experiences related to the internal sensations and senses involved.

As an artist, I am interested in how these sensations and senses connect to CH, and as someone who experiences CH, I want to create more space for conversations I previously felt unable to have. By sharing the stories of these individuals and closely examining their inherent sensory richness, I aim to

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[21] The general discourse of CH is within medical research, and reading medical journals is where I found many of the professionals I have spoken with. However, authors Katherine Foxhall, Maggie Nelson, Klaus Podoll and Derek Robinson and Oliver Sacks should be mentioned for their contribution to literature about CH. Artists like Kustaa Saksi and Lisa Tan have likewise been an inspiration in how they work with migraines.

Figure 11 *Aura*, RCA Research Biennial, UK, 2025, photograph by Chris Lee.

explore better ways to represent them. The structure of this thesis, along with the artworks produced during this period, is shaped by the sensory information and narratives gathered from my recorded conversations with individuals living with or working with pain. However, I have also given myself the freedom to imagine what the often-limited archive of the Migraine Art Competition Collection Archive and spoken dialogue cannot fully convey: the tone and texture of inner lives. Through storytelling that intertwines documentary evidence with imagination, I seek to delve into a deeper emotional truth than what facts (such as diagnosis or treatment) alone can offer, creating an intimate, affective portrait of what living with pain entails. My goal is to shift from the dominant perspective of viewing people with pain to striving to understand the experiences of those living with chronic pain from within.

Early in this process, I realised that to achieve this goal, I had to go beyond my own understanding and allow others to speak for themselves. This approach became the artistic practice of chronicling individuals in pain through spoken word directly integrated into artworks. Through this, I have sought to step into the shoes of those experiencing pain and invited viewers to do the same. I am profoundly grateful for the contributions of everyone who collaborated with me on this project, especially those who have shared their experiences of pain. This represents an act of self-authorship under difficult conditions, which, in my view, is inherently courageous.

The thesis involves formal writing interspersed with reflective pieces, often taking the form of creative writing that ranges from personal reflections on my experience of CH to cross-historical letters to an artist behind a work in an archive of migraine-related images. These serve as a means of engaging with individuals I could not otherwise connect with. This is complemented by reflections on my experiences of living with pain and my interactions with others who also live with CH. Through these reflections, I recognise how my thinking has evolved and how I have developed a broader perspective on CH than I ever imagined. This more-than-factual approach to the archive is especially fitting, as the perspective of those in pain has seldom been afforded scholarly importance in the past, particularly given that this condition is widely misunderstood.[22]

The experience of living with pain is inextricably linked to its representations in popular culture. The stories and stereotypes that typically portray people with CH as malingering or angry women are longstanding social fictions that lack scientific validation; however, they still influence how we perceive and treat individuals with pain. Each person inherits this legacy of caricature, which makes them invisible and misunderstood, affecting one's sense of identity.[23]

Going beyond the limitations of what living with pain is or is not, in writing this thesis – and creating the accompanying artwork – I aim to explore that zone of possibility by approaching each of my conversations, artworks, and writings with curiosity to perceive chronic pain not as non-normative but as a regular experience filled with many nuances.

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[22] Joanna Bourke, 'The Headache in History and Culture', *The Lancet*, 389.10078 (2017), pp. 1509–1510, doi:10.1016/S0140-6736(17)30958-3.

[23] Anke Samulowitz and others, '"Brave Men" and "Emotional Women": A Theory-Guided Literature Review on Gender Bias in Health Care and Gendered Norms towards Patients with Chronic Pain', *Pain Research and Management*, 2018 (2018), pp. 1–14, doi:10.1155/2018/6358624.

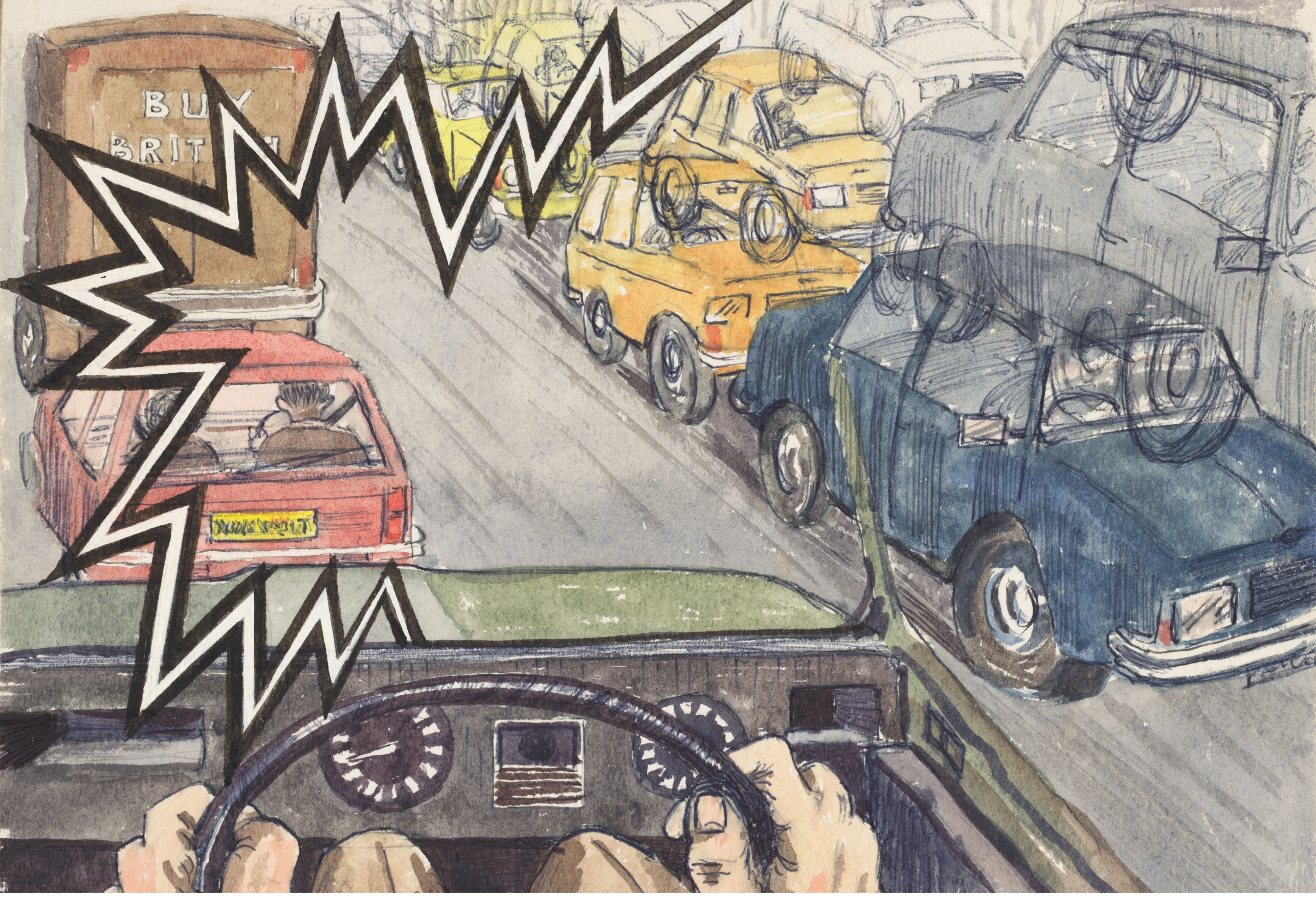

Figure 12 *Traffic jam with aura*, the Migraine Art Competition, SA/MAR/339.

# THE APPROACH

The objective of my research project was to explore how a contemporary art practice can add nuance to the discourse on pain. The approach was to engage vision, sound and touch to share collected chronicles of lived experiences with chronic pain through making artworks that centre seeing, voicing and touching, and where viewers can engage in these different ways of exploring CH. Based on these three main components, intrinsic to human communication, the research focus was multimodal or, more specifically, multi-sensory, drawing on the interactions and dynamics of different modes of expression.

My approach is practice-based, utilising artistic expression as a method of inquiry to explore how art can enhance understanding and promote dialogue about CH. The research is framed within the growing field of critical medical humanities, which supports integrating various knowledge systems to foster deeper engagement with health-related matters, focusing on the contexts of health and illness and their constitution at multiple levels. Through my investigation of CH, I harness the openness and critical perspective of arts methods to envision what medical humanities led by art might entail and how unexpected forms of care could arise through arts-driven research.

Figure 13 *Teaching with a Migraine*, the Migraine Art Competition, SA/MAR/458.

Conversations with and among people living with CH and with a range of professionals working with CH formed a core for my research as well as for my art practice in the PhD project. From a series of recorded conversations, I identified a set of recurring themes and sensations that are particularly relevant to CH, especially regarding the sense of isolation that can be connected to it. The visual hallucinations or distortions associated with visual migraine auras can significantly impact one's ability to perceive parts of the visual field. This difficulty can hinder communication with others and make it challenging to navigate the outside world. Changes in auditory perception can make the voices of others and surrounding sounds unpleasant. An altered sense of touch may lead to discomfort from the contact of those close to you, causing an instinct to recoil or move away. The social impact caused by these factors was a significant reason for my decision to focus on these senses and to make artworks that centre on seeing, voicing and touching.

Within my multi-sensory art practice, these sensations are entangled and serve as different entry points for viewers to engage with the work. Where the artworks prioritise depth, complexity, nuance and openness and synthesise different elements of my practice, this dissertation simplifies divisions among the senses for clarity of analysis. Writing about how the artworks operate, how audiences have responded to the work, and how I have worked with the creation process necessitated separating these variables in the thesis. I have aimed to reintroduce complexity and uncertainty at particular points to express the sometimes conflicting narratives of CH by interspersing academic writing with different reflective modes and by enmeshing my own and other people’s narratives.

Many of my artmaking decisions were inspired by conversation. To engage directly with the lived experience of CH, my process included conversations with people with CH. This allowed me to have a continuous conversation about CH, while paying attention to who gets to speak and whose voice is given authority. These conversations took many different forms, including recorded conversations with individuals who either experience CH or work professionally with it, workshops where participants embroidered representations of their pain while discussing CH, written responses from audiences at exhibitions, and cross-historical letter writing to artists who have expressed their CH experience visually.

My questions for recorded conversations were inspired by micro-phenomenological interviews to seek out granularity of experience, and I am likewise interested in other people's autoethnographic accounts of pain and illness. For this study, I specifically extended beyond my own experience to activate other stories than my own. I have come to do this through artworks, workshops, and music. In my work with materials, I am inspired by material engagement theory and Professor of Cognitive and Anthropological Archaeology Lambros Malafouris' multiple approach to studying artists working with materials, gaining access to information which might not have been accessed in other ways.

After each encounter, I worked with unconventional ways to make these lived CH experiences seen, heard and felt. As an example, the original words from conversations felt important to preserve, so I used them directly in sound collages and songs. Design and sound scholar Dr. Emily Candela has described sound as a medium which prompts questions, destabilises, re-examines and "has an intrinsic instability that provides agency for discrepancy, polyvocality, dissonance, and even resistance." I think

these qualities of sound make it a pertinent medium, aiming to give voice, shape, and form to a complex experience shared by many, and to encourage conversations and encounters with this experience. The sound aspects of my artworks allow audiences to engage with them on their own terms without the negotiation of a written text, giving the artworks and their audiences a mutual life of their own.

Through artworks that also use touch and visuals, I have added dimensionality to my own and other people’s experiences of pain. I have turned archival 2D representations and conversations into soft sculptures, installations and multi-sensory experiences. These artworks have soft, unruly textures that introduce a surprising element that parallels the experience of a migraine: edges can feel and look fuzzy, feelings of texture, weight and volume can change, and the world may seem unstable.

In summary, this combination of methods builds a practice-, care- and senses-based approach that seeks to illuminate the complex experiences of CH through art and offers audiences a space to share their own experiences of pain.

Figure 14 Workshop, Röhsska Museum of Design and Craft, SE, 2023, photograph by Amanda Eriksson.

Figure 15 *Aura*, RCA Research Biennial, UK, 2025.

# OVERVIEW OF CHAPTERS

Through my exploration of headache research, migraine artworks, and in conversations with individuals with CH and experts in the field, I have identified three themes that I elaborate on in this thesis and utilise as methods in my art practice: VISION (seeing, hallucinating), TOUCH (touching), and VOICE (speaking, conversing, voicing, chronicling, singing). I have chosen to concentrate on ways to activate these three senses for my research and my audiences, although other senses also play a role in CH. These three senses are particularly significant as they disrupt our connections and interactions with others. During a headache, especially with migraines, these senses tend to heighten. Experiencing nausea or dizziness can profoundly affect daily life with CH, often leading to unease and fears about worsening symptoms. However, the social impact intensifies when heightened senses make loud conversations, and our own voices or other loud sounds hinder us from going outside and engaging with the world. Additionally, if the touch of a loved one causes us to withdraw, or if we experience visual migraine auras that obscure the face of the person we are speaking to or impede our ability to walk, bike, or drive, our social connections and relationships can suffer. This occurs not only due to the discomfort of increased sensitivity but also because we heavily depend on these senses in our interactions with others. Because these senses are in some ways connected to or worsening the isolation of people with CH, they are crucial to analyse and work with when conveying the multifaceted nuances of living with CH. In the context of my doctoral thesis, I have selected this area of focus.

The thesis outline below reflects these senses through the chapters titled VISION, VOICE and TOUCH. Throughout the thesis, I will discuss the central theme, CH, along with my primary research of talking with both people who experience pain and chosen professionals.

## VISION

*Keywords: visibility, visuals, visions, aura, the Migraine Art Competition*

This chapter explores the inherent lack of visibility associated with CH. I examine visuals and visions related to CH, particularly the phenomenon known as visual migraine aura, which individuals with migraines sometimes experience as an early warning sign of an impending migraine attack.

In the 1980s, the Migraine Art Competition provided a unique platform for individuals to express their experiences with migraines. I derive insights from the visuals in the Migraine Art Competition Collection to unveil the often-hidden lived experiences of migraines, exploring the common threads and themes in the diverse individual experiences I uncovered while studying this collection.

I highlight aspects of my art practice that relate to headache aesthetics to explore how the language of art can expand and create nuance in the understanding of CH. I share examples from my migraine aura tapestries, costumes, and conversations with individuals with CH. Throughout the chapter, I engage in cross-historical letter writing, personal examples through first-hand accounts, and quotes from recorded conversations, bridging the gap between the conceptual and the tangible.

References include artworks from the Migraine Art Competition,[24] physician Hubert Airy's drawings of visual migraine aura,[25] visual artist LJ Robert's work with embroidery,[26] and literature from Klaus Podoll and Derek Robinson's *Migraine Art*[27] and from cultural historian Dr. Katherine Foxhall's *Migraine.*[28]

## VOICE

*Keywords: dialogue, voicing, voice, sound, hierarchies, community*

My primary research involves dialogues with individuals experiencing CH and professionals in medicine, touch, philosophy, and art; many of them are referenced and quoted in these chapters for their lived experiences with CH and their contributions to the field. Some of these individuals provide insights into the auditory dimensions of CH. These examples encompass findings from facilitated public conversations, recorded dialogues, choirs, and polyvocal collages, all highlighting the significance of flattening hierarchies and fostering the sharing and listening of stories to broaden understandings and language related to CH.

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[24] Anonymous, *Migraine Art Competition Collection*, 1980-1987, The Wellcome Collection <https://wellcomecollection.org/works/caav4wtp>.

[25] Hubert Airy, 'XIII. On a Distinct Form of Transient Hemiopsia', *Philosophical Transactions of the Royal Society of London*, 160 (1870), pp. 247–264, doi:10.1098/rstl.1870.0013.

[26] LJ Roberts and others, *Carry You With Me: Ten Years of Portraits* (Pioneer Works Press, 2021).

[27] Klaus Podoll and Derek Robinson, *Migraine Art: The Migraine Experience from Within* (North Atlantic Books, 2008).

[28] Katherine Foxhall, *Migraine: A History* (Johns Hopkins University Press, 2019).

To accomplish this, I collaborate with composer Rosanna Gunnarson to transform conversations into music, allowing voices to interact (both relationally and musically) with the concepts of solitude versus visibility or singing solo versus in harmony with others, to express various aspects of living with CH. By employing voices and voicing in my art practice, I aim to create inclusive and accessible spaces for conversations about CH to emerge, ultimately establishing a space I felt was lacking when I first began experiencing CH over a decade ago. In this chapter, I offer examples from my art practice, where I make these voices heard on equal footing to challenge and address conventional medical hierarchies and types of knowledge.

References for this chapter include Adriana Cavarero's *For More than One Voice: Toward a Philosophy of Vocal Expression*[29], writer Alice Hattrick's *Ill Feelings*,[30] writer and artist, and musician Johanna Hedva's *Sick Woman Theory*[31] alongside the art practices of Janet Cardiff[32] and Rory Pilgrim,[33] and my primary research: conversations with individuals experiencing headaches and professionals in the field, as well as my collaboration with Rosanna Gunnarsson.

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[29] Cavarero, *For More than One Voice*.

[30] Alice Hattrick, *Ill Feelings* (Fitzcarraldo Editions, 2022) <https://go.openathens.net/redirector/umoncton.ca?url=https%3A%2F%2Febookcentral.proquest.com%2Flib%2Fumoncton-ebooks%2Fdetail.action%3FdocID%3D6706473>.

[31] Johanna Hedva, 'Sick Woman Theory', 2022 <https://www.topicalcream.org/features/sick-woman-theory/>.

[32] Janet Cardiff, *The Forty Part Motet*, 2001 <https://cardiffmiller.com/installations/the-forty-part-motet/>.

[33] Rory Pilgrim, *RAFTS*, 2022 <https://www.rorypilgrim.com/the-undercurrent/rafts/>.

## TOUCH

*Keywords: tactility, materiality, tactile analgesia, multisensory, soft, textiles*

Recent studies in neuroscience reveal that slow, stroking touch can alleviate pain and achieve a tactile analgesia. My practice emphasises the potential of tactile encounters and artworks' impact on those experiencing pain. This chapter explores how my work, along with that of others, facilitates intimate spaces through materiality and creates direct encounters with the multi-layered stories of CH. I discuss the significance of tactility and touch-based art in conveying the lived experiences of CH and creating multisensory, embodied ways of relating to CH. I highlight examples of how other artists engage with touch in their textile practices and explore how my art practice experiments with the affective potential of soft materials to create immediate interaction for audiences to engage with the artwork physically. This approach serves as a conduit to make the intangible palpable and foster personal engagement, leading to open conversations about pain by integrating the experiential with the artistic.

This chapter draws on Professor of Psychology and touch researcher Michael Banissy's book, *When We Touch,*[34] recent theories of pain modulation through touch,[35][36] and primary research that includes

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[34] Michael Banissy, *When We Touch* (Orion Spring, 2023).

[35] Flavia Mancini and others, 'Pain Relief by Touch: A Quantitative Approach', *Pain*, 155.3 (2014), pp. 635–642, doi:10.1016/j.pain.2013.12.024.

[36] Pankaj Taneja and others, 'Robotic Stroking on the Face and Forearm: Touch Satiety and Effects on Mechanical Pain', *Frontiers in Pain Research*, 2 (2021), doi:10.3389/fpain.2021.693987.

conversations with Michael Banissy, neuroscientist Assistant Professor Helena Wasling, and individuals with CH. Artwork references include the tactile works of artists Caroline Achaintre,[37] Elisabet Eriksson, Emelie Röndahl, Kustaa Saksi,[38] and Judith Scott.[39]

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[37] Caroline Achaintre, *HEL*, 2023 <https://www.stirworld.com/think-opinions-threading-new-narratives-material-worlds-pushes-the-boundaries-of-textile-art#gallery-8>.

[38] Kustaa Saksi, 'Borderlands' (Exhibition, Vandalorum Museum of Art and Design, SE, 16 November 2024) <https://www.vandalorum.se/en/utstallningar/kustaa-saksi>.

[39] Judith Scott, 'Judith Scott' (Exhibition, The Gallery of Everything, Frieze Masters, Regent's Park, London, UK, 11 October 2023) <https://www.gallevery.com/exhibitions/judith-scott-frieze-masters>.

Figure 16 *Rural scene with c-shaped scotoma*, winner of the first Migraine Art Competition.

# VISION

# MY VISIONS

*Barbecue smoke hangs heavily in the room. As it enters my nostrils, I feel the creeping onset of nausea. I step outside to get fresh air, but the world shimmers with a pearlescent glow, and my body feels detached. In the car on the way home, I slump into my seat. With every turn of the vehicle, I actively suppress the urge to be sick, and I can barely follow, much less engage in my friends' conversation. The overcast day seems to vibrate with neon colours. It blinds me. Once home, I quickly run up the stairs to my apartment, fearing I will be sick. As I draw the curtains and lie in the dark bedroom, the nausea intensifies as fireworks in purple hues flash before my eyes. With my eyes open, I see fast flickering lights, and when I close my eyelids, vivid purple lights flash. Shapes – simplified representations of vehicles – rush towards me at high speed. An intense headache follows, leaving me in bed for the rest of the day. The following morning, my curtains remain drawn shut, my computer and devices are off, and reading is also a no-go as I endure the postdrome aftermath like an awful hangover coupled with continuing sensory overstimulation and sensitivity.*

Figure 17 Inspiration materials from the Migraine Art Competition laid out on a table, Threadbare Collective workshop, Goldsmith CCA, UK, 2025, photograph by Isabel Reed.

# INTRODUCING VISION

Headaches encompass more than just migraines; they represent hundreds of diagnoses, and a plethora of experiences. In this chapter, I focus on visualisations of visual migraine auras to discuss how my research reveals a common visual experience and language among those who encounter these auras – hallucinations that often indicate the onset of a migraine attack.

Migraines are multisensory. As described above in my personal account of a migraine attack, sound, sight, taste, smell, and the kinaesthetic sense are inherently connected to migraines. As warning signs of an impending migraine, many people experience visual, sensory, speech, or motor disturbances, all referred to as aura. While some individuals encounter several or all these types of aura, the visual aspect is the most common. One in three people with migraines also develop these visions or hallucinations, most commonly in the form of flashing lights or blind spots. Some individuals may experience visual auras without accompanying headaches, which is sometimes referred to as a silent migraine. Visual migraine auras typically develop gradually over several minutes and usually last up to an hour. The most common visual symptoms include flashing or flickering lights, zigzag patterns, and coloured spots, as well as blind spots or temporary partial blindness. Other symptoms that may occur alongside a visual migraine aura include tingling sensations in the hands, feet, or face, nausea, cravings, dizziness, and heightened sensitivity to light and sound.[40]

The biomedical model does not adequately explain the causal relationship of visual migraine aura. Nevertheless, scientists generally agree that cortical spreading depression may be responsible for it: a slow-moving electric phenomenon called depolarisation that spreads three millimetres per minute across the cortex.[41] This alteration in brain activity results in temporary changes in blood flow and chemicals in the brain, which may cause both the migraine and the visual migraine aura. Several headache professionals I have spoken with have noted a significant lack of research on visual migraine auras. They suggest that this oversight stems from the prevailing belief that migraine research should prioritise the headache itself, as treating or eliminating the headache would likely resolve the accompanying aura symptoms. Suppose migraine auras were more widely studied and received more scholarly attention. In that case, it might shed light on unknown or hidden aspects of the migraine experience or similarities that are not apparent to the medical sciences.

Studying visual migraines through art is valuable because it allows a freer look at the phenomenon through visual media such as drawing and painting. Studying them this way would enable themes, tropes, and common motifs to appear. What fascinates me about the visual migraine aura is that a distinct, shared visual language seems to emerge the more I study these images, uniting an otherwise

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[40] IHS, 'The International Classification of Headache Disorders, 3rd Edition', p. 20.

[41] Jes Olesen, Conversation with Katrine Skovsgaard on chronic headaches (recorded), 23 November 2022.

individual and sometimes isolating experience. Neurologist Professor Oliver Sacks observes in his book *Migraine* that, unlike the subjective experience of the headache itself, visual migraine auras follow a universal pattern. Oliver Sacks refers to three general ‘levels’ or ‘form constants’ that visual migraine auras adhere to: the most common is the expanding spiral form, known as the fortification spectrum and scintillating scotoma, indicating the shape (fortification) and the movement (scintillating) qualities of the vision. Secondly, there are phosphenes (seeing stars, often perceived as light, dark, or blind spots)[42]. Lastly, it is also common to experience rapidly changing geometric patterns.[43]

Until I had the intense sensory and visual experience of a migraine with the aura described above, I was unaware that one of the various types of headaches I regularly experienced was a migraine. Visual hallucinations are telltale signs distinguishing migraines from other headaches, as they have a direct visual representation and language inherent to their manifestation in different bodies. This kind of fireworks display, visible both with eyes open and closed, is also depicted and described by others with migraines. For example, the ancient Greek physician Arataeus of Cappadocia described his experience of visual auras (though linked to epilepsy rather than the commonly believed migraine) as flashing lights of purple hues: “There are before the sight circular flashes of purple or black colours, or of all

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[42] See for example a detailed description of this partial blindness and its distinct qualities in Hubert Airy, ‘XIII. On a Distinct Form of Transient Hemiopsia’, *Philosophical Transactions of the Royal Society of London*, 160 (1870), p. 262 <https://doi.org/10.1098/rstl.1870.0013>.

[43] Oliver W. Sacks, *Migraine*, Rev. and expanded (Picador, 2012), p. 275.

mixed together, so as to exhibit the appearance of a rainbow expanded in the heavens."[44] It fascinates me that this experience can be somewhat shared across cultures and time in a way that resonates with me 1800 years later. My curiosity has led me to seek visual representations of the visions I, along with others, experience. My research explores how shared experiences of visions can help us collectivise around otherwise individualised experiences of CH or make us feel understood and reflected across time. These common motifs might be useful in the medical sciences, but more so, I think they are important to how we express, negotiate and generally communicate about migraines. To people with visual migraine aura, seeing that this experience is shared with others could also create a sense of community that is not otherwise shared among people who experience a debilitating but otherwise invisible disability.

In the first section of this chapter, VISIONS, I share my personal experience with a visual migraine aura and the accompanying sensory symptoms that occur during a migraine attack. In the piece titled DEAR A.M.B., I explore an artwork from the Migraine Art Competition by writing a cross-historical letter to the artist, reflecting on the similarities in our migraine experiences and striving to better understand their perspective of migraines through a close reading of their work. In the following section, THE MIGRAINE ART COMPETITION, I introduce the context of this archive of significant images depicting visual migraine auras and explore the many themes and commonalities in the subsection MOTIFS. Here, I examine the relationship of these images to Hubert Airy's drawings of his visual migraine from

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[44] Arataeus the Cappodocian, *The Extant Works of Aretaeus, the Cappadocian / Edited and Translated by Francis Adams* (The Sydenham Society, 1856), p. 243 <https://wellcomecollection.org/works/ydqf373z>.

the late 1800s. To conclude this chapter, under the subheading VISUAL LANGUAGE, I investigate the artworks that have emerged from this research practice and the parallels I have found in conversations with individuals experiencing CH and professionals who work with pain.

Figure 18 *Scotoma*, the Migraine Art Competition, SA/MAR/539.

Katrine Skovsgaard

# DEAR A.M.B.

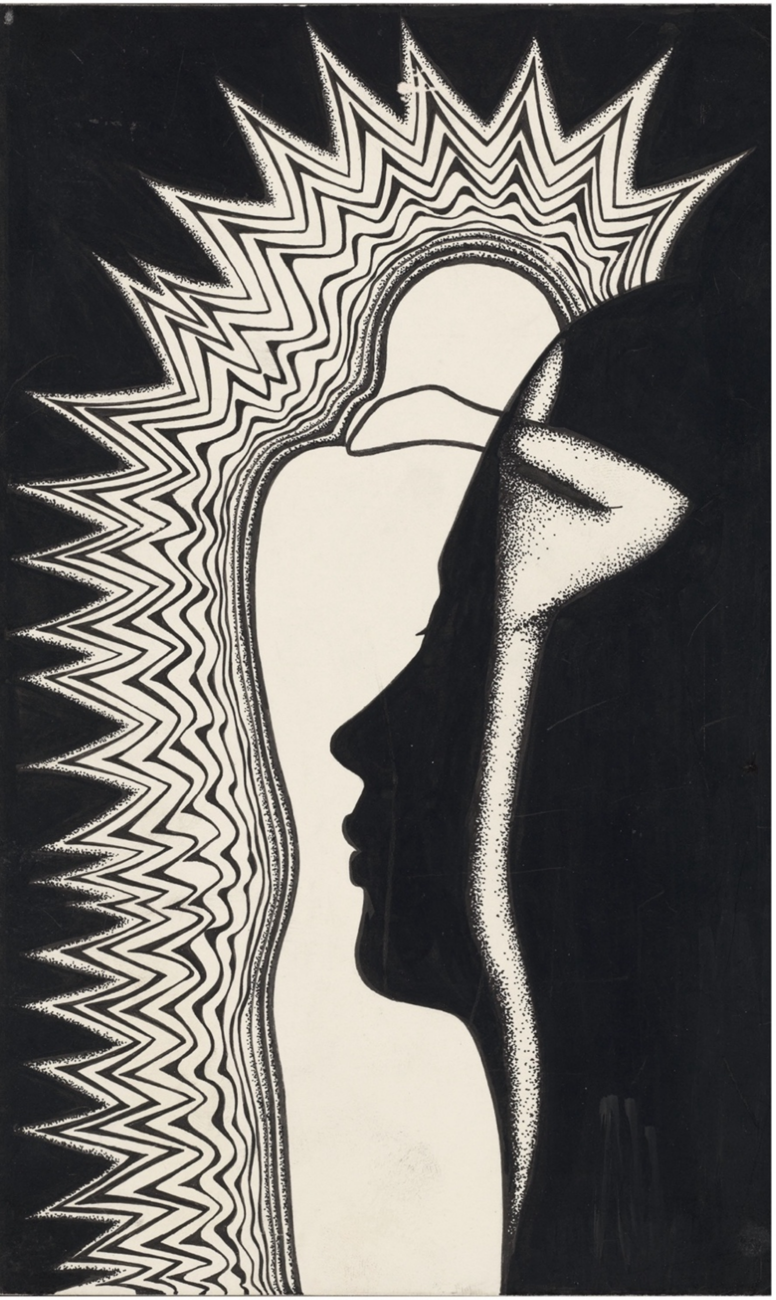
*I only know your initials because you inscribed them on your small artwork for the Migraine Art Competition sometime in the 1980s. Most of the pieces submitted for this competition are paintings or drawings, but yours is the most domestic object I've encountered in the collection. With gloved hands, a conservator gently lifts your artwork from a grey box. A silvery sweet wrapper rests almost perfectly flush against thick cardboard cut from a tissue box, adorned with sizable sugar-pink flower petals.*

*A Polaroid of what I imagine to be your house is glued to the sweet wrapper. A bright blue door, along with white-framed windows with curtains partly drawn, announces, "Welcome!" Over time, your two-story home, surrounded by a waist-high metal fence, has faded to a tinted brownish sepia glow. Your small garden at the end of the house is concealed from view; you've cut a segment of the photograph in a zigzag pattern, exposing the sweet wrapper underneath, crumpled, folded, slightly torn. The silvery reflection of the foil effortlessly emulates the scintillating scotoma you clearly experienced before the onset of a migraine. The foil shines and makes it hard to photograph – I catch my reflection in the images I capture.*

*I've been looking at your collage for several hours now. The fluorescent lights in the archive send tingling sparks through my eyes, resembling the shimmering tinfoil of your artwork and the sugary hard candies*

*I have bought to ease my discomfort. The overcast sky shines brightly and hurts my eyes, while the music in my earphones is too loud, abrupt, and high-pitched. I feel queasy, and at the same time, everything piques my appetite: sweets, caffeine, nicotine, and cold carbonated drinks. My temples pulsate. I must now leave the room before I conjure a scotoma of my own.*

*Yours, KS.*



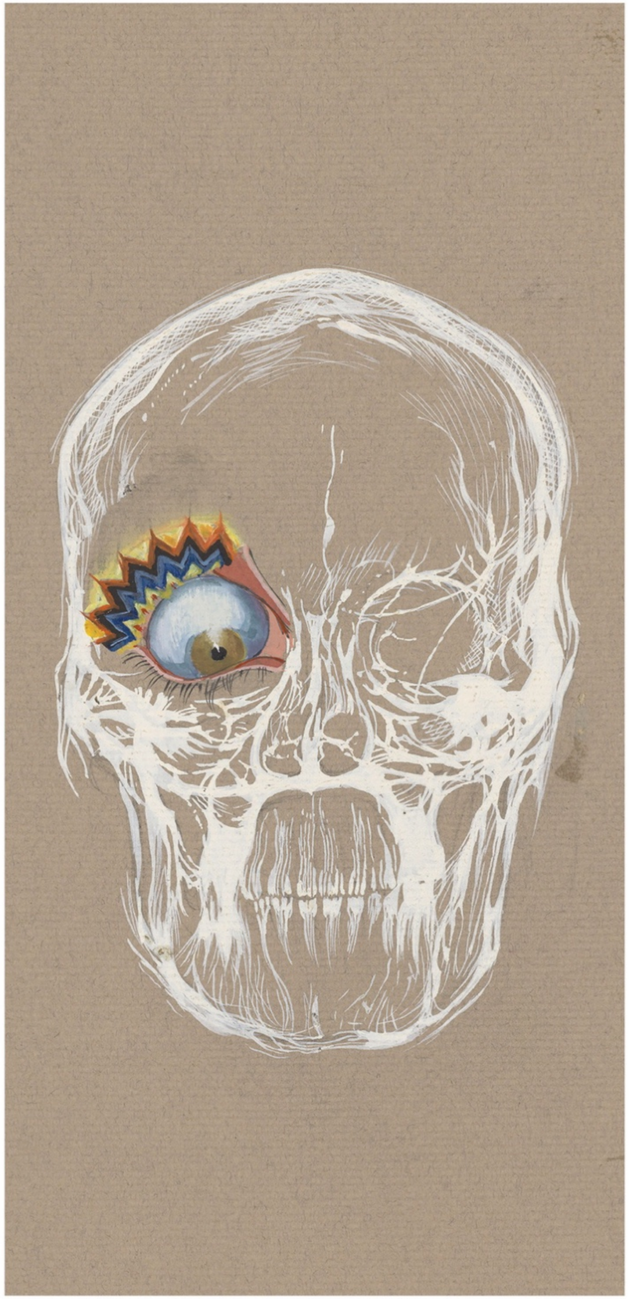
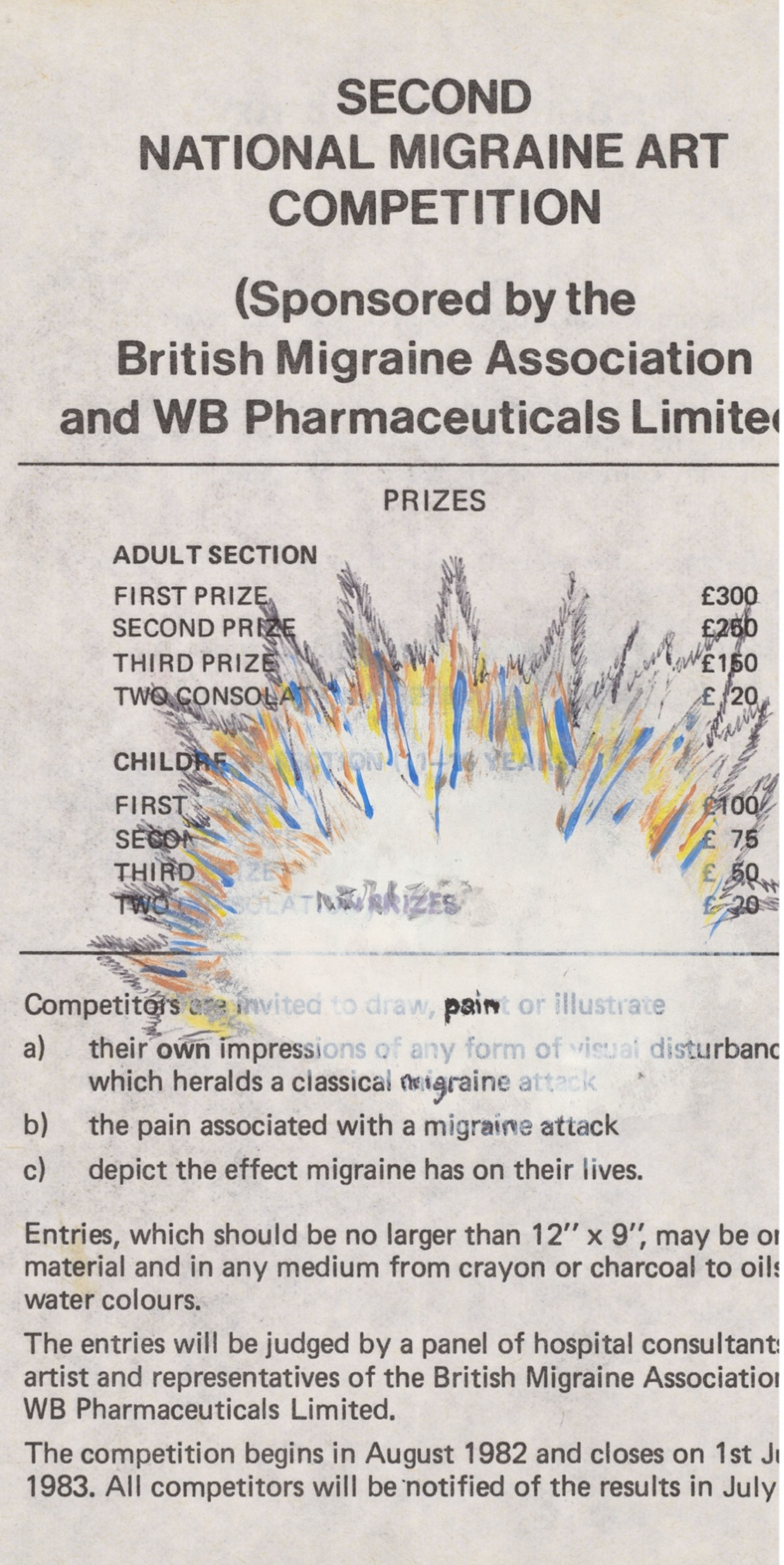


Figure 19 *White figure with silhouette face and aura*, detail, the Migraine Art Competition, SA/MAR/345.

Figure 20 *Skull with right eye zigzag aura*, detail, the Migraine Art Competition, SA/MAR/402.

Figure 21 *Hand and C-shaped aura*, detail, the Migraine Art Competition, SA/MAR/102.



SECOND
NATIONAL MIGRAINE ART
COMPETITION

(Sponsored by the
British Migraine Association
and WB Pharmaceuticals Limite

PRIZES

| | |
|---|---|
| **ADULT SECTION** | |
| FIRST PRIZE | £300 |
| SECOND PRIZE | £250 |
| THIRD PRIZE | £150 |
| TWO CONSOLA | £ 20 |
| **CHILDRE** | |
| FIRST | £100 |
| SECO | £ 75 |
| THIRD | £ 50 |
| TWO SOLATION PRIZES | £ 20 |

Competitors invited to draw, pain or illustrate

a) their own impressions of any form of visual disturbanc which heralds a classical migraine attack

b) the pain associated with a migraine attack

c) depict the effect migraine has on their lives.

Entries, which should be no larger than 12″ x 9″, may be o material and in any medium from crayon or charcoal to oil water colours.

The entries will be judged by a panel of hospital consultant artist and representatives of the British Migraine Associatio WB Pharmaceuticals Limited.

The competition begins in August 1982 and closes on 1st J 1983. All competitors will be notified of the results in July

# THE MIGRAINE ART COMPETITION

I first discovered the Migraine Art Competition during a visit to The Wellcome Collection in London. Over the years, my interest in health and art has drawn me to various contemporary art exhibitions there, and I have come to prefer their library as my workspace while researching for my thesis.[45] One day, when I opportunistically asked a librarian for visual resources on headaches, she enthusiastically informed me that she was digitising an archive of drawings, paintings, and collages related to migraines: the Migraine Art Competition. I selected fifteen pieces of artwork to view the following week. Since then, I have returned to the archive often, excited to find fifteen new artworks waiting for me as I enter the cold, climate-controlled rooms of The Wellcome Collection Library's special collections.

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[45] For example, Oreet Ashery and Jo Spence, 'Misbehaving Bodies' (Exhibition, The Wellcome Collection, 30 May 2019) <https://wellcomecollection.org/exhibitions/misbehaving-bodies--jo-spence-and-oreet-ashery>. This exhibition beautifully combined Jo Spence's self-portraits documenting her experience with breast cancer in the 1980s and Oreet Ashery's moving image miniseries exploring themes of grief, all set against a blood-red backdrop filled with unusual furniture and oversized teddy bears.

Figure 22 *Migraine Art Competition aura*, detail, the Migraine Art Competition, SA/MAR/477.

In the 1980s, the pharmaceutical company WB Pharmaceuticals (later known as Boehringer Ingelheim) and the British Migraine Association co-sponsored a competition to create visual materials for the company and promote migraine awareness for the association. This competition offered a platform for individuals with migraines to express themselves. The initiative took place over four competitions in 1980, 1982, 1984, and 1987. The entry form for the first Migraine Art Competition in 1980 announced that it aimed “to help publicise the more dramatic aspects of Migraine which separate the condition from the more common forms of headache.”[46] The brief stated: “Competitors are asked to draw or paint their own impression of any of the six forms of visual disturbance which normally precede a classical migraine attack … or to illustrate the effects of a migraine attack.”[47] (See a later call for artworks in Figure 22). With the open call referencing ‘dramatic aspects’, I would deduce that these images were intended for visual impact, potentially advertising a new migraine medication for the pharmaceutical company. The wording of the brief likely influenced the types of images the competition received, with individuals who do not experience vivid visual migraine aura being less inclined to submit their more subtle experiences of migraine attacks. Thus, the winning entry from the first year of the competition (Figure 16)[48] illustrates a scintillating scotoma in a manner reminiscent of earlier artworks, such as Hubert Airy’s drawing on black paper (see Figure 28, I will write extensively

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[46] The British Migraine Association, ‘Migraine Newsletter August 1980’, August 1980, p. 12, The Wellcome Collection <https://wellcomecollection.org/works/f6dx27vs>.

[47] The British Migraine Association, ‘Migraine Newsletter August 1980’, p. 12.

[48] Anonymous, *Rural Scene with C-Shaped Scotoma*, 1981, The Wellcome Collection <https://wellcomecollection.org/works/s7xadqzh>.

about Airy’s drawings later in this chapter).[49] These artworks depict migraines from an ‘objective’ viewpoint. The winning entry features a naturalistic landscape with an intricate representation of the shape of a scintillating scotoma. However, a multitude of diverse visual languages and common motifs also emerged from the competition (see a selection in Figure 17).

Interestingly, this collection has been preserved, perhaps due to its original intent as visual material rather than art therapy, which is often considered less worthy and seen as a subjective, introverted activity, or simply because the Migraine Association regarded it as a valuable resource. The Migraine Art Competition Collection, now hosted by The Wellcome Collection, comprises an extensive resource of more than 500 unique works. Visual disturbances, including hallucinations, illusions, and visual loss, are depicted in 426 out of 563 images.[50] I have primarily focused on examining the representations of these visual phenomena, particularly the hallucinations that make up the majority of the visual disturbances portrayed in the collection (a total of 367 artworks depict visual migraine auras). In these images, what Oliver Sacks refers to as form constants appear clearly across visuals from different years, making it fascinating to observe these recurring themes and shared experiences in visual migraine aura.

The competition has not received much attention in the art world. A small selection of scholars have discussed the Migraine Art Competition directly. Katherine Foxhall contextualises our contemporary

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[49] Airy, ‘XIII. On a Distinct Form of Transient Hemiopsia’.

[50] Podoll and Robinson, *Migraine Art*, p. 147.

understanding of migraines by placing them within a historical framework in her book *Migraines*. She argues that historical and cultural frames of reference shape the discourse surrounding migraines.[51] She states that the Migraine Art Competition entries serve a "vivid visual confirmation of how inadequate our treatments of migraine have been, culturally, socially, phenomenologically and medically."[52] She has dedicated a chapter to the context of the Migraine Art Competition expressing: "this period is also notable for being the moment when the idea of the "migraineur" was at its most prominent, in both academic and popular use."[53] These statements pinpoint the time that the Migraine Art Competition was made and show how a migraine would be seen as an individual problem and connected to one's identity. This view, for example, fits well with the essay *In Bed* from 1968 by writer and journalist Joan Didion, who also used the term 'migraine personality'.[54] Whereas I would see this wording inappropriate if it were written today, it shows the spirit of the time it was written in, in which the Migraine Art Competition also took place. Katherine Foxhall writes of the images in the Migraine Art Competition, saying that "the straightforward bluntness of the metaphors is shocking."[55] She has seen the strength in and chosen mainly to focus on the images that metaphorically convey a migraine attack through imagery such as hammers, adjustable clamps or knives. In contrast, I have chosen the

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[51] Foxhall, *Migraine*, p. 2.

[52] Foxhall, *Migraine*, p. 210.

[53] Foxhall, *Migraine*, p. 189.

[54] Joan Didion, *The White Album* (Simon and Schuster, 1979), p. 168.

[55] Foxhall, *Migraine*, p. 196.

representations of visual migraine auras that are less individual because they can be shared as direct representations of lived experience between people with migraine with aura.

Physician Klaus Podoll and neurologist Derek Robinson, one of the competition's founders, have co-authored the book *Migraine Art*. The book features over 300 illustrations depicting migraines, many of which are from the Migraine Art Competition.[56] The book aims to provide the most comprehensive study of migraine auras, targeting medical professionals as its primary audience. It approaches the subject with a broad medical perspective, featuring chapter titles such as Signs and Symptoms, Trigger Factors, Therapy, Abnormal Bodily Sensations, and Visual Disturbances. The authors use descriptive language and reproduce a series of artworks that illustrate these medical themes, effectively quantifying and employing a medical lens to explore the art competition.

The collection has also recently been utilised for comparative clinical studies on the premonitory symptoms of migraines. For instance, a group of scientists published an article regarding visual migraine aura in *The Journal of Headache and Pain*.[57] The study identified and compared the themes and motifs in visual migraine auras to better classify and differentiate migraines from other neurological disorders. The authors conclude that visual migraine auras are understudied and that an improved classification of these auras could enhance the overall understanding of migraines. I have

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[56] Podoll and Robinson, *Migraine Art*.

[57] Michele Viana and others, 'Clinical Features of Visual Migraine Aura: A Systematic Review', *The Journal of Headache and Pain*, 20.1 (2019), p. 64, doi:10.1186/s10194-019-1008-x.

reservations about this kind of study, as its context and usage do not match the open, creative prompt and context of the Migraine Art Competition. Literal readings of images have often led to misunderstandings, such as researchers identifying new types of auras from retrospectively looking at the Migraine Art Competition artworks. I have seen complex hallucinations, out-of-body experiences, and body dysmorphia diagnosed based on information derived from artworks created with complete creative freedom. Some of these images may represent a direct visual experience, such as a visual migraine aura, while others represent the overall experience of a migraine attack. A black figure surrounded by question marks in a drawing of a migraine aura may not indicate that the person is hallucinating a figure or experiencing an out-of-body event; rather, it could illustrate how migraine attacks can make you feel disconnected from your surroundings, unable to express your needs, or even impair your ability to read facial cues and fully comprehend what is happening around you, as seen in Figure 23.[58] Some individuals temporarily lose their ability to speak during a migraine attack, which intensifies the feeling of disconnection from those around them.

Because these images are created as creative exercises, illustrating the effects or auras of a migraine rather than scientifically portraying the visual aura on its own, they should be interpreted as such. A zigzag pattern might signify that a person is indeed perceiving a zigzag pattern, or it could alternatively

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[58] Anonymous, *Man Being Sick from Bed*, 1987, The Wellcome Collection <https://wellcomecollection.org/works/tmejhnqw>.

suggest movement; for instance, the small zigzag patterns depicted around the person in Figure 10[59] or near the bottom of the scotoma in Figure 16 may not represent the scotoma itself but rather relate to movement, uneasiness, the fuzziness of vision or how the scotoma shifts. Accurately interpreting these artworks is challenging because the competition brief is open-ended, and the competition intended to communicate the entire experience rather than conduct a scientific study of the visual aura itself. New medical research into the appearance of visual migraine auras is needed to uncover some of the similarities and the aetiology of auras. I disagree with scholars who posthumously diagnose artists like Pablo Picasso[60] or Hildegard of Bingen[61] with migraines many years after their deaths based on aesthetic choices that may resemble visual migraine auras through their fractures, incorporation of fortification images, or themes related to distorted vision.[62] This approach risks inserting unprovable premises into an artist's biographical narrative. Other researchers argue that the aura experience is insignificant since the aura symptoms would follow suit if the migraine attack were effectively treated. Both viewpoints overlook the potential of visual representations of migraine auras; examining visual migraine auras through various lenses could enhance our understanding of migraines. For instance, I

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[59] Anonymous, *Forbidden Things and Kitchen Chaos*, 1985, The Wellcome Collection <https://wellcomecollection.org/works/f93y9m5w>.

[60] Melinda Nicola and Peter D. Drummond, Conversation with Katrine Skovsgaard on chronic headaches (recorded), 6 March 2023.

[61] Foxhall, *Migraine*, p. 135.

[62] See also Sacks in his book *Migraine*, and Podoll and Robinson in *Migraine Art,* who all mention and study artists like Picasso, Hildegard of Bingen and Lewis Carroll (author of *Alice in Wonderland*) and post-diagnose them with migraines.

envision that a more strictly controlled experiment with a prompt to draw solely the visual migraine aura experienced could help diversify and classify our medical understanding of visual migraine auras.

These authors have studied the competition in depth within their given fields, Katherine Foxhall studying the history of migraine, and Klaus Podoll and Derek Robinson quantifying and approaching evidence-based medicine in their approach to reading the competition entries. However, the competition has not received any artistic attention. Creatively and empathetically, the Migraine Art Competition Collection has incredible potential as a resource to provide novel and diverse ways of understanding migraines. Instead of offering new medical knowledge like Klaus Podoll and Derek Robinson propose, the most significant potential of the Migraine Art Competition, along with disseminating its images, is to showcase visual migraine auras publicly and to bring nuance and visibility to an otherwise widely misunderstood condition.

Figure 23 *Man being sick from bed*, the Migraine Art Competition, SA/MAR/346.

# MOTIFS

*Obstructed vision, blind spots, tunnel vision*
*C-shapes, bean-forms, crescents, round figures*
*Spikes, star-shaped figures, zigzag and jagged lines*
*Explosions, fireworks, flickering lights*
*Flashes of bright light, vivid movement*
*Tiny bright flickers, visual snow, spots of light, black dots*
*Fractured, mosaic, checkerboard vision*
*Vivid, moving, pearlescent colours*

These are just some visual tropes in the Migraine Art Competition Collection. The partial blindness, the c-shape, the zigzag lines, flashing lights, and vivid colours are some of the strongest motifs in the collection. Few artists submitting work for the first competition would have anticipated how others would represent their visual migraine auras. Nevertheless, some evident themes emerge in the visual materials I review. I consistently encounter explosive imagery, star shapes obstructing vision, and c-shaped scotomas. Many of the drawings and paintings include similar, sharp-edged geometrical designs dominated by zigzag lines combined with various black-and-white patterns. Even the more colourful examples often include parts of such edgy and geometrical elements. For instance, a significant percentage resembles Hubert Airy's drawings (Figure 28 and Figure 29) from the 1870s: a white zigzag line interspersed with saturated colours that highly contrast with a black background.[63] The shape is a C with a dark or blind spot in the centre. The placement of the shape is signalled by a central point, where the shape is slightly off-centre. The movement of the shape is shown through different drawings that illustrate its progression, first growing larger and then disappearing. Most people would not have seen or had access to other images of migraines beyond their firsthand experiences, making the many common motifs in the competition even more intriguing.

Many people with visual migraine aura experience visions or blind spots that cover approximately a third of their field of vision, obstructing whatever is in front of them at the time. In competition entries, this is often illustrated from the perspective of a person driving a car whose view is obstructed (Figure 12) or someone in conversation with others whose faces are hidden by patterns or clouds. Sometimes, vision is blocked by blind spots (Figure 18, Figure 23 and Figure 103). Still, more often, it is obscured by half-moon or round shapes surrounded by jagged zigzag lines, either in psychedelic black and white patterns or in a vibrant array of colours, typically flashing from a centre like firework displays or lines rushing outward as if in rapid movement (Figure 26, Figure 58 and Figure 61). Often, the colours consist of a broad palette of iridescent, vivid, and saturated hues.

This collection could be considered as outsider art or Art Brut because the artists who submitted artworks for this competition are largely untrained and, therefore, not typically influenced by the

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[63] Airy, 'XIII. On a Distinct Form of Transient Hemiopsia'.

discourses and conventions of the art world. Instead, they are motivated by a desire to express their unique personal experience of visual migraines, either for themselves or to externalise for others. These artists generally utilise repurposed materials and items from their immediate surroundings to create their works and directly support the subject by using household materials to illustrate a condition that confines many people to their homes.[64] Many of the drawings are figurative, depicting the artists themselves or how these visions disrupt their daily lives, obstructing their immediate surroundings: traffic, school, work, family and friends, home, kitchen, and bedroom. The pieces provide an insider perspective on migraines while reflecting inner and outer conflicting realities.

Despite the striking similarities, particularly in visual migraine aura imagery, there has not been much research conducted into what visual migraine auras might signify or what could cause them. Similarly, the general knowledge of these visual similarities is limited. When I talk to people with migraines, they are often astonished by how closely their internal experiences align with those expressed by others in art. This similarity of the internal visual experience of a big group of people also amazes me, as I have been working with chronic pain in my art practice for years, and the Migraine Art Competition is the first time I have seen such consistent images shared by so many individuals with a pain condition.

When I began working with others who experienced pain on how to visualise their experiences, I experimented with creating images based on my daily headaches. From this clear image and its

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[64] Another artist I will address later in this thesis is Elisabet Eriksson, who is known for her use of domestic materials. For example, she embroiders on inherited dishcloths to explore themes of grief.

connection to form, colour, intensity, and pain, I expected the themes from my visualisations of pain to be reflected in the artworks I would create in collaboration with others who have CH. I perceived my pain as hard shapes in varying shades of red, ranging from orange to purple, but never extending beyond the warm colour spectrum, and always in deeply saturated pigments and intense hues. I was surprised to find my assumptions incorrect when I realised that others depicted their chronic pain not only through hard shapes and warm reds but also through softer forms and cooler colours (Figure 24). In the shared visual language that I could not discern in the visual expressions of CH, I found a glimmer of the possibility of a unified visual language through the imagery of visual auras in the Migraine Art Competition Collection.

In 2023, I worked with the Migraine Art Competition as a resource when the Swedish Arts Council invited me to be the public artist in residence at the Röhsska Museum of Design and Craft in Gothenburg. During the spring and summer, I curated an exhibition at the museum and received support to create new work and conduct research. At Röhsska, I engaged in dialogue with local colleagues, drawing inspiration from the museum's collection and from individuals who witness or experience chronic pain. For the exhibition at Röhsska, I created *Chronicles*, a soft tapestry installation featuring a sound collage of voices from individuals who experience or work with CH in various ways. *Chronicles* visualises my visual migraine aura through a thick tufted tapestry made from deadstock yarns and a sound narrative developed in dialogue with persons with or witnessing pain. The installation showcases a tapestry in a blend of vivid purple hues. Different purple shapes appear to rush to or from a centre, forming a circular shape that either spreads from or moves towards a central point in the installation. Yellow and purple curtains envelop *Chronicles*, creating an intimate space for

Figure 24 *(I)*, Art Museum BRANDTS, DK, 2016, photograph by Frida Gregersen.

introspection. It resembles a hill that ascends from the gallery floor, and audiences engage with the artwork by resting on the tapestry, allowing them to listen and immerse themselves in the diverse experiences of individuals with chronic pain and professionals in the field. I chose to work with deadstock wool yarns to create a tactile and three-dimensional art installation that reflects my experience with visual migraine aura. Deadstock yarns are leftover materials from the textile industry that would otherwise be discarded. This means I work intuitively, choosing colours individually until a particular shade runs out. This approach creates a somewhat chaotic aesthetic, and the messy and sometimes unravelled nature of the final installations reflects the often-chaotic experience of living with CH. When working with these materials, it is ethically essential to adopt considerate and caring methods. As part of this method of care, I also thought that it was considerate to include myself in the artwork, making myself vulnerable while asking others to do so. As part of this practice of care through art methods, it was important to me that viewers could touch the artwork, changing their perception of the work and forming a different relationship with the artwork, complicating the relationship that the audience has with the artworks through a more complex relationship to the senses than the usual ocular centric ways of experiencing art, to including touch, sound, movement, narrative and proprioception in the experience of the artwork, adding senses to experience the artwork through and creating what curator and art historian Amanda Cachia calls ‘haptic activism’.[65] In this way, how I work with my own and others’ experiences and the Migraine Art Competition, enhances the accessibility of these resources by making them available through many senses.

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[65] Amanda Cachia, *The Agency of Access: Contemporary Disability Art & Institutional Critique* (Temple University Press, 2025), p. 179.

Figure 25 Sophie Richings' migraine aura, 2024.

When I shared my exhibition and findings with friends and colleagues, they were astonished that others shared their inner experience of visual migraine auras. This is illustrated in the words of my friend Sophie Richings, who, after attending my exhibition at the Röhsska Museum, found herself with a migraine the following day. As we sat together at the breakfast table, she reflected on her experience:

> It's like there's this colourful edge that keeps moving. It's exactly how you described it to me, and I can recognise it from your artwork. I feel like you know exactly what I'm seeing. Oh, it's moving now! I can't look directly at it, but it's growing, and now it's at the corner of my eye.[66]

There is something truly unique about the experience of CH, something entirely subjective that can be challenging to communicate. As Sophie Richings expresses above, there is something freeing about knowing that your inner experience matches the inner experience of a group of others with migraines. I was intrigued to discover this unifying aspect in the most prevalent, and arguably one of the most debilitating, headaches: migraines, since chronic pain is often felt as a lonely or isolating experience.

Not only do these images provide a collective point of reference while simultaneously highlighting the individual subjective experience of what a migraine feels like, but they also seek to offer a direct visual representation. I am especially struck by A.M.B., the unnamed artist behind the artwork illustrated and described in the section above, who submitted entries to the Migraine Art Competition throughout

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[66] Sophie Richings, Conversation with Katrine Skovsgaard on chronic headaches (unrecorded), 20 May 2023.

Figure 26 *Reclining figure in kaleidoscopic aura*, the Migraine Art Competition, SA/MAR/341.

the 1980s (Figure 18 and Figure 27).[67] [68] Their artwork uses materials commonly found in households: images of a house that I imagine to be A.M.B.'s, scraps of sweet wrappers, sticky tape, and foils found around the home, glued onto the photograph. All of this is set against the background of a tissue box that A.M.B. might have used to wipe away tears of frustration or pain encountered during a migraine attack. The three art pieces A.M.B. has in the collection are all crafted from domestic materials, reflecting how CH can bind the person experiencing it to their home. The chronicity and longevity of migraines connect CH to everyday repetitive actions and activities.

In my conversations, the immediate surroundings of the person in pain often came up concerning physical and social surroundings. Neuroscientist Professor Peter Goadsby described CH as a pan- or multidimensional problem that is difficult to comprehend through intensity measures. This issue necessitates considering the immediate and societal surroundings in which the person in pain exists:

> These are complex problems, and trying to capture them in a single dimension, in my experience, usually underestimates the broader nature of the problem. And that's just to do with the individual, that doesn't consider how the individual is interacting with those around

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[67] Anonymous, *Scotoma*, 1980s, The Wellcome Collection <https://wellcomecollection.org/works/xxwtqw88>.

[68] Anonymous, *Tunnel Vision*, 1980s, The Wellcome Collection, Migraine Art Competition Collection <https://wellcomecollection.org/works/pkr3s2d6>.

> them or indeed interacting with society. It's not even two-dimensional or three-dimensional. It is truly a multidimensional problem.[69]

Professor of Facial Pain Joanna Zakrzewska and I likewise discussed the impact of CH on the lives of people who experience it. While she expressed frustration with the inadequacy of using the 0-10 scale, she suggested that the experiences of loved ones witnessing the pain can be essential in understanding the numerous effects a headache can have on someone's life. Joanna Zakrzewska and several others indicated that the fundamental factors to focus on are those related to everyday tasks: "Looking at the impact, and that's what was giving me the real idea of what this pain is like. If you can't do your housework, if you can't go out, if you feel depressed, *those* are the factors that really tell you how intense that pain is."[70]

I was captivated by the domesticity of A.M.B.'s artwork and its material connection to the themes regarding the impact of CH on one's ability to leave the house or engage in daily life. A.M.B. has three pieces in the collection in total. All are created on household cardboard, incorporating elements of tape and drawing, similar to the tissue paper carton of the piece I analysed in my letter to A.M.B. Two of the pieces incorporate tinfoil or sweet wrapper elements to represent a scintillating, flickering scotoma, or to highlight the changing characteristics of how light is perceived during a migraine attack.

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[69] Peter Goadsby, Conversation with Katrine Skovsgaard on chronic headaches (recorded), 20 March 2023.

[70] Joanna Zakrzewska, Conversation with Katrine Skovsgaard on chronic headaches (recorded), 12 January 2023.

Figure 27 *Tunnel Vision*, the Migraine Art Competition, SA/MAR/332.

All A.M.B.'s artworks feature written descriptions of what is depicted: a scintillating scotoma or tunnel vision. The central motif underlying the visual aura of the artworks is houses, which evokes the domestic implications of a migraine: Is it safe to go outside with an ongoing visual migraine aura, or do migraines confine you to your home? The shapes of A.M.B.'s visual auras consistently include jagged forms, with two featuring circular shapes radiating from or towards a clear centre. Examining A.M.B.'s artwork from the Migraine Art Competition connected me to their experience of visual migraine aura and allowed me to relate it to my own. I yearned to discuss their experiences with migraines and the materials they chose for their artworks. I deeply resonated with the qualities of the artwork, particularly how the foil suggested the ways light might reflect and refract differently for someone experiencing a migraine. The characteristics and immediacy of a migraine were so clearly articulated that I felt compelled to write a letter in response to their work. I have shown these images to others who experience migraine auras, and frequently, they are astonished that something they believed was unique to them is a shared experience. A.M.B.'s imagery evokes a sense of solidarity within me through a correspondence across time.[71] I have connected with researchers and people with headaches through conversations, but with an anonymous figure like A.M.B., my connection is solely with their artwork. By writing a letter to A.M.B., I aimed to bridge the gap across time to connect our individual migraines experiences. This correspondence enabled me to feel within my body and communicate to others the cross-historicity I perceive when viewing A.M.B.'s artworks, as well as the further

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[71] Gemma Blackshaw and Alice Butler, 'Collaging Letter-Voices: Sick Women Correspondents' <https://brooklynrail.org/2024/03/criticspage/Collaging-Letter-Voices-Sick-Women-Correspondents-2020ongoing> [accessed 11 July 2025].

connections I observe when considering Hubert Airy's visual migraine aura drawings and Arataeus of Cappadocia's description of his visual aura. These visual tropes resonate across great spans of time, demonstrated here through close readings of artworks from the 1870s[72] and 1980s.[73] I also strive to connect this to the verbal accounts of individuals I have spoken with who themselves experience visual migraine auras. Professor of Neurology Jes Olesen, a specialist in migraine and headache, describes auras in our conversation as "a kind of vision into the brain."[74]

In 1870, physician Hubert Airy might have had similar thoughts of depicting the brain when he illustrated the visual migraine aura he experienced, naming it 'hemiopsia' (Figure 28).[75] In this drawing, a white, rounded shape contrasts against a black background, outlined by a colourful, jagged zigzag line resembling a mountainous landscape viewed from above or the shape of a fortress on a map. The shape is replicated ten times, indicating each iteration's progression in size, colour, and detail. The drawing predominantly features black and white, with only the extremities of the shape punctuated by colourful lines. These colours seem to flicker or change with every new iteration: white, red, blue, yellow, and green lines define the hard edge of an otherwise softly shaded hand drawing. Inside the shapes, the angular edges are gently mirrored by faint white shaded lines that fade into a black spot at the centre of the drawing. Hubert Airy describes how the vision included a blind spot, remained equally

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[72] Airy, 'XIII. On a Distinct Form of Transient Hemiopsia'. p 255-266

[73] Anonymous, *Migraine Art Competition Collection*.

[74] Olesen, 'Conversation with Katrine Skovsgaard on chronic headaches (recorded)'.

[75] Airy, 'XIII. On a Distinct Form of Transient Hemiopsia'.

Figure 28 *Plate XXV*, 1870, by Hubert Airy, accessed at the Royal Society of London, UK.

intense with eyes open or closed and spread from one corner to envelop the entire field of vision before disappearing.

Visually, he captures the scintillating qualities of his scotoma: “a faintly luminous curved figure in the dark, brilliantly edged along its serrated outline, the bright margin supported by a trench of black, and in different places gleaming with red and blue and other colours. The tremor and boiling are beautifully seen.”[76] Hubert Airy was entrusted to represent his experience objectively as a physician, and headache scholars have regarded his images as the pinnacle representation of scintillating scotomas ever since.[77]

When I examined the colour plate reproduction of Hubert Airy’s drawing at the Royal Society in London, I noticed the smudge of ink that, over time, has transferred from the print to the opposing white page, creating a clear yet ghostly image of the drawing. It resembles a transfer from one body to another of the experience of this migraine aura through the passage of time. On an early sketch attached to a letter dated 30 April 1868, also held by the Royal Society (Figure 29), Hubert Airy’s marks from more than 150 years ago seem more visceral to me: a thin, yellowed piece of paper painted over with thick, black paint in such a way that blotches and smudges have seeped onto the back of the page. The chalkboard-like side left behind creates a rugged surface for Hubert Airy’s coloured pencil marks. The softness of each pen stroke is visible, revealing the person behind the movement of both an

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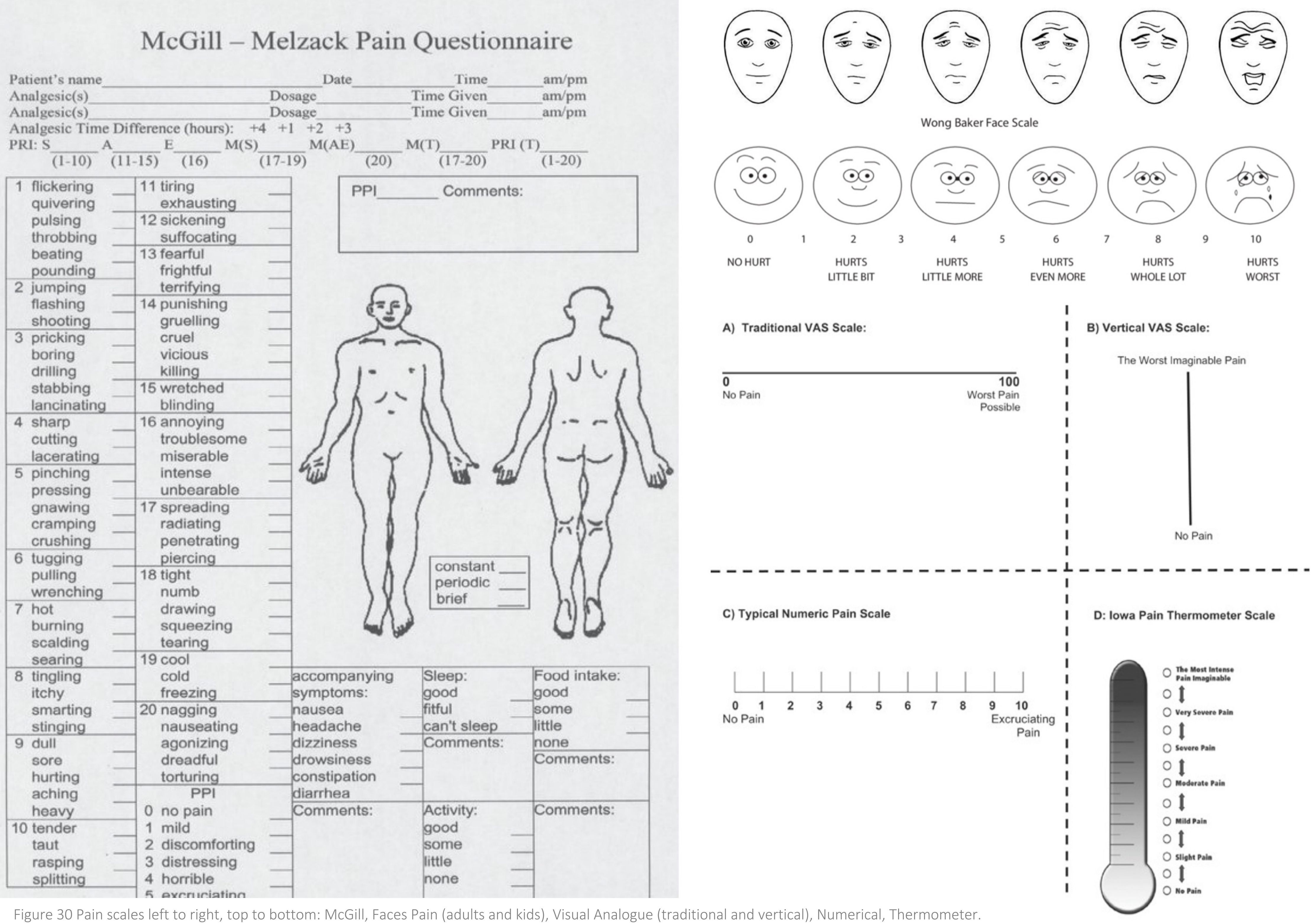
[76] Airy, ‘XIII. On a Distinct Form of Transient Hemiopsia’. p. 258

[77] For example, Hubert Airy’s drawings are the main visual point of reference in Oliver Sack’s book *Migraine*, first published 100 years after Hubert Airy made his drawings.

ordinary pencil and a coloured pencil. In some areas, the drawing has been overlaid with white paint to intensify the contrast against the black and make the pattern pop from the page. It is clear how many times Hubert Airy has gone over the most prominent parts of the drawing, desiring to enhance the gleam of whiteness on the darkened page. Even in numbers that could be mistaken for machine print, I detect the sediments left behind from the movement of the handheld brush that has intricately painted the numbers to look like they were printed. On the following page, Hubert Airy has recorded the exact timings of the visions in minutes. I wonder if the numbers were printed this way and the drawings were done minute by minute to appear polished and scientific, thereby supporting the image of a physician’s professionalism. Perhaps the machine’s aesthetic, rather than the hand, was necessary to meet expectations for a drawing to be regarded as medical knowledge in 1868. I cannot imagine that such a drawing, created by a patient or a medical professional, would be viewed as medical knowledge today, where the medical sciences predominantly rely on functional imaging for insights into medical conditions (see an additional drawing by Hubert Airy in Figure 74). The only widely accepted use of drawings in pain management that I have found is from the McGill Pain Questionnaire (Figure 30), where a small outline of the body allows the person in pain to mark the locations where they feel pain. However, this is not seen as a creative exercise. Often, the individual in pain is expected to draw a circle or a dot to indicate where the pain is, rather than explore colour and shape to suggest the qualities of the pain or the appearance of a visual migraine aura. This serves as the medical practitioner’s only visual understanding of the pain patient’s experience – as functional imaging offers no insight into the condition in most cases of primary CH.

Figure 29 Hubert Airy, 1868, detail, The Royal Society of London, UK.



McGill – Melzack Pain Questionnaire

Patient's name ______ Date ______ Time ______ am/pm
Analgesic(s) ______ Dosage ______ Time Given ______ am/pm
Analgesic(s) ______ Dosage ______ Time Given ______ am/pm
Analgesic Time Difference (hours): +4 +1 +2 +3
PRI: S ______ A ______ E ______ M(S) ______ M(AE) ______ M(T) ______ PRI (T) ______
(1-10) (11-15) (16) (17-19) (20) (17-20) (1-20)

1 flickering ___ quivering ___ pulsing ___ throbbing ___ beating ___ pounding ___
2 jumping ___ flashing ___ shooting ___
3 pricking ___ boring ___ drilling ___ stabbing ___ lancinating ___
4 sharp ___ cutting ___ lacerating ___
5 pinching ___ pressing ___ gnawing ___ cramping ___ crushing ___
6 tugging ___ pulling ___ wrenching ___
7 hot ___ burning ___ scalding ___ searing ___
8 tingling ___ itchy ___ smarting ___ stinging ___
9 dull ___ sore ___ hurting ___ aching ___ heavy ___
10 tender ___ taut ___ rasping ___ splitting ___
11 tiring ___ exhausting ___
12 sickening ___ suffocating ___
13 fearful ___ frightful ___ terrifying ___
14 punishing ___ gruelling ___ cruel ___ vicious ___ killing ___
15 wretched ___ blinding ___
16 annoying ___ troublesome ___ miserable ___ intense ___ unbearable ___
17 spreading ___ radiating ___ penetrating ___ piercing ___
18 tight ___ numb ___ drawing ___ squeezing ___ tearing ___
19 cool ___ cold ___ freezing ___
20 nagging ___ nauseating ___ agonizing ___ dreadful ___ torturing ___

PPI
0 no pain ___
1 mild ___
2 discomforting ___
3 distressing ___
4 horrible ___
5 excruciating

PPI ______ Comments:

constant ___
periodic ___
brief ___

accompanying symptoms: nausea ___ headache ___ dizziness ___ drowsiness ___ constipation ___ diarrhea ___
Comments:

Sleep: good ___ fitful ___ can't sleep ___
Comments:

Activity: good ___ some ___ little ___ none ___

Food intake: good ___ some ___ little ___ none ___
Comments:
Comments:

Figure 30 Pain scales left to right, top to bottom: McGill, Faces Pain (adults and kids), Visual Analogue (traditional and vertical), Numerical, Thermometer.

Figure 31 *Chronicles*, Röhsska Museum of Design and Craft, SE, 2023, photograph by Kristin Lidell.

Figure 32 Worktable with embroidery and inspiration materials, Röhsska Museum of Design and Craft, SE, 2023, photograph by Kristin Lidell.

# VISUAL LANGUAGE

> Did you take a picture of your headache?” the 6-year-old asks as we sit around the table embroidering. “No,” I reply, “I just drew a picture of it and turned it into a rug.” “Wow!” the kid responds, “it’s like I’m inside your headache now. I think I understand! I draw my headache in the morning. I don’t really want to talk about it with my family, but if I show them my drawing, they can see how I feel, and I don’t have to explain the pain.” “Wow!” I exclaim, “Do you do that every morning?” His mum chimes in: “Ever since he got headaches a year and a half ago, he sits down for breakfast and draws how his pain feels that day. I’ve got a folder with over 500 of his drawings at home already.[78]

Using materials from individuals experiencing CH, I aim to challenge and politicise prevailing understandings of CH, speaking directly from one pathologised and marginalised body to another. In my artwork, I have felt inspired to express my interpretation of my migraine aura, allowing others to also express theirs. At my recent exhibition and residency at the Röhsska Museum of Design and Craft in Gothenburg, Sweden, I presented the installation *Chronicles*, a tapestry that visualises my visual migraine aura.

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[78] Anonymous, Audience in conversation with Katrine Skovsgaard (unrecorded), 2023.

A table covered with cloth, tools, and materials for embroidery allowed visitors to engage and stitch their visual auras or visualisations of CH while surrounded by my work and the drawings from the Migraine Art Competition that I exhibited in the space (see Figure 7, Figure 32 and Figure 38). This proved to be an excellent conversation starter between me and museum visitors or within roundtable groups where medical professionals, artists, and people in pain gathered. Most importantly, it fostered an environment for visitors to share their experiences of pain with those they attended the exhibition with.

I observed in these roundtable discussions, spontaneous conversations, and recorded dialogues with individuals experiencing headaches and professionals that visual auras, sensory disturbances, and sensitivity often emerged as examples when people are prompted to consider CH from a multisensory perspective. When asked how she might conceptualise headaches in a multisensory manner and describe her headaches in terms of vision, sound, smell, taste, and touch, Hannah Clarkson highlights the multisensory experience of migraine attacks:

> Sometimes my headache feels like the Victoria line at rush hour. So, it’s like too much taste, too much smell of all these bodies, too much light. It’s always really bright, like too much movement and jostling around; it’s too hot, it’s way too loud. That kind of screeching sound that it makes between Highbury Islington and Finsbury Park is just awful.[79]

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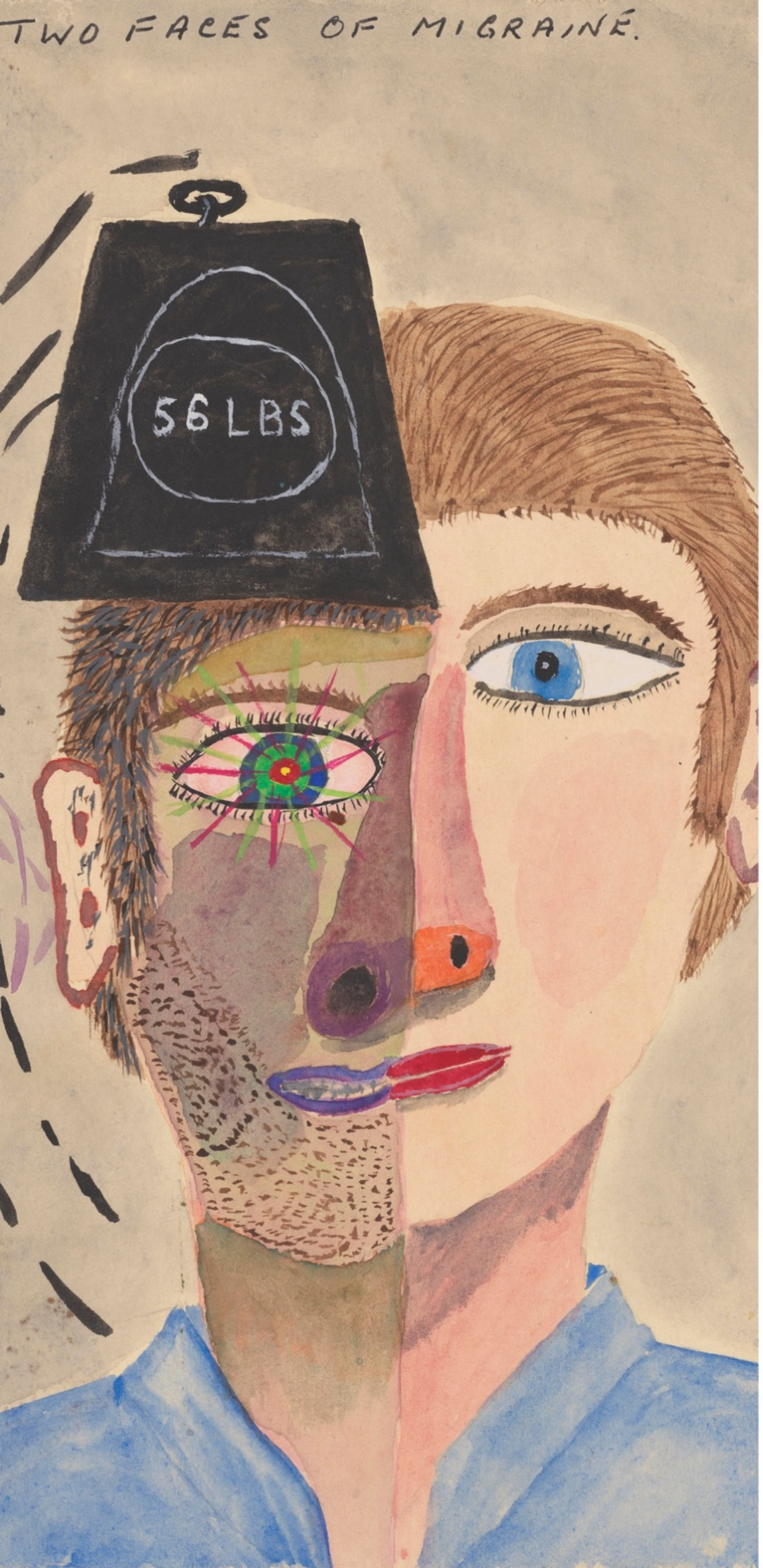
[79] Hannah Clarkson, Conversation with Katrine Skovsgaard on chronic headaches (recorded), 21 March 2023.



Typical imagery that arose in my conversations included having added weight, such as a full cup of coffee without a lid, a rucksack, or a heavy bag, representing an extra burden to be constantly aware of carrying and how to adapt to this added weight to manage everyday life, recognising that it is heavier than what others generally carry: it could spill, or it could become too heavy to bear throughout the day (see also Figure 33). Professor of Creative Writing Sonya Huber, who personally experiences chronic pain, describes her pain visually and as a separate entity from herself, as something that separates her from others:

> An egret, bird-shaped space alien. Just like one that doesn't have our language, we don't have its language. It's just awkward but not cruel. It's just the sense of being in the wrong dimension. That's what I think of, as having this very odd companion that other people can't see, and that it's trying to communicate with me in ways that I don't really understand, but I can co-exist with.[80]

The experience of CH, to some extent, resists the verbal system, leading many people to interpret their experiences through visual language and metaphors, as seen in the works of Sonya Huber and Hannah Clarkson mentioned here. These images exist outside the common vocabulary of visual migraine aura.

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[80] Huber, 'Conversation with Katrine Skovsgaard on chronic headaches (recorded)'.

Figure 33 *The Two Faces of Migraine*, detail, the Migraine Art Competition, SA/MAR/54.

Nevertheless, themes, tropes, and motifs emerge similar to the aura artworks. A shared language develops around overwhelm, sensory stimulation, and describing CH as an entity separate from the self. These themes, along with this visual mode of expressing CH, have not become widely known, and so they remain somewhat distinct from popular cultural perceptions of CH, where metaphors and stigmatising assumptions dominate, in addition to the language of diagnostics and medicine, which tends to prioritise quantifiable data. As a result,[81] it can be more challenging for individuals experiencing headaches to cope privately, leading them to hesitate in sharing their experiences with loved ones for fear of being misunderstood. In my chapter on VOICE, I will elaborate further on how CH resists verbalisation and how sharing accounts of CH could transform our language and assumptions about it.

In my tapestry and sound installation, *Chronicles,* many of these more poetic and sense-focused ways of speaking about pain became essential to the piece. For the choir piece *Six Infinity*, some of the visual language was employed as lyrics,[82] and in both works, different people's attitudes toward medical language, 0-10 scales, and how those without pain describe CH were contrasted (see sheet music in the appendix titled SIX INFINITY, and Figure 8, Figure 9, Figure 48, Figure 50, Figure 51, Figure 52, Figure 53, Figure 54, Figure 57 and Figure 100). In both pieces, I activated various visual migraine representations

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[81] *Pain as Human Experience: An Anthropological Perspective*, ed. by Mary-Jo DelVecchio Good (Univ. of California Press, 1994), p. 181.

[82] Listen to *Six Infinity* and *Chronicles or* read the sheet music and transcriptions via the links provided in the appendices SIX INFINITY and CHRONICLES.

Figure 34 *Six Infinity* costumes, Beaconsfield, UK, 2024, photograph by Federico Clavarino.

using images selected from viewers, myself, collaborators, and from the Migraine Art Competition Collection, along with Hubert Airy's migraine aura drawing from 1873.

For the choir piece *Six Infinity*, I designed costumes featuring embroidery inspired by the numerous drawings I have discussed in this chapter (Figure 34). The goal was for the choir to wear a personalised (non)uniform that represented visual migraine auras, fostering communication and camaraderie, especially among those who experience these visions, enabling them to recognise one another and feel a sense of belonging in a reality where conversations about such experiences of visions and pain are generally absent. The costumes also aimed to illustrate to those without migraines that visual auras are a tangible aspect of the visual experience during migraine attacks.

I have taken to wearing one of my tests for these costumes: a corduroy jacket featuring a skull with a visual migraine aura as an outward sign of my migraines. This jacket has elicited numerous reactions on the street from others who similarly experience visual migraine auras. It serves as a great conversation starter; often, a small group of people with migraines gathers to converse, prompted by the visual cue of the jacket. There is a tremendous sense of camaraderie in recognising another person with CH, as ongoing pain and visual disturbances are part of our lived experience that we typically keep to ourselves. I have recently created stand-alone backpatches like the one I wear (see Figure 36, Figures 39-43 and Figure 66). I have reflected on how backpatches are generally worn as a symbol of belonging or a badge of pride; in motorcycle clubs, as well as in punk, hard rock and heavy metal culture, such embroidered patches display one's affinity for a particular group or identity, proclaiming 'this is me!' or 'I identify with this!'.

Figure 35 *Frederick Weston* by LJ Roberts, 2018, photograph by Megan Martin.

LJ Roberts is a notable figure who works with identity through embroidery. In their series, *Carry You With Me: Ten Years of Portraits*,[83] they represent queer and trans culture via a collection of carefully embroidered portraits reflecting everyday encounters, protest banners, and slogans displayed on clothing. I saw a small selection of the 26 embroideries in this series at the exhibition ‘Unravel - The Power and Politics of Textiles in Art’ at The Barbican in London.[84] I was struck by the tactility, beauty and intricacy of these carefully stitched portraits and how they contrasted perfectly with the unruly back filled with leftover threads, which added a sense of grit to my perception of them. They were displayed in frames hung at a ninety-degree angle from the wall, revealing the embroidery’s front and back. The front of LJ Roberts’ embroideries features photographic images with meticulous stitches. Through the way the frame is hung at an angle, they simultaneously reveal the back of the embroidery process (Figure 35).[85] In the book *Carry You With Me – Ten Years of Portraits*, curator Carmen Hermo states that “Roberts is an ardent proponent of craft from its art historical doldrums, reimagining its quotidian connotation, associations with adornment, and relative accessibility as strength. They embrace craft’s creative resilience, its historical survival, for its queer potentialities.”[86]

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[83] LJ Roberts, *Carry You With Me: Ten Years of Portraits*, 2021 <https://www.ljroberts.net/textiles/carry-you-with-me-ten-years-of-portraits>.

[84] Magdalena Abakanowicz and others, ‘Unravel - The Power and Politics of Textiles in Art’ (Exhibition, The Barbican, London, UK, 13 May 2024) <https://www.barbican.org.uk/whats-on/2024/event/unravel-the-power-and-politics-of-textiles-in-art>.

[85] LJ Roberts, *Frederick Weston*, 2018.

[86] Roberts and others, *Carry You with Me*.

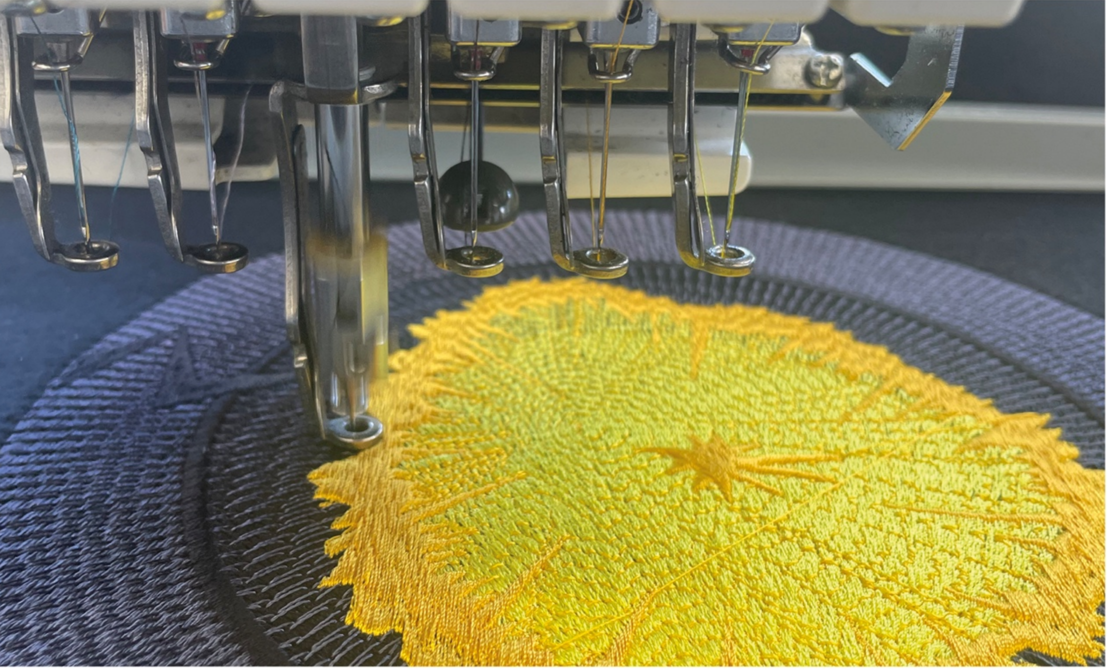

Figure 36 Embroidery process, 2024.

Figure 37 Embroidery gift from workshop participant, SE, 2023.

Figure 38 Embroidery from lecture, HDK-Valand, SE, 2023.

Figure 39 Backpatch, 2024.

I think this is a radical way of thinking about the potential of craft, as well as utilising the tool of a time-consuming, but small and therefore portable medium to add significance to otherwise underrepresented people and stories. LJ Roberts themselves highlights the importance of this in the description of this project on their website:

> One of the central tenants of my practice is the belief that working in textiles mirrors the flexibility and resilience that often permeates queer and trans survival and thriving. The embroideries demonstrate that art centering kinship, persistence, and connection can be made anywhere at any time.[87]

Similarly, these visual migraine aura back patches are small enough to be reasonably easy to produce, portable for display in any context, and visible enough when used on clothing, to foster a sense of community and create visibility among individuals who typically do not come together and whose conditions remain hidden. If I had the time, skills, and patience to work with hand embroidery, I would choose to create by hand rather than by machine because I see how LJ Roberts' way of working adds significance to the aim of elevating the voices of an underrepresented group of people.

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[87] LJ Roberts, 'Carry You With Me: Ten Years of Portraits' <https://www.ljroberts.net/textiles/carry-you-with-me-ten-years-of-portraits> [accessed 11 July 2025].

While it may lack an element of time and artistry, this punk and bike-club aesthetic I have created, similar to LJ Roberts' project, aims to provide a means of gaining political agency over how we wish to be perceived while also creating a potential visual cue and a sign of an otherwise invisible sense of companionship for people with CH. Belonging to a group of individuals who experience invisible, ongoing pain is not something we typically have methods for making visible. However, if we could genuinely perceive how many people live with ongoing pain, we might feel more inclined to share our experiences with chronic pain.[88] By producing visual representations of our experiences and collecting and distributing stories of CH through artworks, I aim to facilitate the development of a shared visual language that can enhance our verbal communication and foster new and nuanced ways of talking about CH. Only when we make our experiences visible can others meet and acknowledge us. As Sonya Huber expresses their sense of community: "I think in understanding how much I and we are up against, I'm very proud of us."[89] At the end of *Six Infinity,* they conclude: "All of us on the pain landscape: all the pain people."[90]

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[88] In 2019, the National Health Service in the United Kingdom (UK) estimated that 34% of adults over 18 experience chronic pain, with 48% identified as CH being the most prevalent. See: National Institute for Health and Care Excellence, 'How Common Is It?', April 2021 <https://cks.nice.org.uk/topics/chronic-pain/background-information/prevalence/#:~:text=An%20NHS%20Digital%20survey%20found,aged%2075%20years%20and%20over.>.

[89] Huber, 'Conversation with Katrine Skovsgaard on chronic headaches (recorded)'.

[90] Katrine Skovsgaard and Rosanna Gunnarson, *Six Infinity*, 2023 <https://vimeo.com/941573561/064eb04ae9, https://on.soundcloud.com/tgHCPLhxh2CxqBCX6>.

Figure 40 Backpatch, detail, 2024.

Figure 41 Backpatch, 2024.

Figure 42 Backpatch, 2024.

Figure 43 Backpatches, 54 Camberwell Green, UK, 2024.

# CONCLUDING VISION

In this chapter, I have explored the intersection of visual art and the subjective experience of CH, particularly emphasising the significance of multisensory perspectives through a discussion of visual migraine imagery over time. Through a cross-historical sense of care through letter-writing, and through making artworks that respond to the Migraine Art Competition, I have engaged in creating a practice-led art-history of visual migraine auras. I have explored how the visual migraine aura artworks I created, inspired by this archive, have encouraged audience interaction. I will elaborate on this in my chapter VOICE. In the chapter TOUCH, I will examine the significance of transforming this Art Brut archival work into human-sized sculptural artworks, giving it both importance and tactility. Through visuals, we may discover ways to transcend conventional medical vocabulary and move beyond assumptions about what living with chronic pain entails. Ultimately, developing a shared visual language and a multimodal focus on unique sensory experiences can facilitate better understanding and empathy among those who do not experience chronic pain. By integrating these insights, I advocate for a broader dialogue that includes the emotional and sensory dimensions of CH experiences. In the following chapters, I will further explore these emotional and sensory dimensions through voice and touch.

Figure 44 *Woman with missing vision, surrounded by concerned onlookers*, detail, the Migraine Art Competition, SA/MAR/22.

# VOICE

# COMMUNING

Partaking in communal singing during my early childhood fostered a sense of connection with those around me and made me feel like an integral part of a whole. It has had a lasting impact on me and has shaped my feelings about sound and music and has since led me to explore sound through my art practice and research. How I now use conversations and choir music to communicate otherwise hard-to-express CH experiences connects to the emotional associations I formed with singing in early life. This ingrained memory of singing showed me the power of song as a unifying force. It inspires me as an artist to delve into the power of singing to express the otherwise inexpressible. Allow me to share this memory with you:

Wooden benches in long rows, neighbours and families arriving in clusters and taking their seats side by side. A bass reverberates through the soles of our feet, and a soprano voice rises to a high pitch. The deep-toned instrument teaches us the melody. The adults look for clues in the lyrics on the thin pieces of paper before us. First, we hum and mumble along, and soon, our voices resound through the entire building. We sing as one.

My grandmother worked as a church singer when I was a child. During this period in our lives, she would take me to the local church on Sundays and seat me and my grandfather on the hard benches while she would sit by my side, closest to the aisle. Her outer position allowed her to rise to her feet when needed, letting her voice echo to the vaulted ceiling, reaching everyone’s ears as she sang prayers and hymns in praise; she encouraged everyone, even the most self-conscious, to join in song, their voices held and guided by hers. While I have shared many warm moments with my grandparents, among the fondest of my recollections are the memories of sitting between them in church, my grandmother a shrill soprano and my grandfather a booming bass, their voices ringing through my ears on either side. Even as a child, I understood that sitting between my two elders, singing with all their might, was something special to witness. It was a visceral experience that I was immersed in, Sunday after Sunday. I became so attuned to singing with others that, even now, as an adult, the physical sensation of singing and being surrounded by other voices allows me to reconnect with my now long-passed grandparents. It is the only clear memory of their voices that I can conjure. On the few occasions I find myself in a church, I revel in the communal singing as a ritual that enables me to grieve them and feel almost as if they were sitting right there, their voices enveloping my juvenile self. At this point in my life, I grasped only intuitively and physically, but in hindsight, singing in a group provided me with a profound connection to those around me and offered a sense of community that continues to inspire me in the progression of my artistic practice.

# INTRODUCING VOICE

My strong sense that singing brings people together in community has fuelled my explorations as an artist, creating a context in my search to find new language for CH and ways to better relate to each other. Working with raising the voices of those in pain to convey the experience of CH through art continuously raises the question of how art can increase our empathy for each other by pulling us to new places beyond our existing perspective. I argue here that the artistic mediums of voice and sound, along with the modes of singing and listening, can be used as methods in art practice to expand and offer critical perspectives and new ways of thinking and talking about CH. By making our experiences public through song and politicising our bodies, we can gain insight into our perceptions of CH and create space for the often silenced and invalidated voices of those in pain.

Reflecting on how to best reveal the experience of CH and the impact the resulting artworks may have on viewers prompts me to recall moments when I move beyond my own perspective and feel a connection to others. A formative memory of my grandparents singing beside me made me feel connected to others, specifically those around me, whose voices I listened to. We often associate empathy with the act of listening. In his book *An Immense World*, journalist and author Ed Yong states, "As the sense that underpins most of our music and language, hearing can be hard to separate from the sophistication of thought, emotionality, and creativity.”[91] Music, specifically singing together, which I will explore here, is a powerful means of fostering empathy and social bonds between individuals.[92]

In this chapter, I will explore the connection that music can bring between people and focus on aspects of voice as sound and narrative, as well as on conversation-as-method, and analyse the process and outcome of the choir piece *Six Infinity*, which I created in collaboration with Rosanna Gunnarson. The first section, CONVERSING, engages with the research process of conversation-as-method. I analyse the potential for art to initiate a conversation that typically goes unheard about CH and rationalise the choices behind a series of interviews, recorded throughout my research, that have served as one of my primary sources. In POLYVOCALITY, I share my findings from these conversations and creative research processes, uncovering and discussing the inherent polyvocality in CH narratives. In SINGING, I examine the process and the art pieces that have emerged from my recorded conversations and have informed my further research on CH. Here, I discuss my decisions with my collaborator, Rosanna Gunnarson, and our inspirations and intentions regarding the piece. Lastly, in INSTALLING, I discuss the materiality of sound and my choices surrounding how I install or present my sound pieces.

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[91] Ed Yong, *An Immense World - How Animal Senses Reveal the Hidden Realms Around Us* (Random House, 2022), p. 135.

[92] Cavarero, *For More than One Voice*.

Figure 45 *Chronicles* and public conversation with Anke Samulowitz, Röhsska Museum of Design and Craft, SE, 2023, photograph by Vanja Van Yurick Hermelin.

# CONVERSING

When we talk about CH outside of medical contexts, it is easy to assume a collective understanding or have a preconceived notion of what living with CH entails for the individual involved. Friends who may lack medical knowledge find headaches relatable (from how we use the term in other contexts) and, therefore, tolerable; however, these preconceived notions may not accurately reflect the experience of a specific person with a chronic pain condition. In fact, pain is nuanced and highly subjective in how individuals experience and respond to it, and preconceived ideas about pain can invalidate the complexity and nuance of that experience.

The way we talk about pain influences our perception of it and impacts how we view those who experience chronic pain. For example, the language of diagnosis places speaking about the experience of pain in a difficult position since diagnostics allow us a common language to express the difficult aspects of being human in a manner that is precise for the initiated but can be impenetrable and easily misunderstood by others. It enables us to speak about pain in an objective, medicalised way, but does not guide us on how to talk about the subjectivity or emotionality of living with pain. We place all other biographies in parentheses, and the richness of subjectivity is set aside when we concentrate on the detached and seemingly objective language of diagnosis. Pain is a profoundly personal experience and may not align with others’ pop cultural understanding of a given diagnosis. For instance, to most people, a migraine signifies a headache. Still, they might not grasp the frequency, duration, and severity of attacks that someone with migraines experiences, or even the personal impact it has on their daily lives and the additional disruptions they may face alongside the pain.

In our conversation, artist Anders Aarvik spoke about his experiences with the widespread misunderstanding of the migraine diagnosis and how it impacts his conversations with friends:

> I couldn’t leave the house … because I couldn’t see – one-third of my vision was failing. When I said to them, “I have a migraine,” they just thought it was an excuse to not go out. It’s always: “You have a migraine? Can’t you just try it anyway?” … I was like, “I’m so frustrated because I wanted to go on vacation, and I couldn’t drive when I was supposed to drive.” They were like, “Oh, you can drive anyway. You can drive with a migraine. That’s easy, I’ve done that.” But that’s not possible when you have an aura. Then I realised that what they talked about was a headache.[93]

This quote reveals that when we engage in conversations with those close to us, and they tell us about a diagnosis like migraines, we often assume we fully understand its implications. However, the air can be filled with preconceptions, and we may neglect to ask for specifics from the person experiencing the diagnosis. This oversight can be harmful in various ways. Sophie Richings shared during our conversation that onlookers have called an ambulance when she has experienced a migraine attack

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[93] Anders Aarvik, Conversation with Katrine Skovsgaard on chronic headaches (recorded), 5 March 2024.

because they misinterpreted her specific aura symptoms, such as slurred speech and slow movement, as a heart attack. She now keeps a note on her phone explaining what is happening.[94]

The language we use to talk about pain, as illustrated in the previous examples where we have adopted the term migraine to refer to a headache, or how researchers may describe a 'migraineur personality' to characterise a difficult woman, shapes our social reality and likely influences how individuals in pain are treated, how they are perceived, and how we expect them to behave. In their introduction to the research paper *Is Chronic Pain A Disease*, pain researchers Milton Cohen, John Quinter, and David Buchanan argue that "disease language is explanatory and powerful and shapes our social reality. In all societies, how diseases are conceived determines not only how people are treated but also how they are expected to behave."[95] Professor of Philosophy Havi Carel agrees: "dominant and culturally specific approaches to illness provide a script for the ways illness "should" be experienced."[96] This perspective invites us to reflect on how pain can shed light on our societal priorities and practices. By bringing pain chronicles into the sphere of normative experiences, it can be normalised, and the exacerbation of stereotypes and presumptions can be avoided.

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[94] Kaitlin D'Avella, Conversation with Katrine Skovsgaard on chronic headaches (recorded), 18 October 2024.

[95] Milton Cohen, John Quintner, and David Buchanan, 'Is Chronic Pain a Disease?', *Pain Medicine*, 14.9 (2013), pp. 1284–1288, doi:10.1111/pme.12025.

[96] H. Carel, 'Phenomenology as a Resource for Patients', *Journal of Medicine and Philosophy*, 37.2 (2012), pp. 96–113, doi:10.1093/jmp/jhs008.

Art can play a crucial role in voicing otherwise invisible and complex experiences of pain in new ways, providing vocabularies that may allow us to step outside our assumptions. By engaging with artworks that chronicle the lived experiences of CH, we can challenge the traditional hierarchies and dichotomies of doctor/patient and emotional/intellectual that often silence or invalidate the voices of those in pain.

Through its multimodal ways of interacting with our everyday lives, art invites us to reflect on and even reconsider how we witness, experience, and express pain. For example, visual artist Deborah Padfield and headache researcher Joanna Zakrzewska showed in a cross-disciplinary study addressing the value of images and image-making in clinical encounters around chronic pain, that including art in clinical interviews about chronic pain profoundly changed the conversation and the behaviour of clinicians. As a motivation for the study, they wrote: “The challenge for those treating or witnessing pain is to find a way of crossing the chasm of meaning between them and the person living in pain.”[97]

Deborah Padfield produced a deck of pain-themed cards in collaboration with thirty-five individuals living with chronic pain (see Figure 46 and Figure 47). The cards show representations of pain, often metaphorical or simplified sensations such as knives, needles, broken glass, fire, tools and electrical wiring. They studied the use of these images in clinical interviews. They found that they had a clear impact on these conversations: using the pain cards changed the distribution of how much patients and clinicians each spoke during clinical conversation, from the regular clinical interviews where clinicians spoke a large portion of the time, to the interview that included Deborah Padfield’s pain cards where

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[97] Padfield and others, ‘Images as Catalysts for Meaning-Making in Medical Pain Encounters’.

Figure 46 Workshop, *Encountering Pain Conference*, UCL, UK, 2016, *PAIN CARDS* on desk, co-created by Deborah Padfield with people living with chronic pain, photograph by Deborah Padfield.

Figure 47 *PAIN CARDS* on desk, co-created by Deborah Padfield with people living with chronic pain, photograph by Deborah Padfield.

patients spoke for a larger portion of the time. They also found that patients and clinicians would get physically closer to each other, and display what the researchers call ‘affiliation- and democratised behaviour’ when using the cards. Deborah Padfield and Joanna Zakrzewska conclude: “Exploring meaning is an essential part of understanding pain better, and art can become both a tool for meaning making and change.”[98]

This demonstrates a clear relational role of the artwork. The cards let people with pain express their pain in their own voice and choice of words and imagery, which adds complexity to the pain experience. In this way, the pain cards start bridging the chasm between the person in pain and the clinician, both physically and by offering a new way to voice the subjective inner world experience of living with pain, thereby gaining control in the conversation. The study clearly shows that diversifying how we relate to and talk about pain can reshape our understanding of how we live with and witness chronic pain.

In their introduction to *The Edinburgh Companion to the Critical Medical Humanities*, Professor of Modern & Contemporary Literature Anne Whitehead and Professor of Medical Humanities Angela Woods write that “the critical medical humanities continues a trajectory already established in first-wave medical humanities, although with a closer attention to whose voice is deployed, how, and with what affects.”[99] Finding different perspectives and starting points for conversations begins with

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[98] Padfield and others, ‘Images as Catalysts for Meaning-Making in Medical Pain Encounters’.

[99] Whitehead and others, *The Edinburgh Companion to the Critical Medical Humanities*, p. 11.

stepping into discordance with our habitual clinician-patient-centred exchanges and thinking about the person’s point of view with lived experience, just like Deborah Padfield and Joanna Zakrzewska did by introducing images into clinical interviews. By focusing on the voice and narrative of the person who experiences CH – and especially on how it is felt through the different senses – we sidestep our habitual encounters and create new interactions about CH.

Witnessing each other’s accounts of CH through listening is as important as seeing it, especially since chronic pain is often invisible. By creating space for diverse narratives and non-normative, sometimes conflicting voices in my art pieces, I aim to foster an openness that facilitates meaningful encounters with CH. Through dialogue in my art practice, I strive to provide pockets where existential engagement can occur and where art amplifies the voices of those living with CH. By engaging in recorded conversations with individuals experiencing CH and professionals in fields such as medicine, philosophy, and art within clinical settings, my art projects seek to even out the hierarchies of doctor/patient to present diverse perspectives on equal terms. The resulting artworks aspire to stimulate encounters and conversations that reframe our understanding of CH.

I have started this process of presenting diverse perspectives on equal terms by recording conversations with people who experience CH and those who work with CH. Throughout my research, many individuals have generously shared their experiences of pain with me. These conversations have influenced my thoughts on CH, and I have incorporated quotes into my artistic practice. I will discuss my approach to conversation-as-method and my decisions during this process. In the following section, I will examine how extracting narratives – pain chronicles – from these conversations has become integral to my art practice by analysing the process of creating *Chronicles* and *Six Infinity*, which used the recorded conversations as a starting point.

I initiated these conversations by developing a semi-structured interview inspired by explication interviewing. I crafted a set of questions whose structure subtly subverted the traditional 0-10 pain scale, commonly used to assess pain in clinical encounters (see Figure 30). Instead, I asked individuals with CH and professionals in the field the same questions, as included below. By posing the same questions to everyone, whether they witness or live with pain, I aimed to address the authoritative voice present in medicine and attempt to flatten its hierarchies. This approach addresses the tensions of doctor/patient and blends objective and subjective perspectives while incorporating emotional and intellectual elements by offering creative, academic, and personal testimonies on equal terms. My goal was to formulate questions that could expand the first-person perspective of CH, contrasting the clinical interview format, which typically explores causal relationships or treatment options. I sought to develop questions to facilitate equal discussion among professionals and individuals with CH. By asking the same pre-formulated questions to everyone I engaged with, I also fostered an environment where my unconscious biases were minimised, allowing diverse viewpoints to emerge.

For this primary research, I recorded conversations with CH researchers, individuals working with CH in their jobs, and people who experience CH. I selected researchers and medical professionals whose work interests me, whose views differ from mine and from each other, and individuals with various headache conditions and experiences. Ideally, I wanted to meet people in person to capture the nuances of a conversation between two individuals in a room. Consequently, I mostly met with people from the UK, Sweden, and Denmark, where I have travelled in the period of my research. However, when necessary, I also conducted online video calls with individuals from other locations, such as the US and Australia. I typically met with one person at a time, preferably in their chosen quiet space. At the start of the process, I recorded both audio and video, but I soon realised that video recording disrupted the intimate experience of one-on-one conversations. Therefore, I shifted my approach to recording only audio, allowing for a more genuine and uninterrupted conversation with each person. It became evident that interviewees felt more comfortable sharing their perspectives with fewer devices and distractions. I valued gaining an intimate understanding of an individual's experience of pain more than accumulating a large volume of material for future artistic endeavours.

When I sat down to formulate the questions, I considered how to initiate a conversation and ask questions that would allow the respondent to share their story. I sought connection, empathy, and identification; from that starting point, I developed a set of questions in hopes that they could prompt dialogue so that each person could be themselves and respond creatively. I asked the same eleven questions to everyone I met, allowing their specialities and experiences to guide the conversation. I kept the questions open and avoided guiding or intervening in the responses, generally staying silent and actively listening. Before the conversation began, I spoke about my research background and its artistic output. I encouraged my conversation partners to select moments and anecdotes to explore, drawing upon their own experiences or specialities in answering the questions. I spoke with Anders Aarvik, Michael Banissy, Lene Baad-Hansen, Katerina Cerna, Hannah Clarkson, Kaitlin D'Avella, Peter Drummond, Peter Goadsby, Sonya Huber, Nadia Lesniarek, Melinda Nicola, Jes Olesen, Cameron O'Loan, Sophie Richings, Anke Samulowitz, Helena Backlund Wasling, and Joanna Zakrzewska. For descriptions of these individuals, please see the appendix titled PEOPLE I HAVE SPOKEN WITH. The questions I asked were as follows:

0) **What is a chronic headache?**
1) **What is something new and exciting you have discovered about CH recently?**
2) **What are your thoughts on the language we use when discussing CH?** How is it expressed and negotiated? What are your thoughts about pain scales?? Do you perceive barriers or bridges in the language surrounding CH?
3) **How does CH feel?**
4) **I would like you to think about CH through a multisensory lens. What does CH look like?** Can you describe it in abstract terms? (Sound? Smell? Taste? Touch?)
5) **What is the relation between narratives of pain and lived experience?**
6) **What is at stake for persons with CH and their families?**
7) **What can be learned from the encounter with CH by those who experience pain and those who provide care?** Or in those interactions?
8) **What are the values of integrating the methodologies of art with those of medicine?** What are your thoughts on how art can be used within medicine? Do you know of artworks that remind you of CH?
9) **How can clinicians respond more productively when encountering bodies in pain?**[100]

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[100] Deborah Padfield and Joanna Zakrzewska, ‘Encountering Pain’, *The Lancet*, 389.10075 (2017), pp. 1177–1178 (p. 1177), doi:10.1016/S0140-6736(17)30756-0.

10) **Is there a question you would like to ask someone else?** For persons in pain, clinicians, etc. What question do you think needs to be asked or is missing in the ongoing conversation about CH?

I formulated questions that I hoped would bridge what cognitive scientist Dr. Michael Kimmel refers to in his lecture, *Phenomenological Interviews*,[101] as 'the double challenge': the fact that people generally know more than they can articulate and find it difficult to access tacit, intuitive, or embodied dimensions of knowledge, compounded by the widespread belief that introspection is often unreliable. However, with a condition like CH, introspection is already the primary source of information that medical professionals can use to gauge pain. Hence, in this context, I found these methods suitable because I aimed to convey the intrinsic subjectivity of pain and access sensory information through a dialogical reconstruction of experience. One drawback of speaking with individuals who are not currently facing a pain attack is highlighted by Michael Kimmel, who quotes professor of Philosophy Giovanna Colombetti, stating that "the pre-reflexive body is a 'background'."[102] This implies that we only notice our bodies when the usual functions we typically take for granted fail. Because this kind of information can be hard to access, I sometimes had to probe further, pose additional prompts, or seek clarifying questions. A further limitation of this approach is that I only had between an hour and an hour and a half with each participant, and that lived experience is much denser and encompasses more

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[101] Michael Kimmel, 'Phenomenological Interviews' (Lecture, Notodden University, Norway, 18 April 2024).

[102] Kimmel, 'Phenomenological Interviews'.

facets than can be verbalised. Nonetheless, I was pleased to discover that many of my prewritten prompts would jog participants' memories and encourage them to share intimate anecdotes.

I focused on managing the conversation by recognising that not everyone needs to answer every question thoroughly. Instead, I allowed their interests, expertise, and personal experiences to shape the interview and guide which questions we spent the most time exploring. I made these intentions clear ahead of the recorded conversation. I intuitively employed what Michael Kimmel describes in his lecture as "embodied relational skills" to reach "inter-bodily resonance." This included silence and active listening, echoing and paraphrasing, while also building rapport with individuals I had not spoken with before. I think that attuning in this way instinctively, I was able to maintain a flow and connect with the individual I was conversing with, allowing them to enter an "evocative state"[103] during which they provided examples and spoke in the present tense about their experiences of pain or, in the case of medical professionals, about treating individuals in pain.

The initial questions on the pain scale of 0-10 were straightforward: "0) What is a chronic headache?" As the scale progresses, the questions increase in complexity: "3) How does a headache feel?" and "4) I would like you to think about CH through a multisensory lens. What does CH look like? Can you describe it in terms of the senses? What does it feel like regarding sight, sound, smell, taste, touch, etc.?" I aimed to get close to the lived experience of pain by asking questions that move away from

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[103] Kimmel, 'Phenomenological Interviews'.

diagnosis and instead engage with the experience of pain and its connection to the senses. I anticipated that some of this information would inform my thinking and art practice.

In retrospect, some of the later questions, such as “7) What can be learned from encounters with CH by those who experience pain and those who provide care? Or in those interactions?” may have been too complex or required a bit more explanation for many people to engage in discussion. However, since I was committed to asking everyone the same questions, I persisted to explore the varied responses they would inspire. The line of questions culminates by inviting the interviewee to pose their own question: “10) Is there a question you would like to ask someone else? Persons in pain, clinicians, etc., or what question do you think needs to be asked or is missing in the ongoing conversation about CH?”

Many of the questions that arose in response to the last inquiry highlighted the difference between other people’s understanding of living with CH and the experience of pain, as well as the numerous complications associated with constant pain. For instance, interviewees posed questions about the social implications of talking about chronic pain and how migraines involve both a prodrome phase and a postdrome phase (symptoms before and after the migraine attack), which is often entirely overlooked by clinicians and those without CH. Both medical professionals and individuals with chronic pain raised questions that called for a closer examination of everything surrounding the headache itself, especially the migraine auras, which do not receive much attention in clinical interviews or academic research beyond serving as a clear diagnostic criterion for migraine with aura. The questions helped me explore CH in a sensory way. When selecting materials from the interviews to incorporate into my art practice, I chose to focus on the sometimes diverging and other times converging viewpoints and anecdotes. I paid close attention to the senses and lived experiences to amplify the voice of the person in pain, trust their knowledge, and give it significance to elevate it to the perceived expertise of the medical professional or researcher.

Conversation, dialogue and coproduction played a significant role in shaping my research. These social elements of my practice enabled me to develop my work, not only through my own experience and existing literature, but also by engaging directly with the lived experiences of many others with CH. My goal was to explore CH in a way that centres the individual experiencing it. These interactions provided me with a closer, yet expanded view of the complexity of living with CH. As an example, speaking with social and medical scientists working with touch and pain led me to incorporate themes of touch into my artworks. As another example, workshops where people embroidered while talking about their visual migraine auras helped me recognise the common patterns I observed in the archives of the Migraine Art Competition. Finally, the many recorded conversations deepened my understanding of the multifaceted nature of CH and allowed me to engage with other people’s chronicles of pain, expanding my focus beyond individual narratives to encompass the plural.

Figure 48 *Six Infinity*, Konstepidemin, SE, 2023.

# POLYVOCALITY

During these interviews, I realised there isn’t just one way to discuss CH. Through these conversations, I have discovered many voices, narratives, and uniquely distinct ways of relating to CH. From the perspective of the person experiencing pain, there is no universal story to tell but a comprehensive collection of chronicles, showcasing a multi-dimensional range of experiences. Even within each person’s recounting of their life with CH, there are multiple, often conflicting, perspectives, voices and modes of expression. I will refer to this as the polyvocality of CH. No two experiences of CH are identical. Rather than seeking a cohesive, universal experience, it is essential to include and recognise contradicting perspectives by allowing the complexity of these diverse narratives to coexist and address their interrelatedness. We can expand our understanding of the vast variations in living with CH by acknowledging that the specific is not universal and rejecting the notion of one voice. Instead, we should invite individual voices to represent this nuance and difference, welcoming the messiness of inconsistencies into a multifaceted understanding of CH.

I aim to reveal this multitude of chronicles through my artwork to deepen the viewers’ understanding of individuals living with ongoing pain. There are many perspectives and no inherent wholeness to the story of CH. I strive to reflect this in my artworks by showcasing the diversity of pain narratives as a collage of voices and as a song that interweaves associations, images, and themes drawn from my recorded conversations. Professor of Political Philosophy Adriana Cavarero's book *For More Than One Voice: Toward a Philosophy of Vocal Expression* offers insights into the power of vocal expression and its relationship to identity, community, and politics. Adriana Cavarero's work advocates for a pluralistic approach and explores the relationality and richness of the vocal expression, which she argues makes it more authentic than the written word. She points to the importance of recognising the diversity of voices and listening to and acknowledging diverse perspectives. She argues:

> Unlike the gaze, the voice is always irremediably relational. It does not allow a detached focus on the object because, properly speaking, it has no object. The voice vibrates in the air, striking the ear of the other, even when it does not mean to do so.[104]

She sees the voice as innately political and a resource to add value to the individuality of experiences. Even within a common experience such as CH, polyvocality allows for the individual to be heard as well as the group. Through the voice, she argues, relationality comes to the fore; the self is revealed actively and is heard and recognised. What is important here is her emphasis on the imperative of voicing invisible or unacknowledged experiences. The voice embodies the lived experience, and its specificity fosters empathy and agency, which is relevant to how I think about polyvocality. My research looks towards her writing and sees strength in sharing the vulnerability of singular and specific voices, rather than the general, as an entry point into letting audiences explore the diversity of views about CH.

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[104] Cavarero, *For More than One Voice*, p. 178.

Emily Candela discusses sound in her paper, *Learning from the Sounding Object:*

> As something that is fleeting but that also is physical and spatial, felt in the body, and connected to concepts and politics of the voice, vocality, and memory, sound is suited for prompting questions, for destabilising that which is thought to be stable, and for re-examining what we think we know … Indeed, sound—the movement of air in the form of waves—has an intrinsic instability that provides agency for discrepancy, polyvocality, dissonance, and even resistance.[105]

This intrinsic aspect of sound, which destabilises, creates, or reveals instability, dissonance, polyvocality, and agency for resistance, as Emily Candela describes, seems perfectly aligned with my work on the subject of CH, since my research demonstrates that pain is more complex than what is recognised in the clinical interview.

Allow me to retrace my steps momentarily. As I researched the medical evidence surrounding CH, in contrast to my findings, it suggested a preference for a one-size-fits-all approach, creating a contained and easily understandable narrative for medical professionals to collect quantifiable data for researchers and fixable narratives for chronic pain. However, CH's lived reality and polyvocality are less neat than a simple scale rating or a singular overarching narrative. My research indicated that CH rarely

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[105] Emily Candela and Eric De Visscher, 'Learning from "The Sounding Object": Sound Design in the Critical Reimagining of Museum Object Narratives', *Design Issues*, 39.2 (2023), pp. 57–71, doi:10.1162/desi_a_00717.

adheres to the tidy records of diagnosis and cure or the measurable and quantifiable nature of pain scales. Clinical professionals require a structured narrative, but this oversimplifies the polyvocality of CH. As I have written, art in clinical contexts such as hospitals and medical practices often feels illustrative of medicine and seldom serves the purpose of reflection. By confining our views to the practical yet narrow domain of medicine and measuring art solely through its relevance to the natural sciences, we only capture the smallest ranges of the human experience of pain using available scales and imaging techniques. Consequently, we mistakenly perceive the natural sciences as an objective and exclusive reality, dismissing knowledge production in art, for instance, through engagement with materiality and multisensory approaches. As artist Rachael Allen states in *The Edinburgh Companion to the Critical Medical Humanities*:

> As visual artists practising at the nexus of arts and human sciences, we venture into sanctioned spaces where the bodies of strangers are anatomised, pathologised and medicalised: to observe, reflect and experiment, to communicate through visual and sensory languages, to ‘entangle’ our modes of knowledge and methods of practice, to extend the peripheral vision of scientists, clinicians, academics, researchers, patients and the public. We immerse ourselves in the dichotomies of the human body – inside/outside, object/subject, personal/universal – in search of the questions and quandaries that are pivotal to our condition as human bodies and beings. Through visual and sensory means, we present these to the public, throwing open the doors to spaces that have privileged access to our bodies in life and death. It is time for the medical humanities to awaken to our proficiency as pioneers of innovative interdisciplinary

> work at the intersection of arts, humanities, medicine and the public, expanding knowledge of the human body and generating new lines of inquiry for more critically engaging research.[106]

This quote aids in understanding the necessity for a space outside of the clinical context where a contemplative environment can be cultivated: a space that expands rather than simplifies personal narratives of pain, accommodates individuals' unique stories, and allows those without pain to enter the life experiences of those with pain with empathy and curiosity. As mentioned earlier by Emily Candela, sound is an excellent medium to destabilise and reexamine our perceptions of these narratives. The clinical context is typically not where these reflections occur. Since bringing this role into medicine would require a considerable paradigm shift, I think it is more attainable to create this space elsewhere. I am not interested in mirroring the aesthetics of the medical space; while artworks that achieve this provide a critique of the clinical and reductive viewpoint in the realm of medicine, mirroring clinical aesthetics does little to foster a new environment with new ways of engagement. I instead develop artworks through voice and aesthetics that achieve the opposite of what I think the clinical space accomplishes. I look towards intimacy, the home, and ways to create a space through sound and material engagement that invites audiences to share their story in novel ways. By shifting the perspective, we can start new conversations and discover fresh and uncharted modes of cognition and ways of understanding CH.

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[106] Whitehead and others, *The Edinburgh Companion to the Critical Medical Humanities*, p. 206.

*Chronicles* was the first art piece I created from these recorded conversations. I became interested in the recurring themes that emerged in the interviews. These themes include the various senses and how they change with pain, particularly during a migraine attack, visual descriptions of migraine auras, and the simplified measuring method of a 0-10 scale. Seeking inspiration for my art practice, I asked several questions about the senses. Contrary to my expectations of needing to ask follow-up questions regarding sensory information, many individuals, both practitioners and people experiencing CH, responded quickly and meaningfully, demonstrating that they intuitively connected CH with multiple senses. They readily shared visual, auditory, olfactory, and tactile information and anecdotes. Clinicians frequently discussed evidence-based knowledge and, at times, its absence regarding migraine auras. Individuals with CH spoke about their bodily experiences and the significant roles that senses other than vision play in their experiences, commonly through nausea, dizziness, heightened sense of sound and touch, and sometimes slow or inhibited movement or speech, as described by Sophie Richings.

To recognise the multiplicity and complexity I heard in the different chronicles of CH, and to share my interest in contradictory viewpoints and experiences, I chose to juxtapose these varied voices as a collage that resembles an ongoing conversation among perspectives and mindsets that likely would not intersect otherwise. The resulting artwork weaves via associations from the observer to the observed and back again, questioning the hierarchy of specialist and non-specialist voices and narratives while decentring medicine as the locus of knowledge about pain. When positioned against one another, these conversations openly explore the threshold between the experience of individuals with pain and the understanding of pain by those witnessing it. I aimed to create intimate encounters by resting on or stroking the tapestry and listening to narratives of CH, not with myself as the sole recipient, like in my early works about pain, but with the person with whom audience members are experiencing the artwork as the conversation partner. Through my art practice, I have observed that activating the senses with art materials and listening to chronicles of CH stimulates the desire to share within audiences. The sound of my art pieces, *Chronicles* and *Six Infinity*, strives to pay homage to this polyvocality. At the same time, the visuals I incorporate portray a range of imagery associated with visual migraine auras. I approach this practice and writing with the understanding that chronic pain is a non-normative experience, and that if we were to accept pain as normative, we would develop a significantly different language, culture, and knowledge surrounding it. By fostering a space for discussions about CH, I want to create opportunities where broader, more expansive, diverse, and inclusive conversations about pain can occur and gain traction.

*Chronicles* invites audiences to lie on a thick woollen tapestry installation shaped like a geometric dome. While standing, faint voices can be heard, but when sitting or lying on the carpet, the voices from my conversations emerge. Each voice articulates their views on CH, with the next voice picking up through association, revealing significantly different perspectives on similar themes. To enhance the experience of polyvocality within the piece, each voice transitions to the next without introduction or context, making it challenging to determine who is speaking and what that person’s area of expertise is.[107] Viewers can relax on the carpet for about half an hour before the installation’s sound loops and starts over. I intend for visitors to feel a sense of community and understanding around the issue of CH.

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[107] This insistence on polyvocality is further emphasised in *Six Infinity*, where quotes from individual voices are linked together and presented as communally sung song lyrics.

Visitors will share their experiences and insights with others and reflect on how we can better support those with CH. The sound and tapestry installation provides a means to explore the intersection of CH, art, and creative expression while offering visitors a multisensory experience. My work is accomplished if visitors linger, engage in discussions about pain, and acquaint themselves further with the available knowledge or activities.

I envision that these narratives could grow: there is no end to the pain; it loops, circles, disappears, and comes back without explanation. For many people with CH, the pain is an ongoing, constant companion. Time distortion is also part of how CH alters the senses. Alice Hattrick discusses the looping and circling of temporality and symptoms, defining the term ‘crip time’. Crip or sick time refers to an evolving understanding of how individuals with disability or chronic illness perceive time, how illness alters this perception, and how normative and ableist expectations regarding time play a role in the construction of disability. The term’ crip’ may seem awkward and unfamiliar to those outside the circles of disability justice and community. In their text, *Crip Technoscience Manifesto*, associate professors focusing on disability studies Aimi Hamraie and Kelly Fritsch define crip as “The non-compliant, anti-assimilationist position that disability is a desirable part of the world.”[108] The fact that current systems and cultures view disability as undesirable or unwanted leads to a lack of accessibility in our social and cultural environments, pushing disability further into non-normativity.

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[108] Hamraie and Fritsch, ‘Crip Technoscience Manifesto’, p. 2.

Alice Hattrick elaborates:

> 'Normal' is different when you live on the precipice, on the edge of both wellness and illness. It is living in 'crip' time: warped, queer, endlessly changed. Alison Kafer's definition of crip time is extra time. Crip – or sick – time is queer, a departure from straight time, 'whether straight time means a firm delineation between past/present/future or an expectation of linear development from dependent childhood to independent reproductive adulthood'. Crip time is different to productive kinds of time, which is really just one – narrow, straight, restrictive – version of time. Crip time is straight time extended, stretched out, bent, warped. Crip time is time that cannot be straightened out. Crip time is the time of being in hospital for prolonged periods, or institutionalized, or in bed in your home most of the time. You can lose a lot of time when you're ill, but you also need more time to do things. You do things slowly, in waves rather than stages. Being crip – sick, ill, disabled – changes your experience of time. 'The present takes on more urgency as the future shrinks,' Kafer writes; 'the past becomes a mix of potential causes of one's present illness or a succession of wasted time; the future is marked in increments of treatment and survival even as "the future" becomes more tenuous.[109]

As Alice Hattrick makes clear, there is a temporal dimension to living with ongoing pain. CH can distort your perception of your future self, altering your understanding of who you are in the present. When you are in pain, it can be challenging to consider your future self. How will you feel tomorrow? Can you

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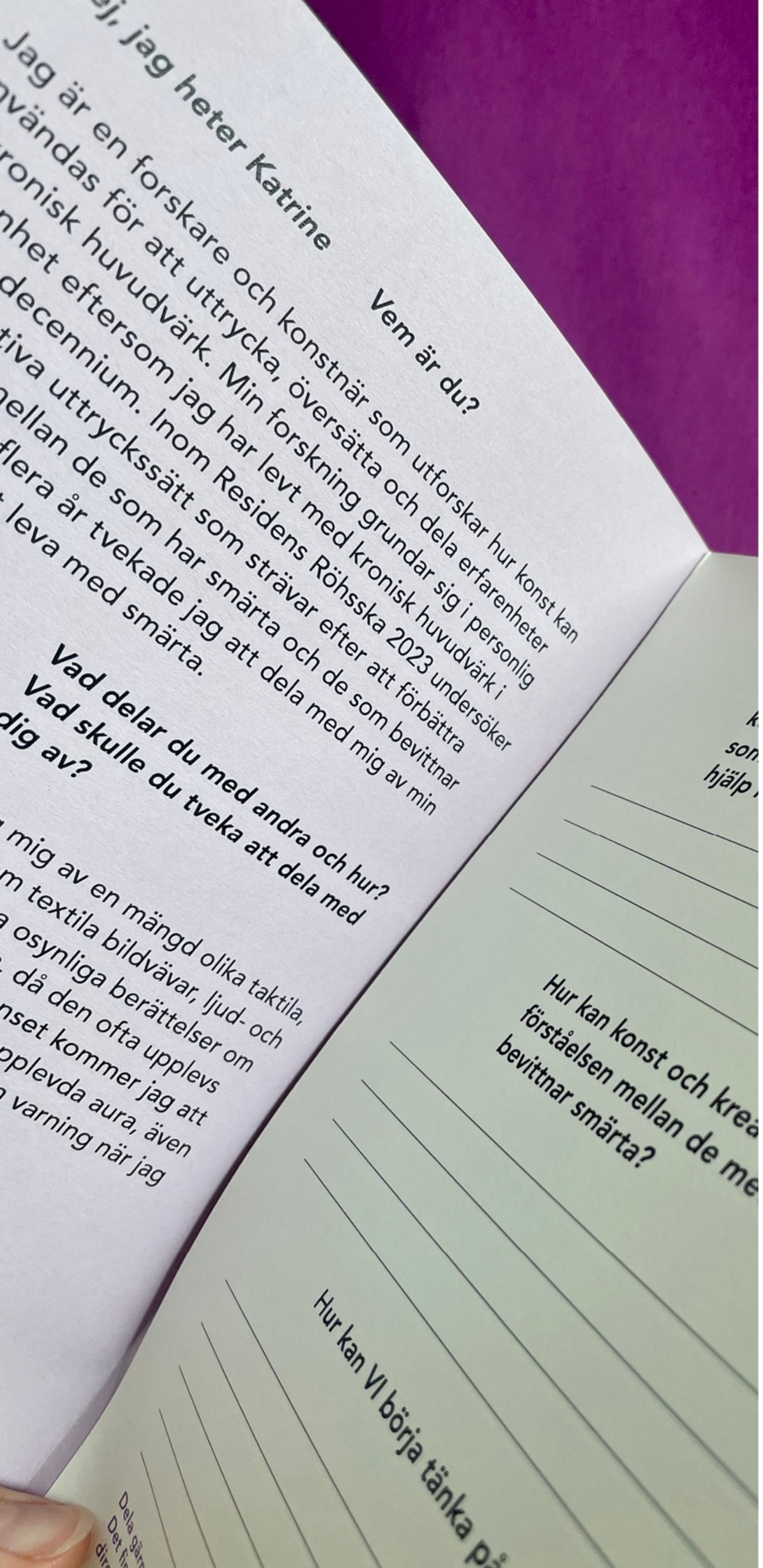
[109] Hattrick, *Ill Feelings*, pp. 81–82.



ej, jag heter Katrine

Vem är du?

Jag är en forskare och konstnär som utforskar hur konst kan
vändas för att uttrycka, översätta och dela erfarenheter
ronisk huvudvärk. Min forskning grundar sig i personlig
nhet eftersom jag har levt med kronisk huvudvärk i
decennium. Inom Residens Röhsska 2023 undersöker
tiva uttryckssätt som strävar efter att förbättra
ellan de som har smärta och de som bevittnar
flera år tvekade jag att dela med mig av min
leva med smärta.

Vad delar du med andra och hur?
Vad skulle du tveka att dela med
dig av?

mig av en mängd olika taktila,
m textila bildvävar, ljud- och
a osynliga berättelser om
då den ofta upplevs
nset kommer jag att
pplevda aura, även
n varning när jag

Hur kan konst och krea
förståelsen mellan de me
bevittnar smärta?

Hur kan VI börja tänka på

commit to your responsibilities down the line? This constant back-and-forth makes planning difficult. Many internal voices are vying for control – should I look backwards or forward? Do I need to relax or push through? The inability to plan isolates you from others, pulling you inward, distorting your perception of yourself and your abilities, and further intensifying the loneliness many already experience.

At my exhibition at Röhsska, many individuals shared these often internal, careful, and sometimes fearful voices with me through letters. I had written a letter inviting exhibition visitors to reflect on how the exhibition's themes resonate in their own lives (Figure 49). The letter contained questions and blank spaces for readers to respond. In return, I received dozens of letters from people who generously shared their personal narratives with me. I received stories about various kinds of literal and mental pain: migrant stories of fleeing and feeling out of place or struggling to fit in; stories about the doubts and fears related to health; and stories of grieving a loved one or a different life. All were handwritten and vulnerable. Some were hard to read and left me touched, knowing that the person who experienced all that grief felt compelled to share their interior story with someone, and that someone became me rather than someone close to them. Some shared that they felt they could not express these painful thoughts to anyone. In my experience, sharing thoughts of doubt and fear for the future can sometimes be hard. My ability to commit to responsibilities and how I feel will also profoundly affect them and our relationship. I felt fortunate to receive these careful first words of opening up from strangers, hoping that these were only the first words of many to come, to be spoken out loud rather than thought privately, while simultaneously feeling heavy knowing that these letters could be a first cry for help, which, through their anonymity, I was not in a position to respond to. Some were brave

Figure 49 Letter for audience members at Röhsska Museum of Design and Craft, SE, 2023.

enough to hang their letters on a corkboard in the exhibition space, while others were sent to me privately through a mailbox in the space. Maybe this was one of many times of opening up for these individuals; perhaps the need to do so is greater when pain waxes and wanes, and symptoms thought long gone reappear, a reminder that time will always be cyclical rather than linear.

The lived experience of crip time is consistently suggested in *Chronicles* through the voices of various individuals. For instance, Sonya Huber reflects on the temporality of living with a chronic condition, which many individuals without such health issues may not grasp: “Oh, you look great. Everything’s awesome. And then I say, Oh, I’m in pain. They’re like, Oh, I didn’t realise you still have that. There’s no way to explain.”[110] She continues, “But the narrative, say, of diagnosis, is like, it doesn’t capture what it’s like to be in the middle of pain because the story has a beginning and an end, and the pain doesn’t end.”[111] Later, she explains that each day feels like living through several short days. I aimed to allow as many of these varied experiences of crip time to coexist in *Chronicle*s, and similarly later, when I worked on the choir piece *Six Infinity*. The title of the choir piece, *Six Infinity*, also suggests crip time. It is taken from Cameron O’Loan’s words when he referenced the challenges of expressing the experience of pain through crip time using the one-to-ten scale: “Usually, it’s very, very rarely a ten. For me, it’s more just like a never-ending six. It’s like a six infinity. And six infinity sometimes can be worse than ten for a day.”[112] Cameron O’Loan questions the relationship between temporality and the

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[110] Huber, ‘Conversation with Katrine Skovsgaard on chronic headaches (recorded)’.

[111] Huber, ‘Conversation with Katrine Skovsgaard on chronic headaches (recorded)’.

[112] Cameron O’Loan, Conversation with Katrine Skovsgaard on chronic headaches (recorded), 19 March 2023.

severity of pain, clarifying to those without chronic pain that constant pain cannot be compared to the acute pain we more commonly experience. With this understanding of the choir piece’s title, I will now delve into the lyrics and contextual framework of the piece.

Figure 50 *Six Infinity*, Röhsska Museum of Design and Craft, SE, 2023, photograph by Maria Jansson.

# SINGING

A person dressed in black slowly walks into a warmly lit, predominantly purple and yellow room. They sit down on a rug-covered purple mound. Their back is turned to the audience, and on it, embroidery depicts a pale skull with a colourful zig-zag pattern protruding from its eye. The person begins to speak: “My pain is very triggered by the weather, so when there’s like a weather system, I think about all of us on the landscape, experiencing it together.”[113] Seven black-clad individuals enter the room while the person on the mound speaks; some gently hum, while others faintly whistle as if imitating the wind rustling through leaves. Everyone wears long black cloaks adorned with multicoloured embroideries depicting explosive imagery of visual migraine auras. When the person on the mound finishes speaking, the eight-person choir sings in harmony: “All the pain people.” These are the lyrics of the song they sing (listen along from hyperlink in APPENDICES - SIX INFINITY):

- My pain is very triggered by the weather, so when there’s like a weather system, I think about all of us on the landscape, experiencing it together: all the pain people.

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[113] Skovsgaard and Gunnarson, *Six Infinity*.

- No doctor has told me anything about my pain, which has been helpful in terms of coping.

- The idea of pain as this constant, unchanging presence, I can’t explain that to someone who doesn’t have pain.

- I don’t talk about it with other people. The concept of chronic pain is so foreign to them that the conversation quickly turns into them trying to give me advice on regular pain that they might have, i.e. “Oh, you’ve got a headache? Have some water!”

- “Oh, you look great; everything is awesome!”
- ”Well, I’m in pain.”
- “Oh – I didn’t realise you still have that.”

- Some days, the pain can be a burning sensation. Other days, it’s a throbbing sensation.

- If a clinician asks me to rate my pain on a one-to-ten scale, they need to also ask me to rate my medical anxiety in that moment on a one-to-ten scale.

- I don’t wash my hair very often because it just hurts to brush it. Some touch is good, and some is not, and sometimes the touch which is good is also not good.

Figure 51 *Six Infinity*, Röhsska Museum of Design and Craft, SE, 2023.

- There are scales with sad-looking faces, very sad-looking faces, extremely sad-looking faces with crying.

- What’s the point of this stupid nought-to-ten scale?

- It’s more just like a never-ending six. It’s like a six infinity. And six infinity can sometimes be worse than ten for a day.

- Like the northern lights in the night sky. A wild and unexpected flow of colours. And you can’t predict where it’s going to go next.

- The pain, it’s always there. Pain alters the sense of time.

- In understanding how much I, and we, are up against, I’m very proud of us, all of us, on the landscape – all the pain people.[114]

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[114] Skovsgaard and Gunnarson, *Six Infinity*.
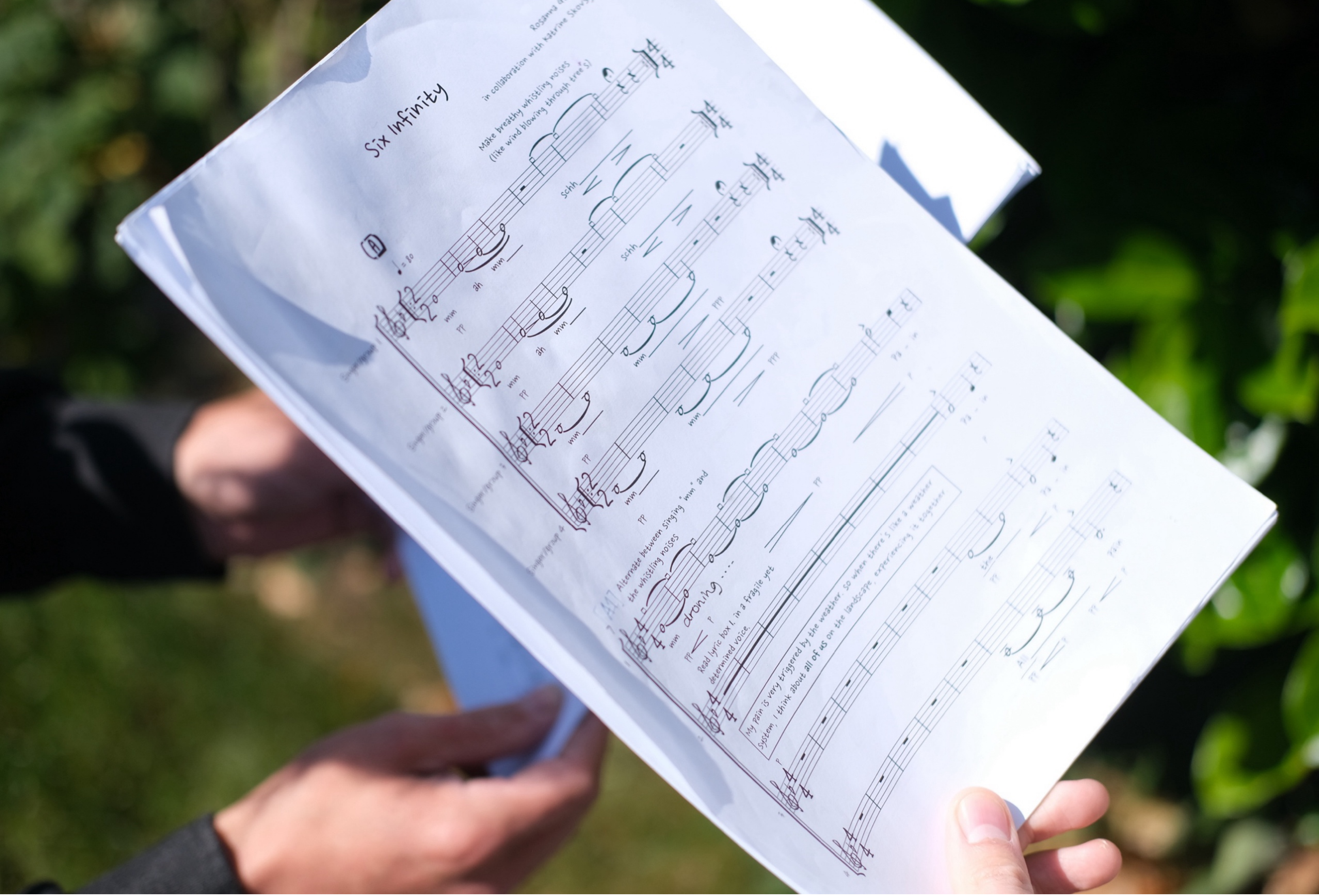
Figure 52 *Six Infinity* sheet music.

During my recent residency at the Röhsska Museum of Design and Craft in Sweden, I collaborated with Rosanna Gunnarson to create a choir piece titled *Six Infinity*. I envisioned this *choir* piece as a polyvocal collage of voices, similar to the sound installation *Chronicles*. The aim was to illustrate the many experiences and stories inherent in CH narratives. For each of the voices to be amplified in the piece to have the potential of being supported by a community of other voices, to convey to audiences that they are not alone, by harnessing the profound sense of community I felt while singing with my grandparents.

Throughout my residency, Rosanna Gunnarson and I worked together. She attended the open workshops I hosted at the museum, providing insights and inspiration for the musical piece (see Figure 14 and 89). As someone without lived experience of CH, her most significant insight was how little she had heard about the headache experience before this and how limited the space is for talking about that experience. After attending a workshop visited by people with chronic pain, artists, and pain researchers, and listening to the voices of *Chronicles* that I had exhibited at the museum, she wrote to me that our collaboration revealed to her how challenging it can be to open up about not feeling well. She expressed her sadness that it was akin to listening to people in hiding who spoke about things they had not had the opportunity to discuss openly. In hindsight, Rosanna Gunnarson shared that she found it humbling to work with lyrics taken directly from people’s stories; the music we created represented their feelings, experiences, and traumas, thereby carrying a responsibility to represent those experiences fairly. She wrote in an email:

> It was important that I didn't over-dramatize with the music or make the words have a different meaning than what I perceived from the interviews. For example, a few persons had a very monotone way of expressing themselves while talking about their pain, so I didn't change that but kept the music monotone in those segments.[115]

Rosanna Gunnarson and I sat down together to draft the lyrics of the piece from a selection of my recorded conversations for *Chronicles*. We identified essential passages to emphasise and discussed musical scales and inspiration. In our discussions, Rosanna Gunnarson and I considered how voice, pitch and emotions could be translated from spoken conversation to music, and how it would be possible to keep the general feeling and content of the conversations when we created a musical score from them. We began by exploring pain scales and emotional diversity, and whether we could convert these dynamics to musical scales or intonations. We debated looping motifs and lyrics to reflect the chronic nature and ebb and flow of pain and crip time, rather than the linear chronology of diagnostic journals. This discussion informed our decision on whether the piece would be in a major or minor key.[116] The choir piece, aimed at liberating chronic pain from the hegemonic judgment of being inherently negative, shifts between the two to convey a multifaceted and nuanced picture of how pain can become a part of someone's life. This approach allowed us to freely express the emotive essence of

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[115] Rosanna Gunnarson, 'E-Mail: Protest Songs', 12 September 2024.

[116] These musical keys have characteristics that distinguish their use based on the feelings the composer wants to convey: the minor scale often denotes melancholy, sadness, and tension, while the major scale conveys a happy, bright, and cheerful mood.

the lyrics and conversations from which they originated by choosing the musical key that aligned with those emotions. By composing a choir piece in this manner, we enhanced the richness of emotion that music can evoke: by utilising both minor and major scales, we allowed contradictory emotions to coexist, juxtaposed and transitioning between different perspectives and the relationships among them. This created tension through minor chords when there was tension in a person’s voice, and relief through major chords when that was the essence of the conversation.

Rosanna Gunnarson initially suggested that the lullaby genre would inspire our choir piece, believing it could have a therapeutic effect similar to how a lullaby lulls a child to sleep. However, my overall vision was for the music to assert its place and serve as a potential agent for change in how we perceive pain. Therefore, drawing inspiration from protest songs, we decided to infuse the piece with the sense of the possibility for change that often characterises such music. By protest songs, I refer to music that has either been inspired by, created in connection with, or appropriated for use in resistance movements or protests, or like in the following example, art that is created as a protest in itself. Artist Mikhail Karikis explores the theme of voicing at protests and proposes listening as a form of solidarity, care and activism in his essay, *Acoustics of Resistance*, highlighting how political agency can emerge through the act of both voicing and listening: “Like a musical instrument in an orchestra, my body was being tuned into a new mutual pitch – a communally shared vibration, an urgent frequency.”[117]

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[117] *Arte Sonora, ecologia e cultura auditiva = Sound Art, ecology and auditory culture: Lisboa Soa 2016 - 2020*, ed. by Raquel Castro (Lisboa Soa, 2021) <https://www.mikhailkarikis.com/wp-content/uploads/2021/10/Mikhail-Karikis-Acoustcis-of-Resistance-EN-PT-Lisboa-Soa-book.pdf>.

Activist artist Rory Pilgrim's multimedia artwork, *RAFTS,* is a collaborative piece that blends videotaped stories, live performances of poems, songs, and dance, along with an exhibition. In *RAFTS,* a group of eight people discusses their mental health, support structures, and how these relate to their environment. Rory Pilgrim created musical scores from poems for the live performance, while singers and dancers performed it live for an audience at Cadogan Hall in London. This highlights and uplifts the stories of their collaborators' voices by giving everyday recollections or poems the significance of composing a musical score. The music provides scaffolding around a personal story that acts as a support structure while simultaneously spreading the narrative and allowing it to resonate with others.

One of the strengths of using music to convey otherwise underrepresented stories is that music allows for different perspectives without creating consensus. The song does not need to present a conclusion; instead, it can contain contrasting emotions and feelings that might otherwise be hard to express without a quick resolution. In an interview with art critic Veronica Simpson, Rory Pilgrim discusses music's ability to embody complex realities as they reflect on why they create music as part of their artistic practice:

> When something feels overwhelming or unquantifiable, maybe you create an emotional resonance with this. That's why songs are so important. Four minutes and they're so graspable.

> and you can listen to them over and over, and they become like soundtracks to our lives, and they change with what we're experiencing in our own worlds.[118]

I resonate with the sentiment Rory Pilgrim brings to light in this quote: that songs can have emotional resonance and encapsulate our experiences in a way that changes how we perceive them. They describe how they want to use song and music to create spaces where we can listen and be heard amidst the complexity of our different lived perspectives, or in their words, "how we deal with such an overwhelmingly global issue on a deeply intimate scale."[119]

> How we create spaces in which we listen. And if I can do anything I just hope that I can create the space where people feel free to speak and also to be heard. To listen and learn and think how that combines and to create a practice in which there is not just my voice but the voices of many.[120]

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[118] Veronica Simpson, 'Rory Pilgrim – Interview: "I Hope the Work I Create Is like a Permaculture – Always Living"', 2023 <https://www.studiointernational.com/index.php/rory-pilgrim-interview-turner-prize-nominee-towner-gallery-eastbourne>.

[119] Rory Pilgrim and Amy Patton, *Tomorrow in Your Hands* (Mousse Publishing, 2022), p. 192.

[120] *Rory Pilgrim: Turner Prize 2023 at Towner Eastbourne*, dir. by Towner Eastbourne, 2023 <https://www.youtube.com/watch?v=ZA8Dt0pIbZM>.

A choir is both an image and a literal practice of working together to make the voices of many heard. Singing in a choir also requires listening to each other to create something powerful through resonating voices. Singing the stories of others, amplifying generally underrepresented voices, becomes an act of solidarity akin to the togetherness I felt with strangers in a church as a kid, or at a concert as an adult. When we agree with someone in conversation, we often mirror their words back to them, fostering a feeling of being listened to. Songs have long provided this mirroring to others while protesting and addressing hardship. For example, during the abolition movement, the suffragettes, and more recently, a 'song bloc' has emerged at the ongoing peace protests. As we protest, we walk in unison, surrounded by the hopeful sound of other voices and, often, drums. One of the songs we sing is musician Alexandra Blakely's melancholic *One Body.*[121] This song expresses the communal essence of the choir in its lyrics: "I don't know if we were meant to carry so much grief in one body"[122] – the song continues to remind the listener (or perhaps the singer) with a repeating chorus line, "yet, we are not alone."[123] Singing this and other songs at a protest becomes, like how Mikhail Karikis describes, a way to participate in the social body, carry the grief of ongoing war as a group, and remind ourselves of our inherent interdependency. The song does not need to provide answers; it simply needs to offer compelling images of what empathy or solidarity might look like and evoke a feeling that others are with us in our

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[121] *One Body*, dir. by Alexandra Blakely <https://www.youtube.com/watch?v=4GzkczKWk_8> [accessed 11 July 2025].

[122] Alexandra Blakely, *One Body, WAILS:Songs for Grief*, 2024 <https://ahlayblakely.bandcamp.com/track/one-body-2>.

[123] Blakely, *One Body, WAILS:Songs for Grief*.

struggles and sorrows. Songs have led revolutions and conveyed important messages even when communication has been challenging or impossible.[124]

The tradition of song as protest can and has sustained movements, even when the people in that movement cannot meet. This is extraordinarily relevant to considering protests concerning disability justice, as illuminated by Johanna Hedva in their manifesto, *Sick Woman Theory*. They discuss the inherent protest of a sick or disabled body: “I thought of all of the other invisible bodies, with their fists up, tucked away and out of sight.”[125] This quote conjures an image of a protest alongside a scene of heavy rock fans pumping their fists in the air in time with the music. These images connect pain and disability to both the joys of music and the inherent protest that Johanna Hedva identifies in disabled bodies, or what they refer to as ‘Sick Women’.

Johanna Hedva discusses how illness is a systemic issue linked to social and cultural values, and they question how we might collectivise and revolt with our sick bodies: “How do you throw a brick through the window of a bank if you can’t get out of bed?”[126] Many have read, received, translated, and

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[124] The Portuguese Carnation Revolution in 1974, which transitioned the country into democracy, was sparked by the signal of radio broadcasting the songs Paulo de Carvalho’s *E Depois do Adeus* and *Grândola, Vila Morena* performed by Zeca Alfonso. Additionally, the movement *Nueva Canción* has allowed South Americans to express collective struggles through song under repressive regimes.

[125] Hedva, ‘Sick Woman Theory’.

[126] Hedva, ‘Sick Woman Theory’.

digested the text since its publication in 2016. Johanna Hedva republished it in 2022 with comments about the scope and implications of their text. Their revisions highlight the ripple effects of the community of crip writers and artists – not only in the unilateral direction from the source of Johanna Hedva's text but also as waves that come back to their source, changing its nature through how the text has been understood and worked with by others, like the echo of a canon song.

The need for sustaining creative outputs about illness and identification with other crip bodies is evident from how this text was received and shared and shared again.[127] It is one of the most widely known and quoted recent writings on illness in academia, art, and online platforms. In their revision of *Sick Woman Theory,* the text *Why It's Taking So Long*, Johanna Hedva argues that the true strength of *Sick Woman Theory* is the call and response and the community it has created among sick writers and artists: "When I'd shouted, "Is anyone there?" into that lonesome dark, they replied, "Yes, bitch, and we're waiting for you!""[128] I would argue that they have also made a significant contribution by creating a manifesto that breaks illness out of its often feminised shell and provides a non-gendered, intersectional term that simultaneously acknowledges and departs from this history.

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[127] Another person whose writing practice deserves a mention here is writer Carolyn Lazard, whose text 'How to Be a Person in the Age of Autoimmunity', 2013 <https://maxwellgraham.biz/wp-content/uploads/2021/08/HowtobeaPersonintheAgeofAutoimmunity.pdf>. is a text about Carolyn Lazard's own chronic condition discussed through other writers. This text brought a discourse about illness into the art world, and, like Johanna Hedva's writing, it has been shared and discussed widely.

[128] Johanna Hedva, 'Why It's Taking So Long' <https://www.topicalcream.org/features/why-its-taking-so-long/> [accessed 11 July 2025].

> The Sick Woman is someone diagnosed with a chronic illness, whose family and friends continually tell them they should exercise more.
> The Sick Woman is a queer woman of color whose activism, intellect, rage, and depression are seen by white society as unlikeable attributes of her personality.
> The Sick Woman has been in therapy for years with a therapist who tunnels into her every childhood trauma but has not once brought up capitalism as a cause of her suffering.
> The Sick Woman is a Black man killed in police custody, and officially said to have severed his own spine. His name is Freddie Gray.
> The Sick Woman is a veteran suffering from PTSD on the months-long waiting list to see a doctor at the VA.[129]

This quote illustrates the inclusivity of Johanna Hedva's 'Sick Woman' and how illness often leads to the othering of individuals. *Sick Woman Theory* has emerged as a creative output and manifesto that paves the way for a vibrant community of writers and artists to reflect on and produce work about their lived experiences with illness.[130] It *serves a*s an inclusive manifesto through its definition and reclamation of the Sick Woman. In this context, a woman becomes a non-gendered representative of the underrepresented or marginalised voice or person. By observing others with lived experiences of pain or disability and recognising how these testimonies reshape my understanding of pain or disability, I am

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[129] Hedva, 'Sick Woman Theory'.

[130] Hedva, 'Sick Woman Theory'.

inspired to share mine and others' experiences of CH to foster more conversations and broaden the understanding of living with CH.

Johanna Hedva discusses in this text how protests in the streets are often inaccessible to people with chronic illness and disability. They assert that sick bodies, however, inherently are a protest against current systems; the way we collectively protest means that individuals with disability and chronic illness remain invisible to broader society. While I agree with Johanna Hedva's argument about the inaccessibility of protest marches, I would suggest that songs can help maintain a movement, even when it does not have a visible presence in the form of organisations, leaders and protest marches. The role of music can be to voice and serve as a vital force in the emergence of new narratives and a catalyst for change. Music's role in identity and identification allows for collective meaning and memory creation, even when the bodies in question cannot meet. Johanna Hedva also discusses and writes about music. In their text, *They're Really Close to Me,* they explore the band Nine Inch Nails and the transcendent and communing power they perceive in music:

> Watching a rockstar onstage, using their body and face to express something interior now made into flesh and sound, can show you all kinds of things: where the edges of your body are, and how they can be dissolved; how you can feel connected to other bodies around you, and also to something you can't see or touch, but which you can hear and feel. It can help you understand *what* you feel, by affording you the sense of recognition: you can hear your feelings

> and thoughts emerge from someone else. But it also shows you what is *possible* to feel, by letting you see what someone else has done with those same feelings.[131]

What Johanna Hedva experienced at a rock concert is akin to the feeling that engulfed me when I was in church surrounded by my grandparents, or at a protest. It likely contributes to explaining why attending concerts is one of my favourite activities – songs can convey knowledge and storytelling, expressing narratives that originate from individuals but can resonate and be enriched collectively. Singing allows for expressing ideas in a collective voice that may be challenging to articulate with the vulnerability and inherent risk of raising your individual voice in dissent or dissonance.

To pay homage to the history of song as protest, we included motifs from a selection of protest songs within the piece for *Six Infinity*. It is possible to identify motifs from songs like musician and activist Buffy Sainte-Marie's *Universal Soldier*[132] and *God Is Alive Magic Is Afoot*[133], heard clearly in the lyric line, "There are scales with sad-looking faces." This monotone moment stands out against the otherwise shifting tonalities of the piece, which vary with the tone of voice of the person I interviewed and the

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[131] Johanna Hedva, '"They're Really Close to My Body": A Hagiography of Nine Inch Nails and Their Resident Mystic Robin Finck', 2020 <https://www.thewhitereview.org/feature/theyre-really-close-to-my-body/>.

[132] Buffy Sainte-Marie, *Universal Soldier*, 1964 <https://open.spotify.com/track/4MCI71gpCGwHsK2rv7c8pv?si=6a7676d6c21e486f>.

[133] Buffy Sainte-Marie, *God Is Alive Magic Is Afoot*, 1969 <https://open.spotify.com/track/4K3glAui6GSMQfYWxC0qy9?si=3878610840024bdd>.
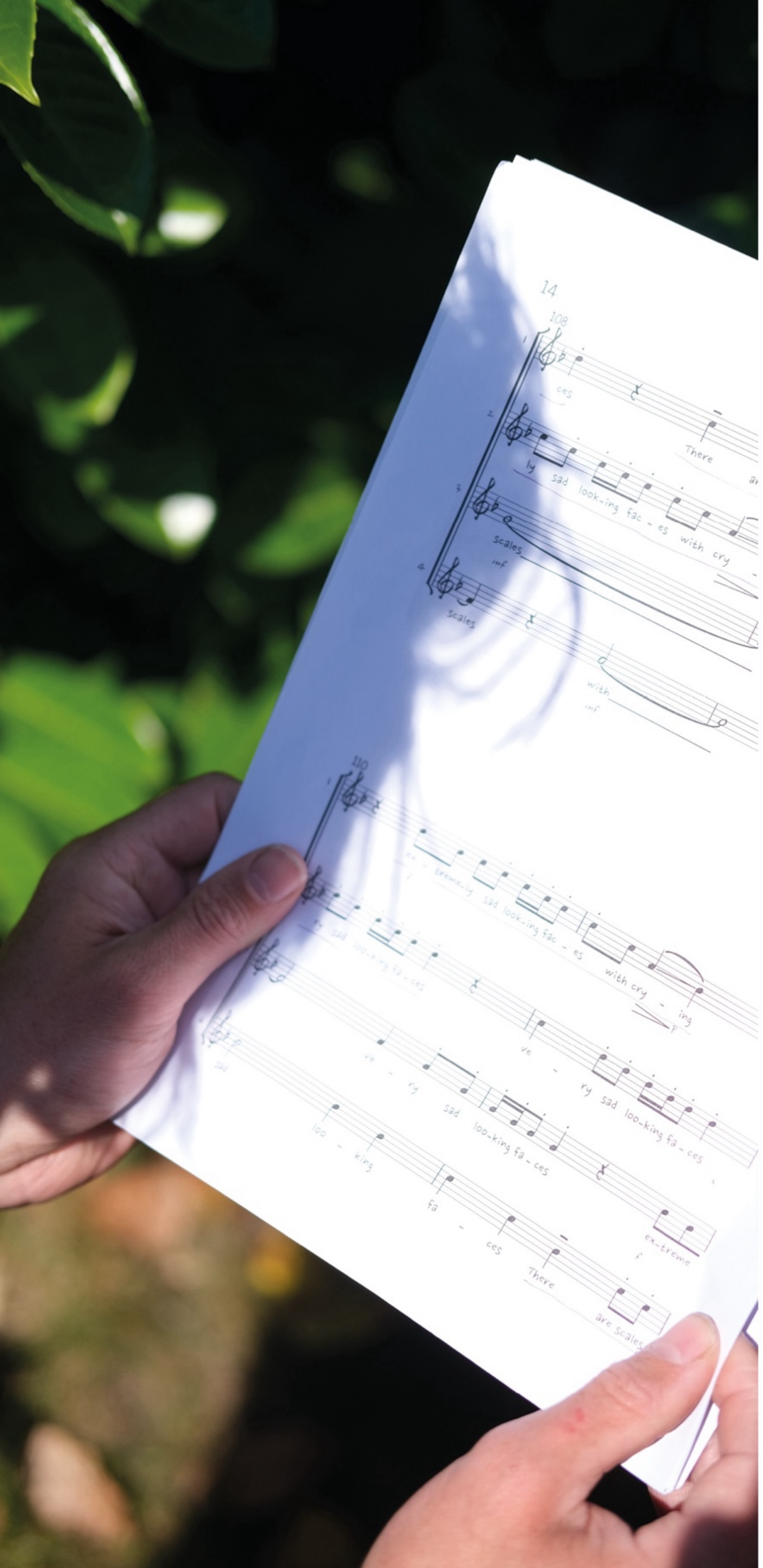
Figure 53 *Six Infinity* sheet music.

sometimes-humorous tone in the conversations that contrast with how many people might perceive living with chronic pain. These songs, used as inspiration, capture the seriousness of how our systems impact our individual thinking and actions, imbued with the hope that love and our understanding of our bodies and relationships can bring about positive change. Buffy Sainte-Marie's album *Illuminations*, where *God is Alive Magic is Afoot,* first appeared, is the first quadraphonic album ever recorded. When I recorded the live performance of *Six Infinity* and later presented it as a sound installation, I felt inspired by this method of recording, which, using four channels rather than the usual two, recreates a realistic effect of experiencing music live in space during playback.

By creating a musical piece for a choir, I aimed to explore the interplays between singular and plural voices, call-and-response, harmony and disharmony – voices that support one another while also creating tension. We experimented with parts of the piece being spoken or sung by a single voice, some featuring conversations between distinct voices, and others transitioning from a solo voice to a supportive choir, ultimately fostering a sense of community as the choir piece concludes. Some of the more monotone sections focus more on rhythm, such as the scales example above, and the spoken parts where the choir mimics how people without pain can inadvertently offer unsolicited advice, thus diminishing the experience of those in pain. The dynamics and range of the music emphasise specific moments, like when Joanna Zakrzewska asks, "What is the point of this stupid scale?"[134] This is musically represented as the highest pitch and volume in the entire piece. In the outro of the choir piece, a solo singer recites: "In understanding how much I and we are up against, I'm very proud of us,

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[134] Skovsgaard and Gunnarson, *Six Infinity*.

all of us on the landscape,” [135] and the entire choir joins in to close the piece and declare themselves as comrades: “all the pain people.”[136] These opening and closing lines pay tribute to the conversations from which the song lyrics stem, framing the entire piece within the context of spoken words and connecting it back to *Chronicles* and the original dialogues that inspired the piece.

At the end of the residency, *Six Infinity* was performed live by Hvitfeldtskas Dubbelkvartett within the context of my exhibition at the museum, as well as at an event at the local residency space Konstepidemin (formerly an epidemic hospital), where I lived throughout my residency, to celebrate all the many individuals who supported or participated in the process through conversations, workshops, and artworks. When the choir first practised singing *Six Infinity* at a practice session and later performed the piece live for an audience, I was surprised by how incredibly moving it was to hear the words of individuals now emerging and filling the room in harmony. Moving but also, at times, humorous. When sung, the serious and weighty elements take on a character of support and lightness. Hearing the music performed, both Rosanna Gunnarson and I found it to be a beautiful experience, not only because it was executed expertly by the choir, but also because the individual voices and the emotions they convey still resonate clearly in the performance. We found this significant, as we wanted to represent these voices and experiences fairly, as touched upon earlier.

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[135] Huber, ‘Conversation with Katrine Skovsgaard on chronic headaches (recorded)’.

[136] Huber, ‘Conversation with Katrine Skovsgaard on chronic headaches (recorded)’.

It felt relevant that the people I spoke with could talk through our choir piece, more or less directly and unmediated, with those who would hear it. Throughout this process, it has been important to consider how an audience received the pieces, particularly how they might relate to and react to the artwork's body. Artist Janet Cardiff similarly speaks about her installation piece, *Forty Part Motet* (see Figure 55):

> To me, the connection with the intimacy of this piece became really apparent because no audience members would stand up to a singer and stand right next to them, but technology is invisible to the audience, so they feel very comfortable if they walk up and they move around… Our ears are designed for three-dimensional sound. You know they are not designed for mono sound. The soundwaves hitting your body from forty separate speakers in such a pure way really affects you emotionally. The sound just goes totally into you, and if it's the right space it really reverberates within your body. [137]

Working with choir music as installation art, particularly by recording and presenting it as surround sound, allows audiences to connect more deeply with the piece; this is an approach I have explored in my presentations of *Six Infinity*. In a critique of Janet Cardiff's work by Professor of Philosophy Alva Noë, he argues:

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[137] *Janet Cardiff's Forty Part Motet*, Tateshots, 2017, Tate <https://www.tate.org.uk/art/artists/janet-cardiff-4499/janet-cardiffs-forty-part-motet>.

> The artist has said that the work is "like walking into a piece of music." Only it isn’t, not really. It’s not the music, but a curious situation in which one has a technologically-enhanced freedom to explore oneself and one’s relation not only to the musical work, but also to sound and the body and other people.[138]

Alva Noë observes an intrinsically voyeuristic quality in what he refers to as a ‘non-sacred display,’ focusing on the exposed technology and the uncanniness of the bare presentation in the piece’s installation, which places audience members amid forty speakers.

While Janet Cardiff primarily engages with intimacy through sound and explores how technology enables audience members to approach the speakers closely, I also consider the audience’s bodies and how they connect with themselves, each other, and the experience of *Six Infinity*. This piece has undergone many iterations, each examining a new aspect of the challenge of creating intimacy – which is not typically associated with gallery spaces or choir performances.

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[138] Alva Noë, ‘The Power Of 40 Speakers In A Room’, *NPR Cosmos & Culture COMMENTARY ON SCIENCE AND SOCIETY*, 2017 <https://www.npr.org/sections/13.7/2017/03/10/519587414/the-power-of-40-speakers-in-a-room>.

Figure 54 *Six Infinity* and *Chronicles*, SQUASH, UK 2023, photograph by Dolly Kershaw.

# INSTALLING

The bodies of people experiencing my artwork are essential to the work. The intention is to encourage conversations about pain through interaction with the artwork and to involve the viewer’s friends so that I am no longer the sole recipient of their intimacy. To create a space where this feels possible, I have intended to approach the body by working with different parameters, for example, by considering the scale of the body in relation to the artwork and how we might be called to interact with texture, which I will explore in the chapter TOUCH. I contemplate how the viewer or listener might engage with the spaces I create. For instance, will they feel encouraged to touch the artwork, lie down, immerse themselves in others’ stories of pain, and feel safe enough to share their own? Immersion is something I will consider for each new iteration of the work. I did not want a traditional stage-and-audience scene, where the choir stands before the audience, as seen in most modern concerts, where the singer and audience are noticeably separated. Instead, I aim to foster a sense of being part of a whole, reminiscent of my experiences with my grandparents and protests, enveloping me in sound. I have experimented with different versions of the piece; for example, in the live performance where the choir interacted with *Chronicles* (Figure 50), the audience surrounded them. In this performance, I still sensed a distance between the audience and the choir, while the audience actively observed and paid attention to the choir as they sang. A few months later, I installed a recording of the live piece in a surround-sound installation where the audience reclined on *Chronicles* (Figure 54 and Figure 56), surrounded by four speakers playing *Six Infinity*. This sound installation created a reflective space where the audience did not have to watch a live choir sing. Instead, they could sit or lie back, close their eyes while listening, and quietly observe their reactions to the piece. This significant difference in how the audience experienced the piece influenced me and revealed potential directions for future iterations. Consequently, I have recorded the choir piece as an 8-channel track with a choir and conductor Alex Mackinder and sound engineer Joe Hirst. It will be installed as a sound installation on eight speakers, each playing an individual voice. When standing in the middle of a circle of speakers, the audience will hear a choir singing together; when walking towards one speaker, they can listen to the raw vulnerability of a singular voice singing their part of the choir in solitude, hopefully enhancing the sense of a space where the audience can be vulnerable by sharing their own experiences, as talking about this subject requires interpersonal trust and a nonjudgmental atmosphere.

In creating this installation version of *Six Infinity*, and in my subsequent studio recording of the piece, I was inspired and informed by how Janet Cardiff exhibits sound as sculpture. In the installation piece *Forty Part Motet*,[139] Janet Cardiff arranged forty speakers in a rectangular structure, one speaker per person, forming a forty-piece choir singing the 1573 composition *Spem in Alium*[140] by composer Thomas Tallis. When I entered the space where *Forty Part Motet* was exhibited, the sound was so three-dimensional that it felt like I walked into a piece of music and became part of the choir. I want the audience to experience *Six Infinity* from the singer’s point of view, as part of a crowd like in a

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[139] Cardiff, *The Forty Part Motet*.

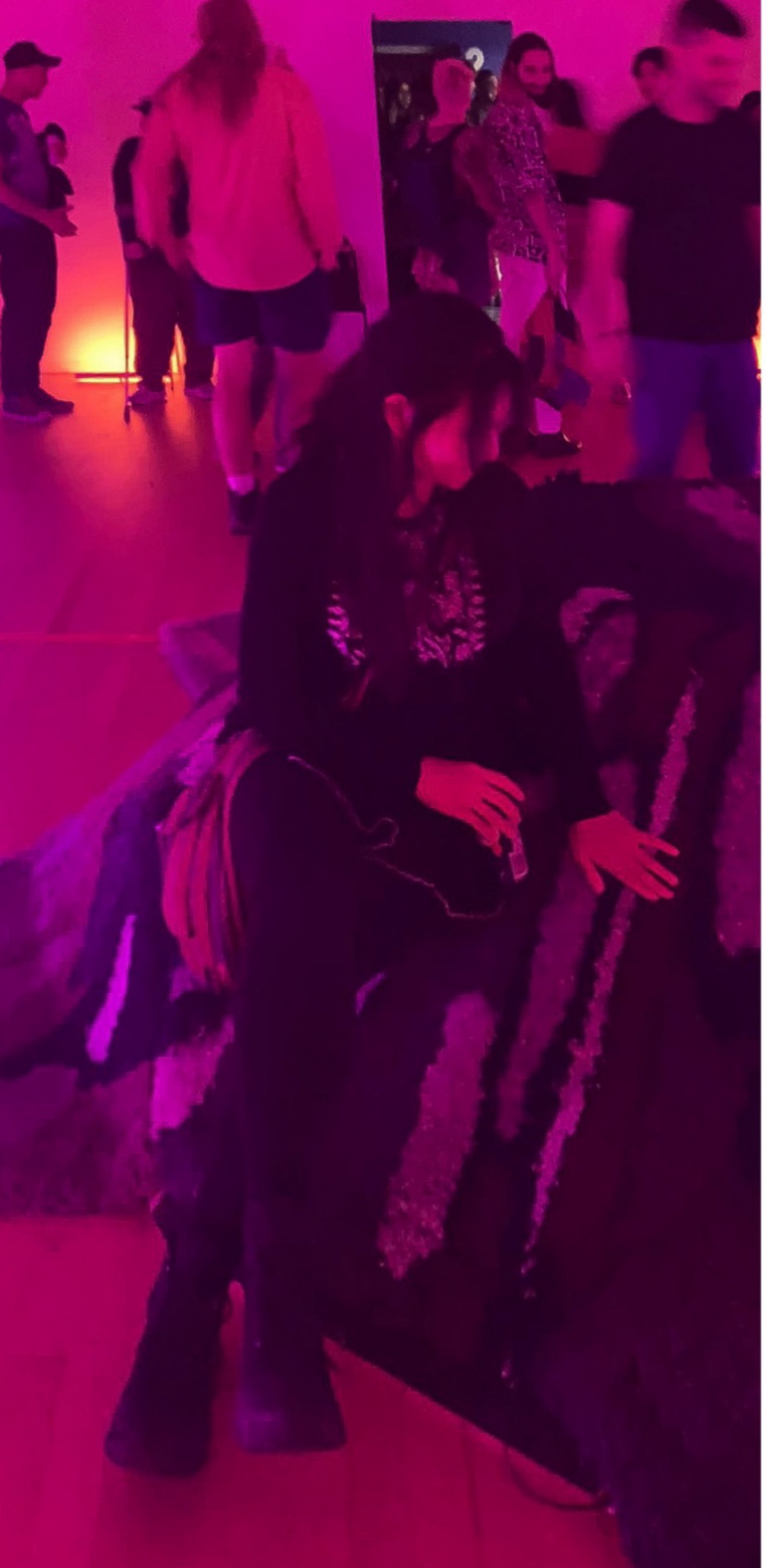
[140] Thomas Tallis, *Spem in Alium*, 1573.

protest march, or as my childhood self seated comfortably between my grandparents, rather than sitting in front of the choir as we would typically experience choir music. This approach allows viewers to be in the space with the voices of the singers, moving through the area to hear different elements of the music, and enables them to connect with the music and the words intimately.

I first tried this surround-sound strategy for the exhibition ‘SQUASH’, where I exhibited both *Chronicles* and *Six Infinity*. In this exhibition, four artists each occupied a squash court in a disused leisure centre, its acoustics heavy with reverberation as the voices from the choir piece echoed throughout, creating new sounds and loops that resonated with ideas of crip time and the cyclical nature of living with CH. Throughout the exhibition, audiences could experience the spoken voices of *Chronicles*. The various individuals I have interviewed about their experiences with or work on CH converse in configurations that would not otherwise occur, weaving through the associations in the conversations to create a collage of voices reflecting diverse thoughts on living with CH.

The choir piece *Six Infinity* would play out in the space at specific times throughout the exhibition. A guide would lead viewers into the dimly lit room and invite them to sit or lie down on *Chronicles*. From every corner of the room, the choir of *Six Infinity* would emerge as a surround-sound installation, with different voices coming from each speaker, enveloping the listener in a three-dimensional soundscape where the choir sang about CH, with lyrics drawn directly from conversations, and several quotes appearing both in *Chronicle*s and *Six Infinity*. Some people had tears in their eyes as the lights came up, and the guide led us to the next performance. That evening, I had many meaningful conversations,

Figure 55 *The Forty Part Motet*, Janett Cardiff, 2001, Fondation d'entreprise Hermès, Tokyo, 2009. Photograph by Atsushi Nakamichi/Nacása & Partners Inc. Courtesy Fondation d'entreprise Hermès.



both with people who themselves had pain conditions and with people who felt they had gained new insight into CH. One person said that the artwork worked as a reminder for them about the dual nature of both positive and negative aspects of pain, and they shared with me their hope that these artworks can ignite more discussions about pain and allow us to embrace pain openly as something that is part of our everyday experience. Another person shared that they do not usually share anything about their ongoing pain because they don’t trust others not to offer unsolicited opinions, which are often inconsiderate and hurtful to receive. A few audience members volunteered that they had CH and asked to contribute to the project by having a recorded conversation or singing in the choir.[141] Music added an inherently emotional and communal element to my art that resonated with the audience in the space, deepening the invitation to talk about CH and creating encounters and interactions among audience members that we likely would not have shared otherwise. My friend, writer Jack Fletcher, shared her reflections and impressions in a text afterwards:

> Lying on the rug next to my friend who experiences chronic pain was particularly profound to me. We felt connected as we were physically elevated, and side-by-side, I could feel his movements next to me, imagine what his body experienced and how different that was from mine. And then there were so many strangers in the room, people who I could never have known outside of this space, and never considered their proximity to pain. It made me connect

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[141] Katrine Skovsgaard and others, ‘SQUASH’ (Exhibition, The Bridge Leisure Centre, Sydenham, London, UK, 9 July 2023) <https://www.instagram.com/reel/Cx-P0oVIw8y/?igsh=MTBveWw3ajJ4ZHpkag==>.

Figure 56 *Chronicles*, SQUASH, UK, 2023, photograph by Jack Fletcher.

> to them, and to wonder how simple things connect to their bodies, alleviate pain, induce it, heighten it.[142]

It is touching to know that Jack Fletcher found it insightful and fundamental to her reflective process to be physically close to both her friend and strangers during that moment of inward contemplation. The many social interactions inspired by *Chronicles* and *Six Infinity* led me to think that, while I agree with Johanna Hedva that many spaces are not accessible to Sick Women like myself, I also reason that there is a fundamental need to be with people in a shared space to initiate conversations about pain. Ultimately, I create environments where the space itself and the collective experiences of those within it enhance the overall experience of the artwork. I aim to create an inclusive and comfortable space, but audiences will need to be present to engage in conversations and feel the intimacy and textures of the art pieces. While I cannot address every artwork to every individual, I strive to provide various points of entry into the pieces through my choices of materials and mediums, allowing for multimodal experiences. Each artwork offers predominantly visual, auditory, and tactile entry points, and the way audiences connect with it will be through their own means to find resonance within the piece, surrounded by stories, emotions, and sensations.

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[142] Jack Fletcher, ‘Choir Reflections’, 17 December 2024.

Ultimately, I hope to foster a communal feeling that arises from sharing what we might not ordinarily reveal. As Johanna Hedva states, when we share vulnerable or otherwise shameful or invisible experiences, the response reverberates far beyond our expectations: "When I shouted, "Is anyone there?" into that lonesome dark, they replied, "Yes, bitch, and we're waiting for you!""[143]

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[143] Hedva, 'Why It's Taking So Long'.

Figure 57 *Six Infinity*, Konstepidemin, SE, 2023.

# CONCLUDING VOICE

This chapter explored the use of voice to bring visibility to CH. From my childhood experiences, I recognised the power of voice, which I developed further in my research and examined in this chapter. I chose to study CH through voice because it is poorly understood and lacks visibility, and the numerous preconceived notions about CH make it difficult to articulate. By conducting and reflecting on conversations, I have gained insight into what I refer to as the polyvocality of CH, to which I could also add plurality and the need for participation in order to politicise our personal bodies. I connected this to my intent of creating intimate encounters that share the multifaceted experiences of CH. There are opportunities for me and other artists to engage with CH, expressing ourselves through voice and music's emotional force. My findings contribute to the repertoire and enable us to nuance our understanding of the lived experience of CH, while also providing care for and between people with CH, by voicing and listening to experiences of CH. In the next chapter, I will delve into the embodied experience of pain by reflecting on the significance of the audience's body in space relative to my artwork. While polyvocality provides a voice to individual experiences and sometimes blurs hierarchies by diffusing the clear boundaries between distinct voices, touch modulates and alleviates pain. I have utilised this capacity in my art practice to create tactile art installations, allowing audiences to touch and interact with the audio pieces I have described here.

Figure 58 *Abstract: a yellow spot on a black background*, the Migraine Art Competition, SA/MAR/63.

# TOUCH

# INTRODUCING TOUCH

In this chapter, I will present the sensory experience of touch and its significance to CH. I will introduce the sensation of touch and its relationship to CH. Touch is vital to our social interactions, especially with those we are close to. Experiencing CH can alter the sense of touch, and these changes in the sense of touch could impact our social interactions. Touch within healthcare interactions can be understood interpersonally to strengthen the relationship between medical staff and patient. Still, more often than not, touch is seen as a tool in clinical interactions and identified with language far removed from how we would talk about social, personal or intimate touch: palpating, probing, percussing, exploring and poking touch, which may leave patient dehumanised or feeling objectified.[144] There is also the 'absent touch' of machines and instruments in the medical practice, the therapeutic touch of certain practitioners, like in physiotherapy, and the fine line between what can be perceived as pleasant, uneasy, inappropriate or invasive touch. I will examine how touch can act as a double-edged sword and how it, in certain respects, is experienced differently, leading to various consequences for those with CH. I will clarify why this is the case and how it has influenced my research and artistic practice. Under the subheading TOUCHING, I will conceptualise the relevance of touch to CH through research related

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[144] Carter Singh and Drew Leder, 'Touch in the Consultation', *British Journal of General Practice*, 62.596 (2012), pp. 147–148, doi:10.3399/bjgp12X630133.

to touch and pain, incorporating recent theories of pain modulation via touch and primary research, which includes my conversations with Michael Banissy, neuroscientist and physiotherapist Helena Wasling, and Professor of Dentistry and tactile analgesia researcher Lene Baad-Hansen, each of whom has integrated touch into their work. Following the discussion on pain research, I will explore pain through touch via a series of artworks and exhibitions I have created. In THREADING PRACTICES, I aim to relate my decision-making process to making art and highlight how other artists have approached touch, including those who have directly engaged with headaches, and how their practices have influenced my work. Artistic references include the tactile creations of visual artists Emelie Röndahl and Elisabet Eriksson, showcased in my exhibition at Röhsska, as well as the works of textile artists Allyson Mitchell, Kustaa Saksi, Caroline Achaintre and Judith Scott. In relation to this discussion of other artists' choices in their works, I will discuss my creations with tactile tapestries tufted from deadstock yarns, which portray visual migraine auras. In the last two sections, titled MAKING and RESPONSES TO THE ARTWORK, I share some reflective writing about my process and explain how my choices in creating artwork are informed by my gathered data, rendering these decisions phenomenological rather than simply stylistic. I draw on examples of how my choices throughout this process have been shaped by conversations with pain specialists and those experiencing CH, as outlined in the VOICING chapter. I discuss how the complexities of these narratives have informed my rug-making practice in my search to create intimate spaces through materiality. I do this by writing about my decisions in the art pieces *Chronicles* and *Aura* and reflecting on how these choices diverge from or connect to those of other artists who are engaging with textiles and visualisations of pain.

Figure 59 Embroidery, Röhsska Museum of Design and Craft, SE, 2023, photograph by Kristin Lidell.

Figure 60 *Chronicles*, Röhsska Museum of Design and Craft, SE, 2023, photograph by Kristin Lidell.

# TOUCHING

Senses become heightened during a migraine attack, as is sometimes also the case for other types of CH. All senses can be affected, but I argue that sensitivity to sound, touch, and vision is among the most detrimental side effects of living with CH. Nausea can leave us feeling unwell, and dizziness may disrupt our balance. However, if the loud sounds of others' voices or the whirring of machines deter us from going outside, if a loved one's touch causes us to recoil, or if we cannot see the face of the person we are speaking to, our social relationships will be impacted too. This is not only due to the pain itself but also because of the heightened sensitivity of our senses, particularly these three senses upon which we rely to connect. We might connect with friends and family through different forms of touch, such as greeting with hugs or kisses. Still, suppose this becomes painful due to CH or the sensory issues related to a migraine. In that case, we might recoil or disengage from these socially accepted rituals, which in turn might be questioned or challenged by those around us. The lack of touch can be isolating, as can the social repercussions of disengaging from normalised social behaviour. I believe that the connection of these senses to our relationships and interactions with others is why they emerged more prominently in my recorded conversations and appeared more intricately woven into the social repercussions of living with CH. They are important to the changed social identity of the person with

Figure 61 *Crouched Figure*, the Migraine Art Competition, detail, SA/MAR/450.

pain, or what Havi Carel calls the ‘ontological attack’ of suddenly having to adjust your life to living with a chronic condition, – socially, physically and philosophically.

Touch, specifically, is the first sense we develop. It is an incredibly nuanced and varied sense, which can mean something different to each of us. With touch, we can transition from inconsequential to salient in an instant. Queer theorist Eve Kosofsky Sedgwick writes in *Touching Feeling* about the irrefutable reciprocity of touch:

> Even more immediately than other perceptual systems, it seems, the sense of touch makes nonsense out of any dualistic understanding of agency and passivity; to touch is always already to reach out, to fondle, to heft, to tap, or to enfold, and always also to understand other people or natural forces as having effectively done so before oneself, if only in the making of the textured object.[145]

This quote illuminates how many contrasting qualities and emotions are connected to touch; it can be comforting and uncomfortable, intimate and connective. The reciprocity of touch is open to debate and cannot be assumed to be symmetrical. In the article *Touch in the consultation*, general practitioners Carter Singh and Drew Leder examine the role of touch within their consultations, specifically discussing the types of touch they integrate into their practice. They address the challenges associated

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[145] Eve Kosofsky Sedgwick, *Touching Feeling: Affect, Pedagogy, Performativity*, Series Q (Duke University Press, 2003), p. 14.

with touch in clinical interviews and the perceptions that may arise from its application. The authors elucidate on the concept of ‘objectifying touch’, which can objectify or dehumanise patients; the ‘absent touch’ arising from the use of machines and instruments in medical practice; the ‘therapeutic touch’ utilised by certain practitioners, such as those in physiotherapy; the necessity of consent; and the delicate distinction between what may be perceived as uneasy, inappropriate, or invasive touch. I argue that the reciprocity of touch extends to entities beyond animate beings. Michael Banissy concurred in our recorded conversation:

> We often talk about touch as a way of connecting with others. But, of course, what do we define others as? Is it other people? Does it extend to objects? What objects does it extend to? And I think in that regard, we can think about our connection to the world around us and our connection to objects and different factors like that.[146]

The context of our lives lies in our interrelations with others; our bodies mediate our experience of the world, whether in interactions with people or other entities. This connection unites us, yet where there is pain, it can divide and isolate. In our conversation, and subsequently in *Six Infinity*, Hannah Clarkson remarked, “Sometimes the touch which is good is also not good.”[147] While some senses may be heightened in chronic pain, touch can sometimes provide relief. Conversely, at other times, it can elicit

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[146] Michael Banissy, Conversation with Katrine Skovsgaard on chronic headaches (recorded), 22 March 2023.

[147] Clarkson, ‘Conversation with Katrine Skovsgaard on chronic headaches (recorded)’.

unbearable pain, distancing us from ourselves and others as we navigate a world where our connections are established through touch.

In our recorded conversation, pain and touch researcher and physiotherapist Helena Wasling explained that touch regulates our nervous system and how we relate to the world:

> Touch has huge implications for regulating your autonomic nervous system. The autonomic nervous system very much influences how you perceive pain and how easily your brain will be triggered to move towards the migraine state.[148]

A well-regulated nervous system is crucial for how pain is perceived and how easily one may be triggered into a migraine attack. Therefore, an effective and accessible method of managing pain is through touch. However, what happens when that touch feels unattainable because the pain amplifies every sensation?

Touch-induced pain modulation has been a significant focus in pain neuroscience since the introduction of the Gate Control Theory of Pain in the mid-20th century. This phenomenon, known as ‘tactile analgesia’, is something we all encounter from a young age; for instance, when we scrape a knee, we instinctively rub the affected area. Studies have demonstrated that touch can effectively alleviate pain. A distinct group of neurons responds to both painful and tactile stimuli, facilitating pain relief when

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[148] Helena Wasling, Conversation with Katrine Skovsgaard on chronic headaches (recorded), 20 April 2024.

these sensations are felt simultaneously in the same region. This effect is particularly pronounced when the head is touched, likely due to the emotional connections formed through facial contact and the associated neural pathways.[149]

There is an exciting opportunity in the impact that tactile encounters, and possibly artworks, can have on pain. Not only does touch alleviate pain, but so does vibration,[150] and sound is merely a form of vibration. In this way, my artworks represent pain through narratives and its remedy through touch and sound. At the 'Tate Sensorium' exhibition, researchers explored how tactile artworks can facilitate the development of emotionally resonant and significant experiences, demonstrating how tactile interactions can effectively create emotional experiences for audiences:

> The multisensory layers on top of the visual appearance of the paintings was described [by audiences] to allow stronger emotional reactions, such as empathy, being immersed, or even scared in front of the artwork. One participant described it as follows: "In a way that gives the

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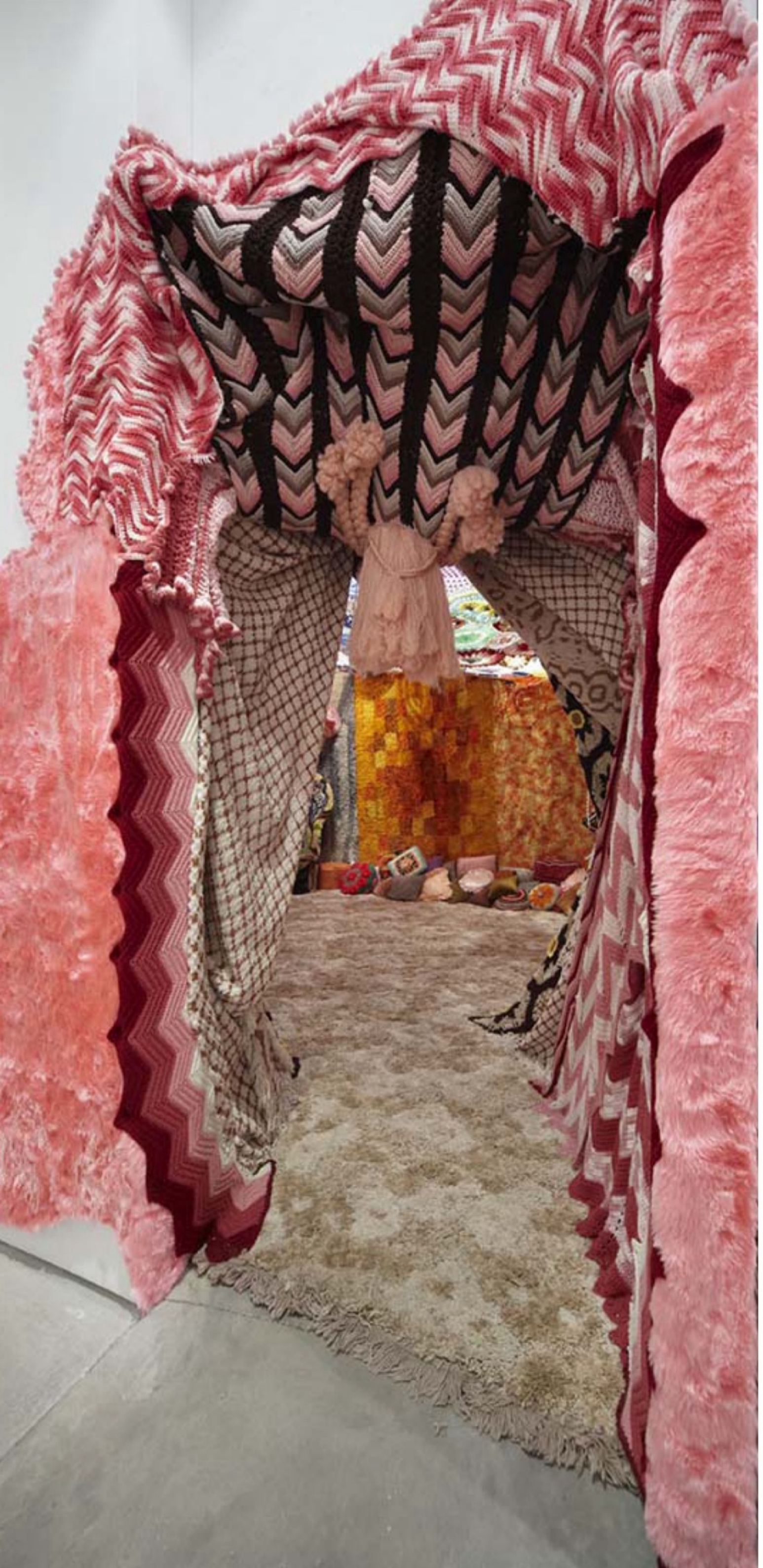
[149] Taneja and others, 'Robotic Stroking on the Face and Forearm'.

[150] R Kakigi and H Shibasaki, 'Mechanisms of Pain Relief by Vibration and Movement.', *Journal of Neurology, Neurosurgery & Psychiatry*, 55.4 (1992), pp. 282–286, doi:10.1136/jnnp.55.4.282.



> painting a narrative having that chocolate, you could build up a story, maybe you're walking in the field.[…] and you could almost pull the mood from the sunshine as well."[151]

Experiments with the affective potential of soft materials strive for immediate interaction with the body, enabling viewers to engage with the work physically. In contemporary art discourse, affect is often defined as the emotional response or intensity that artworks evoke in the audience. Professor of gender studies, Ann Cvetkovich makes the following distinction between affect and emotion: "Where the former signals precognitive sensory experience and relations to surroundings, and the latter cultural constructs and conscious processes that emerge from them, such as anger, fear, or joy." but goes on to say "I tend to use affect in a generic sense as a category that encompasses affect, emotion and feeling, and that includes impulses, desires and feelings that get historically constructed in a range of ways."[152] In this sense, you could say that in my research, the affect surrounding CH is both the subject and method.

Working with affect, materiality and touch in this way could serve as a conduit for making the intangible palpable, fostering personal engagement and nuanced, open, and enriched conversations about pain by bridging the experiential with the artistic. An example of this is how visual artist Allyson

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[151] Chi Thanh Vi and others, 'Not Just Seeing, but Also Feeling Art: Mid-Air Haptic Experiences Integrated in a Multisensory Art Exhibition', *International Journal of Human-Computer Studies*, 108 (2017), pp. 1–14 (p. 10), doi:10.1016/j.ijhcs.2017.06.004.

[152] Ann Cvetkovich, *Depression: A Public Feeling* (Duke University Press, 2012), p. 4.

Figure 62 *Hungry Purse*, Allyson Mitchell, 2004, David Nolan Gallery, New York City, USA, 2010, photograph by Tom Powel.

Mitchell utilises crafts and sensory textile environments to express feelings of apathy and shame associated with vulvas and sexuality. In her piece *Hungry Purse*,[153] she crafted a tactile womb from reclaimed textiles, creating a space where daily life can be experienced differently: from within the physical reimagination of a womb in large scale (see Figure 62). The womb combines many craft methods and materials, comprising various textures: soft, fuzzy rugs and colourful pillows cover the floors, inviting audiences to sit. Intensely orange furry rugs adorn the sides of the womb, and a large crochet canopy is suspended to create a ‘ceiling’ for the womb, making it completely immersive while allowing dappled sunlight to filter through the small holes of colourful crochet. To enter the womb, visitors must pass through a colourful fabric-curtain labia and clitoris made from tactile and textured fabrics and reused rugs. A Public Feeling event, led by Ann Cvetkovich, takes place within the womb to bring this artwork to life by encouraging participants to sit and discuss within the soft comfort of the womb, thereby fostering felt connections and direct communication with others, prompting the audience to grapple with the cultural fears and stigmas surrounding genitals, sexuality, and pregnancy. In this way, Allyson Mitchell works with vulvas and sexuality similarly to how I do with headaches, using soft surfaces and vibrant colours to entice the viewer to approach and touch the artwork. However, upon getting close to the piece, one confronts the reality of Allyson Mitchell’s artwork, challenging preconceived ideas about vulvas, and in my case, by listening to individuals chronicle their experiences of pain. This proximity, and the act of touching, cultivate a uniquely intimate experience with the artwork.

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[153] Allyson Mitchell, *Hungry Purse: The Vagina Dentata in Late Capitalism*, ongoing 2004 <https://allysonmitchell.com/project.html?project=hungry-purse>.

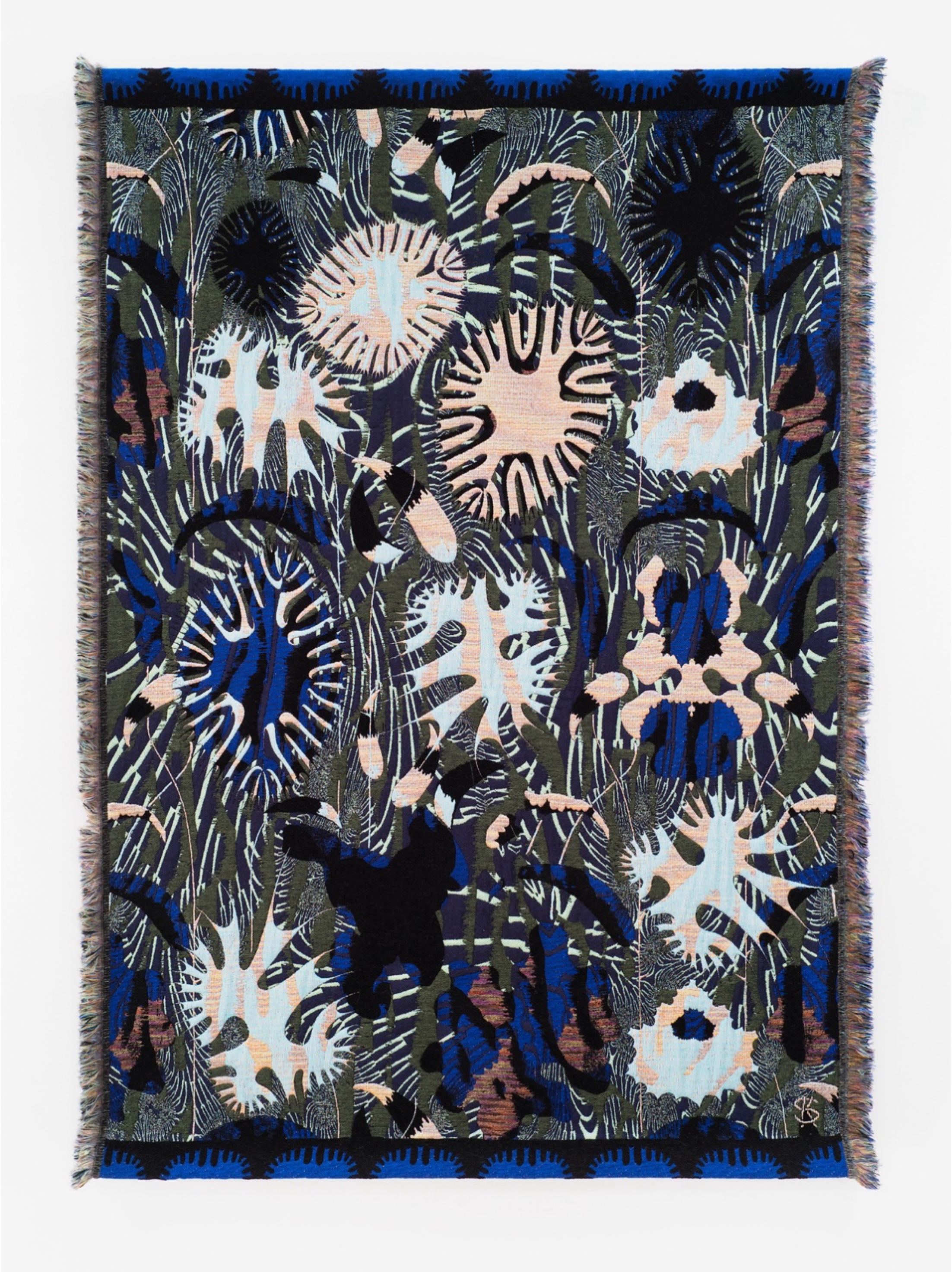

Figure 63 *First Symptoms: Aura* by Kustaa Saksi, 2018, photograph by Jussi Puikkonen.

Figure 64 *First Symptoms: Attack* by Kustaa Saksi, 2018, photograph by Miia Panula.

# THREADING PRACTICES

I don’t intend to depict the migraine aura as solely a visual phenomenon; instead, I aim to transform it into a three-dimensional experience that enhances and adds lived experience to the flatness of the images in the Migraine Art Competition. I want to bring the images to life, allowing them to resonate with the audience. I want to create something sculptural to add dimensions to the flatness of the two-dimensional image, something soft and inviting for viewers to engage with physically, all profoundly influenced by the varied experiences of CH I have encountered through my conversations.

To reflect on my choices in my art practice, I will introduce some visual artists whose work resonates with me and has significantly influenced my thoughts on incorporating touch in my practice: Kustaa Saksi, Caroline Achaintre, and Judith Scott. Multidisciplinary artist Kustaa Saksi creates art closely related to my interests; we both explore the concept of headaches and represent them through tapestries. His reflections deeply inform his artistic choices on headaches, particularly regarding visual migraine auras. An intriguing aspect is that a similar subject and medium have led us in different directions. While I view touch as an essential sense to address in my art practice, he has entirely focused on the visual world of migraines and its connections to other visual phenomena, such as psychedelic hallucinations and sleep paralysis. At the beginning of 2025, I visited Kustaa Saksi’s exhibition ‘Borderlands’ at the Vandalorum Museum of Art and Design in Värnamo, Sweden.[154] He is the only other textile artist I have encountered who creates rugs that explore his visual migraine auras. His intricate, sometimes illusory, kaleidoscopic imagery captivates and excites me, particularly one piece that incorporates reflective yarns, which I find wildly fascinating and extraordinarily appropriate for the subject of migraines. His series, *First Symptoms* – comprising *Aura* (Figure 63), *Attack* (Figure 64), and *Aftermath* – features motifs remarkably similar to my own experiences of migraines as well as those from the Migraine Art Competition.[155] Standing before an artwork created by another textile artist who grapples with migraines is a profound experience, allowing me to sense the parallels between our visual migraine auras – the most striking of which gives me the feeling of logos and artworks from heavy metal music culture. Others hint at the history of scientific illustration, fractals and kaleidoscopic imagery. The size of his work hanging from the ceiling strikes me, along with the substantial impression it leaves on my body while in the presence of new, large-scale works by an artist sharing a similar experience with CH. The wall texts of his exhibitions suggest, “The soft and soothing materials mitigate the painful subject matter.”[156] Likewise, his website reports that he uses “the weaving technique and materials to emphasise the nature of migraine and to accent the healing approach of the artworks as well, them being tactile and gentle constructions.”[157]

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[154] Saksi, ‘Borderlands’.

[155] Anonymous, *Migraine Art Competition Collection*.

[156] Saksi, ‘Borderlands’.

[157] Kustaa Saksi, ‘Kustaa Saksi’s Website’ <https://kustaasaksi.com> [accessed 11 July 2025].

I am drawn to Kustaa Saksi's work because, like me, he finds solace in the tactility of tapestries, but I wonder if this gentleness aligns with my experience of migraines. His neatly machine-made jacquard tapestries are crafted and hung from the ceiling so intricately that they barely reveal any hand involvement in the creation process, which makes me yearn for slight imperfections that could hint at the human behind the work, or the chaotic nature of living with CH. However, Kustaa Saksi holds a somewhat different perspective on this. In the publication *Cosmos*, he discusses the migraine aura as a potential decoder of how our brain functions. [158] His decisions appear well-considered within the neurological approach to migraines, albeit different from my own artistic intentions and contemplations. On his website, there is an abstract conveying how he works with the piece, *First Symptoms*:

> Repeating patterns and rhythmic textures with disorders: sometimes appearing like nerve cells building brain connections, resembling the growing roots of a horseradish or fractal-like Lichtenberg figures – electric discharges on surface. Pulsating, disruptive, delusional, or relieving at times – then aggressive again.[159]

His works exhibit neatness and convey a sense of order to migraines; this quote explores patterns, rhythmic textures and compares migraines to fractal structures in nature. In my experience, migraine auras exhibit these themes, but many of the other symptoms connected to migraines feel disordered

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[158] Kustaa Saksi, Jessica Hemmings, and Niina Tanskanen, *Kustaa Saksi - Cosmos* (Garret, 2023).

[159] Saksi, 'Kustaa Saksi's Website'.

and often uncontrollable. The aggressiveness of his depiction of a visual migraine aura in *First Symptoms,* almost like a heavy metal logo, reveals some of these qualities. However, the overall neatness of his artworks compartmentalises the visual experience, where nothing bleeds into other parts of life, almost as if the artworks serve as a coping mechanism to capture and contain the pain.

My personal experience with CH is that it is far from tidy. When I speak about the messiness I and others encounter while living with CH, I consequently reflect it in my artistic choice of overflowing and sometimes untidy materials. Fabrics fray, yarns unravel at the edges, and backs or sutures remain visible. Observing that someone else has a similar practice centred around migraine auras, yet where the output differs significantly from mine, makes me aware of the multitude of ways that CH can be approached and understood. It also reinforces my confidence in my choices, as they arise from my lived experience of CH, much like Kustaa Saksi's distinct perspective on migraines, which led him to make the choices in his art practice that he does. The contrast between my preoccupation with the physical act of audiences being allowed to touch my artworks and the fact that Kustaa Saksi is also preoccupied with tactile, soft artworks but that I am not allowed to engage physically with his artworks as a viewer, has prompted me to reflect on why touch is so significant to me, as well as which artworks and practices have guided me in this direction.

Caroline Achaintre is an artist whose visceral and inviting work inspires me to explore touch in my artworks. Her work captivates me precisely because of its overflowing and chaotic nature. She creates large-scale tufted rug tapestries with animistic qualities, often alluding to animal hides or masks.

Figure 65 *HEL* by Caroline Achaintre. Courtesy Achaintre and VISUAL, photograph by Ros Kavanagh.

For example, her piece, *HEL,*[160] at the 2024 exhibition at the Warwick Art Centre in Coventry, titled 'Material Worlds: Contemporary Artists and Textiles',[161] was striking in scale, with her choice of materials blurring the line between skin and yarn (Figure 65). The colours in the piece mirror human and animal skin and hair tones. The diverse textures of her yarns, which fray and fall away, evoke the tangles of hair or fur, both rough and soft, suggesting the hair of someone unable to brush or wash it. This brings to mind my conversation with Hannah Clarkson, who frequently avoids brushing or washing her hair due to the pain it brings during her persistent migraines. *HEL* fills the exhibition space with the distinct and intimate scent of wool, akin to the smell of another person's scalp.

Caroline Achaintre's method of hanging her artworks introduces a raw quality that enhances my perception of the piece: the tapestry is suspended by strings from a metal frame, which is positioned slightly away from the wall, exposing the back and revealing her rough treatment of the materials. At times, a threadbare yarn-covered or bald patch appears at the back of the carpet, reminiscent of a balding head; at other times, it droops from the metal structure, resembling the fur of an animal that has recently shed weight.

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[160] Achaintre, *HEL*.

[161] Caroline Achaintre and others, 'Material Worlds: Contemporary Artists and Textiles' (Exhibition, Warwick Art Centre, Coventry, UK, 9 October 2024) <https://www.southbankcentre.co.uk/whats-on/material-worlds-contemporary-artists-and-textiles/>.

Figure 66 *Aura*, portrait with sculpture and backpatch, 2024, photograph by Louise Uth Pedersen.

Figure 67 *Aura*, 2024, photograph by Louise Uth Pedersen.

I aim to harness this kind of rawness in my artworks by bringing these processes to pain, not only to evoke the uncomfortable or uncanny, as Caroline Achaintre does, but also to reflect on the frailty of the human body, the fraying edges of pain, and how it bleeds into many areas of life. There is a need to carry these kinds of materially engaged enquiries to projects that centre on the lived experiences of chronic pain and convey the multi-layered nature of these experiences through choices in materials and tactility, as these processes might illuminate and make visceral and felt aspects of CH that discussing it alone may not reveal. I found Caroline Achaintre's work deeply intuitive; her creations evoke strong bodily connections, in their subtle insinuations through visuals, tactility, smell and general choice of materials, essentially evoking human hair or the hide of some fantastical creature. Before I had even experienced the scale of her work in person, I felt a connection on an aesthetic level; even viewing an image of her work online ignited a desire in me to reach out and touch it. This desire is precisely what I hope to instil through my artworks.

There are numerous ways to instil a desire to touch something and the intimacy that arises from it. Judith Scott is another visual artist whose work has profoundly affected me and engages with tactility in a way that invites intimate encounters. The front cover of Eve Kosofsky Sedgwick's book *Touching Feeling*[162] features a monochrome portrait of Judith Scott, captured by photographer Leon A. Borensztein (Figure 68). Judith Scott stands before a crumpled sheet, burying her face deep within one of her textile sculptures as she embraces it. The sculpture resembles a lump of something concealed

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[162] Sedgwick, *Touching Feeling*.

beneath layers of yarn and rope that envelop the object's core. Its scale and curves surpass those of Judith Scott's body, yet the form quickly evokes thoughts of a human figure. Her gaze appears softened and directed inward. Her body language conveys a sense of relaxation – as if she is profoundly surrendering to the sculpture while tenderly clasping it, akin to a close embrace. This interaction imbues life and agency into her works, and my initial impression of this image was that the art piece transcended being merely an object; through its size and her gesture of tenderness and affection towards it, it acquired vitality and agency. I instantly felt a physical connection to her sculpture due to how she engaged with it. Eve Kosofsky Sedgwick states:

> Through their closeness, the sense of sight is seen to dissolve in favour of that of touch. Not only are the artist's hands and bare forearms involved, but her face is also engaged in the transaction of texture … There is no single way to understand the "besideness" of these two forms, even though one of them was made by the other. The affect that saturates the photo is mysterious, or at least multiple, in quality.[163]

Eve Kosofsky Sedgwick's quote demonstrates the many senses in play in this picture and how Judith Scott's sensitive engagement with her sculpture imbues it with life and makes it an equal body in space. In this way, the sculpture is not only the sculpture, but the photo of the sculpture has also changed how I, as a viewer, feel about the sculpture. Eve Kosofsky Sedgwick's reading of Judith Scott's portrait encourages us to transcend the binary oppositions of subject and object, promoting a more equitable

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[163] Sedgwick, *Touching Feeling*, pp. 22–23.

relationship between creator and artwork. Similarly, this sends threads back to the quote from my conversation with Michael Banissy, where he elaborated on touch as a means of connecting with others, while also questioning the extent of who those "others" can be. He mentioned including objects in his concept of others, concluding, “In that regard, we can think about our connection to the world around us and our connection to objects and different factors like that.”[164] Thus, both Eve Kosofsky Sedgwick and Michael Banissy encourage us to contemplate the reciprocal nature of touch and our relationships with objects – fostering a more fluid and interconnected understanding of relationships and meaning – embracing complexity and nuance.

When I saw her pieces at the Gallery of Everything at the ‘Frieze Masters’ exhibition in London in 2023,[165] I could not help but shed a tear. This came as a surprise to me. I was familiar with Judith Scott’s work and had also visited the Creative Growth Art Center in Oakland,[166] where she created many of her pieces,[167] but I had never experienced her art in person. The physical presence of her works deeply impacted me because of how their size and volume mirrored that of human bodies. Their tactile nature beckoned me to touch them through a deep visual and imagined haptic sensing, because, as with many

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[164] Banissy, ‘Conversation with Katrine Skovsgaard on chronic headaches (recorded)’.

[165] Scott, ‘Judith Scott’.

[166] ‘Creative Growth Art Center’ (Art Space, Oakland, California, US) <https://www.creativegrowth.org> [accessed 11 July 2025].

[167] Judith Scott was an artist living with Down’s syndrome and deafness, who in 1987 enrolled at the Creative Growth Art Center in Oakland, where she produced many of her art pieces. Creative Growth is a nonprofit organisation that supports artists with disabilities.

Figure 68 Portrait of Judith Scott by Leon A. Borensztein.

artworks, audiences were not allowed to touch the artworks at this exhibition. I am unsure whether Judith Scott’s poignant photographic portrait on the cover of *Touching Feeling* influenced my emotional response to her artworks. I can confidently say that my reaction was more intense than any I have had to art pieces. Her artwork’s textures, placement and humanoid qualities shaped how I instinctively engaged with and was moved by her art. I was keen to touch the work (although this was unfortunately not allowed), drawn by how the sculptures were close to me in scale. Since they were placed on pedestals that brought them to torso height, I could easily have envisioned the sensation emerging from embracing one of the pieces like Judith Scott does in her portrait.

I also feel an affinity with Judith Scott as an artist due to our shared sensibility concerning the relational nature of tactile textile artworks. When contemplating my visions for the work, how my sculpture series *Aura* should be scaled, and how this would affect the audience’s experience of and interaction with the artwork, I reflected on my emotional experience of Judith Scott’s work, and how the size of Judith Scott’s sculptures significantly impacted me. It let me relate more intimately to her sculptures, so in my subsequent sculptures for the *Aura* series, I aimed to create works that not only relate to the body through their large size, which one could lie on or interact with, but also related to the body as if it were another body altogether. The scaling of any artwork is a crucial decision that influences how an audience engages with the piece. Previously, I made artworks like *Touch* (see Figure 69) and *Chronicles*, which are larger than bodies to give audiences a feeling of their own body as something small and fragile – in a way like the overview effect of seeing a significant body of water or seeing the earth from space, gives the viewer a certain humility. *Touch* is a tapestry installation that looms 10 meters above the heads of audiences, and *Chronicles* is a large dome that many viewers can lie down on

simultaneously to listen to stories of pain. These artworks relate to the body by being bigger than the body. In contrast, through seeing Judith Scott's sculptures, I realised that humanoid dimensions could create a sculpture that invited a different and more equal hierarchy between the viewer and the artwork. This led me to decide to downscale and make the *Aura* series the size of a human body, inviting viewers to engage with it as another person and further establishing a connection to the work through touch.

Judith Scott's emotional portrait added so much to my experience and understanding of the piece, and in some ways, it may even have primed me for the emotional reaction I had when I saw the sculpture live. When photographer Louise Uth Pedersen documented the *Aura* series and proposed that we also take a portrait of me embracing one of the *Aura* sculptures as a reenactment of Leon A. Borensztein's photograph of Judith Scott, I was immediately enthusiastic about her idea. In the resulting picture (Figure 66), I am seated on a step stool holding a black and yellow aura-inspired rug sculpture. I am wearing a denim jacket featuring one of my embroidered back patches, which carries a similar aura pattern. Both images draw inspiration from the artwork *Abstract: a yellow spot on a black background*[168] from the Migraine Art Competition (Figure 58). I thought this was an intriguing idea due to my instinctual reactions to Judith Scott's work. Seeing her portrait enhanced my understanding of her artwork. It added an emotional and embodied dimension to works that could otherwise be interpreted purely in terms of aesthetics and medium choices. Her portrait made me realise that she

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[168] Anonymous, *Abstract: Yellow Spot on Black Background*, 1983, The Wellcome Collection, Migraine Art Competition Collection <https://wellcomecollection.org/works/z8wnjvpt>.

Figure 69 *Touch*, Southwark Park Galleries, 2022, photograph by Rob Harris.

related to the artwork as a body in space, and consequently so did I. Relating to the artwork in this way is precisely what I hope viewers will do when they encounter my artwork. If the audience perceives my works as bodies in space, this will foster a sense of intimate connection with another person sharing their stories. Observing my portrait may evoke a reaction in audiences akin to what I experienced with Judith Scott’s work, and the urge to touch the piece could further enhance such a connection. By engaging with and reenacting her engagement with her sculpture in my portrait session with Louise Uth Pedersen, I went beyond the imagined touch of seeing Judith Scott touch her sculpture, engaged with my own work in a similar way, and was able to visually communicate the tactility of my installation.

Figure 70 The Danish Art Workshops, DK, 2024, photograph by Louise Uth Pedersen.

Figure 71 *Aura*, RCA Research Biennial, UK, 2025.

Figure 72 *Aura*, RCA Research Biennial, UK, 2025.

Figure 73 *Aura*, 2024, photograph by Louise Uth Pedersen.

# MAKING

I have utilised processes similar to those mentioned above in my work with CH. A crucial part of my reflections on my artistic practice has involved informally contemplating my process through prose writing. This has allowed me to change course in ways that enable the research process to inform my art practice and relate to my experiences and those of others regarding CH. Below are some insights from my process at a recent residency at the Danish Art Workshops in Copenhagen, Denmark:

*The gun sends massive ricochets through my body, leaving blisters and a subtle shake that doesn't entirely dissipate from my limbs afterwards. The nerves at my fingertips cool down, and my palms blister in correspondence with the machine. So full of pus that is never released, sore hands that build up tension, are alleviated at night and then build up goo, and tough layers of hard skin when the loud hum of the gun starts again the following day.*

*The handle is deep red, decorated with small, raised bumps that resemble goosebumps. It seems to quiver even when I set it down after use. It's as though the blisters on my hand extend to the machine itself, precisely where the handle consistently strikes my hand, day in and day out.*

*The air hisses at me, and the rattle-hum of the gun is so loud that I don noise-cancelling headphones. The gun disperses tiny particles all around me, and I wear a mask to protect my lungs. Beads of sweat trickle inside the mask, hitting my upper lip and creating a salty river. I become so thirsty from the exertion that I take a break every half-hour. From the cacophony of the gun, the vibrations, and to drink half a litre of water. Indeed, I must be losing a significant amount of fluid and minerals this way.*

*When I've been using the gun for a few hours, I take a break. I plunge into the dark-blue waters of the harbour, enveloped by a cold shock of electric blue. Pinpricks and blood racing across every surface of my skin replace the thudding pulse in my sore, blistered hands, and the cool water washes away my salty-sweet sweat. As I surface, my hair is damp and chilly; I ascend the metal stairs to my post with the gun.*

*The silvery surface of the gun glistens as I move it over the rough and taut canvas, and when the sun shines, it directs shimmering reflections around the tiny room. Colourful lengths of yarn pass through the needle's eye faster than I can catch, and a motif emerges; the yarn paints, draws and appears in bright, bold shades. It becomes a soft surface surrounded by the vibrations of the machine working, poking, and stretching the skin of the canvas taut around the frame. A tufted tapestry emerges in my chosen naïve colours. It resembles nothing that could have been created so violently – with a tufting gun.*

I would like to reflect on this process and explore why I find it intriguing to consider the contrast between the production and experience of the artwork, as well as how this, in some respects, mirrors the reciprocal and multifaceted nature of touch and how I want my artworks can express both the pain and the remedy of CH. Machine tufting with a power tool unexpectedly reveals something subtle and soft. A violent process yields something that mends. Tufting is associated with folk craft and domestic interiors, yet the modern technique utilises force and a power tool to create something that ultimately appears soft and inviting. By incorporating subversive elements, narratives and images of pain, into a soft, domestic medium where they are rarely seen, I invite viewers to relax and engage with a soft rug that, upon closer inspection, reveals the various realities of living with CH. Stitch by stitch, I mend and piece together representations of those in pain, transforming visual migraine aura representations into soft, tactile, tangible tapestries that can be seen and, I hope, understood. Threads mend and bind, and the rya knot connects to a narrative that may have otherwise been difficult to hear. Stitch by stitch, I seek to reimagine and give voice to the stories of CH that remain untold.

The imagery of the migraine auras depicted in my tufted art pieces draws inspiration from both my own and others’ representations of visual migraine auras. The smaller sculptural pieces of *Aura* are influenced by the Migraine Art Competition,[169] Hubert Airy’s diagram of the spatial development of his migraine aura (Figure 28),[170] and various conversations, personal anecdotes, and lived experiences related to visual migraine aura. By introducing a tactile dimension to these archives and conversations, I seek to reflect on the experiences and corporeal nature of living with pain. When one is in constant pain, it is impossible to disregard that one is biological, mortal, and interdependent. Physicality is

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[169] Anonymous, *Migraine Art Competition Collection*.

[170] Airy, ‘XIII. On a Distinct Form of Transient Hemiopsia’.

inescapable, and the senses often become heightened. As discussed in the chapter VISION, the desire to connect all the various images and experiences of individuals with CH may risk oversimplifying the complexity and physicality of these narratives, just as linear pain scales struggle to measure CH, which is recursive and enduring. Crafting a narrative essentially ties a knot at the end of a thread, creating coherence where there may sometimes be none and tracing something difficult to map in real life by weaving together one story after another, suturing elements in a manner that imparts significance. To avoid tying a knot around something that remains unresolved, I focus on the chaotic nature of the process and strive to maintain some of that disorderliness in the final art piece by leaving unruly threads hanging, and revealing the reverse side of the rugs – thus acknowledging the imperfections and unresolved aspects present in the artwork, the artist, the narratives, and our perceptions of one another.

In the artworks I have created throughout my research, I have chosen to work with deadstock yarns that would otherwise be discarded within the textile industry. It is essential to consider sustainability when creating art, and I recognise an implicit methodology of care in using reused or otherwise discarded materials. This, in turn, reflects how our society perceives sometimes people with disabilities and chronic illness as disposable or of lesser value within a capitalist framework, further underscoring the fragility suggested by the fraying edges and exposed backs of artworks. While visitors can touch and engage with the artwork, *Aura* also provides audiences with a sound collage featuring individuals with CH and professionals in the field of pain as they share their experiences with CH and migraine aura, bringing attention to the otherwise understudied phenomenon of visual migraine auras, transforming it from a personal experience into something that others can see, hear, and feel.

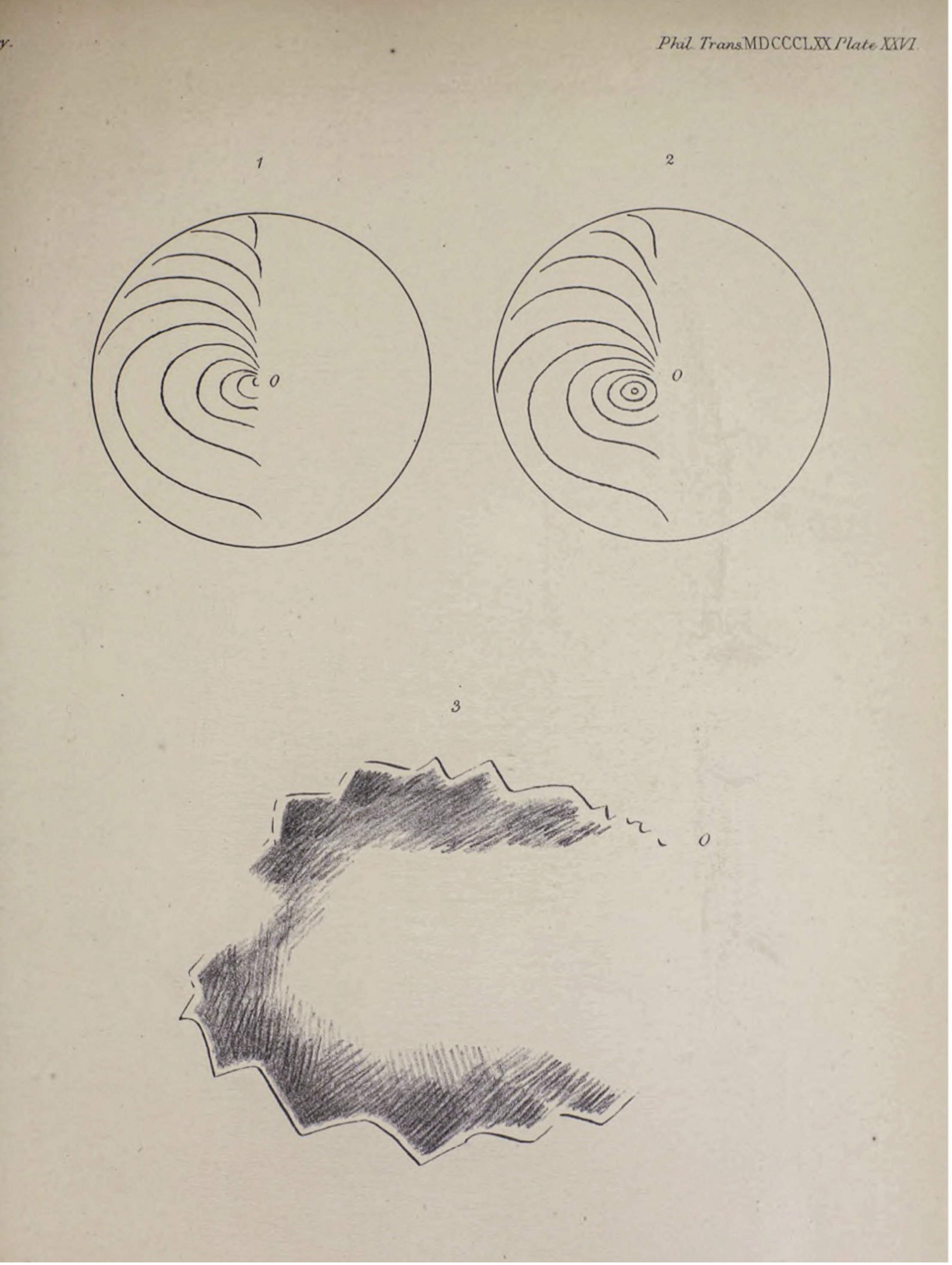

Figure 74 *Plate XXVI*, Hubert Airy’s diagram from 1870 shows the spatial development of his aura.

Figure 75 *Aura*, photograph by Louise Uth Pedersen, 2024.

Figure 76 *Chronicles*, Röhsska Museum of Design and Craft, 2023, photograph by Belinda Nors.

Figure 77 *Chronicles*, close-up, Röhsska Museum of Design and Craft, 2023.

# RESPONSES TO THE ARTWORK

I hoped that viewers would respond to *Aura as* they did to *Chronicles*. In the exhibitions of *Chronicles*, audience members recline on the rug, and many people stay for the entire duration of the sound piece, often continuing to discuss their understanding of pain even after the sound narrative has looped. I tend not to instruct viewers on how to engage with my work. Instead, I utilise small invitations, such as having spoken voices emanating from within an installation, to encourage viewers to come close enough to hear these voices and to touch the work. At my exhibition of *Chronicles* at the Röhsska Museum of Design and Craft, inviting viewers to recline on my artwork proved challenging, particularly as the objects in the surrounding rooms were behind glass and strictly not to be touched. However, from a table with embroidery materials, it was clear that audiences could interact with certain aspects of my exhibition. I selected often tactile artworks from the museum's collection to include in the exhibition. I chose artworks and items where I perceived a connection to CH experiences and how I utilise art to express them (see Figure 78-82).

Curating, writes artistic director and curator Hans Ulrich Obrist for The Guardian, means caring: “I had a productive misunderstanding with my parents. They thought I was going into medicine because

Figure 78 *Skalövning 5* by Eva F Björksström, 1978. Röhsska Museum of Design and Craft, SE, photograph by Kristin Lidell.

Figure 79 *Kvinnan som ligger på sin sofa och klappar sin katt* by Marja Gräset Anderson, 1974. Röhsska Museum of Design and Craft, SE, photograph by Kristin Lidell.

curating means caring. I don’t think they thought it was to do with art.”[171] To curate is to care for which artworks are shown, and by selecting artworks from the deeply buried archives of the Röhsska collection, I chose pieces that may have been cared for by preservation but have not been cared for in the sense of being presented to the world.

On my first visit to the Röhsska Museum of Design and Craft, a conservator guided me through long underground corridors to uncover these forgotten artworks in the archives, inspecting insect traps and humidity controls along the way. Every time we crossed the threshold of a heavily armoured door, sticky pads beneath our shoes ensured that we did not carry any unwanted materials or insects with us. Once inside the right section of the collection, the conservator lifted pristine, conserved artworks from boxes, unwrapping them from tissue paper, and with hands covered in white gloves, brought them into the light for us to explore. Some of the artworks I selected were so affected by time that they would be displayed in museum cases to protect their fragile fabrics, while others were new and had barely been shown at the museum before. Many of the artworks I found in the collection had remained unseen for decades. However, during my re-visit to Röhsska two years later in 2025, I learned that some pieces I chose for my exhibition had become part of the museum’s permanent public display.

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[171] Hans Ulrich Obrist, ‘Hans Ulrich Obrist: The Art of Curation’, *The Guardian*, 23 March 2014 <https://www.theguardian.com/artanddesign/2014/mar/23/hans-ulrich-obrist-art-curator>.

Figure 80 Museum objects, Röhsska Museum of Design and Craft. In the back: *Sorgmantel* by Elisabet Eriksson, 2012. In the middle: *Dubbelhuvud* by Britt Ingrid Persson, 1967. *Foraar in Blominton V* by Joel Philip Myers, 1974. *Terminal Zone IV* by Glenys Barton, 1975. In the front: Embroidery by Anna Casparsson, 1920s.

Figure 81 Exhibition at Röhsska Museum of Design and Craft, SE, 2023, photograph by Kristin Lidell.

Figure 82 Studying *Child Picking Cotton in Uzbekistan* by Emelie Röndahl, 2017, photograph by Kristin Lidell.

Figure 83 *Child Picking Cotton in Uzbekistan* by Emelie Röndahl, rear detail, photograph by Ian Hobbs.

Figure 84 *Child Picking Cotton in Uzbekistan* by Emelie Röndahl, 2017, photograph by Ian Hobbs.

Among the artworks I selected, and whose work is now on permanent display, was Emelie Röndahl's tufted rya tapestry *Child Picking Cotton in Uzbekistan,*[172] whose front side presents a chaotic arrangement of woollen threads, creating the impression of a figure, possibly in tears (Figure 84). However, the long rug pile largely obscures the imagery. When viewed from the back, one sees a precise and almost pixel-like rendition of a child picking cotton (Figure 83). This obscurity between what is visible from the front and what the back reveals resonates deeply with my thoughts on dealing with CH, as it is often invisible and can be difficult to convey clearly to others. Emelie Röndahl's work invited me to touch it, and I thought this might also aid viewers in understanding the connection between pain and touch and how pain is a lens through which to see the world, though it often is not visible. In contrast to how carefully the conservator handled the artwork on my first visit (Figure 82), when Emelie Röndahl saw my exhibition and display of other works, she immediately greeted and cared for her artwork by running her fingers through the tapestry to correct straying pieces of yarn in a display of care so different to the care of gloved hands and carefully calculated movements of the conservator.

I also showcased visual artist Elisabet Eriksson's artwork *Sorgmantel*,[173] a dishcloth bearing her initials inherited from her mother (Figures 85-87).[174] On this cloth, Elisabet Eriksson has processed her grief

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[172] Emelie Röndahl, *Child Picking Cotton in Uzbekistan*, 2017.

[173] Directly, this title translates to grief cloak, but to my delight I have also discovered that this poetic name is also the Swedish name for the butterfly species *Camberwell Beauty*.

[174] Elisabet Eriksson, *Sorgmantel*, 2012, Röhsska Museum of Design and Craft, Gothenburg, SE.

over losing her mother through embroidery. The stitches crinkle the fabric and are arranged in a way that resembles scars, making visible, in a way that evokes physical pain, the invisible emotional pain that Elisabet Eriksson experienced from her loss. I could relate to the tactile experience in these artworks, and I noticed many people discreetly touching them when they thought no one was watching. Thus, I suspect they may have had a similar intuitive reaction to these pieces and that, in some ways, this influenced how they perceived and interacted with the rest of my exhibition. Lastly, and perhaps most importantly for the audience's permission to touch my artworks, photographer Maria Jansson filmed a video introduction to the exhibition where I sat and ran my fingers through the long-piled rug mound of *Chronicles*.[175] In the few days before the video was shown, I occasionally felt disappointed seeing audiences walking past the installation. However, as soon as the video of me engaging with the work was playing, viewers intuitively understood that they were also invited to engage with the installation through touch.

I was not trying to elicit a specific response by letting people work with their hands and touching the artwork. Still, I hoped that my choice of materials, the encouragement to engage with and touch artworks, and the activities available would be a conduit for conversations to emerge. The table with embroidery materials, which in some ways informed viewers that they could touch certain parts of the

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[175] *Röhsska Video Material for Chronicles*, dir. by Maria Jansson (Röhsska Museum of Art and Design, Gothenburg, SE, 2023) <https://www.instagram.com/reel/CrODukKAJve/?utm_source=ig_web_copy_link&igsh=MzRlODBiNWFlZA==>.

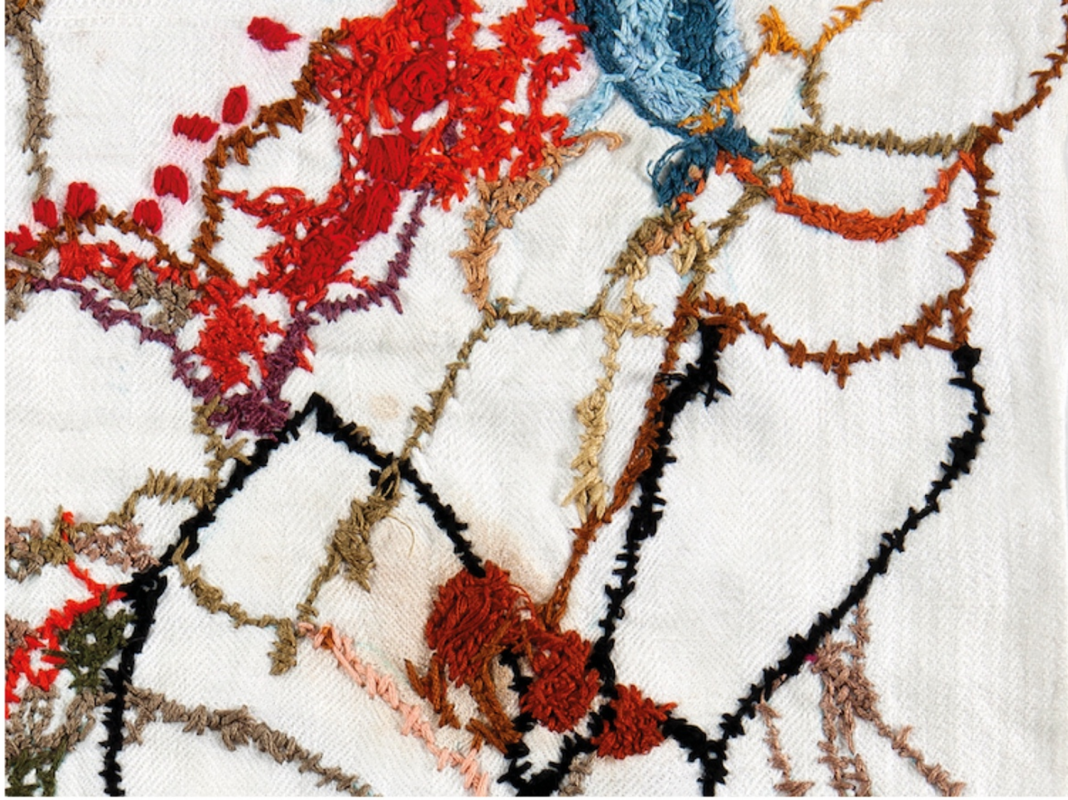

Figure 85 *Sorgmantel* by Elisabet Eriksson, 2012, photograph by Carl Ander.

Figure 86 *Sorgmantel* by Elisabet Eriksson, detail, 2012, photograph by Carl Ander.

Figure 87 *Sorgmantel* by Elisabet Eriksson, detail, 2012, photograph by Carl Ander.

exhibition, also appeared to facilitate conversations after visitors had experienced the sound of *Chronicles.* During my workshops, dispersed throughout the exhibition period, and later in the UK at Goldsmith CCA, a group of individuals with CH, artists, and pain specialists gathered around the embroidery table to discuss CH (see Figure 37, Figure 59, Figure 96 and Figure 97). I realised that engaging in a hands-on activity, finding comfort in touching various materials or working on embroidery, fostered a connection among the participants involved in the activity. Artist Sarah Desmarais reflects in her PhD thesis, *Affective Materials,* about a series of crafts groups that:

> The social ease participants were able to enact in the groups was supported by the crafted object as a flexible prop around which a range of friendly interactions (information and skills exchange, curiosity, admiration, self-disclosure) could be organized without risk. Material objects and processes facilitated the cultivation of connection through talk, so that, for instance, a participant who had struggled to develop friendships in other social situations … found it easy to do so in the crafts group … Making, thus, had distinctive effects on talk.[176]

Working alongside each other, fostered a greater space for listening and created moments of silence where individuals could take their time to respond. These silences extended for longer periods, yet they were not awkward but offered a deeper space for listening and reflection. Sarah Desmarais also

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[176] Sarah Desmarais, ‘Affective Materials: A Processual, Relational, and Material Ethnography of Creative Making in Community and Primary Care Groups’ (PhD thesis, University of the Arts London, 2016), p. 209.

Figure 88 Lecture, Gothenburg University, Steneby, SE, 2023, photograph by Maria Sjöstrand.

Figure 89 Workshop, Röhsska, SE, 2023, photograph by Amanda Eriksson.

observes these moments of silence in craft-making groups and attributes this comfortable silence to social flow. She states: “In the groups, however, there was often a collective mood of peaceful concentration, accompanied by quiet, spasmodic conversation or comfortable silence.”[177]

Professor in Fashion, Fiona Hackney, has led the ongoing CARE project for the past decade, where she has conducted crafts workshops, and in her paper *Taking CARE*, she argues that “connecting and sharing through crafting and making can forge deeper, more meaningful relationships that combat isolation and promote individual and community agency.”[178]

I wanted to lean into a feeling that crafting together could create agency, meaningful relationships, social flow, and comfortable silence. It was reassuring to observe that the artwork fulfilled some of the roles I intended, and it also surprised me with how powerful it was. As I mentioned earlier in this thesis, I wanted the art to facilitate the conversations that otherwise depended on my being in the room. The materials, the tactility, the touch and not least, engaging in an activity using their hands allowed visitors a vehicle to articulate something they might not otherwise be able to communicate. In this way, it also became an equaliser for people. A participant in a workshop co-facilitated with pain researcher Anke Samulowitz had an insightful reaction to the experience. In a mixed group of individuals dealing with

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[177] Desmarais, ‘Affective Materials: A Processual, Relational, and Material Ethnography of Creative Making in Community and Primary Care Groups’, p. 113.

[178] Fiona Hackney, ‘Taking CARE: Building Community Assets through Creative-Making’, *Making Futures Journal*, 2013 <https://makingfutures-journal.org.uk/index.php/mfj/article/view/127>.

pain, artists, and clinicians, he shared that he had never had the space or been able to articulate how his gender identity influenced his interactions with healthcare professionals. He expressed to the group gratefulness for the vulnerable space that both embroidering and talking together created, which contrasted with how he felt he was not permitted to be emotional during interactions with healthcare practitioners. He told us that when he had shown emotion and vulnerability, his feelings elicited much stronger reactions from the medical staff because they expected a certain sternness from a man. By engaging in this activity and listening to Anke Samulowitz's insights on her research regarding gender bias, this man realised and articulated for the first time some of the bias he had personally experienced. The physical workshop outcomes were the embroideries made at the workshops, which were subsequently discussed by the participants and displayed in the exhibitions where they were done.

At the exhibition 'Grænselandsudstillingen 2024' in Aabenraa, Denmark, I installed *Aura,* suspended from the ceiling by leather straps. The leather harnesses were tightly wrapped around the soft rug pieces, serving a similar role to the metal frames of Caroline Achaintre's *HEL*, showcasing the fragility and bodily nature of the woollen tapestry sculptures by contrasting them with harder elements like metal and leather, which contain and constrain the artworks' softness and allow their shapes to yield like the softness of skin, muscle, and fat. These leather straps evoke the physical training of the body in gymnastics or physical therapy, while the metal buckles allude to the training of animals, or the care and consent inherent in the BDSM practice of bondage, where the body is held, suspended, or restrained by rope or leather straps within a consensual practice of giving and taking power and pain. Johanna Hedva also relates kink to care in an interview for *Errant Journal*, saying:

Figure 90 *Aura*, RCA Research Biennial, UK, 2025.

> The kind of conversations that I was having in my kink life, felt like the kinds of conversations I wished I could have in my care, illness, pain life, where I could be like: here's what I need. Here's what I want. Here's what I don't need. Here's what I don't want … And it could all just be discussed.[179]

This quote makes clear the explicit communication necessary in kink practices, and how this could be inspirational for how we think about communicating about pain and care – where it can often be hard to voice needs and wants. In this way, I think the leather harnesses and their connotations lend themselves perfectly to the context of an artwork which explicitly voices experiences of pain that are otherwise not heard. These associations and the contrasting qualities of control and submission implicit in the leather harnesses can also subtly suggest to audiences that the artwork may be interpreted as a physical body. How the artworks hang from the ceiling and the allusions to gymnastics and bondage that this can evoke further emphasise the often-restrictive experience of living with chronic pain, highlighting its impact on the self, future, and relationships with others.

I observed viewers engaging closely with *Aura*. Often, people would lean in to listen to the sculpture in pairs. One audience member mentioned that the leather straps, along with the way they hugged the soft, voluptuous body of the sculpture, led her to perceive it as if it were a person. I noticed her resting

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[179] Ghiwa Sayegh, Myriam de Amri, and Yasamin Ghalehnoie, *Embodying Resistance*, Errant Journal, issue #7 (Framer Framed, 2024), p. 45.

her ear against the soft surface while listening to the piece with her partner. I wonder if this would have occurred without the piece's scale, placement, and tactility. The comforting textures draw people in, and although I intentionally tried to encourage a physical response, it is surprising how many individuals approach the sculpture to hug, stroke, or hold it. Many attendees succumbed to the allure of embracing the sculpture, and one audience member noted that something was comforting and trustworthy about the sensory aspects of my sculpture, which made them feel safe to engage in an intimate interaction with it, even within the expansive exhibition space.

When I exhibited *Aura* at the RCA Research Biennial 2025, my friend and colleague, visual artist Louise Ørsted Jensen, responded to the work by crouching, leaning into, and touching the sculptures. She shared that she experienced the sculptures as individual beings and that the leather harnesses of the piece appeared to lead and offered an intimate gesture akin to helping another person put on underwear. The way the leather harnesses hold the soft rug bodies bends them slightly out of shape, causing them to become wrinkled and roll onto themselves, much like how rolls of fat and muscle might if a human body were suspended in this manner. I appreciate and have chosen these harnesses for hanging the sculptures because they serve as a reminder of these art pieces as bodies by evoking gymnastics, physical therapy, horse training, and bondage, depending on the viewer's perspective. They introduce restraint to the soft and malleable bodies in a way that pulls them into a space of control, which often emanates through our conversations about pain. Have you done the right things, taken the right measures? Yet they also remind viewers of the constraints of living with chronic pain.

Figure 91 *Aura*, RCA Research Biennial, UK, 2025.

Figure 92 *Chronicles*, Röhsska Museum of Design and Craft, SE, 2023.

Figure 93 *Chronicles*, Röhsska Museum of Design and Craft, SE, 2023, photograph by Amanda Eriksson.

Both adults and children were playful with the sculptures, and children often brought their parents over to experience the piece, reinforcing for me the importance and primacy of touch. Observing how the quality of touch and engagement with materials shapes the viewer's experience of the work and allows them to share their own stories of pain leads me to believe that this aspect of the work is more significant than I initially thought. The tactile engagement with artworks and embroidery materials is not just an addition to the artworks; it is an integral and essential part that allows viewers to connect with the work personally and intimately, both through conversation and the comfort of sitting in silence. In my research, I have been concerned with vocality, but silence, possibly evoked in these works by the sense of touch, is filled with presence and potential to listen. In the essay *Acoustics of Resistance,* which I also quoted in the chapter about voice, Mikhail Karikis reasons:

> Listening plunges us into unknown experiences and entanglements with one another and with the world. Listening is not a passive experience. It doesn't just happen to us. Listening is an action. When I listen, I choose to direct my attention to an other. So, when I listen the "I" becomes a "we." And I don't mean listening with my ears, but with my entire body receiving, sensing the other. I mean listening as a way of thinking, as an attitude and a way of being. As such, listening is relational and generates a common – the listening space. In this respect, listening is like love in that love directs one toward an other, and generates something that didn't exist before, new relations, alliances, empathies, affections and solidarities. It does not

> generate communities, in which the whole is bigger than the sum of individual parts, but collectivities, in which individual parts choose to relate and co-exist.[180]

This perspective on listening aligns with my observations of interactions within my exhibition space. I witnessed how friends, family, and strangers chose to connect with one another after engaging with my artworks – and those who attended alone shared their reflections in writing. I noticed a genuine care for the stories and experiences of others during the times I was present in the exhibition. However, since my intention was for the artwork to facilitate conversations rather than to position myself at the centre of them, I was often not present to experience this listening space.

The Röhsska Museum provided me with a list of interactions that their staff had observed in the exhibition, sometimes spoken but often silent and listening. Here, I came across a compelling account of a visitor's engagement with the installation: they decided to sit for several hours to sketch the artwork. By employing a creative writing approach that mimics their perspective, I hope to give a richer exploration of the audience experience and the complexities inherent in the interactions with others:

*I'm sketching an art installation at an exhibition that captured my attention. I recreate the texture of the fluffy, dome-like structure in front of me with soft strokes, while people pass by, observe, lie down, chat, and listen. I get to be the fly on the wall, observing how people interact with each other and the art, while I meticulously try to capture the shape and feel of the artwork on paper as it appears before me.*

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[180] Castro, *Arte Sonora, ecologia e cultura auditiva = Sound art, ecology and auditory culture*.

*I've been tasked with going out, exploring the city, and coming back with an observational sketch and description of the place I visited. I've returned here a few times to revisit the exhibition at different times of day, and on several of these occasions, I've had the chance to witness or speak with others who are also drawn to this piece of art. I would also like to sketch these visitors to the installation, but moments are fleeting. Kids run towards the installation and hug it like a teddy bear, but they are quickly on their feet again. Only one person makes it onto my sketch: a teenager who hilariously falls asleep while listening to the art installation. The structure is foreign yet inviting, and I understand why he would fall asleep here: the dome is covered in thick purple wool, resembling a carpet that my grandparents may have had in their home. A mum and her daughter visit the exhibition and sit beside me to embroider – the daughter talks about what her headache looks like, while the mum silently watches and listens. I almost feel like an intruder in their intimacy, as if they're sharing something intensely private, but the mum looks over and compliments me on my drawing: "Wow! It's really something, isn't it?" she says with a smile. "Yes," I reply," it reminds me of my own migraines. I've been getting them since I was a kid. I never saw them like this." "Look, this is mine," the child proudly proclaims. Two older adults look curious and ask us how we think the design objects and artworks relate to headaches. "It's so different from my daily headaches," one says. They kindly come over to visit the girl, who is intensely focused on her needle and thread.*[181]

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[181] Amanda Eriksson, 'E-mail: Reflektioner', 27 March 2025.

Figure 94 *Aura*, RCA Research Biennial, UK, 2025.

Figure 95 *Aura*, RCA Research Biennial, UK, 2025.

# CONCLUDING TOUCH

In this chapter, I discussed how insights from my research have been transformed into tactile artworks that audiences can experience through touch and sound, revealing multi-layered pain experiences via sensory engagement. I reflected on how a group of artists have influenced my art practice and how my thinking about touch and care is echoed in both the making process and the final artworks. I considered how viewers engaged with the artworks and what they have said about them – particularly the instances when they have engaged in touching the works or sharing their stories. Through these reflections and my efforts to involve viewers in various touch-related activities, I discovered that it fosters a desire or ability to sit in silence with strangers, revealing the importance of the presence that this silence can create and its potential for facilitating listening to others. While I believe that voicing experiences is crucial, I have come to recognise, through the research highlighted in this chapter, that how audiences engage with my work reveals fascinating dynamics about how polyvocality can involve being willing to embrace silence. I discovered profound power in tactile engagement and activities that facilitate moments of exploring various modes of listening, silence, and expressing lived experiences of pain. The artwork served a role of sense-making for audiences, and the open invitation to touch the work had significant consequences for the effectiveness of the open invitation to share and listen to stories of pain.

# DISCUSSION AND CONCLUSIONS

Figure 96 Threadbare workshop, Goldsmith CCA, UK, 2025, photograph by Charlie Hawksfield.

# REFLECTIONS ON MY RESEARCH

My aim with this practice-based research project was to harness my direct experience of CH in order to reframe perspectives on CH and challenge medicalised narratives. Havi Carel argues, "Physicians are competent at providing medical care for medical problems, not philosophical analysis or existential engagement. The consequence is that the experience of illness and the changes it brings to patients' lives often remain unacknowledged."[182] This view was affirmed in the series of conversations I conducted as part of this project with people with pain and professionals.

What capacity is there, in the time of the consultation, for such engagement? What can medical staff realistically be expected to provide? My interests lie in exploring the potential of other disciplines to engage with what it means to care for those with chronic conditions in particular; to think more specifically about a contemporary art practice as one that might be, for a person with pain, adjacent or complementary to a clinical medical practice, adjoining or intersecting with conversations with medical staff, providing more than one vantage point on what it means to live with CH. Rachael Allen further specifies the potential of art in exploring care:

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[182] Carel, 'Phenomenology as a Resource for Patients'.

> If the visual arts hold keys to unlocking emotions from reflexive, empirical grounds, then engaging with artistic work exploring the anatomised, pathologized, and medicalised human body can provide access to complex landscapes of corporeal consciousness and experience. It is clear to me then, that the focus of visual arts in medical humanities must not remain within the educational setting of medicine.[183]

By shifting the focus from diagnosis and management to the bodily experience of CH, my artworks challenge preconceptions of what it means to live with CH and provide access to what Rachael Allen calls ‘complex landscapes of corporeal consciousness and experience’. Centring the lived experience reveals CH as a complex narrative without settling on a single understanding, providing care for the specificity of every person’s chronicle of CH. During this process of widening the scope of whose voice is heard and listened to, I realised the value of thinking about my experience in dialogue with others, acknowledging the plurality and polyvocality of CH, and creating artworks where the complexities of CH can co-exist.

In their foreword to the book *I Care By…* artists and Drs. Ilona Sagar and Adam Walker ask*: “*How do we care in a way that is more egalitarian, that involves more voices?”[184] Asking this question reorients the focus from the medical professional to the person in pain, and from cure to care, which the authors

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[183] Whitehead and others, *The Edinburgh Companion to the Critical Medical Humanities*, p. 191.

[184] *I Care By...*, ed. by Gemma Blackshaw and others (Royal College of Art, 2022), p. 10.

define as an ongoing attention which is plural, equal, dynamic and principally complex.[185] These words – plural, dynamic and complex – are essential to think about how we care for each other and reveal the importance of exploring the ways that different voices can be raised up, thereby adding complexity to how we view, interpret and treat CH. Cultivating multiple understandings through art practice recognises the plurality of CH, adds value to undervalued chronicles of pain, and gives them the importance they might not otherwise receive. This has the potential of creating better modes of communication, reducing stigma, deepening our understanding and creating empathy by finding ways of practising how to live with and communicate about the complexity and contradictions of CH.

Through the specificity of CH, my research has engaged with the philosophical questions that arise from CH. The biggest of these are questions of how we can foster and improve conversations and create or enhance interpersonal trust. CH cannot be seen or proven purely based on medical imaging – medical staff depend on the person in pain to chronicle their story accurately, and that knowledge is essential for a proper diagnosis. This requires communication and trust, but consequently creates a rift in relationships if those witnessing the pain do not believe or understand individuals with CH, when they display the doubt that Elaine Scarry and Deborah Padfield describe. In this project, I have explored what finding different avenues of expressing pain through art does to address and reorient this trust relationship. By giving voice to the lived experiences of CH through art, this research project has documented a possible approach to dissolve conventional hierarchies on whose voice is considered valuable, bringing to the foreground the experiences of those living with CH.

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[185] Blackshaw and others, *I Care By...*, p. 14.

Figure 97 Threadbare Collective workshop at Goldsmith CCA, UK, 2025, photograph by Isabel Reed.

In this project CH emerged and was documented as a particular form of sensory knowledge that encompasses visual, auditory and tactile senses. Throughout, these were essential focal points and in a wider sense also encompassing the olfactory, gustatory, vestibular, proprioceptive and interoceptive senses. This information most often came through, when the conversation was focused and spoken in present-tense, when the person I was having a conversation with felt transported to a specific moment, for example a specific migraine attack, and they would be so attuned to the story, that their senses would lead the story, and they would vividly remember otherwise forgotten details. I have disseminated this sensory information in conversations with individuals with CH into auditory and tactile artworks, focusing on the role of voice to make chronicles of stories heard, and the role of tactility to make visual migraine auras into three-dimensional sculptural, auditory and tactile installations which can be engaged with directly through these senses. Additionally, the project has provided an art history of CH through direct engagement with the Migraine Art Competition, activating a little-known archive of art practice, which gains an extra dimension through being turned into tactile three- or four-dimensional art installations.

Making artwork about CH in this way has provided a space for listening, translating, and sharing these often-unnoticed narratives of pain. I have sought and demonstrated ways to reorient relationships between those experiencing pain and those witnessing it, fostering a deeper understanding and empathy for the profound disruptions that CH can bring to our lives. I achieved this by moving beyond words and two-dimensional representations, specifically by listening for sensory knowledge from those living with pain and using this knowledge as inspiration to transform experiences of CH into artworks that audiences can engage with on both a sensory and a physical level, thereby engaging with CH in ways that spoken word or writing alone cannot.

Through my practice-based research, I have developed and tested a care-led approach to artmaking through touch- and dialogue-centred artworks. Through reflecting on my art practice while simultaneously making, I have come to realise that my decision-making throughout this project has been deeply guided by care. Caring for headache chronicles, and how they are seen by people witnessing pain; caring by resisting or revising existing narratives and stigmas and by creating additional levels of understanding and sharing through music. This approach may be summarised as caring for, repairing and renewing understandings of CH by identifying and using alternative ways of engaging with CH. This type of care extends to all parts of my practice: caring by making with discarded materials, caring by inviting interdependency and collaboration into art processes, caring by bearing witness to and letting others choose their own words for their experiences of CH; caring by inviting complexity and embracing differences in chronicles of CH; caring by revisiting visual migraine auras across time; caring through cross-historical letter-writing; caring by imagining and creating new spaces and contexts for care; caring through touching; caring through making together, and importantly: caring by giving voice to; caring by telling stories and caring by listening. During this process and in my documentation and interpretation of the process, I have been aware of the interpersonal interactions and the sometimes-reciprocal nature of this care, whether subtle or outspoken.

### VISION: CROSS-HISTORICAL CARE THROUGH REVISITING THE MIGRAINE ART COMPETITION

As outlined in the VISION chapter, I have created examples of artworks that can provide alternative dimensions of care for people with CH when a facilitator cannot be present, i.e., essentially without my physical presence and across time. This was exemplified mainly in my engagement with the Migraine Art Competition, where I saw a shared visual language and created an art history for those with CH. These artworks held up a mirror to my experience of CH, and the images inspired me to transform them into tactile, three-dimensional sculptural installations that add a sense of lived experience and physicality to the imagery. This allows audiences to feel and interact with these representations of migraine auras in ways that would not otherwise be possible. The invisible phenomenon of migraine auras has emphasised the need to recognise and validate these experiences by synthesising personal narratives and offering further artistic representations through tactile, dialogical installation art. I recommend that these representations should be further explored and to involve more people in the project, perhaps by hosting a similar contemporary competition. Key questions for such an exploration could be: What does your visual migraine aura look like? What do these examples of artworks from the 1980s tell you across time?

### VOICE: CARING BY CHRONICLING HEADACHES AND RENEWING COMPLEX NARRATIVES

As mentioned in the VOICE chapter, at the beginning of this project, I asked: What role can contemporary artworks have in fostering conversations that extend beyond descriptive language regarding CH? In *Health Autonomy*, Carenotes Collective state: “There exists a need to expand the territory of care beyond the authority of the doctor."[186] In my writing and art practice, I have engaged in conversations about CH with diverse multidisciplinary voices, including renowned experts and individuals with CH, whose underrepresented perspectives deserve a platform. By presenting these testimonies side by side, I have aimed to flatten hierarchies of whose voice deserves to be heard, who has authority to speak, and which kind of knowledge is important. As I listened to these recorded conversations, my own viewpoint was opened on the subject. I focused on their sensory richness, which has guided my artistic process in transforming these dialogues into artworks that collage spoken word or create music inspired by the experiences of those living with CH. Through active listening, the pursuit of sensory information, and understanding how living with pain impacts every aspect of an individual's life, I uncovered a polyvocal choir which broadened and enhanced the language to document CH. These recorded conversations led the direction of my research. I quickly realised that there was no way to bring closure to the diversity of chronicles. Rather, allowing these differing voices to coexist in my artworks has enabled me to introduce nuance and criticality to discussions about CH beyond clinical contexts. In *Learning from the Sounding Object,* Emily Candela states that "a critical dialogue necessarily implies some form of polyphony, in which each voice maintains its independence." [187] By composing music from my recorded conversations, I explored unconventional ways to represent these stories, and by doing so, I have added an additional layer of this polyphony and polyvocality to the chronicles of CH. Furthermore, I have emphasised the importance of listening to the voices of those

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[186] *For Health Autonomy: Horizons of Care beyond Austerity: Reflections from Greece*, ed. by CareNotes (Common Notions, 2020), p. 12.

[187] Candela and De Visscher, 'Learning from "The Sounding Object"'.

in pain by creating music with lyrics drawn directly from these conversations. By employing choir music in the piece, *Six Infinity*, I hoped to challenge traditional notions of audience dynamics, blending the boundaries between performer and listener, caring by inviting audiences into an experience they might not otherwise have access to. These artworks fostered creative, personal conversations filled with sensory information, and importantly, they let many individuals share experiences, that made them feel vulnerable, with other audience members, fostering a collective experience.

## TOUCH: CARING THROUGH TOUCHING, CREATING AND GIVING FORM

As explored and documented in the TOUCH chapter, by introducing a tactile dimension to the Migraine Art Competition Collection and my recorded conversations, I have reflected on the experience and corporeal nature of living with pain. Working in this way, the archive and stories I engage with have become a different mode of expressing CH stories compared to, for example, the clinical approach. My experiments with the affective potential of soft materials such as wool, yarn, and silk, have created a body of work that brings an archive to life and gives voice to the diverse experiences of living with CH. I have fashioned intimate spaces that facilitate new and exciting conversations and encounters. My engagement with these visuals through tactile crafts has enhanced their accessibility for others to explore. The materials provide a raw quality that reflects the chaotic nature of living with CH, playing a crucial role in this project. I see an inherent care in the handmade objects, the time spent giving importance to a subject, and I would also integrate this approach into my embroidery work if I could devote more time to these themes and methods in the future. While my workshops have emphasised hand embroidery, the back patches I create are designed by me and then machine embroidered. Though machine embroidery facilitates accessibility, given my time constraints and allows for producing more badges for a broader audience, I am particularly inspired by artists like Elisabet Eriksson and LJ Roberts, who utilise hand embroidery to convey a rawness in their subjects. Elisabet Eriksson addresses grief, and LJ Roberts represents trans protests and community beautifully by using rough stitches or revealing the unruly backs of embroideries. If I had the opportunity and time to practice hand embroidery techniques, I would certainly create future embroidered artworks in this manner, as it more truly represents the chaotic experience of living with persistent pain.

## OVERALL REFLECTIONS

As I navigated these new ways of understanding CH, it became evident that the explored ways of caring for CH chronicles and the multimodal artworks stemming from them have played a significant role in reaching my aim of creating physical and mental space for vulnerability, reflection, and communication, allowing for interdependence. In *The Care Manifesto*, The Care Collective suggest rethinking dependencies of care and multiplying our circles of care.[188] They define care broadly as a capacity and a radical egalitarian, indiscriminate practice: “a social capacity and activity involving the nurturing of all that is necessary for the welfare and flourishing of life.”[189] They continue to argue that “to put care centre stage means recognising and embracing *interdependencies*.”[190] I believe recognising our mutual interdependencies – and creating caring contexts where these can thrive – represents an improvement

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[188] *The Care Manifesto: The Politics of Interdependence*, ed. by The Care Collective and others (Verso Books, 2020), p. 33.

[189] The Care Collective and others, *The Care Manifesto*, p. 5.

[190] The Care Collective and others, *The Care Manifesto*, p. 5.

in our approach to understanding and handling our approach to CH – allowing that we can freely talk to each other about both the easy and the challenging, and where care and dependency on one another is seen as essential and central to our lives. Art-based research has been my way to carve spaces for this kind of interaction by bringing the body of the audience into direct contact with the subject of CH, creating many contexts for reflection.

## POTENTIAL FOR FURTHER DISSEMINATION

The workshops and conversations I conducted as part of my PhD project provided others with ways to engage with the research and sharpened my understanding of the project's impact and potential for further dissemination. Conversations with and among people with CH and professionals in the field revealed unexpected overlaps across different areas of knowledge. During such conversations, I often wore a jacket adorned with embroidery representing visual migraine auras, which many immediately recognised as a depiction of a visual migraine aura. Healthcare professionals were often intrigued by the fuzzy boundaries between medical diagrams and the subjective representation of visual migraine auras. Some expressed dismay at the lack of visual resources in their medical practice, noting that in consultations, they often resorted to online searches for images of scotomas to show patients. I think this extended notion of the diagram provides space for nuance.

The visual migraine aura is an objective reality seen only by one and rarely shared in drawings such as those in the archives of the Migraine Art Competition. Producing, disseminating and spreading more images like these could produce new kinds of knowledge or perceptions of CH, which could help combat stigma and shame surrounding migraines, positively influencing both medical and public understandings. One possible way to further this would be to host a contemporary competition inviting individuals with migraines to create their own representations of visual migraine auras. If conducted in collaboration with a healthcare team, as some professionals suggested, this could enhance the integration of and exchange between medical and artistic knowledge. This type of collaboration could provide valuable insights otherwise accessible only through personal experience, blurring the lines between scientific representation (such as in diagrams) and the subjective representation of visual migraine auras, and making these representations more easily accessible to people with CH as well as to healthcare professionals.

## CONCLUSIONS

My work with pain has provided ways to engage with pain and care where art does not merely become the 'helpmeet of hard sciences', as Des Fitzgerald and Felicity Callard call it in *The Edinburgh Companion to the Critical Medical Humanities*. Set apart from and outside clinical and therapeutic contexts, this approach offers a critical perspective on existing hierarchies of knowledge by showing how pain affects everyone in disparate ways. It cares for creating contexts for conversations about pain through art in ways that recognise the knowledge implicit in artmaking and address the messiness and ungeneralisable nature of living with CH. Working in this way contributes to the body of knowledge about pain and care and to making sense of the often-messy experience of living with CH. By engaging with the senses related to vision, voice and touch, I have revealed facets of the intricate tapestry of life with CH. The evolution of my art practice thus emerges not merely as a project, but as an ongoing dialogue and a space where experiences of CH are shared and understood, and where, ultimately, the voices of those in pain are heard and cared for.

Figure 98 *Chronicles*, Röhsska Museum of Design and Craft, SE, 2023, photograph by Kristin Lidell.

Figure 99 Reading nook, Röhsska Museum of Design and Craft, SE, 2023, photograph by Kristin Lidell.

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# APPENDICES

Figure 100 *Six Infinity* costumes, Beaconsfield, UK, 2024, photograph by Federico Clavarino.

# GLOSSARY OF MEDICAL TERMS

Quotations in this glossary refer to 'The International Classification of Headache Disorders', 3rd edition, *Cephalalgia*, 38.1 (2018), pp. 18–24, doi:10.1177/0333102417738202 (ICHD), the most comprehensive diagnostic manual for headaches, compiled and published by the Headache Classification Committee of the International Headache Society (IHS).

CHRONIC HEADACHE

The ICHD defines a chronic headache as a "headache occurring on 15 or more days/month for more than three months." I use the term CH to denote any chronic headache, though a majority of people I have engaged with have had a chronic migraine diagnosis. The diagnostic criteria for a chronic migraine additionally have to entail a headache that "on at least eight days/month, has the features of migraine headache."

FORTIFICATION SPECTRUM

See scotoma.

HEADACHE

The ICHD comprises more than 300 diagnoses, all under the umbrella of headache. A headache could be a plethora of pains with different aetiologies or a lack thereof. The only commonality is that they manifest in the head.

HEMIOPSIA

See scotoma.

MIGRAINE AND MIGRAINE ATTACK

The term migraine represents a type of headache diagnosis that covers many different kinds and experiences of migraines. According to ICHD, “Typical characteristics of the headache are unilateral location, pulsating quality, moderate or severe intensity, aggravation by routine physical activity and association with nausea and/or photophobia and phonophobia” (hypersensitivity to light and sound). I use migraine to refer to the underlying condition, while migraine attack denotes an acute migraine episode. An attack typically lasts from a few hours up to 72 hours.

MIGRAINE AURA

All the symptoms of a migraine prodrome, attack and postdrome which are not a headache. This could be visual, sensory, speech, language, retinal, brainstem, or motor disturbances, which often precede the headache. These aura symptoms develop and resolve gradually.

## POSTDROME AND PRODROME

These terms refer to the phases of a migraine attack that precede and follow the headache, respectively. The prodrome is the initial forewarning or first phase of a migraine attack, and the postdrome is the phase following the migraine attack, during which it is common to feel tired, have trouble concentrating, and continue experiencing some aura symptoms, such as photophobia and phonophobia.

## SCOTOMA

A hallucination or visual disturbance which is defined by its c-shape and jagged edges. It is also sometimes called a fortification spectrum. A scotoma can be described as a scintillating scotoma, which indicates the movement qualities of a scotoma. Hubert Airy named this phenomenon hemiopsia.

## VISUAL MIGRAINE AURA

The most common migraine aura, which occurs in 90% of people with migraine with aura. A visual migraine aura is a passing hallucination or visual distortion that often indicates the onset of a migraine attack. Some individuals experience a visual migraine aura without a following headache. This is sometimes called a silent migraine.

# PEOPLE I HAVE SPOKEN WITH

I have written a short description here of each person with whom I have had recorded conversations throughout my doctoral research. I provide insights into each person’s significance to the project, along with a quote that contextualises their contribution. First, I will discuss the professionals who I spoke with, and then my conversations with individuals experiencing pain. They follow in alphabetical order.

To start my project, I read medical journals, primarily focusing on articles that studied CH, art, and touch. I also explored books on the subject and *The International Classification of Headache Disorders*. I contacted researchers whose work inspired or resonated with me to ask to have a recorded conversation. Some pain researchers reached out to me because they were interested, and where I deemed it relevant, I decided to include these self-selected people in my project.

### Michael Banissy, Professor of Psychology and researcher with a focus on touch, UK

Michael Banissy is a social neuroscientist whose research centres on touch. I first heard him speak at the Touching Matters Symposium at Siobhan Davies Dance in 2021.[191] Since then, his book, *When We Touch,*[192] has been published, and I found it fascinating to hear him discuss the intersections where research on touch and pain overlap. I was especially engaged by how he described touch as reciprocal and interrelational in an expansive way:

> We often talk about touch as a way of connecting with others. But, of course, what do we define others as? Are others other people? Does it extend to objects? What objects does it extend to? And I think in that regard, we can think about our connection to the world around us.[193]

### Lene Baad-Hansen, Professor of Dentistry and researcher in tactile analgesia, DK

I spoke with Lene Baad-Hansen, who Michael Banissy quoted in his presentation and whose research I had subsequently read with interest. In a study,[194] she and colleagues Pankaj Taneja, Håkan Olausson, Mats Trulsson and Peter Svensson test the effects of touch stimuli in pain modulation by having a brush

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[191] Michael Banissy, 'Why Do We Touch? The New Science of Our Most Underappreciated Sense' (Conference presented at the Touching Matters gathering with Charlotte Spencer Projects, Siobhan Davies Studios, London, UK, 16 January 2022).

[192] Banissy, *When We Touch*.

[193] Banissy, 'Conversation with Katrine Skovsgaard on chronic headaches (recorded)'.

[194] Banissy, 'In Conversation with Katrine Skovsgaard'.

attached to a robotic arm stroking patients and recording their response to different speeds of touch. I think this is both strange and fascinating, and I thought it had potential in how the tactile artwork could be used to create tactile and potentially pain-modulating encounters amid conversations about pain. She shared her considerations of the emotional and communicative difficulties connected to pain in the face, how stimuli and the senses interact with how we feel pain. This later worked as a direct link between the opinions of the medical practitioners and researchers and the people with lived experience of pain. Lene Baad-Hansen also provided insight into the disconnect that CH can sometimes create for individuals experiencing it, especially when thinking about heightened sensory perception:

> The mouth and face have such a huge impact on communication and intimacy between individuals. We have some patients who have, especially, nerve injury pains again; if they have something in the lower part of their face, then they cannot kiss their spouse. So, if they have grandchildren or children, they cannot have them come and hug them because it’s associated with excruciating pain.[195]

**Katerina Cerná, senior lecturer in information design with a focus on chronic pain, CZ**

I was contacted by several researchers who had either heard of or seen my art and wanted to connect. I decided to hold public conversations and workshops with some of them, while others participated in the recorded conversations. Katerina Cerna both works with and experiences headaches and spoke

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[195] Lene Baad-Hansen, Conversation with Katrine Skovsgaard on chronic headaches (recorded), 20 December 2022.

about her experience of growing up with a mother who has CH, her experience of the hospital system, and how she sees pain from both a professional and a personal viewpoint. She shared an anecdote from when she was a child, which highlights the scepticism that many people with CH meet:

> I had these intense headaches for half a year. Because I lost sight, we went to see a neurologist or some doctor. This was like a sweaty, hot Friday afternoon when the person wanted to leave work. But my mum was like, “Oh, you have to see her.” The doctor asked me, “What pain did you experience?” I said, “Well, it’s really sharp here at the back and it’s really numb here in the front.” It was two sensations at the same time. The person wrote “patient cannot recognise or describe what pain she has.”… And it feels like I can’t escape. It feels like I’m locked in this experience.[196]

**Dr Melinda Nicola and Professor Peter Drummond, researchers in pain invalidation, AU**

In many of my conversations with people with CH, the discrediting of their experiences surfaced. As a result, I decided to consult with Melinda Nicola and Peter Drummond, who have researched pain invalidation with a clinical and quantitative perspective on the consequences of having one’s pain experience undermined by others.[197] Melinda Nicola discussed the challenges of expressing pain:

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[196] Katerina Cerná, Katerina Cerná and Katrine Skovsgaard recorded conversation 18 April 2023, 18 April 2023.

[197] Melinda Nicola and others, ‘The Pain-Invalidation Scale: Measuring Patient Perceptions of Invalidation Toward Chronic Pain’, *The Journal of Pain*, 2022, p. S1526590022003510, doi:10.1016/j.jpain.2022.06.008.

> People express their pain differently and not everyone has a language for expressing pain. Pain can be dismissed in some families, and in some family cultures the expression of pain may not be allowed. Individuals who believe that communicating pain is not allowed may minimise their own pain or that of others.[198]

Peter Drummond also discussed how managing pain by attempting to lower pain levels can be problematic, as the main concern for a person in pain may be how it impacts their overall life:

> When you're in pain, you're not only having to manage an uncomfortable sensation, but you're also having to manage the disruption to your life and to other people's lives. The disruption to your life might mean having to experience side effects from medication. It might mean that you're not able to do things that you otherwise would like to do. It might be a financial threat if you lose your job if you can't work because you're getting frequent headaches. That might be the main problem.[199]

**Peter Goadsby, Professor of Neurology, researcher in diagnostic delays in CH, AU/UK**

We spoke about his research into diagnostic delays and how the term "headache" is often used pejoratively. He offered intriguing insights into how many researchers approach their work with CH, and how he perceived the general public to view headaches differently:

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[198] Nicola and Drummond, 'Conversation with Katrine Skovsgaard on chronic headaches (recorded)'.

[199] Nicola and Drummond, 'Conversation with Katrine Skovsgaard on chronic headaches (recorded)'.

> Well, I think sometimes headache, broadly speaking, is used in a very pejorative way. If something's a problem, people will colloquially refer to it as a headache. You often hear in media someone saying that "that's providing a headache for so and so" when something doesn't work. A problem with something that's common in experience and varies in experience from mild to very severe is that the words can get tossed around. And I don't think they're meant to demean the person with headache. It's simply that the word is used in a range of ways… I think headache probably suffers more from that than many medical problems because the experience is ubiquitous.[200]

**Sonya Huber, Professor of Creative Writing and author of *Pain Woman Takes Your Keys*, US**

Sonya Huber spoke about her experiences with chronic pain, including the invalidation and loneliness that accompany it. Her writing inspired me early in my research, and our conversation, along with the vivid metaphors of pain she described, continues to inform my practice. The opening and closing lines of the choir piece *Six Infinity* were inspired by our conversation in which Sonya Huber said:

> I feel a need for constant contact with other people's in-the-moment experience with pain because I really feel supported by that. I feel it, especially because it's so invisible and it's isolating. My pain is very triggered by the weather. And so, when there's like a weather system, I think about all of us on the landscape experiencing it, all the pain people. And I feel it's this

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[200] Goadsby, 'Conversation with Katrine Skovsgaard on chronic headaches (recorded)'.

> sense of collectivity as opposed to my individual self. And I find that both terrible and beautiful at the same time.[201]

**Jes Olesen, Professor of Neurology and initiator of international headache diagnostic criteria, DK**

I spoke with some early pioneers in neurological studies of CH, such as Jes Olesen and Peter Goadsby. Jes Olesen mentioned how he perceives popular culture surrounding CH to be detrimental to the condition, and how it affects a person's self-understanding much more than other types of pain:

> It's much worse to have a headache than to have pain in your back or pain in your legs. Because the head is where the brain is, that's our centre of communication and control. And when you have a headache, it's more difficult for the brain to work than it is if you have pain in another part of your body. The brain is the organ that makes us human, and all other organs can be replaced. You can have a new heart, you can have a new kidney, you can have a new liver, you can have new lungs, and you are still yourself. But just imagine if you had a brain transplantation, nobody would know who the person is. Is it the person with the body we know, or is it the person who got the brain from the person we know?[202]

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[201] Huber, 'Conversation with Katrine Skovsgaard on chronic headaches (recorded)'.

[202] Olesen, 'Conversation with Katrine Skovsgaard on chronic headaches (recorded)'.

**Dr. Anke Samulowitz, expert in gender bias and gendered norms in health care for pain patients, SE**

At a public event for the Science Festival in Gothenburg, I spoke with Anke Samulowitz, an expert in gender bias and gendered norms in health care for pain patients. In our public conversation many people shared their own experiences of health and care and chronic pain. Many people shared their experiences with us during and after the talk, and some joined for the workshops at the Röhsska Museum. Anke Samulowitz reflects on the gender bias of chronic pain:

> When I conducted interviews with patients and we had questions asking them, "If you had been a woman instead of a man, or if you had been a man instead of a woman, do you think you would have been treated differently?" Women said, "Yeah, everyone knows that men are getting more examinations and treatments. If I'd been a man instead of a woman, I would have been treated much more seriously and better." Men could say, "Yeah, everyone knows it's a shame that women with pain are not taken seriously. But they could also say, "Well, on the other hand, as a man, I am expected to be tough, not to have pain, to be resistant. So, I think if I had been a woman, I would have been met with more empathy."[203]

**Joanna Zakrzewska, Professor and expert in facial pain and the role of art in clinical settings, UK**

Joanna Zakrzewska, a professor and expert in facial pain as well as the role of art in clinical settings, conducted a cross-disciplinary study with visual artist Deborah Padfield, focusing on the effects of using artworks within clinical practice. This study, their conference on pain, and the subsequent book

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[203] Anke Samulowitz, Conversation with Katrine Skovsgaard on chronic headaches (recorded), 10 April 2024.

*Encountering Pain*[204] inspired me to find my balance between art and therapy. While they strive to achieve therapeutic value, I chose a path more aligned with art practice and the role of art in creating alternative spaces to clinical settings. Joanna Zakrzewska's voice highlights the apex of *Six Infinity*, where the choir sings, "What is the point of this stupid scale?" This phrase was lifted from our conversation and also appears in *Chronicles*:

> If you can't do your housework, if you can't go out, if you feel depressed, those are the factors that really tell you how intense that pain is. What's the point of this stupid zero-to-ten scale? But we have to correlate it with other things, and it is a terribly subjective thing.[205]

She also showed me the deck of cards that Deborah Padfield had created and discussed their value through an example from their study,[206] which indicated that these cards were useful for addressing otherwise challenging topics in conversations with patients:

> We're not psychiatrists, so it can induce in the clinicians a feeling that the patient doesn't want to tell you that they're not taking their drugs, but they'll show you this picture of a rubbish dump with medicines thrown around, and they might tell you this way, "Why did you choose this?" If we question, "Why did you choose this?" "Oh, because, Doctor, the drugs don't work,"

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[204] Deborah Padfield and Joanna Zakrzewska, *Encountering Pain: Hearing, Seeing, Speaking.* (UCL Press, 2021).

[205] Zakrzewska, 'Conversation with Katrine Skovsgaard on chronic headaches (recorded)'.

[206] Padfield and others, 'Images as Catalysts for Meaning-Making in Medical Pain Encounters'.

> but they don't want to tell you because they want to remain positive. So those sorts of things bring out sometimes a conversation that may not have happened if you didn't have these cards.[207]

Other than these professionals, I have spoken with people who experience CH. In my selections from the conversations to make art from, I have tried to create a balance towards the interviewees with lived experiences of pain and supplemented with supporting or contrasting statements from the different professionals. Some professionals were also crossovers who both work with and experience pain, like Katerina Cerna and Sonya Huber and Helena Backlund Wasling.

In previous projects conducted in Scandinavia, I collaborated with patient organisations; however, there seem to be few in the UK, and they are not patient-led as they are in Denmark and Sweden. Therefore, the selection of individuals with chronic headaches included in this project has primarily been self-selected. By this, I mean that every person involved has had a point of contact with me or the project and has expressed a desire to participate. This means that these conversations have had a real, tangible impact on how my circle of friends, colleagues, and acquaintances now discuss chronic pain.

### Anders Aarvik, DK

In our conversation, Anders Aarvik discussed the complexities and challenges of living with migraines, particularly focusing on the prolonged aura that can occur before a migraine attack, which for him can

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[207] Zakrzewska, 'Conversation with Katrine Skovsgaard on chronic headaches (recorded)'.

persist for hours, days, and even weeks, obscuring his vision. He emphasised the societal misconceptions surrounding migraines that often result in dismissive attitudes from others. Anders Aarvik shared his frustrations about how people minimise the severity of his condition, equating migraines with simple headaches, and explained the physical and emotional toll it takes on him. He also highlighted coping strategies, such as seeking a quiet environment and using sunglasses or noise-cancelling headphones, while expressing the profound impact migraines have on his daily life and experiences, including the inability to enjoy activities he once loved. He described his visual migraine aura in form and colour:

> It would be very sharp pink and green and blue and purple colours. They would usually be so sharp or strong and saturated to a degree where it was really uncomfortable. If you imagine a light installation with psychedelic colours, and someone was pointing the light directly at you. That is how I would describe them... It's like lines, a lot of lines of colours. It's in the periphery of either the left or right side, and then it would become circular, so it would be like a half circle. Then it will be in the periphery, and it would go towards the centre and would bounce back and forth from there, maybe at an interval of five minutes or so. Then it would be a lot of zigzag lines, maybe like a whirlpool, but it's just half-circled.[208]

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[208] Aarvik, 'Conversation with Katrine Skovsgaard on chronic headaches (recorded)'.

**Hannah Clarkson, UK**

Hannah Clarkson spoke about how the senses are heightened, and about the double-sided nature of touch when experiencing a migraine attack. She compared the change in senses with overwhelming environments such as the crowded London Underground during rush hour. She shared how it can be hard to communicate how these changing senses affect her and highlighted the importance of attempting to communicate these experiences despite the inherent challenges.

> There's something about if someone strokes your hair that really helps, but at the same time, I don't wash my hair very often because it just hurts to brush it. If I've got a headache, which is all the time, then to have to tug at my head is just not what I want to do. So, again, there's that some touch is good and some is not. And sometimes the touch, which is good, is also not good.[209]

**Kaitlin D'Avella, US**

Kaitlin D'Avella detailed an intense pain that begins with sudden shocks and evolves into a prolonged state of discomfort marked by dizziness and cognitive issues. She spoke about the ways in which societal perceptions trivialise migraines as excuses. She spoke of using pain scale ratings as her tool of validation, in contrast to the many people who did not like using the 0-10 pain scale:

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[209] Clarkson, 'Conversation with Katrine Skovsgaard on chronic headaches (recorded)'.

> If I tell them I'm having nine out of 10 pain or I haven't been able to get out of bed for two weeks, then they value what I'm saying more. So, I'm quite happy to use numbers to get someone's attention or get someone to believe me. I've had doctors say to me that I should get a boyfriend, that would help with my migraines, or that maybe I should move home and that would help, or it can be so hard moving to a big, hard city like London, and away from my parents and my family, and that must be why. But that's not why I have migraine. It's a genetic condition that I got from my grandmother. Even if doctors don't ask me to rate my pain out of 10, I will tell them. I like to use it as a way to get attention or feel legitimised. It helps me. It's almost like code switching. It helps me use their language against them.[210]

**Nadia Lesniarek-Hamid, UK**

Nadia Lesniarek-Hamid expressed how headaches can prevent her from engaging in intellectual conversations and everyday activities. She reflected on the impact of CH on her ability to communicate the depth of her experiences to others, including medical professionals and loved ones. She spoke about the concept of "crip time" and highlighted how chronic pain alters her perception of time and productivity, emphasising the need for a flexible understanding of time that accommodates the realities of disability.

> Cripping time is like to sort of bend time. Instead of bending the disabled body to the rigid framework of time to bend time to meet the needs of the disabled body. That could

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[210] D'Avella, 'Conversation with Katrine Skovsgaard on chronic headaches (recorded)'.

> incorporate the extra time that it takes to do a task if you're disabled or chronically ill. So, like resting before or after something. Or if you're in a wheelchair, having to navigate planning routes and things like that. So, I guess it's not just stretched out, it's like exploded time. So, it's like totally questioning the whole concept of how we relate how our body is to time. It's a really important thing that I find as a way of understanding my position in the world because I feel like time is one of those things that dictates so much about productivity and also with language, the way we talk about chronic illness, it so much relates to time, like whether something's intermittent or permanent or temporarily disabled or whatever, different things like that. So, I think even just questioning the concept of time as something that we, or that dictates us, is quite useful in reframing the way we live and reframing production.[211]

### Cameron O'Loan, WAL

Talking with Cameron O'Loan led to the title of the choir piece, *Six Infinity*. He discussed the various gendered expectations surrounding individuals with pain, highlighting the difficulties in balancing work responsibilities and the trouble of getting time off for chronic pain when in an attack or flare-up.

Six infinity refers to the inadequacy of the pain scale in measuring experience, and he highlights that it can also be incredibly difficult to measure one's experience in this way:

> For me personally, saying one to ten isn't actually productive. You could describe being pinched as like a five, but if you were going through that same feeling constantly, for like a week, it

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[211] Nadia Lesniarek, Conversation with Katrine Skovsgaard on chronic headaches (recorded), 7 October 2024.

> wouldn’t be a five anymore because it would just become unbearable. It would be a ten, I guess. So, yeah. The one-to-ten scale is not very helpful because you don’t want to be dishonest with your doctor and say it’s a ten because it’s not a ten when you have chronic pain; usually, it’s very, very rarely a ten. For me, it’s more just like a never-ending six. It’s like a six infinity. And six infinity sometimes can be worse than ten for a day.[212]

**Sophie Richings, UK**

Sophie Richings chronicled the various sensory symptoms associated with her migraines, noting that seeing images of visual migraine auras for the first time was an incredibly emotional experience for her:

> To be shown something that is only ever inside my head before was profound, really profound. It looked like when I have a migraine, it was the same. Yeah. Also, because the first few times I experienced it, when I was trying to talk to other people about it who had not or didn’t have one, I tried to explain the extent to which the image, my normal visual field, was just not there. It was just gone. I’d say it’s like it’s the back of my head. I cannot see it. Then over time, I began to realise that actually that fuzziness was into different colours and had a c-curve and would come in and out or close in. Seeing that image, I was like, Oh, yeah, that’s actually what I experienced in terms of the c-curve and the lights and the slightly different, like black and white jaggedness, but then also bits of other colours.[213]

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[212] O’Loan, ‘Conversation with Katrine Skovsgaard on chronic headaches (recorded)’.

[213] Sophie Richings, Conversation with Katrine Skovsgaard on chronic headaches (recorded), 20 January 2025.

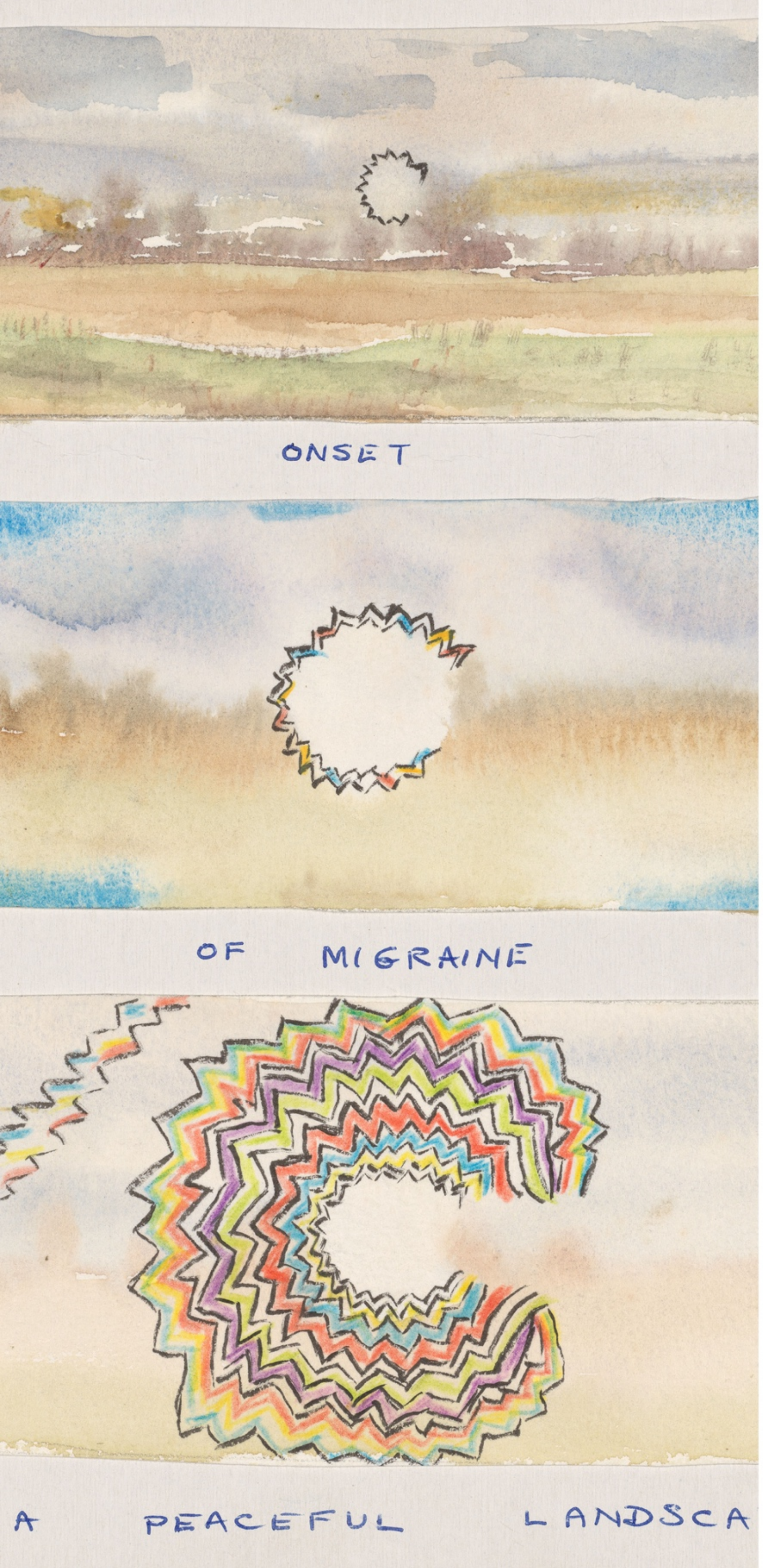


Figure 101 *Onset of a Migraine in a Peaceful Landscape*, detail, the Migraine Art Competition, SA/MAR/511.

# SIX INFINITY

Read the sheet music from *Six Infinity* on the following pages. The choir piece was written in collaboration with composer Rosanna Gunnarson in 2023.

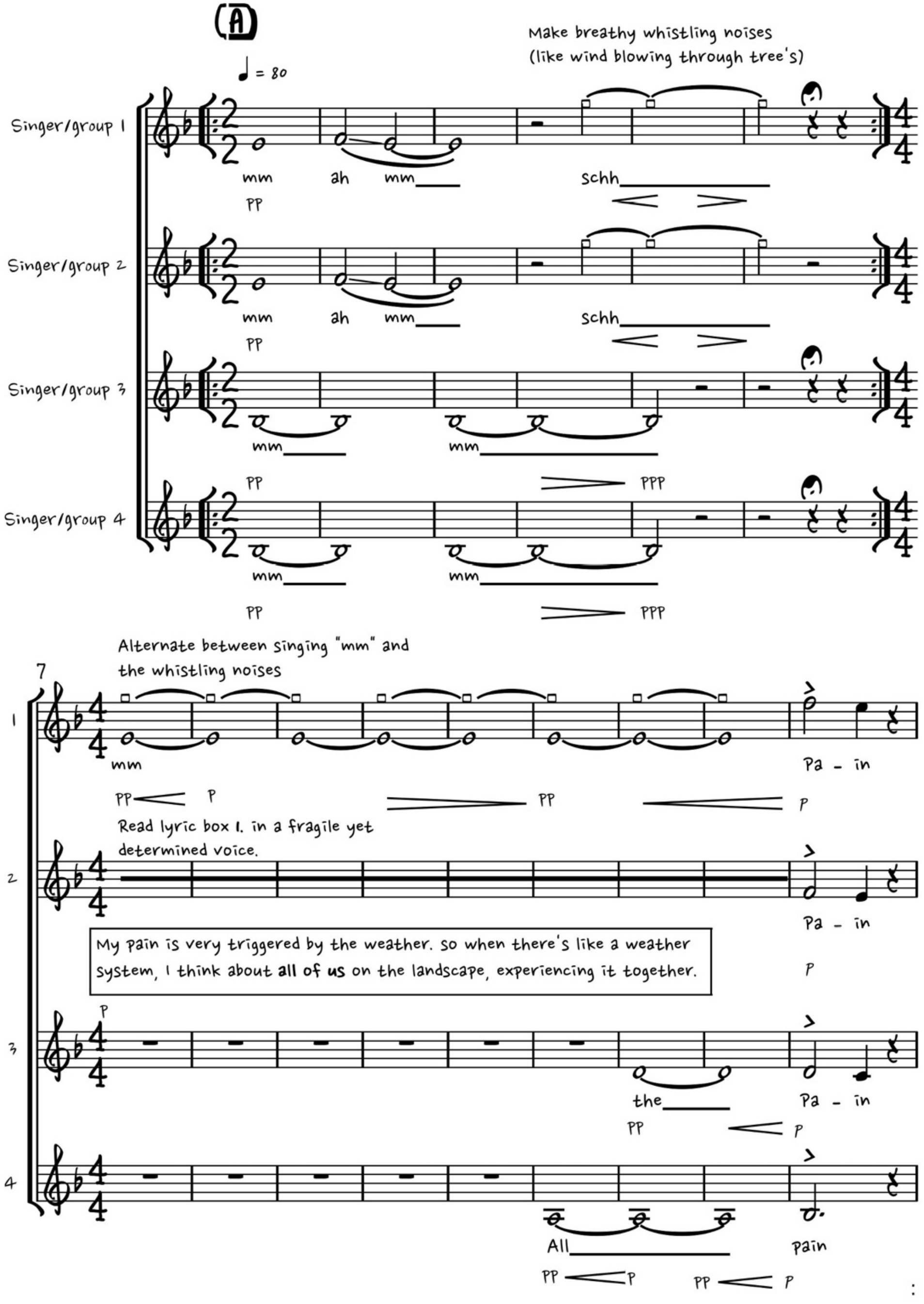
A stereo mix of the multi-channel sound installation *Six Infinity* can be heard here: https://soundcloud.com/kat-skovsgaard/sixinfinity

A video recording of the piece performed at Röhsska Museum of Design and Craft in Gothenburg, Sweden, in 2023, can be accessed through this link: https://vimeo.com/katart/sixinfinity?ts=0&share=copy

# Six Infinity

Rosanna Gunnarson

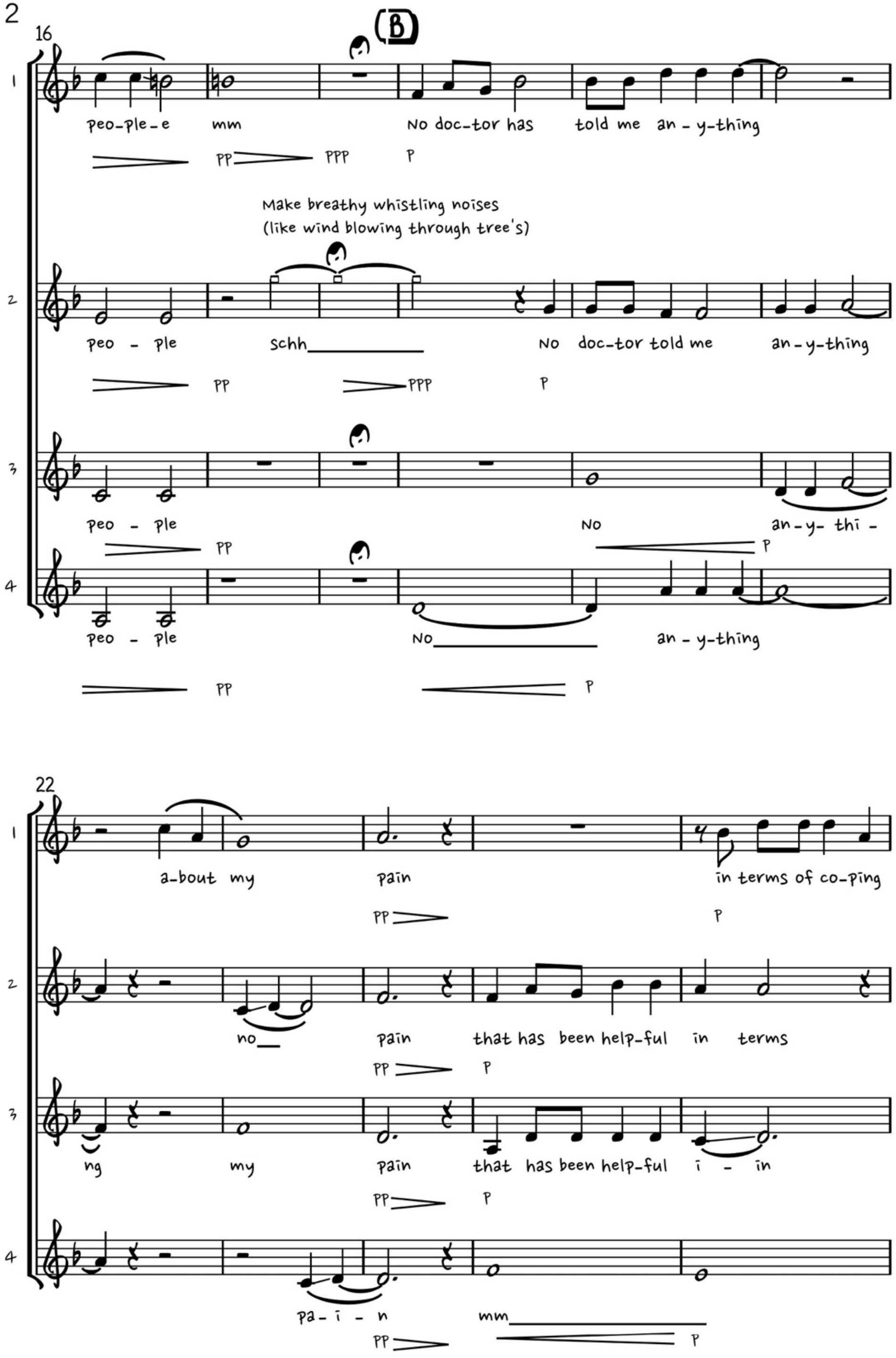
in collaboration with Katrine Skovsgaard

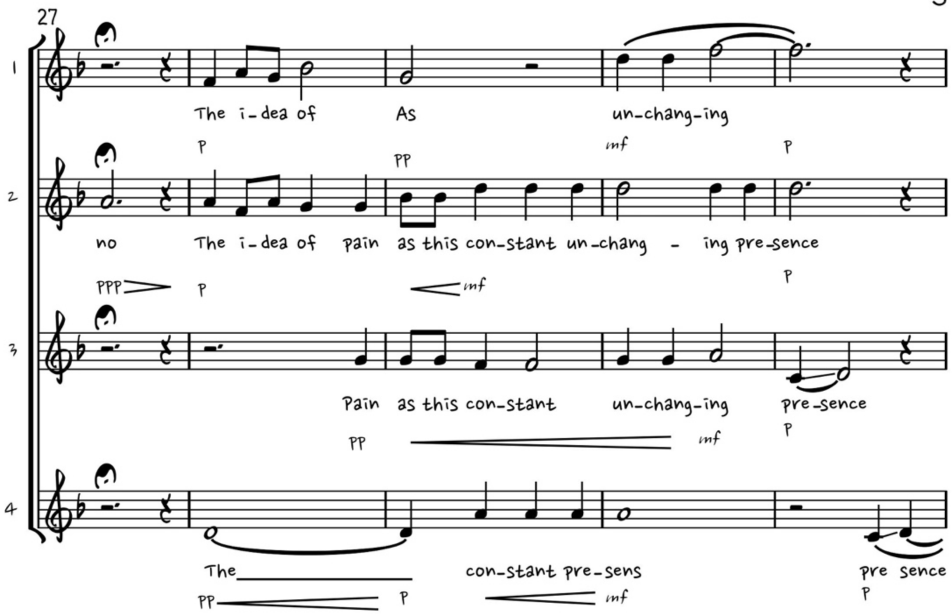
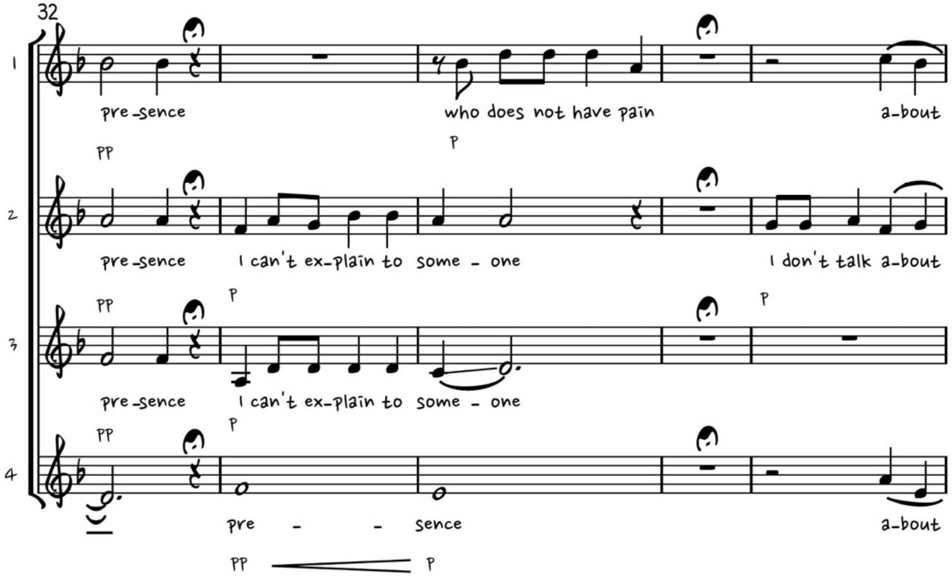


Make breathy whistling noises (like wind blowing through tree's)

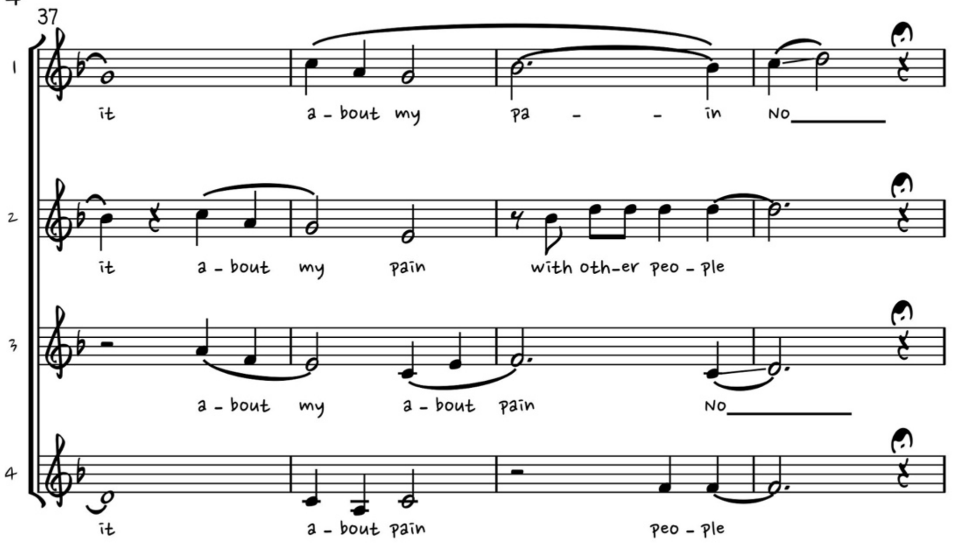
Alternate between singing "mm" and the whistling noises

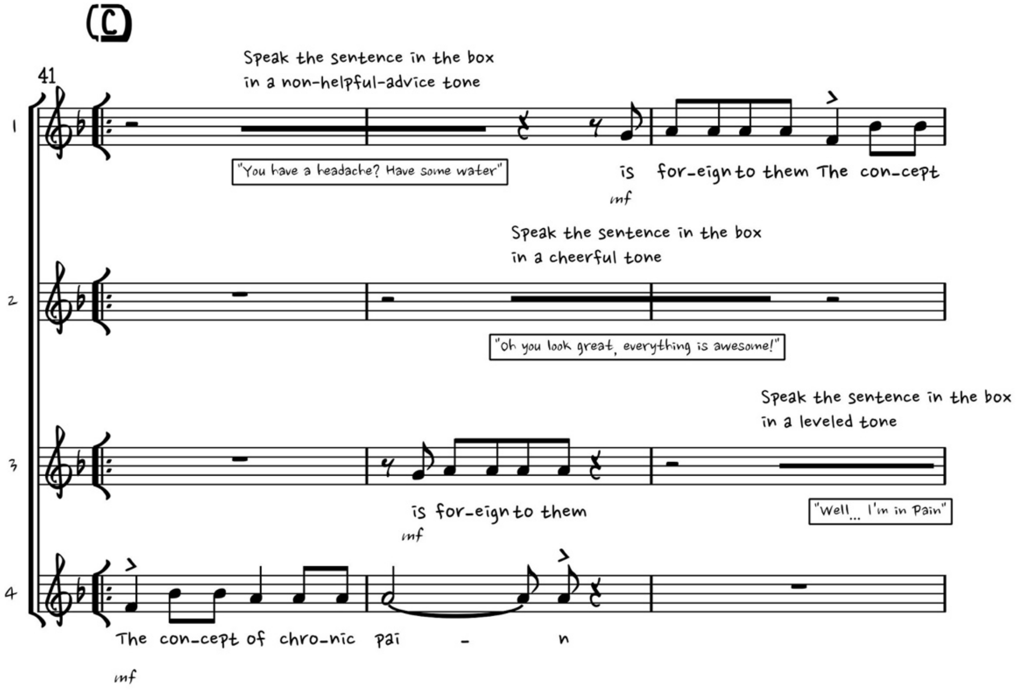
Read lyric box 1. in a fragile yet determined voice.

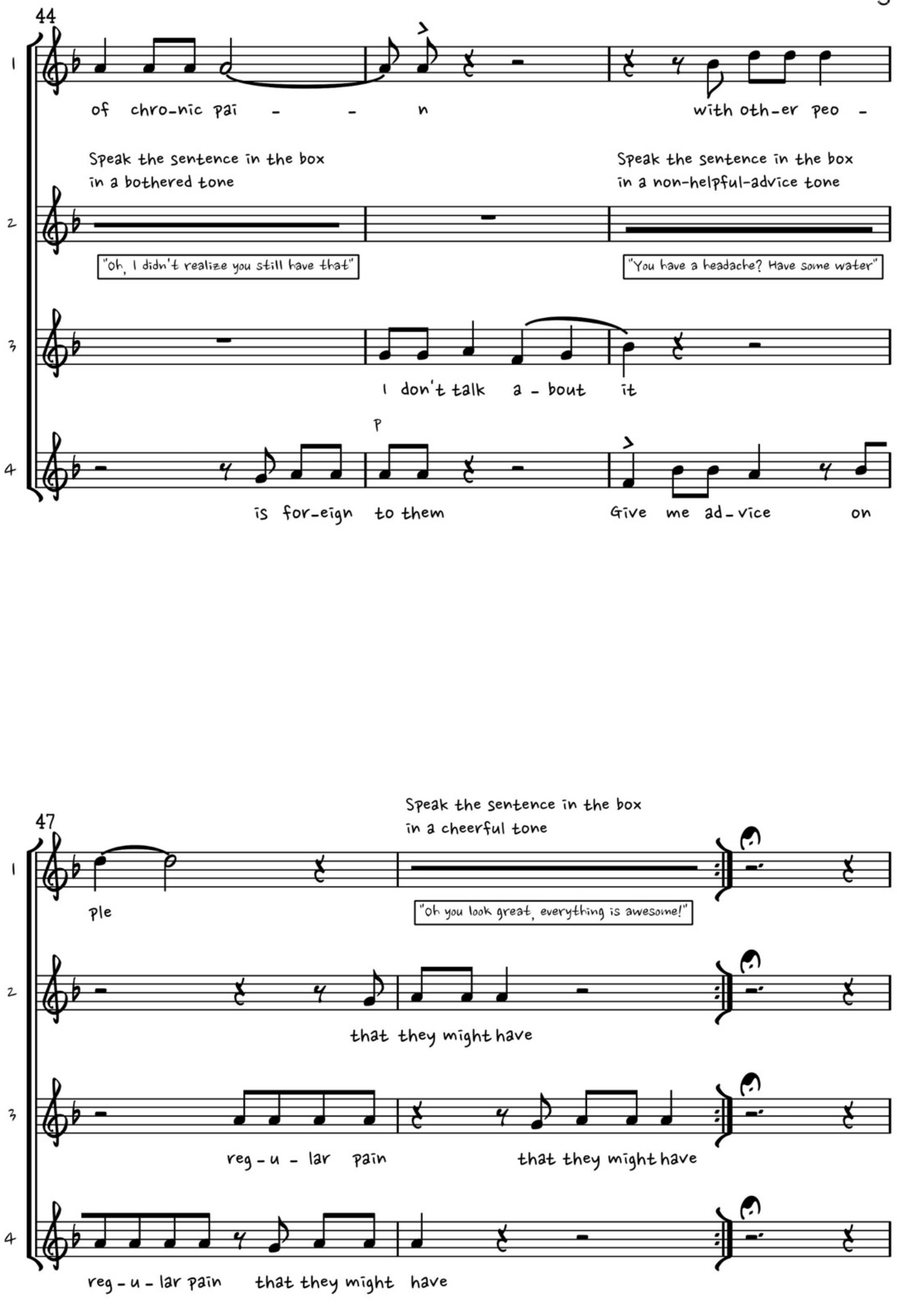
My pain is very triggered by the weather. so when there's like a weather system, I think about **all of us** on the landscape, experiencing it together.

Make breathy whistling noises (like wind blowing through tree's)

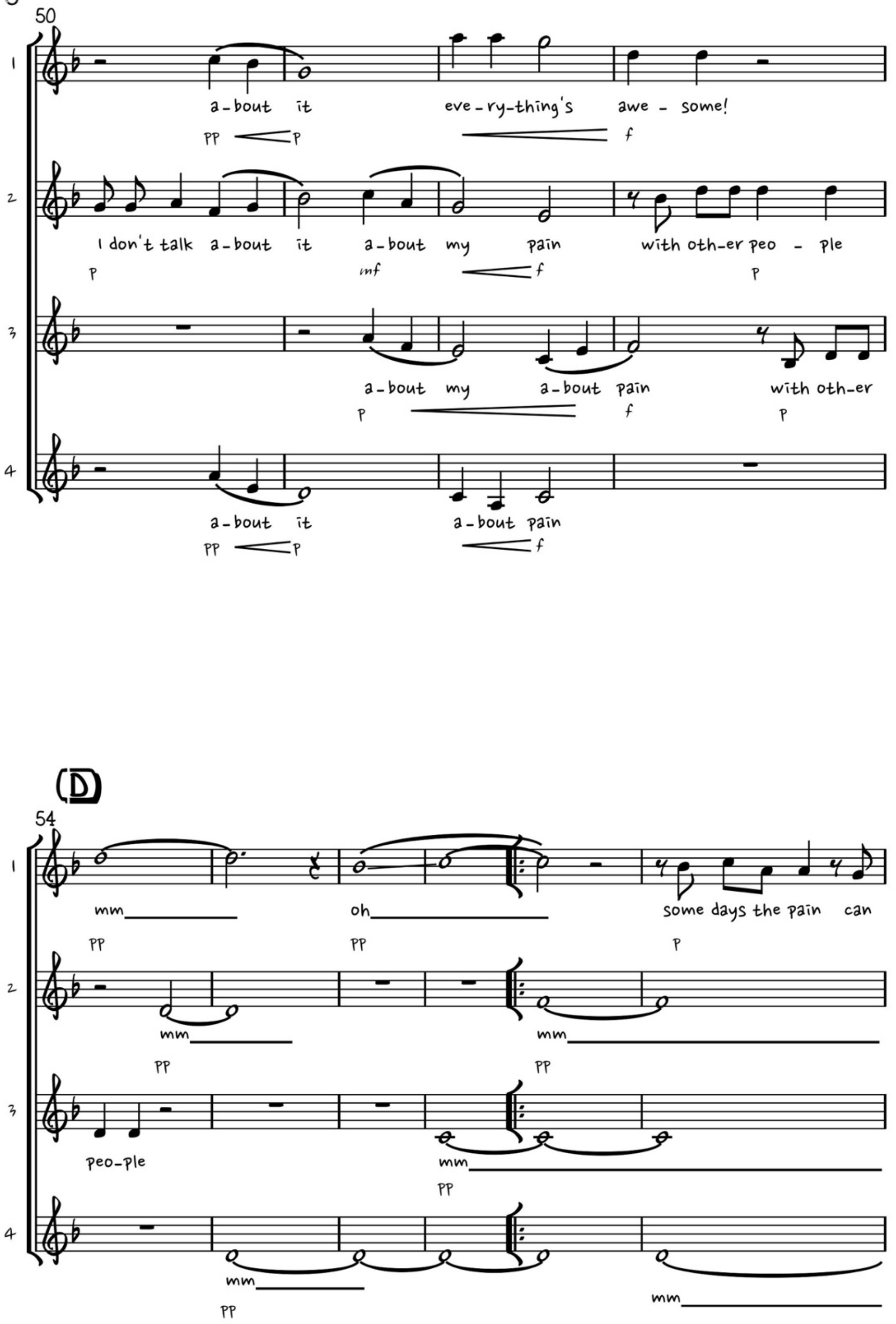
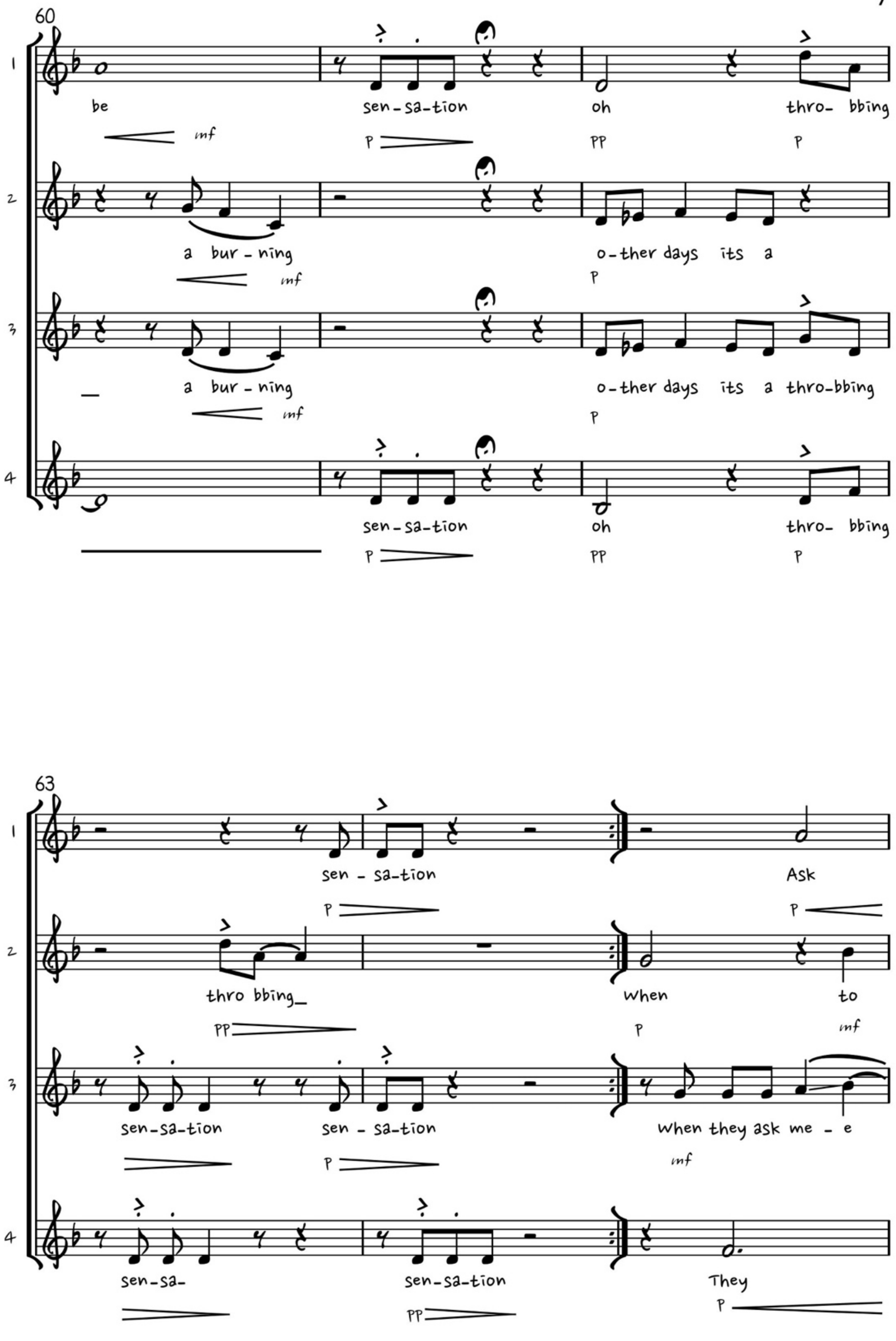

27
1
2
3
4
The i-dea of As un-chang-ing
no The i-dea of pain as this con-stant un-chang - ing pre-sence
Pain as this con-stant un-chang-ing pre-sence
The con-stant pre-sens pre sence
p
pp
mf
ppp
pp
p


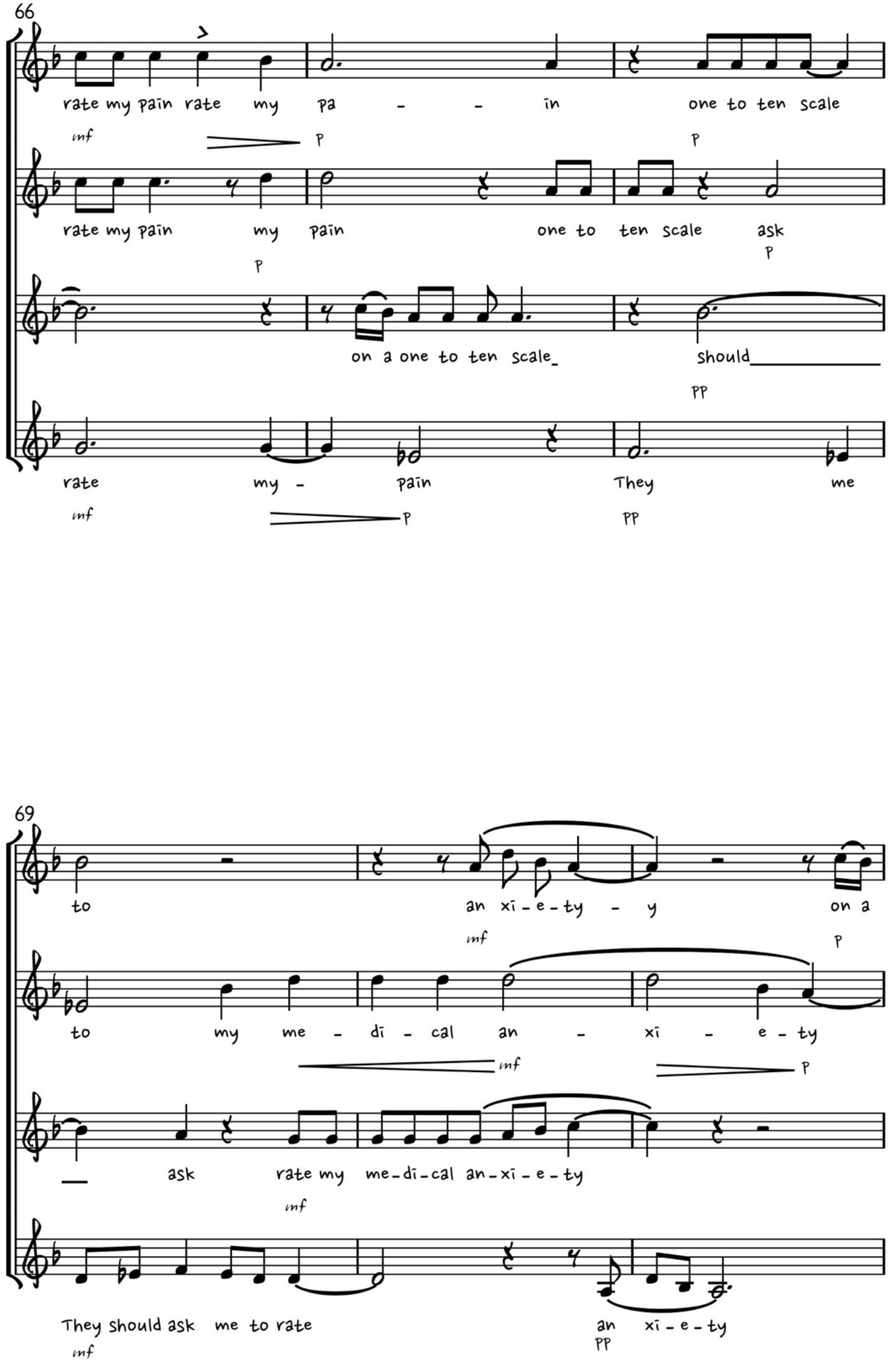
32
1
2
3
4
pre-sence who does not have pain a-bout
pre-sence I can't ex-plain to some - one I don't talk a-bout
pre-sence I can't ex-plain to some - one
pre - - sence a-bout
pp
p

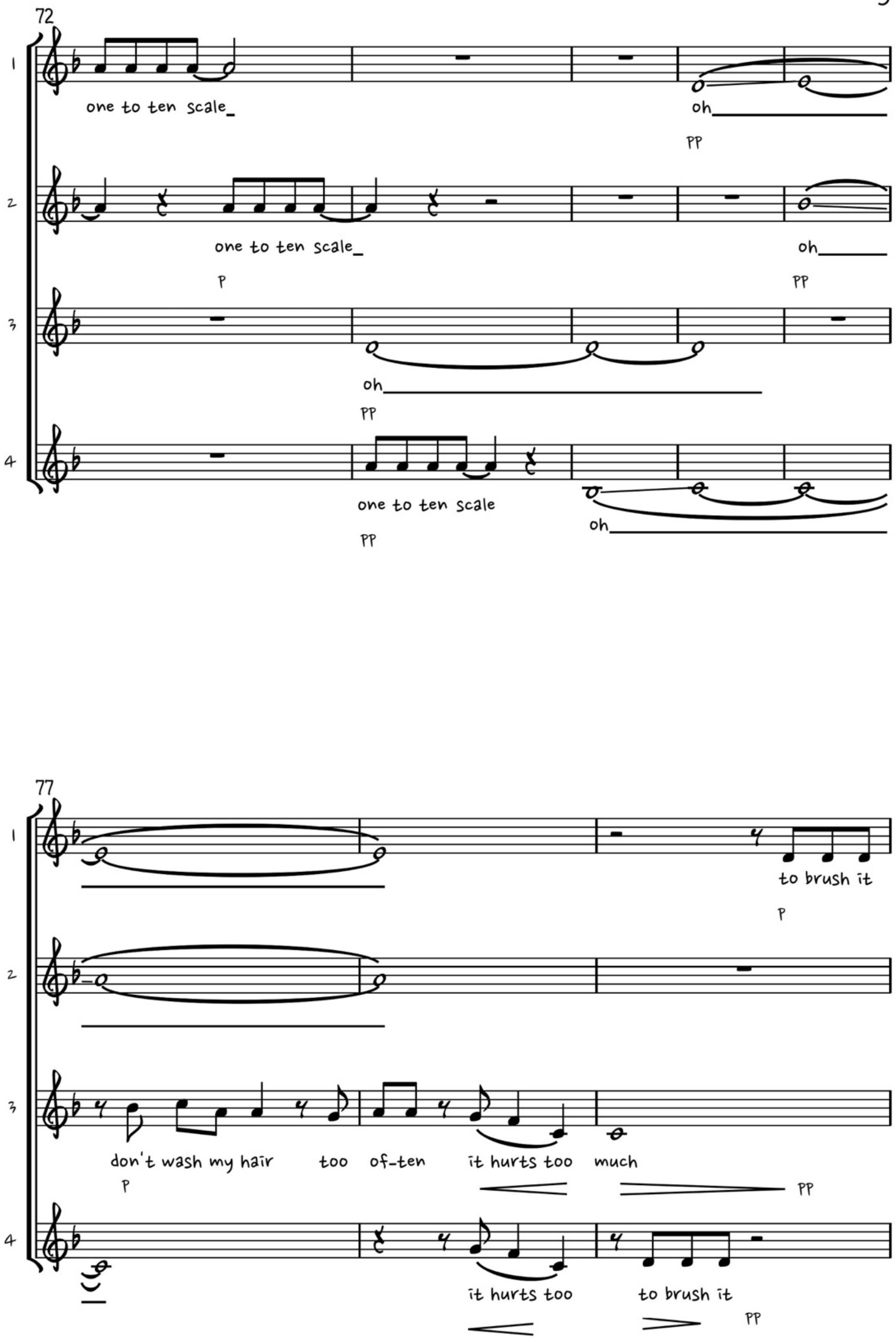

37
1
2
3
4
it a-bout my pa - - in No
it a-bout my pain with oth-er peo - ple
a - bout my a - bout pain No
it a - bout pain peo - ple

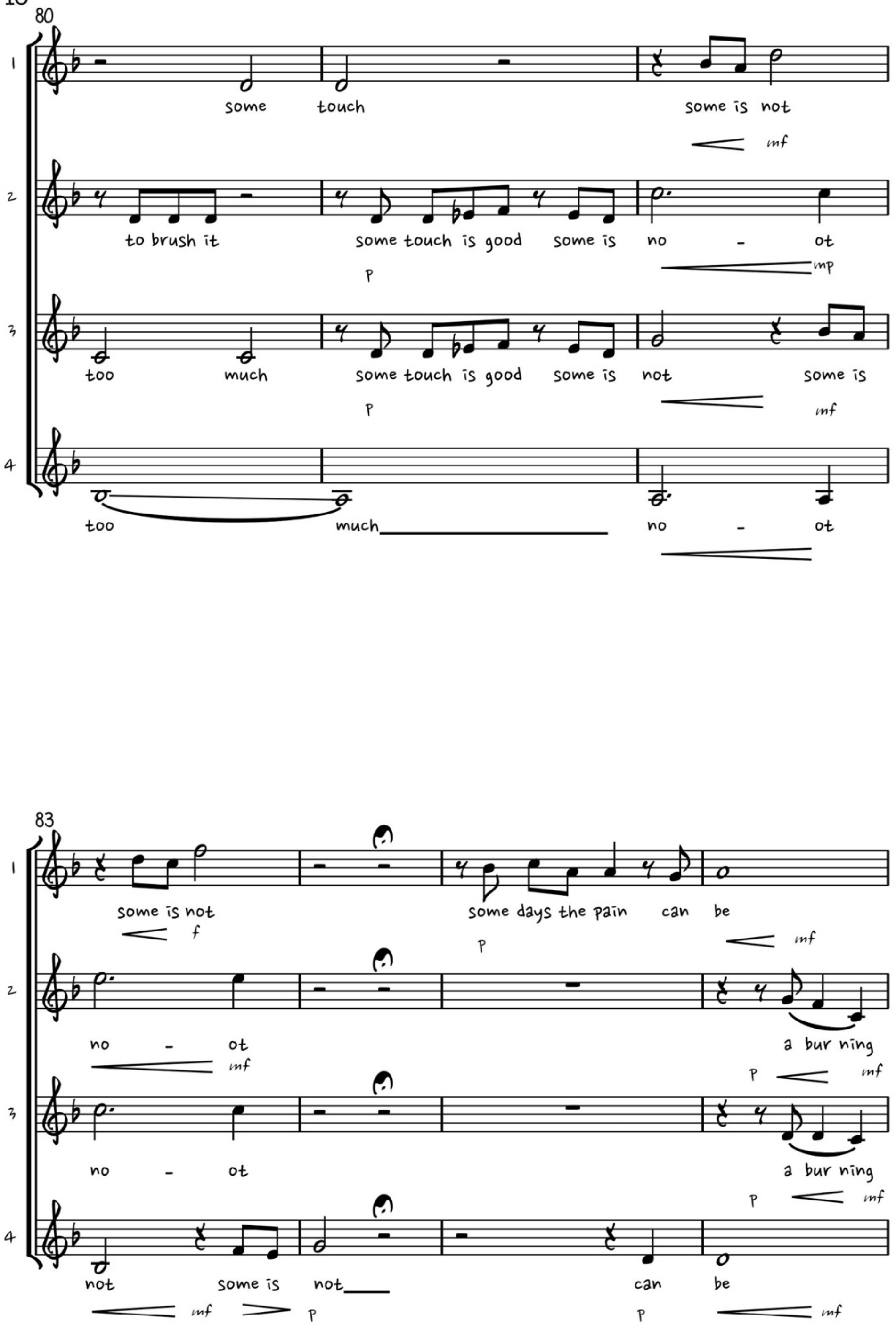

C
41
1
2
3
4
Speak the sentence in the box
in a non-helpful-advice tone
"You have a headache? Have some water"
is for-eign to them The con-cept
mf
Speak the sentence in the box
in a cheerful tone
"Oh you look great, everything is awesome!"
Speak the sentence in the box
in a leveled tone
is for-eign to them
mf
"Well... I'm in Pain"
The con-cept of chro-nic pai - n
mf

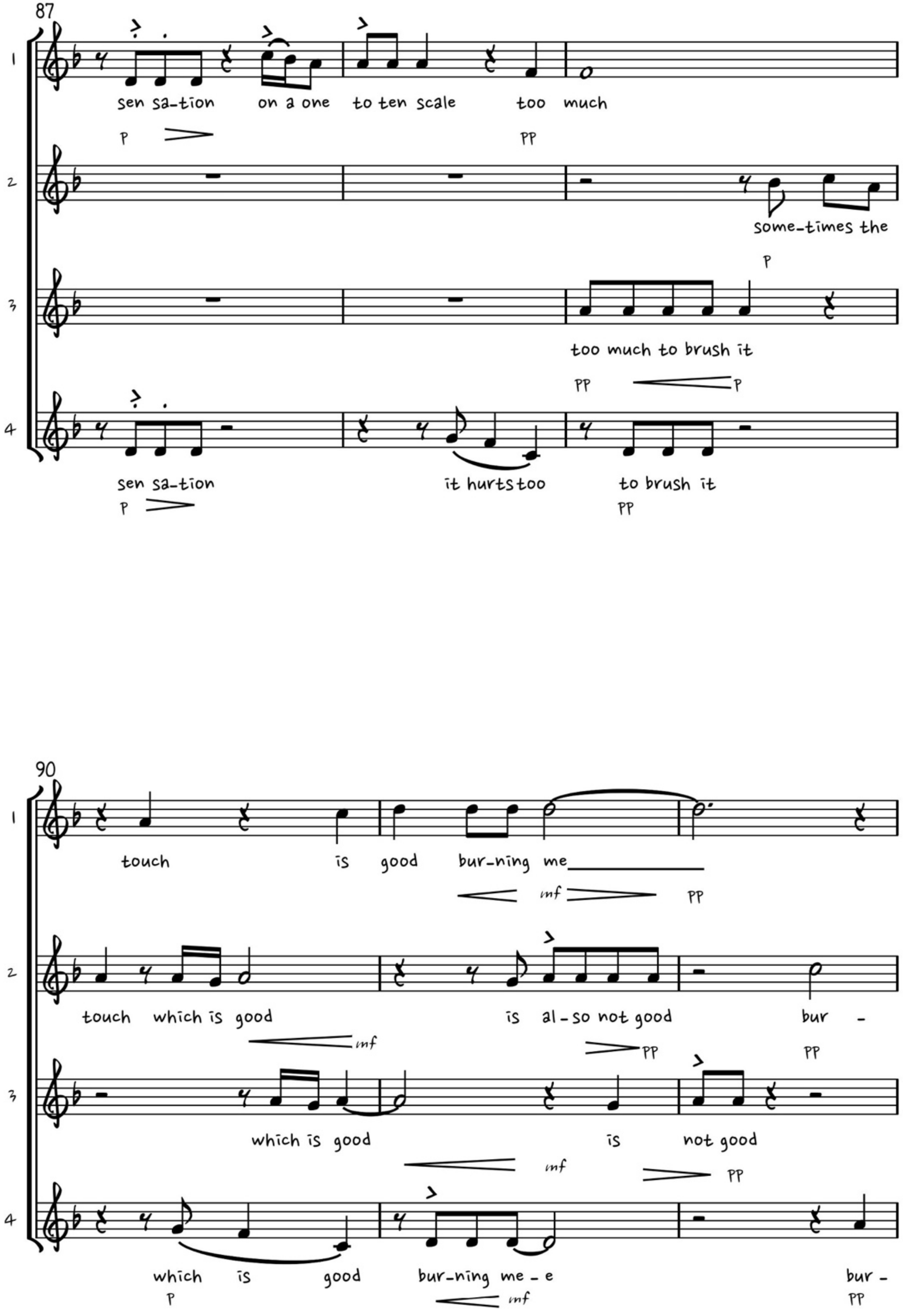

44
1
2
3
4
of chro-nic pai - - n
with oth-er peo -
Speak the sentence in the box
in a bothered tone
"Oh, I didn't realize you still have that"
Speak the sentence in the box
in a non-helpful-advice tone
"You have a headache? Have some water"
I don't talk a - bout it
p
is for-eign to them
Give me ad-vice on
47
ple
Speak the sentence in the box
in a cheerful tone
"Oh you look great, everything is awesome!"
that they might have
reg - u - lar pain
that they might have
reg - u - lar pain that they might have

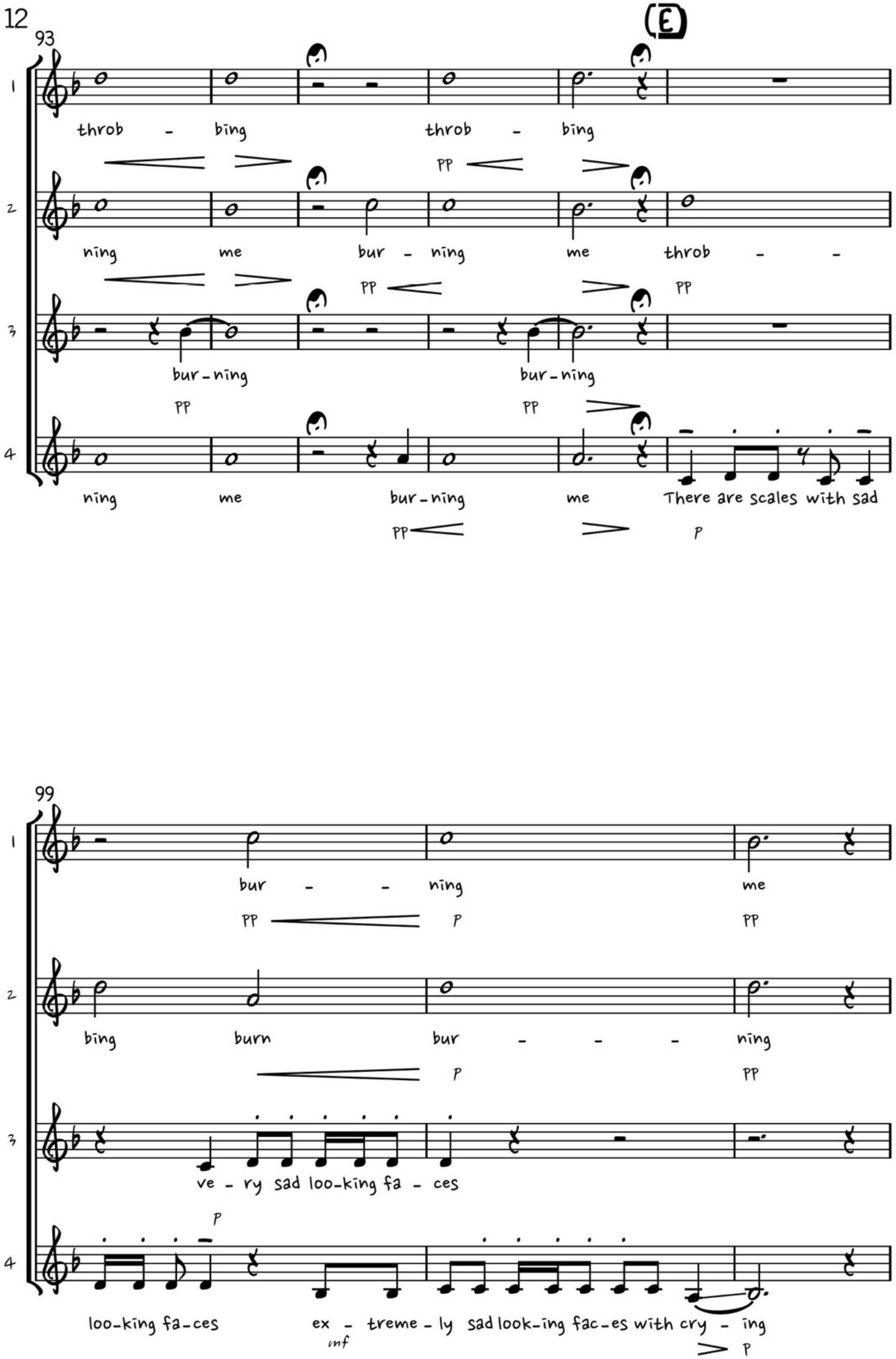

50
1
2
3
4
a-bout it
eve-ry-thing's
awe - some!
pp
p
f
I don't talk a-bout it
a-bout my
pain
with oth-er peo - ple
p
mf
f
p
a-bout my
a-bout pain
with oth-er
p
f
p
a-bout it
a-bout pain
pp
p
f
D
54
mm
oh
some days the pain can
pp
pp
p
mm
mm
pp
pp
peo-ple
mm
pp
mm
pp
mm


60
1
be
mf
sen-sa-tion
p
oh
pp
thro- bbing
p
2
a bur - ning
mf
o-ther days its a
p
3
a bur - ning
mf
o-ther days its a thro-bbing
p
4
sen-sa-tion
p
oh
pp
thro- bbing
p
63
sen - sa-tion
p
Ask
p
thro bbing_
pp
When
p
to
mf
sen-sa-tion
sen - sa-tion
p
When they ask me - e
mf
sen-sa-
sen-sa-tion
pp
They
p


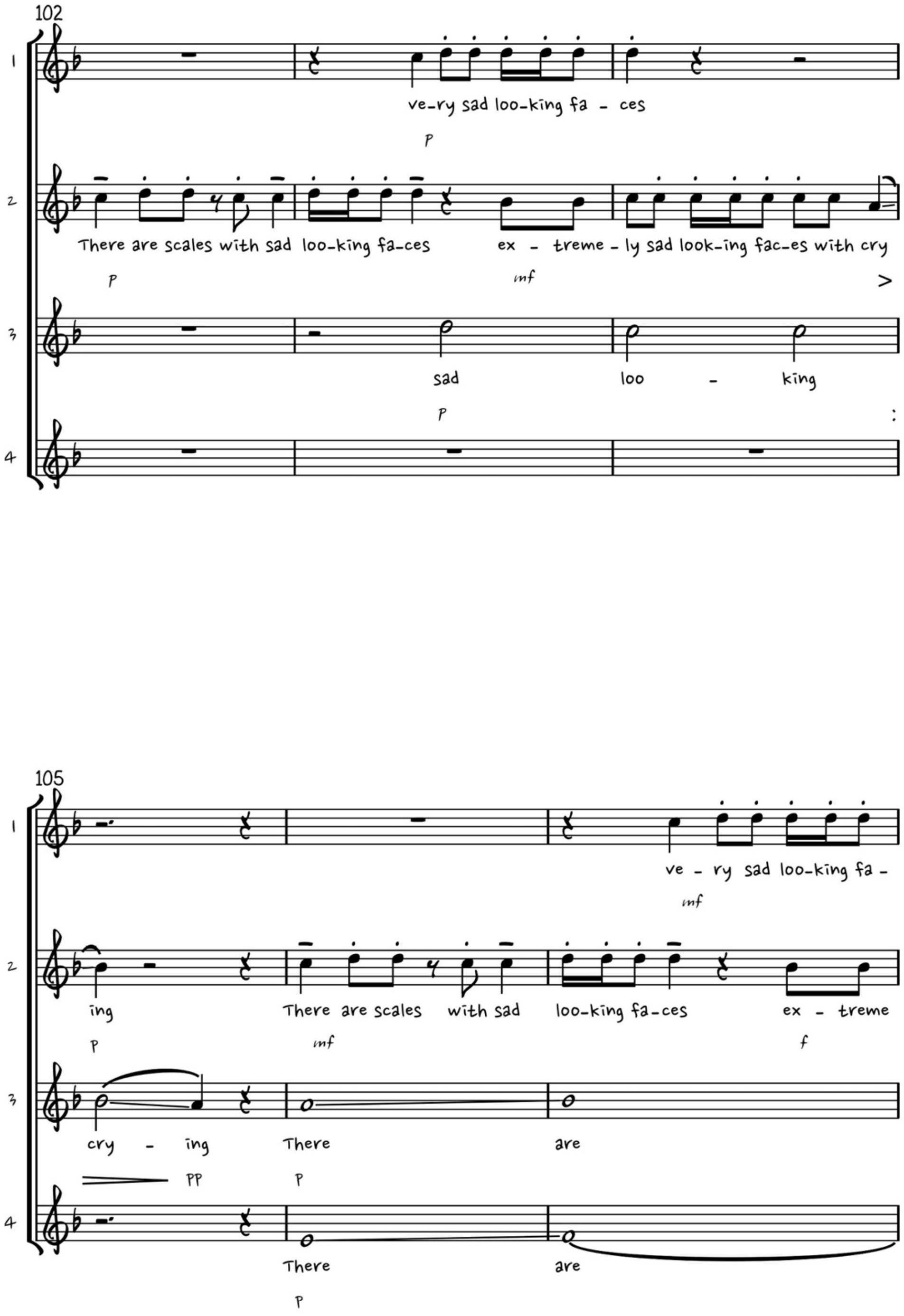
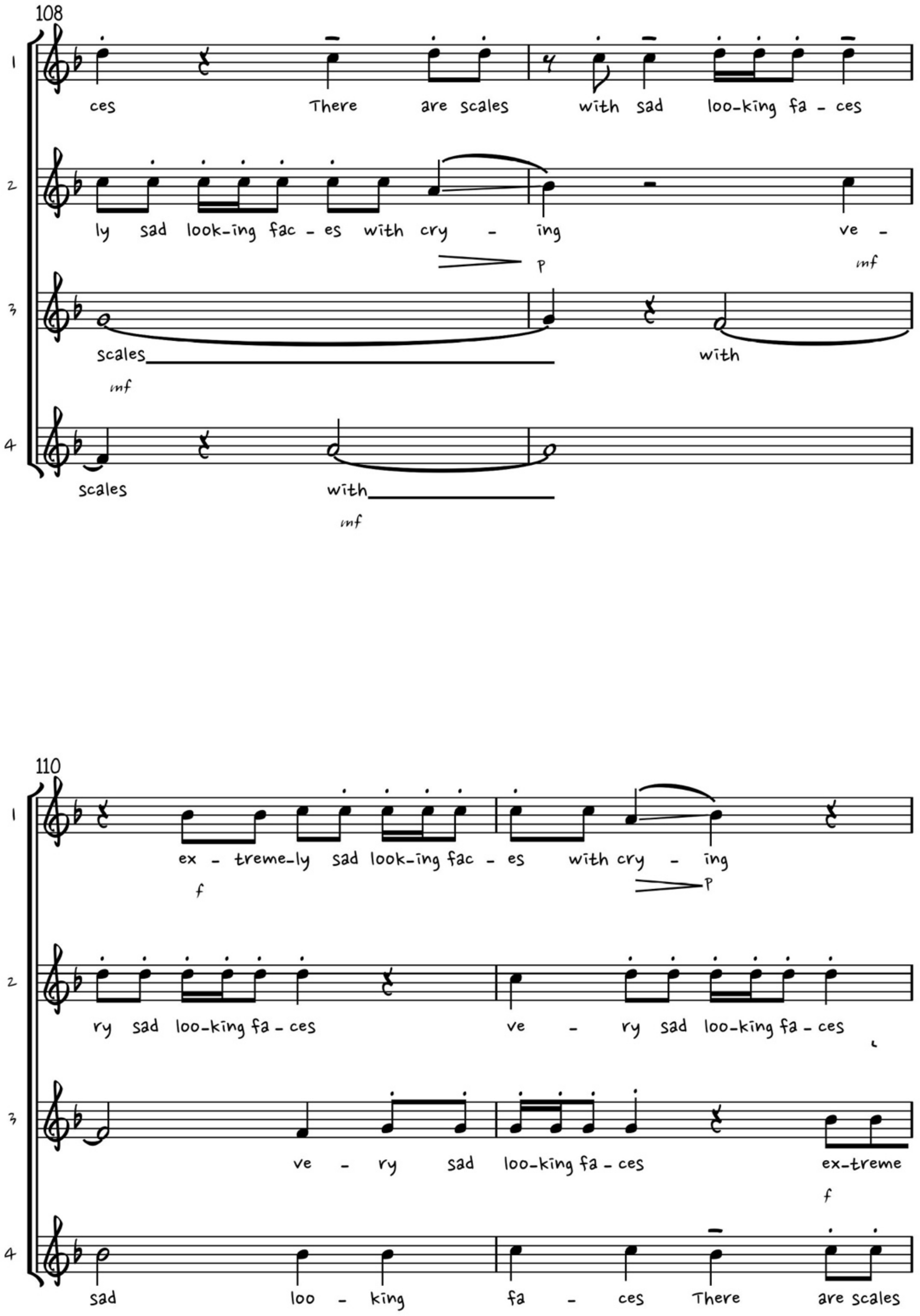
66
rate my pain rate my pa - - in
mf
p
one to ten scale
p
rate my pain my pain
p
one to ten scale ask
p
on a one to ten scale_
should
pp
rate my - pain
mf
p
They me
pp
69
to
an xi-e-ty - y
mf
on a
p
to my me - di - cal an - xi - e - ty
mf
p
ask rate my me-di-cal an-xi-e-ty
mf
They should ask me to rate
mf
an xi-e-ty
pp


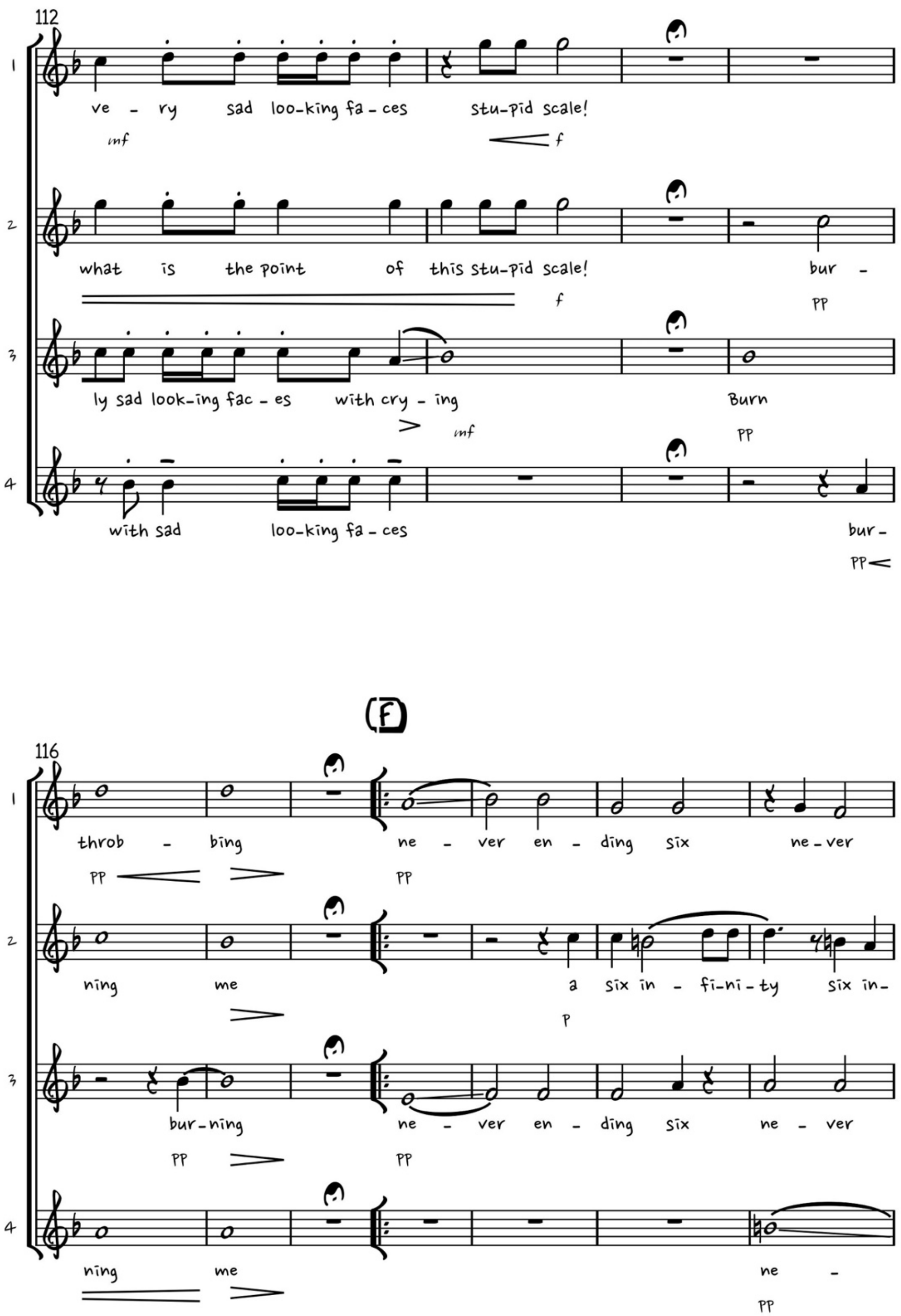
72
1
2
3
4
one to ten scale_
oh
pp
one to ten scale_
p
oh
pp
oh
pp
one to ten scale
pp
oh
77
to brush it
p
don't wash my hair too of-ten it hurts too much
p
pp
it hurts too to brush it
pp


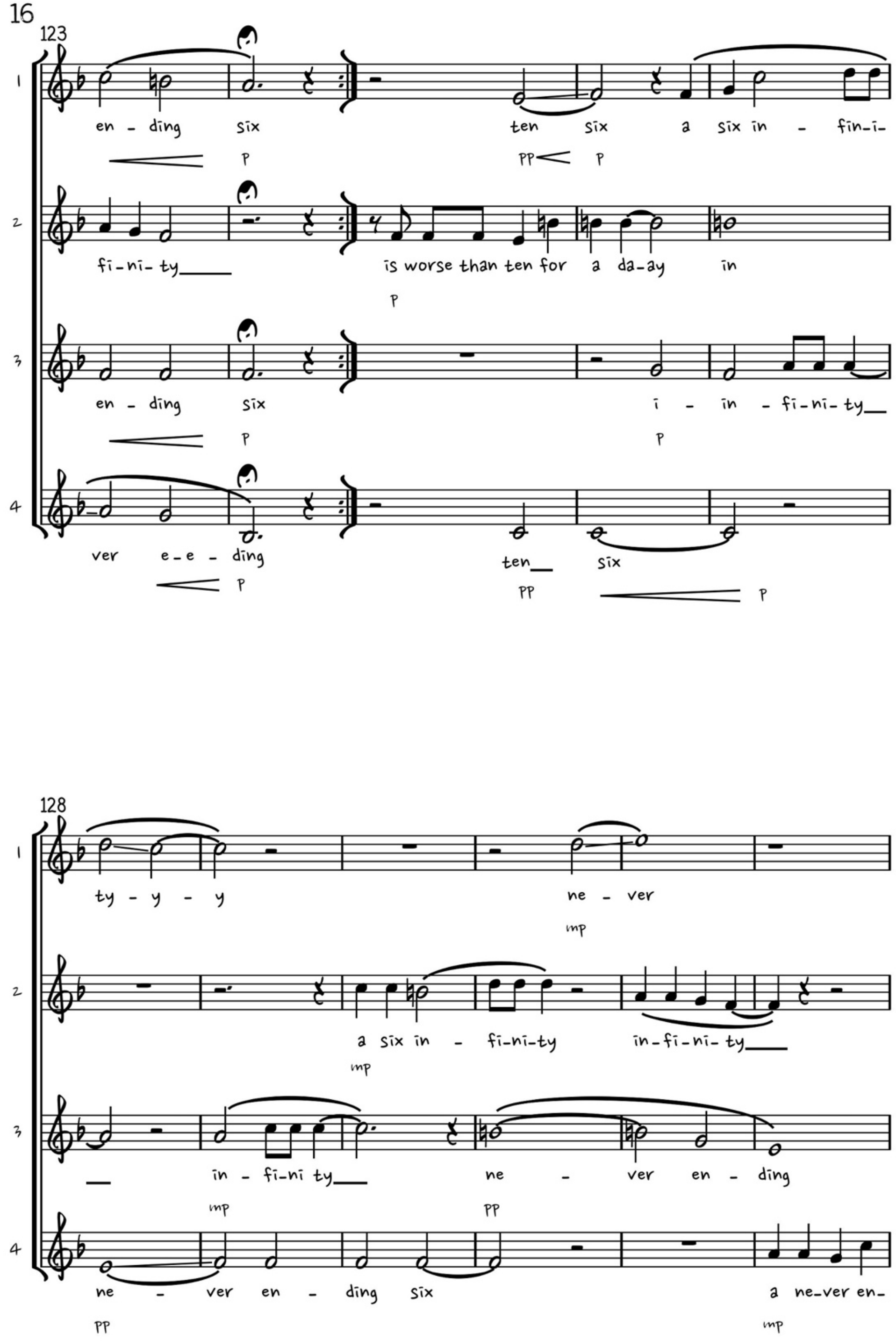
80
1
2
3
4
some touch some is not
mf
to brush it some touch is good some is no - ot
p
mp
too much some touch is good some is not some is
p
mf
too much no - ot
83
some is not
f
some days the pain can be
p
mf
no - ot
mf
a bur ning
p
mf
no - ot
a bur ning
p
mf
not some is not can be
mf
p
p
mf


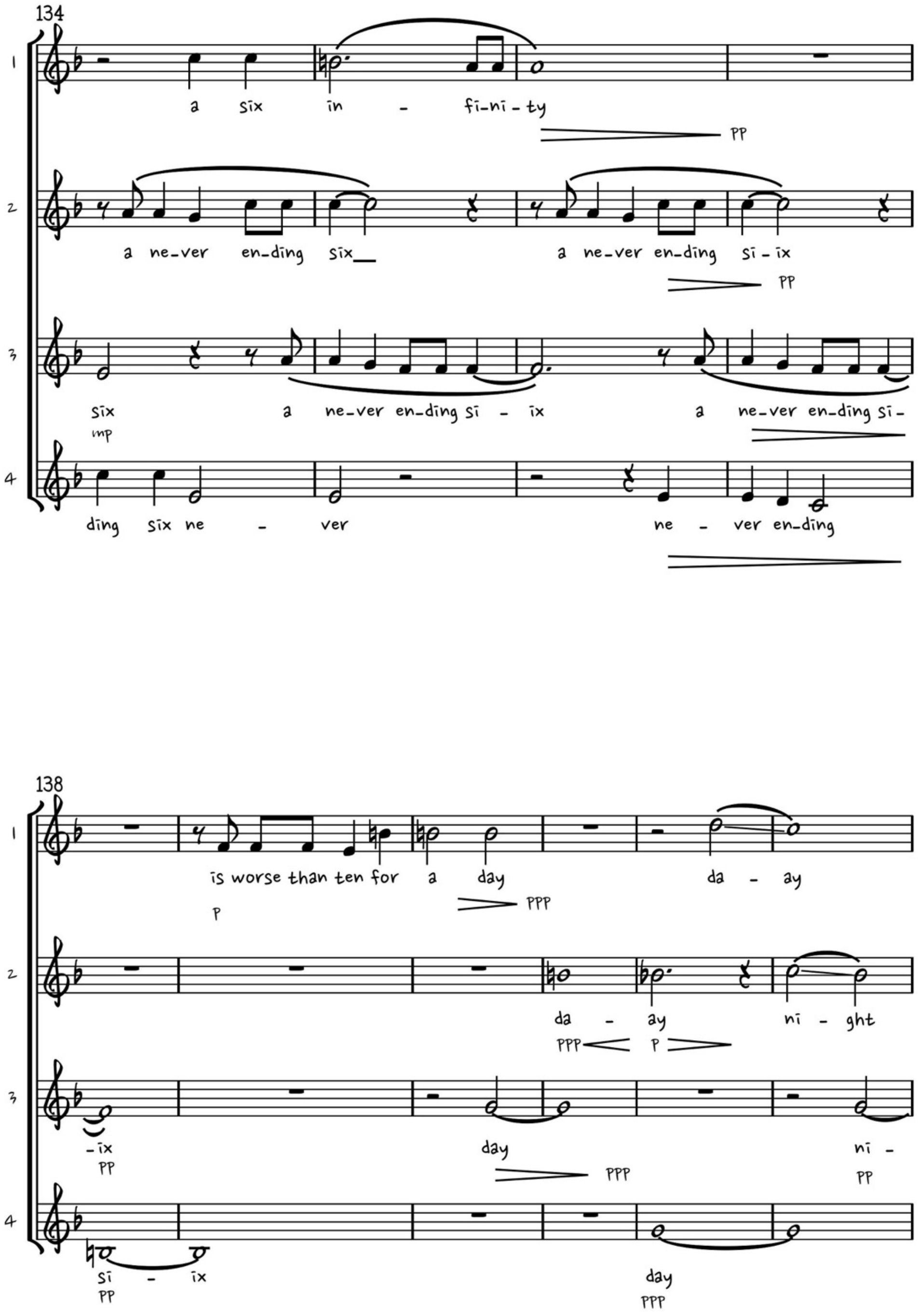
87
1
sen sa-tion on a one to ten scale too much
p pp
2
some-times the
p
3
too much to brush it
pp p
4
sen sa-tion it hurts too to brush it
p pp
90
1
touch is good bur-ning me
mf pp
2
touch which is good is al-so not good bur -
mf pp pp
3
which is good is not good
mf pp
4
which is good bur-ning me - e bur -
p mf pp


E
93
1
throb - bing throb - bing
pp
2
ning me bur - ning me throb - -
pp pp
3
bur-ning bur-ning
pp pp
4
ning me bur-ning me There are scales with sad
pp p
99
1
bur - - ning me
pp p pp
2
bing burn bur - - - ning
p pp
3
ve - ry sad loo-king fa - ces
p
4
loo-king fa-ces ex - treme - ly sad look-ing fac-es with cry - ing
mf p


102
1
2
3
4
ve-ry sad loo-king fa - ces
p
There are scales with sad loo-king fa-ces ex - treme - ly sad look-ing fac-es with cry
p
mf
sad loo - king
p
105
ve - ry sad loo-king fa -
mf
ing There are scales with sad loo-king fa-ces ex - treme
p
mf
f
cry - ing There are
pp
p
There are
p


108
1
2
3
4
ces There are scales with sad loo-king fa - ces
ly sad look-ing fac - es with cry - ing ve -
p
mf
scales with
mf
scales with
mf
110
ex - treme-ly sad look-ing fac - es with cry - ing
f
p
ry sad loo-king fa - ces ve - ry sad loo-king fa - ces
ve - ry sad loo-king fa - ces ex-treme
f
sad loo - king fa - ces There are scales


112
1
ve - ry sad loo-king fa-ces stu-pid scale!
mf
f
2
what is the point of this stu-pid scale! bur -
f
pp
3
ly sad look-ing fac - es with cry - ing Burn
mf
pp
4
with sad loo-king fa-ces bur-
pp
F
116
throb - bing ne - ver en - ding six ne-ver
pp
pp
ning me a six in - fi-ni-ty six in-
p
bur-ning ne - ver en - ding six ne - ver
pp
pp
ning me ne -
pp


123
1
en - ding six ten six a six in - fin-i-
p
pp
p
2
fi-ni-ty is worse than ten for a da-ay in
p
3
en - ding six i - in - fi-ni-ty
p
p
4
ver e-e - ding ten six
p
pp
p
128
ty - y - y ne - ver
mp
a six in - fi-ni-ty in-fi-ni-ty
mp
in - fi-ni ty ne - ver en - ding
mp
pp
ne - ver en - ding six a ne-ver en-
pp
mp


134
1
a six in - fi-ni-ty
pp
2
a ne-ver en-ding six
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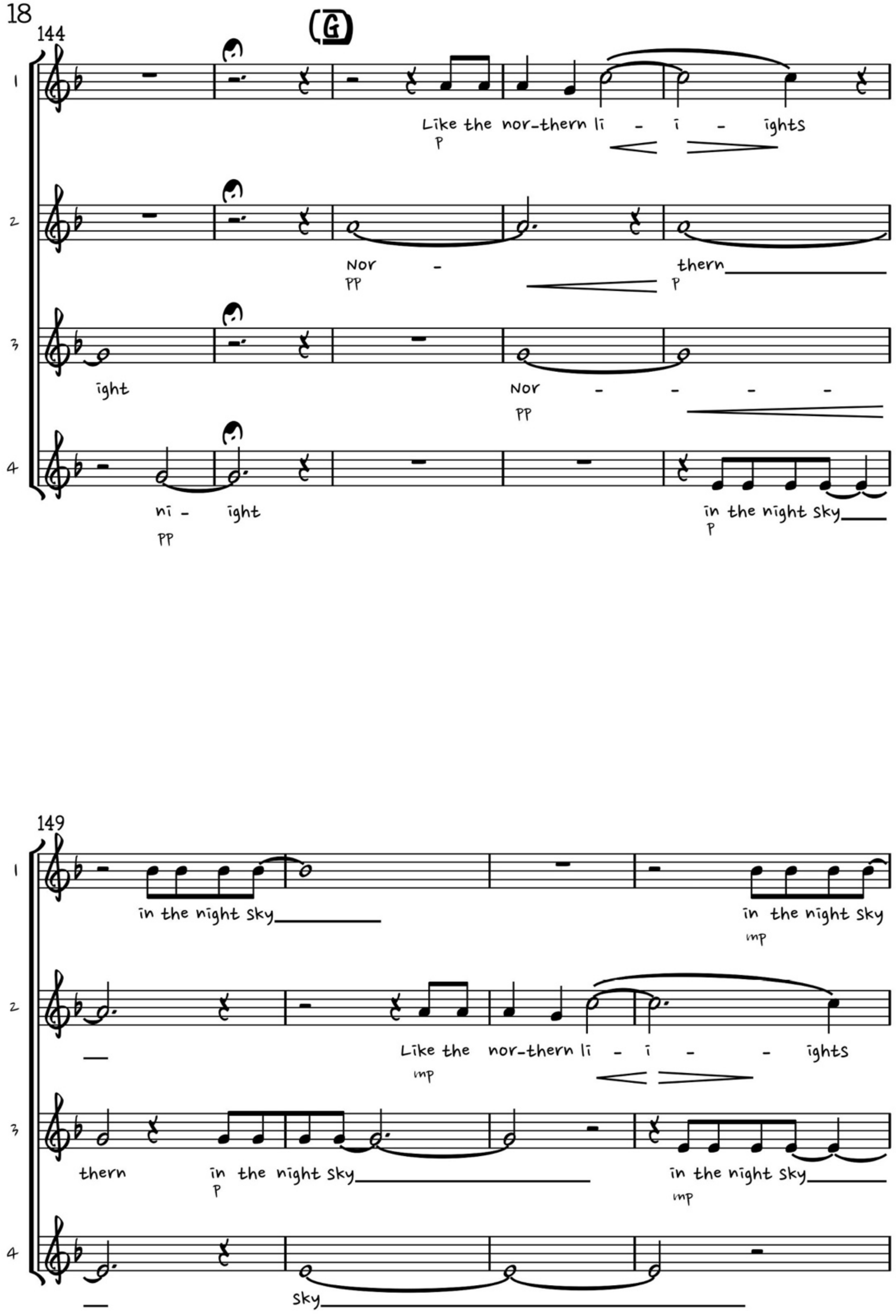

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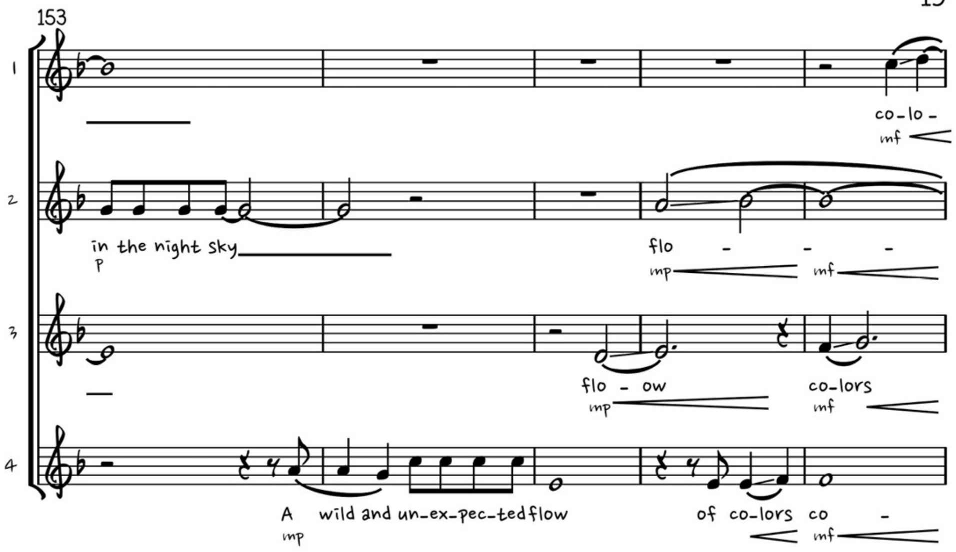
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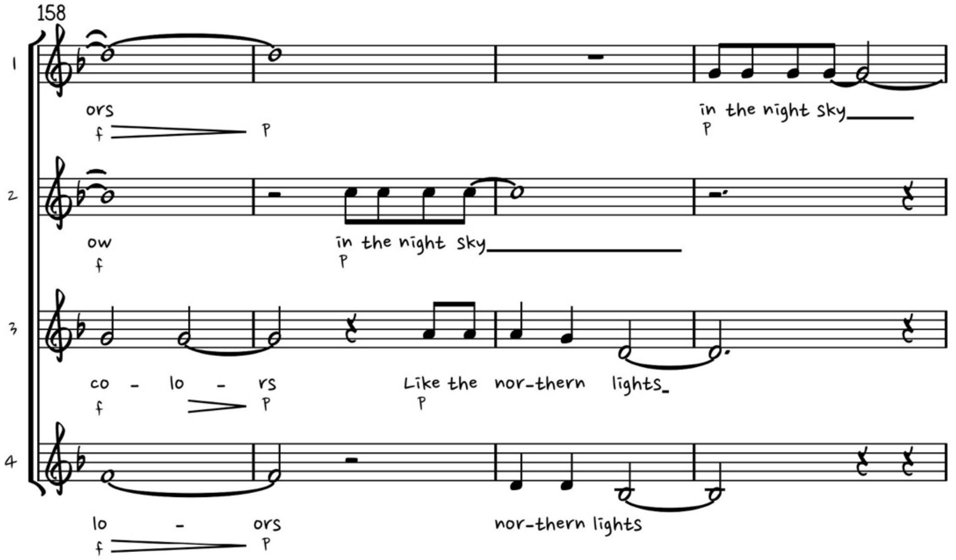
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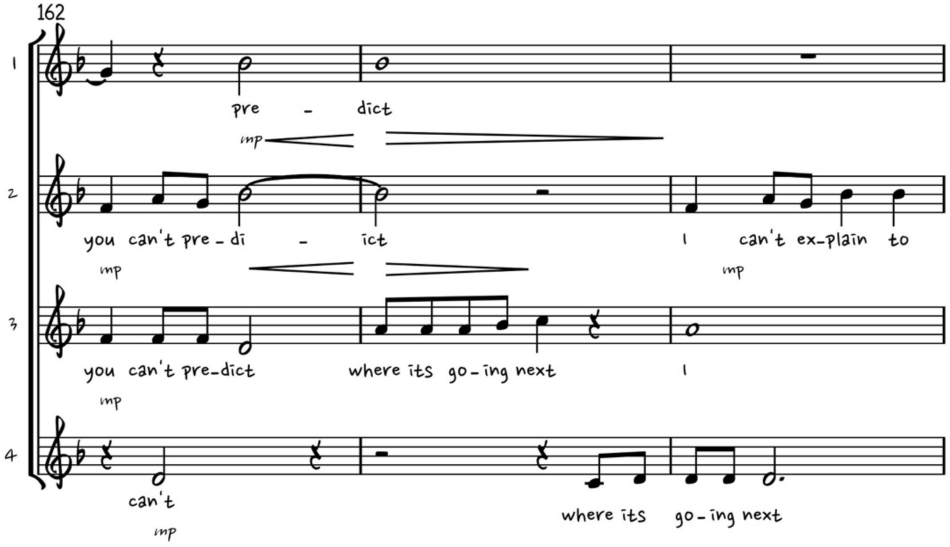
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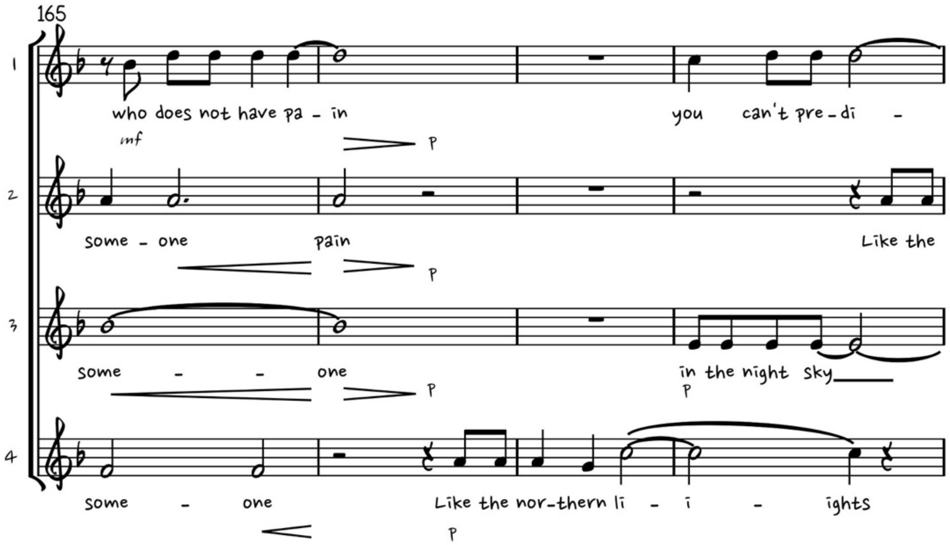
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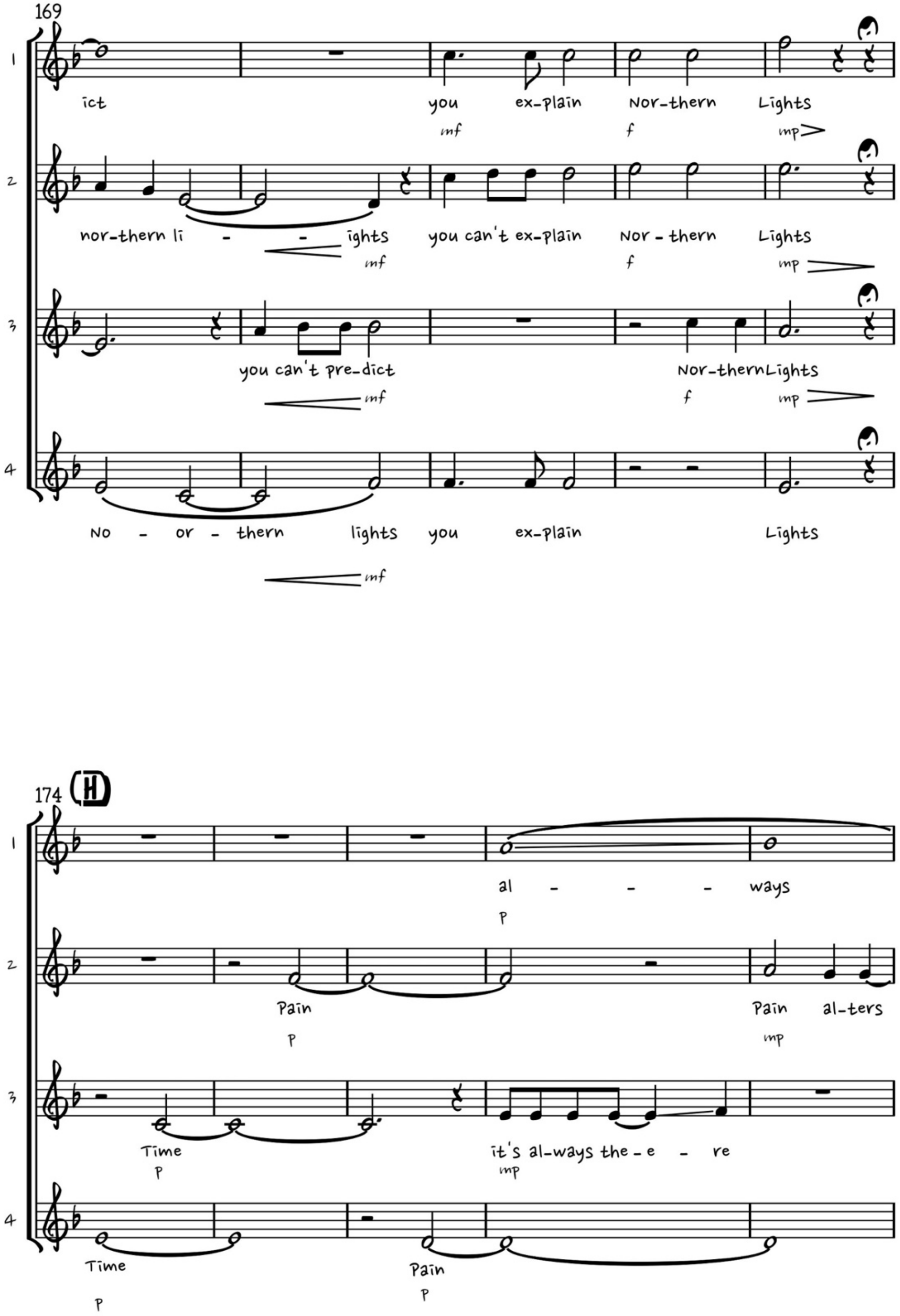
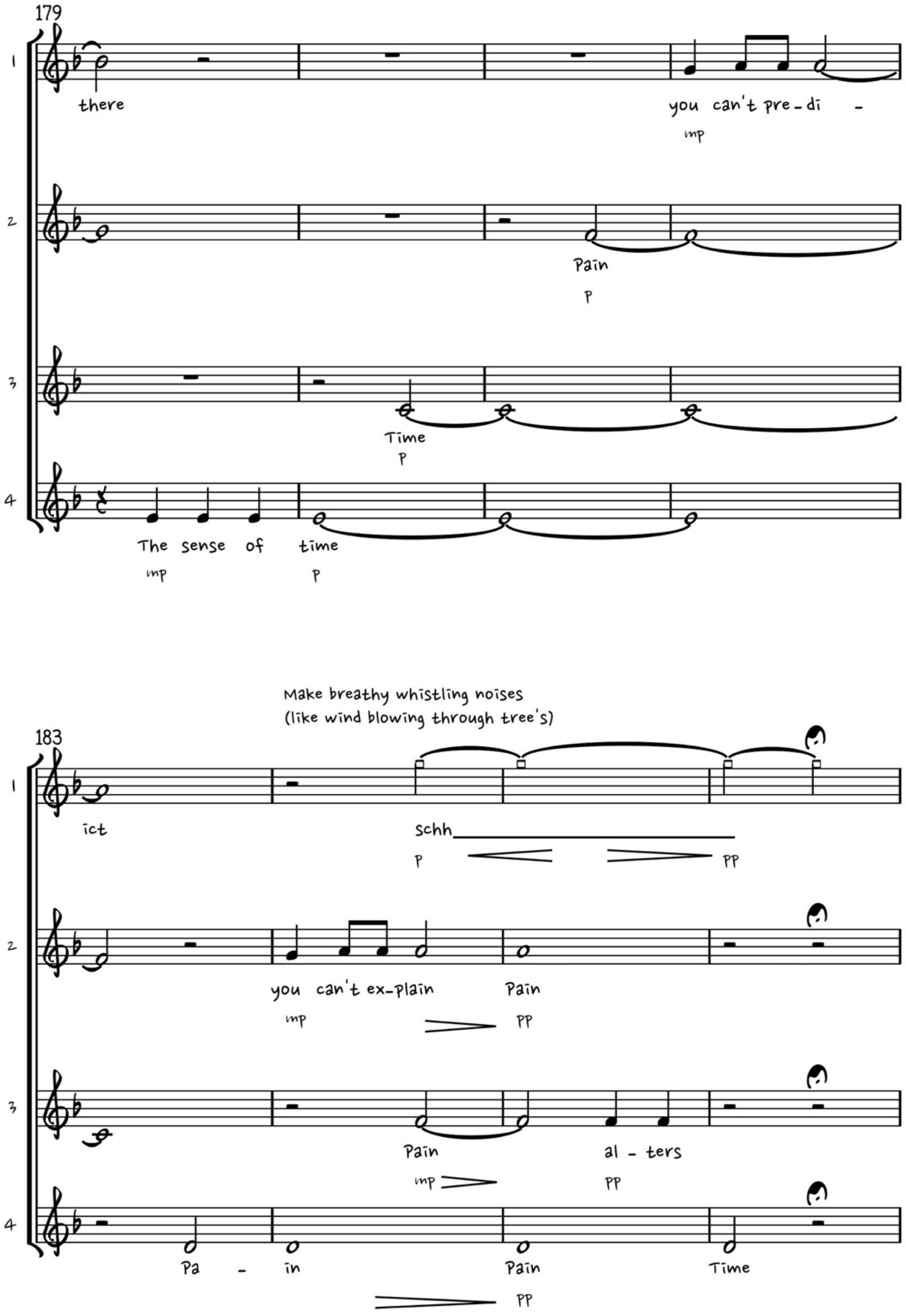
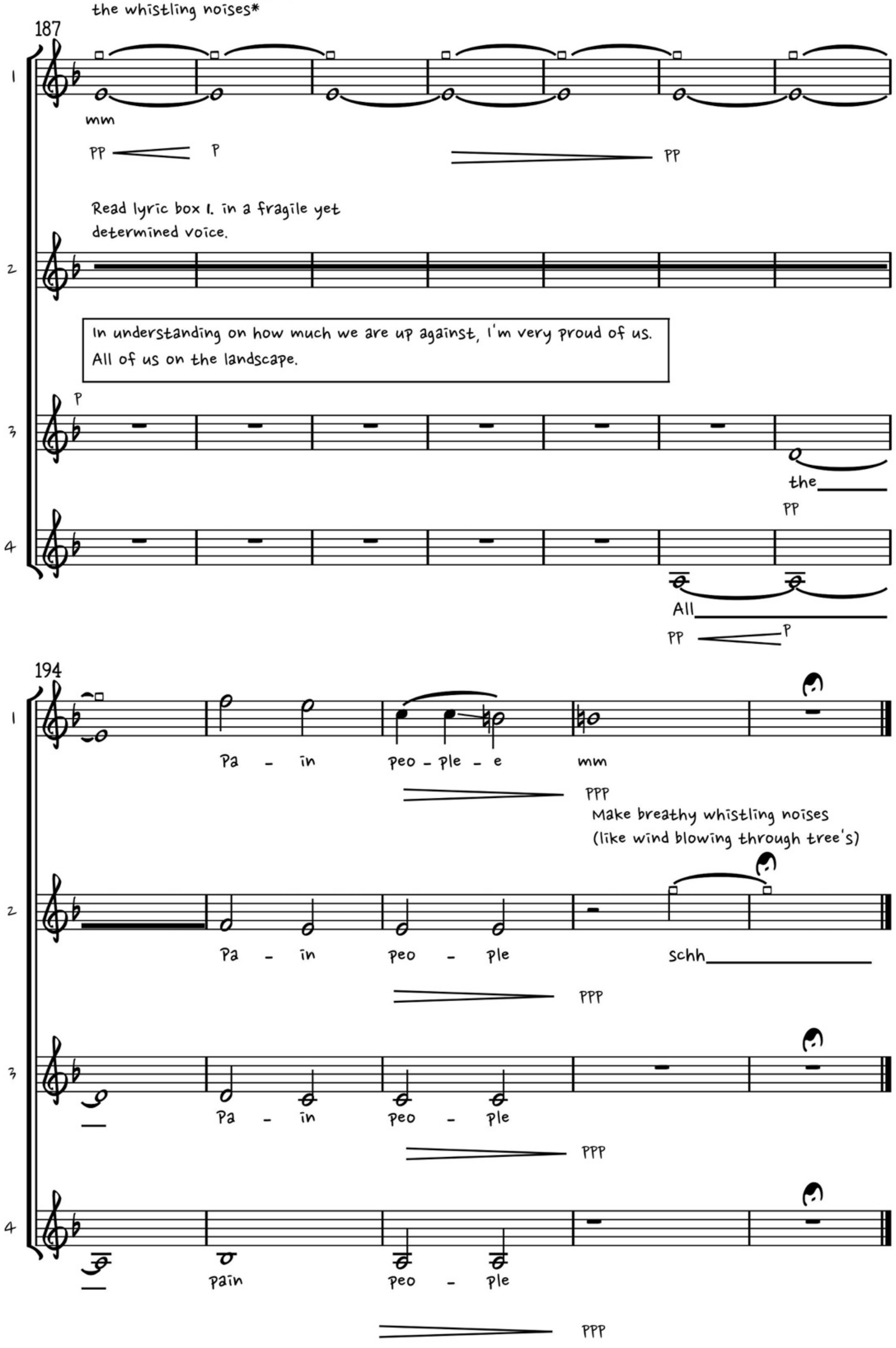


Make breathy whistling noises
(like wind blowing through tree's)

Alternate between singing "mm" and the whistling noises*

Read lyric box 1. in a fragile yet determined voice.

In understanding on how much we are up against, I'm very proud of us. All of us on the landscape.

Make breathy whistling noises (like wind blowing through tree's)

# CHRONICLES TRANSCRIPT

A transcript of the artwork *Chronicles* can be read in the text below. A stereo mix of the looping sound installation can be accessed via this hyperlink: https://soundcloud.com/kat-skovsgaard/chronicles

Jes (00:00)
Let's say you have a stomach ache and then pinch your skin very hard in some other place. Then, your stomach pain becomes less. Other pains can inhibit the first pain.

Hannah (00:18)
If I press against my temples, it really hurts, but it also feels quite good. Or the way in which sometimes going for a run almost displaces the pain.

Lene (00:36)
So basically, any type of stimulus will actually relieve pain. So also, if you do something painful to a patient in pain, that will relieve the pain that they're already in. But the gentle touch or the pleasant touch can also have a similar effect. It's not as effective as inducing competing pain, you could say.

Figure 102 *Why me? Why now?*, detail, the Migraine Art Competition, SA/MAR/16.

Hannah (01:06)

There’s something about if someone strokes your hair that really helps, but at the same time, I don’t wash my hair very often because it just hurts to brush it. If I’ve got a headache, which is all the time, then to have to tug at my head is just not what I want to do. So, again, there’s that some touch is good and some is not. And sometimes the touch, which is good, is also not good.

Sonya (01:35)

Yeah, I just wanted people to be like, Oh, you look great. Everything’s awesome. And then I say, Oh, I’m in pain. They’re like, Oh, I didn’t realise you still have that. There’s no way to explain. Yeah. Oh, boy, that’s a big one. Yeah. The better you’re doing at managing it, the more you’re, in some ways erasing your own experience in the eyes of other people.

Joanna (02:03)

Well, as my patients say to me, you don’t suffer from this condition; therefore, you don’t know. I’m lucky that I don’t suffer from any headache, and it is difficult. How does it feel? And so, you get this huge variation. But there are certain words that you look out for that do seem to be, as we call them, pathognomonic. If a patient says it’s sharp, shooting, or electrical, my mind immediately goes towards my trigeminal neuralgia. If it’s throbbing, it feels as if it’s going to burst out. That’s a migraine, a volcano because they feel as if their head is full and it’s going to explode any moment. Whereas a patient with temporal mandibular musculoskeletal is going to talk about a dull ache, a neuropathic pain is going to talk about burning. Now, a trigeminal neuralgia never talks about burning pain.

Cameron (02:59)

Some days, the pain can be a burning sensation, and then other days, it can be a throbbing sensation and other days, it can be light is giving you a headache, or noise is giving you a headache, and the nature of it is so changeable. For me personally, saying one to ten isn't actually productive. You could describe being pinched as like a five, but if you were going through that same feeling constantly, for like a week, it wouldn't be a five anymore because it would just become unbearable. It would be a ten, I guess. So, yeah. The one-to-ten scale is not very helpful because you don't want to be dishonest with your doctor and say it's a ten because it's not a ten when you have chronic pain; usually, it's very, very rarely a ten. For me, it's more just like a never-ending six. It's like a six infinity. And six infinity sometimes can be worse than ten for a day.

Hannah (04:12)

Pinpointing it in time and in relation to triggers, and it feels almost like you're kind of falsifying the evidence because, it's like, I can't pinpoint exactly what minute it got worse or alleviated slightly, but yet you're trying to put it into some kind of linear time in order for somebody else to understand or to make some connections or to fix it.

Sonya (04:41)

If a clinician is going to ask me to rate my pain on a one to ten scale, they need to also ask me to rate my medical anxiety in that moment on a one to ten scale, because that frames everything. If I have a new doctor, they need to know that I'm so anxious that I almost can't function. Or they might then understand why I seem a little scattered.

Peter (05:15)

When you’re in pain, you’re not only having to manage an uncomfortable sensation, but you’re also having to manage the disruption to your life and to other people’s lives. The disruption to your life might mean having to experience side effects from medication. It might mean that you’re not able to do things that you otherwise would like to do. It might be a financial threat if you lose your job if you can’t work because you’re getting frequent headaches. That might be the main problem.

Joanna (05:50)

If you can’t do your housework, if you can’t go out, if you feel depressed, those are the factors that really tell you how intense that pain is. What’s the point of this stupid zero-to-ten scale? But we have to correlate it with other things and it is a terribly subjective thing.

Sonya (06:12)

If there was more latitude for understanding. I feel like I live actually several short days as opposed to one long day often. And so I think that there’s a way in which the stress on people’s bodies could be drastically lessened if we re-examine what’s required for a workday or what we think of as being what a productive worker looks like, acts like.

Hannah (06:46)

Sometimes, I have this feeling that I just want to go to bed and not wake up for maybe three or four weeks and then wake up again and feel refreshed, and all of the stuff that needed to get done during that time just somehow got done, and nobody really noticed or missed me. I was just like, then, yeah, just restart again, feeling better.

Cameron (07:17)
I’ve had two instances where, with jobs, I’ve been honest and had to go home because of chronic pain. One of them was very understanding. The other one was just like, no, you’re not going home. And I ended up disassociating for a lot of that shift. I was in so much pain; I just don’t remember the shift.

Jes (07:42)
How often do people have to take off from work because of migraine and other headache diseases? And I said it’s very common. It’s about, I think, 15 to 17% of all absenteeism from work. But they don’t say that. They don’t say that. They say, no, I couldn’t come to work because I had the flu, because I had gastric upset or because I had a sick child. If they come and tell their employer that they stayed at home because they had a migraine attack, it will not be accepted. They fear it will not be accepted, and they are probably right.

Sonya (08:25)
Yeah, that is so interesting. The idea that it’s my first job, I think one of the things it’s really taught me in a way that I didn’t understand viscerally before was exactly how much I need other people and how connected we all are. I think I understand often that I wouldn’t be able to survive this without other people who are surviving it. And so, it really pushes me in the direction of community, mutual aid, assistance, telling stories. It changed the fundamental orientation of my life.

Hannah (09:20)
Even now, she will sometimes text me and say, is your head really bad today? Because I've got a bit of a headache. And she will echo in her own body the feelings that her children have. There's four of us, and it's not just me that she does this for. It's not just about headaches, but if my brother has fallen off his bike in Cardiff, like, miles and miles and miles away and scraped his knee, and then my mum will get a twinge in her knee and call him and be like, Are you okay? What happened?

Sonya (09:58)
I do feel a need for constant contact with other people's in-the-moment experience with pain because I really do feel supported by that. I feel it, especially because it's so invisible, and it's isolating. My pain is very triggered by the weather. And so, when there's like a weather system, I think about all of us on the landscape experiencing it, all the pain people. And I feel it's this sense of collectivity as opposed to my individual self. And I find that both terrible and beautiful at the same time.

Michael (10:46)
We often talk about touch as a way of connecting with others. But, of course, what do we define others as? Is others other people? Does it extend to objects? What objects does it extend to? And I think in that regard, we can think about our connection to the world around us and our connection to objects and different factors like that.

Hannah (11:07)

Some little guy sitting on my shoulder. Most often my right shoulder – though sometimes it’s my left – and he’s, like, just turning it. It’s getting tighter and tighter and tighter. And he’s sometimes, like, singing some really annoying song in my head so that I just get more and more wound up and more and more sensitive to all those kinds of the noise and the light and everything else.

Sonya (11:35)

Sort of like an egret, bird-shaped space alien. Just like one that doesn’t have our language, we don’t have its language. It’s just awkward but not cruel. Just the sense of a being in the wrong dimension. And then, yeah. I guess that’s what I think of as having this very odd companion that other people can’t see. Yeah, and that it’s trying to communicate with me in ways that I don’t really understand but I can co-exist with.

Peter (12:27)

Well, Picasso was thought to have migraine with aura, and that might have been one part of the inspiration for some of his divided images.

Sonya (12:42)

Like the Northern Lights in the night sky. Just the wild, unexpected flow and colours. And just that you can’t predict where it’s going to go next. Yeah, I feel like I think about pain in terms of vividness, whether it’s vivid colours or vivid movement, which isn’t all bad... I think you know what I mean. I don’t think of pain as a demon or a monster. I can’t think about living at war with myself like that.

Jes (13:36)
There are so many jokes about headache patients, and that contributes a lot, I think, to the prejudice against headache as a serious disease, a disease that you have to take seriously, at least. So I think that if I could do it, I would forbid all jokes about headache, and I would forbid all cartoons making fun of headache.

Sonya (14:13)
There's also... Have you heard of this thing on social media, hospital glam? That's a hashtag you can search. But it's basically people who... It's mostly femme-presenting folks, but not all of them, who will go to a specialist, dolled up to the nines, looking amazing. Then, the pictures are of them in a waiting room or a hospital room when a clinician isn't there. I see it as this representation of self and self-esteem. I'm looking fabulous even in this situation and to play with the contrast between the clinical anonymity, which can often feel like it's erasing yourself and you and your full fabulousness. I've never done anything like that, but I like them.

Hannah (15:17)
During this time that I spent in the hospital, the only clothes that I had with me out of kind of that's just what there was. The rest of my sensible clothes were in another country, but I had all these silly little party dresses that I used to wear when I was 16. And so that is what I wore for two and a half months on the hospital ward. And that did help because it was a sense of, okay, I know that I'm where I am right now, but I'm also at the party. If I say I'm at the party and I'm dressed like I'm at the party, then I'm at the party.

Sonya (15:53)

I’ve gained very little understanding of what’s the right way to act around a doctor or a nurse, like what they want. I know that I shouldn’t cry, except for sometimes they’re looking for that. Their biases, like any bias, is so all over the place that actually, there is no one right way. I just spent a lot of time pressuring myself to be the perfect patient, but that’s impossible.

Michael (16:26)

There’s an undercurrent and all of this, assuming that there is a substantially different meaning at the moment in the way in which narratives are being used. And that may well be the case. But I also have to recognise in that, that I carry my own biases and my own experiences into that perception. So, I’d like to bring the voices that aren’t like me into that room to understand that better. And I think that’s where we want to really try to improve.

Peter (16:54)

Children, for instance, where they’re trying to describe how much something hurts, there are scales of sad-looking faces, very sad-looking faces, extremely sad-looking faces with crying. And that is meant to indicate the level of intensity, of distress and/or pain, which perhaps that person doesn’t have the vocabulary to describe.

Hannah (17:32)

During this time that I spent in the hospital, I refused to go to the art therapy class because I felt really patronised. I was like, ‘I’m a professional artist.’ But anyway, I think it can be really helpful and a really good thing. I was just an arrogant snob. Don’t tell me to draw my feelings, but I probably would have found it really, really helpful to draw my feelings, actually.

Michael (17:57)
And all that as well also, I mean, when you don’t think about the day-to-day side of it for those working in health care if you have a situation where you’re experiencing empathy, there’s always those risks that you get overwhelmed by that over time as well. And none of that training is really talking about how you regulate and support your own self-care on the back of it. Actually, again, just come back to the arts, that’s another example where we know that things like journaling and those just writing, whether it’s poetry, whatever these different dynamics are, can actually be a really helpful way to help us reset our own individual baselines and things like that. And that somewhat gets lost for a checklist way of doing things, right?

Jes (18:46)
It’s more of a dysfunction. There is no growth abnormalities in the brain or outside of the brain, which makes it difficult to picture it. So, one would have to picture what is in the people’s mind when they have a headache. You can’t picture it in the traditional medical sense.

Lene (19:11)
Even though it is not something that we can see, they feel swollen. So, they feel that they have some swelling in the face, and they may also have what we call perceptual distortion. So, when they perceive themselves, they think they look distorted like one side of the face is bigger than the other: usually, it’s

bigger. Even though when they look at themselves in the mirror, they can see that they are as symmetric as they have all... We’re all a little bit asymmetric, of course, but the way that they perceive themselves or their face is different from what they see when they look in the mirror.

Sonya (20:02)
I actually had to constantly remind myself I still am myself. I still am myself. It feels really different, but this is also me. And I think there’s also a way in which the pain selfies helped me understand love and compassion towards my current experience. Yeah, it’s just like a mapping in a way, in a way to begin to contain the fact that this was still me.

Cameron (20:41)
I get very stone-faced when I am in my chronic pain. I have a very, like; it’s been a thing since I was a kid where I’ve always had a very expressionless expression or like a resting bitch face is what some people call it. But I think that’s just a male reaction to women not expressing constant joy. Yeah, I’ve always had a pretty stone face, and that’s because, I think, in part due to the chronic pain being related for me to movement and using my face and having expression.

Lene (21:19)
The mouth and face have such a huge impact on communication and intimacy between individuals. We have some patients who have, especially, nerve injury pains again; if they have something in the lower part of their face, then they cannot kiss their spouse. So if they have grandchildren or children, they cannot have them come and hug them because it’s associated with excruciating pain.

Michael (21:56)
Obviously, there's the experience of pain itself, but then there's the carry-over effects, right? The way in which it may well fatigue, the way in which it may well impact your mood and your wellbeing, impact your sleep, impact all these different dynamics. And the unfortunate thing is you can often find yourself in a bit of a vicious cycle in those contexts. So, if you're having disrupted sleep or something like that, that can start to impact your emotion regulations and your behaviours the following day, your stress activity. But because those activities have then increased, let's say you're not going to sleep as well because your body's not coming down to rest. And it's that type of cycle you can get in.

Sonya (22:43)
I think a lot of the stigma against pain comes from people's absolute fear of the state of pain. I think often what people think is that it blocks you out completely, and you don't exist, and you're like a complete other person or a representation of suffering. I can see it in people's bodies when I talk about chronic pain. There's like a visible recoil, which I feel is, on some level, understandable and biological. So, the idea of pain as a negotiation with myself, as opposed to this constant, unchanging presence, is something that I just... I've never been able to explain that to someone who doesn't have pain.

Jes (23:47)
It's much worse to have a headache than to have pain in your back or pain in your legs. Because the head is where the brain is, that's our centre of communication and control. And when you have a headache, it's more difficult for the brain to work than it is if you have pain in another part of your

body. The brain is the organ that makes us human, and all other organs can be replaced. You can have a new heart, you can have a new kidney, you can have a new liver, you can have new lungs, and you are still yourself. But just imagine if you had a brain transplantation, nobody would know who is the person. Is it the person with the body we know, or is it the person who got the brain from the person we know?

Joanna (24:47)
What are your three goals for coming to this clinic? And if they write complete disappearance of pain, I immediately say, I can’t achieve this. Yesterday, the patient had put relief of pain. I said, I can’t do that, but I’ve come to you because everybody said you were the world expert. I said, It’s not because I relieve pain, but I teach you how to live with pain. And that’s what I do.

Sonya (25:19)
I fear death less. I mean, yeah, I just don’t see a binary anymore between suffering and not suffering. It’s changed my relationship with everything. But I also understand; I think I can relate to a whole range of struggles by which or in which people feel like they can’t do another day. And I just feel like that notion is so widespread, and we have to stop stigmatising it because it’s the very inability to talk about it and normalise it that makes it so crushing and isolating.

Joanna (26:08)
Suicide is a real option. American studies have actually documented it in the veterans and shown that two of the headaches: cluster headache and our trigeminal neuralgia, have an increased risk of suicide because it’s such a horrendous pain.

Sonya (26:27)
Have you had thoughts of harming yourself? Oh, you've got to go to the psych ER. Whereas I think, in reality, every pain patient has their relationship with the idea of length of time, severity of pain, and how I make my peace with this.

Cameron (26:48)
For me, it's like my brain tries to rationalise the fact I'm always in pain as 'you're a bad person and you've done something wrong, that's why you're in pain, that's why you're suffering.' The alternative to that isn't much more tasty. My thoughts aren't pretty tasty most days, anyway. But the alternative to that is that, actually, the world's just unfair, and the fact that you're in pain is completely meaningless, probably, and random.

Joanna (27:26)
I was very concerned when one showed one of the slashed wrists, and the patient was clearly telling him I felt suicidal. He totally ignored it, didn't get it, It was used at the beginning of the interview and then wasn't. You've missed the lived experience. This guy felt that he wanted to slash his wrists, and he ignored it because it was uncomfortable. It is uncomfortable if patients say to us, they feel suicidal, what do you do? We're not psychiatrists, so it can induce in the clinicians a feeling that the patient doesn't want to tell you that they're not taking their drugs, but they'll show you this picture of a rubbish dump with medicines thrown around, and they might tell you this way, why did you choose this? If we question, why did you choose this? Oh, because, Doctor, the drugs don't work, but they

don’t want to tell you because they want to remain positive. So those sorts of things bring out sometimes a conversation that may not have happened if you didn’t have these

Melinda (28:40)
People express their pain differently and not everyone has a language for expressing pain. Pain can be dismissed in some families, and in some family cultures the expression of pain may not be allowed. Individuals who believe that communicating pain is not allowed may minimise their own pain or that of others.

Cameron (29:20)
I don’t really talk about it too much with other people. I find that if I start talking about it with people, it’s not so much that they have a negative language about chronic headaches, but rather it’s that the concept of chronic pain is so foreign to them that the conversation quickly turns into them trying to give me advice on regular pain that they might have. I.E.,’ Oh, you’ve got a headache, have some water, or try taking some ibuprofen or paracetamol or whatever.’ It becomes this very like them usually wanting to be quite helpful, but them being so disconnected from what’s actually going on for me that they can’t even employ any language about it, let alone a positive or a negative language.

Sonya (30:14)
I think pain is really hard to capture in a narrative. I always want to read people’s lived experiences with pain. But the narrative, say, of diagnosis, is like, it doesn’t capture what it’s like to be in the middle of pain because the story has a beginning and an end, and the pain doesn’t end. It ebbs and flows. And so,

when I was trying to figure out how to tell the story of my pain, I just reacted against chronological order. And I feel like pain really alters my sense of time.

Hannah (30:59)
Is something still chronic and kind of inside of time if it's actually all that you can remember? That word chronic, I think, is interesting because I guess we talked the other day about the word chronicle also. And when something is so much a part of your story that it's kind of outside of time, what does that mean? Like headaches? It's always there.

Sonya (31:35)
Once pain comes into your life, there are all kinds of emotions: grief, anger, loss, and acceptance, but they don't come one at a time. They're constantly flipping around. And so, I'm interested in the emotional journey because the diagnostic journey doesn't really give me anything. It hasn't given me anything. No doctor has told me anything about my pain that was really helpful in terms of coping.

Joanna (32:09)
In medicine, we're taught to win. That's where we're heading for. That we are great, we can do something, whereas pain is really the end. We know we can't cure pain.

Sonya (32:26)
I know how well I'm doing. I know based on... That almost makes me emotional. Gosh. I know how well I'm doing because I know how hard this is from the inside. And so, the systems that I've created, like I

tell people, and I feel like they can’t hear it, that I’m brilliant with time. I don’t often say I’m brilliant about anything, but I know my understanding of time, what to do, what, when, it’s like a symphony. Do you know what I mean? I understand I’m taking care of myself so well, and I’ve completely changed my expectations for myself. I’m much more loving of myself. And yeah, my understanding of a day is so much more complicated. So, I think, in understanding how much I and we are up against, I’m very proud of us.

# AURA TRANSCRIPTS

## AURA 1

Sophie (00:00)
It’s a really clear core memory for me because I can remember where we were. I can remember the place I was sitting in when you showed me this. I know that because there’s only a few times in my life that I can think of that, where I can visualise absolutely everything about it. You said, "I’m looking into chronic headaches and art around it." It’s going to make me cry to think about it. You showed me a picture from the 19th century that someone had drawn. I think the 19th century, it wasn’t recent, that someone had drawn of their migraine You showed me the inside of my head, and it was from another human being from long ago. I can’t describe. There were so many things as a human where you see something in your mind’s eye as such, if you’re lucky enough to be able to visualise. And to be shown something that is only ever inside my head before was profound, really profound. It looked like when I have a migraine, it was the same. Yeah. Also, because the first few times I experienced it, when I was trying to talk to other people about it who had not or didn’t have one, I tried to explain the extent to which the image, my normal visual field was just not there. It was just gone. I’d say it’s like it’s the back of my head. I cannot see it. Then over time, I began to realise that actually that fuzziness was into

Figure 103 *Figure with zigzag aura in red, black and green*, the Migraine Art Competition, SA/MAR/351.

different colours and had a c-curve and would come in and out or close in. Seeing that image, I was like, Oh, yeah, that’s actually what I experienced in terms of the c-curve and the lights and the slightly different, like black and white jaggedness, but then also bits of other colours.

Sophie (01:44)

It begins to feel frustrating if you try to do very much because I can’t speak. I see a sentence in my head and then I look at the keywords in the sentence and I pick out those words and I say those words. I can also observe other people looking either distressed or perplexed. I care, but I don’t have enough emotions to empathise and be on a level with them because it’s exhausting just choosing the words. It’s easier to just relax and go into it and accept that. That’s taken me many, many years. It’s okay if on my own or if I’m with very close friends or family. But if not, it’s a stressful situation because essentially, I’m no longer able-bodied for a period of time.

Sophie (02:46)

For me, it’s like trying to put my... I often put my glasses back on or off, or I grip something, and I realise what it is, is because I’m losing clear vision. But in a in a very light way in a, "Oh, yeah, I’m going to just put my glasses back on. Oh, no, just take them off." Because I can’t quite see and things aren’t quite sharp focus. Or I’m gripping something because I’m losing sense of, I presume there are words for this, but I don’t really, I don’t know the, I don’t have the vocabulary. But things that are solid suddenly become less solid. And things that are big feel small. And things that are like my spatial existence and awareness goes. What I also feel is like I’m sitting on a roller coaster and then you’re waiting for that moment and, wwwhhiit, then it takes you backwards. And that’s how it feels. And it’s not pleasant and it’s really disorientating. And then over time, I’ve learned to be like, "Haha, I know what’s happening. I’m having a migraine." And then I think, okay, I’ve got a short amount of time now to explain to the people around me what’s happening and the fact that I might lose my ability to speak.

Sophie (04:05)
And also, that it’s not something distressing, I just need to be removed from other people, and it will be fine, but it could last for an hour and a half, and then I might get a massive headache. And so, I have a kind of routine that I go through, and I have a write-up on my phone to explain what they need to do. Then I come in and out and there’ll be moments where I can talk and moments where I can’t. I can kind of observe conversation and that’s fine. But also, it begins, I usually feel absolutely exhausted afterwards. Like a video game character that’s ... All the energy has suddenly gone, and it goes blubelubelup. It could be that, or it can be the start of a gnawing headache that begins at the back of my eye and then kind of takes over the front of my skull. That headache can last for quite a long time.

Sophie (05:05)
When I was a teenager and it started, and I was quite young, I would have been 11 or 12, it looked like only being able to see half of my teacher’s face. And that’s quite scary when people’s faces disappear, frankly, when you don’t know what that is. Or only being able to see half the whiteboard or the blackboard or half a page or now not being able to look at a screen because a lot of my life is spent looking at screens. And so, if you can only see half of a thing, what it feels like sometimes is if actually I close my eyes, if it’s just a... I suppose I have three types of migraines. I’ve never thought about this before. Ha! I have a migraine that affects my vision, a version that affects my speech and a version that

is pain. If it’s just my vision, sometimes I’m able to keep working and I will have a call with someone or be able to keep talking in the office and I will say, I’m fine, I’m just going to have to have this meeting with my eyes closed because I can still think about concepts, but please don’t give me something to read. I think for other people that’s distressing because normally I can see and interact. But to some extent, I’d rather get on with it and think about the problem and task in hand than focus on the fact that I’m blind or partially sighted. And the partially sighted looks like, when I was little, it’s about the reference points you have and The reference points I had was like the Donald Duck cartoons when they would fall over and little stars would appear above their heads. That’s what it was. Because they would twinkle, it would twinkle a bit in my vision. My vision would be little lights, but then also I couldn’t see anything where the lights were. Then over time, having seen it visualised by other people, I realised that it’s this c with shards of light, black and white and jagged c, the letter c. Then that begins to overtake and looms and slowly fades away. Within that, there are multicolours. I’d love to know which parts of my brain are creating that. The physical sensation, which is that I do not weigh 11.5 stone anymore. I weigh a stone, and I float, or the chair I’m sitting on is floating, but feels very soft, no longer hard. If I grab a surface, it’s because it might just be me on the surface there in the middle of a, I don’t know, floating world. And then that surface might disappear at any moment or might become thinner. It’s really hard to describe, but the substance of an object may or may not be there. And I presume that’s a form of dizziness. It’s not just like the world is spinning. It’s like the world cannot be relied upon in terms of its form. Plastic might suddenly melt into water. That’s how you feel it and you feel like, well, it could disappear because it is because you’re sitting there in a normal, upright fashion and gravity exists, but it doesn’t because in your head, you’re going backwards on a roller coaster. That’s all quite bizarre, frankly. It’s happening at a time when you’re not quite able to speak. I don’t think I’ve ever sat down and thought about it this much before when I’ve not been in it. It’s quite nice to have full language capacity to describe it.

Sophie (09:11)
So, the sound doesn’t change that much, but my capacity to listen to it reduces significantly. And so, I feel distant from the world around me. I start to shut off the sound. It’s not like it phases in or out, like you’d see on a TV programme where it’s like whoomwhoomwhoomwhoom, not like that. It’s more that I can hear it and I just choose, or I can’t even choose to focus in on it all. I can focus on one conversation, and even then, I can’t necessarily intellectually keep up with it. Sometimes I can, but I almost don’t... I’ve had this weird feeling of I don’t care, which is very strange. I think what it is, is I don’t have enough capacity in my brain to keep holding on to the feeling of sitting and not riding on the roller coaster, choosing the words, and then also hearing. It’s almost like when you faint and your body just knocks out some of the senses to keep your heart and everything going. I think it feels like my brain is just choosing to keep minimal function going. So, I almost don’t hear all the sounds. If I am in a busy place, then it’s almost overwhelming. A lot of the time, what I want to do is be asleep. And it’s not that I want to actually go to sleep, it’s that I want to shut everything out because it’s too much.

Sophie (10:54)
I didn’t learn to drive for many years, partly because I was so worried about if I was in control of a car and the world became dizzy around me and I had other people in a car with me, but also I was in possession of this enormous machine of what could happen, and I could hurt other people because I couldn’t fully control my own body anymore. I’ve slowly got myself essentially to a point where both

the driving vehicle licence authority have let me do that in the UK, so I’m legally allowed, but also emotionally that I actually don’t have a vehicle at the moment. I don’t drive routinely, but I can. It’s that knowledge that I will essentially, every time I feel like I might be slightly dizzy in any way, which as someone who has low blood pressure does happen quite a bit and it doesn’t turn into a migraine, that I have to listen to that. And if I’ve got any form of tiredness or I’m hungry in any way, that I cannot, I have to look after myself before I get into a car and not, which is quite difficult. You often get into a car early in the morning or late at night. And yet I am, I say, quite worried, but it’s just how I’m going to live my life. I make sure that I’m always looking after myself in order that I’m not ever in a position where I’m in a car and I have a migraine and that causes an accident.

Sophie (12:33)
And I described my symptoms to him, and then he proceeded to describe back these other people who had what I had, and I was not crazy. It wasn’t me, and it wasn’t my periods. And it was just... It was like a diagnoseable known thing: migraine with aura, and specifically, basilar migraine. He could pinpoint this part of my brain where blood wasn’t being uptaken, or in particular, I mean, there’s a medical explanation, I’m not a doctor. And I wasn’t mad. And I came out and I phoned my mum, and I cried because other people had tried to suggest that this might be either to do with my periods or some form of anxiety. And I was just like, “It’s nothing like that. I have zero control over it. I get it outside of my period. It’s nothing like that.” And this man calmly described that other people had this, and they were men, and that actually I had a very light touch form of what these other people had. And began to work through it and said, "You might want to consider this vitamin, you might want to consider that. This is how the thinking on your condition has evolved." And that was life-changing: to be heard. When,

depending on your experience of a chronic headache, whether or not that’s the pain, the visuals, if you have aura, the effects on speech and therefore social interaction for me, and indeed, the fact that it takes you out of whatever you are doing at that moment, be that trying to work, trying to cook, trying to move from one place to another, trying to converse or be with others. It’s incredibly isolating. And other people try to move from their own experience of having once had a headache to what you might be going through. And generally, they’re trying to do that with empathy. But it’s often quite different in your experience from what they’re describing. And so, you sit with this isolating gulf.

Sophie (14:52)
And how does that affect? I’m a white woman from London in a white-collar job. How would that feel different if I was black or brown in a white-collar job? How would it feel if I was in a blue-collar job? How does that feel as a man? If I was a black guy, how would that feel different and how would I be treated differently for it? If I was a brown woman in a blue-collar job, how would that feel? And how would that feel when I go home to my family? How would the overlay of a particular family and a particular culture feel? There’s a lot of the other people I know who have this who are white women. So perhaps we’re just the people who are creating a space to talk about.

# AURA 2

Anders (00:00)

The most exciting thing, which is also the most horrible thing, is the prolonged aura, which is a clear visual aura with very certain patterns. That's very exciting. I'm an artist as well, so of course, I feel like I want to use that for something. I want to think about it at least, and what does it mean in terms of just seeing and where do these patterns, shapes and forms come from? I think that's very interesting in general. But yeah, how can these just occur from nothing, which is, of course, not nothing, but I'm learning now where they are coming from. But it seems like it's quite mysterious still.

Anders (00:50)

If I say that I couldn't participate because I have a migraine, and then they say, "Oh, I also have migraine." Then I'm like, "Oh, do you?" And then I figure out that they don't have it [a migraine]. Because this wider misunderstanding in society about the word migraine and what that is as a neurological condition which affects you in many different ways and not just after work and you're okay the day after. That's not how it works when you have a migraine attack. For most people, it isn't. They're all different, of course. But it just makes the wider population misunderstand it, and then you feel like you're not taken seriously when you talk to your employer or people in general, if you couldn't participate in a meeting, which was really important, and they feel like it's not enough reason to not

Figure 104 *Silhouette hand with flames*, detail, the Migraine Art Competition, participate. And you are really sick, or really ill. I couldn’t basically go out of the... I couldn’t leave the house because it was dangerous for me to leave the house because I couldn’t see one-third of my vision: one-third of my vision was failing. When I said I had a migraine, they just thought it was an excuse to not go out. It’s always, "You have a migraine, can’t you just-you can drive anyway. I was supposed to go to a summer house at the time, and I had this a couple of times, actually, with people I talked to, I was like, I’m so frustrated because I wanted to go on vacation, and I couldn’t drive. I was supposed to drive. They were like, "Oh, you can drive anyway. You can drive it for migraine. That’s easy. I’ve done that." But that’s not possible when you have an aura. Then I realised that what they talked about was a headache.

Anders (03:03)
You can’t taste the coffee properly. When you walk up to the door, you feel like you’re distant from the things that are around you, like you’re in a bubble, for example. That’s in the spectrum of migraine, maybe you can say, which is also connected to a headache. That’s some of the feelings you can feel, or I can feel, yeah, because they’re so different, I can feel quite disoriented. I can feel like I’m not in my own skin in a way, like I’m not in myself. I’m more external to myself or distanced to myself. I can also forget where I am in that stage [of a migraine attack]. Also, in the postdrome after the attack, I can also forget where I am, for example, which can be quite scary when you don’t know what it is. It’s nice to learn those things so you don’t panic.

Anders (04:07)
I would usually be in bed and just cut off all or as many senses as possible and wearing sunglasses indoors because the light would feel too intense.

Anders (04:28)
Usually, I would ask my partner or a friend to walk with me. Like now recently, when I had a prolonged aura, because I can't basically be alone, because it's quite dangerous, then I would have maybe one pair of sunglasses or maybe two, even. Maybe I would have noise-cancelling headphones. Then I would try to get some fresh air and see how it would affect me. But I realised also with the aura, that if I stand up and go outdoors, that it could trigger another aura attack, attack off migraine with aura, so usually, I would... I've recently been staying indoors, so I haven't been able to leave the house, basically. It's been very uncomfortable. But when I don't have an aura, I can go outdoors with a lot of painkillers and sunglasses.

Anders (05:28)
Because it's quite strange when you start to see blinking lights in front of your eyes, but you don't have a headache. You might think that you are hallucinating in some way, and in some way, you are. I've had quite a tough time with singing birds, for example. If I have a migraine and can hear birds in the summer, which I would usually love to hear, they would remind me of warmth and life. [Instead], they would remind me of pain, and it would be unbearable for me to hear the sound of birds.

Anders (06:11)

Seeing a friend that I haven't seen for a long time, where suddenly I would sit and talk to the person and I would realise that half of the person's face is missing, and that could be the start of the aura, which would then develop throughout the next 30 to 60 minutes, or less sometimes even. Sometimes it would just be 10 minutes, but then it would start in the centre. Then suddenly I would be like, Well, why can't I see? I know that the person's face is there, but it's like I can't take it in. Then I realised, okay, this is a migraine attack, and I know what's coming now. That's the usual. That's how it has been for me until recently. That has been like that for the last 15 years or so, and it is unclear how it will develop. Then it would start to go from the centre and then to the edges in this zigzag, wavy lines. Blinking, all the colours you could imagine would be there. Then it would disappear, and I would be extremely tired. Or beginning to be extremely tired and get a throbbing headache. Then the light and sound sensitivity would just intensify at the time, and then I know I would have to lie down. Then, usually the day after, I would be okay. I would have some postdrome symptoms of being a bit tired, not necessarily exhausted. I could feel a bit depressed or euphoric, even. It's random. I would start to see this very intense blinking light on the right side, in the corner of the periphery, but it would be extremely realistic. The first time it started happening was at the end of January, the start of February, around there, where I was walking outdoors. I was walking next to Valby Station, the train station close to where I live, and I would see this blinking light, and I was 100% sure that it was some kind of streetlight. I was sure they had put up something new over there, and then it would be blinking and blinking. I was like, well, this is not - this is not right. This is coming internally; it's in my vision. Then it would actually not develop for quite a long time. It would maybe continue for five minutes with the same visual phenomenon with this blinking light. Then it would start to be a bit more visible, a bit less in the periphery, coming a bit more in, but staying on the right side of the vision. Then, it would start to take a very certain shape in different colours, but it would still be this square. Then there would be these round circles on each corner, on each of the four corners of the square. There would be these circles which would also be blinking, and there would be circles inside of them, if you can imagine that. They could actually be like a very intense light installation at some kind of light festival. It’s very beautiful, but it’s extremely invalidating [disabling] because I can’t see anything else in one-third of my vision, I suppose. Then, that would develop into these crystal shapes. It would be either just like this - I made a drawing here, I don’t know what the shape is - I think it’s like a hexagon, hexa-something. It’s like six - I think it’s like six squares, something like this. It’s like six corners, and then there would be lines going in from the corners to the centre of the form. So, the square would develop into something like that. Then the circles would be placing themselves from inside of the square to the outside of the new form. Then this square shape would be like crystals. I would call them - I think about crystals when I see them - also because they’re in many colours and lights, and they would be hanging down from a chain coming from this form, this source of it in a way. Because it was inside of that, but then it’s coming out and taking more space in the vision. Then I think after that, slowly, there would start to be this very classic, I would say, if you think about migraine aura, like the zigzag, it would start to develop a bit into that. Where I would have these zigzag lines. That’s something that I recognise very well. When I started to see this after I saw the new aura, I would feel more relaxed - I know this one, you know. That would then start to disappear after the classic 30 to 60 minutes. Then I would go indoors someplace. I thought it was gone then, like usual. I thought I was like, "Okay, I’ll take some painkillers, and then I will go home to bed when I can." I couldn’t do that at the time. Then, when I was indoors, I think it was like a café or something. But then, when I went outside again, it started happening again, exactly the same thing with this blinking light. I was like, "Well, this is not something I’ve tried before." I got really scared, actually. I went home, and then I started to get a bit of a headache, like a throbbing pain. Then I was lying down. Then I was like, "Okay, I just have to lie down a bit here. Then let’s see. The aura will probably go away, and then I will get a headache, and then I’ll be okay tomorrow, so I will not postpone any of the things that I have tomorrow." But then, 6 hours later, I would stand up to make some dinner, just a bit of some easy light dinner, what I was capable of at the time, when I had the pain. Then I would start to get an aura again. So, after 6 hours, I would still have an aura. That’s something you need to have checked at the hospital. So, I called the hospital and talked to a doctor, and he said, "I think it’s a good idea you come in and have a look just to make sure that it’s not something else." Because it was a new symptom, basically. I went there and I had all the scans of the brain and all of those things. It was really tough in the hospital because there was a lot of light there. It is not very migraine-friendly in general. You’re moved around to different sections in the hospital. I first got a bed at three o’clock in the night when I was just feeling like I needed a bed to sleep for the whole day, basically. I was sitting in a chair for 12 hours with migraine with aura. But they didn’t find anything unusual. We talked about the medicine and how I should take it at a certain point for it to be able to help with the attack. That certain point was after the aura. But how could I know when it was over, if I stood up? It’s two hours and it’s still going on. I realised that it was what it had always been: the migraine, but that the condition had changed for me. It can happen, I was told. It can be many different factors that can play in, both the other medicine, but also just different things happening in your life. They [your symptoms] develop with you and it can go away again. But right now, that’s how migraine looks like from a sensory point of view, I think.

Anders (15:55)

It would be like very sharp pink and green and blue and purple and those kinds of colours. They would usually be so sharp or strong and saturated to a degree where it was really uncomfortable. If you imagine a light installation with psychedelic colours, and someone was pointing the light directly at you, that is how I would describe them. The colours would be towards that it's just like very intense light of pure white light. But then there are these saturated colours in between, if you can say it like that. It's like lines, a lot of lines of colours. It's like in the periphery of either the left or right side, and then it would be circular, so it would be like a half-circle. Then it would be in the periphery, and it would go towards the centre and would bounce back and forth from there, maybe for an interval of five minutes or so. Then it would be a lot of zigzag lines, maybe like a whirlpool, it's just half-circled and it's just whirling in towards some kind of centre-point, which would not be the centre because it will still be on one side. It would be like a very specific line. The zig-zag pattern would be extremely visible, similar to the chain pattern I was talking about before, with the crystals I mentioned. It's very, very clear that it's zig-zag lines. I think it always creates some precarity of what's possible: are you able to participate? Are you going to miss out on things? Will it affect the whole family, your relationship with your family and friends, or wider family? Anyone in your life, basically. Can I walk with my dog, for example? Am I going to see my friend that I haven't seen for three months, or is it going to affect that? That worry would be... Maybe it's nice to go away from that, it's a worry necessarily, but it's maybe just a premise. It's just a part of you.

Anders (19:15)
I think there are a lot of structural problems. The hospital, for example, has so few resources. I think if you are taking care of a patient who is in pain, you really need to both listen very carefully and also handle that person very carefully. I think they don’t have time for that, basically. But I think they want to. You already have the roles of authority and citizen, or patient defined from the beginning. I think that’s already a bit problematic in that way. I’m asking something from you. I’m asking for something here. I want to be healed. I want to feel better. I want to be listened to. When it’s this client and authority relation, I think it’s quite unbalanced in a way. It’s not the doctor’s fault, and it’s not the clinician’s fault, but I think there have to be other ways of communicating and taking up these roles or feeling that you have some ownership of your own body and your own conditions, in a way, to feel better about them.

# AURA 3

Nadia (00:01)

I think of myself as a very smart person. So, I think I find it hard not to be able to use my brain in an intellectual way when I want to. I think also because a lot of my friends are having intellectual conversations, and I just feel like it's a really big barrier. Because there are certain things I can talk about really easily. It's really smooth to think about. And then if I try and understand something, it's just like a block. I guess like a brain fog. So, I think understanding it, learning more about how the headaches affect my ability to use my brain is quite useful to me because it's accepting. More accepting of it instead of just pretending, like masking it. With women, because women are so taught to socialise and perform your way in situations that make other people feel comfortable or make people not realise the difficulty you go through in assimilating into the same space as other people. I feel like I have probably been doing that a lot.

Nadia (01:38)

I was learning about crip time, the concepts and stuff about how you experience time and how when you have chronic pain, it's really condensed. Because everything you're doing now affects your immediate future in terms of whether or not you're to have more pain or less pain. It feels like there's a lot of pressure on basically everything you do; you're trying to navigate and weigh up different forms of

Figure 105 *Toilet bowl*, detail, the Migraine Art Competition, SA/MAR/85.

things that might trigger the pain. But yeah, I feel like it means that you’re living immediately in the future that’s just ahead of you. I guess it’s difficult to think longer term or even just live in the present because you’re always thinking about the impact of what you’re doing, which in a way is also problematic because then you stop trying to get better. And there might be cures or other things and coping mechanisms that come out that you just don’t use or don’t seek out because you’ve become so accepting of the fact that it’s a chronic condition. So, I feel like I guess it’s hard to communicate to someone who doesn’t experience chronic pain themselves what it is to always be in pain or to have very, very regular flare-ups. But I’ve really, really struggled with medical professionals, but also interpersonal relationships, family and friends, trying to communicate how deeply it affects pretty much every facet of your life and your perception of things and feelings of freedom in your future. I think it’s like, uncommunicable, but then I also appreciate that that’s just accepting it, that’s like accepting the worst, and I guess it’s important to try and communicate it. Cripping time is like to sort of bend time. Instead of bending the disabled body to the rigid framework of time to bend time to meet the needs of the disabled body. That could incorporate the extra time that it takes to do a task if you’re disabled or chronically ill. So, like resting before or after something. Or if you’re in a wheelchair, like having to navigate planning routes and things like that. So, I guess it’s like, the thing that I read, it was like it’s not just stretched out, it’s like exploded time. So, it’s like totally questioning the whole concept of how we relate how our body is to time. It’s a really important thing that I find as a way of understanding my position in the world because I feel like time is one of those things that dictates so much about productivity and also with language, the way we talk about chronic illness, it so much relates to time, like whether something’s intermittent or permanent or temporarily disabled or whatever, different things like that. So, I think even just questioning the concept of time as something that we, or that dictates us, is quite useful in reframing the way we live and reframing production and stuff like that.

Nadia (05:49)
Well, it’s like tension in my forehead and then pain in the back of my neck and dizzy and nauseous. It feels like an emergency. Sometimes I’ll be out and about and then I feel like I need to lie down somewhere. But there’s nowhere to lie down, but I feel like... It sounds very extreme, but I feel like my head’s going to fall off if I don’t lie down. I feel like I can’t hold it up anymore. I don’t really know why. It feels just like an aching, but all over my whole head and face, every part of my... Just below my skin really, really hurts. But it’s also very sensitive to touch. Then I just have to... I mean, I guess it’s best if I’m at home, but it’s weird to think of the best place to be when you have these sorts of headaches because it can kind of happen anywhere. But with mine, I do need to act when I’m out and about. But then if I can make it home, then by the time I get home, it’s way worse. I just need to lie down with a hot water bottle behind my neck and a flannel on my eyes. Because I have double vision, it’s like my eyes feel like they’re squeezing and converging, but it feels like my vision’s converging into my head. And there’s like something pushing from the sides of my temples into the middle of my head, but there’s no space for it to go, so it’s just pushing over and over again into the middle and down. It’s squeezing. It really kind of feels like I’ve only just hit my head against a wall. It feels like my head’s been shaken in a really abrupt way.

Nadia (08:29)

I’ve become quite sensitive. I really started to appreciate really soft things. Sounds, I have become really, really sensitive to sound. Like any, any sound. I’m quite sensitive to sound anyway. But I actually heard from a friend once who also has chronic pain, that one thing she does when she has a flare up is she just hums to herself. Actually, I find that really soothing. Because I guess it’s distracting, but also, it’s a really soft sound. Like someone singing to you, but it’s yourself. But also, I have the hot water bottle that’s really fluffy on the outside that I use to help relieve my pain. And some cuddly toys as well. But I think having soft things, I don’t know if it’s an animal instinct, but it feels like having a cuddle. Especially with the hot water bottle because it’s warm and it’s furry. It feels like another body or something that’s there, being pressed against your skin. I think when I’m vertical, I’m basically just always a bit uncomfortable. When I’m horizontal, that’s the only time I can be totally comfortable. I just associate it with all these soft things and pyjamas and dressing gowns and things. Maybe it’s an association, but I think also maybe when I’m, I don’t know if it’s because of my chronic pain thing, but I think my skin is quite sensitive as well to touch and warmth. I’m quite a tactile person anyway, with my friends and family. I think touch is a really important way of me expressing myself, love and things like that. But also romantically, I’ve realised recently that I feel quite anxious just before I go to bed. But if I have some skin-on-skin contact just before I go to bed, then I actually feel so much less anxious, which, I wonder if that’s a biological thing. The feeling of maybe anxiety is feeling a lack of calmness or unsafe in some way. But then having the skin contact, just like having a hot water or something, it makes you feel like you’re not alone or something like that.

Nadia (11:39)

I guess narratives of pain are probably on one side often communicated by people who experience pain as a way of letting able-bodied people or other people understand. Because I feel like pain, or chronic pain is an invisible disability, and it’s quite difficult otherwise to feel like people understand you if they don’t understand what you’re going through in your pain. So, I suppose the narrative is a way to maybe build empathy and understanding.

Nadia (12:25)

Relationships with people that, because it’s people in positions of authority, who you might usually have deference for, I just feel like my chronic pain breaks through any form of deference because I can’t afford to be deferent to people if they aren’t giving me what I need or aren’t allowing me to do what I need to do. In a way, it makes me relate to the world differently, but also these kinds of hierarchies differently, which I’m quite grateful for. Within the first week, I’d basically be like, "I can’t work any overtime because I’ve got this head injury, and then I need to reduce my hours, I need to do this, I need to do that." People would push back against it, but I would have to be really, really strong on it because I just didn’t have a choice. Then I’d see that my work relationships, although they’d get frustrated with me, I think they respected it, and they let me set my boundaries and then just perceived them as these rigid boundaries. Whereas I think with other people, like my sister and other friends I have as well, they didn’t feel able to set boundaries. And then because of that, their body took its toll. I mean, the work took its toll on their body, and they almost didn’t really know where their boundaries were and didn’t feel strong enough in themselves to say anything because they were so scared of not getting through their probation period or losing their job or whatever, which is a really terrible situation that the world is in at the moment. But I felt so strange talking to people like that because I was like, "Why can’t you just have those conversations? Why can’t you just pace yourself?" But it was different for me because to me, it was like an act of survival that I physically couldn’t work overtime. Otherwise, I’d have an enormous flare-up that would last for at least days, maybe weeks, maybe even months.

Nadia (14:38)
I always think about how in the olden days, if there was a disabled person in the village, everyone in the village would help them out a bit. Whereas now it’s like, supposedly the state helps that one person out a bit, and then maybe if they’re lucky, they have friends and family who will help them out a bit. But it just really feels like it’s considered society’s responsibility anymore. How able-bodied people interact with narratives about pain and disability. Is it through a little bit of a pornographic lens? Is there something that people do it because it’s cathartic to engage with it and then come out of it, be able to come out the other end and carry on living a normal life and be like, "Oh, I’m so grateful I don’t have what they have."

*In understanding how much I, and we, are up against,*
*I'm very proud of us, all of us on the landscape,*
*all the pain people.*

- Sonya Huber