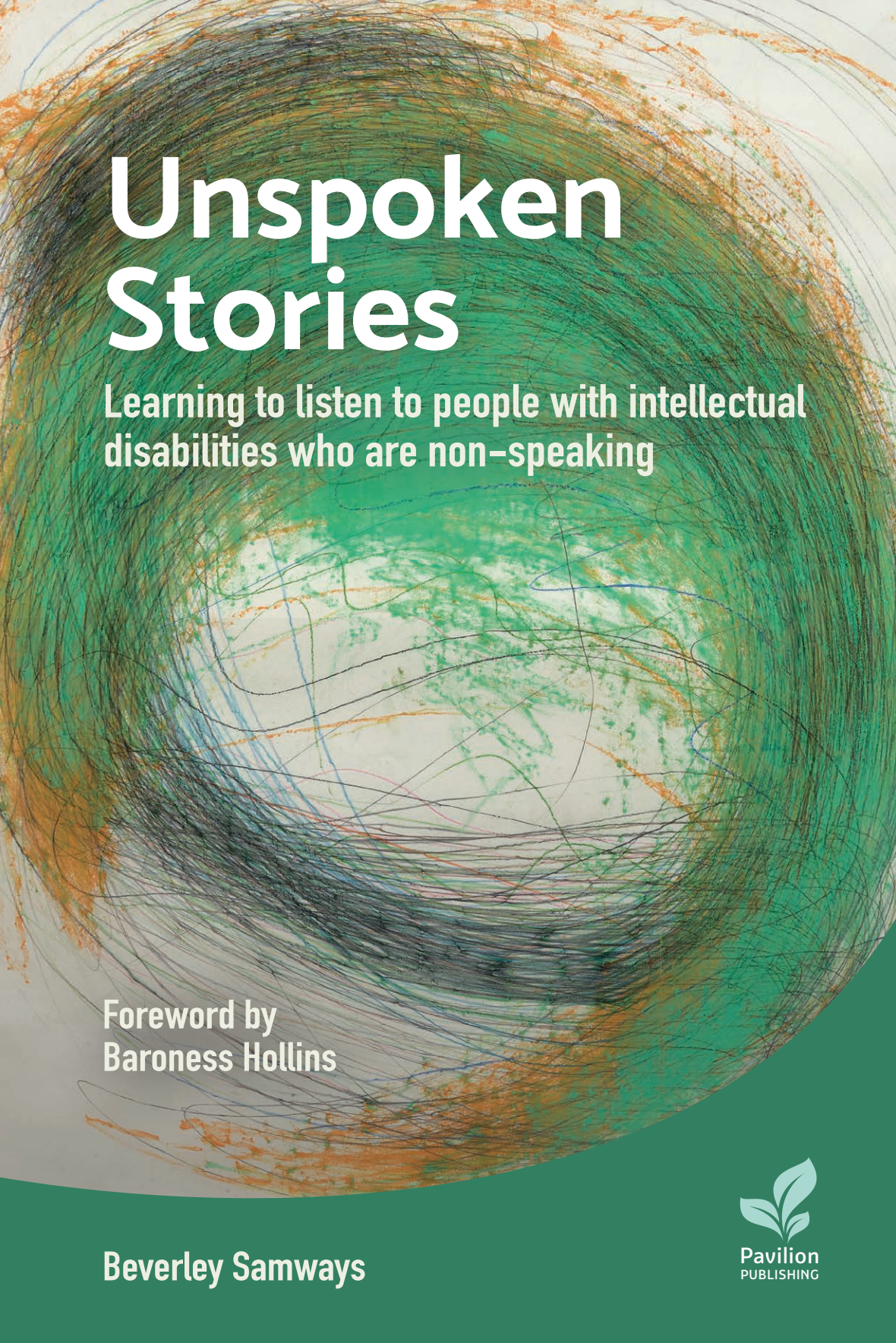




Unspoken Stories

Learning to listen to people with intellectual
disabilities who are non-speaking

Foreword by
Baroness Hollins

Beverley Samways

Unspoken Stories

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Chalk pastel, chalk pen, pencil and pen on paper

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“Electric. For too long non-speaking people with learning disabilities have been viewed as unable to share their stories; this book shows us that they can.”

Dr Lucy Series, Associate Professor, University of Bristol

“We seldom get the opportunity to challenge our thinking about young people who are non-speaking and have high support needs. ‘Unspoken Stories’ is a beautifully written book that sensitively lets us into the internal world of two young people who can become overwhelmed and distressed from their experiences of their world.

I found this book most novel in allowing the reader to go on a journey of relational discovery with the author and the young people, whilst providing an accessible therapeutic understanding of the process. I highly recommend it to anyone who provides help to a young person who is non-speaking and requires high levels of support.”

Dr Paddy McNally, Consultant Clinical Psychologist

“This book is not merely clinical observation; it is an act of ‘life-sharing’ that reveals the power of being truly present. Through a lens of timeless curiosity, the unspoken hardships and internal worlds of two non-speaking individuals are brought vividly to life, moving the reader to walk with, lean into, and feel the weight of their experiences.”

Throughout these pages, Bev offers snippets of wisdom that guide us toward new ways of thinking and being. While ‘trauma-informed care’ has become a modern buzzword, Bev’s work embodies its true heart. By understanding the profound life-altering experiences held within the souls of children like Cassie and Owen, she leverages a relational approach to empower those who have been silenced.

Perhaps the most poignant takeaway is the necessity of humility. For too long, people with intellectual disabilities have been diminished by paternalism, ableism, and the shadows of institutional care. Echoing the sentiment of ‘He must increase, but I must decrease,’ Bev’s work challenges us to set aside our pre-judgments. By stepping back, we finally allow the person space to tell their own story.”

Dr John M. Keesler, Associate Professor, Indiana University

“In the Christian tradition, making ‘unknown’ languages accessible to whole communities is a time-honoured and deeply incarnational spiritual practice. It is the interpretation of worlds, not merely of words. That is evident in these pages, shedding light on Cassie and Owen’s stories while reminding us that such work is not beyond any of us. Bev Samways has ventured where few have chosen to go, making visible what many did not even realise was within reach.

I have long believed that our best leaders are multilingual, i.e. able to listen deeply, interpret wisely, and communicate across contexts with clarity and courage. By that measure, and in charting fresh paths and giving voice to what has too often remained unheard, Bev is an extraordinary leader, and this is a compelling and extraordinary book.”

Rev Dr Kate Coleman, Author, Coach and Founder of Next Leadership

“This is a compelling book. Having worked with non-speaking learning-disabled adults and children for many years, Beverley has seen how their emotional lives remain invisible or ignored because ‘they are too much’. This is often an unconscious act by carers and professionals; however, the resulting distress is the same as if it were deliberate.

Beverley has a strong scepticism about the dominant narrative of behaviour and diagnosis and instead immerses herself in her subjects’ lives, applying ‘deliberate unconditional listening’ to gain a much rounder sense of Owen and Cassie. The result is a vulnerable account that often takes your breath away. With both subjects, Beverley discovers deep, raw grief that has not previously been understood or fully seen by the day-to-day staff. Some wonderful surprises happen because of the time and consistency she offers through her unconditional presence. This is hugely moving and bold.

I think the power of this book is in opening people’s eyes to what is right in front of them, hidden in plain sight. If it takes some of the focus away from the behavioural framework, Beverley will have achieved her aims beautifully.”

Dr Noelle Blackman, Psychotherapist and former CEO of Respond

For Shelley

Contents

Dedication	xiii
About the author	xv
About the cover artist	xvii
Foreword	xix
Acknowledgements	xxi
 Part One	 1
Introduction	3
Writing people	3
Challenging ‘challenging behaviour’	5
Diagnosis	6
The research	7
The context for the research	7
The research process	8
Those in the story	9
My position in the space	10
Introducing Cassie and Owen	11
Cassie and Owen’s process of participation and consent	12
 Part Two	 15
Cassie’s Story	17
Prologue: Who tells the story?	17
1. Cassie has a secret	19
2. A drum and a girl	22
3. Is it okay?	24
4. Double empathy	27
5. Missing Jon	30

6. Cassie is telling this story.....	33
7. Mum and Dad in our minds and hands.....	37
8. We cannot reach her.....	45
9. Here we are.....	51
10. Taming the waters that overwhelm us.....	55
11. The lightness of her.....	60
12. Her capture of me.....	63
Part Three	69
Owen's Story.....	71
Prologue: This is Owen.....	71
1. A door ajar.....	74
2. Rest is a person	75
3. What just happened?	79
4. A return to proximity	86
5. Triads	91
6. Intangibles	97
7. To speak and be heard	102
8. Stories told about us.....	106
9. Leaving and returning.....	111
10. A defence against the cold.....	117
11. Being with	118
Part Four	121
Reflections	123
Unlearning.....	124
Behaviour: yours, mine and everyone else's.....	124
What to do with diagnosis	126
What story are we telling?	127
Working with our shared emotional lives.....	128
Emotions and the body.....	128
Four frames for understanding our shared emotional lives	130
Projection	130
Containment	131
Transference	133
Enactments.....	134

Re-framing	135
Reflective space and story	135
When organisations split	137
All that is held inside.....	138
Final thoughts: Telling new stories together	139
Background and references	141

Dedication

This book is dedicated to Shelley, with whom my journey into all that this book represents really started.

I met Shelley when she was 16, living and learning in a residential school for young people diagnosed with severe intellectual disabilities, not dissimilar to the one Cassie and Owen lived in. I was a 22-year-old agency care worker, completely unprepared for how meeting Shelley was going to hijack my life. I supported Shelley for the next 18 months, and learning how to listen to her, respond to her, build a connection with her, internally ruined and then rebuilt me. When Shelley moved on, we remained friends, and we've now known each other for more than half a lifetime, recently celebrating her 40th birthday together.

Shelley, my friendship with you has been a joy and a revelation. You have continually challenged and pushed at my assumptions. The moments when you have chosen to trust me with your voice and story have felt like a window in my mind opening. You were the first person to disillusion me – to allow me to glimpse something of the wealth and depth of love and uniqueness you hold inside. You laid a foundation of curiosity in me that has allowed me to start open-minded and open-hearted, each time I meet someone new.

For all you've gifted me, Shelley. This is for you.

About the author

Dr Beverley Samways is the founder of Unique Connections and a specialist in supporting people with learning disabilities who have experienced trauma and use little or no spoken communication.

Bev is a Churchill Fellow and holds a PhD from the University of Bristol alongside postgraduate qualifications in social work research, child and adolescent mental health, and psychoanalytic observation. Drawing on over two decades of practice and research, everything she teaches, writes, and shares comes from real relationships with people who have challenged traditional support – and shown what’s possible when we stay, listen, and truly see. At the heart of her work is a clear belief: everyone is made for connection – no exceptions.

About Unique Connections

The Unique Connections team helps people with learning disabilities with little or no spoken communication to recover from distress. Whether it presents as self-injury, withdrawal, anger, or other fight-flight-freeze responses, they focus on root cause understandings. They collaborate with the team around the person, helping them to understand the person’s story and experience, and equipping them with tailored, practical, compassionate tools to create lasting change. Alongside frontline support, they partner with leadership to embed trauma-informed principles into culture and practice – so organisations become safer, more empathic spaces where staff and those they support can thrive.

If you’re interested in finding out more, they would love to hear from you.

About the cover artist

Nnena Kalu (b. 1966, Glasgow, UK) lives and works in London, UK, based at ActionSpace's South London Studio. Her practice is rooted in two-dimensional works, sculptures and installations. Through binding, layering and wrapping materials, Nnena Kalu explores space, scale and materiality with repetitive and durational sculptural processes. Her installations often begin with multiple compact 'cocoons' or 'boulders' of textiles and paper tightly packed in cellophane and tape. With an emphasis on colour and volume, these spheres of bound materials are clustered together around frameworks and existing structures. Kalu's energetic installations become an extension of her physical movements, focusing on an important relationship between the artist's body and her sculptural forms.

Kalu's two-dimensional works are also viewed as sculptural explorations of space dictated by the length and reach of Nnena's arms, as well as the size of the paper. Drawings and paintings are frequently produced in pairs, the second an echo of the first, a rhythm is built up and multiple layers are constructed. As with Nnena's sculptural works, the drawings are an exploration of continuous line, shifting and ever-evolving forms.

Nnena Kalu is the winner of the Turner Prize 2025.

ActionSpace supports adults with learning disabilities across London, providing access to creative studios, professional guidance, and the support they need to grow as artists. They ensure learning disabled artists are seen and heard and fully included at the heart of the visual arts world. By creating opportunities and championing their work, ActionSpace helps artists thrive.

Foreword

I often reflect on how Pope Francis described listening as ‘a grace that we have to practise’ (2016:np). Communication is so often seen as something dependent on words, yet true listening requires a deeper awareness – not only of the other person’s state of being, but also of how I feel when I am with them.

During my psychotherapy training, I learned that meaning lies in the *music* between and behind the words. Research into communication shows that most of what is shared between people is non-verbal. And yet, those of us who speak so easily tend to assume that words are what matter most.

In psychotherapy, we speak of *transference* and *countertransference* – of the importance of knowing what I bring of myself into an encounter – my current mental state, my preoccupations, my feelings of the day – and what, in contrast, truly belongs to the person I am there to listen to.

We expect so much of support workers, as if they will automatically understand the needs of the people they support. They imagine they must always be *doing* something. But listening itself is active. It *is* doing something – even if, to an observer, it may appear that nothing at all is happening.

In this remarkable book, Beverley shows us how we can learn to listen to the stories of people who do not have words with which to tell them.

Professor Sheila the Baroness Hollins

Acknowledgements

Many wonderful people have walked with me on the journey here. It's been slow and connected, like all good journeys. 'Together, we can go far', as the African proverb reminds us.

I was supported and encouraged through the research process by so many generous people, but none with the dedication or kindness of Professor Pauline Heslop. You agreed to meet me when this whole thing was only the kernel of an idea, and walked with me all the way through to the first and second published articles. I'm grateful, Pauline. Thank you also for introducing me to Noelle Blackman, who has remained a faithful friend since then.

I find myself in the odd situation of feeling gratitude towards an organisation, though I have not even the name of a person to ascribe to the way they have supported me. The Economic and Social Research Council (ESRC) fully funded my PhD, even generously covering the costs associated with my lengthy field work. They have extended this generosity by funding this book to be open access (grant number ES/P000630/1). None of this would exist in the world without their support.

It's been a little scary putting a book with so much of myself out into the world, and so I have sent the stories out to people who I love and trust, for their feedback. So, to those of you that have been 'in the arena' with me – reading the drafts, and talking me through your thoughts, I'm grateful: Duncan Clark, Shirene Agbelusi, Keren Tennant, Jude Fransman and Paddy McNally. Particular gratitude must go to Keren, Jude and Paddy who have shaped the stories considerably with their feedback, helping

me to articulate myself better, so I am saying what I actually want to say. Thank you. Further thanks goes to those who have read later drafts and provided endorsements, people I trust immensely and respect, and who have journeyed with me in various ways: thank you Kate Coleman, John Keesler, Lucy Series, and Noelle Blackman.

A particular thank you to Baroness Sheila Hollins. You were my first and only choice for introducing these stories, and your foreword is, as anticipated, beautiful. I came into this discipline, in part via the work by Jane Hubert, which you supervised. So, to have you introduce this book is a full-circle moment for me.

I don't do much in life without expressing my gratitude to the God I love. He gave us the 'ministry of reconciliation' (2 Corinthians 5:18), which I think about often in our work – which is the work of reconciling ourselves and each other back into loving connection with Him and one another. All for you, Jesus.

And to Cassie and Owen, for all you have entrusted to me, I'm grateful.

Part One

Introduction

I'll let you in on something – when I'm talking to students who are getting to grips with academic papers, I often tell them: *Make life easier for yourself, scan the introduction, skip the methods and head as quickly as possible to the findings – that's the really good bit. You can always come back to the introduction and the methods later on.*

This is not an academic paper, though it came from research. It tells the stories of Cassie and Owen, two teenagers with intellectual disabilities and almost no spoken communication. If you're here for the 'findings' then go on – it's alright – skip on ahead to Cassie and Owen's stories. You can leave this introduction here, and come back to it later if you feel like it.

For those of you who like context and would prefer to weave your way into Cassie and Owen's stories via the big picture, then read on. These pages are going to foreground the research process, give you some things to consider as you read the stories, and briefly introduce Cassie and Owen to you.

Writing people

These stories have come out of research: a particular type of research called *ethnography*. This literally means 'writing people' (ethno = people; graphic = writing). It's a type of anthropology, if that helps you any. In ethnography, the researcher's job is to immerse themselves in the worlds and lives of the participants, to listen and to pay close attention, as a way of attempting to understand a person's experience, and then to write the stories of those lives.

People with a diagnosis of ‘severe intellectual disabilities’ (more of that later) have typically been left out of research, as they can’t easily complete questionnaires, take part in standard interview formats, or participate in other traditional data-gathering methods. However, for the last 40 years, a small number of researchers have used this ethnographic method to include people with intellectual disabilities as participants in research¹ (Gleason, 1989; Hubert & Hollins, 2010; Davis *et al.*, 2008).

One of the ways this research differs from traditional research, is that it is not – by design – ‘objective’ (whatever objectivity is). Rather, it requires the researcher to take their whole selves, with all of their experiences, beliefs, and assumptions, into the research, and do their best to listen and learn. Therefore, ethnographers generally start by being open and reflective about themselves. This shakes off the idea that the researcher is some kind of human ‘blank slate’, and means you understand a little of what they are bringing into the process. All of this helps us remember that the most effective way of understanding each other well is not through objective experiments, but through relationship.

So, with this in mind, a little about me.

Today, as I write here in my little shoffice (shed-office), I am 46 years old, with around 25 years of professional experience working with children and adults with intellectual disabilities. (Yep, all my working life.) I am neurotypical, white and middle class, from English parents. Unravelling the associated privileges and blind-spots that go with that list is work-in-progress. I am well-educated; even so, my sister and I were the first generation to go to university on both sides of our families. I am a practising Christian, committed to my local Pentecostal church (one of the loud ones). I’m wired for connection deep in my core – connection with people and with God. And I’m wired for justice. My work and life is fueled by an intermingling anger at injustice, and love for people.

I came into this research intentionally and deliberately, driven by my experiences in the care sector, supporting young people with intellectual disabilities, sensory loss and autism. Over the years, I had lots of experience working with young people diagnosed with ‘severe intellectual disabilities’, who were distressed. Many of them had little or no verbal

1 Jane Hubert’s ethnographic research about the lives of the men with intellectual disabilities in an institution first opened my eyes to what might be possible.

communication to express themselves, and some expressed their distress physically towards themselves or others. I had got to know a number of young people who had self-injured routinely and dangerously, and had felt increasingly frustrated that – though the narrative around young people who self-harm was generally around prior trauma and overwhelming emotion – this was almost never considered for the young people with intellectual disabilities who were hurting themselves.

Frustration at the status quo, and encouragement from others, led me to propose a PhD research project to inquire about the emotional experiences of young people who self-injured and had no spoken communication. This journey, via lots of encouraging and facilitating people, led me to the residential school that sets the context for these stories, and finally to Cassie and Owen.

Challenging ‘challenging behaviour’

I entered Cassie and Owen’s lives from a context that wasn’t neutral. I was curious about their particular experiences. But I was also increasingly skeptical about the dominant narratives of ‘behaviour’ and ‘diagnosis’, and wondering what else might be going on for them.

For decades now, people with intellectual disabilities have been considered through the lens of ‘behaviourism’, and episodes in which they might hurt themselves or others have been termed ‘challenging behaviour’.

Behaviour simply means the way we act and interact with those around us and our environment. ‘Challenging’, in this context, refers to the challenge that other people might experience, not the person themselves. So the term ‘challenging behaviour’ is not really about the person’s life or experiences, their emotions or what happened to them, but the way in which their response to their immediate environment challenges the people around them.

We all have ‘challenging behaviour’ from time to time. If you stand on my toe, I might shout and push you off. My behaviour, even whilst it might temporarily offend or disrupt you, makes sense as a response to an immediate ‘stimuli’ (in this case, pain). Similarly, for people with intellectual disabilities, ‘behaviour’ has been understood in relation to ‘triggers’ in the environment: if a person begins to hit themselves,

what might they be responding to or trying to communicate about the interactions and environment in this moment? The ‘triggers’ have been broadly categorised into five groups:

- A need or want (e.g. I’m hungry / thirsty / screentime)
- Attention (I need someone to attend to me socially or emotionally)
- Escape (I need to get away from a person or place)
- Sensory (I’m finding this environment overwhelming or under-stimulating)
- Pain

So in the example above, the main trigger is the pain in my toe, but there is also a need to get the person’s attention so they move, so I can escape from the situation. Straightforward enough, right?

The difficulty is that our responses to ourselves and others are not always straightforward – and, crucially, they are not always a response to our immediate environment and relationships. Assessing ‘triggers’, and changing environments as a way of addressing behaviour, is fair enough for a metaphorical toe-squashing moment. But what if this isn’t the problem?

What if someone’s ‘behaviour’ is actually a response to past experiences? Or hurt that won’t go away from a previous or current relationship? Or overwhelming emotions that rise up unexpectedly in response to any number of things that have happened to them – things that are not about the people around them, or their environment?

What then?

Diagnosis

I came into Cassie and Owen’s lives with almost twenty years of working with people diagnosed with ‘severe intellectual disabilities’, but reconsidering what we might mean when we use this diagnostic term.

‘Intellectual disabilities’ is the international term for what we call ‘learning disabilities’ in the UK, which is based on three core criteria (National Institute for Healthcare and Excellence (NICE), 2022):

1. *‘a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligent);*

2. *a reduced ability to cope independently (impaired social functioning);*
3. *which started before adulthood, with a lasting effect on development*
(Department of Health, 2001: 14).

Whilst the definition above does not mention IQ, it is still common to reference a person's IQ as part of diagnosis. A common marker is that a person with intellectual disabilities will typically have an IQ lower than 70. Beyond that, there are further categorisations – mild, moderate, severe and profound intellectual disabilities, intellectual and developmental disabilities, and so on.

Whilst it can be helpful to notice when, how and at what pace someone is developing, and put in additional support as necessary, it is also worth noticing that these diagnostics all sound very definite, when they are not particularly.

'Intellectual disabilities' is little more than an idea, something constructed to categorise people together. These categories can help to direct additional resources and support appropriately. But we need to acknowledge that we only need to release *additional resources* because our world is built for the few, not for everyone. They can also promote better understanding for and of the person. But they can just as easily be used to dismiss or reduce a person.

Both Cassie and Owen had been diagnosed with 'severe intellectual disabilities'; but when you see this term used here in this book, it should signal more to you about the world they are in than their own internal capacity.

The research

The context for the research

Cassie and Owen lived and learned in a residential school (effectively, a children's home that co-existed with an education provision). It specialised in supporting and educating young people with intellectual disabilities and autism. It had been consistently judged very favourably by Ofsted, and was run by managers and a team who were largely proud of the work they did and wanted to do an excellent job.

Cassie and Owen lived in different houses on the same site. They each shared their home with three peers. Each house was staffed with between three and five support staff during waking hours; their job was to support the young people in their homes and to access their curriculum and social activities.

The grounds of the residential school were self-contained and so arranged that there was no particular need for anyone to leave if they didn't want to. There was a wide variety of activities available, including a pool, animals, walks, sensory equipment and so on. The outside space was hugely helpful for many of those living there, providing wide skies to live under. You'll see this generous environment repeatedly providing exhalation for Cassie and Owen.

As you read Cassie and Owen's stories, you may notice when things go awry – the power mismatching, moments of insensitivity, things in the culture that make you uncomfortable, moments of unkindness erupting in interaction and speech. Such is it in most homes – and this is a home with all the complexities of bureaucracy, and hierarchy and funding pressure. So, despite the moments that go wrong, as is so often the case in social care, I hope you also notice that the people who feature alongside Cassie and Owen were, broadly speaking, people doing their best with what they had, in amongst the inevitable complexities of running a social care and educational organisation.

The research process

The organisation generously agreed to participate in this research during the second half of Covid. I was seeking to find participants who had been diagnosed with severe intellectual disabilities and had a history of self-injury that was continuing to cause concern. They facilitated me meeting three young people they were caring for who met the criteria to be invited to participate in the research, and they supported and advocated for them during the consent process.

We went through a careful recruitment and consent process, about which I'll say more below – and which you can also read the full details of in an open access article published about the methods of this research. It's called *'Learning to listen to non-spoken voices. Including young people with intellectual disabilities who are non-speaking as primary participants in qualitative research.'* (Samways & Heslop, 2025).

I typically visited for two days most weeks, spending between four and five hours a day with one of the three participants.² This eight-month period started in the summer of 2020 and finished before the spring of 2021.

Over that time, I visited 41 times, spending 188 hours altogether with the participants (so around 60 hours with each young person). The stories are adapted from my ‘dataset’ – a large bank of transcripts from many hours of audio notes made following each visit. From this dataset, I have crafted their stories, which sit loosely in the genre of ‘narrative non-fiction’³. Each chapter represents a new visit (unless stated otherwise).

Those in the story

These stories are not about anyone but Cassie and Owen. However, I wanted to learn about their emotional and relational experiences – and so their families and carers do, of course, feature in the stories.

I wanted to particularly acknowledge and honour Owen’s family, who agreed for me to be present on a couple of occasions when they were with Owen. Their love for him is woven all the way through his story, as you will see.

Participant names are anonymised, as are the names of the staff, organisation and location. However, people who knew Cassie and Owen during the period of the research might be able to identify them from the stories. To whom that applies, I trust that they will feel no need to undo the anonymity; there would be no value in doing so.

Lots of different staff members appear in the stories. Following advice from one of my pre-readers⁴, some staff are an amalgamation of several original actors in the story. This helps improve the readability and flow of the story, and has some further benefits in terms of anonymity.

However, you will see that there are also times when I mention ‘a staff member’, unnamed. This is to reflect the reality that some staff appeared only briefly, supported Cassie and Owen, and I didn’t see them again.

2 This book tells the story of two participants. Jacob was the third. His story was dominated by acute self-injury, and consequently, felt to me like it needed a separate focus, perhaps as a future book focused on self-injury from the perspective of unspoken distress.

3 Ethical approval was granted by University of Bristol Research Ethics Committee, ref: 116530 on 09.03.21. An ethical amendment to present the findings as narrative non-fiction in a book was granted on 15.12.23.

4 Thank you, Keren Tennant.

They were not around long enough for me – nor perhaps for Cassie or Owen – to learn their name. Thus, I occasionally retain the appearance of unnamed staff members, because of the reality that people did pop in and out of Cassie and Owen’s lives in this way.

My position in the space

I arrived into Cassie and Owen’s life with access and power that they did not have. At reception, I was handed a card that got me through locked doors, and a key that got me into locked cupboards. You will read me opening cupboards and doors in the stories *for* Cassie and Owen. This was not something I chose, but the context in which they lived, and so it was important that I listened to their experiences within this context.

I also arrived in their lives as a researcher, which was not a role they were familiar with. My position in their lives could only be meaningfully communicated to them through my actions and interactions, so I worked at offering them something different from the care team around them. I tried (not always successfully) to extricate myself from ‘caring’ tasks – getting meals ready, helping with shoes or coats, policing spaces or things – and I ensured I had little or nothing to do with personal care. This could perhaps be frustrating for over-stretched staff, but it established a different relationship with Cassie and Owen, particularly in the busiest moments: when everyone else was over-loaded, I remained available to them.

I also operated very differently in relation to what I shared with whom. In these contexts, so much of people’s lives are written down, shared and reported. However, as a researcher, I needed to establish that what Cassie and Owen told me – verbally or nonverbally – would be kept confidential (unless it was a safeguarding concern). Cassie and Owen noticed this very quickly, and began to test the bounds of our relationship, to see what they could trust me with – doing things which they knew I was observing, but no one else was noticing. This was sometimes difficult to navigate, and I was grateful for careful supervision and therapy to manage these silent negotiations with them safely. But this positioning proved essential groundwork, as Cassie and Owen had stories they needed to tell, things they needed to say and be heard, and they needed to work out whether I would listen and hold their stories safely.

In the stories, you might notice me referring to myself by name when addressing Cassie and Owen (e.g. ‘Beverley is here until dinner’, rather

than ‘I am...’). This practice is something I learnt from a young man years ago who found pronouns hard to follow, and had just enough language to let us know this. I learnt from him that it can be hard to understand that I am ‘I’ to myself, but ‘you’ to you. (Already confusing, isn’t it?) You’ll read later in the story that Cassie reverses her pronouns sometimes in a similar way, so this habit of using names not pronouns proved useful over time.

My foundational posture was that I was there to listen to them unconditionally, and, as much as I had capacity, to feel what they were feeling, experience what they were experiencing. They were my primary research participants, and I needed to prioritise listening to their voices. This always took intention – because a spoken voice is literally and metaphorically louder than an unspoken one. So I did not consistently achieve this, sometimes through my own inconsistency, and sometimes because my position as researcher was (consciously and unconsciously) contested in all sorts of ways by those with whom we shared the space. However, in the best moments we shared, many of which you’ll read about, this is really all I’m offering: deliberate, unconditional listening.

Introducing Cassie and Owen

You’ll meet Cassie and Owen properly in their stories. But here’s some background, mostly so you don’t have to wonder about these things as you’re reading.

Cassie was white British. She was 14 at the start of the research. The local authority had made a decision to remove her from her family, and to move her into this specialist setting. Family contact, during the period of time I was with her, was limited to very occasional video calls with her Mum. I know from the stories of the team that she had come a long way since she first moved in a few years prior. It’s important to hold in mind that, because of the way she had arrived, this place was home to her – providing relative safety in a way she had not previously known – and there was no other.

Owen was white British. He was 17 at the start of the research. His journey was quite different. He had come to live here following the local schools that supported children with intellectual disabilities, and his family, becoming overwhelmed by his expressions of distress. Thus, this place had become home to him for a different reason than Cassie – and perhaps meant something different for Owen. His family visited him faithfully every

week, which maybe allowed him to remain aware of the home he had left, and still belonged to, but would not live in again. The team told me how ubiquitous his distress was when he first moved in aged 14. So the Owen you meet here in this story is probably the most settled and stable he has been over the course of his life.

Cassie and Owen's process of participation and consent

Cassie was legally too young to give informed consent to participate in this research; her guardian gave consent on her behalf. Owen was deemed not to have capacity to understand all the consequences of participating, so we followed the process that is laid out in the Mental Capacity Act for Best Interests decisions for research participants who lack capacity to consent. The article previously mentioned talks this through in detail.

However, it was important that Cassie and Owen retained agency over their own involvement, that they had an understanding of who I was, what they were participating in, and that they could make decisions about their involvement at any point. This is called '*process consent*'. It meant it was my job to keep checking in with them about their understanding of what I was doing there, and that they still wanted to participate. This meant I looked for signs that they did not want me to be around in a certain situation or on a certain day, as well as any indication that they didn't want me to keep visiting anymore. It was my job to keep the conversation about my role and their participation in the research alive and active, involving the staff and leaders that knew them best in checking that it remained a process with which they appeared to want to continue. This extract from one of my first visits to Cassie illustrates one of the ways I explained who I was and what I was doing:

'[One of the staff asks]... "What are you actually doing? What are you trying to find out?"... I turn to Cassie, so it's clear I'm involving her in my conversation, gesturing my hand toward her: "It's based on the idea that Cassie is the expert on Cassie. So, if I spend some time with Cassie and get to know her, and I see what she has to say, we may be able to understand a little bit of what's going on for Cassie"' (07.07.21)

Cassie and Owen were pretty good at letting me know when they wanted me around, and when they didn't; you'll see that in the stories. However, I guess I wasn't expecting them to share as much with me as they did,

and towards the end of my time with them, I felt some real anxiety about the re-telling, particularly of Cassie's story, which she had shared with extraordinary vulnerability.

In the end, I decided to talk to her about it again, and it went like this:

Beverley (speaking slowly and signing): 'Cassie. Thank you for talking to me so well and telling me how you feel. Because that's what I came to find out. I wanted to know more than anything else, not what you know, but what you feel. And you've been able to tell Beverley about that so well. So thank you.'

Cassie: Thumbs up

Beverley: 'I'm not going to visit anymore, Cassie. I'm going to go away so I can write your story. I'm not going to use your name. But I'm going to write about your story and people you haven't met will read it.'

Cassie's smile broadens across her face and she pushes her thumb towards me, she shakes her upturned thumb once, twice, three times at me, looking at me carefully to ensure I am understanding.

I had wondered if Cassie would continue to extend permission for the retelling of her story that she had so carefully shared with me. Her response to me in this conversation didn't feel like it confirmed her permission, but felt closer to a commission. It was this final encounter with Cassie that seeded the idea that this story should not be held in journals locked behind firewalls, but just out there for anyone to find. This moment has compelled me to find the written language to accurately translate the unspoken moments I shared with her and with Owen, albeit from my own partial, relational perspective.

Before you turn into the stories, let me say that the experience of meeting and listening to Cassie and Owen has changed me: my heart has been wrenched bigger, my understanding of the depth of humanity irreparably stretched wider and deeper. So, the stories are shared from my perspective – but from a perspective moulded by the imprint they have left on me, and, I hope, in a way that honours Cassie and Owen and their experiences.

Part Two

Cassie's Story

Prologue: Who tells the story?

Cassie is sitting on the sofa, her arms wrapped tightly around a football.

A staff member, alleviating his boredom, has been flicking the football – that is not his – around the space between the sofa and the dining table. The unrelenting pt-pt-pt of the ball and its jagged bounce around the small, shared space has made it difficult to think straight, difficult to rest.

He finally chips it over to Cassie's lap and now she holds it determinedly still.

Despite her arrest of the ball, Cassie is still encircled with hustle and bustle and noise and movement and chaos and now there is Esther lifting her voice over the cacophony and saying loudly and suddenly to Jess across the room: 'Oh, she did so well. Last night, Cassie FaceTimed Mum'. I look over at Cassie as a stabbing pang arrives in my stomach.

Esther continues her public announcement: 'She FaceTimed her Mum, and she did really well. I just held the iPad out like this...' Esther places the flat of her hand right up in Cassie's face, turning back to Jess '...and she jumped straight up, went to her bedroom...'

I feel it keenly inside me... stab-stab-stab, with Esther's flicking of the story – that is not hers – around the small space. My head swims. Against the insistence of Esther's broadcast, Cassie hugs the football hard into her stomach and bangs the ball over and over with the flat of her palm, shouting out with each slap of the ball: 'ah-ah-ah'.

Who tells the story when you don't speak?

This is Cassie's story. And I will try to tell it gently and slowly, like she told it to me.

She said I could share it with you.

One: Cassie has a secret

Cassie half-runs, half-gallops into the room. Her head is down, her arms slightly pushed back as if for a photo-finish: she asserts herself into the room as a force, forehead first, bursting through an unseen barrier. It is as if the world itself requires a run-up to gain entry.

Abruptly, she plonks her weight down into the dining chair. Her hair is wet from swimming, dangling in clumps around her face. Her shoulders are curled over the table, her leggings and hoodie crumpled around her heavy 14-year-old form.

She waits expectantly for her lunch which is placed on the table in front of her. She leans herself further over the plate, shoveling the food into her mouth with urgency, hunkering down over the food and underneath the exchanges happening over her head: 'How has she been?' 'Has she been to the toilet?' 'Has she been good?' She pours her attention into the act of eating – stuffing the food in as if as a bolstering of defences.

She finishes eating, and finally raises her head to me, seated opposite, making eye contact and holding it. We look at each other. After a while, I offer: 'I'm Beverley; we met before. I'm going to come and see you most weeks.' She shows no sign that she has registered my words, no offer of recognition. But she keeps looking, and I have a sense of her needing to observe me, consider me, take me in and decide: if I am to 'come and see' her, then she will see me first.

I look away and let this first observation be hers, not mine.

It's time for a break from schoolwork and Cassie chooses the iPad. She leans over it, typing with intention and focus. Hallie peers over to see what she's doing, exclaiming with surprise: 'Oh, she's on the calendar. She's making a new event'.

And I have a thought that perhaps Cassie's musing intention – now that my 'weekly observations' have been considered at length – is to, carefully and thoughtfully, add them to her diary. I have been diarised as she makes space for me, writing me into her days.

Cassie has opted out of the walk, remaining behind to draw and write at the table; her supporter, Sade, sits opposite her, colouring. They work quietly, both engrossed in their work.

The other staff and young people return and the place is busy and bustling. Jess – the teacher – brusquely and with an air of authority, walks into the dining room. She says ‘hello’ to Sade and peers at Cassie’s work, placing her hand on her head to ruffle Cassie’s hair. She leaves the room, returning a second time, neither looking at nor addressing Cassie, but running her fingers through her hair again, like a well-formed habit. It’s intimate, familiar, tinged with ownership. Cassie does not acknowledge her, but keeps her eyes on her work, quietly tucking her harried hair back behind her ear, as Jess walks away.

Jess returns and hands them a small pack of card and stickers, glue and scissors. As Sade opens it, Cassie immediately reaches for the scissors and begins to cut up a square of yellow paper into tiny pieces. She cuts with the blades scuffing at the insides of her fingers, each snip bringing the scissors closer to her hands, like a veiled threat. Sade does not look up.

Cassie’s cutting gets gradually slower and more thoughtful, and I find myself slightly leaning in with curiosity. Then, with absolute stealth and total intention, she moves her left hand that’s holding the scissors up to her face. She rests her chin on the heel of her hand, with the scissors, held by thumb and forefinger, pointing up towards her ear. It’s a very natural movement, but I see that the scissors are open and they face towards her neck.

Sade does not look up.

With deliberate care, aware that I am watching on, Cassie snips off several locks of her own hair.

I watch the thin locks of hair fall onto her shoulder. Silent casualties of re-asserted ownership.

Cassie puts her hand down again and carries on cutting the paper. Several minutes later, Sade looks up and sees the locks of hair on her jumper, gasps quietly, and quickly brushes them off onto the floor to be forgotten.

Cassie has a secret life.

She practises quiet ways to re-establish her sense of self: a self otherwise eroded in casual conversations and absent-minded contact. She is capable of holding herself still as her hair is ruffled like a shared commodity, only to reclaim it later: *her* hair to shear. An act wholly for herself: restoration of ownership through demolition.

And she has invited me into it – to witness the tiny acts of revolution, in which she takes back authority over her body, over her identity.

I know already that there is much more going on inside her than the outside would suggest.

And I know now that I will need to wait for the quiet moments – the non-moments – when it looks like nothing is happening. These are the moments when the life inside will creep into plain sight, like moonflowers, waiting for the sun to set before stretching open.

Two: A drum and a girl

Emma is crouched in front of Cassie, helping her to put her shoes and socks on, simultaneously craning her neck around to tell Henry he needs to support Cassie at music therapy. I head to the hallway to wait, and suddenly Cassie is bowling towards me, head down, arms swinging. I open the door just in time and she charges through, bent forward, stampeding at pace.

Cassie arrives at the therapy room ahead of us, throwing the door open to reveal the small girl she shares her home with, who is raucous and explosive against a drum kit, whilst the music therapist affirms the feral smashing from the piano. I follow after Cassie and notice lightness bouncing in my sternum as I cross the threshold: this small room is a Tardis.

Cassie eyes the small girl with dislike, pushing her palms over her ears and hovering awkwardly in the centre of the room. At the therapist's cue, she plonks herself onto a foam rocking chair, head down. The other student leaves, and the music therapist moves himself over to the drum kit. Cassie looks up as his steady drumming starts, rocking her chair a little. I sit next to her and pull a Bongo drum between us, tapping the side of it. She leans forward and begins to match my tapping, catching my eye intermittently.

The therapist slowly increases the volume of his drumming. Cassie responds in kind, raising her hand higher and higher above the drum, before bringing it down with greater force. She holds my gaze, as I focus on the sensation of the drum and on Cassie.

We move into an alternate beat – she hits the drum, and I respond, her palm smacking down on the drum skin, so that her little finger and ring finger overlap with mine on the drum. I follow her lead, her hand touching my hand and my hand touching her hand with each thwack. The thunderous tones rise like flood waters in the room and the vibrations from the drum throb in my palm and fingers.

‘We’ve found the beat, Cassie!’, the therapist cries, suddenly elated. We move into the same rhythm, hitting the drum together at the same pace. And the beats begin to fill the room, rising higher, until they are filling my eardrums, crashing waves over everything. Cassie is rocking back on her chair with her arm raised high over her head, bringing it swinging in towards the drum with a crash. I do the same, though I don’t know where

to put all the sensation. My mind gives in to the intensity, as I begin to float in the visceral overwhelm, my skin tingling from my fingertips all the way up to my neck.

And suddenly Cassie stops. She hugs her shoulders in, wrapping her arms around them, and slides her hands up and down her shoulders and upper arms, lightly and softly, soothing her arms and skin. I follow her lead, leaning back, and find my senses regulating slowly: a return to the ground.

The therapist has not stopped.

Cassie leans forward and begins to drum again. Without me to accommodate, she squeezes her eyes closed, as her drumming crescendos in force and rhythm. Her face scrunches, her body rocks back and forth, back and forth, as the strength of the sound and the violence of the air around us intensifies. With each forward sway, she smacks her hand down hard so that the drumskin vibrates and shakes and the drum reels. There is no restraint, no caution – just a deep, visceral expulsion of so much unsaid. And the room roars and bellows with her.

There is no PECS⁵ symbol for adolescent rage, I think; no Makaton⁶ sign for the excruciating craving for independence against the gnawing need for family and tribe; no sign for accommodating the changes to the female frame that force a girl into womanhood whether she is ready or not; no symbols for grief or confusion, jealousy or possession, belonging or rejection.

But here is a drum and a girl with a vast internal world that she can rain down upon it with intermingling fury and joy.

5 PECS = Picture Exchange Communication System – small pictures that together provide a way of communicating and requesting things.

6 Makaton is a form of sign language, often used by and with people with non-spoken communication.

Three: Is it okay?

Bamboo grows so fast, it's said that if you sit still you can physically see it happening. Today, as I watch Emma, so present with Cassie, I feel like I'm watching bamboo grow. And it gives me a sense of what is possible for Cassie, relationally, emotionally. And how precarious it is.

Emma and Cassie are working together at the table – matching shapes, signing colours, writing and drawing. Cassie works with cranky competence, punctuating Emma's gentle encouragement with harrumphs of annoyance, and occasionally making a fist and punching the fingers on her other hand sharply.

Emma redirects Cassie back to herself over and over again: 'Look at me, Cassie. Look'. With her first two fingers, she draws a sweeping line between Cassie's eyes and her own, and Cassie follows the line, finding Emma's stable attention at the end of it. And so Cassie continues to work, matching, writing, conceding to the work with half-hearted moments of resistance.

A sudden burst of irritation erupts and Cassie strikes out her hand to grab Emma's hair. This is met by Emma's wide eyes in quiet rebuke as she leans back in her chair away from Cassie's stretch. She puts a tissue in Cassie's outstretched hand and nests a pen into the tissue, wrapping her own hand around Cassie's, as she wraps her attention around her. Together, their hands follow the dotted lines on the page, and the dotted line between them closes up simultaneously, as the agitation in Cassie slowly lifts off her like morning mist.

They complete the work slowly in this silent symbiosis, until finally, Emma sits back with a smile: 'Cassie, I'm very happy. You did good looking and good listening and good thinking'. She signs these words slowly and deliberately. Cassie's eyes are locked in on Emma's; she absent-mindedly mirrors Emma's signs, as if her body can't help but reciprocate what Emma offers out to her. They both lean back contentedly in their chairs, and in the satisfaction of work done together.

Emma stands and pulls a dining chair out from the table: 'Come and sit here, Cassie; I'll do your hair'. Cassie jumps up eagerly, plonking herself down, and settling her back against the chair, familiar and expectant. A sudden spurt of movement to find stillness.

Emma begins to wordlessly take strands of Cassie's hair in her fingers, first from one side of her head, then the other, leaning into Cassie's mother tongue as silence sits with us. She lets the glossy brown softness slip in between her fingers, as they find rhythms of under and over, and the patterns write themselves into Cassie's hair. Cassie leans back into the slow rhythm of the plaiting.

The third point in this triangular thinking space, I too settle back in my chair, letting a glowing sense of contentment rise in me, as the space fills up with resonance of mother-daughter relationships. And as Emma moves the three locks of hair over and under, slowly incorporating more and more wisps until all of Cassie's hair is built into the whole, so the three of us seem to assemble a settled joy plaited between us.

Emma lifts her hands from the completed plait and steps back to look at her work; Cassie meets the absence, running the flat of her palm down the back of her head, feeling the order and pattern – physical evidence of the shared moment.

Emma turns to me, her eyes shining and alight: "I just love her".

And together, we let the warmth of those words swim and swirl in the air around us.

Is it okay to 'just love her'? I find myself wondering later.

Of course it is⁷.

So why does it feel like a moment of counter-flow, of pushing against something, like something risky? That out of Emma's mouth popped what the three of us already knew, articulating something that was concrete and sure: that she, the teacher, loves Cassie.

I wonder if I asked her about it in another moment, whether there would be a temptation to qualify it, temper it, even to take it back?

In the next conversation I have with Emma there is not a taking back of the sentiment, but much more significantly, of herself. She tells me, pragmatically, that she is altering her hours and consequently will not work with Cassie anymore. This is undoubtedly a loss to Emma, a loss to Cassie. And yet it is not couched as such, but only as a professional decision, an

7 It's literally written into the UK legal guidance surrounding children's homes.

inevitability, that might feel sad, but should not be cried over. And I find myself pondering on whether those words sent swimming into the air represented a risk too great – a breach of a wall through the articulation of a professional taboo, a wall that must now be rebuilt through distance.

Loss is the price we pay for love⁸. But if loss must be avoided, then love must be quietly, decidedly refuted. And if words cannot be taken back, plucked and swallowed down from the air into which they were sent, then maybe the whole self must be.

8 This is an adaption of 'grief is the price we pay for love', attributed to Queen Elizabeth II.

Four: Double empathy

We are out walking. The grounds of Cassie's school and home spill easily into the countryside, and we are wandering through long grass, stray wheat and cicadas, the summer sun beaming on us. Cassie's hand is tucked into the crook of my elbow; her supporter, Esther, is chatting on the other side of her, and it is warm and amicable.

I greet some passersby and stop to pet their dog, checking with them that it is friendly. I notice the trip leader scowling disapprovingly at me, and once they are out of earshot, I am soundly told off. The implication is that Cassie and her peers represent a capricious risk to others, and that my brief pause and short exchange had been thoughtless and unsafe.

I accept the rebuke outwardly, but inwardly wrestle with feeling aggrieved about the assumptions behind it, and the trespassing of risk assessments upon ordinary social pleasantries. Injustice rises in me at the sense that Cassie, her arm tucked into mine, plodding through the fields, is someone from whom the public should be shielded. I feel the tension in me rise with the effort of controlling my response and my tongue. And as I work on this internally, Cassie, still with one arm hooked in mine, lashes out suddenly with her other arm and grabs the trip leader's hair, shouting gruffly. The trip leader quickly wriggles free as I place my other hand over Cassie's hand hooked into my arm. My hand firmly and gently over hers says, 'It's okay. It's okay'.

Cassie's hand has stayed relaxed on my arm, whilst the other meted out fury: one side of her a shield, the other side a grabbing fist. I wonder about self-fulfilling prophecies – and the naming of Cassie as dangerous over her head as if she would not take it in. And I wonder about Cassie wanting to defend me, defend herself. I cannot unravel her response from mine, and the thought crosses my mind that I felt the anger and she enacted it. What I am sure of is that her lashing out has been intentional and meaningful, not random. She is not a force of nature, but of empathy.

We walk on and I reflect on this moment of enmeshed and entangled emotions – my vexation for Cassie, hers for me – though the start and end of these are blurry. Cassie takes a hold of my lanyard and studies the photo, pointing at my name and picture. I say 'Yes, that's me and that's my photo'. As she returns to the photo again and again, it gently distinguishes us from each other again, unravels the knotted emotions, and reminds me who I am.

So I remind her too: 'I'm here to find out how you experience the world – what you feel. It's my job to try to think about what you think about, and feel the things that you're feeling.'

As I say this, I recall how Cassie appeared to do this for me, as I had wrestled with rising anger: 'Cassie, I've noticed that when other people have strong emotions, you feel it with them. When people feel sad, you feel sad. And when people feel happy, you feel happy. You feel people's emotions with them. Not everybody can do that. It's not easy to feel what those around us feel. It can make life difficult. But I'm here to do this for you. So we can think about that together'. She listens, her arm in mine, tilting her body ever so slightly towards mine, as we walk on.

Esther falls into step with us as Cassie tires and hooks her other hand into Esther's arm. Esther tells me about Cassie in a way that acknowledges that she is listening. We think together in a way that circles and holds Cassie in between us. She tells me the nicknames different people have for Cassie, and reminds her about the people she has known for a long time. It feels warm and shared and joined up.

Esther, caught in her own enthusiasm, pierces the gentleness with a change of topic: 'I called your Mum at the weekend, Cassie...' The word 'Mum' has jolted me with surprise: a knifing feeling in my abdomen. As Esther recounts the good things she has said about Cassie, I look at Cassie's face, but cannot read any change in response from her. I continue to feel the word 'Mum' like a sharp stab inside me. And I do not know how to protect her.

But as we go through the gate into the grounds of the house, Cassie peels off from Esther and me. As I watch her, shoulders hunched, head down, tramp back home, with Esther's chatter in my ear, I miss her.

Back in the lounge, Cassie and I sit at the table together. She picks up her communication book and flicks through the pages. I see that she is jabbing her finger assertively on the picture that says 'family' underneath it. I say, 'you're pointing at family'. The stab from Esther's sudden launch into talking about Mum is still raw in me, and perhaps in Cassie too. So I try: 'Cassie, would you like to talk about family?'

She doesn't look up and it feels like the question lands in a vacuum – a space where it can't be held and can't be thought about. It's like I've said it to no one. At the same time, I feel ashamed of my words, and hope that none of the staff overheard me. And as the shame blooms like a poppy in no man's land, the question – 'Would you like to talk about family?' – tolls in my mind until it has hollowed itself out and I cannot even think what it means anymore.

Five: Missing Jon

I'm back with Cassie after a week away. Even so, the abeyance that the question 'Would you like to talk about family?' found seems to have mushroomed out in my absence. The whole unit feels aimless and empty somehow, with unasked and unanswerable questions hanging in the air.

Cassie is in her room. The team tell me she hasn't had a good morning: she tried to grab and pinch Maisie, the younger girl she lives with. It's not a school day and there's no particular plan, so I go to find her, asking her if she wants to come and do some writing and drawing with me.

And now we are at the table, opposite sides, the whiteboard on the table between us. She looks a little blankly at me. So I try: 'What would you like to draw?' Another blank look. I say, 'Do you want to draw a face?' She does a circle around her face, so I draw a big circle, and then I say, 'What should I draw on the face?', she pulls her forefinger across her lips, signing red. I draw the mouth in red. 'What next?' She points to a nose, then her eyes. 'Oh, I'll put some eyelashes on,' I say as I get to those. She touches her eyelashes. I stroke both my eyebrows, and she copies me. 'Let's do some eyebrows'. I touch my ears; she does the same, and I draw the ears in. I ask her, 'What sorts of hair shall I do?' She runs her fingers through her hair. I draw hair like hers: slightly longer on one side, long and straight. We do another face together, then a series of faces with different expressions. We swap different emotional expressions, Cassie grimacing, grinning and growling at me alternately, and I draw them on the board in response, naming each emotion.

And I notice that we are finding a way to speak using both her preferred language – non-speaking – and mine, with words. I also notice that the less I say, the more she settles into the conversation.

We think together about what happens to our face and body for different emotions. I offer, 'This is what the face is like when we feel worried or we feel uptight about something'. I draw a face with shoulders up high. I say, 'Sometimes when we're worried our shoulders go up like this, and we feel really tense'. She bunches her shoulders up and tenses her face and neck. I draw an angry face with a big, wide open mouth. I say, 'Sometimes when we feel angry, we really shout'. I ask her to show me what she's feeling at the moment. She doesn't know. Neither do I really. 'Sometimes we feel a mix of things. I feel happy, because I'm glad to see you today, but I also

feel a little worried because I think that Cassie might be feeling a bit sad today'. We wipe these away and I draw a person with rainbows on their t-shirt like Cassie's.

I hand her the pen and she writes, 'Jon'.

'Who's Jon?' I ask Leo, a team leader who has just arrived on shift.

'Jon who lives in [another house] now. He lived here for 18 months. But he's moved and Maisie has taken his place. Maisie has taken his room actually.'

I feel like someone has turned the light on in my head. I look at Cassie and she turns her mouth over, pushing out her bottom lip and makes the start of a crying face. I say, 'Oh, perhaps you're missing Jon'.

She takes the pen again and on the bottom she writes, 'Maisie' ... I say, 'How'd you feel about Maisie?' She makes a quiet, sharp grunting noise. I say quietly – with all my attention on her, and trying to rebuff what feels like some curiosity from the staff around us: 'Maisie lives in Jon's old room now. Maybe you feel cross about Maisie sometimes.'

I have been told by several staff that Cassie doesn't like Maisie's noises. But now I consider this more ordinary explanation: maybe it's not her noises, maybe she just doesn't like Maisie. She likes Jon. Jon was her friend. And Maisie has pushed her friend Jon out of the house. I wonder about this ordinary, relational explanation being replaced by a 'sensory' explanation about sound and noise.

I continue: 'Jon doesn't live here anymore, and you miss him'.

Cassie pauses and thinks about this and then she writes 'Mum'. I feel very sad.

I say quietly and gently, 'Yes, you miss your Mum too'.

I pause and take this in.

I say quietly and slowly: 'I was talking to Hallie before. She tells me that you last saw Mum in February. That's a long time ago, in the winter. You miss Jon because he has moved and you don't see him so much. But it's a long time since you saw Mum, and we don't know when you will see her again.'

The sadness intermingles with a growing sense of powerlessness. She hasn't visited. She isn't planning to. So we sit in this for a bit, and then I remember again the connection to Jon's loss – which has known entities.

Leo finds me some paper. I say to Cassie, 'Maybe you can write to Jon and tell him how you're feeling'. I write at the top of the paper in small letters, 'Dear Jon'. She takes her pen and writes underneath in larger letters, 'Dear Jon'. She sits back in her chair and looks a bit lost, unsure how to proceed. I say, 'Show me what to write'. I hold the pen out, holding it still over the paper. She wraps her hand around mine and begins to move my hand, moving it in the shape of a big circle underneath the writing. We end up with a neat circle.

I look at the circle: 'Do you want to draw a face for Jon?' She signs, 'Yes'. I draw the eyes and nose and ears and I do curly hair like Jon's, talking her through each step. She draws another big face and hands me the pen. 'Who am I drawing?' I ask, and she points to herself. 'Okay, we're drawing Cassie. You show me what mouth Cassie has'. She takes my hand in hers, and she draws a sad mouth. She points to her cheek, dotting her finger from her eye down to her chin, indicating tears. I look at her, checking for agreement: 'We're drawing a sad Cassie ... because she's missing Jon'. She puts her thumb up. We finish the sad-faced Cassie picture and she writes underneath 'Cassie' in big letters.

A manager comes in to see us, and I tell him about the letter. He talks to Cassie and tells her that he will take her to visit Jon later and deliver the letter. We do a little more writing, but Cassie seems to tire. We have been writing and talking for an hour and a half.

The lethargy of this morning is replaced with a deep tiredness. And I note again that this opportunity to sit and write with her has come out of the space of doing nothing. And I remember how activity sometimes serves to cover over our difficult emotions, but that this empty space has allowed us to rehearse, name and consider the tumultuous emotions that whirl inside Cassie. We haven't got far from the shore today, just touched the edges.

And I remember that we are in a season riven with loss – that Covid has ravaged our worlds and there is a fear that if we engage with the grief it has brought we will be overwhelmed in it, drown in the sadness.

But to push it down is perhaps a greater risk.

Better to swim the raging sea than attempt to swallow it.

Today we paddled.

Six: Cassie is telling this story

Today, Cassie has been doing table top work with Emma. We are about to head out for a walk, Cassie, Emma and I, a familiar activity for the three of us. I am waiting by the door for Cassie and Emma to appear with shoes and coat on and ready to go. But it seems Cassie has other ideas. I can hear Emma's tense tone from the bedroom. Something isn't going well.

I go in tentatively. Cassie is sitting on the floor of her bedroom against the open door of her cupboard so it cannot be closed. This is not the first time I've seen her do this: rushing for a cupboard as it is unlocked, blocking the door so it cannot be closed and hoarding the things that she finds, like the world is on fire and the only thing left to do is loot.

She has one arm stretched deep inside the cupboard, and she is trying to pull something out. I have to remind myself that she is not raiding the cupboard; this is *her* cupboard in *her* room full of *her* things. It just doesn't feel like it.

Emma is trying to reason with her, but Cassie is a wall. She says, 'If you move away from the cupboard, I will get the box out. But you need to come away from the cupboard, so that I can help you'. I find myself wondering if this is actually true or a trick to get Cassie to move.

She tries a different tack. 'Cassie, do you want to go for a walk?' She brings the communication book over, and shows Cassie the symbol for the grounds. 'Do you want to go out to the grounds?' Cassie signs 'yes' and taps the picture. 'Okay then, let's go. Move away from the cupboard and we'll get you ready'. Cassie puts her head back into the cupboard and rummages again. She pulls on a plastic box that's next to her; it's full of dolls. I sit on the floor next to her, lean my back against the wall and settle in. She pulls hard at the box and it begins to rip, the plastic jaggedly splitting. 'You mustn't destroy the box', Emma says.

Cassie grabs the box with both hands and hauls it over her lap and onto the floor. She picks out a stylised doll with huge eyes, thick make-up and a sardonic expression; it's got lots of brown, matted hair and no clothes. On its bottom Cassie's initials are scrawled with a black permanent marker.

Cassie holds the furious doll in front of her, considering her face at length. With one hand, she carefully smooths the hair away from the doll's snarky face three or four times, tenderly, gently. She keeps her eyes on the doll's face, then snatches a glance up at the wall above my head. I turn to see a photo of Cassie with her Mum and Dad. She turns back to the doll.

She looks back at the pile of dolls again and picks up a cloth ragdoll. It has woollen hair and a large smiley face; it is soft, in contrast to the hard plastic and features of the first doll. She casts her eyes slowly over the figure and face of the doll, before drawing it into her chest, the face of the doll buried into her neck, and hugging it, long and deep.

Emma, breezing past the weight of the moment, is task-focused, picking up the remaining dolls and putting them on the bed. She says, 'Why don't you move away from the cupboard and come over to the bed?' Cassie does just this and Emma quickly closes and locks the cupboard with relief. Sitting on the bed, Cassie reaches both arms wide, sweeping them across the bed to pick up all the dolls at once, hugging the bundle of dolls into herself. Emma looks on: 'Let's go. You can choose a doll to bring with you'. Cassie looks at the first doll, the wide-eyed fashionista with attitude. She picks her up by the hair and carries her out of the room.

Cassie ambles slowly down the corridor, stopping by the row of winter coats. She reaches for a coat and runs her fingernail up and down the zip slowly, thoughtfully. As I watch, I can feel the texture of the zip under my nail and on the tip of my finger. And I feel a sense of wanting to stop and notice the connection between emotions and what is felt in the body: that things get 'under the skin' – itches that need to be scratched, little sensations that need to be repeated and explored. The dolls feel like a visceral, emotional something – like running your finger up and down a zip, which opens and closes the warmth we wrap around ourselves to stave off the cold.

As we head outside, Cassie's amble morphs into large strides, her arms swinging boldly with each step. She is marching ahead of us, as if she is trying to get round and back to the house as fast as she can – a task to be done. She leaves Emma and I in her wake, as passive observers to both her and the doll, soaring through the autumn air with each swing.

As we come back into the house, Cassie does not change her stance nor her pace, continuing to swing her arms and stride forward, despite the tight corridors. She is swinging the doll powerfully by the hair that was just now smoothed back, swinging it against the walls of the house; its naked body and graffitied bottom hits against the staircase, the radiator, the doorframes. And still she does not even glance at it. The sound of it rings in my ears, and I want it to stop.

As we return, Cassie heads for the sofa and I go for a break.

Because I need it.

My relationship with Cassie in these moments came with a commitment not to look away, along with the decision not to intervene. But bearing witness to this particular moment cut me deeply. I understood it in real time as Cassie enacted these two realities against her furious doll with its accusing stare: the tenderness and the terror, the kindness and the neglect, the attention and the disregard. And I wanted to make it stop.

And later, as we head out again into the countryside, Cassie abandons the doll, discarding it like trash, and I can't tolerate it. So I intervene, picking it up and putting it in her bag, tucking it inside with care. And even as I do it, I know that I am doing it for me, not for her. She seems to know the same as she watches me, making a wry allowance for what she knows is a breach of our contract: that I will simply be with her, listen and see her, and that I won't do this sort of thing – I will not try to fix.

We walk for an hour or so outside, and find some space to breathe. The insects are whirring about in the sunlit shimmer, and I say to Cassie: 'Can you hear them singing? They're so small. Too small to see'. 'Dah', she agrees. Leo is with us, and we chat about this and that, and Cassie listens between us, giggling at Leo's funny stories.

Towards the end of the walk, she's got one arm in mine, and with the other hand, she reaches for Leo's hand and I watch him take it. She's in between us, an arm tucked into mine, a hand tucked into his, and I feel the joined-up-ness of it and the security that comes from Leo and I talking and of her being in the middle of this, both a part of it and not.

She gets tired, and we keep stopping for rests. She puts her head on my shoulder and, instinctively, I stroke her hair. At the next pause, she leans right onto Leo's chest, resting all her weight on him. He looks down at her leaning on his chest and smiles.

And I head home, eyes pricking as I reflect on the echoes of these moments with Cassie, resting on us for affection, and having her hair smoothed back, as she had done with the doll. I replay the doll bouncing up against the walls of the house, flying through the air by her hair, her arse owned in black marker, before being flung down and forgotten. Even so, I resist the desire to draw the dots, make a narrative arc, and accept what I know is the deeper reality: that this is a many-layered thing. That it's everything and nothing and all things in between.

Cassie is telling this story.

Seven: Mum and Dad in our minds and hands

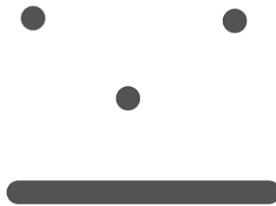
Cassie is at the table with Sade, the whiteboard between them. Sade looks bored and glad to swap with me. I sit down at the table saying, 'Hey Cassie. It's Beverley; I'm here until just before dinner time.' She looks me in the eye, smiling and gives me a thumbs up.

Before I can settle into the chair opposite her, she is glancing up at me and clearing the board, rubbing off the words with her thumb. With her pen digging hard into the board and a growing fierceness across her face, she writes 'Jon' in large letters. Underneath she writes 'Maisie' even bigger, pressing hard with the pen. She's been waiting for this, I notice, and take a deep breath in. And out.

'You're thinking about Jon. And you've written Jon big, but you've written Maisie bigger.'

I pause. 'Jon lives in [another house] now, so you still get to see him. But Maisie lives in Jon's room now. And I think you miss him'. She does me a thumbs up and scrubs them out with her hand.

She writes Jon once again, very hard with the pen. And then underneath she draws a straight horizontal line, and then three dots in a triangle above it – four shapes formatted into features, like shorthand.



I say, 'is this Cassie? Or is it Jon?' She points to herself.

She writes some of the other names of young people that she lives with on the board. As we look at the names, I become aware of the sadness of the house. The atmosphere is very quiet.

Cassie looks at the board and puts her forefinger beside Jon's name; she taps beside his name and looks up at me. I say, signing, 'you're still thinking about Jon and I think you miss him'. Thumbs up.

She writes on the board – but it's hard to read. 'S-a- and then what looks like a sun: a round circle with some lines coming out of it. I tell her that I'm not sure what it says. She writes it again and I look carefully as she writes it and realise that she is writing 'sad'. 'Sad'. I say to her, 'you're feeling sad about Jon', and I sign 'sad' as I say this, sweeping my flat hand, thumb towards my nose, from my forehead to my chin. She signs it back at me.

Cassie writes 'sad' again, but this time she puts the letter 'u', so it says, 'usad'. I can't work out what she is doing until she points to herself, and I understand that she means 'I'm sad'⁹.

She writes it again 'u sad', and I say, 'It feels sad when we can't see our friends anymore'.

I say, 'I think you miss him'. I think about this for a while and we sit in the stillness together.

I say, 'Let me show you how to write it'. Hand over hand, I help her write 'I' 'Miss' over Jon's name. Underneath that she draws a really sad face.

We sit together and I feel the sadness. It feels sad everywhere. There's a heavy feeling in the air, thickening and settling and beginning to overwhelm.

I say to her, 'Why don't you draw the house?' She scribbles everything out and draws a big sad face.

Sade comes into the room and begins to talk to me from the sofa. The verbal-ness of this interruption, though pedestrian, bests the deeper non-spoken exchange with Cassie, and I cannot find my way back. The spoken conversation with Sade that ensues feels easier, even in its triviality.

Only when something distracts Sade do I find a way back to Cassie, shifting my focus to her and realising that she's been writing the whole time – writing with some fierceness.

She has written: 'U sad, Jon'. And the names of those she shares the house with – she's just kept on going. She's kept writing, then wiping out the words with the side of her hand, and writing them out again, the residue of the names smeared onto her hands in ever-thickening blue stains.

⁹ I interpreted, both from the context, from my experience with other young people, and from the transference, that Cassie was using pronoun reversal. I have tended to understand this as a logical response to the way questions are phrased e.g. 'Are you sad?' 'Yes, you sad').

Sade returns and sits behind me on the window seat, watching on. Cassie continues to talk on the board, but we're not particularly getting anywhere. I'm just sitting with the fact that she misses Jon and I don't know where to go with it anymore. I say to her, 'would you like to draw a picture?' She signs 'yes'. There's no paper to be found, so I pop down to the office and get some paper.

Briefly absenting myself from the scene helps me to once again note the abeyance I feel – an empty space inside me and around me into which I know the conversation needs to go – something is there in the void, though I don't know what it is.

When I come back up, Henry comes to get Sade for something and the two of them leave the room, walking into the corridor.

Cassie watches them go, straining her neck around to watch them leave the room, waiting until their conversation disappears down the corridor. It is at least half an hour before anyone comes back into the room again.

As soon as she is confident that they've left the room, she snaps her attention back to the whiteboard, wipes off all the writing briskly and writes in big letters:



The words feel like they land on me as much as they land on the board. Quietly, letting my words settle like snow looking for dry ground, I say, with all my focus on Cassie: 'You miss Mum and Dad, Cassie. And you feel sad'. We sit with this for a while. Just sit in the weight of it.

After a long pause, signing as I speak: 'Beverley's feeling sad. Because Cassie's feeling sad. Beverley can feel it in her body: it feels like a heavy weight in my chest and a heavy weight in my tummy'.

I sign for her to look as I say this, and press my hands firmly on my chest and then on my tummy. As I do it, she mirrors my actions. I say, 'This is where we can feel sadness'.

I hold her hand in both of mine, and I press it – hard enough for her to feel the weight. 'Sadness feels heavy, like this'. Together we sit in the weight, the heaviness of the sadness as it fills up the space.

She taps her finger on the board next to 'Mum'. I sign on my hand, 'Mum'; she signs back three fingers on two fingers, a mix of the Mum and Dad signs. Together, we hold Mum and Dad in our minds and in our hands.

She taps her forefinger next to 'Dad'. Picking up the pen, she goes back over his name pushing the pen hard onto the board: 'Dad'. I say and sign: 'Cassie's thinking about Dad'.

After a pause: 'Beverley knows a little bit about Cassie's Dad, because Hallie's told me the story'.

I stay quiet for some time, feeling the fragile precarity, the high-stakes, the risk of saying too much, not enough. I mirror her posture, hold the heavy sadness.

She writes 'Hallie' on the other side of the board, away from Mum and Dad and missing them. I say, 'Hallie's your special friend, because she went to see Dad with you. And she saw the things that Cassie saw'. She signs friend.

The sadness thickens around us. Here it is. The great unsaid. Though I am afraid to speak it out, I decide to name what we both know but only I can say, 'When Cassie saw Dad, he was very sick. And now he's died'.

She doesn't respond. And the words hang in the air. We sit there for some time in the silence, letting it shout of absence. After some time, she picks up the pen and writes 'di' on the board.

I remember where this started – with Jon. And I think of the variance of loss – and that when we have a deep, unprocessed loss, the smallest of losses can land like salt in the soreness. I try: 'Jon has moved to another house, so you don't see him so often, but you do see him around. But, Cassie doesn't get to see Dad anymore because he's gone'.

Over my last few words, Cassie opens her mouth wide, a gaping wound, and shouts:

‘Dad, bad, Dad, bad’.

She points at ‘Dad’ on the board and then she points at her mouth.

Like reaching for dandelion clocks in the wind, I am trying to pull together the threads she is letting fly: ‘You’re thinking about Dad’s mouth’. She gives me a thumbs up. ‘Dad was very sick when you saw him.’

She pushes her fingers into her jaw line where her neck meets her jaw bone. She pushes her fingers into the flesh and the bone very hard, then opens her mouth and exhales, as if with great pain: ‘Ahhh’. I listen with my whole self: trying not to miss the nuances of her attending emotion, recollections, fears, hopes...

She brings her fingertips up to her lips and strokes her lips with her forefinger, pushing past her lips to her teeth, letting her fingers bump over the ridges gently. She brings her other hand up to her face, and, with her palms either side of her cheeks, squeezes them in tentatively, looking at me.

Hallie’s account of Cassie’s last visit to see Dad in hospital, told to me just two weeks prior, comes back to me vividly. And I feel like I can almost see him there in the hospital bed. Close to death. With a hole that has opened up in his jaw running right through to his mouth. I recall Hallie’s words, as I watch Cassie squeezing her cheeks:

‘The thing is, Cassie was on the side where she could see the hole in his cheek... when he moved and I saw that hole, I got petrified, because it was really scary...like “oh my god”... I cannot imagine how it was for Cassie... constantly seeing that face’.

I say, ‘When Cassie saw Dad in hospital with Hallie, he had a very poorly mouth’.

She looks so distressed. I begin to feel overwhelmed. ‘These are very big emotions. These are very big feelings.’ I say. I reach slowly for a non-verbal response.

I sign for her to look at me, drawing a line between her eyes and mine with my two fingers. Then, as she watches me, I take the palms of my hands, and I gently stroke them from the back to the front of my cheeks towards my mouth. I don't speak.

She watches me briefly, then mirrors my actions: taking her own hands, she starts to stroke her own cheeks, slowly running her fingers and the tops of her palms along her cheeks. We do this together for a few seconds, looking at each other and I say, 'It's okay, Cassie, it's okay. Your mouth is fine'. I put my hands back down on the table and she continues. She presses her cheeks with her fingers, making circular motions, feeling her gum line, her teeth, the inner workings of her mouth, all intact.

I watch her stroking her cheeks, and then she begins to gather up saliva in her mouth and hold it. I think how it seems that she needs to feel that her mouth is full – to feel the entirety of her mouth, both from the outside but also from the inside. She fills up the whole of her mouth with saliva and when it is full, she opens her mouth a fraction and some of the saliva falls out of her mouth and runs down her chin. I pass her some tissue, but rather than wipe it away, she pushes it back up into her mouth. She keeps her mouth full of saliva for the next 15–20 minutes.

Seeing her cram her mouth with saliva – wanting to have her mouth full of something, anything ... can she plug it full? Will it leak? Is there a hole? – I feel loss and grief as well as the fear of her final visit to Dad. The fear of sickness and the fear of what has happened to him, what might happen to her, mingled in with the loss.

As she sits with her mouth fully explored on the outside and now full from the inside, we think about these things together, without speaking, and time blurs in the presentness of it.

A staff member comes back into the room and the precarious held-space between us is decompressed. The lunch is arriving. I look down at the few small words on the whiteboard between us – and I am filled with anxiety that these precious words on the board, treasure of her grief so raw, will be dismissed or forgotten. Not quite knowing what to do, I say to Cassie: 'Cassie, lunch is coming. Do you want to clean the board so that it's fresh for next time?'

She signs, 'No'. (She does not share my anxiety about her grief on display; it is fierce and fixed enough to be tended sometimes, trampled other

times.) She stands up quickly, grabs the board, and half-runs over to the high chest of drawers and chucks it on the top. Then she walks over to the sofa; looking at it briefly, before throwing herself on the sofa headfirst and turning herself over into a headstand against the wall. Her head is scrunched up on the sofa cushion, her body flopped and leaning jarringly against the wall. She is an upside down bundle of clothes and flesh and hair; impossible to make sense of. Nobody says a word.

After lunch, Cassie settles on the sofa, the remote in one hand and a near-empty bottle of ketchup in the other. The TV has signed itself out and no-one can remember the code. Cassie types 16-digit codes in competently, but to no avail. With the other hand, she squeezes and scrunches the ketchup bottle, poking her fingers in the neck of the bottle, pushing it into her mouth, her tongue digging out the remnants until she has horror-movie smears all over her face. All over her cheeks.

Caleb, an older staff member, who rarely succeeds in hiding his affection for Cassie, comes over and says, 'Come on, go to the toilet'. He assertively pats her shoulder, moving her forward. Cassie slaps her leg hard and shouts 'No'. He tries again. 'No'. She lifts her feet up onto the sofa defiantly.

He leaves the room, returning with a wet cloth. With a gentle smile of concentration, his face leant in close to hers, he gently, firmly works his way around her face – her cheeks, her nose, around her mouth, wiping off the smears of red. She giggles as he does this, looking up into his face. She lifts her hand to his mouth and places the base of her hand over his chin, feeling his stubble. She pushes her fingers in between his lips, trying to push inside his mouth. Caleb jams his lips together tight. Her face takes on a look of concentration as she continues to try to jam her fingers between his lips. Caleb manages a small smile, but keeps his mouth sealed shut tight.

As he gets the last few smears off, she puts the other hand round the back of his head and pulls him into a hug: one arm around his neck, one hand over his mouth that has no hole. He chuckles, reaching down and puts his arms around her shoulder, hugging Cassie into himself gently. She pulls him in close, suddenly brimming over in a high, bursting exclamation:

'Daddy!'

And I swallow a sob bursting in my throat.

Eight: We cannot reach her

Cassie is sitting at the table. There is a Barbie doll with impossibly long legs on the table, bedecked in a sparkly mini dress and plastic pink heels. She has been pulled from the box and lies abandoned on the table. Hallie tells me that they've been out shopping.

'Is this what Cassie bought?' I ask.

Hallie says, 'She wanted to buy a baby doll that you could feed with a bottle and change – you know those ones that are like living babies, and do all sorts of things? But she didn't have the money for it. So she's bought a Barbie doll instead'.

As we talk, Cassie picks up the Barbie sullenly, smoothing back her hair with dissatisfaction.

Jess walks in and hands me three activity books with stickers. 'You can do these with her', she says decisively.

I sit with Cassie and open a book. There's some numbers that are dotted out; I show her how to follow the lines with a pen, and she does the rest competently, compliantly. Turning to the sticker page, she begins to peel back a sticker. It tears as she lifts it. She looks at the half-sticker, with the ragged tear, and sticks it back on the page. Reaching for the next sticker, I reach with her, and help the sticker lift without tearing. She gently but firmly resists my intervention. I watch her slowly, deliberately rip one sticker after another – always down the middle. She begins to make whimpering noises as she does so. Today, although I am next to her, there is no connection between us; she is distant from me in her quiet, benign destruction.

As I listen to the distance between us, I notice a growing sense of her agitation, and a nervousness creeps inside me. I try to check and regulate it, and then realise with a start that I am too close. There is a rage bubbling underneath the quiet agitation – a deep, unnamed maelstrom of something. What I thought was a summer breeze is the edge of a coming monsoon.

Hallie looks over, her face tense with concern, and she seems to read in more definite terms that of which I can only reach around the edges. 'Do you want to go to your room and relax, Cassie?' She looks at me, speaking

across Cassie: 'It's best for her to go to her room when she's like this otherwise she's gonna blow'. Cassie gets up quite readily, and I am grateful for Hallie's well-tuned intuition.

After a while chatting to Hallie, I ask if I should go and see how Cassie's doing. Hallie seems grateful that I can give Cassie my focus, leaving her with breathing space for the other young people in the house.

Cassie is sitting slightly slumped on her bed, feet on the floor, facing the door. The curtains are closed, making the room dingy, but she is clear with me that she does not want them open when I offer. She is also clear that I can stay, and, sensing that she needs my company – or a witness at least – I sit myself on the floor just outside the threshold of her room.

There is a TV cabinet on the wall at the end of the bed; Cassie lifts herself up a little so that she can see the perspex, which dimly mirrors her reflection. She looks at herself with some curiosity, taking herself in, and then, with the suddenness of habit, shoves herself headfirst into the space between the bed and the wall: a rapid and violent upside-down-ness. The gap is maybe a foot wide, and she lands sideways so that she is wedged in the gap, one shoulder pushed up against the wall, the other shoulder against the mattress. Her head is fully upside down looking towards me.

As I look back into her familiar face, it is strange. Her upside-down face is blanked out, she shows no recognition of me. And I barely recognise her – as if I am watching her on a screen. I sense that I don't have any meaning to her in this moment, and she is wiping all meaning from herself, tipping herself upside down and emptying herself out onto the floor.

I look at the shell of her – the form of her person only. There is nothing known about her upside-down face, nothing that feels relatable or connectable. And her body – all misaligned, all angles and shapes, limbs and bits – feels fractured and disjointed; a collection of parts only.

Her eyes remain on mine, but it is of no consequence.

After some time, she rights herself. A short pause to lift herself up again, looking at her dim, shadowy reflection in the TV before tipping herself upside down with great force, posturing herself once more in relation to the furniture and the walls, violently disconnected, tipping the image of

herself – the story of her face – into the gap between the bed and the wall. Meaning is being actively erased: the wiping of a hard-drive. I too feel lost, eviscerated, struggling to hold on to any narrative, my mind blanking out.

Leo wanders around the corner: 'Is she okay?'

'No, I don't think she is.' I don't ever talk about Cassie in front of her, but right now it does not seem to matter if she hears us talking about her. 'But I don't know what's wrong,' I say.

We watch her right herself again. She looks once more at her dim reflection in the TV and begins to move her mouth a little; she pulls her lips into odd contortions before peering briefly inside her mouth, empty of words, and violently throwing herself over. One leg is stuck straight up, taut in the air and leaning on the window, which she begins to intermittently kick and scrape down the window, banging her foot against the frame. It looks painful, but there is some kind of chasm between us making it hard to intervene.

I wince as her foot scrapes and scrapes against the window frame, until I finally check myself and remember I am there; I can respond. I stand up and cross the threshold into her room: 'Cassie, is your foot okay?' I ask, taking it in my hands and checking it carefully. 'Owww', she responds. 'Cassie, you need to look after your feet. Your feet are important.' She stops kicking and scraping and I am so surprised that she responds to this small act of concern. Leo wanders back towards the lounge.

She sits back up, reaching for a hair band on her wrist, pulling the threads carefully with her nails until two little threads unravel and stick out in big loops. Determinedly, she picks at it, though it seems that its brokenness distresses her somehow. I find it inexplicably difficult to watch, as with quiet intensity, I hear her say:

'Don't break it.'

It is the longest phrase I've heard her say, and immediately after she has said it I wonder whether it really happened.

I feel a rending inside me, and I dig deep for an invitation into connection. I remember a hairband I have in my coat pocket and go to get it. I sit back on the floor outside her room and, with it on my wrist, pull at it to loosen a thread. Absentmindedly and quietly, and with only half an eye on Cassie,

I pick enough so that there are some threads sticking out on the side. Cassie looks over at me – and seems to see me briefly – she gives me the littlest smile: a fragile bridge, a brief affinity.

Hallie comes in. ‘Do you want me to open the curtains?’ Cassie signs ‘No’. She asks, ‘Do you want your toys? I could open the toy cupboard?’ Cassie signs ‘No’. She asks again, ‘Shall I open the toy cupboard?’ Cassie flashes her a reluctant thumbs up, and Hallie opens the cupboard, and pulls out a box of books and arts and crafts. Cassie doesn’t move off the bed or look at the things in the box and Hallie goes back to the dining room.

Cassie returns again to her reflection in the TV, followed by overthrowing herself into the gap. She does it over and over again and I feel her distress and her distance. I know that I am losing the narrative of what is happening. My efforts to listen to her, to attune with her, are somehow dulling out clear thought, numbing out my thinking brain, closing off my critical thinking. This insistent self-objectification – the treating of her body as a collection of parts, entangled and muddled together, dismantles purposeful connection and ordered thought.

Leo appears again: ‘I don’t think she’s doing well, Leo,’ I say. ‘But it’s hard to say why.’

He half-whispers: ‘She made a visit last week to see her brother [mouthing the word ‘brother’]; I wonder if it’s about that’. I say, ‘I’ll come and talk to you about it in a bit’. He nods: ‘Probably best’. We whisper these things to each other, as if she doesn’t know that she made a visit to her brother. Despite the bodily rituals taking place in front of us, the obliterating of thoughts from her head that no-one will talk to her about – we double down on it and make sure our conversation is out of her hearing.

About 15 minutes later, Leo and I walk up the corridor out of earshot, and he tells me that Cassie went to meet her brother and Mum last week with a couple of the team. Just before they left, her Mum had got in touch to say she couldn’t make it – she had tested positive for Covid. Hallie had prepared a social story for Cassie about the visit and, with no time to make a new one, had Tippexed out the pictures and words about ‘Mum’. Tippex which Cassie had duly scratched off in the car.

Leo tells me the visit was very positive, but she had come back very unsettled – ‘all the normal things, but up a gear’. His face is worried as he says: ‘It’s difficult to describe as it’s more of a feeling than a behaviour. But the feeling is that something’s wrong’.

He pauses. ‘How do you record something like this on a behaviour chart? Maybe I’m there for an hour with her and I’m able to notice a couple of things. But there must be things that we’re missing between us. And overall – she’s not right. We know she isn’t. But it’s far more of a feeling than data or a fact.’

He is right. How does the deep sense that something is wrong get recorded on a behaviour chart? How do we translate an atmosphere into a story, or verbalise that for which there are no words?

Leo is wondering out loud about this: ‘I’m sure that this is about her missing people. Who’s to say that this isn’t as much about D-A-D as M-U-M? Maybe she still thinks about him’. He continues: ‘You know, if what’s going on for Cassie is a reaction to missing her Mum and the death of her father, then that’s a lot more complicated, but it’s also a lot more relatable.’

I think about this relatable-ness. We cannot ‘reach’ her in the moment, but maybe we can relate to choosing to make ourselves unreachable in a dark moment – to cutting everyone out and tipping ourselves upside down to shut out the world?

We head back to Cassie’s bedroom door to find her standing on the bed. Around her on the bed are a number of cardboard-paged books which she has ripped in two so that the thick card pages lie scattered around her. There is a gap between the window and the Perspex that covers it, and she is working on posting one of these cardboard pages into the gap. There are other pages which have been posted all around the edges of the window. Though her back is to me, I can sense that she’s really pleased with this work, as the story book is dismantled and posted into available gaps.

She reaches up to a page sticking out of the gap at the top. She begins to wiggle it, trying to force it all the way through. There’s not enough space for it to go through, but she tries her best. There is a slightly gleeful, manic energy to her work, as she drives the ripped pages through the gaps – and a sense of accomplishment at this something that she can do upright, towering over her space, powerful and big.

Leo leans on the doorframe. He nods towards some laminated photos that are Blu-tacked on the wall: I see a photo of Cassie, happy and smiling in a new Disney hoodie. Leo says, 'I don't know whether they're helping'. I look again, and see that these are from the day of the visit. Most are of the process: Cassie on the bus, eating a McDonalds, smiling for the camera. But there are two photos of her with her brother. He has his hood pulled over his angular face, as he slouches over the table where they are sat. Cassie is holding a baby doll, the sort that you can feed and change. Hallie tells me later that her brother spent the visit showing Cassie how to look after the baby doll.

The photos have been Blu-tacked up in a higgledy-piggledy way. I look at them and turn to Cassie, signing: 'Cassie, look. Look'. I wait for her to turn in my direction. 'Cassie, these pictures will come off the wall. And you can take them off if you want to'. I show her that they can come off the wall, and she can stick them back on again.

As I'm saying this, Leo and my concern that these are 'reminders' of last week suddenly seem ridiculous. She can take the pictures off the wall, but she cannot stop thinking about it – it is overwhelmingly present.

Cassie ignores me, reaching instead into the box on the floor; she picks up a blue heart made of crafting foam. Holding it with two hands, she slowly and intentionally rips it in half, pulling hard on the two pieces, and watching it tear. Then she rips another piece off so it is in three pieces. It's so caricatured it feels unreal.

I feel very small and shallow; overwhelmed and not big enough for her.

Nine (same day): Here we are

Hallie has finally coaxed Cassie out of her room with a snack, and now we are sitting in the dining room with Asher and Henry, two staff who don't know her so well. Caleb is around as well, but he has disappeared into the office as there are so many of us. Everyone else has gone out on the bus. Henry's attempts to occupy Cassie with activities have waned fast and we are sitting in silence, not sure what to do with a girl who doesn't want to do anything.

Cassie begins to cry softly to herself. Asher leans in towards me and says quietly: 'It's because the others have gone out on the bus and she hasn't'. I reply, 'It isn't; she's been sad all day'. I gesture for him to come into the corridor and continue: 'She saw her family last week, but Mum didn't come'. Asher considers this, thoughtfully: 'Oh okay. Because sometimes it is the bus'.

Cassie turns to the side so that she is hanging on to the back of the dining chair; she leans her chin on her hands and lets the tears fall down her cheeks. I crouch down next to her: 'Cassie, you're feeling very sad'. Cassie lifts a flat hand up 90 degrees to her nose, thumb inwards, and draws her hand down her face slowly signing 'sad' and once again 'sad' in line with the downward trajectory of her tears.

'Do you want to write or draw?' I ask. Thumb up. I place the whiteboard on the table and turn to open the tall cupboard behind us to get some pens. As I turn the key in the door, she leaps up and runs over, pushing herself into the gap between me and the open cupboard door, positioning herself so that I cannot close the cupboard.

She begins to scan the contents. It's full: four shelves of folders, paper, pens, stationery, cleaning products and various detritus. Her hands flutter in front of her, moving towards the contents of the cupboard uncertainly and back again; she whimpers, fighting herself as to whether to reach out or not, her whole body seemingly caught in the conflict. I can't identify what the dilemma is for her, but it feels high stakes.

She makes a sudden move, grabbing up a much fatter communication book than her own. It has lots of pages with dozens of symbols and photos. She scampers over to the sofa with agitated murmurs as if she has stolen it. She puts the book on her knees, and with little cries and moans, begins to scan through it, page by page, examining each picture carefully.

I sit on the arm of the sofa next to her: 'You want to tell us something, Cassie'. She flicks through and pulls out a small symbol. Underneath it says 'Life story'.

I feel a stab in my chest and say quietly: 'You're thinking about your life story, the story of your life'.

She doesn't acknowledge me, scanning carefully through the pictures, past photos of staff, pictures of activities, bathrooms and snacks, all the mundane things of life, searching desperately until she finds a picture of a sofa and chair. Underneath is written: 'Family room'. It is the only card that has the word family on it.

She jabs her forefinger on the family room card, one, two, three jabs, and wails. I say, 'Okay Cassie, well done. That's really good communication. You're thinking about family'.

Cassie cries. Big tears are coursing down her cheeks with sobs and then wails. I feel Asher's hover of uncertainty next to me – his not knowing what to do, his confusion.

I say, 'Cassie, let me tell you what I know. Leo told me about your visit. Beverley knows that you saw your brother last week – you saw Harry. Who do you want to talk about? Do you want to talk about Dad or Mum or Harry? [signing Dad, Mum and H]. Without missing a beat, she signs back H and Mum. 'Okay Cassie, well done. So you want to talk about Harry and Mum. Beverley knows that last week, you saw Harry. You went out on the bus to meet him, you had lunch together, and you had a baby doll to look after whilst you were there'. She points to the TV symbol, 'You also watched some TV'. I sense the importance to her of getting the story straight, telling it with accuracy. Cassie signs Mum again.

I say, 'Beverley knows that Mum wasn't able to make it. You weren't able to see Mum'. Cassie lets out a huge sob, the tears pour down her cheeks and she follows them with her flat hand, signing slowly 'sad', 'sad', 'sad'. The frantic searching has broken through into something found. And it is simply this: Cassie is sad, sad, sad.

All day, I've not been able to connect with her: she has cut herself off from her emotions, and with it, I have been cut off too. But, here we are.

The numbing, the emptying, the destroying has brought us here to this loss, which has been all around us, too big to name, too sharp to connect over, too difficult to feel. It has been seen dimly in the reflection in the TV and then deposited into the gap between the bed and the wall, posted into the gaps in the window frame. And the loss, the deep ripping loss has been torn into stickers and hairbands and feet and books and foam hearts. Retold and discarded. Retold and discarded. Retold and discarded.

But here we are.

Together.

I am crouched in front of her, our eyes are level, my heart is rent open, and she fixes her crumpled face on me, her eyes intensely locked onto mine and she signs over and over, as the tears pour down her cheeks amidst wails and sobs. Sad. Sad. Sad. The fragile bridge between the two of us is just big enough to let the waves of sorrow flow under and not break. We are holding it together.

But then the noise and the emotion fill the room like a huge wave arching over us, threatening to crush us as I say: 'Cassie didn't get to see Mum. And that's very sad'. She cries and cries as I say so slowly: 'Cassie misses Mum'. The noise coming out of her feels huge – a roar of sadness that tears at me. I am struggling to hold back my own tears, and then suddenly decide not to. 'When Cassie feels this sad, Beverley feels very sad as well'. As I say this, her chin juts forward, her face is fixed on me, her eyes bore into me.

I say and sign to her with slow deliberateness, 'Cassie, these are very big feelings. We have talked about big feelings before. And this is a very big sadness. And it feels like it takes over your body and your mind, because this is a big, strong sadness.'

She is absolutely fixed on me as I say this, her eyes absolutely locked in with mine. Everything is full of loss as I let all of her body-feelings in and there are no more words for it – but this, this shared sadness, this is everything.

A guttural yell of grief erupts from her, filling the room.

It's so big and I feel like I'm going under.

Caleb is running into the room, like the yell is a siren: 'What's going on? What's wrong? What's happened, Cassie?' He almost leaps on her like he is her personal lifeboat, throwing himself down on the sofa next to her, 'What's

wrong, Cassie? What's happened? Tell me what's happened. Don't be sad.' Asher, suddenly released from his paralysis, runs over to grab some tissue, making it into a big ball; he wipes all over her face with it, soaking up all the tears. Caleb continues: 'Come on, princess. Cheer up. Where's that smile gone? What do you want? Do you want to watch the TV?' Cassie puts her thumb up. He hands her the remote and she carefully types in 'Simpsons' and chooses an episode. She watches one episode after another, watching for a few minutes before skipping forward to the ending and then watching another.

I watch as Caleb smooths over all the sadness that is too painful for him. But it's okay. Asher and Cassie and I had reached capacity, and seeing Caleb arriving as a father and protector, making it all alright again, I know she needs it. She needs to watch a funny yellow family for a while, skipping to the end of the story over and over, to check that it always resolves.

She watches with the aftershock sobs catching on her breath still; each time Caleb squeezes her tightly around the shoulders, drawing her into himself, and wiping his hand across her face to brush away the tears: 'Come on, princess, where's that smile?' He jollies her back onto the surface, and away from unbearable sadness, with gentleness and kindness. And I'm glad for teams, for timing, and for father figures.

And whilst there's a part of me that knows that the sadness got wiped away with tissues and TV because it was unbearable, not for Cassie, but for the house, for the team, maybe somehow for the organisation, I can't find it in myself to resent it. For a short time, Cassie and I rode the waves of her grief together, let it wash around us and let the flood waters rise. And just as the sudden and desperate rescue cannot be undone, neither can our shared swimming in the flood waters. She knows these things can be borne when they're shared; and so do I.

I sit with them until it's time for me to leave, meeting her forceful 'No' at my announced departure with the assurance that I will keep her in mind whilst I'm away. She does not resist me leaving on these terms, but as I walk away, I feel the draw to stay like a thread pulling taut between her and me.

Loss connects us.

The things that make sense of life for us – meaning, connection, purpose – germinate in the places of shared pain. This helps us remember that the connections we search for often happen not in spite of pain, but, if we can find a way to stay with each other in these moments, because of it.

Ten: Taming the waters that overwhelm us

It's 2pm and Cassie is going swimming. Leo says to me: 'If you've got your kit, you can go in', and I remember it's in the car and go to get it, meeting them at the pool.

I change quickly and wait on the poolside for Cassie. She slowly walks the steps down into the water, and reaches for the side of the pool. She holds on with both hands, looking as if she is not going to move. I walk over: 'Come on, let's go for a swim, put your hand on my shoulder'. Instead, she grabs a hold of me with both hands, and goes to do the same with her legs; I push her off gently, encouraging her to hold on around my shoulders. Jess says gently, 'Why are you being a limpet today?' We swim around awkwardly for a bit; I am an anchor to hold on to only.

Then slowly, almost imperceptibly, I begin to sense a connection between us: occasional eye-contact, a small smile, and I notice that she sees me again. There is a beach ball and we push it between us a little, but if she lets go of me she tends to head for the side again. I leave her to hold the side a bit, and she slowly pulls herself around the edge of the pool, until I notice her stretching one leg up onto the side as well. 'Get out if you want to. That's fine', I say. She hauls herself out the water and sits on the side with her legs dangling, toes dancing on the surface of the pool. I watch as she slowly leans her head right over further and further until it is upside down in the water. Then, unexpectedly, she rolls herself forward, tipping the weight of herself over her head until she plonks into the water with a big splash just in front of me. She surfaces and swims with some franticness to the side – where, once again, she raises a leg and heaves herself up out of the water.

I get out too and sit next to her, my legs dangling in the water. 'Let's do it together', I suggest. Slowly, I count to three and as soon as I say 'three' she's tumbles herself in; I am well behind her as I follow her lead. We do this a few times, and I move to 'ready, steady, go', feeling her concentration, her anticipation, as we count into the splash. Slowly, together, we set some form, some meaning, some connection around the upside down-ness.

On the fourth time of doing it, I try: 'Do you want to stand up and jump? We'll jump in this time'. She gets straight to her feet and we stand on the side together, both looking into the water which seems a long way away now.

I offer my hand and she takes it. 'Ready... steady...' I feel her firmly rooted to the spot. We go again: 'Ready... steady...go!'. I jump in, leaving her behind. I clamber out and retake my position. She holds my hand and I can feel the tension in her, the worry that I'll pull her in. I say slowly: 'Relax; relax and breathe'. I relax my arm so she can feel the looseness. I slow my breathing and feel her arm relax, hear her breathing slow intentionally.

Holding her body taut, she leans over, tipping herself into the water like the toppling of a statue. I jump with her, and we surface together and head to the side, ready to go again. This time, I try to imitate her tipping, toppling fall into the water, sensing the hardness of the water as it meets me, the loss of control as the fall inescapably sets in.

We are back on the side, standing side by side, the anticipation of the next topple high in our bodies. 'Ready... steady...' I say slowly, my tone rising at the end of each word. Cassie rolls her arms forward in a sudden movement, fists clenched, the movement of jumping swinging through her body: 'Go! Go!' Her voice unexpectedly piercing the air, as her feet stay very much on the ground.

I smile at the halted leap of faith. She is fully focused on this – this risk, this brief abandonment of control – this move from solid ground to chlorinated liquid via thin air. I smile at the pep-talking, at the burst of verbal encouragement to herself. I smile that she defies it, feet rooted on the side.

We stand together, her arms occasionally swinging fiercely forward in determined and then terminated flight – until she is suddenly sailing through the air, not a tip, but a jump, as I follow her in flight and splash-landing.

Agency found, she has translated her falling into flying, and it is glorious.

Henry comes over and tells me it's time to get out. On cue, I relay the message unnecessarily to Cassie. She is holding onto the side next to me. She looks me in the eye and says with great vehemence: 'No! No!', signing sharply with the back of her hand against her face. I largely agree with Cassie, but maintain eye contact and say: 'Five more minutes, and then we're going to get out'. Thumbs up. 'You want to jump off again?'

We jump off together again and again for much more than five minutes until I say it is the last jump. She stands on the side for a very long time,

playing at needing to work herself up to it. But I am next to her and there is no tension anymore. Just traditional stalling at an imminent ending. This too, I feel great affection for.

Finally, she makes an almighty jump into the water and we surface together. The journey has been a good one – the water changing from something to roll into upside down, like an inevitable force, to something to fall prone into so it smacks the body punishingly, to, finally, something to smash through, feet-first, with defiance and zeal. What to do with the things that scare us, I think. And to do it together. Only together we can tame the waters that threaten to overwhelm us. And to Cassie I find myself saying: 'I'm so proud of you'. It pops out before I know it. 'Let's go and get changed and you can have a break'. She gives me a thumbs up, reaches for my hand, and we walk slowly out of the pool together.

It's time to go. Cassie has had some help from Henry to get dried and dressed and is hovering in the foyer of the swimming pool, showing no signs of leaving. Henry is trying to coax her out the door. I ask her, 'Are you coming back for break?' 'No,' she says. 'Are you staying here all day?' I ask, forgetting the redundancy of rhetoric. I see her do a thumbs up from inside her pocket.

After some time, she leaves the building reluctantly, but with the sense that she is barely listening to either of us. She gives out an air of being determinedly decided – digging her heels in somehow, or taking a stand, although it isn't clear about what or why.

We get to the gate of the garden and Henry is fiddling with the lock. He can't get it open. As he focuses, Cassie reaches out and grabs his top, winding her fingers into the material and pulling. She is stoic; not aerated, not upset.

She reaches the other hand out and grabs the collar of his zip-up top. 'Stop doing that, please', says Henry calmly. She tightens her grip, twisting the clothing around her hands and fingers. 'Can you stop so that I can open the gate?' She is pulling at his clothing, really pulling now. No aggression, but resolve.

I step forward: 'What are you doing? What is it that you want?' She pulls harder on his clothing; Henry continues to ask her to stop, remaining calmly stoic himself. But I note that there is an undertow of embarrassment for him as his shoulder and then his chest are bared.

I position myself between her and him so that I can talk to her, and with my back to Henry. She leans her face onto my fluffy coat and snuggles her head in.

I talk to her about what she's doing, noting that she's in a reasoning frame of mind. This is not a fight-flight moment. She's intent, decided, thought-through.

What do these moments mean for her? I wonder. She is pulling back Henry's clothing, leaving him exposed and ensnared. She holds his clothing like it is an anchor, twisting her hands up into the material, making it knot around her hand and fist. She pulls it as tight and taut as she can, locking him in close, tethering him.

It's not a fight – but it is a hold. I will hold you by your clothing: it is no longer something to protect or cover your body, instead it is something to make you tethered and captive.

I look her in the eye and say, 'Cassie'. Her hair is hanging in water-soaked clumps around her face. I am speaking gently, sweeping her wet hair back from her face with my finger tip and tucking it slowly behind her ears so she can see me. 'Cassie. What is it that you want?'

Even as I'm saying this, I feel bombarded with the many, many experiences she will have had of people – people she knows well and doesn't – helping her to dress and undress with a range of attitudes from kind patience, to a job to be done, and the rest. How many times has somebody, without reference to her or without her choice, pulled at her clothing when she wasn't ready? How many times has she resisted someone's 'help' in undressing? All of these questions hit me at once as I'm saying 'It's rude to pull at someone's clothing'. The deep injustice of what I'm saying lands in me, and I feel instant regret.

We take our time, she loosens her grip and soon Henry is free. 'Come on, let's go back to the house. And you can have a drink and a snack'. We walk back slowly together. And I try again: 'Cassie, it isn't nice for Henry if you pull his clothes.' And then I say, because I can't let it go in my mind: 'Cassie, if that has ever happened to you – if anyone has ever pulled at your clothes like that – then I'm so sorry because that wasn't right'.

She is thoughtful, with her arm in mine. She changes course and directs me towards a small walk-on trampoline across the garden. I step on it after her and she bounces up and down solemnly for a bit, holding my hands so I bounce with her, regulating slowly.

We're back in the lounge and it's time for me to go. I crouch down so we're eye to eye. 'Cassie, thank you for today. It's time for me to go home now. I'll be back next week – that's when I'll see you.' As I'm talking, she stretches out her hand, and gently sweeps my wet hair back from my face with her finger tip, tucking it slowly behind my ears.

'Thank you, Cassie. That's so kind.'

A rich, relational day of mirroring each other and back again. It's the first relational move a baby makes, part of the bedrock of human connection – these shared experiences, shared moments, mirrored actions. It moves me. Her instinctive reciprocation and connection moves me. And I remember how much we say without words. The tucking of hair behind ears, the smashing of water with feet, the anchoring of another by their clothing: and we make sense of it as we are seen, as we are listened to and seen.

Eleven: The lightness of her

Esther comes in the room holding Cassie's pink tablet. She hasn't seen it for some months whilst it's been fixed. 'Don't break it, Cassie', Esther says firmly.

Cassie grabs it, flicks to YouTube and immediately begins typing carefully into the search bar. I ask if I can sit with her and look over at the iPad. I watch with her as a man in a Spiderman suit on a beach plants three Spiderman heads into the sand before pouring Coke into them. It's a slow process, with different fizzy drinks being opened and poured into heads. And then the man pours another liquid in along with Mentos, prompting a huge explosion of foam that comes shooting out of the heads. Cassie watches carefully and clicks on the next video. This time a teddy bear face is traced out on sand. The Spiderman pours in a variety of things: different coloured beads, different coloured fizzy drinks and then finally the Mentos. Foam shoots into the air out of the teddy bear face.

Cassie has the iPad for half an hour. Over and over again we watch foam exploding out of heads. I feel like my eyes are wide like saucers and my own head is exploding with what she is choosing to watch with me.

Esther tells Cassie that there are five minutes to go, then later two minutes and one minute. Finally, she is standing over us and reaching for the iPad. Just before she takes it, Cassie reaches out to the screen and shoots the video forward so that we watch the foam exploding on the screen as Esther grabs the iPad out of her hands.

We are out in the minibus. We've been for a walk in the countryside, and Cassie has trundled along with me quite nicely, but she's been a bit out of sorts with others, grabbing Asher's top a few times whilst we were walking, and grabbing the hair of a staff member before we set out. She sits on the front seat and a staff member sitting behind her hands her a couple of biscuits. Cassie takes the biscuits, puts one in her mouth, doesn't bite and her face crumples. She thumps the side of the bus with her fist and makes loud crying noises, though there are no tears. I look over: 'Oh, Cassie!' I feel for her general state of confusion and irritation. I get out her bottle of water from her bag and pass it to her. She takes it and the sounds of crying give way to real tears.

I move to sit down next to her, despite the warning glances of the team around me, and put my seatbelt on. I put my arm around her shoulder, saying, 'Oh, Cassie – you're really having a good cry. Are you feeling sad?' She flashes the sign 'sad' and begins to wail.

She moves her head closer to mine, leaning in. I watch her curiously, and then notice her reflection in the perspex behind the driver: she is looking at herself crying. I turn my attention to her reflection: 'You can see how sad your face is. You can see the tears going down your cheeks. Have a good look'. She peers at herself closely.

After a while, I say to her quietly and slowly, signing, 'I wonder what you're thinking about, Cassie? Are you thinking about something?' She gives me a thumbs up. 'I wonder if you're thinking about family?' Immediate thumbs up. I ask, 'Can you sign and tell me who you're thinking about?' She doesn't respond.

After a while I venture: 'Beverley has been thinking about the conversation that we had two weeks ago – that you were able to talk about Harry and Mum. And you were very sad. And it was a very big emotion, a very big feeling. And it was very powerful in the room – and Beverley could feel it as well'. She puts her thumb up in response. I note the unusualness of this – she tends to only respond 'yes/no' to closed questions. I take this to mean, 'Yes, I remember as well'.

I continue: 'I've been thinking a lot about that. And I'm also thinking about the videos you watched this afternoon: how we watched all those different heads exploding'. I wait for a bit. Cassie is still crying, but quietly; she is listening. I feel the connection between us as we talk.

'That's a bit like how it feels sometimes – we have one more thing in our heads and it feels like we're going to explode. And last week, you didn't explode – you had a good cry, you did some talking and some thinking and Beverley was able to feel what you were feeling.' She does a thumbs up, the crying abates and I feel her calming.

I take my arm off her shoulder and put it on my lap, inviting a more parallel conversation. I continue: 'Beverley has been thinking – because she's not here every day. It seems like we need to find someone that you can talk to regularly about the way you're feeling. It's better for you to talk and share it, rather than explode, like the videos we watched'.

'Can you think of anyone that you could talk to regularly?' She folds her arms, tucking her signing hands away. The silent treatment. I say, 'yeah, there isn't really anyone; I get that'.

We sit for a while. I offer: 'I wonder if you could talk to Jenny¹⁰?' I watch her tuck her arms in more tightly, folding herself up a little further. I say, 'Yes. You don't know whether you can talk to Jenny, do you? Because I don't think you've had those conversations yet'.

'Would you be happy for Beverley to talk to Jenny about the things you've been sharing with me?' She thinks about this and gives me a thumbs up. I say, 'Thank you, Cassie. That's very helpful, because I'd like you to have someone else to talk to'. I feel heavy as I say this; it's not what I am saying, but what I am not saying. And it sits between us.

We are both quiet after this, but as the journey goes on, Cassie begins to get a little giggly – a happiness coming from somewhere, but with a slight edge on it. When we arrive, she sits on the bus, watching everyone else get off, like she has no intention of moving. But I stand to get off, descending the couple of minibus steps, and note she gets up behind me. I decide to make little of it, and so I wait with my back to her, so she can use my shoulder or arm to rest on as she gets off if she wants.

I suddenly feel her two arms around my shoulders, as she throws herself off the bus and onto my back. Her full weight is across my back, her arms around my shoulders now, her head planted into my neck as she giggles and giggles. Leo says in surprise, 'No, Cassie! You mustn't do that'. But she doesn't feel burdensome somehow. It feels like playing – like boundary-pushing, sure. But I find myself laughing with her, as she untangles herself and finds the floor with her feet. 'That was a funny thing to do, Cassie', I chuckle with her.

Later on, I find myself reflecting on the lightness in her, and the lightness of her. I feel hopeful for a way forward for her – that perhaps she can find someone else to continue these conversations with. But I also note her resistance; she will not readily 'let me go' – planting herself across my back and around my neck, as a gentle resistance of my thinking of who else she might talk to, and my coming departure.

¹⁰ Jenny was a staff member Cassie had known for a lot of years, but who wasn't involved in any direct care with Cassie. I had met Jenny and felt that her role, her aptitude for connection and her relationship with Cassie made her a good person for Cassie.

Twelve: Her capture of me

Cassie is sitting with a therapist on the floor, engaged in their work together. I watch for a bit, reluctant to interrupt. Jess looks over at me and I smile at her. 'It's so sad,' she says to me quietly, 'Why can't you just stay?' I smile back at her.

As the therapist gathers her things together, I wander over, smiling. 'Hello, Cassie, I didn't want to distract you. Shall I sit down here?' I indicate the spot that the therapist has just vacated.

Cassie jabs the empty space between where I am standing and the floor next to her. She has a clinical mask over her mouth, but I can see her cheeks are bloated. I say lightly, 'I think you've got something in your mouth'. She looks at me and growls a warning quietly.

She is holding a CD and using the back of it as a mirror, into which she peers, sometimes pulling the mask down a little to look at the fullness of her mouth, the roundness of her cheeks pushed out.

It's soon time to head back for snack, and with irritable grumblings, Cassie pulls her Ugg boots on and gets up. I stand next to her, my arm out to take, but she puts her head down and makes a charging gallop towards the door, her rucksack heaving up and down on her back. As she reaches the door, she tips herself upside down and the rucksack collapses over her head, pulling her shoulders down towards the floor. I put my hand on her shoulder, 'Come on, Cassie'. She flings the bag back with her shoulders as she stands abruptly, careering forward and out of the door. The bag thumps on her back and she is suddenly huge and loud and furious.

She arrives upstairs, flinging off her boots and bag and sitting on the sofa. 'Can I sit next to you?' I ask, indicating to the seat next to her. Thumbs up. She is making occasional gruff, shouty noises, irritated bursts of sound. I say, 'You sound upset, maybe angry'. I sign 'angry'. Her breathing is laboured and shows no sign of abating.

I say, 'Cassie, you sound really wound up. Can you do some deep breaths with me?' I begin to breathe in and out really slowly, with exaggerated sound. She watches my chest rise with the inhalation and then sees me blow the air out of my mouth; and as she watches, she slows her own breathing. She pulls her mask down to look at me and I see that her mouth is still absolutely full.

'Your mouth is full. What have you got in your mouth?' She makes an angry noise. Jess looks over and says encouragingly, 'Cassie, tell Beverley where you've been today'. Jess tells me that Cassie has been visiting another house – and that she is moving there in two weeks. It is just across the site, but it will be with a new team and new peers. She will have more space, an en-suite, and a peer group closer to her age.

I begin to realise that Cassie's signs of overwhelm may be connected to the upcoming move, and decide to ask Jess about it as a way of helping Cassie listen again to what is going to happen.

'When's she moving?'

'21st of February'.

'A big lead-in time then?'

'Yeah, we popped over on Monday and Tuesday, we had a snack there. Wednesday, we stayed a bit longer. We're doing a little bit more every day.' She pauses. 'They're also coming over and seeing her routines and so on in the evenings.'

Jess continues, 'It's so sad. We're sad that she has to go and we want to keep her. But I think it is time for her to move on'. I ask, 'How is her bedroom there?' She says, 'Yeah, it's really beautiful, actually. She's got her own bathroom. She's got a really big room, and it's really nice. She's got her name above the door already. It seems like she should have her own space. She hasn't really got that here'.

I hold the question burning inside me about how Cassie is feeling about the move. These are not my conversations to have anymore. This is my goodbye visit. Not a visit to start a whole new conversation.

Jess continues, 'She's been really emotional about it. There have been lots of tears'. She pauses, 'You know, she went over the other day, and then she and I went out for a meal. And we had a really lovely time. We went to Matalan and she chose a new jumper. But then she cried all the way home. Sometimes she doesn't want to leave the new place, because she's just not able to take it in. She's very emotional'.

I note the ease with which Jess can talk about this loss, that they are orchestrating and overseeing for Cassie, and I wonder about the struggle to talk about and hold the losses that they have not overseen and orchestrated. I remember that sometimes we enact smaller losses to root and rehearse the feelings connected to the loss we cannot hold or bear; we manage the overwhelm of things we cannot control by enacting and then holding something we can.

I sit quietly, noticing that Cassie has been quietening since we started to talk. She is looking at herself in the CD. As she listens, she pulls her mask back and tips her head back, opening her mouth wide. Her mouth is full of water – as full as it's possible to be while still being able to open your mouth. She juts her bottom lip out to contain the water, hovering the water right on the edge of her mouth so she can contain it all. Having taken a good look, she shuts her mouth again, puffing out her cheeks to store the water. Her mouth looks bloated. Her face looks bloated. Bloated with precarity, the too-much-ness, the likelihood of it all overflowing everywhere, the overwhelm of things outside her control, held in water she can control.

I say: 'I think you feel very full, Cassie. I think it feels like you're really full of so many things that are happening'.

She is called over to lunch, where she eats with her usual pace and insistence – pouring food into her mouth as if to fill a vacuum. I chat to Caleb over lunch, making a point of telling him – and reminding Cassie – that, after eight months, this is my last visit. She stays at the table when she has finished. I ask her if she wants some more water and pass her the jug. She pours slowly, concentrating, until the cup is full – the water domed over the edges of the cup, stretching into a convex bubble over the rim. She lowers her eyes to the level of the water, looking at it carefully, before extending her lips slightly to slurp the top of the water. Everything is full up today: absolutely full.

Reluctantly, I get the gift bag I've brought in for her. 'I bought you some things: I want to say thank you for helping me'. I take the card out of the envelope and show her how to open it so the audio message plays.

'Hi Cassie, Thank you so much for being part of my research project.

It has been very special that you have chosen to share the things you're thinking and feeling. I have learnt so much from you. I will be writing about the things I've learnt so that other people can understand a little better about young people's emotional lives and how they experience the world.

I'm wishing you all the best. Take care and thank you again. Beverley.'

As the message plays, I watch her face change. The boundary-pushing of the full mouth, full cup, full tummy, fullness drops away and is replaced by a face that slowly comes into rest. Cassie's eyes focus on the middle distance, and she looks, suddenly, much older.

My message, spoken as to a peer, calls forth her older self. Something of the depth of her comes over her face. Something of her great capacity to think, to reflect, to consider. And I find myself realising a connection with Cassie the adult: here I am, and there she is, and we are just two people – not a child and an adult, not a researcher and a participant. Two people, sharing space and time and being.

She has listened to it once with great thought. And now she listens to it again. And again. She picks up the card and pushes it against her ear, as if to push the sound into her ear and block out the rest.

She puts the card down again open in front of her and begins to poke at the recording mechanism underneath the card. Gently, she pulls back the card that is stuck over it, and peers inside, looking at the small mechanism. She pushes her fingers in between the stuck down pieces of card. I say, 'Cassie, if you break the card, it won't play the message anymore'. She puts it down on the table again and looks at it. But her curiosity is piqued and she pushes at the recording mechanism again, finding the recording button. She presses it and I hear it beep. Noticing that my careful goodbye is not going to make it, I show her how to hold it down and record a new message. I encourage her to use her voice, to make sounds as the button is pressed.

We listen back to her sounds and my chatter and she laughs and laughs at it. Then she holds the button down again. When we listen back it is a recording of me laughing. She plays it back once and then another time and then another. By the time we're done the card is covered in smears

from her sticky hands, ripped and torn, with a poor recording of my laughter. This is her capture of me: erasing my thought-through goodbye with the sound of a laugh I did not notice she was recording. Perhaps some small reciprocation for the things of her she did not notice I was recording, and which I am now recounting.

I show her the Coke-bottle-shaped poppit, reminding her of the videos we watched together of the Coke and Mentos mixture pouring out of people's heads. She gets to work popping the circles in and out, and I reach over and pop some with her. The next time I reach out, she moves it slightly away from me. And finally, when I reach out my hand to pop a circle, her hand meets mine and very gently moves my hand away. A slow but definite transfer of ownership.

The envelope is on the table between us. I write her name on the envelope and my name below it. She writes her name and points to herself, and then points to my name and waves at it. I say, 'That's right. This is my Goodbye visit today'. We sit at the table quietly together. And then it's time for her to go to a lesson in the library and a therapist comes to take her there and she's gone.

And I go home. And there are no plans to go back. But I'm full, like Cassie. I can't take any more in. And Cassie, knowing that I was going, stopped her mouth today, acknowledging that this was not a day for talking and sharing and questions and emotions. No, it was a day for goodbyes and the anger of them, and the laughter of our connection.

And my carefully thought-through goodbye gets deleted, ripped up, messed up, so I don't get to finish it the way I want, leaving her with carefully constructed 'thank yous' and 'goodbyes'. No, she deletes the message, anonymising me, just like I will anonymise her in my writings. And instead she records my laugh, my warmth. This will do better.

And what stays with me is my moment with adult Cassie – even as her adolescence oscillates her in and out of childhood and adulthood and back again. A moment of her being a person, and me being a person, and being together in the simplicity of all of that. These moments where all our differences and otherness falls away, and we are just two humans. Two humans who have found a mostly wordless, shared, rich connection, that is shored up inside me, and maybe in Cassie too, even as our lives separate.

I had feared this ending, this loss for both of us. But it was loss that connected us – and Cassie's willingness to share it with me that brought us together. And my departure has been swallowed up by the grief of her moving from one house to another, and any sadness she has felt merges like a stream into the sea of the many sadnesses she has and is navigating.

And I leave, not confident, but hopeful that the roar of her grief will be met by the roar of her resilience. Knowing that she is hard-wired for connection, and will find others to connect with, not in spite of, but inside of her grief, magnetising the few others that cross her path who can swim with her in those deep waters.

And she will be loved. Please God, she will be loved.

Part Three

Owen's Story

Prologue: This is Owen

Climbing the stairs, I look up as I reach the top step to see a tall, wiry young man flick his head around, startled to see me. He is emitting a spiky vocal sound like radio static that walls the space around him. He has a stuffed teddy in one hand, which he flicks back and forth intermittently and with detachment.

Jane is following close behind me. 'This is Owen', she says quietly. 'Just ... stay back a moment.'

I leave one foot on the final step, waiting – an offer of retreat. It feels as if those around me have frozen, the world paused for Owen's response.

I meet Owen's accusing stare with a small smile. He is still: the effort of meeting my gaze requiring the whole of his being. Then he launches forward suddenly – his hand flashes out, finding my forearm and pulling me assertively towards him.

Against my instinct, I relax my arm, returning his gaze as he pulls me close. I step into the proximity he demands; he is now well inside my personal space. He keeps his hand on my arm, possessively. Slowly, I speak into the small space we share: 'Hello, Owen. I'm Beverley. I'm hoping to spend some time with you in the coming months.' He listens, his head swinging gently from side to side.

I hear Jane, behind me, begin to climb the remaining stairs to the top. Owen pushes his free hand out straight, waving her urgently away. 'Ooop', I hear her say to herself as she stops: 'He doesn't want me'.

Owen demands my complete attention. He concentrates himself on me, less with his gaze, but – more significantly – with his listening. He listens less with his ears, which he continues to fill intermittently with his low, growling hum; rather, he listens with his hand on my arm, which reads my response, my heart rate, my skin, my regulation. He reads me like Braille and, as he does so, I begin to suspect he is trying to answer a question about me, something like: is she safe?

Am I safe? I wonder, as the imperative for me to answer this question rises.

As Owen asks it, he intimidates me, offering out fear, like a temptation to resist.

He is not safe, I am learning.

I learn it from his closeness, the growl, his hand on my arm, his hypervigilance.

But I also learn it from the space around us: from the frozen responses and holding of breaths of the staff, from the deathly quiet encompassing us, from the overwhelming sense that something terrible is about to happen hanging heavily in the air like a gas leak. It seems Owen's internal belief that he is not safe finds agreement in his external world.

So perhaps Owen's wordless question goes more like this: 'Are you safe? Because I am not.'

Safety is a shared endeavour. But I must do this alone. Owen believes he is not safe and his world agrees. I must silently break agreement with both, and oh-so-quietly assert the possibility of safety between and around us.

I work hard to regulate all that Owen is reading: my breathing, my senses, my nervous system. Internally, I acknowledge the offered fear and gently turn it down. I breathe slowly, relax my arm under his hand, dig down for a peace to offer back in exchange for his intermingling fear. I know the peace is there, but it is under attack. Can I find enough calm, for myself and some left over for Owen? I breathe again, and feel the muscles in my face relaxing as peace surfaces.

I feel him register it.

Satisfied, he beckons Jane up the remaining stairs, letting go of my arm and turning back to his original interaction with his support staff. His world exhales collectively, the freeze lifts and ordinary life resumes as if nothing has happened.

But something has happened. It took less than a minute, but I will learn from this brief exchange for many months and years to come.

This is Owen. A reader of people.

He cuts through my half-lies – my forced smile and reassuring words. He reaches past the superficial and right into the core of my nervous system to perceive how I actually am – forcing me to ask myself how I actually am.

And he doesn't do it with neutrality, but with his own suspicion, anxiety, anger, dominance flooding the airwaves.

And so, even as I learn about him, I learn something about myself through his fluency, through his intensity, through his expertise.

And all of this happens without words, as we narrate each other in our mother tongue: the language we were born with.

One: A door ajar

It is my first observational visit with Owen and he has absented himself into his bedroom, despite the late-spring call of the garden.

I am left in the corridor, and my mind drifts until I somehow find myself pondering the experience of Owen's parents as they discovered, as all parents do, the uniqueness of their son: of baby Owen, with ice blue eyes and sunshine blonde hair, and the slow unfurling of neurodiversity – atypical responses, heightened senses. And as I hold baby Owen in my mind's eye, I also hold the imperceptibility of all that was before them: the slow-motion landslide over years into the sorts of grief and collective lost safety that would have finally led Owen here. To a home away from home.

A sadness creeps up on me, and I let it morph imperceptibly into a heavy loss that I hold and wonder at: a foreshadowing of something to come, for which I internally steel and ready myself.

Sometimes, a door opens to feelings that are too big to hold by those they belong to, and so they overflow into the atmosphere and we breathe them in.

Two: Rest is a person

I arrive, finding Owen outside. He is kneeling on the grass under the shade with his head up, looking around him and pulling up handfuls of grass absentmindedly. He has an air of contentment, happy in his work. His shock of blonde hair has been cut since last time, with the faintest hint of a Mohican. As he pulls up the grass, he swings his head from side to side at a diagonal angle: a rocking swing-boat in the breeze. He takes in the wide space in front of him with continual movement, as if expecting something new to erupt from any quarter at any moment. His is an oddly calm and commonplace hypervigilance.

Patricia, Owen's supporter, chats happily to me about him, ignoring my lack of questions about him and my comment that, 'I'd rather just observe him – get to know him that way'. But it is not unhelpful. She isn't telling me *about* him in a Wikipedia way; she's chatting with fond familiarity.

He is far across the lawn from us, and as Patricia speaks with the ease of her well-proven relationship with him, I find in myself a rising impatience for the same. I want to bridge the gap, and convince myself that an explanation of my presence is necessary. I walk slowly towards him and, from a distance of ten feet or more, direct my voice clearly towards him: 'Owen, I'm Beverley. I'm going to be with you all afternoon'.

He fixes his eyes on me, immediately irritated. I realise with instant regret that I have fully interrupted his flow. He gets up and, without looking at me any further, walks briskly over to the door which leads into the house, as Patricia falls into step with him. I follow, snubbed, trailing behind me the withering hope of connection.

We head inside, and after some time, go to the dining room for a snack, where Owen eats his previously-abandoned breakfast and some crisps. 'He'll be happier now he's eaten,' Patricia says to me generously, as if this, rather than my interruption, has been the problem.

Smiling at Owen, she gets out some card and a glue stick and puts them on the table in front of him. He sweeps his forearm across the table, decisively knocking the card off. He reaches for the surviving glue stick and throws it right across the room. Patricia neither comments nor appears to notice the trajectory of the flying items. As if this is the first time she has

done it, she reaches for new card, glue and scissors and places them back on the table. She sits down next to him: 'Let's just try – just do a little bit of sticking for me,' she says conciliatorily.

She holds the double-handed scissors and gently coaxes Owen's fingers into them. Together they cut some shapes – or maybe she cuts and he complies. Owen swings his head, looking from one corner of the ceiling to the other, distancing himself from the movement of his fingers in the scissors. She puts her hand over his gently, and together they pick up the glue stick, and apply glue to the card. She intermittently signs 'Look' with her free hand, speaking the word gently as she does so, directing Owen's gaze to the card and the glue. He looks fleetingly at the activity on the table, and only ever in response to her encouragement. The effort seems considerable, his gaze glancing down like a stone skimming the water. Otherwise, he keeps his head moving – looking up at the ceiling, at the corners of the room, ever moving, never settling.

There is a small digital camera next to me,¹¹ and I pick it up. Looking through the viewfinder, I see that it costs him to be this close, and he is paying the toll. The viewfinder frames the two of them together – omitting the glue stick hurled across the room, and the card on the floor, and the remnants of breakfast, and the over-glossed skirting boards, and the boxed-in windows, and the extra-sturdy furniture, and me. As I look through the viewfinder at Owen and Patricia, I realise how close they are. And I notice that – fleetingly, sporadically – Owen lets his gaze rest softly on Patricia's face which is inches from his.

Patricia gives me the nod and I click the button on the top repeatedly.

11 Typically, the capturing of images in social care settings is well-protected. Digital cameras, which cannot send and receive images, are often preferred over phones. This was the house's camera, used to capture the day.

Looking back later, I see myriad shots of Owen staring up at the ceiling, or having his hand pulled about reluctantly, or grimacing: shots of disconnection and distancing, missteps and misunderstanding. I know that these shots will not make it to the scrap book or the review report or the letter home. But amongst them are one or two shots of Owen looking with great affection at Patricia, as her face is turned down to the work; there is a smile creeping into the corners of his mouth and his eyes are soft. And there is another of him looking with her at the work they are doing together, as if they are in complete agreement: a flash of harmony amongst a cacophony of discord. And I know that these few images of connection and concord will be printed off and displayed.

And I know that this is good, because though they are fleeting moments, they are also true.

Though we pan through mountains of silt to find the gold, it is the gold we live from, the gold we bring to those who love us.

Minutes later, Owen has had enough and is throwing himself onto the sofa – but with a faint sense of satisfaction at a job well done. Patricia collects some printed out photos from the previous week and sits on the sofa next to him to cut them out.

Owen seems steadied, his movements less staccato, his head still. He looks over at the photos in Patricia's hands, before reaching out and taking them off her.

With undivided concentration, he looks carefully at the picture of himself, leaning over to pour himself into the images in his hands. He looks and looks for several minutes, staring intently at the pictures of himself with a focus which is new to me – his gaze no longer a stone skimming the water, but a stone plotting the depths. He moves his interest slowly and carefully from one photo to the next. And then he points at the picture of himself with his finger.

Patricia looks over and smiles: 'Who's that?'

Owen taps the photo of himself and then taps his chest: that's me.

And somehow, I sense that the connection between him and Patricia facilitates this reflective capacity, this solid self-awareness. As Patricia holds Owen in her mind and heart, Owen finds enough stillness to consider his past self in the photos with his present self in the here and now – linking the two selves together, as he taps the photo, taps himself.

And Owen, so often preoccupied with processing the world through his hyper-tuned senses, finds a place of rest for his usually ever-moving self. In this moment, he is present in the now and the then, with Patricia. This has not been easily found, but hard-won – the final landing place after so much distance negotiated, resistance soothed, and missteps forgiven. But in this moment, right here, there is Owen and there is Patricia, silently challenging the received wisdom that rest looks like Netflix, and presenting the possibility that, sometimes, rest is a person.

Three: What just happened?

As I arrive, one of the team has let me know that Owen has had a 'good morning'. After finding some brief focus for participating in an activity at the dining table, I have followed him up to his bedroom, where he points to the TV symbol by the door and slumps down on his bed. One of the team has explained that he likes one particular episode of a programme, and, this now playing, Owen has seemingly settled in.

He lies on his back with his knees in a bridge, feet flat on the bed. His arms are raised in the air, and he waves them from side to side as if they are branches blowing in the breeze. He rolls his head to the side, pushing his temple and cheek into the pillow carefully, and then, forcefully swinging his head around, pressing the other side of his head into the pillow again. I focus on Owen's intentional and practised movement, and consider what sensation it might be giving him, soon finding a blurry feeling moving up my neck and into my head: a tingly numbness.

I try Owen's movements later, once I've left, and find that it quickly disrupts my sense of my body in the world. The intense impact on my internal senses – particularly the balancing (vestibular) sense – is so consuming that it makes it hard to think about anything at all. Plus, even after a few seconds, I feel nauseous. Owen, presumably with an under-stimulated vestibular sense, keeps this intense swinging movement up for around 30 minutes. It appears that this side-to-side, sway and swing achieves for him a settling of his body alongside a deliberate and deep shut-out-ness from the world.

Having observed Owen settle into this visceral, noise-scaped, blocking out of the world, I settle myself into one of the chairs in the corridor. Tom, one of the team, appears and begins to chat with me. He tells me that Owen is on his bed like this for four hours a day in the summer, more in the winter: this is the way that he regulates himself. He won't let anyone else help him with this process, and he doesn't particularly like anything designed to help him with integrating or regulating his internal senses (swings, wobble boards, etc.). Anytime he becomes overwhelmed – and he feels overwhelmed periodically every day – this is his way through it.

Owen's distance from the world once again impresses itself on me. It is unusual and relationally debilitating. He presents himself to the world as the exception to the rules of attachment, connection, and relationship: wanting significant physical distance, avoiding eye contact, appearing to ignore speech. He is aloof and alone. Any attempts to bridge the gap seem to irritate and antagonise him. I am here to understand his experience of the world, his emotions, his relationships. But can it be true that only distance from people makes the experience of being him bearable?

The few seconds of intense exchange with Owen from our first encounter feel increasingly like an anomaly – the briefest glimpse of connection from an otherwise detached young man.

Tom tells me that Owen had a blood test this morning, and was prescribed a sedative to help him cope with the physical contact and proximity it required. I see no noticeable change in Owen's presentation from the sedative, and Tom agrees that it doesn't appear to have affected him much. The regular blood tests are needed because of a medication I'm very familiar with – one commonly used to treat anxiety in young people with intellectual disabilities and autism. But there are risks associated, and I ask some questions about symptoms and side effects¹². Tom tells me that they tried a small reduction six weeks ago, but 'it had not gone well'.

I hear other things, as Tom talks. I hear not just his own sense of how things are, but the transfer of emotion from the team, and perhaps from family too. I hear in the undertow of his words and tone many years of feeling overwhelmed with Owen's agitation, and the relief that he is now settled-enough. This is not only Tom's – it is everyone's, and he holds it as good leaders do, containing the shared fear as best he can. I listen to the worry – so familiar to me – that even a small reduction in medication, or any other change, might lead back to the young man who did little but hurt himself and others, and who spent much of the day distressed. He does, of course, still get distressed, but it is episodic now. And whilst there is relief about this, it is a relief teetering on the memory of how he was, and anxious for Owen not to return there, anxious that *they* do not return there.

12 For the curious: whilst this medication, like most anxiety medication, lists a wide range of side effects – including worsening the concern it is treating, e.g. heightening a person's anxiety and agitation – this one also had a small risk of inducing hormone imbalance in teens. This was what I was asking about.

Tom is not telling me this straight up. But I hear it. I feel it. I feel the anxiety; I feel the loaded history. And, as he talks, seemingly glad of the opportunity to do so with freedom to a listening ear, I start to notice every mention of Owen's Mum and Dad. It feels like little firecrackers inside me every time he says their names.

Simultaneously, I become increasingly conscious that this conversation between Tom and me is happening outside Owen's bedroom. He is across the threshold, rocking and blocking out the world. But as the firecracker mentions of Mum and Dad continue, I have a creeping feeling that Owen's strong defences are coming under attack. I feel my shoulders rise and my chest tighten with an anxious and rising suspicion that every mention of Owen's parents are piercing his sensory-shield.

I move along the corridor, feeling somehow stretched between my conversation with Tom – who I can see and hear – and an intense awareness of Owen – who I cannot see or hear – rocking behind his sound fortress. I lower my voice a little as we talk, wondering how I can be sure to pitch it under the sound of Owen's TV programme. Tom also moves further down the corridor, ducking into another young person's room to put some things away, but then raising his voice to make sure it reaches me, and becoming increasingly animated in the conversation, which continues to include thoughts about Owen's relationship with his Mum and Dad.

My preoccupation with Owen's world-shutting-out intensifies, as Tom projects his deep voice down the corridor. His voice finds me, as planned, but I feel it travel past me too and on...

And I don't know how to make it stop.

Each mention of Owen's parents is like an explosion inside me now, and I feel sure that these cluster bombs are somehow breaching Owen's walls against the world. As Tom's voice booms down the corridor, from behind me, I hear the growl of Owen's soundtrack.

I turn to see Owen in the doorway.

He has his flat hand in front of his mouth and into it he is shouting and growling, so that the deep sounds reverberate back into his face. My heart sinks, and I turn back to him. As I round the corner, Tom at my heel, Owen has his long fingers pointing at a photo on the wall. Tom says to him briskly: 'Yeah, that's Mummy, that's Daddy and that's Owen.'

Owen looks at him hard, and then points again with urgency. He is standing on one leg, the other foot resting flat on the side of his knee, flamingo-style. As Tom repeats his response, he flicks his torso backwards in anger, his waist a hinge, and lets out a shriek. His arm is up around his head, to catch the growling shouts. I feel the air sparking with anxiety, and the muscles in my jaw tighten.

Owen is flicking his head from side to side. His usual low-level soundtrack, which is only audible when you're near him, is now loud enough to bounce off the walls of his room and the corridor. He folds again at the waist, pushing his body backwards, and then points to the 'garden' symbol looking expectantly at Tom.

Tom helps him with his shoes and socks, though Owen can barely keep still long enough, his body twitching and moving with ever-building energy. He is up and out of his room at pace, but despite his request to go outside, he does not go down the staircase to the outside door, but heads to a door at the other side of the house, which leads to a corridor that will take him any which way through the many other rooms and buildings.

I catch Tom's eye as he opens the door for Owen and can see him bracing for what's next. Owen has asked to go one way and then insisted on going another: these are early signs of internal disarray, chaotic thinking. Owen flashes through the door as it opens and breaks into a run down the corridor, shouting and hurtling his body forward, the sound echoing and bouncing around the space. Tom races after him, and I follow.

Owen weaves his way up corridors, banging through doorways. Tom follows behind, calling ahead to other small groups of staff and young people to clear the way. He reaches the end of a corridor with a door he cannot open, and looks back at Tom, his brow furrowed and his eyes slitted. Tom tentatively reaches his pass across Owen's taut body to release the door, but Owen can't handle the proximity and grabs Tom's t-shirt at the neckline, pulls it into his mouth and bites hard into his own fist wrapped in Tom's top, squealing.

Tom wriggles away and opens the door for him, but Owen races back down the corridor towards me. I feel frozen. Everywhere is loud and intense. Everywhere feels too small for us – the corridor is too small for the sound, too small for the movement. But it is not just the space around me: suddenly, I realise that my own body is too loud. My body is too small. My

chest is thumping; my blood is pumping in my ears; my shoulders and neck are locked in tension; my breathing is laboured. Even so, I can only seem to move in slow motion, as I hear him coming, shouting, screaming. He is here now: grabbing my hands, my clothes, my neck and pulling me into his face as he shoves his own fist into his mouth and bites down again, his eyes bulging out of his sockets as he glowers and squeals in my face.

It plunges on me like ice water, irresistible and overwhelming: fear.

Everything goes blurry, and I lose track of the shape of what is happening. The story fades somehow – perhaps Tom runs towards us both, I don't know. But in time Owen has let go and is running back after Tom down the corridor and through the now open door, which bangs shut behind them.

I walk slowly up the corridor, open the door between us and go through, trying to slow my heartrate, my breathing. Owen is racing around the space which has several doors. He bangs on each of them, screaming at the ones that won't open, and racing into the rooms of the ones that will, pouring himself into every corner, racing around the edges of the room and back out of the door again, and on to the next room. He's running and jumping, as if the pent-up energy inside is throwing him around. And finally he bangs on a door that leads outside, as Tom manages to get it open and he is exploding outside like a dam bursting, and as I follow I feel such relief at being in a space with sky and trees and air – a space I finally fit in: a space in which I am not too loud and my body is not too small.

Owen heads around the side of the house and Tom glances at me, saying: 'I know exactly what he wants', and running ahead of Owen to get to the gate that goes into the car park. He bolts it shut as Owen catches him up. Owen grabs his t-shirt and bites his hands. Tom gets away and standing at a distance says as he catches his breath, 'No, not today. Not today. Owen, we're not going there today'. Owen bites his thumb knuckle and shouts angrily, stamping up and down. He shakes the gate really hard; I see the bolt wobbling, but it holds fast.

Having established that the gate is shut, we seem to recover there together, under the expanse of blue sky, with the warm breeze playing in the grass and a reasonable guarantee of distance between us. All three of us take a breath, as if for the first time since we left Owen's bedroom. My thinking mind emerges slowly, drifting upwards inside me, like bubbles in Coke: I am re-emerging as a thinking self again, not only a feeling, reacting self.

We quietly welcome back in the things we lost in the too-small too-loud space of the corridor and our frightened bodies: choice, reason, reflection. And a question begins to emerge, not to be answered yet, but only to be held for now:

‘What just happened?’

As Owen's soundtrack diminishes slowly to its ordinary level, and he uses the wider space to release the last anxious energy into the open-armed sky, Tom comes back my way and offers an explanation of sorts. Owen wanted to get into the car park. I wonder why? Well, if he could get into the car park, he would go from car to car, banging on the car windows, after that he would try to get to the main gate to leave site. If this was thwarted, he would start to throw things – including the stones from the gravel drive; he had put a car window through on one occasion. I take this in, but it is not the answer I'm looking for.

After a while, we notice we are all tired, and Owen potters towards the door leading back to his home away from home, and we head together up the stairs. Owen crashes back down on his bed, and Tom and I into the waiting chairs in the corridor.

I notice how exhausted I am.

In a couple of days I will also notice the discomfort from the bruises and pinches on my hands and arms, some of which I don't remember happening. And I will find some words for the things I felt: the different stress sensations that had crept up so fast in my body. I'll notice the difficulty in recording what actually happened during the most heightened moments, as the narrative-writing part of my brain shut down in favour of the urgently-needed primal instinctive responses. I will reflect on the difficulty of being present to myself or connected with myself in those moments, as my amygdala fired up like a gas boiler from a pilot light, and flooded my reasoning self with my reactive self. And I will remember how necessary this all was, how brilliant our bodies are at reacting to danger – as well as noticing the cost of ending up in this process: the time it will take to regulate.

And I will notice the intensity and entanglement of the three of us heading into our reactive-selves simultaneously.

It is not until later that I will be able to start to track that most of my fear responses were ordinary. But, alongside an ordinary fear response, some of my experiences were unusual.

So I'm able to consider that some of what I felt – my body's firecracker response to the mention of Owen's Mum and Dad, the sense of my body being too loud and too small, the relief at the sky and the breeze, the blanking and blocking out moments – were more likely to be a projection: a window into Owen's experience in these moments.

As I do this, I work back through the sensations, the 'body-words'¹³, the flashes of things, the jolting narrative, the shifts in time and pace – I work through these jagged moments as if I am walking in and out of different doors, exploring new rooms. I am looking for a story in answer to the question: 'What just happened?'

As I search back through my experience for the 'what', I notice that this moment with Owen had all the hallmarks of what I am doing right now: my careful exploration of the rooms and corridors of my muddled-up memories, is a mirror of Owen's own hunt through rooms and corridors.

And of course, for Owen, this was meltdown and overwhelm and frustration and overriding fear and other things I don't understand. But alongside the fear – the too-small, too-loud, too-much-ness – I find another answer to 'What just happened?'. As I replay Owen's tearing down corridors, banging on doors, racing around the corners of each room, and – had he got his way – out into the carpark, banging on car windows, and, on through the main gate and away into who knows where, I have to conclude that this was not random. It was not meaningless. What just happened?

It was a search. A search that started with the repeated mention of his own Mum and Dad up and down the corridor in a conversation in which he was not included, but had to listen to, followed by an un-answered question, fingers splayed over the faces of his parents.

13 Pizer, 2024:1

Four: A return to proximity

It's taken me a while to find Owen since arriving today, but here he is in the sensory garden. I can't get through the gate with my pass, so I look through the wooden slats and say to a staff member I don't recognise: 'Hello, I'm Beverley. I'm here to observe Owen this afternoon. My pass isn't working; I wonder if you can let me in?'

She is standing several metres from Owen, eyeing him nervously, and reluctant to lift her concentration from him to me. I wait, seeing that it is all rather precarious, finely balanced. My arrival is an irritation – an unpredictability to factor in.

Finally, she opens the gate, eyes on Owen still, and says, 'You need to stand back, because Owen has passed urine and he needs to get out'.

I take several steps back and see Owen: he has urine on his trousers and bare feet. He walks gingerly out of the gate, head swinging slowly from side to side, as if curious about the world he is entering. I step back to give him some distance and say, 'Hiya Owen, it's Beverley'.

The words come out of my mouth and fall to the ground, as he neither acknowledges me nor registers me speaking. I have said them to no-one, and with nowhere to go, the words echo back at me in my own head: 'Hiya, Owen'... 'Hiya, Owen'. I feel self-conscious, foolish, and I notice a look pass across the staff member's face that seems to say, 'What did you expect?'

He feels his way carefully over the pebbly path towards the back door. I fall in step behind him and say to the staff member, 'I'm Beverley. I'm here to observe Owen until around 4'. 'I'm Emma', she replies. Though Owen's back is to us, I sense that Owen is aware of this short exchange. I am faintly present to him somehow. And this feels new.

Emma and Owen go into the bathroom and then into his bedroom as Owen gets cleaned up and changed. I stay around the corner, out of sight, listening to his low-level soundtrack humming away, like a distant lawn mower.

Suddenly, he appears around the corner, striding towards me with purpose; there is no sign of Emma. He walks right up to me, and out of his happy humming come two syllables: 'Hi-ya'.

It takes me a moment. The two syllables spoken in close proximity are not matched by the usual eye contact or body language that accompanies a greeting. They fall out of his mouth as if accidentally – and as if they too are expecting to hit the ground. So I nearly miss them. But, just in time, I catch the words, as he begins to turn away from me: ‘Hiya, Owen’ I repeat with a smile.

He returns to his room.

After a few minutes, Owen emerges looking smart in joggers and a new green t-shirt. It is on back to front, and the scoop at the back shows that his neck is reddish brown. ‘Owen, you’ve caught the sun on the back of your neck,’ I say. He ambles around the corridor as Emma comes out of his bedroom, putting away and organising things. After several minutes, I see that Owen is stroking the back of his neck, looking for the sun he has caught there¹⁴. It has taken him a few minutes to connect my comments and respond.

I pop out to get something from the car, making some breathing space to let our brief verbal exchange settle inside me. There is much going on internally, I notice. Our first encounter was not an anomaly, but a window.

I return to find Owen downstairs in the lounge with Emma and one of Owen’s peers, who is racing from one side of the lounge to the other, loud and unpredictable. Owen’s movements are increasingly spikey and his soundtrack is louder and punchier. Emma looks uptight; she asks another staff member to take Owen’s peer to get some snacks from the kitchen.

Despite the other young man’s departure, Owen is getting still louder and more agitated. He begins to move fast around the room, from one corner to another, head flicking wildly upwards from side to side. With each tip of the head, I see the muscles across his neck and shoulders tighten and flex.

There is a plate on the mantelpiece with the remnants of breakfast. He wipes his hand across it and licks his hand. Then, as an afterthought, he picks up the plate and hurls it like a frisbee across the room; after it goes a fork. He prowls across the room, and I notice that Emma is carefully moving out of his reach. I do the same, keeping a table or sofa – anything substantial –

¹⁴ I shared this little story at Belong conference and a number of those attending explained back to me what had happened in this exchange. My gratitude to those who called out: ‘He was looking for the sun on his neck!’

between me and Owen, as the air of threat rises like dust around our feet. He bends down to retrieve the plate and fork from the floor to hurl hard across the room again, as we duck. Returning to the mantelpiece, he notices a large jug of juice; Emma and I watch helplessly as he throws it hard across the room, leaving a pool of juice expanding across the floor.

Emma doesn't say anything. She picks up the jug, puts it back on the mantelpiece, and reaches for a roll of paper towel, tearing off a couple of sheets and letting them fall to the floor. Owen looks on with interest, and then approaches her. She tears him off some paper towel and gives it to him; he throws it on the floor, watching its colour darken as it soaks up the juice, picks it up and licks it like a lolly.

'Don't do that, put it in the bin.' Emma's tone is sharper than I expected. But Owen does as instructed, coming back for more paper towel.

I realise Emma cannot leave the room and she does not have what she needs to clear this up. I go up the stairs for the mop and return with it.

'Owen may like to help,' Emma says. He comes over and Emma passes the mop to Owen, who begins to mop the floor vaguely with one hand, whilst looking in the opposite direction.

He drops the mop and returns to an increasingly haphazard and chaotic stalking of the room. The brief clean-up has only been a pause, it seems, and I notice that Emma and I are once again moving with Owen, dodging and ducking to keep space and preferably furniture between us and him.

I can see anxiety stealing onto Emma's face and tension into her frame, even as I feel it creeping into my own. Fear is arriving once more. Owen's volume is filling the room, as his erratic movements and hurling of objects have increasingly established his control over this space. He is intimidating, I notice, and fear is finding landing space inside me again.

But I am forewarned and forearmed this time...

It has been two weeks since I was last here, and during my long journey in this morning, I noticed my anxiety grew with the miles covered. The last time I was here, Owen had been anxious for the full four hours. He had grabbed me numerous times, most of the time, with something that felt like self-restraint from him – giving me the sense that he was holding himself back, as best he could. Even so, in the days that followed, I had noticed nail marks on my hands, small bruises on my arms and some scabs where he had broken the skin. My arms and shoulders ached, a hangover from the effort of trying to stay regulated against Owen's jagged bursts of contact, that spiked against me with muted rage.

As I drove, I remembered and acknowledged how much fear I was experiencing when I was with him – and now anticipating. And I remembered again that I had been around many young people like Owen over the years, and that the fear had something to tell me about Owen. Perhaps this was less my fear of Owen, and more Owen's too-strong feelings of fear projected into me as a question: what will you do with this?

And here I am now with fear once again dominating the frequencies around us. It is pouring out of Owen in a way that invites Emma and I to soak it up, like the paper towel soaked up the juice, changing its colour and expending all its usefulness. I deliberately disrupt this fear, that is masquerading as my own, with the thought: this is not my fear. As I internally separate myself from it, I allow the possibility to rise that I might have the potential to overwhelm the overwhelm – to digest the indigestible.

Thus, I rally myself. And as I do this internal reorganising, I stop moving out of his way. I stop placing distance and furniture between my body and Owen's. I decide to bring my besieged body and mind under the rule of the peace and stillness inside me, and see what happens next.

And so here I am in the middle of the room: still. Owen is pacing past me back and forth with energy, but he's beginning to look at me as he sweeps by. As I stand my ground, his pace slows until finally he comes to rest right next to me. The fear swirls around us both, but I am still and now Owen is too: his head, hands and soundtrack coming to rest.

I look up and he is looking back at me.

I breathe and feel the air lighten around us, as the swirling fear dissipates like vapour.

I am still and so is Owen.

It is seconds, but it is enough: Owen's capacity to connect with me vanquishes the anxiety.

I hear Emma, who has simultaneously stilled and steadied herself, whisper to herself from the other side of the room: 'Nice'. Owen turns away and I turn to Emma and share a smile with her of so much unspoken.

As if the whole room has had a switch it off and switch it back on again reset, Owen ambles across the room, heads to the bin, and reaches into the bottom to retrieve a half-eaten packet of crisps he had put on deposit there earlier. He munches them contently, as Emma, also moving into action, reaches for a new pack. 'Don't eat those,' she says, taking them off him and handing him the unopened one.

Owen hands them back for her to open. Emma holds the crisp packet out, pinching the foil either side with both hands to pull it open and nods at Owen to come over. I watch with interest at this rapid return to proximity, in response to the recaptured safety. She takes Owen's hands and puts them where hers were on the seam of the packet, resting her hands over the top. She encourages him to pull it apart. He does, but it doesn't open. She pulls hard too, and still it doesn't open. They are standing face-to-face with the packet between them. And now all thoughts of this being a 'teaching moment' evaporate, as Emma pits her will against the stubborn packet. Her face breaks into a grimace as she pulls against the edges of the packet, still to no avail.

As I watch on, I see that Owen is watching too: and as Emma's expression shifts to frustration, a flash of a smile crosses Owen's face.

It's so ordinary: the amusement that she is trying to teach him to do something she can't do herself. And it's tender, even as it's brief – face to face, their bodies mirrored and united and thwarted by a crisp packet. And I see that he is able, in this moment, to think about her and the interaction they're having, to pull back and notice this small shared moment. And it's connected and relational, and full of sweetness, just minutes after so much juice-hurling, fork-throwing, fear-fuelled chaos.

Five: Triads

Tom looks up as I enter the lounge-diner, surprised to see me. The unexpectedness of my arrival sits palpably as I put my things away and explain to him that I'm here for the afternoon. I watch Tom slowly acclimatising to the idea; making space for me in his mind and plans.

Perhaps Owen does the same.

I sit at one of the dining tables and say hello to Owen. He is sitting at a smaller table, one foot up on the chair, eating roast potatoes with his fingers. Tom and I watch him with amusement: he is relaxed and happy, as only the consumption of copious carbohydrates can achieve for a teenage boy.

Tom goes through the trays of food – he waves a chicken breast at Owen on a fork, saying, 'Do you want this, it's kind of dry?' Owen pushes his hand out, waving it away: 'No, I didn't think so,' responds Tom. He puts some more gravy and potatoes on a plate, and Owen's face breaks into a smile. He eats with glorious indulgence, bending down occasionally to slurp gravy.

Once finished, he deposits his plate on the mantelpiece and slumps on the sofa. Tom looks around the splattered floor: 'Can you help me clear up?' He hands Owen a dustpan and brush. Owen wanders across the room and waves the brush over the table, in a magician-style gesture. Tom lets a smile escape from the corner of his mouth, but says, 'No, come on, I need you to really help me'. He puts the pan on the floor next to some of the debris: 'Just push this pea and this piece of potato into the pan and we'll call it a day'. Owen bends down and pushes the food into the pan. Then, on Tom's instruction, he carries the dustpan and brush over to the bin ceremoniously, sliding the two small items towards the large mouth of the bin and missing. 'Never mind buddy, it wasn't your fault'.

Tom finishes his lunch at the dinner table. He tells me that Owen has 'visitors' today, and I remember that Owen's Mum and Dad visit on this afternoon each week. He says that when 'they' arrive, he'll check with them whether it's okay for me to observe. I suspect that, just as I know who Tom is talking about, so Owen knows too.

Whilst Tom is chatting, his back to Owen, Owen takes off his shoe and throws it arching up towards the ceiling, so it lands quietly on the floor behind Tom. I see him going for the other shoe and say: 'You might just

want to watch your head as the other shoe is coming your way'. Tom turns and watches; and Owen, with Tom's attention gained, innocently slides the second shoe along the ground, making a mockery of my warning.

There is something about our triad today: something performative and comforting. Owen's visceral pleasure in his food, with exaggerated smiles for Tom and me; the comedy of errors in Tom and Owen's clearing up; and now the 'behind-the-back' attack that Owen makes on Tom, for my eyes only, to see who I will side with. This affectionate interplay intertwines with the conversation about Owen's parents arriving imminently. Owen is more than ready for the three-ness of being with his parents, who are not yet here. And perhaps he is making do with the three that is available, in this home away from home. Certainly, it seems that we could play like this all day.

We head upstairs and Owen slumps contentedly onto his bed, lying with his knees up and his feet flat on the mattress. He holds a stuffed teddy by the foot, flipping his hand forward and back, settling into a contented rocking.

I feel soporific as the phone rings. The rest of the staff and peers from the house are arriving back, filling up the space with noise and movement, as a conversation ripples around them about how to manage Owen's parents' visit if it rains, as they always see him outside. They are running late; perhaps the rain will have stopped. I feel some low-level anxiety creeping into the space.

Owen gets up and taps on his cupboard, which Tom opens. It is full to bursting with stuffed bears. Owen begins to work through them, judiciously flick-flacking each teddy back and forth, before discarding it and moving on to the next one.

Tom sends a staff member off for a break, as the young men Owen shares the house with struggle to make sense of this pause in the day, getting steadily louder and more antsy. The movement of the young men around the house begins to feel relentless, and the agitation is growing in the air. I hear Tom asking questions about who is with each young man, but there doesn't seem to be any order or sense in the terse replies. The atmosphere feels increasingly precarious and fragile.

As the fractiousness grows, Owen comes to the doorway of his room and points to the TV symbol on the board next to his door. I am the only one outside his room so I go in and check the TV. 'I think the TV's fine,' I say to him. He looks at me, obviously not satisfied with this answer. He does a circuit of his room and returns, pointing to the photos of his Mum and Dad and himself on the wall. I say, 'Yeah, that's Daddy and Mummy and that's Owen'. I know they're on their way... but I don't know how much to say.

Owen takes another circuit of his room, his vocalisations becoming louder and spikier. Suddenly, he is rushing out of his room straight for me. Aaron, a cover staff member just arriving, steps between us with speed, and Owen grabs his t-shirt with both fists clenched, leans in and bites his own hand, shouting into it. I step back to let Tom through, who is running, and it's all a blur. Tom's hands are up around his face, and Owen has hold of his wrists and is trying to push him out of his bedroom. Tom doesn't concede. He's saying, 'You need to talk to me; talk to me and tell me what it is that you want'. Owen is growling and shouting, as one of the other boys appears, leaping and jumping chaotically, before being taken out by a staff member, in response to Tom's sharp instruction.

I feel frazzled: my mind is full. So many sounds and movements and people – and I can't make sense of any of it. But I feel responsible – implicated – what am I doing wrong?

As the other staff and Owen's peers make their exit from the house, Tom steps out of the way and Owen pours like water into the corridor, straight for me. He arrives like a storm, but his hand is gentle, settling on my arm softly, as if soothed by the contact. Perhaps this is all he wanted. I breathe and relax my arm with deliberateness, allowing it to flop in the light grip of his thumb and finger encircling it. He leads me to the corridor, placing my hand on a cupboard door, and I say, 'Do you want me to get your remote control out of the cupboard?' I open the cupboard, and hold it out to him, only for him to push my hand away.

Dejectedly, he sits heavily on a chair in the corridor, his hope in me disappointed. He gestures feebly again to the open cupboard, looking lost and defeated. Tom and I stand and watch helplessly.

Rallying again, Owen stands to his feet, reaching up to the top of the cupboard and pulling at a cushion that is barely visible. Tom says, 'Oh,

do you want your bed made?' Owen, energised, glances into another bedroom, running in to sit on their newly-made bed, looking pleased with himself.

Together, Tom and I make his bed up, and Owen returns to his room and settles onto it. Somewhere in the midst of this we've had the message that Owen's Mum and Dad have arrived, later than expected – it has stopped raining now – and Tom is saying to him, 'It's time for you to put your shoes and socks on. I think you want to go downstairs – Mum and Dad are there'.

And they are. The Mum and Dad from the photo, who Owen was just asking for, are here in the flesh.

Tom takes Owen to the window and points outside: 'Whose legs are those? I know. Whose are they? They're your Mum's. Whose cool bag is that? You know whose it is – even I know – it's Mum and Dad's ... Let's go downstairs and see Mum and Dad'.

We watch Owen peering out the window at the legs and cool bag of his parents, their heads and hands obscured by the frame. He sits back on the bed, and I realise Owen is resisting Tom helping him with his shoes and socks and a change of t-shirt. He does not want to go.

I wonder as Tom continues to persuade Owen to get ready. Perhaps, in the waiting, the intolerable waiting for parents about which he could get no straight answer from me, Owen opted instead not just for a newly-made bed, but a bed made by Tom and me, the triad reunited. An engineering of surrogates, to escape the anxious waiting and the ambivalence, in this home away from home.

Owen and Tom finally go down the stairs and outside, and I wait inside to hear back from Tom whether Owen's parents are happy to have me observing this precious once-a-week moment with their son.

Tom returns almost immediately, but with Owen, who has had an 'accident' as soon as he stepped outside. I stay out the way and ten minutes later, they head outside again together. This time, Tom returns and tells me I can join them.

I leave the house and round the corner to see Owen sitting on his bench, neck stretched tall, head swinging from side to side hawk-like, surveilling

the space like a prison warden. He is stern and intimidating. His Dad is crouched down in front of him, head lowered, passing him crisps one at a time. His Mum stands to one side, cool bag at the ready for whatever might be needed next. Owen snatches each crisp from his Dad's hand without looking at either of his parents. He is aloof, superior – head in the air, a king among peasants. This is not an Owen I recognise – or like. And as I watch his Mum and Dad, so attentive towards their decisively-distant son, something inside my heart snaps painfully.

Without looking, Owen seizes the bag of crisps from his Dad and throws it across the lawn. There are two new stuffed bears on the bench beside him, and he picks one of these up and hurls it across the grass, followed by his Mum's coat. His Mum says mildly, perhaps more to me than anyone, though I am a good distance away, 'Ah, are we in a throwing mood today, Owen?'

Dad hands him a carton of juice. He sips it, one foot on the bench, head swinging, eyes searching the trees and the skies. He picks up the second offering – a beautiful, patchwork stuffed animal – and begins to flip it haughtily.

Standing, he takes his Dad's hand and pulls him hard towards the gate that leads to the carpark. His Dad pulls in the opposite direction and soon they are pulling against each other with force. His Dad quickly loses this tug of war, and is dragged close to the gate; I find myself struggling against the anxiety building in my chest. However, I sense simultaneously that the little calm I have might be useful, so I move close: an offering of presence, nearness.

His Dad says, 'That's not where we're going today, Owen. We're going to stay in the garden'. His voice is cracked and shaky. 'Stay in the garden'. Owen reaches the gate, lets go of his Dad and rattles the gate hard with both hands. It is bolted and he accepts it, turning back into the garden. His Mum and Dad pass me as they follow Owen and his Dad says to me, 'That was a close one', and I respond quietly and instinctively, 'Well managed'.

Owen strides onto the lawn, stopping near a waterlogged patch. He throws the patchwork animal and the other stuffed bear into the mud. His Dad steps forward and passes them back to Owen, who takes them and throws them over the fence. His Dad climbs the fence and hands them back to Owen, who throws them again.

Owen's throwing, as I'm learning, is not random, he likes to watch things follow the same arc through the air, and often one item after another will land together in a pile. But today, each time, his Mum or Dad go to retrieve them.

And somewhere along the line, I join in and go to get them too. I don't know why, but the action comes out of my gut, and is directed at Owen's parents not him. Perhaps I need to understand what this means for them. Perhaps I want them to feel joined-with by someone. Perhaps something else I can't articulate. But I notice that the retrieval is a simple, concrete thing to do for him: to bring him things, carefully chosen, and bring them back to him again and again when he discards them. They bring these things back and back, regardless of his response, just as they bring themselves.

And today at least, Owen, as so many of us do with those who love us unconditionally, luxuriates in bringing his worst self to this endless generosity.

It begins to rain and Owen goes to the door of the house. His Mum and Dad look at me expectantly, until one of them says to me apologetically: 'We can't bring him back inside'. I feel so uncomfortable that I can get in the house and they cannot, so I say, 'I've got a pass – I can get you in'. Even as I say it, it's all wrong.

They are silent until his Mum looks at me and says quietly, 'We can't go in'. I say, 'Oh, okay'. But I don't understand. She sees that I don't and says, lowering her voice to reach me, but not him, 'He gets aggressive if we go inside'. I feel so sad, and hear myself saying, by way of an apology: 'It's a very small space, isn't it?' She smiles at me and says, 'Yeah, we prefer to stay outside with this space'.

And I feel all their love for him, still deep and wide underneath the fear and loss.

As I follow Owen into the house, the door closes behind me, leaving parents in the rain and patchwork animals covered in mud. Owen is quietly waiting for me to come with him. And I know where we're going: to find Tom. To regroup the triad.

But I can't do it this time. Not with real Mum and Dad outside in the rain. I see him settled, collect my things and go home.

Six: Intangibles

I'm here early, on the recommendation that it might be useful for me to see Owen first thing. Reuben, a well-established member of the team, has woken and coaxed a reluctant Owen out of bed and downstairs for breakfast. Owen is not a morning person, and I sympathise.

After some intense negotiations with Reuben, Owen has headed back upstairs for a bath. Reuben has said I can come and 'see his bath', but I have explained – intentionally in Owen's hearing, so we're all clear – that there is 'no need for me to see Owen without clothes on'. After a pause I add, for Owen's benefit: 'I expect most people in Owen's life see him naked sometimes. It might be nice for him to have someone that doesn't'.

Bath finished, Owen finally appears with a towel wrapped around his waist, his hair jumbled, looking fresh, clean and happy. He walks jauntily past me and into his room, where he begins to jump up and down with enthusiasm. The towel stays on somehow but, not taking any risks, I disappear around the corner away from the doorway.

Reuben heads into the bedroom with Owen and I hear the sounds of clothes being chosen and prepared. I settle in to waiting, only for Owen to appear around the corner, parading towards me confidently, naked. He walks right up to me, looks me in the eye to check he has my attention, utters 'Hi-ya', and turns on his heel to his bedroom.

Body-confident, he asserts his wholehearted disagreement that it 'might be nice' to have someone who hasn't seen him naked, instead deciding that I do, actually, need to see all of him. I note Owen's clearly-avowed opinion on the matter, and silently, amusedly, agree to disagree.

It's several hours later, with much of the intervening time having been spent outside in the sunshine, and I am back in the corridor and Owen is back in the bathroom. I can't see Owen, but I can hear the sounds of the taps on full blast and the splashing of great waves of water pouring out of the bath onto the floor. A river is now pooling into the corridor. Emma emerges from the bathroom, drenched from head to foot, and gives me a wry smile. Just a few years older than Owen, Emma seems to get into these scrapes with Owen quite regularly. 'He sits over the plughole', she says to me, and then leans her head into the bathroom

again: 'Can you just move away from the plug, Owen?' The splashing intensifies in reply. Emma disappears up the corridor, returning with a water-suction machine. She concentrates on setting it up, then takes it into the bathroom and I hear her encouraging Owen to help her suck the water up with the machine. Gruff sounds of his annoyance accompany Emma's expulsion from the bathroom, as I see his hand pushing her out the door.

Tom walks past, glances at the tsunami-ed corridor and gives me a bemused smile, 'This is an Emma thing', he says. 'He only does this with Emma.' Rolling her eyes at me good-naturedly, Emma heads back into the bathroom, pushing up her trouser legs, as if they are not already water-logged. The team continue to paddle through the corridor, with knowing nods at each other, and I notice that this very particular maritime battle between Emma and Owen has familial, perhaps even sibling overtones: a well-rehearsed and harmless clash of excess versus containment. The responsible older sibling risk-managing the reckless exuberance of the younger. The waves of warm bathwater and familial squabbles, the gentle tuts and sighs, the rolled up trouser legs and even the at-the-ready water pump feel warm and homely and the stuff of dinner time anecdotes.

I retreat further up the corridor, away from the gentle brook of bathwater meandering towards me, and notice that in Owen's bedroom there are three cleaners, giving each other frustrated glances and seemingly stuck as to whether to proceed with cleaning Owen's room. I feel anxious; they should not start cleaning, as he will be here any moment. And almost immediately, Owen arrives in the corridor, walking towards his bedroom, his soggy towel held out in front of him by his finger and thumb, as if it is contaminated. Emma is in the bathroom, head down, working the water pump. The cleaners pack up their things and retreat to the corridor, as Owen rounds the corner into his bedroom, naked.

There are lots of people around – there were before, I guess – but the homely familiarity of those paddling down the corridor is dissipating into something else. There are team members and young people and three cleaners and me, and no-one has put clothes out for Owen and he is naked. He begins to wander. He goes back to find Emma, but her back is towards him – she's busy vacuuming up the water. So he goes back to his room,

reappearing quickly, as if at a loss to know what to do next. He walks the corridor with a defeated air, back and forth past his peers, staff and the three domestic staff, who lean on their mops and trolleys, watching him silently.

The previous familiarity of the moment splurges seamlessly into voyeurism, and Owen's oceanic dominance in the bathroom becomes othered, dignity-stripping in the corridor. He is naked and he cannot cover himself, and everyone is watching.

I feel small and powerless. The pain of his exposure and abandonment cuts me inside, and I lower my eyes and wish I could unsee – not his body, but his humiliation.

Later I will remember Owen's earlier assertion of himself with bold confidence in this same space, which had made me raise my eyebrows and smile at his surety, now acting as a foil for this moment of powerlessness. And I'll remember that it was not the nakedness that was the problem, but the intangibles around it: choice, power, agency...

Emma's back remains towards all this and I *will* her to turn and see him. Eventually she does. She sees. And is mortified. Apologising profusely to Owen, she hurries to put his clothes out, bringing him to the bedroom, and closing the door.

But it cannot be undone and it sits in me like a burning stone.

What does Owen, with his strong opinions and ordinary inclination towards self-confidence, do with these moments – with the white-hot humiliation, and the quiet rage that evaporates off it?

He is dressed now, relaxing in his room, the lostness, the vulnerability all covered up again. No sign of it, so I try to shake it off and move on too.

His peers are heading down to the dining room to do some activities, and Milan, a team member familiar with Owen, calls as they go: 'Come on, Owen. Come downstairs'. Unusually compliant, Owen gets off the bed and follows them down. I follow too, and find the staff and the four young people standing awkwardly in the doorway, as the cleaning team are now mopping the dining room. There's some discussion, and then they're all told to go back upstairs again until the floor is dry.

Before long, Owen has pointed to the grounds symbol, and I am outside with him and Milan, away from it all, in familiar territory and relieved. Milan and I are chatting, settling in for the long-haul, as the sun beats down on Owen and the grass is dry and everything is primed for the rest of the afternoon being spent outside. Owen has, unusually, strayed with a teddy away from his bench and disappeared behind a raised flowerbed. But we can hear him, as his soundtrack is ringing out, sounding somewhere between a hive in transit and a distant motorbike, with some musical notes thrown in for good measure.

As Milan and I settle into easy conversation, I notice that Owen's soundtrack changes to a gruffer, sharper tone. Milan has stopped talking, his eyes looking up and to his right in thought, before saying resignedly: 'I know he's doing a wee'. We stand and walk over together, rounding the flowerbed.

Owen is kneeling on the grass, his knees apart, looking down and concentrating on the urine that is soaking through his shorts. He looks up at us angrily, hollering, and then looks down again. The urine has formed a puddle between his knees, and he is shouting furiously and patting it. Milan says, 'Come on, let's get you changed'. Owen looks up at us both, then with an enraged shout he takes teddy – who is sparingly attired in a red bowtie – and dips him into the muddy puddle, dragging his face and torso carefully through it so he is saturated. Milan and I watch, wordlessly, bearing witness to teddy's decline, as he cannot help but soak up that which he is dragged through.

Owen stands up; his shouting has stopped. Teddy hangs from his hand by one foot, bedraggled and dripping. And, now apparently calm, Owen walks steadily back to the house. As he approaches the door, he throws teddy high in the air. He does not turn his head to watch his flight. Teddy, abandoned and exposed, lands on an air conditioning unit behind a shrub up against the wall, expelled from the hand that humiliated him. Owen, Milan and I head into the house and upstairs together.

Owen takes a bath. A do-over, perhaps.

But I find that I cannot get teddy – sprawling and heavy in the back of the flower bed – out of my mind.

At least I know now. This is what Owen does with it – what he does with the humiliation, and the anger that rises like piss off a teddy on a sunny day.

And how many times has he done this, I wonder, noting that he so often holds a teddy in one hand like an appendage, a useful extra limb that can be amputated at will, split off and discarded. But this time, though teddy is severed from Owen, humiliated, and rejected, he remains in my mind – even now. I will hold the split-off part of Owen's shame and rage, though it hurts. I will not rescue teddy, but neither will I forget him.

Seven: To speak and be heard

Owen's bedroom door is propped open; he's lying on his back on the bed, rocking side to side, and seeming to have disappeared into the internal world of his own body.

I'm in the corridor with a number of staff who are milling around. One staff member has just announced to the team that she is pregnant, and happy chatter is bubbling between the staff of babies, children and parenting – alongside an unspoken hint of something. Betrayal or abandonment perhaps: soon she won't be coming here anymore.

The conversation doesn't escape the other young people in the space, and one of them begins to ask repeatedly, 'When will I see Mummy? When will I see Mummy?'

It seems that thoughts of family have also arrived in Owen's mind.

He gets off the bed and goes up to the pinboard in his room. With his forefinger and middle finger in a V, he points to a photo of him with his Mum and Dad from when he is maybe 10 – a much younger, smaller Owen, with wide eyes that look a little scared and lost. He places each finger right over the picture: one on Mum and one on Dad. He looks at me. I say, 'You're thinking about Mum and Dad'. He looks at me hard and then turns to Milan and Freya, the teacher, and firmly places his two fingers again over the pictures. Freya says in a sing-song voice into the room, as if she has said this line a hundred times, 'Mummy and Daddy love Owen very much and they'll come and see him soon'. She ends the sentence on a downward note that communicates, 'and this conversation is over'.

He puts his hand down and looks across the room, then he turns back and does it again. The atmosphere begins to shift, and I feel the nervousness of all three of us rising. Milan says quietly and more directly to Owen, 'They're not coming today, mate'.

Milan quietly shows me the scratch marks on his hand, from the last time he had pointed at these photos repeatedly like this. 'If he points to a drink symbol, we get him a drink. Does he think we can do this with his parents?' he muses, as I see him begin to brace for the coming whirlwind of Owen's distress. The scratch marks on Milan's hand – and those healing

on mine – are shorthand for the next chaotic hurtling through the house, for the too-small-ness, too-loud-ness, and the deep sense of something – someone – lost, and needing to be found.

And here we are with Owen asking again, and not unprompted, but seemingly – to me at least – in response to conversation about families and babies and ‘When will I see Mummy?’ and absence and questions bubbling around tumultuously. Owen’s two fingers remain splayed in request over the pictures of Mum and Dad. I understand that Freya’s scripted, muted response is an offer of some predictability to reduce confusion, but I am fast becoming convinced that confusion is not the primary issue.

I note that anxiety is rising once again like dust at our feet, even as I watch the staff drift away down the corridor – an air of nonchalance covering over their urge to flee the coming chaos.

I am left with Owen.

Owen has turned away from the photo of Mum and Dad and him, and is sharply pacing his room, pausing only occasionally to peer through the window at the lawn below. His soundtrack is rising in volume and agitation, the crescendo matched by his body. The ordinary fluidity of his movement morphs, until he is all limbs and angles, like Bambi on ice. He throws his body – or his body throws him – from corner to corner, from window to bed, with increasing velocity. In the air around us is a progressively powerful anger, thickening like smog, and I am resisting the desire to shrink under its glower. His sounds match his movements, piercing and capricious. His vocalisations seem to bounce off the walls and windows, reverberating back and forth like bullets that cannot find their mark. I feel the threat from the sound and movement – feel it on my body, like the slap and sting from rain which precedes a coming storm.

I don’t know how long this space can hold him. But I sense that if I move away from this doorframe, under which I am sheltering, it will not. I didn’t plan to be here. But I’m here now. And, seeing as it looks like I’m caught in this particular storm, I may as well put my head up and take it all in.

So, although the sound and movement are like hail on my face, I lift my head and listen. I breathe it all in deeply and slowly, carefully bring down the drawbridge of my defence system. I put to use my heightened senses that the threat is provoking, and pay close attention to the sounds

Owen is emitting. As I attune slowly, with each deep breath, to the reverberating grunts and muted shouts, I am surprised to find some rhythm and cadence there.

The first time I hear it, I let it go. It sounds like Owen is talking underwater and I cannot believe my waterlogged ears. But then I hear it again, emerging from the cacophony:

‘Dadda. Daddy,’ And I catch my breath as it registers in my ears and then my heart.

Owen is suddenly in front of me again. He is planting his fingers over the pictures of Mum and Dad. He bends one leg, resting his weight on the other, puts his head slightly on one side and stares at me accusingly. I take a small step forward, noting the intimidation. He flicks his torso backwards in annoyance; I meet his intense eye contact – his eyebrows are raised as if to say, ‘What are you going to do about this?’ I say with slow deliberateness, with all my attention on him, ‘Owen is thinking about Mum and Dad. I can hear you saying “Daddy”. Because Owen is thinking about Mum and Dad, Beverley is thinking about Mum and Dad too. We are both thinking about them now.’

He considers me – what I have offered – before turning back into his bedroom, picking up where he left off in both words and warfare.

He continues to spike his frame around the room in a jolting way, as his vocalisations thunder and overwhelm the space, keeping me on the edge of the threshold. But he returns over and over to the window and I hear him say intermittently, with his deep booming voice, ‘Dad-da, Dad-da, Daddy’.

A meerkat-curiosity grows in me, and as I try to listen with my whole self, I make out a new repeated sound: ‘Um-eee, umm-eee’. I am taut with the effort of listening, as if my whole self is on tiptoe, peeking over a wall of sound to catch a glimpse of something rare, something beautiful, something spectacular. And as my ears adjust to the music, I understand that the third in the triad must be voiced as this young man tells his own story, and I hear it clear as day: ‘Ow-ee, ow-ee’.

For around half an hour, Owen looks out of the window and talks – and the three words that are clear, as much from the sense of transference as the voice itself, are, ‘Daddy, Mummy and Owen’.

And something happens. It's so quiet you wouldn't have noticed had you been there. But it's this: as Owen speaks, these words do not fall to the ground, but are heard and held in my heart. As I hold them – even with their sharp edges that cut at the inside of me – the whirlwind dissipates. The storm soothes into a simple exchange: Owen talks and I listen.

We hold home together, in this home away from home. And it's okay.

Later that day, long after Owen's musings have come to an end, he is resting on his bed. I ask if I can sit with him. He signs 'Yes' on his chin. I push myself back on the chair, and he sits up on the bed and pushes himself back against the wall. We are sitting at 90 degrees to each other, our postures mirrored. I look at him, and he looks back intermittently, making brief but intense eye contact, and then looking around the room. After a while I say quietly, pitching my volume to make it clear that I am keeping my voice within this shared space ... 'I've heard you talking about "Mummy", "Daddy", and "Owen". We've been thinking about them together. Owen, it's been good to hear you talking about them'. He takes me in with a sweep of his head. He has a small smile on his face.

It is enough. I leave the room and wonder at this ordinary connection: just to speak.

To speak and be heard.

To be heard – not as someone requesting his parents like a symbol for drink on the wall – but as a teenage boy living away from family who is feeling the ordinary longing for home that rises up in all of us with ferocity when we least expect it.

Who will listen to this? Who will pay attention? Because this – just this ... being with, listening to ... this can dispel whirlwinds, call off a frantic search, and defeat the fear that home has been lost somewhere inside this home away from home.

They have been here all along, and we can think about them together: Mummy, Daddy, Owen.

Eight: Stories told about us

It's lunchtime. Owen sits apart from the main group at a smaller table, one foot on his chair, and picks up a sausage between his thumb and forefinger, looking at it carefully, gravy dripping down his hand.

I am the only female present today, a first for me. I notice this at the same time I notice that the lunch is sausage and mash, and that there are no knives. Everyone, staff and Owen's peers alike, stabs the sausages with their fork and gingerly bites bits off. Except Owen, who eats sausages with his fingers, and with relish. And me, sitting in the corner on a sofa (no space for me at the table), cutting the sausages with the side of my fork, hoping they don't jump from the plate and shame me.

Owen and I are the other side of the room from each other, with the larger group of staff and young people around the main dining table between us. Owen bridges the gap between us with periodic glances. This too, is a first: my careful observation, generally met with an aloof indifference, is today met with regular eye contact. He watches me as I watch him, as if checking that I am present to him. Which I am. So the connection between us has intention from Owen that I'm not used to, and it makes me wonder.

The conversation rolls between the staff in an absent-minded fashion. Amongst the chatter, the conversation returns to a theme that has become familiar to me: that Owen 'targets women'. The team discuss this as a point of interest, debating whether it is that women are more likely to 'give in' to Owen, less likely to stand their ground, or that Owen finds them easier to manipulate. There is something victorious in the atmosphere as this is discussed, maybe because Owen as persecutor, and me as victim, leaves the rescuer position up for grabs¹⁵.

I feel weary, aware that Owen and I exist in theory only to them during this conversation: their scripting and role-casting necessitates our being silenced and sidelined. Yet we flank the chatter, physically and psychically present, but uninvited. Owen (persecutor) reaches out to me again (victim) with his eyes and I look back at him. There is the plot we are both listening to, and there is this: real-time, solid connection. It is not an accident, it is a necessity.

¹⁵ This is a reference to Stephen Karpman's (1968) 'drama triangle', a social model of human interaction, which poses that three roles must be taken in conflictual spaces: victim, persecutor and rescuer.

Even so, I have an internal wrestle: I have something to say, don't I? Perhaps I could join in. But I find alongside this a fear that my voice would be squeaky or frail if I did. The story told about us settles further over my mouth like a muzzle. There is no occasion to speak. Much like Owen.

I look over at today's team – they seem strong, tall and physically powerful. This is only an advantage if physical dominance is the goal, which presumably it is not.

Against them, Owen looks slight, spindly even. And again he turns his face down to his plate, but lifts his eyes to catch mine. And I stretch my mouth into a flat smile and hold his gaze. This is where the strength is today: between us. In silent agreement – I just don't know what we're in agreement about yet.

Something has happened in the lead up to this moment between Owen and me today; something I don't understand yet.

The day started differently: as I had greeted him on arrival, he had acknowledged me with a brief moment of stillness and quiet as I talked, pausing his soundtrack and movement as I spoke.

The house had been busy, and Owen seemed restless. He had walked decidedly out of his bedroom, past the staff chatting in the corridor, taken my hand and led me towards the staircase to go downstairs. A staff member I didn't know broke off his conversation to try to physically pull Owen's hand out of my hand, until I had reassured him it was fine, I would just need a staff member with us. We had gone downstairs to the dining room, where Owen had tapped the microwave and the staff member had told him to wait for lunch in 25 minutes. Owen, who still had my hand firmly in his, led me over to his little table, indicating for me to sit in one chair, sitting opposite and holding my hand across the table.

It wasn't something I'd ever seen Owen do before. Whilst I had seen him take a person's hand to ask to go places, I hadn't seen – or heard of – him choosing to sit with a person and keep this level of contact. It seemed straightforward, just unusual: he wanted me to be there, needed me to be there.

After a while Owen had gone for his medication, and I'd waited for him to return at a distance, familiar now with the all-too-common rushing down the corridor from the meds bay, as he attempted to dispel the anxiety of both waiting for and taking his medication. I had held the door open so he

could spill out into the grounds, find the space he needed to shake off the overwhelm of nasty liquid medications being swallowed in a small space. But as he had charged out the building into the open air, he had slowed, and then reached his hand back to take hold of mine, leading me around to his precious bench, his place of sanctuary, and gesturing for me to sit next to him. He sat down after I had, my hand in his. I was close enough to be inside the reach of his quiet soundtrack, its hum encapsulating us both. His head flicked from side to side, as if keeping guard for us both – and at some point, instinctively, I placed my other hand on top of his, so his hand was between both of mine.

And so it is within the context of these recent memories from the morning held in my mind that I find Owen and myself sitting like brackets around a tangent, held together across the breach by a connection Owen has reached out for with intention and deliberateness.

Before I finish my lunch, Owen comes over and takes my hand. I say, 'Just wait a minute; let me put my plate down'. He listens and allows me to go over to the mantelpiece and deposit my plate, but he keeps hold of my hand, trailing after me lazily. We go over to the board and he points to the grounds symbol.

I say to Jon, 'Is that okay?'

We go outside with Jon in tow. Owen seems calm and settled, but asks to come in again and I notice that he limps in, his toe lifted off the ground and throws himself down on the bed.

He is flagging, I realise. He lies on his back, rocking gently with his arm swinging in the air. But it seems to me that he's still present. He's not cutting the world out today.

He remains unusually aware of the activity around him, not utilising any of his usual blocking-out tactics – a TV or song on loop, forceful head-swinging, an accompanying sound-wall of noise emitting from his throat. Instead, he remains present. And I remain present to him. After a while, he turns onto his side and appears to go to sleep.

The next hour is full of things that Owen is asleep to. There is some disappointment and upset regarding the manager, which is met with banter from the seemingly ever-male team. There is a brief conversation about Owen sleeping – whether to intervene or not. Which is replaced by a

conversation about me – whether, because he is just sleeping, they should send me away or not. I repeat several times that I am not here to see Owen ‘doing things’ or ‘learning’, but here for his whole experience. I am content to be here whilst he sleeps. This is finally, and grudgingly, conceded to.

Soon everyone disappears except me, a support staff member I don’t know well and the sleeping Owen. I sit back in my chair in the corridor and ponder the day so far: Owen’s proximity and presence with me, and his checking in that I am with him. Really with him. I feel rested, even as he rests. And the connection, I guess, remains between us. He has sealed it in.

Here’s the odd thing about the next bit of the story: I can’t tell it.

I can’t tell it because it involved a speaking, neurotypical person exerting power over Owen. They made a series of emotive decisions which implied that, when it came to Owen, physical dominance was, indeed, the goal.

And I watched this playing out without stopping it. I had felt frozen to the chair: paralysed. Like I was watching a film, my hands over my mouth, my knees drawn up to my chin.

Not until much later in the evening, when I had several hours and miles of distance, could I think straight again. Only then did I come back into myself and reach out to tell the people that needed to know that something had gone wrong today.

I told them, but I can’t tell you.

It’s almost certainly not as bad as you’re thinking. But it wasn’t nothing.

But I will tell you this: several days later Owen, leveraging a brief height advantage over that same staff member, returned the favour, having learnt that, apparently, physical dominance was the goal.

No-one but me and those I had told knew what had preceded this. And so it was recorded as another random and unprovoked outburst of violence from Owen. A product of his autism. A product of his otherness. Evidence of his inherent unpredictability. But it was little more than a mirror, an exhalation of what he had previously breathed in from them.

And of course, this not-told-story reframes the day: Owen's relentless present-ness and his bid for continual proximity with me. His checking in: am I with him? Really with him?

I have wondered – did Owen know this was coming? Could he feel it in the air? Had he read it like Braille on skin?

I don't know.

But I know he sought proximity with me, sought a tethering to me, a safety. As a manager, who knew the whole story, said to me later: I assume the hand holding was for reassurance? Yep. I assume so too.

But it was not enough.

Despite Owen's intentional seeking of reassurance from me, despite me working hard to remain present in the space whilst he slept, in the critical hour, I succumbed to the powerful narrative spoken over us: the narrative that I, the victim, was less likely to stand my ground. It played out as if it were a truth just hours later, as I gave ground to power asserted – not by, but against – Owen, and fell silent under the intimidation. Knifeless and non-speaking, I couldn't find my voice until I left.

Unless resisted, the stories told about us retell us in time.

Nine: Leaving and returning

It's the same day. Owen is back on the bench outside looking sleepy and bedraggled.

I am so sad – sad and confused – and still deeply connected to Owen, and struggling to pull back to think about much else. This time, I ask him: 'Owen, can I come and sit next to you?'

He taps a 'Yes' on his chin.

We sit together. I am very still. He is very still.

A staff member is chatting chaotically to both of us. We ignore them.

Owen needs to go back inside for the bathroom. I follow him in, wait, and then come back outside with him. Rob joins us, having just arrived on shift.

As we go outside, I walk in front of Owen without looking behind me.

I don't usually do this. Knowing how he likes to fly from the house, I tend to stay out of his way. But today there is a deep connectedness between us. And though I can't see him, I can feel him. I can feel the sadness in him slowing his pace, weighing him down.

Owen makes his way towards the bench and settles into the grass.

I sit down some distance away with Rob, who eventually breaks the silence:

'Hey, listen, don't ever walk in front of any of these kids. Always have them in the front.'

I feel weary. I say, 'Yeah, I understand what you're saying. And thank you for the heads up. But I've been with Owen all day. And he's been very gentle with me. So I get what you're saying. But I think it's fine today.'

Rob doubles down: 'You never know what they're going to do next. No one understands him. No one can understand him.'

He settles down on the seat next to me, uninvited, and with more words.

'It's different with these kids, because they're minors. If they attack you, even if they attack you badly, all you can do is put your arm up.'

He puts his forearm in front of his face to demonstrate. I feel a bit sick.

He continues. 'It's different in an adult mental health hospital. There, if someone attacks you, you can just grab them and put them to the floor.'

I have a thousand words to say. And say nothing. I shut my mouth tight and remember that this too is Owen's experience of the world that I am here to understand: these assumptions, these beliefs. They are held in Rob's heart, but seep up, overflowing, and Owen will read them with his expert literacy in body language, touch, tone, emotion, regulation. So I shut my mouth and sit with the nausea. Non-speaking.

Soon enough, I take my sadness over to Owen; perhaps seeking some sanctuary in his wordless authenticity. I ask Owen if I can sit with him on the bench. He signs 'Yes' on his chin and I sit down.

He is agitated. He swings his head with large movements. His soundtrack is loud and prickly in my ear: a low roar. He stands up and looks around, wary and vigilant, his head swinging sharply from side to side, looking quickly from left to right out into the distance for signs of coming danger or trouble. But he stays close – occupying the space with me. And I stay inside this realm of anxious agitation, and let Owen be watchman for the both of us.

After 15 minutes, Owen's roar is overwhelming me, and I reluctantly return to sit with Rob.

Owen shows no initial response to my departure, but shortly afterwards, he stands on the bench, and, with great deliberateness, hurls his stuffed bear over the locked gate. He turns accusingly to Rob and points in the direction of teddy's flight. Rob sighs, getting up to retrieve it, making his way through the gate and disappearing behind the hedge.

Owen watches, stepping off the bench as Rob walks away. He strides quickly to the edge of the flower bed in front of him and stretches his long hand, forefinger pointing, into the back of a bush, looking intently at me. He is vocalising at me with some urgency.

I walk over: 'What is it you want?'

He takes my hand, and pushes it towards the bush. I step gingerly into the flowerbed, to try to see what he has seen. Right at the back of the bush is a red teddy lying discarded and muddy. I am so surprised – and

I look back at Owen in wonder, as my mind begins to catch up with the story Owen is telling me, the secret he is bringing me into – even as Rob is the other side of the hedge. Owen threw this teddy here – how long ago? Perhaps yesterday, perhaps weeks ago, he expelled this teddy to the back of the bush, just like the bowtied teddy who had carried Owen's humiliation into exile. I had assumed exiled teddy was forgotten by Owen. But here is a teddy remembered: split off, out of sight, but retrievable.

Playing for time as I take this in, I look at Owen and again at the dense shrub: 'Owen, it's a long way back'. He takes my hand again and looks me very intently in the eye: now is the time. He pushes my hand towards the back of the bush.

'I'll see what I can do'. I push my way into the bush. And I find not just one bear there, but a store of teddies. I hand him the first, saying, 'There's more. Wait.' I hand him the second, then the third, and I am reaching for another when Owen spots Rob reappearing around the corner and scarpers into the wide open space of the lawn, the three teddies caught up in his arms.

And I stand tall to watch with satisfaction Rob's appearing through the gate holding the one discarded teddy, only to see Owen flying helter-skelter out onto the lawn, erupting with shouts of glee, the three retrieved teddies in his arms.

Owen, like Cassie, has secrets to tell, stories inside him, precious things hidden but not forgotten.

And on this occasion, Owen sends Rob off – the Rob who asserts that Owen cannot be understood, who is a law unto himself, unpredictable, a force without reason – Owen sends this Rob on a wild goose chase, a distraction, so that he and I can talk about the safe storage of his treasures, the teddies who hold a multiplicity of things for him, and that he is now ready to bring back into the fold. And will I please retrieve them for him.

No doubt the expulsion of the teddies behind this particular bush looked as random as the forlorn teddy who is still sprawled on the air conditioning unit, wearing shame on his coat like a scapegoat. But it is not just me that has not forgotten. Owen knows where they are. He holds them in his mind. He remembers. He is a thinker of thoughts. A holder of stories. And when it's safe – when he has an ally – he retrieves them, like buried treasure.

This is something which is, to me, somehow full of light.

And I hold the stories for him too. Even now, as I write, I continue to hold the richness and vastness of Owen in my mind. I remember. And when it's safe – when I have an ally – I retrieve him.

Here he is. On the page. Full of light.

Another staff member, Eduard, takes over. We sit quietly, watching Owen.

The bears are gathered into his arms as he jogs across the grass. He stops suddenly and throws each bear in turn out in front of him, watching them arc. Then he takes his shoes off, and throws them across the same arcing swoop, down onto the grass with the bears. He looks at them briefly, then runs to gather them up in his arms. Once again, with great fury and precision, he throws his teddies and shoes into a neat pile, then runs to retrieve them.

I think of the many comings and goings of things and people in and out of Owen's life. So many things he can't control. And the deep sense of loss that he has shared with me already – the love of his family, the departure of staff he trusts, the arrivals of those he doesn't. And so on. And so on.

Eduard interrupts my thoughts of Owen's furious power grab, his precise unleashing of control, the careful choreography of the here-ness and the gone-ness of the bears and the shoes. 'I don't know what will happen to Owen, when he leaves here.'

Owen's departure is not imminent; he could be here another two years. And so Eduard's interruption sounds like an echo of Owen's enactment of departures and retrievals playing out in front of us. And, perhaps, there is a parallel question that I am trying to avoid: what will happen to Owen when I leave here? My time is running out, and I don't want to go.

Eduard continues: 'I just don't know where else he's gonna get what he gets here. Because we understand him. We know what he wants, what he needs. We know what he's trying to say'.

I listen to Eduard, as I recall Rob's assertion from just a few minutes ago in this same space – that no-one can understand him.

To be simultaneously known and not known. Seen and unseen. Dismissed and received. To be knowable and unknowable. All in one small space and time: a garden and an afternoon.

Owen is running across the lawn to gather up his teddies and shoes, before throwing them again. He throws them all in a heap with a look of annoyance – as if he wants them away from him – and then runs to pick them up again. A simple act of restoring order and control: a discernible pattern to the leaving and returning. Expulsion and retrieval. Absence and presence. Rejection and embrace. There and here.

Eduard watches on with rising annoyance, then goes and picks everything up, piling the shoes and bears on the table where we are sitting.

Owen watches him, furious. He picks at the grass angrily and throws it with a violent thrusting of his arm.

Inexplicably distracted, Owen suddenly inspects his t-shirt closely: he's been wiping his hands on it, damp from the grass. His eyes widen at something I cannot see and he roars. Tearing his t-shirt off over his head, he walks over to Eduard and hands it to him – a concrete expulsion over which he can take control. Eduard, seated on the bench, and caught off guard, takes it. Owen stands over him, lifting his arms above his head and waving them violently at Eduard so they shake around him like autumnal branches. He launches a ferocious roar into Eduard's face.

I find myself exhaling with Owen's roar: relieved. The freedom to rage against the one who has gathered up his things: his discarded and retrieved things. Eduard is big enough for this, and though he leans back out of the squally anger, he does not move away or push it back, but remains and receives it along with the infuriating t-shirt, allowing Owen to leave them both there with him – the t-shirt and the wrath.

Having thundered eloquently at Eduard, Owen lowers his arms, turns on his heel, and parades across the lawn, shirtless, quickly slipping into an easy saunter.

Eduard grins at his white back glistening in the sunshine: 'Classic Englishman'.

We watch him walk away.

'First minute there's a little bit of sun out ...' I say with a smile.

It's time for me to go.

Power has torn around the space all day, oppressing and raising up, intimidating and asserting, offered out and relinquished. But inside – or maybe it's outside – the power dynamic is something better, stronger: connection. It encompasses the jabs of power-struggle into an exhaled panoramic, big enough to hold it all together.

As a war against the stories told to me, and the stories I cannot tell, I tell the story I have: this is Owen, a thinker of thoughts, a holder of sadness, with home held inside him like a precious bear at the back of a flowerbed, rediscovered together with joy and defiance.

Ten: A defence against the cold

Reuben helps Owen get changed and gets his shoes ready. He looks so smart, sitting on the bed, an air of happiness around him. Reuben has put his favourite programme on the TV. The call comes through to say his parents have arrived. Emma wants to be the one who goes in and tells him. But, oddly, she doesn't really. She simply taps the photo of them on the wall and says, 'Guess who's coming?'

Reuben helps Owen get his shoes and socks on, and he goes downstairs and outside. They're not there. Owen sits on the bench and looks bereft. Reuben helps him put a jumper on and I go to find his parents, turning the corner to see them making their way towards him ahead of me.

I stand at a distance, watching him smile to greet them. His Dad brings a picnic blanket out of the basket, and Owen stands with apparent familiarity at this ritual, as his Dad folds it up into a cushion and places it under his bottom, as a defence against the cold of the bench – the cold bench that Owen has sat on all morning, and will sit on again when they leave. Owen sits back down on the homemade cushion contentedly. His Mum hands him a new stuffed bear which he pushes gleefully into his face, smiling broadly, nuzzling his face and mouth into the fur. He holds the bear up to look at it again and gives it a good grin. Then he throws it across the lawn with delight, watching it fly.

This time, his Mum and Dad let it be, reaching instead into the cool bag, with Owen looking on expectantly.

And I turn and walk away, letting their easy rhythm and familiarity warm me from the inside out on this bitter January day. Here is home, in this home away from home.

Eleven: Being with

Owen is standing at the window looking happily out at the day which is shrink-wrapped in frost. I call to him as I'm setting my winter layers down on the chair: 'Hiya, Owen!' 'Hiya!' he calls back without hesitation. There is a new staff member sitting outside his door and he does a double take at what appears to be an ordinary greeting and response between a speaking visitor and a non-speaking Owen.

I say slowly from the doorway: 'Owen, can I come in and talk to you?' He glances around at me, and says loudly and enthusiastically 'Yi-yeah!' I smile and turn to pick up his gift bag, walking past the staff member, who looks as if he's wondering whether he just imagined this exchange. I note that it stills surprises me too – the fluidity, the conversational tone.

'Can I sit here?' I ask as I walk in. He taps a 'Yes' on his chin.

I sit down and settle myself. I look in Owen's direction, but shifting my gaze into the middle distance, looking out for a moment of eye contact until it arrives between us. I mark the connectivity with: 'This is Beverley's last visit'. I sign finished. 'Beverley's finishing her visits with Owen today.'

I reach behind me to get the card from the gift bag. I see that Owen's eyes are fixed on the fluffy pillow sticking out of the bag and he leans gently towards it.

'Oh, that's what you want. That's fine'. I pick up the bag and hold it out to him and he pulls the pillow out. He smiles as soon as he feels it – a big, wide-mouthed, toothy grin – and brings the pillow straight up to his face. He gently glides his nose and mouth across the fibres, feeling the tickle, before pushing the pillow on his lap and kneading his hands across it, grinning broadly at me in appreciation. He squeezes at the sides so it folds in half, and brings it up to his nose and mouth, nuzzling into it. He smiles and smiles and looks over at me, his blue eyes wide with pleasure.

Then he finds the zip, undoing it slowly and carefully. He reaches for the pillow inside and takes it out of the fluffy cover. He puts the cover on the floor and then squeezes and squeezes and squeezes the pillow with delight.

I bring out the card and show him how to open it so it plays the message I recorded earlier for him. As soon as the message starts he snaps it shut, and the message stops. I say, 'That's fine, Owen', and put it on his chest of

drawers. I show him the classical CD, telling him what it is. He looks across at it and I take the cellophane off. He opens the case and looks at the CD inside. I put it on his chest of drawers and come and sit back down again.

I look over and wait for eye contact. I say to him again, 'Owen, this is my finishing visit'. With his piercing blue eyes, he looks straight at me, holding my gaze with great intensity and expectation. I remind him: 'Beverley is leaving to think and write about you'. I pause. 'I'll be writing Owen's story – all that you've told me and shown me – and other people will read it'. He taps his chin, 'Yes'. 'Thank you, Owen. I've learnt so much from you.' He taps his chin, 'Yes'.

I sit back. I don't want to go. I wonder how long we'll have together today. What we'll get up to. What he has left to tell me. And then I feel his hand on mine, his fingers wrapping around mine. I look up. He lifts my hand and gently, firmly pushes it towards the door.

He's right. It's done. I'm not ready – but Owen is. The goodbye has been said and Owen has taken it at face value, and it must be honoured.

I stand up and head out into the corridor – the place of our first encounter, recalling the day when it felt like Owen could read my body language, but not really listen to my words. But here we are – talking, listening, being with. We've come a long way. But it's time now.

Time to tell the story Owen has told me and hope that, above the soundtrack, and despite the distance, you hear his voice too and do not shake the sound of it out your head, but let it ring out, loud and true.

This is Owen.

A reader of people, a teller of stories. Like so many of us, he is searching for home in this home away from home. He is full of light.

Part Four

Reflections

It's almost five years now since I said goodbye to Cassie and Owen, departing to write their stories. This has given me time to reflect on all they shared. Much of the learning from my time with Cassie and Owen we¹⁶ are taking forward into our current work with staff teams, who are in similar positions to the staff in the story.

Stories don't give us answers; they don't neaten things up. Rather, we instinctively look for – and find – ourselves and those we love inside the stories we read. As we find echoes of our own stories, some of the narratives we have been telling ourselves expand and splurge, like a jug of squash dropped on a Lino floor. It's kind of messy. But somewhere amidst the mess and the attempt to clear things up, we find new connections.

It has been messy for me, as some of the received wisdom, confidently asserted frames and theories I've picked up from working and learning in this space have needed to expand rapidly. So I want to return to the ideas discussed briefly in the introduction around 'challenging behaviour' and diagnosis. I'll do that in the first part of this section: *Unlearning*.

The dismantling of the old makes space for the new. So much of the stories with Cassie and Owen are about finding room for, and listening to, their emotional and relational expression. I will explore some of the constructs that allowed me to do this intentionally in *Working with our shared emotional lives*. In this section, I draw on the stories to illustrate four frames for understanding shared emotion, applying the ideas to explain

16 'we', as in the organisation I work for – Unique Connections.

key moments with Cassie and Owen, before thinking about these ideas more widely, including applying them to teams and organisations. I'll end with some brief *Final thoughts*.

I'm still learning from my time with Owen and Cassie, and will likely do so for many years to come. But, for now, here are my reflections.

Unlearning

Behaviour: yours, mine and everyone else's

You probably noticed that there's a good deal of 'challenging behaviour' in Cassie and Owen's stories.

I think of Owen's hurtling, fear-and-anger-fuelled ripping through the house, during which both Tom and I are hurt, which I recount in the chapter 'What just happened?'.¹⁷

The team understood this incident as challenging behaviour that was 'triggered' by a desire to escape the noise of a peer that Owen didn't like¹⁷. They were answering the question: 'What was the trigger?' (i.e. 'What happened *just before* the behaviour?'). Answering this particular question in order to understand an incident is textbook behavioural analysis, i.e. they were doing everything right. However, it's worth noticing how this answer neatly situates the 'problem' squarely *inside* Owen, and vindicates the rest of us present.

Sometimes we don't need a new answer, we need a new question. If we pull the frame beyond the moment in time, and consider Owen's emotional and relational experiences – something we'll talk further about later – we can move the question from 'What happened *just before* the 'behaviour'?', to the simpler, but much more unruly: 'What happened?'.

As Owen's story unfolds, it becomes clearer that perhaps Owen was grappling with an anxiety about where his parents were in the world, perhaps with a nameless dread that he had lost them. This was almost certainly brought to the surface by hearing Tom and I talking about them.

17 You won't have heard that mentioned in the story, because quite honestly, I didn't hear it. I completely trust that there was a peer vocalising in a way Owen didn't like, and I'm sure it didn't help matters – but I don't think this narrative explains why Owen continued to escalate in distress once he'd left his peer's noises behind.

When he tried to ask about them, we would not include him in the conversation, or talk with him about them. This led to Owen experiencing an intermingling fear and anger, and we know how this then unfolds.

This resituates Owen's response from a neurodiverse 'sensory overwhelm' (a response driven by diagnosis and coming from inside him), to stress driven by an interaction with past and present relationships.

Such an explanation takes some time and reflection to piece together, and probably isn't going to make it onto a chart. But it does a number of new things.

Firstly, it gives us a story (rather than an answer). We do much better relationally with those whose stories we begin to understand.

Secondly, the story draws on ordinary explanations for Owen's responses, explanations we find for yours, mine, everyone's moments of distress. The story is that Owen's 'behaviour' is a response to overwhelming emotions that rose up from distress related to past and present relationships and experiences. This is a human story, not a story linked to diagnosis or otherness.

Thirdly, now that the problem is not primarily *inside* Owen (as Owen's behaviour in challenging staff), but manifesting in all of us (in the way we all responded and reacted, as well as our shared stress/distress), we can begin to imagine that new ways forward might be found *together* – not doing *to*, but doing/being *with* the person in distress, and perhaps addressing some of the root problems, such as finding ways to talk with Owen about his family.

All of this to say that, for me, the behavioural frames are irrecoverably cracking. They simply don't stand up against what I learnt from being with Cassie and Owen. And they don't stand up against my own experience – my broader understanding of how we function and co-exist as humans. We are rarely at the mercy of the moment; rather, we are people trying to process and deal with our experiences so far.

Somewhere along the line – somewhere between incarceration and de-institutionalisation, perhaps – we appear to have collectively forgotten the ordinary shared humanity of people with intellectual disabilities. Instead, we record moments of screeching distress on charts that ask the wrong

questions, and confidently assert the wrong answers. Of course, they sometimes apply – sometimes we all ‘behave’ our way out of situations. Even a stopped clock is right twice a day. But they are grossly inadequate.

Perhaps it’s time for us to put the behavioural frame back into its place – inside a much wider, more human understanding of inter-relational emotion and response.

What to do with diagnosis

Throughout my time with Cassie and Owen, to greater and lesser extents, I observed both of them being talked *for* and talked *about*.

Sometimes I would greet Cassie on arrival, and her staff member would respond *for* her. When this happened, Cassie would act as if she hadn’t heard me. However, if I ignored the staff member and repeated the question, Cassie would often give me eye contact, and respond with a sign – and sometimes a little grin of appreciation. Her non-responsiveness was, in part, learnt, not intrinsic.

Owen was often talked about. I had a rare opportunity to experience what that felt like, as Owen and I were both talked about in our hearing in the chapter ‘Stories told about us’. I learnt that, when someone talks about us as if we cannot contribute, we quickly experience a sense of muteness, a silencing, and it feels hard to raise your voice:

I have something to say, don’t I? Perhaps I could join in. But I find alongside this a fear that my voice would be squeaky or frail if I did. The story told about us settles further over my mouth like a muzzle. There is no occasion to speak.

On occasions, I was told with confidence that Cassie or Owen were not listening or not able to understand what was being said. This was presumably based on the diagnosis of ‘severe intellectual disabilities’ and the belief that they were both ‘nonverbal’. This is not because the staff were presumptuous or ignorant – this is what we have encouraged teams to understand is meant by these terms. The trouble is, it’s invariably wrong.

As you now know, both of them spoke to me during my eight months with them. I still find this reality wondrous: that they so quickly met silence, presence and an expectation that they had something to say with so much communication, including a few spoken words.

For the first few months, when Owen used occasional words with me – ‘Yes’, ‘Hiya’, etc. – he only did so when no-one else was around to hear. On the first occasion Owen spoke to me in the hearing of another staff member, I watched them shake their head in disbelief, as if shaking the hearing of Owen’s voice out. Owen’s did not appear to be ‘audible’ to everyone. It was as if Owen’s spoken words could not undo the truth in his file that he was nonverbal. I have wondered if Owen only speaking in my hearing for the first few times was because a part of him knew this.

We cannot allow a diagnosis to dictate the terms for a person. Rather, we must limit the bounds of a diagnosis, and allow space for a person to push beyond it, however and whenever they’re ready. And we must seek to hold and understand the fullness of the person in front of us. We all have richness, mysteries waiting to be discovered, and brilliance inside us. And if given half a chance, we all have something to say, however this might sound.

What story are we telling?

Getting to know Cassie and Owen has consolidated for me some thoughts that were already embryonic: that the frameworks we have leant on, the questions we have asked, so many of the stories told so far, do not reflect the real-life stories Cassie and Owen told me about themselves and their experiences. And this matters, because stories lay paths for us, shifting our expectations; they influence our founding assumptions and our interactions. They boundary what we believe to be possible, and they frame and filter what it is we think we’re seeing. Stories are powerful, and they have the power to re-tell us – in that we occasionally find ourselves inadvertently walking into the story arc so confidently told to us, whether we meant to or not.

Like Cassie, perhaps it’s time to rip up the cardboard story book we used to read – the one that says: ‘Ignore him and he’ll stop’; ‘It’s a learned behaviour’; ‘She’s in her own world’; ‘They aren’t listening to us ...’.

Perhaps we can take a deep breath, shift our attention, try a new question. What story is each person holding inside them, waiting for a listening ear to retrieve it from the back of a flowerbed?

Working with our shared emotional lives

My time with Cassie and Owen was as much about what was felt as what was said. One of the joys for me was working with them to name and process their emotional experiences: sometimes we did this out loud, but often without words. I was drawing on some frameworks from psychodynamics for this work, which has helped me to understand the ways in which we transmit and take in emotions.

As emotional transmission happens nonverbally, the ideas I share here are particularly useful for being with people who are non-speaking. In fact, if you have someone in your life who is non-speaking, you've probably been doing some of this already. These sections should give you some language for what you have perhaps often done, though unconsciously and instinctively. I also hope that as you find language for it, it might help you move from instinct to intention.

I'll start with some foundational ideas about what emotions *are*, followed by illustrating from the stories the key concepts of projection, containment, transference and enactment, and then applying these further to ecosystems and organisations.

Emotions and the body

It's common enough to understand an emotion as something we 'think', but emotions are not thoughts. Emotions happen in the body: they are physiological. You can think *about* your emotions – and you'd do well to. But you cannot think an emotion.

Emotions are organised around two systems in the body called the 'appetitive' and 'defence' systems¹⁸ (Vos *et al*, 2013).

When we feel positive things such as happy, calm, rested or enthusiastic, this is broadly promoted by the sense that we are *safe*. Your body isn't built to focus on experiences that will make it feel wonderful or giddy or spectacular – rather, it's mostly assessing: *am I safe*? You might aspire to the 'pursuit of happiness', but your body is on a lifelong pursuit of safety, and all your feelings of wellbeing start with it. When your body feels safe, your heart rate settles, you breathe more deeply, and your body regulates

18 Lots of people have written about this, using various language. I recommend Nummenmaa's Bodily Map of Emotions (2014) for illustrations of how we feel emotions in the body.

your temperature and senses. When you feel safe, you can problem-solve, you can be curious and sympathetic, you can cope with inconveniences and annoyances, you can have new ideas and you can learn.

In contrast, emotions such as anger, anxiety, helplessness or frustration are activated by threats to safety. This activates your defense system – your fight, flight or freeze responses. This system begins to raise your heart rate and breathing, it primes your body for physical action. Your sensory system heightens, attuning you to hear, smell, sense and see anything that might represent a threat. As it does so, it subdues the slower parts of your brain that allow you to be curious and learn new things.

Our bodies are generally moving gently and subtly between these states, responding and reacting in tiny and imperceptible ways throughout the moments of each day, but ultimately always seeking to restore us to a felt sense of safety.

These two systems are adaptive – the more you use them, the faster and more responsive they become. So, the more experiences of threat or lost safety you experience, the more responsive/reactive your fight-flight-freeze response will become. This means that how our bodies respond now is not the end of the story: if we have a heightened fight-flight-freeze response, frequent new experiences of feeling safe, will allow our system to slowly adapt back to build from safety as a default.

Now here's the really interesting bit – and one of the foundations to these stories, that you've read about again and again: *we don't do this alone*.

Your body notices what is happening in someone else's body. We transmit our sense of safety – or lost safety – into the world around us, and we impact each other accordingly. Long story short: emotions are a shared endeavour.

The four frames below help us understand a bit more about how this happens, and how to work with our shared emotional lives. These four concepts, drawn from psychodynamics, formed the basis for a good deal of my interactions with Cassie and Owen, and continue to inform my work with teams supporting people with intellectual disabilities.

Four frames for understanding our shared emotional lives

Projection

Projection is the idea that, when a feeling is too powerful and threatens to overwhelm us, we manage this by unconsciously splitting off and projecting or pushing the too-powerful feeling into another person (Klein, 1936). This allows us to keep hold of remaining feelings of goodness, hope and trust. This is not deliberate – it's an unconscious process that we all use from birth onwards to lesser and greater degrees.

We see this happening with Cassie in the chapter 'Mum and Dad in our minds and hands'. I feel a deep sense of sadness even before we start 'talking' on the whiteboard. This is not 'my' sadness, though I feel it as my own, and neither is it sympathy or empathy; this is Cassie's sadness that has been overwhelming her – and she unconsciously projects it into me. My taking in of it, and naming of it, allows her to stay in a thinking, processing frame of mind, which assists our conversation.

We work with projections a lot in social care settings, particularly when teams are supporting those with no spoken communication. The strong emotions of children, teenagers and adults with little or no speech have even fewer outlets than usual, and so are more likely to be experienced as overwhelming and projected (Sinason, 1992).

Projections, when we learn to recognise them, name them and differentiate ourselves from them, can become insightful and informative. They were the starting point for many of my interactions with Owen and Cassie, and they continue to inform my work.

In the chapter 'What just happened?', I am unable to contain Owen's projected fear, and it overwhelms me. However, this visceral projection of his own experiences gives me a window into what is happening for him – the sense of the space and his own body being too small, too loud, and the relief he experiences when he makes it outside.

We can learn about someone's experience, even when it is too much for us. Taking time to reflect on these moments, name them, notice them, helps us prepare for next time differently. I take this opportunity in the chapter 'A return to proximity', breaking down my experience of Owen's projections and what I do with it in real time.

‘Perhaps this was less my fear of Owen, and more Owen’s too-strong feelings of fear projected into me as a question: what will you do with this?’

When we notice that someone else’s emotional overwhelm has been unconsciously projected into us, this is the question we need to notice that comes with it: what will you do with this? This is an invitation into containment.

Containment

The chapter ‘A return to proximity’ within Owen’s story continues:

I deliberately disrupt the fear, that is masquerading as my own, with the thought: this is not my fear. As I internally separate myself from it, I allow the possibility to rise that I might have the potential to overwhelm the overwhelm – to digest the indigestible.

This is containment – that we work internally to notice the projection, name the emotion, own that it is not ours, and then bring our own capacity for calm to digest it, break it down (Bion, 1962). As we learn to do this – and it takes support and practice – we can also learn to offer something back to the person who is overwhelmed (Saltzberger-Wittengberg, 1970). Something more digestible – something that can overwhelm the overwhelm.

On this occasion, this was not something I was doing alone – and it often requires some co-working with others in the space, and some receptivity in the person to take back in what is on offer. I acknowledged this, as I wrote:

It is seconds, but it is enough: Owen’s capacity to connect with me vanquishes the anxiety. I hear Emma whisper to herself from the other side of the room: ‘Nice’. Owen turns away and I turn to Emma and share a smile with her of so much unspoken.

This is a three-person interaction, as Emma and I work together to settle the fear that is beginning to overwhelm Owen. As discussed already, this sort of thinking and interacting problematises the idea that the source of the problem is *inside Owen* and resituates the problem *among us*, something we can work on together. It’s worth noticing that Emma engages and notices this process happening between us, though perhaps she had no language or frame for it.

Many staff have a natural capacity to hold and contain emotional projections. It is often the very quality that makes them ‘good carers’ – it is this capacity that makes people want to be around them, and leads them to experience fewer episodes of distress with those they support. But without a name or an explanation, it isn’t clear what they are doing that it is different; nor is it something that can be taught or explained.

Reuben, one of Owen’s ‘preferred staff’, was very much like this. I once asked him what he thought Owen was feeling during moments of distress. He paused thoughtfully and then responded: ‘I think it’s anxiety. Because if you can be calm yourself, then he can calm down too’. This wasn’t a theory – I had watched Reuben work extremely hard at remaining composed and calm when in interaction with a distressed Owen, and I had seen the anxiety dissipate from Owen in response. Reuben’s succinct and articulate answer reflects the concept of containment as our capacity to receive and hold unbearable feelings, as well as the possibility of offering something different back.

This starts by learning to regulate our own emotions, noticing what is happening in our bodies, and naming the emotions we’re experiencing. Naming an emotion helps move the feeling from the brain stem – our bodily senses and responses – into the frontal cortex, where we can be curious, tell sense-making stories about what we are feeling, and reflect on the experience.

We can also do this with the emotions we receive from those around us. We can hold them, and we can name them. And if we are able to digest – or process – the feeling, we have an opportunity to offer back to the person something more manageable.

This is quite different from that which challenging behaviour frames offer us. If Owen is ‘triggered’ by the noise of another, losing control, and consequently posing a risk to me, then I will do well to protect and defend myself. This happens not just physically, but we tend to internally defend ourselves simultaneously, becoming less and less available, disconnecting ourselves relationally, physically and emotionally.

However, reframing these moments as a person experiencing overwhelming emotion that could be taken in, digested and offered back as something easier to manage, offers interactional and connective possibilities. And connection, once found, starts to break the rules.

Transference

Transference represents the transfer of unconscious thoughts and feelings that we have towards one person into a new relationship (Joseph, 1985; Klein, 1952). I find it helpful to think about this as a three-person transaction that is usually happening between two people – so there's always an un-named other somewhere in the background (the unconscious).

We see some transference and counter-transference at work in the scene with Emma and Cassie, in the chapter 'Is it okay?' We might take Emma's plaiting of Cassie's hair at face value: an expression of care and trust between Emma and Cassie. However, it's also likely that they bring into this moment something of their own experiences of parent-daughter relationships, whether it be the presence or absence of them.

I became aware of my own counter-transference¹⁹, partly in the moment, and partly later as we reflected on it in my regular supervision with a child psychotherapist. My Mum plaited my hair every morning for years, just like this. So this moment was an echo of something from my own childhood. My job, as a researcher (and more broadly in my work), was to be aware of my own transference – not so I could cut it out of the frame, but so I could hold it at the level of consciousness (Winnicott, 1956). This helped me ensure I did not overly entangle myself in the moment, or in the interpretation of the moment.

So looking at this moment through the lens of transference – what we might each be bringing to the moment from our past experiences – we can see why there was such a lot of mother-daughter resonance in the room. It wasn't just about the three of us, but perhaps amplified by maternal transferences – significant relationships we each held inside ourselves that the moment called forth.

Transference is a really useful concept for helping us disentangle relationships that feel stuck, or patterns of interacting that feel like they're caught on repeat. We often start to consider transference when teams are talking to us about a young person being 'obsessed' with something, or that they have a 'ritualised behaviour'.

¹⁹ Counter-transference is what (traditionally) the therapist, but in this case, myself as the researcher, is bringing to a moment from their own past relationships and experiences.

We see this later in the chapter ‘Missing Jon’. Cassie wrote Jon’s name over and over again, not just with me, but all the time. The team found it wearing and sometimes referred to it as ‘obsessive’. This was partly because it was hard to understand; whilst her friend Jon had moved out of Cassie’s house, he had only moved next door. He wasn’t gone – he just wasn’t present to Cassie very much. She rehearsed this loss over and over again, like a small wound she wouldn’t let heal, and the team, understandably, could not make sense of it.

But behind Jon was another loss. An unnamed other, a transference of feelings and patterns from another significant relationship: her Mum. The transfer of feelings was fairly straightforward – like Jon, Cassie’s Mum also wasn’t gone – she just wasn’t present to her very much. Cassie was stuck in this interaction around Jon, because she was stuck in her loss around her Mum. When I sat with her and made space for the loss of Jon, the transference could begin to be named and thought about. Once she had said all she needed to say about Jon, she trusted me with a conversation about her Mum – and then later her Dad. Jon was Cassie’s metaphorical gatekeeper – if we could think about him safely, perhaps we could think about her Mum and Dad. Thus, Cassie’s feelings about her relationship with her Mum were unconsciously transferred onto her feelings about her relationship with Jon until they could be thought about and processed²⁰.

Transferences are harder to notice than projections; but it’s worth considering what absent person or relationship might be unconsciously ‘in the room’, when we feel stuck in an interaction with someone.

Enactments

Connected to transference are enactments. These are moments when past experiences are unconsciously acted out in new situations and relationships. Enactments can happen in interactions with others, and they can occur with toys or objects, as a way of shifting the power from something that happened to the person, to something of which they are the protagonist. Enactments are more common amongst people with little or no spoken communication, because ‘that which cannot be spoken will be acted out’ (Beail, 2021: 15).

²⁰ Notice the level of conscious and unconscious emotional and relational strategy that Cassie employs in this process. Her careful testing of safety in our relationship is both wise and sophisticated. We should not underestimate the emotional skillset of those with no spoken communication.

I pause in the chapter ‘Cassie is telling this story’ to talk about Cassie’s enactment of tenderness and terror with the teenage doll. For me, the mirroring with her own experience – throughout her life – was very heavy. The doll Cassie had treated so tenderly was bouncing off the walls – the walls of the ‘organisation’, with all the inevitable limits, procedures, staff changes and so on. But this place was also Cassie’s home and her family – the place where she had moments in which love overflowed as she had her hair plaited, where she leaned on Leo’s chest because she was tired. And as Cassie enacted this incongruity out upon the teenage doll, with all its attending conscious and unconscious emotion, it felt like a re-telling of some of the extremes of love and abandonment, affection and function that she had experienced during periods of her short life.

For me, these were some of the most difficult moments to observe, as the pain of past interactions was played out before my eyes. But I also knew that to sit with the attending emotion – to hold and *contain* these moments – gave Cassie and Owen a space to ‘talk’ about the things that they had experienced, and to be heard.

When enactments are this loaded, it’s hard to imagine that a quiet listening is anything at all. But sometimes not-enough, where there was none before, offers more than we could hope.

Re-framing

Reflective space and story

Quite honestly, it is a daring thing to notice transferences and enactments for those we care for on a day-to-day basis – because it’s emotionally costly. When I worked in a children’s home, there were perhaps two occasions when I was able to notice and name the enactments of young people we cared for. Both times it was difficult to get agreement around what was being communicated and what to do in response.

So many enactments go up into the ether and evaporate; they provide a catharsis for the person, but it goes unheard. To catch them out of the air and pay attention takes deep breaths and bravery and all of us. Thus, external consultancy or facilitation is often necessary to create enough safety for a team to reflect on what they are seeing and hearing, so they can move out of ‘stuckness’ with the person they are struggling to understand or relate with.

A key aspect to this is making space to hold the person's story. Many teams are trying to support distressed individuals with no 'big picture' of their lived experiences. All they have to work with is the here and now, with behavioural frameworks affirming that this is all they need. (Perhaps, when the emotional distress of those we support is significant, behavioural frameworks also operate as unconscious defenses, allowing systems to function in a way that detaches them from the powerful emotions that might otherwise overwhelm them.)

When working with young people who cannot tell their own stories verbally, there has to be some cogent holding of their story by the team around them. There is less need for detail, but we need to know the broad brushstrokes of a person's experiences and their significant relationships, including those they've lost.

In addition, there needs to be enough reflective space to help teams to notice and process when they themselves are getting caught in enactments. Cassie's grief was known to the team. They were aware of her story – the death of her Dad and the relative absence of her Mum since then. But the team could not bring themselves to be present to it, something we see playing out very painfully in Cassie's opening scene. This was likely a combination of being unsure of what to do and the weight of the emotion Cassie was holding, as well as potentially the team unconsciously re-enacting Cassie's sense of abandonment. This happens much more commonly than we can bear to admit.

Making space for emotions such as those that Cassie was holding is not a neutral act. It can feel like the strength of the feelings we are being asked to hold may overwhelm us, sweep us away. Listening is most difficult when what we are hearing is grief, or fear, or anger. But whenever we can, these are the moments in which we should stay. Stay and listen. Something always happens when we choose to stay.

When both reflective space and story are available, teams are more likely to be able to work with the emotions and distress transmitted by (and around) the person they support. They are more likely to be able to notice their own interactions when distress mounts, notice when things feel 'stuck', and look for new ways through.

Once a team is supported and equipped to think in this way, a person's interactions and presentations start to make sense in a way they

didn't before. A team can, through practice and support, develop new patterns for trying out different ways of responding, or recognising the 'thing behind the thing', in order to help the person move forward. This sort of work can feel scrappy and require more internal wrestling and honest conversation, but it can be deeply satisfying work, even when incomplete.

Once again, sometimes not-enough, when there was none before, offers more than we could hope.

When organisations split

Understanding how emotions unconsciously move, split and are projected and transferred is useful not just for people, but also for place – particularly when we think of organisations as living organisms, with their own emotional lives and unconscious processes²¹.

We see some of this happening in the place Cassie and Owen lived. For Cassie, this place was home; there was no other, not really. She moved here like another young person might move into foster care – and so this place was home and family, everything. For Owen, this place was home away from home. He had a family, and they were present weekly, though he did not go 'home' anymore. For others of their peers, who went back to their family home some weekends and most holidays, this place was perhaps nearer to a boarding school. Thus, this organisation was being a home, a home-away-from-home, and a boarding school all at once and simultaneously. In many ways, it was having a perpetual identity crisis²².

We feel anxious when we lose clarity of purpose, and so do organisations. The feelings arising from the ongoing difficulty of the work can easily get split up, projected and enacted.

We see these split and projected anxieties playing out in the stories on multiple occasions. For instance, in the 'Intangibles' chapter of Owen's story, we witness an affectionate squabble between Owen and Emma during his bath. It has overtones of family and home; we can almost feel

21 Obhozer's (2019) book, *The unconscious at work*, expands these thoughts much more fully.

22 This is not at all uncommon in spaces that are trying to be both learning spaces *and* homes ('residential schools'). In UK policy, there is an emphasis on love in children's social care, whilst educational policy emphasizes professional responsibility, but never mentions 'love'. This leaves places trying to offer both with a tension to manage (or avoid).

the warmth of *'children in children's homes should be loved'*²³ in action. In a matter of minutes, this is replaced by the voyeuristic stoicism of the cleaning team, an enactment of humiliation and depersonalisation, reminiscent of sanitised and professionalised group-care. This scene-flipping is less about good and bad people, and more reflective of split emotions from an organisational unconscious that cannot settle what or who it is – cannot agree whether it is primarily loving or professional, and so unconsciously splits and projects the two extremes.

The tension and anxiety of straddling two purposes needs thinking, reflective space, so that the anxieties arising can be contained. This organisation, in something closer to survival mode post-Covid, which removed almost all external support, did not have enough thinking space to hold these things together. So the anxious emotions split and dispersed around the teams, and we see the impact of all this – and many other systemic anxieties – playing out over and over again.

Intentionally working through the tensions of encompassing a vision for educational excellence, alongside a vision for a *'stable home, built on love'*²⁴ would not have solved everything, but it may have given the anxiety and fear that so often careered around the place somewhere to be held. Such work is not straightforward, and often requires some external support, but it is ubiquitously needed in organisations doing unrelenting emotionally and relationally complex work.

All that is held inside

Both Cassie and Owen were holding whole worlds inside them, the fullness of which we had the privilege to only glimpse. Cassie shared with me much more than I had expected about her family, and it felt like a relief for her to sign, write or say their names and let loose the attending emotion as she did so. It was a privilege to be entrusted with this.

Both Cassie and Owen's stories continually remind me that we must never forget that we each carry our families inside us one way or another. This is particularly pertinent for those who have left home before adulthood. Regardless of the quality of relationship we have with our parents, we hold

23 This is a quote from the Key Principles in: Department for Education's (DfE): (2015) Guide to the Children's Homes Regulations including the quality standards

24 *'Children's social care: stable homes, built on love'* is the title of a DfE consultation on children's social care, including children's homes, published in 2023.

something of that relationship inside us, and we carry it into all future relationships. This is true even of those who never knew one or both parents. The absence of someone can work itself out powerfully in us, just as presence does.

However, we are often struck in our work by the speed with which organisations forget or sideline families. This too, can be a manifestation of overwhelming organisational anxiety being split and projected.

Every child that leaves their family home to live in children's social care does so with loss. Certainly, there may be many other emotions: relief, the restoration of safety, the breathing space that predictability brings, and so on. But the loss is still there. And we have to be collectively big enough to hold it. When we don't, it gets acted out in troubling ways. Sara Ryan warns us against treating a disabled child as an 'atomized' individual – 'a separate person who has little contact with others' (Ryan, 2020, p. 25). Instead, we must remember that the child in front of us holds their family (both the presence and absence of them) inside them, just as we all do. They need us to think about this with them, and to help them rediscover a sense of home and hold it safely inside them.

Final thoughts: Telling new stories together

The final thoughts of my PhD thesis ring true again. My hope has been in the telling of Cassie and Owen's stories,

*'to share them as the treasure they are: as gold
mined from oft-hidden lives ... It is my hope
that these accounts of their experiences have
honoured their stories, even as I have tried to
share them from a heart made bigger by their
loss-tinted, joy-speckled generosity'*

(Samways, 2023: 204).

Cassie and Owen's stories have changed me. Their voices echo in my mind and heart. Their extraordinary generosity in sharing the richness of their internal worlds has done irreparable damage to my assumptions, and opened up a vista of new hopes and possibilities.

It is my hope, both in telling the stories and in exploring how it was that I learned to listen, that perhaps we can reframe the experiences of others living similar lives to Cassie and Owen. Perhaps we can find some new questions to ask, and discover some shared ways forward.

As we still ourselves, lean in, learn to listen again, what first-word might we hear coming from the lips of those who have thus-far stayed quiet? What might we learn from crisis and mess when we put ourselves back in the frame and consider the inter-relatedness of our emotional lives?

I hope you can learn to stay, despite the storms. To stay present and listen.

And to tell new stories together.

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