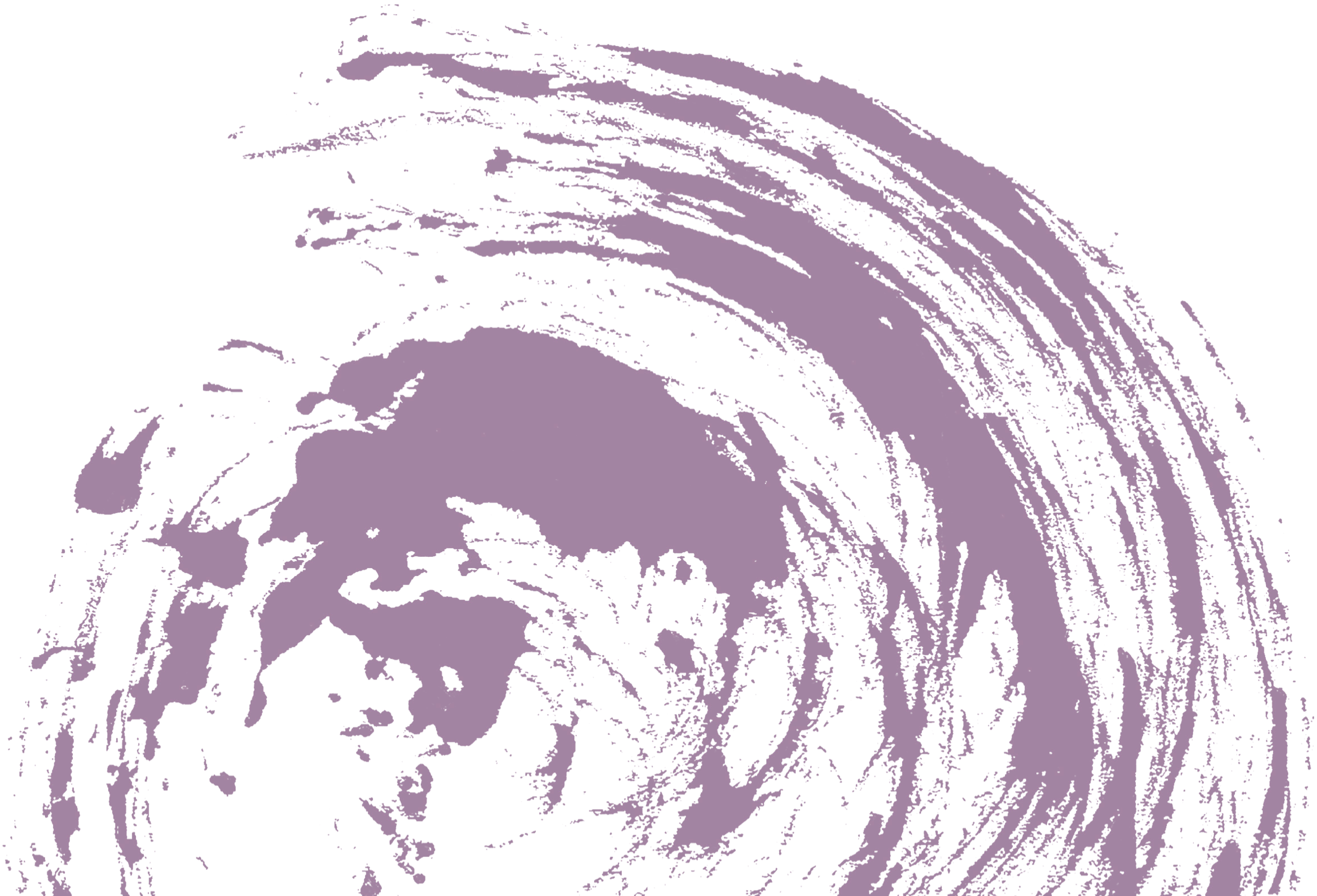
Sibs
For brothers and sisters
of disabled children and adults

Autism: The Sibling Perspective

A collection of stories, poems and creative work by adults who have grown up with an austitic brother or sister.



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October 2024

Sibs is the UK charity for brothers and sisters of disabled children and adults.
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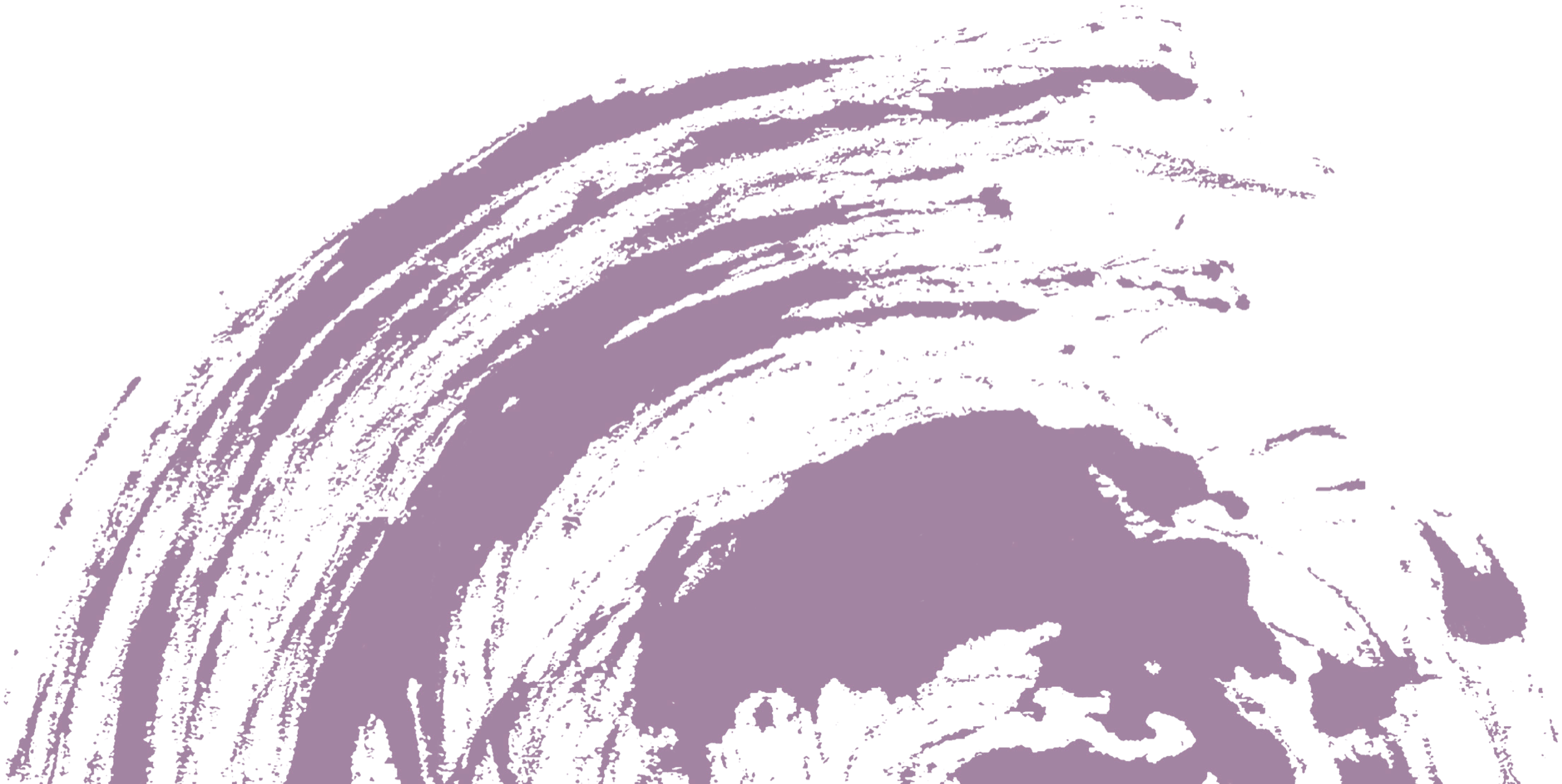
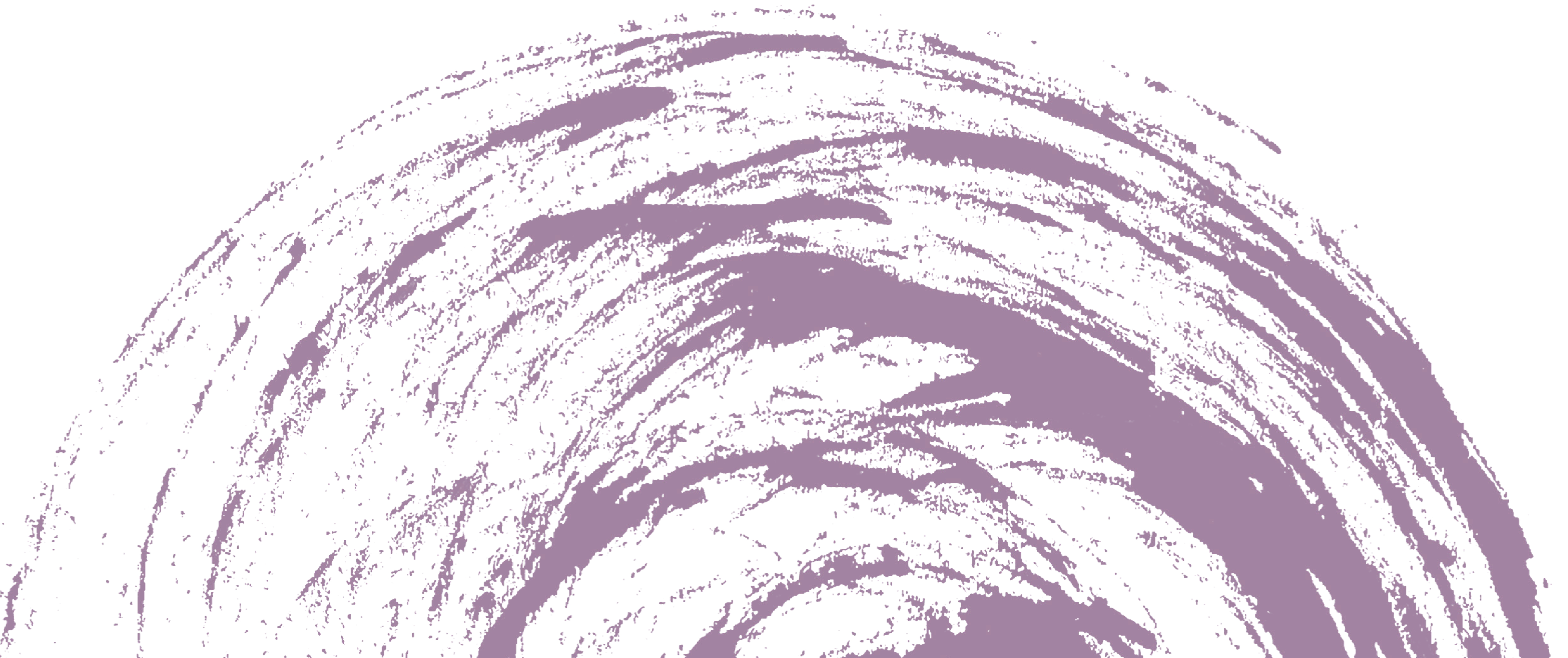
Contents



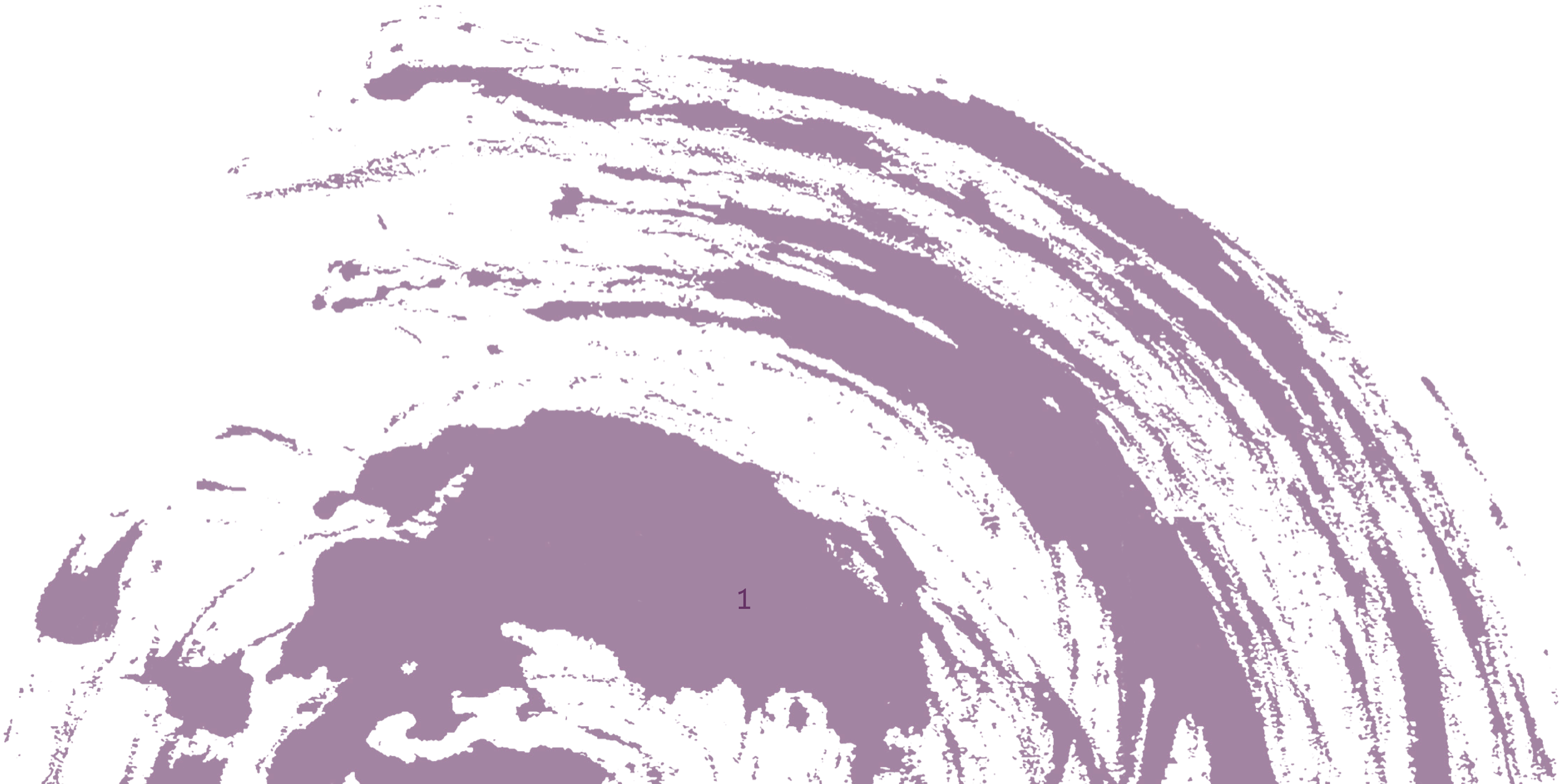


Acknowledgements

Sibs would like to extend an enormous thank you to:

- Our contributors: all the siblings who have grown up with an autistic brother or sister and who generously shared their experiences to make this collection possible — Barbara, Charlotte, Diane, Esther, Jack, Jack R, Josh, Judith, Kate, Louise, Maura, Monica, Mohamed, Pam, Poppy, Rachel, Rachel O-H, Ruby, Shamini, Tyler and Zeinab. Your words and images help other siblings to feel less alone in their experiences and help non-siblings understand what sibling life is like.
- Our reviewers: the following siblings from our volunteer reader panel, all of whom have a brother or sister with a lifelong disability and/or a neurodiversity — Freya, Helen, Joanna, Michaela, Pam, Rachel, Ruberta and Tricia. Thank you for reviewing this work. Your eye for detail combined with an inherent understanding of the topic has provided valuable insight throughout the process which has shaped the collection.
- Our funders: the Boshier Grant Scheme and the National Lottery Community Fund (Awards for All). Without this generous funding, this collection would not have been possible. When a funder chooses to invest in siblings they deliver an important message to a group of people who have been overlooked: you matter.

"I have just read Kate's story (p.56). The part that resonates with me is her realisation that she does not have to do things for her brother. She can say no without feeling guilty. It is only recently I have come to the same conclusion. I am aged 81 with a brother of 78 and a sister of 76. Both are learning disabled and are in supported living. If possible please let Kate know how much I appreciate her article. ***Thank you****."* Anon



Preface

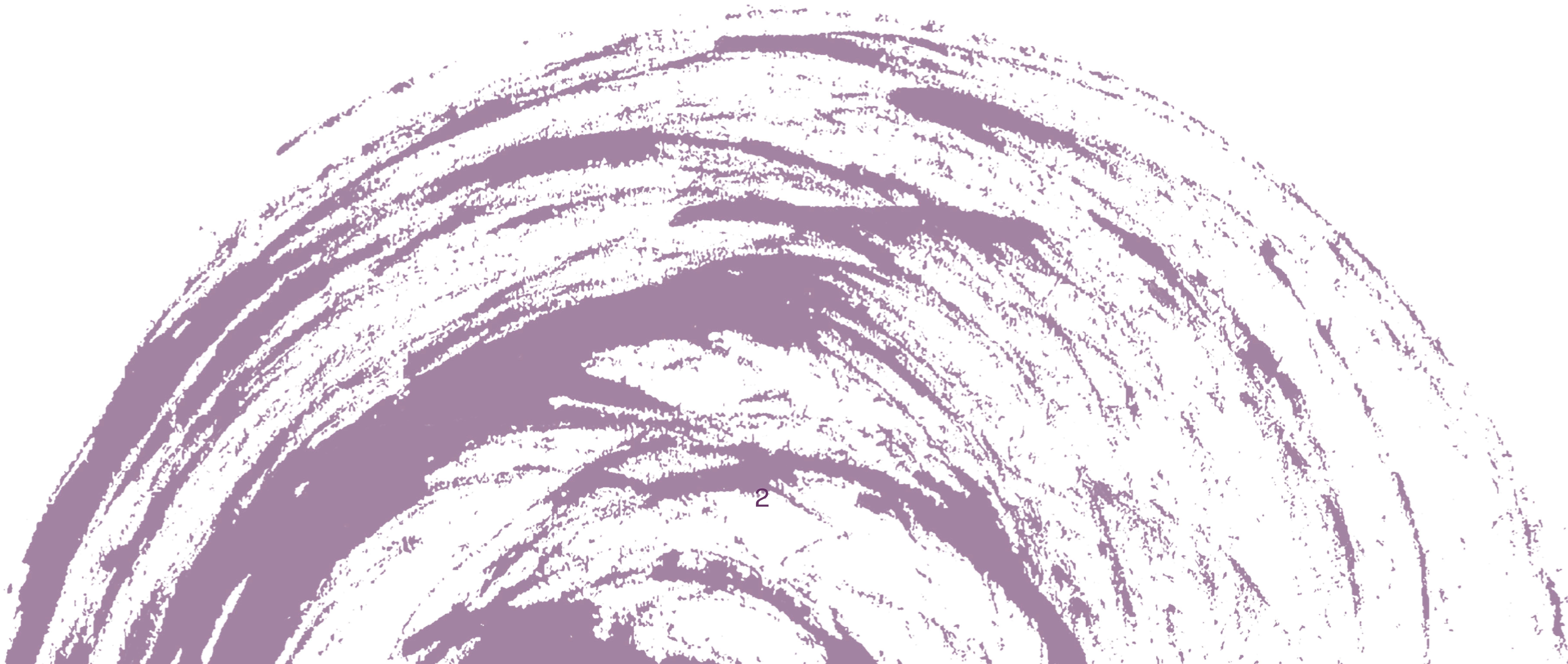
Adult siblings of people with lifelong disabilities and/or neurodiversity are likely to have the longest standing relationship with a brother or sister across the lifespan. Siblings have told us for a long time how helpful it is to read about the experiences of others. Many adult siblings have grown up feeling isolated. They may not have met or spoken to another adult sibling until they came across our charity. They may have wondered if their thoughts or feelings were unusual and may have felt different from their peers as a result. Reading about the experiences of other siblings breaks that isolation.

Adult siblings are often told by others that they shouldn’t feel the way they feel. When a sibling is fiercely proud and protective of their brother or sister, they’re told he or she isn’t their responsibility or that they shouldn’t worry so much. Conversely, when a sibling doesn’t experience a connection with their brother or sister, they often feel judged. Both of these feelings and everything in between, are very common for siblings. No sibling should be led to believe that their feelings are somehow “wrong”. We hope that this collection of sibling stories and creative work send a strong message to siblings - your feelings are valid.

We are very grateful to the Boshier Grant Scheme and Awards for All for funding this work, because it is important that this collections exists. We are also grateful for the expertise and dedication of Frances Danylec, Adult Sibling Development Officer here at Sibs, who has curated this collection with such care and sensitivity.

As well as validating the experiences of adult siblings, we hope that this collection will open up wider discussion amongst parents, partners, family, friends and colleagues of adult siblings. Our aim is that is helps the wider world to understand more about what sibling life is like and improve whole family support for autistic people

Clare Kassa
Chief Executive
October 2024
www.sibs.org.uk



How to experience this collection

Thank you for picking up this copy of *Autism: The Sibling Perspective*. Our sibling community have worked hard to create this and ensure that it reflects a range of situations and experiences. Whether you're a sibling or a supporter of siblings, we hope that you find the collection useful and interesting. To help with your reading, here's a few notes on the collection:

Terminology

- We use the word 'sibling' to refer to the people we support at Sibs and the term 'brother or sister' to refer to their neurodivergent and/or disabled brother or sister. This helps to make it clear who we are referring to.
- We tend to say that a person 'is autistic' rather than 'has autism' as we acknowledge that this is generally preferred by the autistic community and by the National Autistic Society (NAS). However, we recognise the variation within this too. As one sibling who contributed to the collection told us: "Language can be really tricky. I know that my sister prefers to be described as having autism, rather than 'being' autistic." Some siblings also describe their brother or sister as having Asperger syndrome and some identify with the term disabled. Everyone is individual, so each story reflects the language preferences of the sibling and their brother or sister.

Important: These are personal accounts

- When one of our contributors, Zeinab, shared her story with us, the first line she wrote was "Important: This is a personal account that may/may not be reflective of other people's experiences". It resonated so much with our reviewers that we wanted to ensure that our readers knew as well. Each piece reflects the individual, and the views shared don't reflect siblings as a whole or the views of Sibs as a charity. Please keep Zeinab's words in mind as you read.

Taking care of you

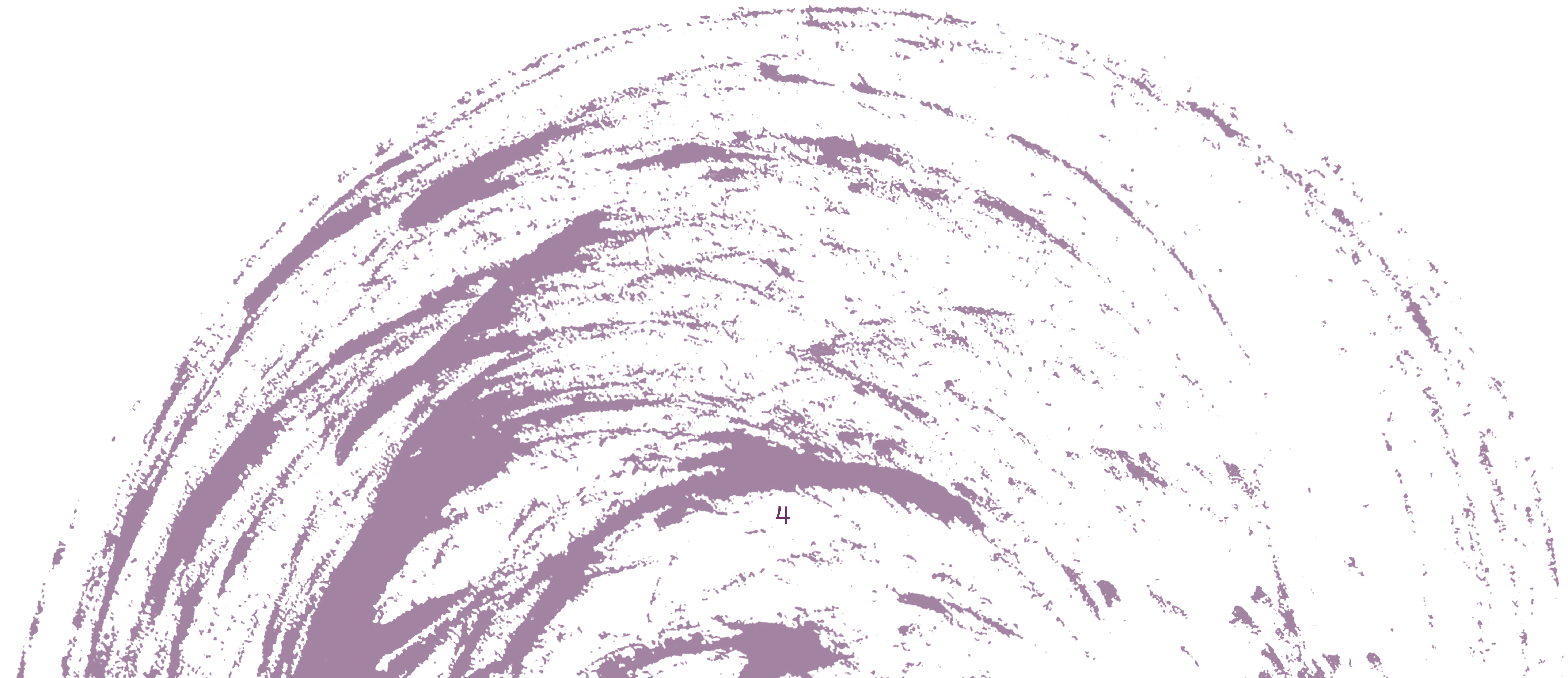
- This is a lively, colourful and honest collection that we hope will inspire and empower readers. Parts may also be challenging to read at times and with that in mind, we encourage you to look after yourself as you read. Take your time and share your feelings with others.
- None of the entries contain vivid descriptions of traumatic events; however, the following stories have trigger warnings for mentioning or referring to certain content:

Diane (mention of violence)
Esther & Judith (content focuses on the pandemic; references to self-injurious behaviour)
Josh (references to the pandemic)
Kate (references to verbal/emotional abuse)
Maura (historic offensive language relating to disability)
Monica (references to the pandemic)
Pam (mention of sexual violence)
Poppy (includes artwork/images of self-injurious behaviour)
Rachel (reference to offensive language relating to disability)
Shamini (mention of abuse; content focuses on the pandemic)

After reading the collection

- Share the collection with your friends, family and colleagues. Use the questions on page 69 to start a conversation about the experiences of siblings.
- Find out more about Sibs and where to seek further advice and information as a sibling on page 70.

Thank you for taking the time to read this collection. We'd love to hear what you think of it — drop us a line at info@sibs.org.uk



Mohamed

“I’ve really been through a range of emotions — from joy and happiness to isolation and loneliness”

The thing about being a sibling to someone with a lifelong disability is that it is very difficult to know how you feel about it. The depth of emotions are never linear and only as an adult have I realised the significance of what this has meant, how it has shaped me, and how it will continue to shape me.

I am the eldest son in my family of six, and I have a brother who is five years younger and is non-verbal autistic with complex needs. My earliest memories of him were mixed. My first memory was the language used to describe him being different. Language like, “Special”, “Not like us”, “He won’t talk”. Even the looks, the murmurs, that people had about him was something that still leaves a bad taste. But my brother is more than the medical terms and language used to describe his individuality.

The fondest memories were of how innocent he looked and how easy it was for us to build a relationship. This is something many people might be surprised about as most people build relationships based on shared understanding and communication. For me, there was no shared communication, but there was an unspoken understanding of brotherhood and similarity. An understanding that has guided us until now where we retain this brotherhood. Albeit this often comes with a well-meaning slap or strike of my door.

These contrasting feelings foreshadowed much of what being a sibling who’s also a carer came to be. While it has its rewarding moments, the role is fraught with complexity.

Many of us grow up with siblings; we share so much with them and grow up together. This is no different to me and my brother; we grew up in the same household but had profoundly different experiences. This was something that was difficult to manage at times, I remember I used to feel resentful at other people for having younger/older siblings they could do things with.

"My role as a carer has taught me so much and fundamentally shaped my identity"

There is so much an older male sibling could share with a younger one that I never had. Playing football in the park, riding a bike around the local area, watching things together, seeing each other in schools. Even a little bit of sibling rivalry, dare I say. It is difficult to describe, as whenever I catch myself feeling isolated or distant for not having a sibling I could do things with, I feel guilty and have a sense of disgust.

Equally, some of my dearest memories are because of him — moments where we had a good time, moments he'd seek me out or we'd be out in a park. Even now, it is difficult for me to even identify what to even feel about this chapter, besides that it's complex. In some ways too, I didn't and still do not really afford myself a chance to really understand how I feel.

When I decided to share this story, I spent a lot of time working out what my message would be. I wanted to show the complexity and the range of emotions a sibling carer could have, which is entirely normal and acceptable. The truth for me is I still don't really know how I feel about being a sibling carer as I haven't had much of a life without being one. What I've come to realise is that my role as a carer has taught me so much and fundamentally shaped my identity. Spending a significant part of your life alongside someone who perceives the world in a unique way influences who you are, how you see things, the level of empathy you have for others.

When you spend much of your life trying to communicate with someone who might not understand you, the lessons you learn through doing it are priceless. You're a better communicator, a more patient person, and highly aware of almost everyone's slight changes in behaviour. These are the traits and qualities that not only define me on a personal level; these things have also influenced me as a professional.

Reflecting on my role as a caregiver for a sibling with a lifelong disability, I've really been through a range of emotions — from joy and happiness to isolation and loneliness. Finding a supportive charity like Sibs validated my experiences, showing me I'm not alone in this. It motivates me to advocate for sibling carers across the UK and work on projects enhancing the lives of non-verbal autistic individuals. I am shaped by these experiences, I am better at communication, listening, and observational skills, because I've needed to be. These experiences have not only deepened my understanding but also ignited a passion to make a difference.

Rachel O-H

“Autism is not Ben and Ben is not autism — he is my baby brother”

When people hear I have an autistic sibling, they always seem to jump straight to an apology… like I should feel sad that my brother has autism. Personally, I have never understood this. I love my brother more than life itself and he is the greatest person in my life. It’s hard to say whether our relationship would be different if he was not autistic, but I’d like to think we would still have our Disney obsession. I don’t ever remember not being close to my brother. Autism is not Ben and Ben is not autism — he is my baby brother.

My brother didn’t have a sleep routine. This made my parents sleep deprived too and made their behaviour different. They were more irritable and this impacted on me. I do not in any way blame them for this irritability as I know what I am like if I have one day of disrupted sleep, let alone the months they suffered. I am not sure if she knows, but I remember my mum crying. I remember seeing the sleep deprivation take its toll. I was so young that all I wanted to do was give her a big grin and make her smile back at me. My brother’s sleep got better but by then the sleep deprivation had already set in. My current sleep patterns are very odd and I have always suffered with fatigue. Whether this was inevitable or due to sleep disruptions when I was a child, I will never really know.

I did feel left out when I was younger. This was not intentional on my parents’ part, but it is how I felt. It was all about Ben. Ben needed the support and I understand that. My parents used to say I was “self-sufficient”. It was not easy for them, it was not easy for Ben and it was not easy for me. As I grew up, I felt ignored.

There is a lot of information out there about how supporting a child with autism affects parents, and there is a lot about the child who is autistic. But what about me?

“Despite feeling that I was not as important as Ben, I was always protective of him”

The most important part of my life, the part of my life where my core personality was built, became all about how to help Ben, or how things were for Ben. I know how much my parents love me, I know how much my brother loves me, but it was still hard thinking that I came second.

I was so jealous of my brother and this pushed me to become attention-seeking. I pushed my parents to notice me, but as a young person, you do not quite see the negative impact this has. I was very good at mathematics but purposely became bad at it on paper “just because…”! My rebellious attitude completely changed the path I took and I achieved average grades. Looking back on this, I wish I had accepted the subjects I was good at. The thing is, despite feeling that I was not as important as Ben, I was always protective of him and never treated him like I was jealous of him.

I was diagnosed with dyslexia when I was 19 years old, yet when I told my parents, they did not seem surprised at all. In fact, one of the first things they said was, “Well, I always thought you were.” This really angered me! They were told through both primary and secondary school that I was lazy. I wish my parents had demanded that I was not lazy and that there was something else going on. I couldn’t help but think “But you didn’t do that with Ben”. When there were signs that something was happening to Ben, they ran around like headless chickens to get an answer. But not with me. With me, they left it.

This is by far the hardest thing to feel. I know my parents love us equally, but this point in my life was hard to get past.

My parents supported Ben, but at school I feel the baton was passed to me and I tried to look out for his wellbeing throughout primary and secondary school. He watched me get into university and I think this helped encourage him to decide to go too. Once he got into university, I supported him by becoming his disability mentor. I was there with him every second through his degree. His determination to be the best version of himself was inspiring. When people used to tell me that Ben wouldn’t amount to much, I used to just see red! It both baffled and angered me that somebody could pigeonhole him like that because he was under the autism umbrella.

Sometimes I worry about the future. I worry about a time when my parents are no longer with us. I worry about Ben’s mental wellbeing because it takes him longer to adapt to change. I worry that one day this support circle he has won’t be there. Even if I am scared about what the future may hold for Ben, all I know is that I will keep supporting his autonomy until his independence really is all him.

I feel my extended family gave my brother a wide berth when he was younger as many of them thought autism just meant you were violent and rude. I had cousins that would call him “troubled” and they would never

“It's me who really understands him”

understand why he would always “hide behind my mum”. As his life progressed, he later began to “hide behind me”.

We are always protective of our younger siblings, and I always felt there was more to it with me and Ben. I always wanted to make sure that people were not treating him differently. It was always easy for people to point at Ben being different.

It’s me who really understands him. You can sometimes see my parents get annoyed at my brother for things that are directly related to his repetitive behaviour. For example, Ben showers at 8am. When my mum is still in the shower at 7.59am, Ben starts to feel agitated at the idea that my mum does not care enough about his normal routine. It is situations like this that make Ben gravitate towards me.

I owe my career to my brother. I knew one day I’d want to be an autism researcher. I want to get my PhD so that I can offer my knowledge to others. I want to show the world the awareness I wish I could have given my family about autism.

Jack R

“The cringier or more painful memories came from the ignorance of others”

I sat down to write about my sibling strengths for National Siblings Day (April 10th) and this is what came out. I began thinking about my experiences growing up, and realised a lot of the cringier or more painful memories came from the ignorance of others. So my sibling strengths are being patient when I need to be, assertive if I have to, and knowing how to make my brother feel safe. I’m thankful to Sibs and everyone who attends the support group meetings for helping me realise I have these strengths.

Making plans for Nigel

He's a lovely lad
Such blue eyes.
He looks like you, you know?
You'll be a good brother now, won't you?
Some of those kids can be so cruel.

He likes Thomas the Tank Engine, doesn't he?
Does he watch it all day long?
He's not quite like the other kids
With his trains all in a line
Away from the others, playing alone.

What's that thing he does with his hand?
Is he talking to someone we know?
He should get into football
That'll put him right
In no time, you'll see.

Oh I thought you said artistic
Well aren't they super smart?
He'll probably be a maths whizz
And you can make a few bob
Down the casino!

I don't care what he is,
He's bothering the other kids!
He knows exactly what he's doing
And if he doesn't
Then he should stay at home.

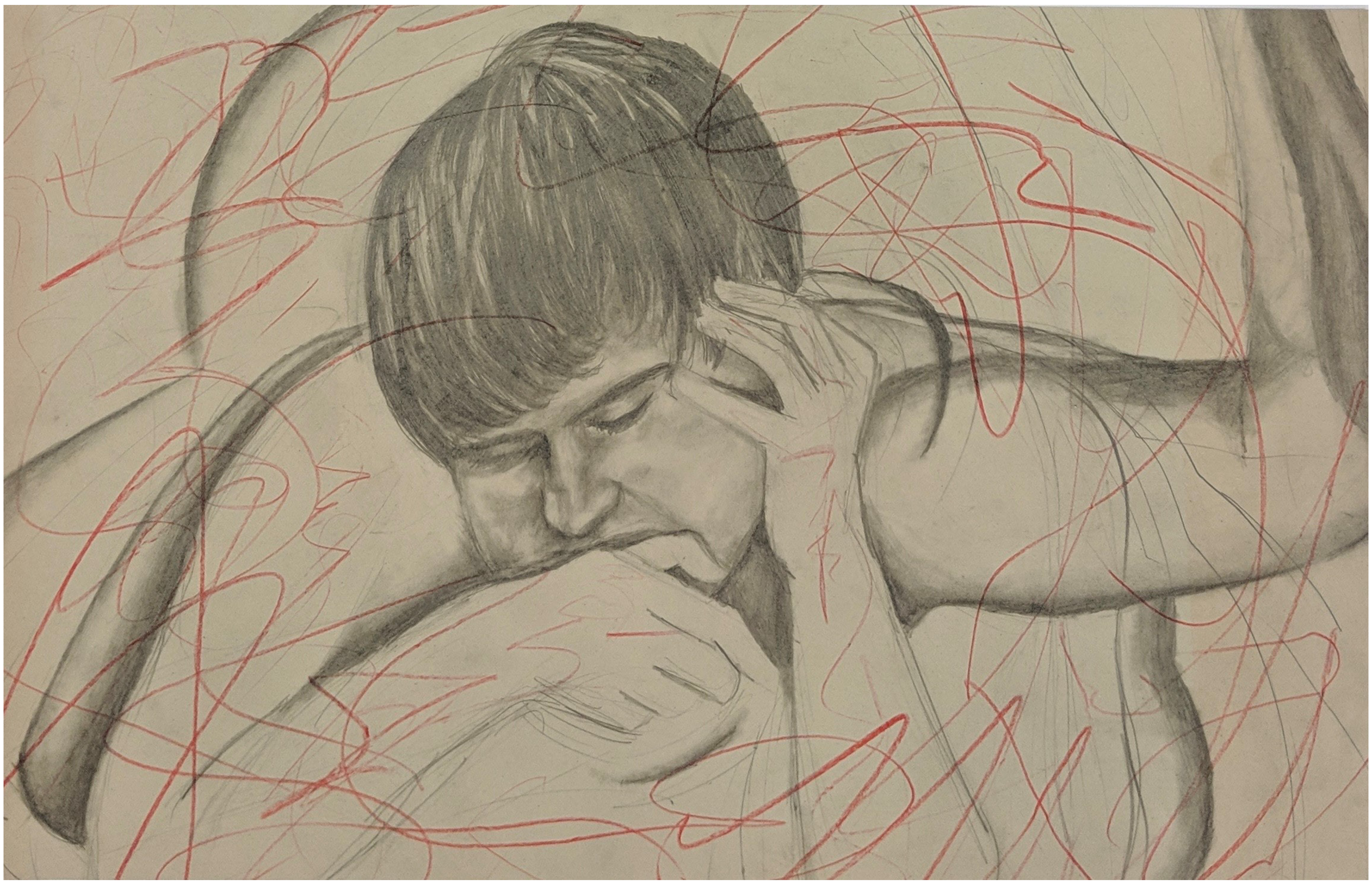
He just needs a bit more experience
He couldn't really be customer facing
What with the way he...
We'd love to be able to help you here
But there's really nothing we can do.

He goes all that way on his own?!
Are you sure that's safe?
There are some really dumb people out there, you know?
What if something happens?
He won't know what to do.

He's a proud employee, punctual and popular.
He's a devoted dog owner. An intrepid traveller
He's fit and strong. Independent and brave.
He's kind-hearted, polite, gentle and sweet.
He's my brother.

Poppy

“These are a few paintings I have done of my brother who has autism”



Artwork by Poppy Scoffings

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Scan here to visit Poppy’s website
https://poppyscoffings.com

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Ruby

“I feel every pain that passes through his body”

Ewen is my big brother and he has consumed my life from the moment I entered this complex world. I never recall questioning why Ewen didn’t talk, nor why we couldn’t attend the family meet-up or neighbour’s birthday party. My pride for my brother has always been in great abundance, not leaving any space for potential resentment. Every essay or art project in school was made about my big brother’s special soul. I wanted everyone who knew me to know about my brother too. (We are a package deal of course).

We had a happy childhood really, although I don’t think I’ll ever let go of the fact my brother managed to eat my homework or my library book at least once a week. (How does one explain this to their teacher?) I laugh now, but trust me, little Ruby wasn’t even cracking a smile. Ewen had an unprecedented obsession with tearing paper and eating it — apparently my homework jotters and stinking library books were particularly inviting!

Ewen moved into a residential school five days a week when he was ten. From once being identifiable to myself as Ewen’s sister, I felt empty coming home to the quiet house. No one to tickle or share snacks with. No one to serve at my pretend shop or take orders from in our made-up kitchen. Ewen never understood these concepts but all I truly needed was his company. I felt I couldn’t forgive my parents for making me an only child. The sailor of my ship was taken away before I could warn everyone it was going to sink.

Sometimes I feel time has stopped moving around us and this bubble of being purely my brother’s sibling is never going to change. I still won’t stay out past 10pm with friends on a “Ewen” weekend and I still give up much of my life to make my brother’s a better one. This adulting thing really sucks. I’m now 19 and I struggle to separate my life from Ewen’s. I feel every pain that passes through his body and under any condition I will always put him first. We are the real-life version of E.T. and Elliott.

“As my match begins to burn out, I find myself existing and surviving, rather than living”

Ewen came home permanently in 2021 after reaching crisis point. Things went from bad to worse and he was detained under the Mental Health Act for fifteen months, in a psychiatric hospital. Something that no one outside of our situation could ever begin to comprehend.

Those months felt like someone had stolen all the air from my lungs. Every breath was a fighting one and all I truly wanted, was to scoop my brother up and look after him for the rest of my life. I was still in school at this time, sitting those life-dependent exams. How on earth was I supposed to retain information when my head was stuck in flashbacks of my brother's soul-destroying cries, whilst my shirt rubbed on the raw injuries from his fingernails covering my chest?

People compliment how beautiful my relationship is with Ewen. However, as my match begins to burn out, I find myself existing and surviving, rather than living. From once not being identifiable without my brother, I now feel engulfed by his life completely.

Every event is second-guessed by “What about Ewen?” I hope I won’t regret spending my young adult life in the shadow of my brother’s. But man, is that hard to navigate. Truly, at the end of the day, he is and always will be, my whole entire life.

Scan here to follow Ruby on
Instagram @ewenandme

Monica

"Finding out I was a carer was my light bulb moment"

I've been a sibling carer for my non-verbal autistic and epileptic twin brother my entire life. Yet, I only labelled myself a "carer" at the age of 23, just two years ago.

I found out I was a carer in the midst of the pandemic, a time where, like many, I was riddled with fear over the health of my vulnerable family members. At the same time, my mum's health suddenly declined, her treatment was delayed and we lost essential care for her and my brother.

As I live at home and have no other siblings, I supported my dad, filling in with the care whilst balancing this with my first full-time job, adjusting to working from home, my own hobbies and social life, all while my mum was shielding. Sadly, our mum passed in November 2020.

During the pandemic, people were experiencing that feeling of uncertainty for the first time. We'd been hit by a virus we knew little about, all of our lives changed and everything familiar stopped. But for me, it was multiplied and I felt angry.

Because of my brother's needs, we deal with uncertainty every single day. I've never known a life different. My brother will never be self-sufficient; he can't tell us if something is wrong and I don't know when his next meltdown or seizure will be. Our routines revolve around him, sometimes we need to leave a supermarket mid-way through shopping or leave a family gathering early. Yet it was difficult to see memes where people complained about not being able to do certain things and their lives being uncertain for this limited period of time.

As my brother was exempt from a mask, I was committed to doing everything I could to protect him and those around me. We needed a vaccine but it was taking time. Yet still, I was going to wait my turn, just like everyone else, even if my age group were far down the list, because that’s what I thought I needed to do. The truth was, I wasn’t like “everyone else”.

A distant relative encouraged me to enquire about getting a vaccine early. I thought, “Why would I be entitled to that?” My parents are my brother’s carers, not me. But when I enquired, I was told I could get one, because I was caring. This changed everything. I was validated as a carer.

Being validated as a carer is everything. It’s essential to understanding yourself. So many of us don’t recognise we’re carers and that’s problematic. Carers can come in many different forms and you can even be a carer from a distance.

From a young age, I helped with small tasks like getting my brother’s shoes and coat on, to later watching him when my parents were out. I never thought of this as caring though, just simply helping out. Since my mum’s passing, I’ve taken on more responsibility as someone always needs to be at home with my brother, either myself or my dad. And I know that my responsibilities are yet to increase. When I’m not caring, people assume the worry stops. They ask what will happen in the future as if it’s never crossed my mind. Really, it’s something I think about almost every day.

As an adult, I now realise I was entitled to support I’d never had and that there are charities and organisations out there, like Sibs, to guide me through it all. I just never knew to look for them. You can be surrounded by a huge network of family, friends and colleagues but still feel alone when they don’t understand you. When your only sibling is disabled, you can feel like an only child.

You watch other siblings talking to each other, playing together or helping around the house and that’s tough when your relationship doesn’t look the same. Sometimes you overcompensate and try to do and achieve more. I now know so many others have the same worries and are making the same difficult decisions.

At 15, when my brother started having epileptic seizures, a paramedic told me to ring a friend after she left. People forget it’s traumatic to see. I never rang anyone though. I felt they wouldn’t know what to say.

Looking back, I know I’ve had a tendency to over-explain and over-justify my decisions. Things like going to a local university and moving back home when I graduated and started my first job. That’s come from a place of being misunderstood. My parents never asked me to do these things but as a sibling carer, you want to.

“So many of us don’t recognise we’re carers and that’s problematic”

“As a member of the Asian community, I know there is a lack of understanding and representation of disability and caring”

That’s why organisations like Sibs are so important. It’s that feeling someone can relate to you. Whilst I have always been passionate about spreading awareness of autism and have done so on social media, at school, university and work, I have never really spoken from the perspective of a carer.

Perhaps some of this is down to culture. As a member of the Asian community, I know there is a lack of understanding and representation of disability and caring. There seems to be an ingrained need to “be strong”, “hide” disability and to “just get on with it”. It’s also normal for girls to help out more around the house, so to others, I was seen as no different.

In a way, it made me fearful of talking openly about my caring responsibilities, in case they were viewed as a weakness or made me seem unreliable. But who is this really helping? All of this only normalised my responsibilities, leading to unhealthy comparisons. I now realise my caring responsibilities are my superpower.

Recognising this and how misunderstood carers are was my light bulb moment and what sparked *Carers with Dreams*, my Instagram community dedicated to helping carers feel better understood, not just by themselves but also by those closest to them, and inspired to achieve their career dreams. If there’s one thing us carers are good at, it’s putting ourselves second. One time, I was talking about the future with a friend who also has an autistic brother. I talked about having my own place and my career plans. All of this, however, was shaped around my brother’s needs. She stopped me mid-way and asked, “But what do YOU want, Monica?” I want to remind carers not to forget themselves and to chase their career dreams. I’m also using my platform to be a face for ethnicity minority carers and spread awareness of autism, because without talking, there is no awareness.

In essence, I created the community I needed, a place where I could connect with other carers, particularly those who looked like me, those who don’t know they’re carers and those with big career dreams. This idea had been brewing since 2020 and I know it took me some time to start. Some of it was confidence, some of it was grief, and some of it was time.

There’s an assumption that my generation have the least responsibility. Many of us are not married and are child-free, so we can supposedly use this “free time” to start side hustles, TikTok accounts and online communities. But carers my age often find themselves on a hamster wheel, trying to keep up with others, forgetting how much we’re already carrying. We sometimes need extra time, but that doesn’t mean we can’t be successful.

It’s hard to watch others live your dream and do the things you want to do, but my advice to other sibling carers would be this — celebrate others and trust that your time will come. Mine did. Starting *Carers with Dreams* has not only given me a healthy outlet, but it's also allowed me to adopt a positive perspective. Rather than asking, "Why me? Why did I get the autistic twin?" I view my brother as the most incredible gift from my mum — my power to help others and make a difference.

When I talk about my brother's autism and my caring responsibilities, people say they can't imagine what it's like or understand. They say you have an "old head on young shoulders". Even close relatives don't know every aspect. But whoever you are, to everyone reading this, you can do one simple thing to help us carers — listen and show empathy. I've found it's more of a case of who's willing to take that time to learn and do better.

> **"To everyone reading this, you can do one simple thing to help us carers — listen and show empathy"**

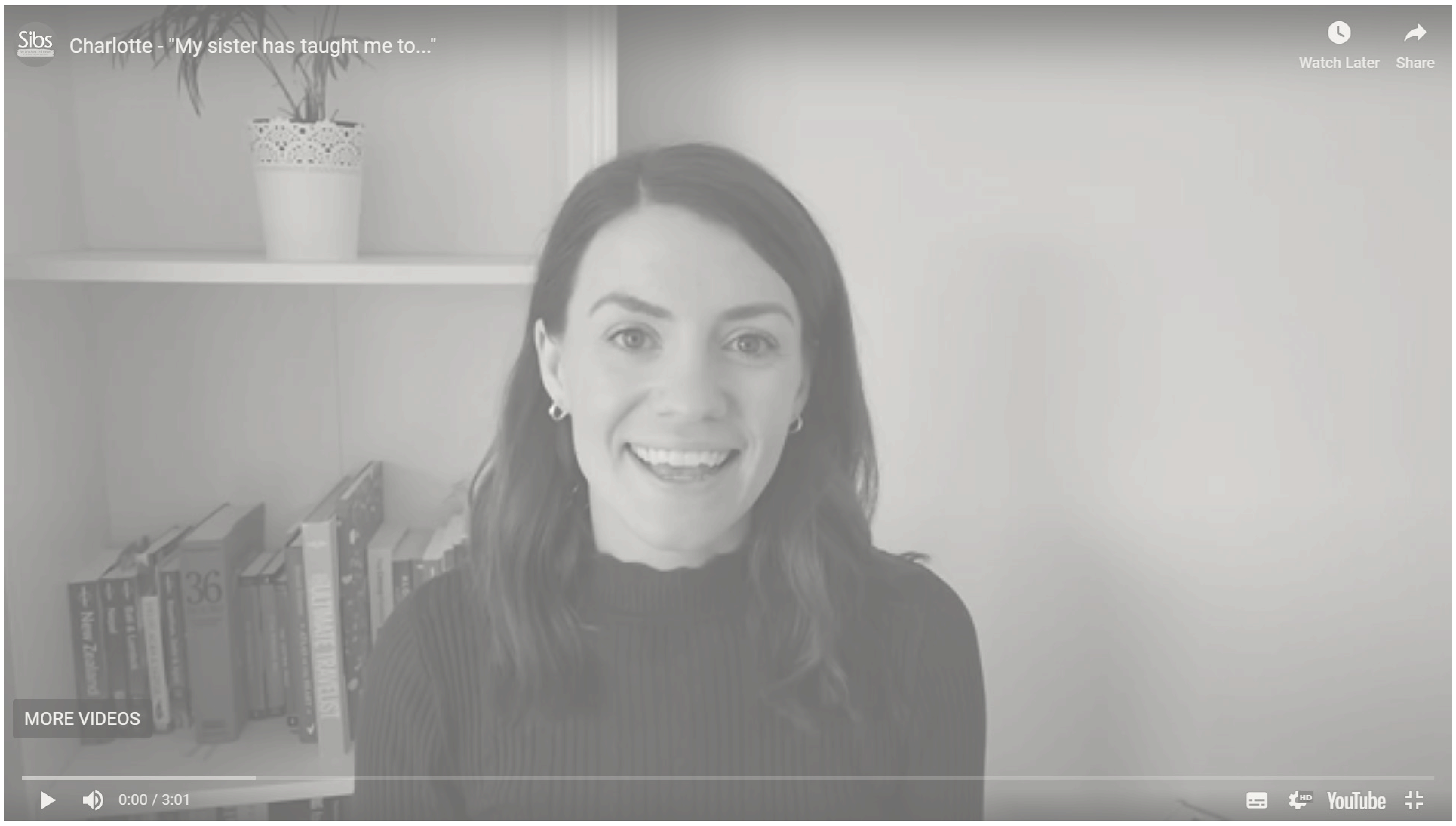
Scan here to follow Monica on
Instagram @carerswithdreams

Charlotte

“Knowing the impact that kindness can have gives me a passion to be that person for others”

In this video, Charlotte Flynn shares what she has learnt from her sister who is autistic, has learning disabilities and mental health issues.

Scan here to watch
or go to sibs.org.uk/charlotte



My sister taught me to…

Be compassionate.
There are people who interact with my sister in exactly the way that she deserves. These people brighten her day and make her feel like the incredible person that she is. Knowing the impact that kindness can have gives me a passion to be that person for others. I'm kind and I have time for people because I know the deeply positive impact this can have on people and their families.

Be brave.
One example is that as kids on a ski slope, she was inspiringly quick and was willing to do the scary stuff in a way I didn't — this kind of bravery ignites a bravery in me. She has had to be brave in all sorts of more extreme ways, and I am so proud that her bravery is so core to her being.

Be a reader.
Her reading speed is incredible, and she immerses herself in books. I love that I can borrow books from her and talk about them with her.

Be strong.
Because just like any sibling relationship — we've had our fair share of arguments and play fights!

Be a traveller.
Seeing new places has always been important to my sister. I love hearing about her trips, going on trips together, and telling her about mine.

Be better.
I know for certain that I am a better person because of my sister. For that I will always be thankful. Being a sibling has inspired me to be a coach so that I can help people to reach a life that feels fulfilling to them. Knowing how determined she is to conquer challenges gives me the determination to do the same.

While life hasn't always been easy for her, and our world is still not truly inclusive, I am so proud of who she is and how she navigates life. It's not always easy being a sibling — I'm sure my sister would say the same — but I'll forever feel lucky that I'm my sister's sister.

Diane

"I never fully switch off, and I don't think people realise that"

My brother Mike and I were born in the late 1960s. In our early years, we were very close as we were near in age. We grew up with an extended family of grandparents, aunts and uncles. We used to mimic TV programmes of the time like *Bonanza*, we painted each other's faces, we were typical little children, playing with the clothes horse and pretending it was a tent. We were always in each other's company. I remember really happy times.

Getting towards our teens was difficult. Autism wasn't easily recognised back then, and Mike got a late diagnosis in his 30s. He'd managed a short amount of time in what is now called reception class, but when his differing needs became apparent, he was moved to a special needs school where he was diagnosed with a borderline learning disability.

Things at home were brushed under the carpet. Mike would break windows, abscond, run away, lash out at us. He was aggressive and violent. Sometimes, I'd sit too close and once he hit me with a metal toy, cutting my head open. Another time he threw a toy at me and it cut a gash underneath my eye. As we got older, I had to have a lock on my bedroom door because he would come into the room and wreck it. There was a sense of shame around his behaviour. I generally wouldn't admit I had a brother at school because no one else had a brother like him. If the topic came up I felt I had to avoid it, which felt painful. I wanted to be "normal". I just wanted to be like everyone else. One of my friends, Susan, had two adopted brothers who had Down's Syndrome. I used to go round to her house and we'd listen to music and dance. It was good to know someone who had a different life.

> **"I wanted to be "normal". I just wanted to be like everyone else"**

“It’s me who is fighting his corner and trying to get a better life for him. There is no one else. No one else will care as I will”

We had no help outside our family circle so we just coped the best we could. The shame felt too great. It just wasn’t something you talked about. Now I know his distressing behaviour was due to his autism, sensory processing disorder and the environment in which he found himself in.

Our family broke down in the early 80s. Mum had been a victim of domestic violence, which I didn’t find out until my 30s — it was all kept from us. My parents divorced in our teenage years and Mike’s behaviour became erratic. He’d run away and we’d find him at the neighbour’s having a cup of tea. He just had no idea of danger.

In the mid-1980s we had some input from Social Services. They provided us with a telephone and a washing machine, which we hadn’t had before. They also put up a six-foot wooden fence in the back garden, as the rented property had low Victorian walls and Mike would jump over them.

When Mike hit his teenage years, the change in his behaviour was phenomenal. His behaviour became destructive. Partly, I expect, due to hormones, parents divorcing and the effects of a trauma.

Mum and I started having respite care with Mike staying at a local unit on the weekends. It gave us a much-needed break. We used to go with him to settle him. It was always upsetting leaving him there. In his mid-teens he went to a residential school over 70 miles away because we could not cope during term time. There then came a point when Mum had to say that he couldn’t come home outside of term time. We just couldn’t cope with him at home anymore.

It was a relief when he went and it was also incredibly sad. I just cried and cried. It was difficult to manage his behaviour at home — but it was just so empty when he left. I’d lost my brother. We didn’t know what to do with ourselves without him. I became a bit of a counsellor to my mum.

We visited Mike when we could, but then he had to move schools. He was placed in a school in North Wales, which was over 170 miles away. We could only see him when the social worker drove us up there, which was about twice a year. Mike was distraught. He lost his whole family — me, Mum, Dad, our grandparents, extended family, everyone. We used to phone weekly but that became distressing for him. We sent him gifts regularly.

Over the next three decades, Mike was moved several times. There was no provision “in county” for him. I started going to his reviews when I was about 15 or 16. I’d sit in meetings and listen to what was being said. I did that for a few years and then I kind of fell off the scene. I had to go to uni. I took a ten year break but I was always getting reports. I felt guilty but it was such a relief. My dad stepped in at this point with visits. My aunt and uncle visited once. My paternal grandparents visited once and my maternal grandmother never saw him again. It was heartbreaking for her as she was so attached to him.

Mum had had a nervous breakdown after the incidence of domestic violence and couldn't be involved anymore as it was just too stressful. Dad oversaw Mike's care, going to reviews with the social worker and visiting him in between. I oversaw reports that came in and Dad was the main person, but he began to find this too much. The units where Mike lived were quite depressing so he stopped visiting altogether, which really upset me. So I started taking it over. Dad has since passed away and I haven't seen Mum in a long time — things are very strained between us.

Mike and I had a good relationship to start with but we don't have that now because it wasn't able to be nurtured. When I visited Mike recently he hit me and he hasn't done that since I was a child. It was quite a shock but I later realised that his behaviour is because he is distressed by the poor environmental conditions of his flat.

His care providers tend to jump to the most restrictive solution to any issues. And they let things slide. It's me who is fighting his corner and trying to get a better life for him. There is no one else. No one else will care as I will. I worry about people abusing him because he can't self-report. It's exhausting. For staff, it's a job. For me, he's my brother. The quality of his care worries me all the time. I never fully switch off, and I don't think people realise that. I wish I could just step away from it all. But you just learn to manage it and live with it.

I feel guilty about having my own life. When I'm enjoying myself, I feel sad, because Mike isn't able to enjoy the same freedom. He's entitled to a good life, and he doesn't have it. It's difficult because I try my hardest and I still can't get the best for him. It's difficult winding down from that injustice.

Something that really helps me is my faith. Prayer helps. I also find I've got to let it go sometimes, accept the things I can't change and keep fighting for the things I can. I have to tell myself he's OK in a general sense. I find I've got to take time out for myself too. I have to say to myself, "Stop", take a step back and say, "Actually, I'm not going to check those emails now. I'm going to have half an hour and go and have a bath." I can dwell on it and I can ruminate, and it's not good. I have to focus on the positives too — I know three support workers who would say, "I'd do anything for Mike." And that's wonderful.

"I feel guilty about having my own life"

All names have been changed.

Jack

“Stay positive! See difficult situations as an opportunity for both of you to grow”

I am a 20 year old who has a sister who is now 21. She received an autism diagnosis at birth. Growing up with my autistic sister certainly had ups and downs. On reflection, a feeling of volatility stands out: you would never really know how a day would go. Many days were happy, such as the summer days playing tag outside and having nothing to worry about; others had arguing and frustration. This experience is very normal — indeed, it happens in all relationships.

The biggest challenge for us, from which most of the disagreements came, was the difficulty of finding a school that would suit my sister’s needs. This problem created lots of stress for me growing up because the whole family had to put trust in multiple institutions, and they all seemed to let us down.

Now that we are both adults, the uncertainty seems to have mostly gone. The situation seems more settled, and I can go into most days knowing whether there will be any challenges. This has made daily life much less stressful and has allowed me to not only enjoy our relationship more, but also to focus more on other aspects of my life.

When challenging situations do arise, they seem to resolve more easily because we have matured and have a better understanding of the reality of different situations. Now that I am at home less, I play a less active role in caring for my sister, but still make sure to have frequent conversations, whether over text or in person, and help to make sure she has enough provisions. The most significant role I currently play is helping my sister deal with change and the uncertainty she is facing.

“You become excellent under pressure as being a carer often involves resolving problems quickly”

> **“You develop adaptability and resilience through being exposed to and having to deal with problematic situations that are often unexpected”**

For example, she’s not sure what she would like to do in the future, which is an uncomfortable situation for anyone to be in. I enjoy helping her to overcome the challenges she’s facing, especially because it fills me with optimism about her future.

There are many positives of having an autistic brother or sister that should be remembered despite negatives like stress, having to explain their behaviour to others with little understanding of autism, and frustration.

You develop adaptability and resilience through being exposed to and having to deal with problematic situations that are often unexpected. Similarly, you become excellent under pressure as being a carer often involves resolving problems quickly. These types of skills will help you thrive in your personal life and career.

Supporting an autistic brother or sister develops your emotional intelligence because they can find it difficult to express themselves, meaning you may have to read their emotions. The emotional intelligence this requires improves other relationships in your life and puts you more in touch with your own emotions. It can be helpful to remember all the benefits of having an autistic brother or sister, especially when you are faced with difficulty.

I would like to share some advice for young adult carers. I have learnt that when your autistic brother or sister is dealing with a change, it is essential to balance engaging with the issue in conversation and giving them space to think about it for themselves. Relentless conversation can often become overwhelming for them, so I think it can be more effective to briefly say what you think, then give them time to rationalise the situation on their own. This often leads to them realising that a change they have opposed isn’t so bad after all!

My second piece of advice is to make sure to check in when you are away, for example by sending a text. It is easy to forget that they may not have as many people to talk to as you, so really make an effort to make the periods when you are away as seamless as possible by staying in touch.

My final piece of advice is to stay positive! See difficult situations as an opportunity for both of you to grow. I hope my advice will help you with your own relationships with your autistic brothers or sisters.

All names have been changed.

Pam

“My own artwork, and that of others, helps me to uncover meaning and better understand my life as a sibling”

My severely autistic twin brothers were institutionalised at the age of seven. I was six and our younger brother was five at the time. This was in 1962. I do not remember our parents explaining to us what was happening, nor why our family was being broken up.

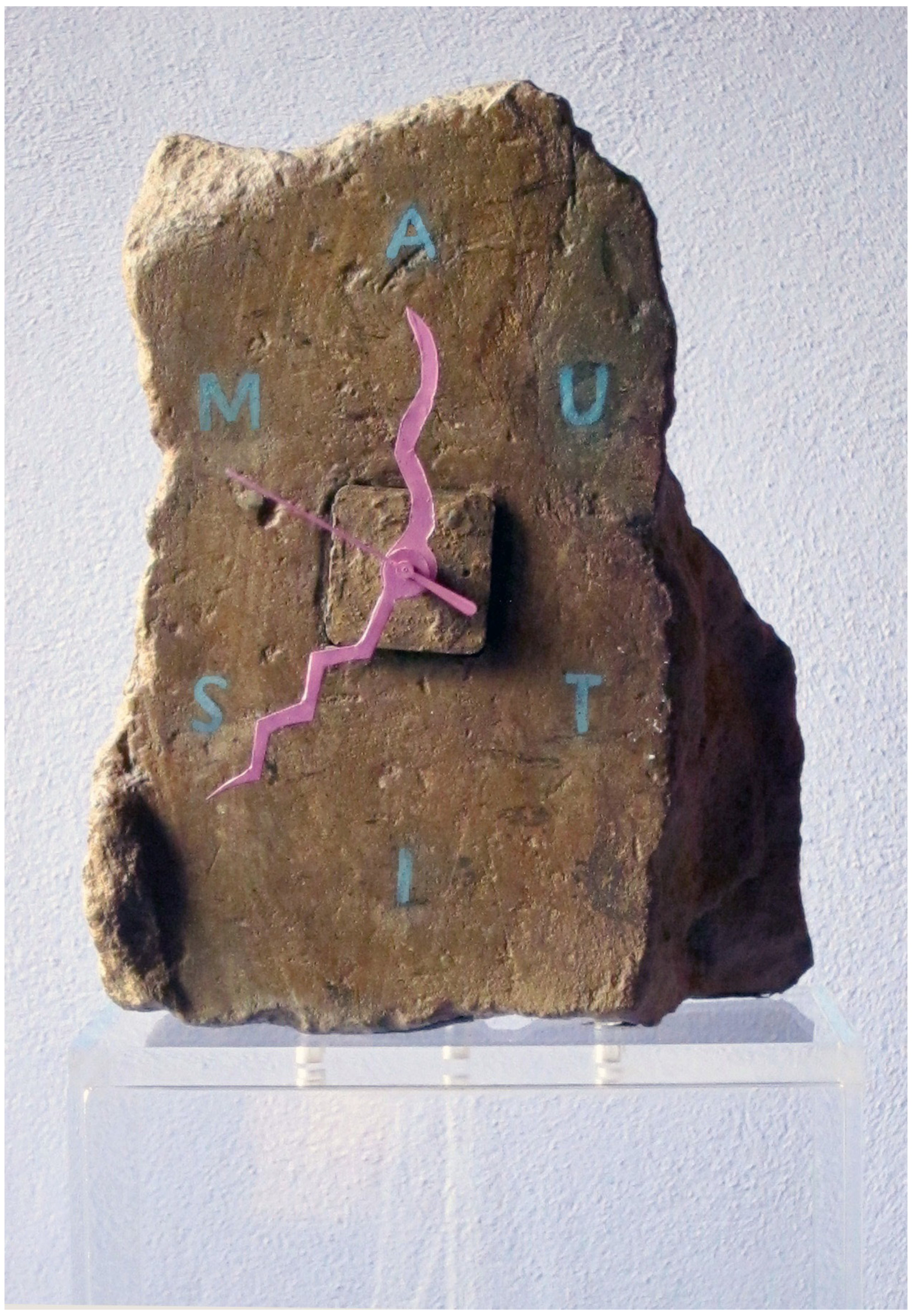
I remember that my twin brothers were not “normal”, and they were a handful for our mother, but why were we all living under the same roof one day, and then two of us were living elsewhere the next?

Ever since, I’ve had a feeling I can only describe as a weightiness of responsibility for my brothers, even when they were under the care of adults, and I was a child.

> **“I’ve had a feeling I can only describe as a weightiness of responsibility for my brothers”**

A picture paints a thousand words — and a sculpture lends them weight.

As a sibling of non-verbal autistic twin brothers, I've always felt that I was *Born to be Responsible*, the title of this piece I made of hornton stone in 2019. My mother said that I was born independent — but is a child equipped to fend for herself, especially concerning her emotional growth — alone? Somehow I managed to reach the age of 62 more or less intact.



Born to be Responsible by artist Pam Foley

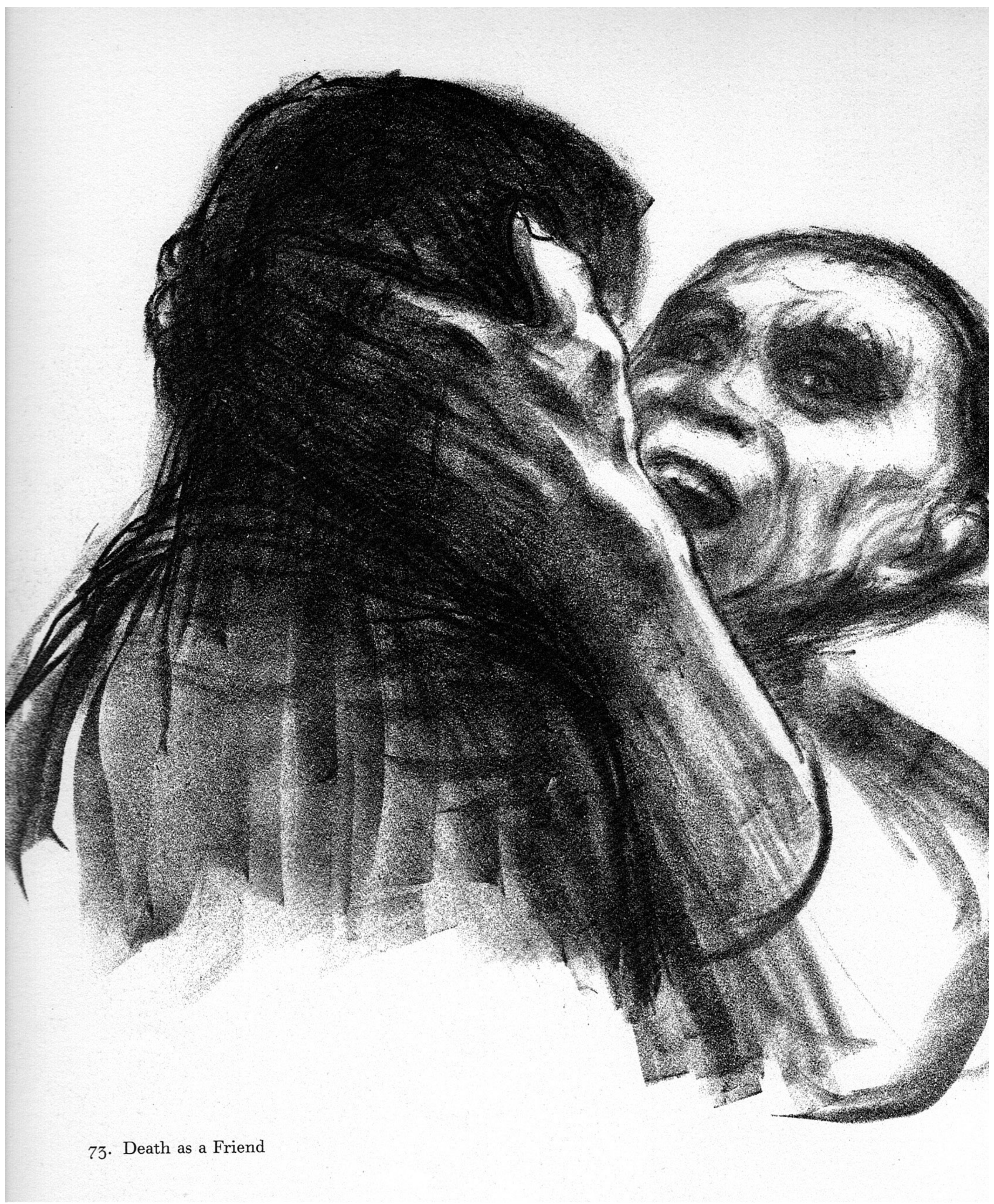
Joyous art belies the early suffering of its maker.

This is called *The Three Graces*, by my favourite artist, Niki de Saint Phalle. Her “nana” figures — large, rotund, and colourful — convey a jubilant and exuberant feeling of freedom and abandon. It’s humbling to think that the person who made this had been raped by her father. As I look at this artwork and contemplate her story, I find it a powerful reminder to find strength and self-acceptance in pleasurable acts. Her childhood suffering is incomparable to mine, but need not be. The fallacy that children are resilient is repeated as a truth — but do children really have a choice when faced with hardships and challenges they have no control over? It’s what we make of our struggles that I find interesting in others, and now, as I become used to self-identifying as a sibling, in reflection upon my own life and how I have lived it.

The Three Graces by artist Niki de Saint Phalle

My autistic brother died, and it was unexpected.

When my autistic twin brother Kevin died in 2015, I was deflated — shedding tears alone didn't seem to be enough to let loose the unbearable sadness I felt. When I look at the face in this drawing by Kathe Kollwitz, it expresses the anguish I felt at the time. The title of this is *Death as a Friend*. Kollwitz witnessed death constantly, whether drawing the poor patients in her husband's doctor surgery, living life between the two World Wars, or when she experienced the death of her soldier son. She possessed the tools, technique and vision to help us understand the incommunicable, without the need for words.



Death as a Friend by artist Kathe Kollwitz

What does a “normal” family look like?

When I was young, and my twin autistic brothers were living in an institution, they were often home for special events such as their birthday and holidays. To those who didn’t know us, we seemed like the typical 1960s family: mom, dad, girl and boy. A childhood friend who lived a few doors down, Carol, often spent time at my house, and me at hers. Our mothers would make cakes and we would play games with the neighbourhood kids. Carol and I have remained friends and she recently told me that she thought our household was “normal”. She had seen and knew about my twin brothers. When, years later, she told me about some unspeakable events that went on in her household, I was in disbelief. To me, hers had seemed so “normal”. What does “normal” mean, and why is the appearance of normalcy so important to children? This is a question I’m particularly interested in exploring.

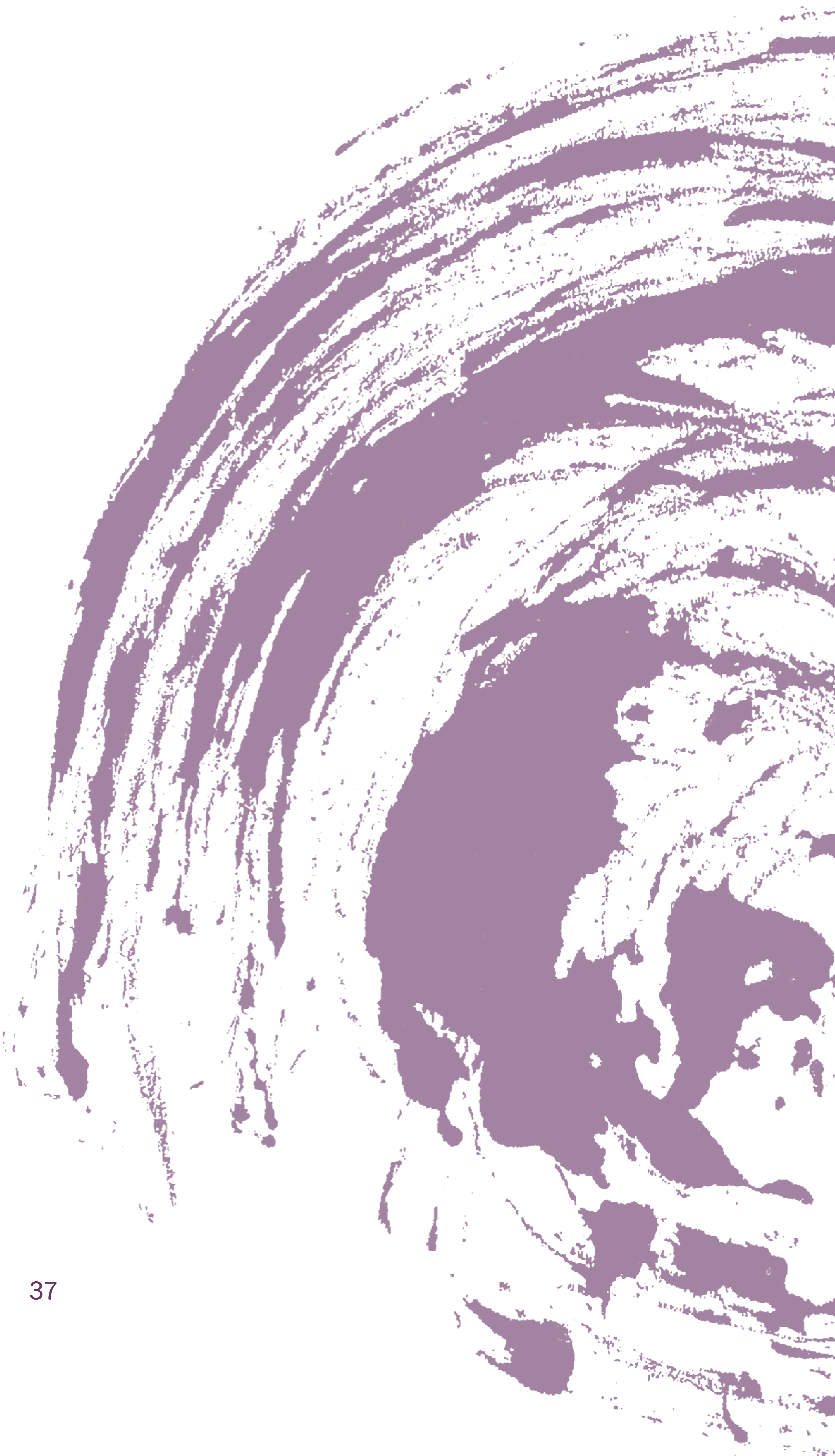
Looking Back by artist Pam Foley, 2010

A chiselled smile on the face of my brother, Kevin.

Kevin wasn't a naturally welcoming sort of person. In fact, he was a curmudgeon. I would often say to him, "Come on, crack a smile!" This is why I choose to make a print of him using the stone lithography method whereby greasy pencils are applied to a smooth stone. The stone is inked up and then run through a lithography press. What I love about this method of printmaking is the use of tusche — a grease-like liquid mixture that, when applied to the stone surface with an eyedropper, will pool and run, to create unexpected textures. I placed the tusche within Kevin's face and in the background because, to me, he could be unpredictable and multi-layered in his responses. And on the rare occasion, accompanied by a twinkle in his eye, he would "crack a smile".

Kevin by artist Pam Foley, 2018

“The fallacy that children are resilient is repeated as a truth — but do children really have a choice when faced with hardships and challenges they have no control over?”



Scan here to visit Pam’s website
www.pamfoleysculpture.co.uk

Louise

"A day out without words"

We are going to the farm today and we are going to have a picnic. You watch me write the words on your whiteboard. You jump up and start pacing the minute I put down the pen. You are ready to leave now.

I tell you to go and put your shoes on and get your coat. I speak to the care staff to find out how your morning has been. You woke up at 4:30am after two hours' sleep. You were pacing your room all night and peeking out of the curtains to see when it would be light enough to get up. If you didn't have autism, you would at the age of 22, be getting two hours' sleep after being out on the town.

We gather all the things we need to take on a day out together. We must have your epilepsy medication and a pillow in case you have a seizure. We need some spare clothes and shoes and your camera for all the photos you will take. We say goodbye to the staff and make our way out of your flat and to the car.

You are so excited to be going out in the car you are jumping and bouncing. I'm nervous and thoughts are whizzing around in my head. Have we remembered to bring everything? Will we have an enjoyable day? Will something go wrong? You strap yourself in the car and the minute we start driving you are recording a video of the world going by out of the window.

You like it best when I turn the music up to a really loud volume in the car. People walking along the street stare at the car driving past blaring the *Tweenies* theme tune.

When we arrive at the farm you jump out of the car, and I rush around to your side. You are so excited, but there are so many cars in the car park that I'm worried. Most drivers think a 6-foot man will stop if they see a car coming but you would happily jump in front of it in the middle of a bounce.

“If things go wrong, I know I will blame myself and feel like I have failed you”

We go to the farm ticket office and see the large queue. There are families with pushchairs and big groups of school children. You can’t possibly wait with all of these people. We walk quickly past the queue and to the front. There is lots of muttering and tutting.

We walk into the farm, and I breathe a sigh of relief. I had done hours of research to check that the farm will be spacious and that it will be a good day out for you. Luckily, it seems the website details were correct. Planning a day out like this takes so much research and time, and I just want it to be right for you. I feel a sense of pressure to plan the day in a way that you will enjoy. It is only because I know you and all of your little quirks that I can do this. If things go wrong, I know I will blame myself and feel like I have failed you.

We visit the cows and the goats. You hold out your hand to feed the goats and giggle when they lick your hand. We steer well clear of the chickens because I know that you hate any type of bird. Walking around the farm I can see your eyes taking everything in. It is the best feeling to know I’ve planned this day out and you are enjoying the experience.

But you suddenly now seem distracted. You are pulling my hand away from the animals in another direction. I’m second guessing what it could be. Are you hungry? Do you need the toilet? Do you want to leave already? I see now, the ice cream van comes into view. Again, there is a queue.

I try to persuade you that we need to wait in the queue for the ice cream. I write on the back of a screwed-up receipt I find in my bag, “good waiting” then “ice cream”. It’s no good, you decide to borrow the ice cream that a small girl returning from the front of the queue has in her hand instead. Why wait in line when there is one just walking past?

Luckily the girl seems to be stunned into silence. Several very cross words from the girl’s mother later and we manage to walk quickly away and escape. I can understand it must be surprising for the girl and particularly her mother when a tall man walks over and takes an ice cream without warning. There are no flashing lights or sirens that say, “person with autism incoming”. Although I can understand how they feel, it doesn’t sting any less to be spoken to in an unpleasant way.

I think we should try and find some lunch. There is another queue but not a big one as it is only the middle of the morning. We walk to the café, and I order you some food. Although I’m hungry I don’t order anything for myself. I need to be fully focused on you and I know I won’t be able to eat anything until I get you home safe. The food arrives but you don’t seem happy. You are looking at the garlic bread as if it were an alien. You are pointing at the garlic bread, and looking directly into my eyes willing me to understand what you are trying to tell me. This is the same meal you have eaten a thousand times before, what could be wrong with it? I look closely at the garlic bread and then notice the tiny leaf of parsley they have added. I call the server over and as politely as possible ask if they might bring back a new meal without the parsley. The server looks at me like I have lost my mind, as most people would just take it off. I know that won't be enough for you — we need a new one. The server returns with a new meal, and you're happy enough to eat it.

We leave the café to find it has started to rain. We try to duck under some cover, but it is too late. Your shoes are now wet which is one of the things you hate most in the world. You are pointing at your feet and trying to wipe the soles of your shoes with your hands to dry them. You know I understand what you are trying to tell me, but you are wondering why it is taking me so long to fix the problem. I pull a packet of tissues out of my bag and try to dry them off. You are holding on to me for balance whilst I wipe the soles of your shoes dry. The tissue drying method doesn't seem to help today, there are a couple of small bits of mud on the rims of the shoes. We will have to resort to plan B. Luckily, we were prepared this time and packed the spare shoes.

I decide we should go and see the horses. Horses have always been one of your favourite animals. We find the horses and the delight on your face is beautiful. You call out a loud neigh sound at the sight of them. You walk up to a dark brown horse and place your hand on the bridge of its face. You stare into the horse's glassy eyes, and it is like you are looking into each other's souls.

You take photos of the horses with your camera. You pull me into the exact position you want from me so you can take my photo next to the horse. It always feels special when you want to take my photo. I know you want to look back on this moment that we spent together.

All of a sudden, a nearby child let's out a high-pitched wail. I'm instantly on alert as this is exactly the type of noise that you hate. I can see from your face all other noises have been drowned out and it seems as if the small girl is screaming directly at you. Your eyes look like you are in pain. This is your personal hell.

My heart is pumping. I'm poised to react. I know you just want to stop the noise, but you don't know how. Does the little girl have an off switch like the car radio? I need to be prepared that you might try to stop her from screaming. My mind is suddenly ten steps ahead. Will we have to leave? Will I have to restrain you? Will someone phone the police?

I've got to think of a distraction and quickly. "From the day we arrive on the planet, and blinking, step into the sun". I've pulled my phone out of my bag and I'm playing *The Lion King* soundtrack at full volume. People are staring but it doesn't matter. Slowly your eyes move away from the screaming child, and you reach out to take my phone. You change the track until you find the one you are looking for — Michael Buble, *Cold December Night* playing at volume 100 in July in the middle of a farm.

> **"I've got to think of a distraction and quickly"**

“As long as you have had a good time, that is enough for me”

I decide that we should head back to the car after this. We haven’t seen everything on the farm, but I can sense that you are ready to leave. We make a quick stop off in the shop. You buy a plastic elephant toy. This is the exact same elephant you had when you were a toddler — it always amazes me that you can remember the toys you had when you were little and that you still love them now.

You are happy to be back in the car and rocking steadily backwards and forwards. You are staring intently at your toy elephant. I think you must be checking that every tiny detail is the same as the one you had. You seem satisfied it is the right one because you take a few photos of it in different positions.

We are back in the car and I feel relieved that we have made it through the day and you seem to have enjoyed yourself. As long as you have had a good time, that is enough for me and it makes everything worth it. I am already thinking ten steps ahead to when we take you back to the carers and what I will need to fill them in on. In the back of the car, you turn to me. You lean forward and place your nose against my nose. There are no words needed, I know what this means. This means thank you. It means I know all that you do for me. It means I love you.

Maura

“I always looked forward to visiting my sister Alison”

Once I had a sister. Her name was Alison and she was twenty-one months younger than me, the middle child of our parents. We shared the same straight brown hair and green eyes, different from our younger brother with his blue eyes and blonde hair.

Alison and I were born uneventfully at home. In the first year of my sister’s life, our mother began to worry about her development. “This child is strange,” she told a close friend, “She smiles at things that are not there.” Alison’s howling would be the first thing our father heard as he turned into our road each evening. Alison reached her second birthday without walking or talking. Professional help was sought and my parents were told that there was “a permanent problem” and they needed to plan for her long term future.

Alison was given a diagnosis of “mental handicap” (now termed learning disability). Before this, it was suggested to my parents that her difficulties might be caused by the way that our mother was interacting with her. This was not the case but was a theory circulating in the early 1960s about the cause of autism. A decade later, blood tests established that her disability was likely to have been caused by a chromosomal abnormality occurring at the point of conception. Nowadays, Alison would have been described as having a “severe learning disability” and possibly autism. She was small in stature and a restless child, always on the go. She developed epilepsy that worsened when she reached puberty.

Alison learnt to walk and proved herself to be an adept runner and climber, skills that placed her at risk, as she had no sense of danger. There were times when she went missing from home and the police had to be called. Once we lost her on a beach when we were on holiday and twice I stopped her from climbing out of an upstairs window. We all learnt to be vigilant.

> **“We all learnt to be vigilant”**

“There were social events that we could attend as a family, and we benefitted from this contact with other families”

Alison did not learn to speak beyond a few words. These included our mother’s name — Elsa. She could hum a tune and enjoyed music and nursery rhymes. Her favourite toy was a hand-held cord-pull music box, and her favourite game was a nursery rhyme on our father’s lap or running around the dining table with me and my brother. Alison ate with her hands rather than cutlery, and mealtimes could be a messy affair. She loved ice cream and, on more than one occasion, snatched an ice-cream cone from an indignant child when we were out. Alison could remove all her clothes but could not dress herself and depended on others for all her personal care needs.

Our extended family lived too far away to offer practical support and the emotional support our mother received was limited. Most neighbours in our small cul-de-sac were understanding but the main support for our parents came from other families who were members of a local society for “mentally handicapped children”. There were social events that we could attend as a family, and we benefitted from this contact with other families.

During our childhood, our parents faced a difficult choice. To continue as a family of five when the only respite support available was one week a year, or to place Alison into full-time care, so that the rest of us could have a “normal family life”. They chose the latter and at the age of eight, Alison went to live at Essex Hall in Colchester. In 1969, the world was changing but for vulnerable people it was still the era of institutional care. Essex Hall was a hospital housed in a Victorian building and formerly known as the “Essex Counties Asylum for Idiots”.

Each month, we would make the two hour round trip to see Alison and take her out for the day. As we pulled up into the hospital car park, a sea of faces would appear at the tall, Victorian windows, looking down at us. This was discomforting, and I was glad that Alison and the other children lived in a separate place on the hospital site in modern accommodation with a school attached. The walls of the children’s ward were brightly coloured with murals, and there was a separate kitchen and dining area. The children slept together next door in another ward filled with cot beds made from metal.

When Alison came home to stay for the weekend, breakable items had to be moved out of her reach and home security intensified. We had acquired a cat and Alison picked him up by his tail before he was moved upstairs to safety. I remember my parents being exhausted at the end of these weekend visits, and the return to peace and calm after she left.

I always looked forward to visiting Alison when we were a family of five again. Days out together were spent in Castle Park and at the Lyons Tea House. The ending to these days was always sad though because Alison would howl in distress when we said goodbye and left without taking her with us. The atmosphere in the car would be strained and uncomfortable and few words would be spoken. Our "normal family life" brought benefits to the four of us, but this was cut short when our mother died suddenly, three years after Alison went into care.

Alison spent half her lifetime at Essex Hall before she too died unexpectedly a month before her sixteenth birthday in 1977. I have often wondered whether Alison's life at Essex Hall was a happy one. On our regular visits, she appeared to be well cared for and the nurses were kind and friendly. The fact that she often repeated our mother's name and her distress at being left behind convinced me that she would have preferred to be at home with us.

When we were young, I found it hard to answer questions about Alison from other children encountering her for the first time. Why is she wearing a nappy? Why doesn't she speak? Why do you have to hold her hand? Why do you have locks on the outside of your bedroom doors? With my close friends who lived across the road, it was easy as they accepted Alison and understood the importance of keeping her safe: "last one lock the gate" was our mantra whenever we came round the back of the house. When we played our imaginary games together, using Alison's enormous cot as a wagon (our father added a roof to this to stop her climbing out at night), she would play quietly in a corner of the room. "I remember Alison. She was a nice little girl," one of these friends told me last year.

I turned 18 in the year of Alison's death and left home for university. Back then, and for many years afterwards, I preferred not to mention Alison and pushed the memories of her life and of our family loss deep inside myself. As a social worker, I avoided working with disabled children and their families for at least half of my professional life. When I overcame this barrier, it turned out to be one of the most rewarding parts of my career.

I have wished with all my heart that Alison had lived longer to benefit from the introduction of care in the community and that my parents had been offered the range of family support

> **"As a social worker, I avoided working with disabled children and their families for at least half of my professional life. When I overcame this barrier, it turned out to be one of the most rewarding parts of my career"**

“The [group] has been very healing for me”

services that exist today, instead of two impossible choices. Essex Hall closed in 1985 and a new housing development was built over the site that sits next door to Colchester train station.

A few years ago, when I was passing through the station, I looked out of the window searching to see what was left of the old hospital site. All that remained was a large cedar tree that had once stood in the hospital car park. It made me happy to see it still growing there, a surviving marker of the place, and I make sure to look out for it whenever I pass through the station.

In recent years, I have tried to recover memories of Alison and our relationship. I am grateful to our father for sharing his narratives of family life and for looking after the three of us after our mother died. Other family and friends have also helped me to develop and shape my own narrative through their stories: my grandmother, uncle and my mother’s close friend Sally. Also my daughter’s curiosity and questions about her aunt propelled me forward in my search. “What was she like? Can I see a photograph? Would she have liked me? Would I have liked her? Would we have visited her where she was living? Would she have come to see us?” Yes is the answer I gave to each of these questions.

The Sibs group for bereaved siblings gave me the opportunity to share with others the complexities of our sibling relationships: the guilt, the shame, the anger and the love, in a way that has been very healing for me. Lastly, thanks to my brother for understanding me and for our enduring relationship.

Tyler

“I wonder if you were different how could I end up the same?”

Dear Connor

I sometimes sit and wonder just how different life would be
If the Gods had made you the “standard” of what a young man should be.
I wonder if you’d be out all day, playing with your friends.
Or chatting up the girls and driving our mum round the bend!
Would you have a silly haircut just to fit the mould?
Or would you be eclectic — someone free inside their soul.
I wonder if you’d live at home but spend all day down the gym.
Or would you be more like me and go off travellin’?
I wonder if we’d sit up late and put the world to rights.
Or if you’d have a job somewhere that kept you away at night.
Maybe you’d be a fireman, maybe you’d drive a cab.
Or would you be a bricky and build houses like our dad.
I wonder how you’d talk to me and what it is you’d say.
Maybe we wouldn’t speak at all or would we talk all day?
I wonder if you’d be proud of all the choices I have made.
I wonder if you were different how could I end up the same?
There is a certain heartbreak when I think of all these things.
These questions keep me up at night, these sombre wonderings...
But the question I don’t have to ask because I know for sure,
Is that you are perfection. I love you just the way you are.
x x x

Zeinab

“On many days, I am utterly fed up or angry or sad or scared. And it’s really OK if you are too”

There are many times when having a sibling with a disability is hard; life-changingly, cripplingly hard. I feel we don’t speak about this enough.

Social media is full of posts of parents celebrating their children’s disabilities, sharing moments of triumph and determination. It is right that they do this, and I know that not every person will deal with a situation in the exact same way.

Many of these posts give hope of what is possible, in many cases giving a platform for the voices of disabled people themselves. It’s worth noting that many of these families seem financially secure with stable homes and established support networks.

Perhaps I’m looking in the wrong places, but many of these families also seem to be from empowered white backgrounds (whilst I am also aware that many white families share struggles too). I’m not from that background and perhaps some people will identify with my experiences.

Sometimes as a sibling, you get tired of seeing the jovial social media posts. You can’t identify with these moments of happiness. Disability to you is not a power or a triumph. It’s exhausting.

It’s exhausting for several reasons. Maybe because it’s rare that you get a good night’s sleep, especially if you’re in a far from ideal accommodation where you hear every stir, and your disabled sibling happens to have a poor sleep pattern. Your life is unpredictable, and at any moment something dramatic could happen, a meltdown for example. It could be just before bedtime, in the middle of the night, or first thing in the morning.

“Disability to you is not a power or a triumph. It’s exhausting”

It could be when you are sharing a proud moment of your own success with your parent who then has to divert their attention elsewhere. You can never be sure that a moment will be just what you had hoped for. Your disabled sibling may and will embarrass you, or be angry with you, sometimes bringing you to tears. Every second of your life has to be planned in advance — it becomes difficult, so difficult that it becomes easier to stay at home.

You can see the exhaustion etched into your parents' faces, and slowly yet surely, you start becoming a young carer yourself. You become an expert of your siblings' disability — whilst you watch your friends travel, party and grow into themselves...you then become the person they can't identify with. You're now in the "other" category too. Now, as an adult, I know the name and research interests of every prominent autism expert, I know how to critically read a research paper (undoubtedly this has its advantages) but I have no long lists of other interests, places I've been or things I've done. Naturally, my social conversations amongst many people are stunted.

Things change with time. It's not all awful — and in many ways living with a disabled person opens up your eyes to many related social justice issues. However, I won't deny that for me at least, life continues to be very hard at times. People will often wonder why you haven't explored avenues of help available earlier, and why you are singing this miserable song instead of doing that now. I say to these people that if this help is out there, why don't families like ours know about it?

There are plenty of stories about families pursuing support for disabled people through litigation. Even when families know this is possible, it doesn't stop it being a long-drawn and expensive process. You can't do it without the time, the energy and the means. There are many things I think about. Who is the disability advocacy movement representing? Is it representing people like my sibling or families like mine? As a minority within a minority, you question every challenge you make to people of authority — will this be used against my disabled sibling? Against my family? You hear the stories of disabled people incarcerated in hospitals through no fault of their own and you

"Who is the disability advocacy movement representing? Is it representing people like my sibling or families like mine? As a minority within a minority, you question every challenge you make to people of authority – will this be used against my disabled sibling? Against my family?"

> **“It’s an anxiety-loaded, unpredictable life where every day you just have to hope for the best”**

think “If that is the price we need to pay for challenging the system, for asking for help, we don’t want the help”. You just carry on.

On the rare occasion when there is respite from caring for a disabled sibling, you get glimpses of what it could have been like, how much lighter, how much easier...these are the things you cannot say out loud. There is so much guilt and shaming associated with feeling your feelings.

You feel guilty for your parents’ struggle; they feel guilty for yours. You worry about your disabled siblings’ future and also your own life. You can’t plan ahead because you don’t know how to or what you’re planning for. It’s an anxiety-loaded, unpredictable life where every day you just have to hope for the best.

Having a disabled sibling changed my life in ways I could not have predicted. My love and support for my sibling is unfailing, and I never blame him/her for systems around him/her not adapting to his/her needs, when they can and should. But as a sibling carer, I will say that on many days, I am utterly fed up or angry or sad or scared. And it’s really OK if you are too.

All names have been changed.

Esther & Judith

“Both our disabled brother and mum needed care during lockdown, so we divided the responsibility between us”

We are Esther and Judith. We’re sisters to our brother, Jonathan, who is autistic and has a learning disability. He has a weekly routine of activities and supported training placements.

In March 2020, the café he works at closed, and the rest of his activities, including all social and sporting groups, were cancelled. This left Jonathan without any structured schedule to his day. One of his key support workers was off work for over a month, and his team was reduced to just one member of staff for the first month.

Initially, Dad took over organising Jonathan’s care, sorting out the shopping and taking him for walks almost every day. Then Mum became ill, and Dad was no longer able to visit Jonathan because of shielding restrictions. Mum was in and out of hospital.

So we decided to divide up the care between us. Esther moved out of her flat and moved into our parents’ home to take care of her Mum and Dad. Judith took on more responsibility for Jonathan.

Written July 2020.

> **“One of his key support workers was off work for over a month, and his team was reduced to just one member of staff for the first month”**

“It’s been challenging being thrown into this [caring] role so suddenly”

Judith’s story

Jonathan and I have always been close, but I’ve never had to have a “caring” relationship with him before. I always knew that, one day, my sister and I would take on more responsibility for his care, but I never expected that to happen so soon and so suddenly.

Throughout lockdown, I’ve been trying to give him some structure by taking him out for a long walk in the nature reserve near where he lives, four days a week. I’ve been liaising with his support staff to come up with ideas on how to talk to him about the situation, help him cope with the change in routine, and how else to give structure to his days.

It’s been challenging being thrown into this role so suddenly. I’m trying to juggle it with working full time; often making up for missed work hours in the evenings and weekends. It’s also been really difficult trying to manage his expectations.

He knows that he can’t do everything he usually does because of the coronavirus, but I don’t think he fully grasps what that means. It’s been hard to see him upset – sometimes to the point of tears – about not being able to spend time with the rest of our family and friends.

In the early days of lockdown, when he was struggling the most, he was often tearing up his favourite objects, biting himself to the point of leaving bruises all over his arms, refusing to engage with anything or anyone. Thankfully now the restrictions are less strict he’s a lot happier and has settled into his new routine well, but for those first eight weeks of complete lockdown it was a real challenge.

“The pressure that we, as siblings, [should provide care] is constant”

Esther’s story

I often feel guilty that as I can’t drive I can’t visit Jonathan and take him on walks like my sister does. I can’t provide her and the care team with any respite. Instead I can only speak to him on the phone. This has made me feel left out. Seeing how my sister has had to cope with a full-time job, our mum being ill and being the sole family member providing care has made me feel incredibly guilty for having the luxury of not being in a place where I am responsible for Jonathan’s care.

At the start of lockdown I was getting video calls from him maybe ten times a day. Most of the conversations were around his anxiety at not understanding why he couldn’t see family and continue as normal. It’s been incredibly difficult to see him so upset on the phone and knowing that I can’t explain the situation in a way he can understand and that I can’t visit him.

As I am working from home and providing additional support to my parents, the addition of ten phone calls a day really affected how well I was coping with the situation. I found myself choosing to ignore his phone calls rather than talk to him, because I didn’t want to see him upset, and I didn’t want him to feel jealous that I was with our parents, but he couldn’t see them.

When the restrictions eased, I saw my brother in person for the first time in nearly three months. Normally I see him once a week. It was so amazing to see him again in person, and see how happy he was being out of the house and around more family members. Jonathan initially struggled with social distancing, but by the time I saw him last week he knew that we couldn’t hug and had to sit far apart.

I want people to know that there are a number of different roles that adult siblings play. In my family alone we have two distinct roles: My sister is now a carer and activities coordinator in addition to being a sister, while I remain just a sister. She has taken on so much more responsibility and handled the early challenges of helping Jonathan adjust to lockdown life.

In contrast, I’ve been fairly cut off from his situation and left feeling incredibly guilty that I am not helping him, I am not caring for him and, beyond a few video calls, I am not engaging with or entertaining him. The pressure that we, as siblings, should care for and be responsible for our disabled brothers and sisters, either now or in the future when our parents are no longer able to, is constant and has been exacerbated by the lockdown.

I feel conflicted, sad and frustrated by my inability to see and care for my brother. I can only imagine how much more difficult it is for people who are currently living with their siblings, providing full-time care without much respite, if any.

Shamini

“The words of the risk assessment made it sound as though I were an untrustworthy stranger”

Shamini entered *Poetry for Good,* a national competition that ran in the Spring of 2021. Her piece *Risk Assessment: High* was highly commended in the spoken word category. Many siblings will relate to this powerful and articulate poem that highlights the unseen work of sibling carers during the pandemic.

Scan here to watch or go to sibs.org.uk/riskassessmenthigh

> **“There is little to no support for family carers whose work is seen as voluntary rather than essential. There are no formal risk assessments; we just get on with what each day and night throws at us as though we are machines”**

I entered this competition because I thought it was a chance to shed light on the unseen work of family carers. In our case, this includes a lot of speedy cleaning — my sister frequently spits or throws food on the floor but doesn’t like the sound of the vacuum cleaner because of her autism. We often use a dustpan and brush to clean carpets because it’s quieter, but it’s harder work! And I work fast to vacuum clean when she’s in the shower or very occasionally when she’s out. It’s exhausting.

There is little to no support for family carers whose work is seen as voluntary rather than essential. There are no formal risk assessments; we just get on with what each day and night throws at us as though we are machines. I also wanted to highlight the treatment of family carers by some professionals and care home providers, especially in light of Covid-19 restrictions.

I wrote this poem especially for this competition. I had just been sent the risk assessment from my sister’s care home (where she lived from November to April) for me to be the nominated indoor visitor — until the end of March, they’d had a blanket ban on visitors because of Covid-19.

The words of the risk assessment made it sound as though I were an untrustworthy stranger. The fact that my one-hour visit — in which I would have first tested negative in front of staff, worn a face mask and cleaned my hands — was classified as a “High” risk level was particularly cutting. The irony being that my sister contracted Covid-19 from staff in January and was attacked in her care home bedroom in April, leading rather bizarrely to her eviction. In fact, this video was recorded just before I visited her after finding out about the attack, which is why I look so miserable.

She was at great risk in the care home. I’m glad she’s back with her family now and we’re working hard to keep her safe, well and happy. But as this poem shows, there are risks every day. So far, it’s nearly two months since she came home, but we’ve had no respite and no help with getting her to recover from her trauma.

Kate

“I’m the only family member for my brother with Asperger’s and my mother, who has dementia”

I’m the only family member for my brother aged 52 with Asperger’s and my mother, aged 88, who has dementia. When we were young, my brother’s shouting when he was upset used to go on for a long time and his inflexibility and refusal to do what was asked of him — regardless of the impact on others — made the house a place I found it hard to relax. Luckily my hobbies of reading and crafts gave me the escapism I needed. Despite being 18 months younger, I seemed to get the blame a lot, while my brother got off scot-free with just about anything he did. My mum blamed me for getting irritated by him — but she and Dad got irritated too! I was expected to tolerate and accommodate his behaviour, without anyone ever explaining why!

When my brother was older, Mum just couldn’t cope anymore, so they scrimped and saved to be able to send him away to a boarding school. That gave a lot of relief during my teenage years and I’m very grateful that they chose to do that, although my brother had a very hard time at boarding school because his behaviour antagonised other pupils and teachers. He got the grades to do a degree in his favourite subjects. Luckily these academic subjects are also his Asperger’s “special interests” — the things that he focuses on and talks non-stop about, regardless of whether or not other people want to hear.

My brother was thrown out by Mum and Dad aged 22. At that time, he hadn’t had a diagnosis as even autism was something most people hadn’t heard of, let alone Asperger’s. He’d somehow managed being away at university and got a 2:1 in his degree, but his returning home was too much for my parents. They found him a flat, where he lived in semi-independence, relying on Mum to

“I was expected to tolerate and accommodate his behaviour, without anyone ever explaining why!”

calm down his emotional meltdowns over the phone, and Dad to give him enough money to cushion whatever kind of difficulty he was going through.He's never managed to get a job due to his poor social skills, and somehow the Job Centre seems not to have spotted anything in his 30 years of signing on. They did sanction his benefits a couple of times because he wasn't doing what they expected in his job search, which I suspect would be due to his "Asperger's" way of doing things.

When we were both in our forties, Dad was diagnosed with dementia and Mum became his carer. My brother didn't really understand how much help he needed, but in one of those unexpected moments that happens with Asperger's, he once willingly helped my dad to have a shower. All through his life, there've been times like this, when he surprised us all by suddenly making a leap forward in his understanding, or by being able to do something he'd never managed before. This is something probably most people with a relative with Asperger's can relate to!

After my dad died, my brother was evicted from the same flat my parents had moved him into 27 years before, as his increasing hoarding and lack of hygiene had caused damage to the flat. Again, Mum bailed him out with enough money to pay the landlord for the damage. My brother was studying online for a master's degree, and as he can only focus on one big thing at once, he couldn't organise himself to find another place to live and wouldn't go to the council or accept help from anyone. Mum had been recently diagnosed with dementia and this might partly explain why, as his eviction date loomed, she found herself agreeing for him to stay with her — only for three months. This marked the start of the most physically and emotionally exhausting three and a half years of my life.

Mum was always the one my brother would phone to rant and rave at when frustrated, until he felt better. She'd also advise him on practical problems, which were at the root of most of his "meltdowns". Mum's language skills were the first things to go with the dementia and so she found this more and more difficult. My brother struggled, as Mum now needed help herself to do things like online food shopping and kept interrupting him while he was doing his coursework for his master's degree. As a social worker, I could see the likely outcome for him if he stayed at Mum's house, with her dementia getting worse and worse. His hoarding began taking over more and more rooms in her house and most of the floors were covered with his things. Eventually she'd be likely to slip and injure herself, or wouldn't be able to use the kitchen properly because of all the things piled up on the counters and cooker.

Also, my brother's behaviour towards her was getting more and more abusive. He'd shout at her until she was terrified and called me begging for help and saying she wanted me to take legal action to get him to leave — but after a day she'd forget what had happened and go back to saying that she couldn't throw her son out, that'd be cruel — and what a terrible sister I was for suggesting it!!

> **"There've been times like this, when [my brother] surprised us all by suddenly making a leap forward in his understanding"**

“It wasn’t just my brother who had Asperger’s [...] my dad and mum had both had traits of Asperger’s too!”

With my social work experience, I knew that when things got serious enough, the council would need to get the police to remove him under safeguarding adults procedures — but he wouldn’t have anywhere to go and would most likely be placed in a hostel, where he’d be an easy target for any dodgy people living there. I knew that if my brother had a diagnosis of Asperger’s, this would mean the council would have to consider whether this made him a “vulnerable person” and this might be the only thing that would save him from the dangers of a hostel. My brother would always get very angry when Mum or I suggested he might have Asperger’s, so there’s no way he would voluntarily seek a diagnosis.

I was at this stage receiving phone calls several times daily: from Mum asking me to get my brother to leave, from my brother asking me to tell Mum to do what he wanted, from concerned neighbours, the local pharmacist, the police – anyone who got dragged into their situation. Social services were unable to help at this stage, as although they knew Mum was experiencing domestic abuse (verbal/emotional), every time they spoke to her, she insisted everything was OK and refused to take legal action.

Even though I’m a social worker, I couldn’t work out what else I could do to help my mum and brother out of the situation they’d got themselves into. Out of sheer desperation, I tracked down a clinical psychologist who’d been a family friend when I was a child, to see if she might be able to help me find some way of getting a diagnosis for my brother. What she then told me opened my eyes! She said that it wasn’t just my brother who had Asperger’s: with her experience as a clinical psychologist, she’d also noticed that my dad and mum had both had traits of Asperger’s too!

Suddenly, my childhood experiences made more sense – the excessive punishments from Mum (such as making me carry my Christmas presents to the bonfire and watching her burn them, because I hadn’t kept them tidy), Dad’s withdrawal and indifference (too much for him to deal with at home after having to put on a “sociable” front when being around people all day at work). So now I consider myself as having grown up as part of an “Asperger’s family”. The family friend I mentioned made it clear that she thought I was the only non-Asperger’s person among the four of us!

She then advised me to find a private clinical psychologist prepared to do a home visit without my brother’s advance consent. He stayed for four and a half hours and my brother talked almost solidly about his frustrations with my mother’s dementia, and his special interests for over four hours out of this! The psychologist had a hard time getting a word in edgeways! At the end, my brother somehow had the impression that the psychologist was there to deal with his complaints about Mum’s dementia, even though the questions had all been about him. I was shocked! Somehow my brother’s habit of constant talking had for almost 50 years had masked how little understanding he has of people's motives. When I realised this, I was even more concerned about how he'd cope in a hostel, with the kind of people who might be living there. He was furious with me when he received an A4 letter with the diagnosis and a long report on his difficulties. I felt bad as I could imagine how hard that was for him — he must have been singled out for being different so many times in his life and this probably felt like the ultimate betrayal by his sister.

The situation got worse and worse between him and Mum. Social services did a safeguarding adults investigation and put a safeguarding plan in place for my mum. Unfortunately, this didn't help Mum at all, and I was getting just as many phone calls and emails as before, with people expecting me to be able to persuade my brother to move out. I really wished there was another family member, or a family friend, who could intervene — but there was only me. My brother had little idea of what Mum needed help with as her dementia got worse, so I was having to deal with paying bills, arranging household repairs and so on, as well as dealing with their constant phone calls to me.

But then a few months ago, a miracle happened — my brother had to go to A&E and was admitted for urgent treatment. He hadn't been going for his diabetes checks and wasn't managing his insulin well. This had led to a sore on his foot that he'd ignored and he was now at risk of having his leg amputated below the knee. Now I knew just what to do to protect Mum! I called the hospital social work team, explained the situation and asked for a discussion about discharge arrangements. I spoke to a very capable and understanding social worker, who took my concerns seriously. For the first time, someone considered doing something called a mental capacity assessment, looking specifically at my brother's ability to decide on where he should live on discharge. And my brother — who'd just passed a master's degree — was assessed as lacking mental capacity to decide whether he should return to live with Mum. Not because of any risk to him, but because he just couldn't understand the ways in which his behaviour was putting Mum at risk. He couldn't even take it in when the social worker explained it to him. Somehow his brain doesn't work that way. The social worker did a great job, finding an emergency placement for my brother in a sheltered housing scheme. But problems started immediately and staff from the scheme and the care agency still keep ringing me to ask me to sort things.

My brother sends long abusive emails telling me what a terrible person I am — and then asks me to do things for him, usually expecting me to do them immediately. I'm still sorting out the damage he caused to Mum's house as well as doing all the things that paid carers can't.

> **"I really wished there was another family member, or a family friend, who could intervene — but there was only me"**

“It's changed me as a person. I’ve been forced to set boundaries, something I previously tended to avoid”

It’s a rare day when I don’t have to do something for one or the other of them, and some days it can take two to three hours, or most of the day. Fortunately, I have a very understanding manager and can work flexible hours to fit around this. But after so long dealing with the intense situation when they were living together, and then this, I became exhausted and I’m still not back to my normal energy levels… which in my 50s are lower than they were.

Again, I’m so glad I’m a social worker, as I know that I don’t HAVE to do things for my brother. Although it goes against the grain, I’ve started telling people that no, I won’t see if he’ll let me sort out his finances because he’s somehow not able to manage this himself now; no, I can’t persuade him to apply for housing benefit even though he’s a few months in rent arrears because he wouldn’t let staff at the scheme help with this; no, I’m not even going to try to persuade him to accept help with sorting out the dirt and clutter in his flat that’s already led to them raising a safeguarding alert, due to the risk to himself.

Sometimes, as siblings, we’ve grown up going along with the idea that we should automatically help our brother or sister. But when we also have ageing parents needing help, and in some cases our own children or other major responsibilities, sometimes we will have to make some difficult decisions, especially if we don’t have other siblings or family who can help. When I read other sibling’s stories, many of them seem to mention the fun times they manage to have together, regardless of all the difficulties and obstacles they face. I’d like to be able to say this about me and my brother — but I honestly can’t. I’ve worked hard to find positives in my brother in other ways, though. I admire that despite all his struggles in life, he’s never said one jealous word about my successes, which have come much easier and much more often than his. I appreciate his depth of knowledge about his special interests and his ability to stick with his degree and master’s degree through all the frustrations.

But although I love my brother and want to protect him, since childhood I’ve found it excruciating to be around him because of his constant talking, shouting and insistence that his needs and schedule override everything else. I love him, but I don’t like him — and I’m sure there are many siblings who feel this way.

So, if I can’t see anything about my relationship with my brother as a positive, how do I, as a great believer in the life-changing effects of focusing on positives, find a positive in having him as a brother? For me, it’s about how it’s changed me as a person. I’ve been forced to set boundaries, something I previously tended to avoid. I’ve started putting less importance on how professionals, neighbours and my brother’s carers may judge me for not doing the tasks they try to pass on to me. And most importantly I’ve learned that reacting

> **“I love him, but I don’t like him — and I’m sure there are many siblings who feel this way”**

emotionally to being bombarded with urgent and essential tasks for my brother and Mum only makes things worse for me. There have been many tasks where there was literally no one else who could legally or practically do them — so I’ve learnt to accept this, rather than waste energy reacting with tears or negative thoughts when I get yet another phone call from someone!

This lesson is transferrable to every other part of my life. My life has become less stressful and tiring, because I no longer waste energy having a negative reaction when anything challenging comes up. I’ve had a daily yoga and meditation practice for years, which has been a great help in helping me relax and look at my unhelpful ways of thinking about people and situations. The situation with my brother has motivated me to go more deeply into this, as a way of coping. There’s truth in the old saying: What doesn’t kill you, makes you stronger! I hope that reading this has been of some help to other siblings and wish you lots of strength and positivity in dealing with your own situation.

Rachel

“I forget the world sees my sister differently to how I do”

For as long as I can remember, I have been close to my sisters. I’m the youngest of three — it feels like having two best friends who will always look out for me. I was drawn to Sibs because one of my sisters, Joanna, has autism and a learning disability.

When Joanna and I were in primary school, I realised I would have to do more to look out for her. Joanna got a diagnosis of what was then known as Asperger’s Syndrome when she was very young, and when I was too young to understand what it meant. At primary school, we were both bullied a lot. Older children would follow us home and call her names, like “r****d”. It was upsetting for both of us.

Things got better when I moved to a different school. Around this point, Joanna began attending a school for students with autism, where she stayed until she was 19. I began to understand more about her autism, as we went as a family to her school events, my parents met with professionals in our home to discuss Joanna, and I noticed the challenges that she had with social interaction especially.

Joanna and I have been through too much together to write in a few short words. Sometimes, we are so in our own little bubble, with our own quirks and jokes and stories that we love to share, that I forget the world sees her differently to how I do. I would say the most challenging times for me have been helping her to manage her distress. It can be very intense when she is upset. For example, when I attended her cervical screening appointments with her a few years ago she could not cope with the physical discomfort she felt. It was very hard to take care of her when she had a meltdown after her appointment — she was screaming and crying outside of our doctor’s surgery.

> **“Sometimes, we are so in our own little bubble, with our own quirks and jokes and stories”**

“I wouldn’t change a thing about our life together”

Sometimes, it’s dealing with other people’s lack of knowledge that can be hard. Because of her autism, Joanna has struggled sometimes to understand appropriate social boundaries. This has led to the police coming to our home in the past. It was always stressful answering the door to police — I genuinely feared for her safety at times. At one point, I was alone dealing with a police officer who asked if I could act as an appropriate adult to represent Joanna in court. I was 17, so this wasn’t possible. The officer did not seem to understand this or the impact Joanna’s autism and learning disability had on her.

The way that I see it, all families have challenges. It’s the way in which you learn to manage those challenges that brings you closer together. Joanna is now 27 and I am 24. We live together and we have made some really good memories, even with our turbulent past. Nobody can make me laugh like my sisters. Joanna is such an important person to me and I will always want to look out for her. That’s not necessarily because she has a learning disability — that’s because she is family. She will just need more support as our lives go on.

Nowadays, we enjoy day trips together, playing with our pet rabbits, going to the cinema, and spending time as a family with our mum, my oldest sister, and my partner. I wouldn’t change a thing about our life together.

Josh

"People often don't realise I am an identical twin"

Olly and I were born twenty years ago. We were identical in every way until he was diagnosed with autism, learning difficulties, and ADHD. This has led to us having different life plans from the start: I am destined to care for Olly all my life, while Olly is destined to be cared for.

Olly was diagnosed at 18 months old at Great Ormond Street; I don't remember anything of his diagnosis time as I was still 18 months old myself. I believe my parents found it difficult, and it was a moment that altered their lives forever more, but for me, I still had a great early childhood without the understanding of Olly being different.

My earliest memories of Olly and me together were at nursery. We attended the same nursery, which ended up being the last school we would attend together in our educational careers. Olly was different from the other children and required a helper with him all day, every day. Despite this, he still graduated from nursery like me. My mum still hangs the picture of our nursery graduation, as it is the only thing we will graduate from together.

From the earliest days of my school years, when Olly was no longer at the same school, I learned what it meant for Olly to be autistic, have ADHD and have learning difficulties. For me, this meant that Olly could not speak and might never speak; it was not a genetic thing but a thing for us that was given to us by God as we, as a family, could cope with Olly. Religion became so essential for us that we attended church once every two weeks, and the community rallied behind us and prayed for us and Olly.

When I joined high school, Olly matured me as a person. I grew massively because I had to look after Olly more. I helped him dress, shower, clean the house, and look after him.

“I was very protective of my brother, but sometimes I felt that life was all about him; this made me feel a bit guilty”

I was very protective of my brother, but sometimes I felt that life was all about him; this made me feel a bit guilty, but I realised as I grew that he needed extra time with my parents, who still never forgot me.

I often had Josh and Mum (JAM) nights, where we would have the night off to go to the cinema or for a meal. In addition, I also spent time with my dad on Wednesdays, where we would watch TV together and talk about life. My grandparents were also a key part of my support for me, and I often went around on Thursday nights to see them and spend time with them, playing board games or cards. Every other Sunday, we also had a roast dinner and attended church.

This is where I also noticed the first stages of support I received from the council; they allowed me to attend a carers club on a Tuesday, which made me feel supported by a group of people going through the same thing. My school finally acknowledged me as a carer and, in Year 10, finally allowed me to attend breakfast club, of which the staff were excellent, and this ensured that I could eat breakfast before school in case I didn’t have time before I got to school.

Next in my development was when I joined college; my parents wanted me to be able to be me without Olly and decided to send me to a boarding school for my A-levels. This made me feel nervous as I was no longer with Olly on a day-to-day basis, and excited that my existence was not defined as being a carer. However, when the Covid lockdown struck, I had to become a primary carer for Olly due to us having Covid and Olly now being off school.

Again, I felt alone in the school I attended; I had Olly through all my online lessons, having to feed, entertain, and help him to the toilet. Some of my teachers did make comments about Olly screeching (as he is unable to talk, it is a way of communicating excitement), which made me feel embarrassed to participate in lessons. I also had my camera off to ensure Olly’s dignity, making me feel different, as some teachers highlighted this difference. When I went back to school again, I felt excited again. I was no longer a carer but nervous as I realised that my existence had been about Olly for a long period of my life.

When I went to university, I realised that I was doing something for both of us; my grades and degree were for me and Olly, as he would never be able to get one. I realised how difficult it is for carers to get a university education, and that is something that is often neglected within academic study. In addition to this, I realised that people often don’t realise I am an identical twin as most twins text or call or come up to visit their twins, and people get to know them. Olly cannot, and people forget that I am one.

For university, though, I do feel like Olly has had a massive positive impact on me; he has helped mould me into the independent,

“This support network allowed me to vent when I had a difficult time”

self-sufficient person I am who has a drive for my degree because of him. He has also helped me to decide on doing a post-grad when I finish my undergrad, which I am to do in intellectual and developmental disabilities so I can study people like me who are siblings of disabled people, as I have realised as my time at university has gone on how we are often forgotten in research.

I think now when looking back on my life so far, I would say that three things helped keep me going as Olly’s carer. Firstly, the idea of faith has been integral to me as I have grown. The reason we had Olly was because we could cope, and having the support of the wider church community as we grew up helped me understand why Olly was different.

Secondly, I would say having a support network of parents, friends and family helped while Olly was growing up, this support network allowed me to vent when I had a difficult time and allowed me to feel like a normal child growing up and now while I am at uni I can have a normal time being me.

Lastly, I would say when the going gets tough take it one day at a time. The next day can be better than the last day, because who knows where Olly will be in a day, week, month, or year?

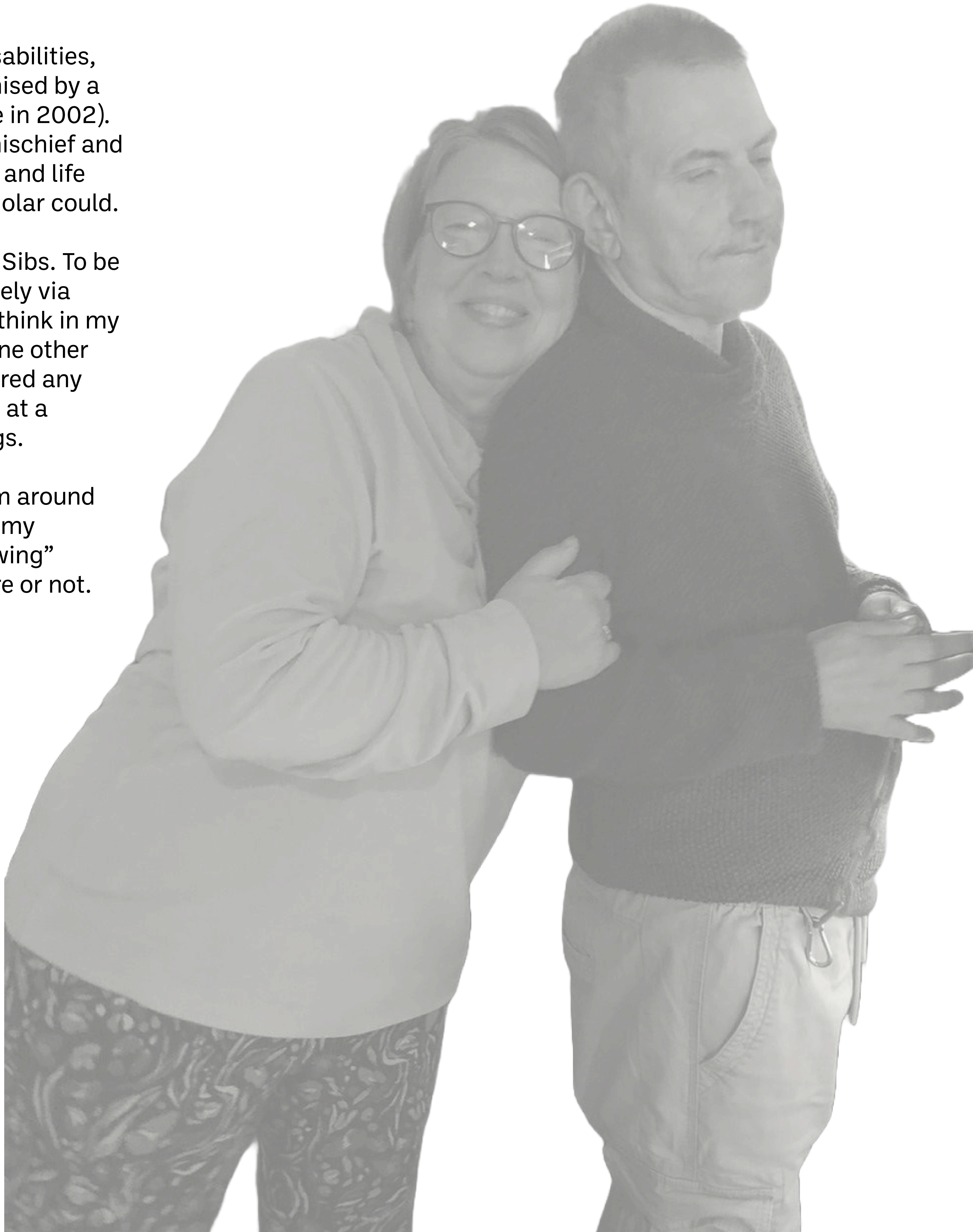
Barbara

“My brother has taught me more about life than any university ever could”

My brother has severe learning disabilities, autism and is physically compromised by a shortened leg (caused by a seizure in 2002). He is a gentle soul with an air of mischief and has taught me more about myself and life than any university lecturer or scholar could.

I took part in an online group with Sibs. To be part of a sibling group (be it remotely via Zoom) is something new for me. I think in my 62 years I had only encountered one other sibling of my generation that I shared any depth of feeling with and that was at a swimming session with our siblings.

To see a screen full of siblings from around the country immediately widened my opportunity to connect with “knowing” others with kindred stories to share or not.



Glass child

Apparently I am a glass child,
We don’t have any problems and don’t make a fuss.
We’re doing fine so don’t worry about us.

Yet in truth every day I felt guilty as my life rolled on.
With my school, my friends, my hobbies...while for you there were none.

I sensed the angst of my parents.
Yet as a child couldn’t express
The sorrow and difference of our nuclear family mess.

My story is over 60 years old now.
You were my silent instructor unable to speak.
Yet wondrously able to somehow reach me and teach...

Tolerance and empathy, to stand up for the weak.
Despite outcomes uncertain and when it all looked so bleak.

Hold fast glass child with so much to gain and give.
Your sibling has blessed you.
It’s your right to live!

Be the best for them.
Work through your stuff.
The love for, and of your sibling, will always be enough.

Barbara’s poem references a TED Talk by Alicia Meneses Maples called *Recognising Glass Children*.

Scan here to watch or go to sibs.org.uk/glasschildren

Questions

1. How do you feel after reading this collection, and why?

2. Did any of the stories resonate with you? If so — which one(s), and why? If not — what is different about your experience that isn't included in this collection?

3. What have you learned from reading it? How has it made you think differently about your own situation or that of others?

4. Which story were you most curious about, surprised or inspired by?

5. If you could reply to one of the stories, which would it be and what would you say?

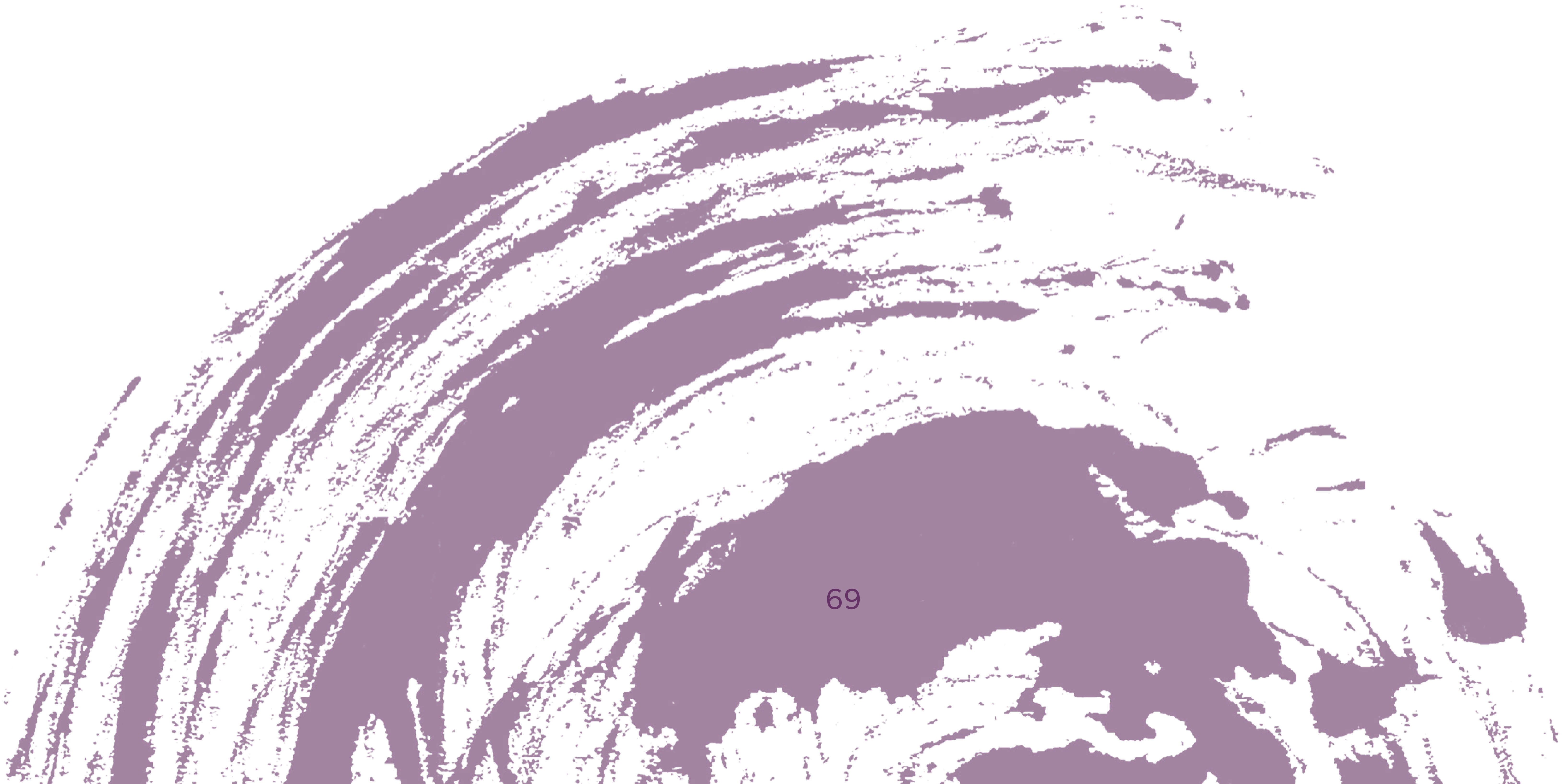
6. Did you notice some common feelings that were experienced by several of the siblings? What were they?

7. The collection includes experiences from siblings aged 19–62. What do you think has changed in the sibling experience across the decades? What has stayed the same?

8. What do you think siblings need the most?

9. As a result of reading this collection, what one thing will you do differently going forward?

We'd love to hear your responses. Email info@sibs.org.uk or tag us on social media.



About Sibs

Sibs is the only UK charity representing the needs of siblings of disabled people. There are over half a million young siblings and at least 1.7 million adult siblings in the UK, who have grown up with a disabled brother or sister. Sibs aims to enhance the lives of siblings by providing them with information and support, and by influencing service provision throughout the UK.

More support for adult siblings

Being a sibling can be a complex and challenging experience. You are not alone:

- Meet other siblings at a support group
- Chat with other siblings on our private Facebook community, #Siblife
- Download our eBook *Self-care for siblings*
- Read our guides on topics like mental capacity and managing finances

We need your help

Sibs relies on donations and grants to support siblings. If reading this collection has helped you, please consider making a donation or becoming a Friend of Sibs. You can also support our work in other ways, such as sharing our posts on social media or by doing a sponsored event.

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