

# ‘Though the earth gives way’: An autoethnographic account of autistic grief

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## **Abstract**

Through an autoethnographic account of my mother’s death, I reveal how grief and the desolation it brings the autistic person is vastly different to neurotypical models of grief (such as the Kübler-Ross model) determining when, where and how I was permitted to feel my emotions. Grief takes those with autism spectrum disorder (ASD) a greater amount of time to work through, often resulting in periods of meltdown and shutdown (heightened anger and fear) as well as an unawareness of the emotion they are feeling. However, I will also show how parental death can also be transformative, providing a powerful reason to persevere.



God is our refuge and strength,  
a very present help in trouble.  
Therefore we will not fear though the earth gives way,  
though the mountains be moved into the heart of the sea.  
(Psalm 46:2, ESV)

Psalm 46 was her favourite. The recognisable words from verse 10, ‘Be still and know that I am God’, were cross-stitched and framed above my parents’ bed – until I smashed it. It had been months since her death,

months since the funeral when I had stood at the lectern in the crematorium chapel and uttered the same words. As I began, knowing what mountain I was about to climb, it really did feel as though the earth had given way. Picking up the fragments of glass off the floor, I knelt and felt the flood of overwhelming emotion as the anger and fear subsumed me, the earth gave way once more.

My mother's battle with cancer is probably one that is not unusual in today's society. She had been diagnosed with primary breast cancer in my first year of sixth form college. As time passed, she was signed off work in preparation for surgery and then awaiting results for chemotherapy and radiotherapy. Her head covered with a colourful array of headscarves or a wig for going out, she came to as many music concerts, days out, and school events as she physically could manage.

When the cancer returned, it did so with renewed fervour and unforgiving zeal. It was too late. After a short stay in hospital, she was moved to the hospice for end-of-life palliative care and finally returned home for what became the first week of lockdown in March 2020. That last week was spent as a family, gathered around her bed and looking at photo albums of what life was like when it was easier and simpler.



## **Introduction**

I am not writing this because I want to. I am terrified and every word hurts. These words echo down the ages and generations. One may draw comparisons with the Old Testament prophet Jonah, relocating attention anywhere but where it hurts most in order to ignore the imperative to speak (1:1–4). Speaking up is a potentially shameful, embarrassing and exposing exercise in regurgitating past feelings, thoughts and emotions, yet there is something therapeutic as well. Something cathartic.

A common phrase in the autistic community is, 'If you've met one autistic person, you've met one autistic person'. Despite diagnostic criteria, each individual on the autistic spectrum encounters autism differently. I write as a neurodivergent individual, who has a diagnosis of dyspraxia and non-verbal learning difficulty. It was also noted by the psychologist that I have characteristics of ASD, particularly in terms of rigid behaviour and weak interaction skills. However, I do not have a diagnosis of ASD. I do not write about having experienced non-verbal autism, autism and racial discrimination or autism and femininity (female

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experiences of autism differ and are not as diagnosed as male experiences).<sup>1</sup> I can and will, however, chart a course through my own autoethnography that raises questions and poses challenges that provoke further reflection upon grief and autism.<sup>2</sup>

Autoethnography is the academic practice of telling stories of the researcher's life. In so doing, autoethnography seeks to understand the personal experience of the researcher in the context of social and political life. I use autoethnography here as a method of theological reflection, upon my experiences of both grief and autism. Autoethnography allows deep and careful self-reflection (referred to as 'reflexivity') to both name and interrogate the intersections between the writer and society. As an autistic Christian, I engage in reflexivity through the lens of autism, which lends itself to seeing the world in a stereotypically black-and-white manner. This becomes evident in observations of other people's grief, for example, observing my father putting on a façade of calmness led me to assume he had moved on from the loss of Mum, no longer wanting to talk or think about her.

The method I shall use is similar to the 'Writing the Body of Christ' method outlined by Elaine Graham, Heather Walton and Francis Ward.<sup>3</sup> I frame this via an interaction between theologies of autism and grief in order to find a way through the maze of pain and suffering that has been such a great part of my adulthood. I will describe the experience of encountering bereavement as an autistic Christian, critically examining it and offering a constructive response. I will attempt to explain the notion

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<sup>1</sup> Thereby attempting to avoid privileging my own voice over others: Anna Fisk, *Sex, Sin, and Our Selves: Encounters in Feminist theology and Contemporary Women's Literature* (Eugene, OR: Wipf & Stock, 2014).

<sup>2</sup> The telling of evocative stories was first developed by Caroline Ellis and Art Bochner, cf. Norman K. Denzin and Yvonna S. Lincoln, eds., *Collecting and Interpreting Qualitative Materials*, 2<sup>nd</sup> ed. (Thousand Oaks, CA: Sage, 2003). The aim of the stories told by the researcher is to provoke empathy and feelings. The stories told were used to reflect upon culture via the accounts of personal transformations. Writing these accounts is a crucial part of the research from which deeper understandings and views are drawn. Autoethnographic work endeavours to understand the self in relation to culture, to describe emotions and to use the intersection between self and society as a descriptive tool to make the world better.

<sup>3</sup> In *Theological Reflections: Methods* (London: SCM, 2005).

of autistic grief and its models and hope that it will be of value to the wider Church community.



### **A peculiar life<sup>4</sup>**

How is this account of grief and the trauma it leaves behind any different from any other sad story of an adolescent losing a parent? All the pieces are there, the sadness, the loneliness, the occasional good days followed by occasional bad days. It is an account of an odd young man who, after finding the grief he experiences as isolating, realises there may be a reason for this. Grief might work differently for the autistic brain, but it is also so much more. Autism is experienced by others, sometimes even by the individual themselves, as peculiar: the teenager who collects novelty mugs or knows all the numbers of the buses in the local area, the non-verbal daughter who communicates through groans and cries, the highly successful tech billionaire who needs routine lest they crumble into a nervous wreck. The main presentation of autism is as a peculiarity, a non-normative approach to social life, thinking and sensing the world. The National Autistic Society defines autism as: ‘A lifelong developmental disability which affects how people communicate and interact with the world. One in 100 people are on the autism spectrum and there are around 700,000 autistic adults and children in the UK.’<sup>5</sup>

Whilst no singular definition is sufficient to describe the lived experiences of these 700,000 people in the UK who exist on the spectrum of experience from verbal to non-verbal, intellectually impaired to academically above average, writing on individual experience can open up more developed conversations and give greater attention to the circumstances of those with ASD.

Theologies of neurodivergence, including papers from the University of Aberdeen’s Centre for Autism and Theology, are generous in their encompassing nature. From a medical and psychological point of view autism requires a distinctive set of criteria to be met, but this is not the case

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<sup>4</sup> I take the language of peculiarity from Claire Williams’ autoethnography on autism and trauma. Claire Williams, “Autism: An Autoethnography of a Peculiar Trauma”, in *Bearing Witness: Intersectional Perspectives on Trauma Theology*, ed. Karen O’Donnell and Katie Cross (London: SCM, 2022).

<sup>5</sup> National Autistic Society, “What is Autism?”, <https://www.autism.org.uk/advice-and-guidance/what-is-autism>.

for theologians. Marcia Mount Shoop refers to the ability of theologians to ‘know it when we see it’.<sup>6</sup> Attendant to this is the requirement of theologians not to diagnose but to describe the conditions they experience or witness.<sup>7</sup> Claire Williams writes, ‘Theology can, however, answer the cry of the non-normative body-mind with acceptance.’<sup>8</sup>



### **A different ‘kind’ of grief?**

I moved out the summer after Mum died. I was due to be beginning work in Somerset as a youth minister, but something still didn’t feel right. Months on, I still felt the wrongness of it all, and as I perceived my father and brother beginning to move on I felt like I was being left behind. I thought that I was the only one who still felt the pain of Mum’s death. I alone was responsible for this family. I alone wanted to remember Mum. People move through grief in different ways and at different speeds, but this didn’t feel like that, it felt like there was a gaping chasm with me on one side and everyone else on the other. As the chasm widened, efforts to make myself heard and to keep emotional contact became fraught and I became angry. Within myself, my autistic self, my brain was overwhelmed to a point of no longer coping.<sup>9</sup>

Grief, by its nature, is contradictory. On the one hand, it is a complex and painful maelstrom of thoughts and emotions triggered by losing someone precious. On the other hand, it is a natural and positive healing process that plays an essential role in helping us work through and hopefully let go of the often-unavoidable trauma of loss. As I will elaborate on later, there are many models and theories which attempt to describe how individuals travel through the liminal space that is grief to varying degrees of success. A particular model used in church pastoral care, and the model I experienced, was devised by Elisabeth Kübler-Ross.

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<sup>6</sup> Marcia Mount Shoop, “Body-Wise: Re-fleshing Christian Spiritual Practice in Trauma’s Wake”, in *Trauma and Transcendence: Suffering and the Limits of Theory*, ed. Eric Boynton and Peter Capretto (New York: Fordham University Press, 2018), 242.

<sup>7</sup> Shoop, 243.

<sup>8</sup> Williams, “Autism: An Autoethnography of a Peculiar Trauma”, 191.

<sup>9</sup> A connection may be made between this feeling and Jesus’ own state of mind in Gethsemane (cf. Matthew 26:38 and Mark 14:34).

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In her 1969 book *On Death and Dying*,<sup>10</sup> Kübler-Ross proposed a five-stage theory based on the experiences of terminally ill individuals coming to terms with their death. She argues that news is met with the first stage of denial, the second is anger, then bargaining, depression, and then finally, acceptance. This linear progression sequence has been challenged and refined, by later models, including the ‘grief cycle’ model, to show that individuals can skip or go backwards through stages.

‘Autistic grief is not like neurotypical grief’, declares Karla Fisher, an autistic writer and resource maker.<sup>11</sup> In her writing, Fisher notes that it was only through her grief that she discovered her autism. When finally the shock came, it coincided with being signed off work for grief counselling. After outlining her experience with counselling and then her diagnosis of ASD, Fisher describes what has been called the ‘meltdown model’ of grief. In my case, I had a combination of both meltdowns (temporary loss of control of my behaviour) and shutdowns (the ‘freeze’ alternative, with the meltdown response being identified as ‘fight’).<sup>12</sup> What this looked like to the people around me was that my autistic symptoms worsened as, in fact, they had done. I had less ability to process information and therefore less ability to be social or to do any tasks, as my executive functioning skills were also impacted.

The theory behind the meltdown model is similar to the emotional ‘cup’ metaphor used in the mental health profession. The autistic brain has a set amount of emotions it can cope with at once, given that each emotion takes up more processing space than it would in a non-autistic individual. As emotions increase in intensity, they range from being totally unaware of them to being fearful of them, and then into a meltdown or shutdown where the mixture of fear, anger and other emotions result in overwhelming confusion.

The feelings I had felt as I came upon this article on autistic models of grief were a profound realisation of experienced alienation; an alienation from life, friends and family, but most of all from church. The church that

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<sup>10</sup> Elisabeth Kübler-Ross, *On Death and Dying* (London: Tavistock Publications, 1970).

<sup>11</sup> Karla Fisher, “Autistic Grief is Not Like Neurotypical Grief”, 2012, <https://thinkingautismguide.com/2012/08/autistic-grief-is-not-like-neurotypical.html>.

<sup>12</sup> For a case study on shutdowns, see Ingrid M. Loos Miller and Hendricus G. Loos, “Shutdowns and Stress in Autism”, *Autism Awareness Centre Inc.*, <https://autismawarenesscentre.com/shutdowns-stress-autism/>.

looked after me during the year after Mum’s death did not realise that because the autistic brain behaves differently throughout life in general, then, of course, it wouldn’t behave in ways apparent in the general populace. The inability to explain to the church why I was struggling was even harder and so compounded the earlier feelings of alienation. Theories of the social construction of disability state that disabled people only experience the world as disabled because of the way in which society disables them.<sup>13</sup> Autistic theologies stand as a challenge to the supposedly normative values of practice that the Church presents. If disability models find that society’s construction causes disability on top of their impairments, the Church can be found accountable for its own dis-abling influence.

For me, this invalidation and exclusion led to a feeling of shame – shame that I was still experiencing grief in this raw, sometimes terrifyingly uncontrollable way. In his study,<sup>14</sup> Gordon Gates investigates this feeling of shame, finding that the stigma surrounding autistic people as constructed as being incompatible with God’s outrageous breaking into the experience of humanity has devastating consequences. Shame is greatly associated with worth, especially in a community like the Church where the state of being forgiven and accepted is paramount.<sup>15</sup> This sense of shame was further exacerbated by the church we were a part of. While Mum was alive, they had been great, providing meals and coffee chats, but after she died, when the realisation that the prayer hadn’t worked sunk in, they didn’t know what to do. The coffee chats, once useful to me for processing thoughts, were hijacked into what felt like an assessment of which stage of grief I was in. It was an exam, and I wasn’t answering the questions quickly enough.

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<sup>13</sup> Vic Finkelstein, “The ‘Social Model of Disability’ and the Disability Movement”, 2007, <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/finkelstein-The-Social-Model-of-Disability-and-the-Disability-Movement.pdf>; Frances MacKenny-Jeffs, *Reconceptualising Disability for the Contemporary Church* (London: SCM, 2021), 27–32.

<sup>14</sup> Gordon S. Gates, *Trauma, Stigma and Autism: Developing Resilience and Loosening the Grip of Shame* (London; Philadelphia: Jessica Kingsley Publishers, 2019).

<sup>15</sup> Gates, 13–14.



## **Moving forward through time: Embracing peculiarity**

An alternative narrative for journeying through autistic grief may be provided via the use of ‘crip time’. This is a deliberately provocative phrase to describe the experience of disability.<sup>16</sup> It is an outlandish and offensive term employed to embrace the difference of disability in an otherwise ableist society. It is profoundly useful for disabled people to narrate different experiences in the Church. Crip time exists in a different key – a different time frame, it is delayed or late.<sup>17</sup> In the same way as ‘queer time’, it understands that events do not always occur when they are expected. In the same way that Judith Halberstam says that queer time defies the linear progression of dependent childhood, independent adulthood through to marriage and procreation, so crip time says that the future is questionable.<sup>18</sup> This is a future that is not imaginable or overridden by the disability that has robbed the imagined future from us. The disability, be it acquired or born into, permanently distorts the future. Not only does this idea apply to autism but also to the experience of grief. For what does grief do if not rob us of the ‘things that could have been’?

This crip time future is one without complete healing. Just as autism will always remain, so does grief in unique and personal ways. Not only this, but crip time challenges our understanding of a future that does not seek healing. That future dwells in the Holy Saturday time of Shelly Rambo, the time where survivors exist.<sup>19</sup> For autism in a non-autistic world, Holy Saturday offers an alternative to the narratives of improvement that pervade society. In Holy Saturday time, Williams writes, ‘Autism is not healed, the trauma [...] is not overcome but instead time is understood differently. It is crip time during Holy Saturday.’<sup>20</sup>

Similarly, Flora Keshgegian suggests that time should be understood not as linear with a *telos* but with conclusions that are undetermined. Surprisingly, this is an optimistic stance, because it is not aimed at future

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<sup>16</sup> Alison Kafer, *Feminist, Queer, Crip* (Bloomington, IN: Indiana University Press, 2013), 15–17.

<sup>17</sup> Kafer, 26.

<sup>18</sup> Quoted in Kafer, 35.

<sup>19</sup> Shelly Rambo, *Spirit and Trauma: A Theology of Remaining* (Louisville, KY: Westminster John Knox Press, 2010).

<sup>20</sup> Williams, “Autism: A Peculiar Autoethnography”, 199.





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achievement in a linear narrative time but at simply being and stability.<sup>21</sup> Stability speaks of an eagerness to remain and a hope that is not directed towards accomplishments. This is a futurology that corresponds to crip time, where the future is not the imagined future of productivity, achievement or healing, but the acceptance of love. As Rambo says, 'love remains'.<sup>22</sup>

I have used the theory of crip time to offer a meaningful narrative of the trauma associated with autism and grief. There is scope for hopeful theological moves that offer possibilities in the midst of traumatic memory. The death of my mother was a significant turning point in my life. It was the breaking point which has become the symbol of what seem to be two separate parts of life, the life before and the life after. My journey through 'life after' has been one full of painful memories and joyful memories. As I have begun to discern a calling for ministry and studying at theological college, both Mum and that hopeful future are still with me.

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<sup>21</sup> Flora A. Keshgegian, *Time for Hope: Practices for Living in Today's World* (London; New York: Continuum, 2006).

<sup>22</sup> Rambo, *Spirit and Trauma*, 42.