

## Care-givers and Care-receivers: Changing Maps of Self when Illness Strikes

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Illness is the night side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.

(Sontag, 1978)

### Summary

This article explores the ways in which people's sense of self changes when they become immersed in chronic illness or lose crucial aspects of independent functioning because of disability, or old age and dementia. Underpinning the discussion are a number of questions: What is it like for someone used to caring to become the 'cared for'? Or for the 'carefree' to find their lives increasingly invaded by the needs of a relative – be it a parent, partner, sibling or child? And who can we become when the anticipated future is lost and many taken-for-granted things seem impossible? The author's personal and clinical experiences will be used to illustrate how the nature of attachment for both care-giver and care-receiver is transformed when disabling illness strikes. The article ends with a discussion about what psychotherapy can offer to support people on a journey of transformation and transcendence when things feel hopeless and a return to life as it was is impossible.

### Introduction

Situations sometimes occur that shatter our assumptive world (Stolorow, 2007, p. 18), derailing our plans, unsettling our sense of self, transforming our relationships, and calling everything we took for granted into question. Michael Rosen's moving, poetic account of what he described as disappearing in April and May 2020 because of contracting Covid-19 is an example. One of his poems begins with the lines:

I am not who I was.  
I am who I was.  
This is not me.  
This is me.  
I am now the person  
who had Covid:  
the thing that came in March.

And after charting some of the disabilities he was left with after 47 days in an induced coma, Rosen ended with a verse suggesting that, months later, he had started to come to terms with his new, frail body and sense of self (2021, p. 160):

I am now the person  
who is alert to every twinge  
or mark anywhere on me.  
I am getting to know this person.  
This is not me.  
This is me.

Rosen's book captures how disorienting it was when he came out of the coma, completely unaware of how ill he had been and with a body that no longer worked in the way it used to work. It had become strange to him. Medical emergencies – such as being suddenly admitted to an intensive-care unit, as were a lot of Covid victims in 2020, or undergoing a complex operation, or being sectioned because of psychotic behaviour can be thought of as 'strange situations' (Ainsworth et al., 1978).

I can think, too, of other scenarios to which the concept of the strange situation could be applied – the experience faced by people fleeing a war-torn country, for instance, or a home destroyed by a fire or flood. It is also a way to imagine what life must feel like for people with Alzheimer's Disease. Instead of the familiar routines and rhythms of everyday life, such events lead to a world that is confusing and unpredictable and, as observed by Ainsworth in her strange-situation experiments, can trigger attachment behaviours designed to restore a sense of safety and security (Bruce, 1999, p. 192).

In March 2022 I wrote a poem called 'Invaded' at a point when I realised that my mind was consumed with thoughts and worries about my mother, who was suddenly unwell and increasingly forgetful and confused, by the savage storms that had hit the UK the previous month, and the war that had just been declared in Ukraine. The poem begins:

Many days now I feel invaded,  
colonised by,  
taken over and undone by  
the latest piece of terrible news.

My thoughts go to the nightmares  
as I hover between sleep and wake,  
and wish I was asleep and it was only that  
– a weird dream.  
And during the day I struggle  
to refocus my mind on the task in hand.

For weeks now I have felt invaded by  
thoughts and worries  
about my elderly mother,  
suddenly no longer able to cope.  
Distracted by plans and counterplans  
about managing the weeks ahead.  
Wishing it wasn't happening.

This combination of events felt like a strange situation and, following on the heels of the pandemic and unprecedented, life-destroying weather events in the preceding few years, was yet another reminder that life is fragile, and of how much we take for granted – having agency, choice, a brain and a body that do what we expect them to do, and living in stable-enough conditions to carry out our usual routines. The precariousness and preciousness of our health have also constituted a theme in my work with a number of people over the last few years, people who were catapulted into the roles of care-givers or care-receivers and whose lives were transformed because of this. They were people I came to know well and had a fondness for. Their journeys into therapy had not been because of illness. But during the course of our work, shifting into the role of a care-giver or -receiver took centre stage – a young father struggling with exhaustion as he tried to juggle work and looking after two little ones; a couple who both had ongoing health problems and, despite their love for each other, found offering care hard because of much earlier stories of illness in the past; a supervisee who underwent treatment for cancer during our second year of work; and two women suddenly hit by disabling conditions. The dramas of their lives – the good things and the bad – interested, concerned and moved me. I'd think of them if I knew they had something challenging coming up like a difficult health appointment,

or were supporting a relative who was seriously unwell – almost as if they were family. I also held in mind what I knew of past traumas, attachments and losses, and they were useful lenses to contemplate each person's responses as a care-giver or a care-receiver. So too was what I learned about earlier stories of ill-health and the nature of care in their families. Who was ill? Who had to care? How were they cared for? Perhaps even more important was what I learned whilst working with them because of my own experiences – my occasional brushes with ill-health and the memories I hold of my parents' illnesses and increasing frailty, of moments of crisis that called for urgent responses, and of the time and emotional space needed to respond to them whilst trying to carry on with 'ordinary' life.

Hearing week after week how my clients were feeling, of good news and bad, details about professional appointments, delays, treatments, indignities, and their fears and frustrations, has made me curious about the ways in which people's sense of self changes when they become immersed in chronic illness or lose crucial aspects of independent functioning because of disability, or old age and dementia. What does it feel like to acquire the 'label' of someone with a disability or chronic health condition? To have to relinquish former roles, either because of personal health issues or in order to spend more time looking after someone else? What happens to your 'relational maps' when you have to rely on a child or partner for care – the former a reversal of old roles, the latter entailing a shift from equal partners to a more parent/child relationship (Ryan, 2007, p. 64)? And what is it like for the 'carefree' to find their lives increasingly invaded by the needs of a relative – be it a parent, partner, sibling or child?

My reflections on illness and identity have also inspired questions about who we can become when the anticipated future is lost and many taken-for-granted things seem

impossible. Can the transition from well to ill, from independent to dependent, be used as an opportunity for growth? Or will it lead to anger, bitterness, melancholia and despair? What, thinking of Erikson's task of later life, can help us to negotiate the tension between integrity and despair (Erikson, 1965/1950). And how can psychotherapy support people in developing a new story? In what follows I will draw on examples from my work and personal experience to explore these questions.

## **An Interrupted Life**

Spending several weeks with my mother and witnessing her confusion and struggle remembering how to do simple tasks, I was aware of a sense of disconnection. There was the time- and mind-consuming process of physical care and acting as a thinking, planning mind on her behalf, and there was my life outside which I tried, not very successfully, to stay connected to. 'This must be how baby-brain feels', I wrote one day, commenting that my mind could not focus, much as I wanted to use the interludes between dressing and undressing, meals, pills, and sending update messages to others productively. It was hard holding the tension between my identity as a care-giver and the other more familiar 'me's' at home. But this experience helped me to empathise with other people I knew personally and professionally who struggle with the challenges of juggling caring for others, work and all the other demands of modern life. Like many other care-givers, I became immersed in this strange situation.

Illness and disabling conditions sometimes strike without warning. Covid-19 is a good example. Sometimes they creep up on you – some niggling discomforts, unusual signs, lapses of memory, tiring more easily. In many cases the illness is temporary, an interruption to our life. But there are two other levels that can be used to conceptualise our encounter with illness – intrusion and immersion.<sup>1</sup> The

experience at each level has a different impact on our relationship with ourselves, others and our sense of past, present and future (Charmaz, 1991, p. ix; Wright, 2020).

At the first level, interruption, something goes wrong with our body. It could mean taking time off and resting. It could be frightening, entail hospital or tests, be a one-off or involve several crisis moments over a certain period. Depending on the severity and nature of the interventions, it might be hard to process and assimilate what is happening. However, although our plans get interrupted, we trust that it won't be long before we get back to life as normal and, significantly, we don't lose touch with our pre-illness identity. When an illness is intrusive, having a body that feels all wrong and does odd things, and facing recurrent health crises, become the norm, even if one's health waxes and wanes. The condition takes time, and it forces self-consciousness. It creates an element of uncertainty – 'I might be able to... but I might not'. The third level applies when ill-health becomes a permanent part of life – an engulfing, immersive experience that leads people into 'an extraordinary reality with its own structures and rules' (Charmaz, 1991, p. 75). Life revolves around the illness. Priorities inevitably change. Nothing can be taken for granted any more, and the loss of abilities, roles and future dreams, coupled with the need to depend on others for help, can significantly undermine people's sense of self.

This is not me. This is me.  
(Rosen)

## Networks of Care

Our sense of self grows within the crucible of networks of care (or, for some people, of uncare); from how we are welcomed into the world, attuned to, accepted and encouraged as unique human beings, as well as how others responded to us when we were poorly, or had hurt ourselves. Our networks of care – and by

this I mean reciprocal units of care-givers and care-receivers, two roles that we all assume and with different meanings at different points in our lives – encompass our family unit, the communities we live in and the institutions we turn to when in need of support.<sup>2</sup> 'Our capacity for care', as Stuart-Smith pointed out, 'is one thing that sets us apart as a species and we are unusual amongst primates in the extent to which we share food and look after the sick' (Stuart-Smith, 2020, p. 123).<sup>3</sup> And yet it has been argued that we face a care deficit in a world of fragmented social networks, entitled attitudes that disregard the needs of others, and so many demands on our time that we find it hard to care adequately for children, elderly people and ourselves (ibid., 2020, p. 31; Tronto, 1993; Weintrobe, 2021).

Our experiences of being parented – and, I would add, of being ill and observing other people who are ill or in pain – shape how we negotiate care-giving and care-receiving later in life (Bruce, 1999, p. 199). As I worked on this article it suddenly struck me – and perhaps it is why I became interested in the subject in the first place – that my awareness of illness may have begun in an embodied way in the womb; for whilst my not-yet-born self was slowly developing, my grandfather was dying of cancer. I was born. He died three days later, and I remember the humorous way my father described going to register both events, and how the registrar's face shifted from smiles and congratulations to awkward condolences. Two contradictory experiences needing to be held at the same time. I have often wondered whether my parents' worries about my grandfather seeped through to me in the womb, and how my father's grief might have coloured my first days of life. Did my role as a care-giver start at that point – a child who could cheer her parents up by being amusing or doing well? A child who learned to attune to the moods of others? All this is conjecture. What I do have a language for is how, in the crucible of care I grew up in, I absorbed two conflicting

models. My mother got on with things, and if you asked how she was, she'd downplay it – a problem in her later years, as it was hard to gauge how much discomfort she was in.

My father was a hypochondriac. He worried about minor symptoms, took increasing numbers of pills for this and that (probably competing with each other), and in his later years was frequently on the phone to his GP about his latest health anxiety. As a counter-reaction to this and to my mother's over-fussing care – well-meaning, I know, but as I got older, irksome – my tendency is to carry on regardless; and at times I can feel impatient when my partner is off colour. Having named this, I always knew that care was there. But that is not the lot of many people I have worked with.

Adapting to a life interrupted by illness or disability is particularly hard when one's first care-givers were 'scare-givers' – the history of two women who were suddenly hit by disabling conditions (Epstein, 2015, p. 292). Zoe and Bernadette were very different in character, and in the choices they made and the things they did as adults. But what they had in common was that their disabilities shattered the identities they had built up over the years, for they meant no longer being in control of their lives, and they hated depending on others for help.

The other thing they had in common was that neither had been brought up in a culture of care. They had witnessed and experienced abuse as children, and both had very self-centred, hostile mothers who oscillated between neediness and petulance when they could not get their own way. Zoe developed a tough shell, an appearance of self-reliance and not caring, and prided herself on her independence. 'If you do it yourself, you won't be let down' was her mantra. After years on heavy drugs, taken in an attempt to forget the traumas of her childhood, and in and out of coercive relationships, she had gone into Rehab, went to college and found a

job she enjoyed and that paid well. Until an accident when on holiday. Her hire car suddenly went out of control due to an engine fault and careered down a steep bank. Zoe's arm was crushed and several vertebrae were broken. Overnight her world collapsed. As the weeks passed, the severity of her injuries became increasingly clear. They left her with intense pain and, because of nerve damage, difficulties walking and using her dominant hand. This was her 'strange situation'.

Zoe had to stop work. Her life became patterned by medical appointments, assessments, and fighting a legal battle to get compensation – and she did this with a vengeance. 'I learned in Rehab that I don't deserve to be treated like shit. I have to stand up for myself', she explained. And so whenever she felt that the people dealing with her case had made a mistake, she complained. She knew that her language could be out of order, but she was also insightful about what drove her: 'I'm scared I'll just give up if I don't keep fighting'. Feeling vulnerable was intolerable.

Like Zoe, being self-reliant was crucial to Bernadette, a position driven by a fear of trusting others in case she got to like them too much and they then vanished, or ended up hurting her. Bernadette had learned to be a care-giver from a young age. She'd stand between her parents when her father threatened her mother. She looked after her three younger siblings, and years later still felt a need to protect them. As her mother got older, she became increasingly demanding, bombarding Bernadette with phone calls whenever she felt unwell, and alarming her with lists of awful symptoms, which usually proved to be imaginary. Her 'ailments' got significantly worse whenever she knew that Bernadette was looking after someone else or about to go on holiday. Although Bernadette began to set firmer boundaries, the fear that her mother might really be ill often undermined this.

Bernadette's identity as a care-giver was intensified when her husband developed a brain tumour. Three years of heartache as he became increasingly disabled and a shadow of the man he used to be, and then, a year after his death, her back gave way. Bernadette was diagnosed with degenerative discs and a trapped nerve that caused intense pain. Walking was painful. Driving was impossible and, unable to use her car, Bernadette lost something crucial for self-reliance. She began to hide away, fearing to go outside, shutting the curtains so no one could see inside, and plagued yet again with the memories of abuse.

While her identity was bound up with being a care-giver, Bernadette was also desperate for care. I became someone who represented what she had needed but never got as a child – and a younger part of her became extremely anxious when she couldn't see me, or if she observed something that she interpreted as a sign that I was not well. She'd leave me messages asking, 'Are you still there?', 'Are you OK?', 'Are you cross with me?' Over time she hesitantly shared the fantasies she had of living in my house and looking after me when I was old – tender offerings that required very sensitive responses in order not to shame her but that reminded her that I could never be the caring mother she longed for. That loss had to be grieved.

## Therapeutic Care

To return to the questions posed earlier – what can psychotherapy offer to support people when illness strikes, and especially when things feel hopeless and a return to life as it was is impossible? What helps people to transcend the challenges, heartaches and losses of being a care-receiver or a care-giver, and to grow despite the shattering of their assumptive world?

My work with Zoe, Bernadette and other people who I came to care for has crystallised

my thoughts about the transformative elements of psychotherapy. I would imagine that most psychotherapists would say that one of the most essential things is to create a safe, holding environment. Serious health conditions undermine our sense of safety. There is so much more to fear than when we or those we love are well – fears about the future, about what a symptom might mean, about seeing a specialist or undergoing a particular treatment, about just getting through the day without our taken-for-granted body letting us down in some way.

My own journey has made me appreciate why people might hide away like Bernadette did, or resort to anger – Zoe's main strategy – or become depressed and shut down. It can be traumatic to suddenly find oneself in need of care, out of control, in hospital, and subject to invasive procedures. It is also traumatic to find a friend or relative in a desperate state, to be summoned to hospital in the middle of the night, to see our loved one on a drip, to be left waiting for information, and in a more ongoing way to carry the burden of supporting someone at home on a daily basis. Traumatic situations evoke instinctive threat responses. Our minds and bodies become reactive. When we feel safe, welcomed and listened to, our system quietens down and our thinking becomes more flexible and open-minded. We are more open to change.

What matters most in a therapeutic relationship, then, is not the theories we espouse or the 'techniques' we have learned, but being human. It is the quality of presence we offer – our outstretched hands, our compassion (or feeling-with), along with a genuine interest in what is going on in someone's life – that makes a difference. Of course when we communicate our care and concern for the people we work with, they may well push this away with remarks such as, 'You're just saying that because it's your job'. They are probably unaware how often we think about them, just as most of the time

they are unaware when we are dealing with dramas in our own lives, our own brushes with illness, or a member of our family falling ill or having an accident.

Elizabeth Corpt used the term ‘clinical generosity’, which she described as including ‘when necessary and appropriate, something beyond the usual and customary: a potentiality for a kind of care-full responsiveness that may, at times, challenge the analyst’s restraints, psychic comfort zone, or usual modes of relating’ (Corpt, 2016, p. 102). I believe that there are times when the frame has to be different, and that small acts of kindness that go beyond our usual remit are often transformative, even though we may not realise this at the time. Several examples of going beyond the usual come to mind. One was giving Zoe a call one Christmas Day after she had told me, ‘I’m dreading f’ing Christmas – just me and Billy No Mates. The only reason anyone in the family would get in touch is if they wanted something. I can’t keep going on like this year after year – stuck, angry, lonely.’ Meanwhile, when Bernadette’s husband’s rapid deterioration left her too distraught to speak, I let go of the idea of a more ‘conventional’ therapeutic conversation. Instead we sometimes went into my garden and looked at what was growing, and sometimes we sat together on the sofa looking at pictures in nature books. Being alongside her was the most important thing.

Another example is of supporting someone who was terribly scared about having another operation. So great was his fear that he envisaged not being able to manage walking from his car into the hospital. So I invited him to imagine both of us holding the end of a piece of ‘magic string’ that day. Alun liked the idea, and embellished it by proposing that we both actually wore a string bracelet. I thought about Alun whenever I saw my bracelet, and he told me later that he hadn’t bottled out. He had felt far calmer than he had ever done before. I also send people condolence cards, or a card to wish them well

before a significant event. Some might see such gestures as acting out – avoiding the pain, rescuing, alleviating my sense of uselessness. But I believe they are a ‘care-full’ response to a fellow human being, a message that we hold our clients in mind and that we value them.

This takes me to another essential ‘ingredient’ on my list – restoring dignity. When our body does not work in the way it should do, it can be embarrassing. The normally private becomes public. There can be mess. We can do odd things. We feel out of control and, although not their intention, the care systems we become immersed in can be very depersonalising – ‘I-it’ relating rather than ‘I-thou’. As Bernadette angrily protested one day, ‘I’m just a number in a system. No one really cares.’ For some people, our respectful care and acceptance of their need for choice is part of the creation of a new story. But I am thinking here not just of how we relate, but of the need to adopt a way of working that is an expression of reverence, of doing what we do in a ‘sacred’ way. As the philosopher Paul Woodruff pointed out, ‘without reverence, things fall apart’ (2001, p. 4). ‘Without reverence, a house is not a home, a boss is not a leader, an instructor is not a teacher’ (ibid., p. 13); and to this I add that without reverence people become ‘cases’ and ‘statistics’. We lose sight of their uniqueness and the many contexts that have shaped them.

‘Sickness creates a silence that is not easily shared’, commented Roberts, and this silence ‘is compounded by centring our accounts of sickness on disease and disorder rather than on the person. The clinical struggle is then with and against the illness rather than an engagement with the ongoing life of the individual.’ (Roberts, 1999, p. 4) We lose sight of the person as limiting illness narratives take over (Bruce, 1999, p. 198). These views accord with my argument about restoring dignity, and my belief that another crucial thing we can do to support transformation is to act as a witness to the

unfolding narrative, and as someone who holds the history of each client's journey into needing or giving care, as well as many other stories about their lives. As a 'partner in thought' in a process of story-making and story-breaking (Wright, 2020), we can help them construct a new narrative that encompasses the changes and transitions that have occurred, what they have shared about early experiences of care and about illnesses in the family, as well as of more recent events.

We often think of psychotherapy being predominantly about what Bollas called 'doing history', meaning reviewing the past, finding new meanings and, thereby, transforming it (1995, p. 144). But when illness strikes, it is the present that commands attention, with occasional forays back in time or forwards with conversations about the feared and hoped-for future. When illness narratives combine with earlier stories of trauma, loss and attachment failure, they challenge people's sense of worth and what they believe is possible. They can also set up negative expectations of care in the present. For example, when Alun came out of hospital he desperately needed time to rest and recover. But his toddler, who was teething, suddenly became very needy, and kept waking in the night and wanting Daddy. Alun was worried about how angry this made him: 'I hate the person I'm becoming. I just want to scream and push him away. And I'm impatient with everyone else. I know it's not his fault. He's just a little boy. But I'm exhausted.' When I asked Alun if being interrupted in the middle of the night reminded him of anything, he recalled many occasions when he was woken because his brother, who was autistic and had severe epilepsy, was having a meltdown or a fit. 'Sometimes my parents had to take him to hospital and left me with the neighbours.' 'I guess you must have felt very cross with him', I suggested. 'Yes', Alun replied – 'with him, with my parents, everyone. It felt like no one cared about me, especially when they said

I was making a fuss if I didn't feel well.' 'No one cared, so I didn't care about me, either.' Working on these early memories helped Alun to regain equanimity about his care-giving role, and to prioritise self-care.

In helping people to construct a new story, we often need to challenge them about things they say and do. Sometimes my challenges are directed to old beliefs about self and others that prevent the people I work with from accessing the help that is available or that limit them. We at least have to believe that they are more than the illness and more than they believe is possible. Sometimes my challenges are a fierce gesture of care. As I wrote to one young man in a poem I sent to him:

Sometimes, with a burning energy  
and unflinching honesty Care says –  
'Don't!' 'Stop!'  
'This is crazy!'  
'I don't want you to.'

My hope is that my 'tough love' is a message that somebody cares enough to set a boundary; my disagreement when people put themselves down or say 'I'll never be able to ...', a reminder that they *do* have strengths, even if they cannot see them, or that there are other ways of doing things. I challenged Zoe on many occasions when she had become so wound up with anger that the messages she was sending to people were sabotaging her cause. More 'tough love', matching her street language with my own expletives, but staying true to our mutual respect. I challenged Bernadette when she said things like, 'I'll never find work again. No one will want me.' 'How do you know?', I asked. 'Do you have a crystal ball? I don't, but I believe that you have lots of skills and qualities, and when you have recovered from your operation, who knows what you might find?' And I challenged Alun when he neglected himself.

And of course, sometimes we need to challenge ourselves to avoid the hubris of



believing that psychotherapy is the answer and the traps of over-identification, rescuing or avoidance. We need clinical humility. As Donna Orange wisely observed, ‘every so often there comes a time to surrender to the passivity and vulnerability of my clinical limitations, and to say that this is beyond me’ (Orange, 2016, p. 71). Clinical humility also demands being aware of our own frailties, foibles and shadows. Humility enhances presence. It helps us to tolerate what is hard to bear, and that what we can offer to people dealing with adverse situations inevitably falls short of what they most want and need. Much as I wish I could magically change their situation, I can’t. What I can do, most of the time, is to sit with the despair.

The final thing on my list of essential ingredients is humour. With all the people I have mentioned in this article, laughing at the ridiculous aspects of a situation has been important – a moment of bonding, of putting things into perspective, of release. Humour is another marker of our humanity. It challenges the myth that we are ‘sorted-out’ experts. To greater or lesser degrees we are all kin-in-suffering. So I have laughed with people about the embarrassment of being caught short in a public space, of having to ask someone to tie one’s shoelaces because it’s too painful to bend down, and undergoing some of the weird and uncomfortable things of a routine lady’s check-up. I have commiserated with the wish to strangle the voice at the end of the phone that keeps repeating the ‘Sorry to keep you waiting’ messages when we need to book a medical appointment, and the impatience we can feel when the needs of a relative trump our need to collapse into bed. *Moi aussi!*<sup>4</sup>

## Transcendence

Returning to one of my opening questions about whether our encounters with illness can be used as an opportunity for growth or leave us bitter and hopeless, a short but evocative

poem by a poet familiar with mental-health problems comes to mind:

In the darkest night  
suffer changes or lose yourself;  
barren trees may bud.

(Alldridge, 2016, p. 1)

What do we need for something new to bud? To transcend the losses, inconveniences and indignities of ill-health, even though we rail against it and can feel impatient with our bodies and those trying to help us or, as a care-giver, with those we look after? When I shared Alldridge’s enigmatic poem with a supervision group, there was a struggle with the idea of *suffering* change. But expanding on his words, we risk losing ourselves and the sense of meaning in life if we cannot find a way to transcend our suffering.

Transcendence is often associated with spirituality. It is linked with the idea of rising above the ego and relating to something greater than the self. Put in more everyday terms, it’s about accepting our lot with patience and equanimity. The mood in the supervision group changed when someone mentioned that the word ‘patience’ (and ‘patient’) comes from the Latin *pati*, meaning to suffer and endure, and that *pati* is also the root of the words ‘patience’ and ‘compassion’. To rise above suffering we have to acknowledge that this is how it is, rather than hiding in denial, or resorting to rage and blame or wishful thinking (‘If only...’), and to let go and mourn former roles and plans. We have to be compassionate with ourselves, accepting that it’s human to feel vulnerable, scared and angry. It also necessitates separating our notion of self from cultural expectations about productivity, accomplishment and success (Charmaz, 1991, p. 259). An ability to see the funny side of dark situations can help. So, too, can the ability to see and appreciate small miracles around us. The place of acceptance is a quiet one, far more spacious than when our mind is full of bitterness or overwhelming anxiety

about what is going on – and space is needed for something new to emerge.

Zoe had been told she needed to come to terms with things. She knew this. She was a clever woman, and on one occasion, one of those moments towards the end of a session when the energy of her anger gave way to sadness, she said wearily, ‘I know I have to get resigned to it. But that’s easier said than done. I know how practical I can be. I get things done. But this... it’s taken all my choices away. It’s a killer.’ It was as if she had become imprisoned in the situation – in limbo – and the stuckness ate away the resilient, feisty activist Zoe used to be.

On the News we often hear of people who do amazing things after tragedy or whilst dealing with a terminal condition, and there are some inspiring books written by people facing life-changing conditions, people who found a ‘why to live’ (Nietzsche, in Frankl, 2004, p. 109). But hearing such stories can add to the shame and despair of people like Zoe and Bernadette, for whom it is incredibly hard to find something meaningful to hang on to. Is this because they can’t focus on anything but surviving day by day – and when we are in pain or intensely worried about someone else that dominates our attention? Is it because past traumas and losses have undermined their capacity for hope? Or because they have no reliable network of care to turn to?

‘The notion of a meaningful life that transcends the self is not merely an existential appendage that becomes relevant only after our basic needs are met and biological survival is secured’, wrote Peter Shabad. ‘Living for something or someone other than oneself is fundamental to being human’ (Shabad, 2001, p. 38). Before the accident, Zoe’s ‘something’ included ‘getting things done’ – whether this was practical tasks like improving her house or working to support other survivors of childhood trauma. Zoe’s story highlights how chronic illness and disability can set up vicious circles. Stress

about her future undermined her mental health, and being unable to sleep or eat well added to her physical symptoms. Her story also highlights how hard it is to move on when there is no closure. Zoe wanted it ‘sorted’, meaning for her compensation claim to be resolved so that she knew how much she would have to live on in the future and make firm plans. But the deeper meaning was a wish for justice and for action to be taken to prevent similar things happening to others.<sup>5</sup> On many occasions Zoe would sigh and say, ‘I’m so tired of it. I just want it to end’; and, feeling rather useless, all I could say was, ‘I know’. In the brief moments when Zoe shared her desperation, her loneliness, how tired she felt of fighting and how tempting the idea of suicide was, I knew that I was hearing her authentic voice. Of course I would love to believe that in time, something will transform her life and, with it, her sense of self. And it may. But perhaps my honest sharing of thoughts such as, ‘I wish I had a magic wand, but I don’t’, or ‘I don’t want you to kill yourself. But I know that may be your choice one day’ – and my willingness to sit with Zoe week by week, whatever mood she was in – offered something potentially and powerfully transformative.

And what of my own journey towards acceptance, transcendence and a new becoming whilst immersing myself in different stories about care – the stories of people I work with, the periodic interruptions of personal health problems, the moments when I have felt invaded by the needs of those close to me, and the wider context of crumbling care systems in our society? I haven’t always been very accepting. I have my own versions of anger, avoidance and despair. Yet I believe that I have learned, or rather am learning, more humility, and am coming to appreciate all that I have, other people and the world around me more deeply. When I wrote the following poem I was thinking about how this interruption to my week and the pain that led to the call paled in

significance compared with what some of the people I work with endure on a regular basis.

Reluctantly I call the Doctor's  
– hating the ten minutes or more of  
intrusive sound while I wait to speak to  
someone,  
– hating having a body that is doing  
things I don't want it to  
and not doing things with ease that I take  
for granted.

Not well. Off sick.  
Why the sense of failing to admit to this  
very human thing?  
I'm used to soldiering on and saying 'I'm  
fine'.

Getting to speak to someone,  
waiting for a GP to call me back,  
driving later to the surgery with anxious  
thoughts  
(my father's legacy) of all the things it  
could be.  
Not easy to focus on what I had been  
doing.  
And tomorrow I must drive 15 miles to a  
pharmacy.

An intrusion, an interruption to my time,  
my life.  
But I am lucky.  
This is not serious.

Perhaps these micro-dramas have a  
purpose.  
They help me to see more clearly  
what it must be like for people who are  
far less fortunate.  
Wake up calls that remind me of the  
riches I have.

Reluctance shifts to gratitude.

Gratitude underpins transcendence. But  
transcendence is not a static state. After a  
brush with something that reminds us of our  
mortality and the preciousness of health, we  
can have honeymoon moments. We resolve to  
eat more healthily, exercise more, work less  
and spend more time with friends. And then  
we get pulled back into life's busy whirl and  
forget our resolutions for a while. On this life-  
long journey of 'becoming', the events of

recent years and the people I have  
encountered as a care-giver and a care-  
receiver<sup>6</sup> have reminded me over and over  
again not to take things for granted.

I am not who I was. I am grateful.

## Notes

- 1 Here I am drawing on the work of Kathy Charmaz, a sociologist who explored the lived experiences of people affected by chronic illness (Charmaz, 1991).
- 2 We could also add the natural world around us.
- 3 Although the increasing evidence about the networks between trees and fungi, and how trees recognise and support kin, mean that we might need to alter this view.
- 4 How much, if at all, we share with our clients about our personal encounters with illness needs careful thought. I believe that timely congruence can be valuable. But with some people it would be insensitive, and with others it might generate an unhelpful level of worry.
- 5 Is this not what has driven the relatives of the Hillsborough victims, and the mothers of Steven Lawrence, Harry Dunn, and Nicole Smallman and Bibaa Henry to keep campaigning?
- 6 Here, my gratitude goes to the friends, colleagues and neighbours in the reciprocal network of care around me for what we share.

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## About the contributor



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