

Living with Dying and Bereavement: Reflections on Repositioning through Performance

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Abstract

In this paper we describe how we write and speak in public settings about living as a couple with life-limiting and life-changing illness. Our intentions are to demystify cancer and to show how priorities and positions change over time through talking and writing. Our writing, like our speaking, is performative and transparent and preparing this paper has been an iterative and reflexive process. We connect to systemic ideas to offer readers ideas for future conversations with friends, family and clients.

Introduction

Be like the headland, on which the waves break constantly, which still stands firm, while the foaming waters are put to rest around it. 'It is my bad luck that this has happened to me.' On the contrary, say, 'It is my good luck that, although this has happened to me, I can bear it without getting upset, neither crushed by the present nor afraid of the future.'

(Marcus Aurelius, Meditations, 4.49)

This paper has been in the making for more than a year. We began by imagining it to be a description of our relationship with cancer and the story of our joint and individual journeys into what Susan Sontag (1978) calls "the kingdom of the sick". We have discovered it is the story of how we, as a couple, are dealing with the fact that one of us is likely to die sooner than we might have expected.

We have been talking, writing and performing our thoughts and feelings about the situation we find ourselves in, across a number of contexts, in order to make some sense of what seems sense-less, and to find ways of going on. Increasingly, audience has become an important factor. We have an individual and shared need to communicate in a more public way; but why? about what? and to whom? As we wrote this paper, answers emerged. We are going to show you some of our "work" as an invitation to you to enter into conversations of your own with friends, family members and clients.

Who are we?

We are Liz and Gaby, a married couple. For thirty years we have lived in the same house in South-East London. For twelve years until her death in 2000, Gaby's mother lived with us. We have no biological children, but we have been "adopted", quite independently, by two women in their 40s, each of whom has asked us to play a parental role in her life. This has brought us enormous and unexpected pleasure.

Gaby is aged 74 and Liz is 68. Gaby worked as a lawyer and after her retirement volunteered in the National Health Service (NHS) as a public and patient voice. Liz is a systemic family therapist who worked for an NHS Foundation Trust in a child and adolescent mental health service. She now supervises systemic doctoral research and is a public and patient representative involved in NHS research.

What has happened to us?

Until April 2013 we were in good health. Then Gaby was diagnosed with locally advanced cancer of the rectum. Bowel cancer is very treatable. After undergoing chemotherapy and radiotherapy, in January 2014 she had surgery to remove the tumour. She was pronounced cancer free. It was hoped she had been cured.

Unfortunately, in June 2015 she had an aggressive local recurrence. Her cancer is inoperable and there is no longer any question of a cure. She is having palliative treatment which initially cleared the cancer and kept it at bay. The cancer is now growing again and other palliative treatments are being considered. When treatment options run out, there is the possibility of enrolment on a drug trial. We expect the cancer will kill Gaby eventually, but no one knows when.

There have been side effects of chemotherapy and radiotherapy - all, by the standards of these things, quite mild – and there were quite serious complications from the 2014 surgery, which caused endless infections and other problems.

In October 2017, following a routine mammogram, Liz was diagnosed with grade 2 invasive lobular breast cancer. It is Stage 1. She underwent surgery twice, followed by radiotherapy, and is now taking the drug Tamoxifen.

Performance

For more than five years, we have been thinking and talking to each other about what it means to live our lives in the shadow of cancer. Gaby's recurrence three years ago sharpened and lent urgency to those conversations. We started speaking and writing publicly. In October 2017 Liz published a paper, *Picturing the Graig*, in the first issue of Murmurations. At the journal's launch the following month, Gaby was invited to speak about Liz's paper. She used the occasion to reflect on facing death. This talk was unscripted – a performance rather than a speech. She wrote it up immediately afterwards.

Liz has participated in evenings of performed texts at the last three Bedfordshire Systemic Practice and Research Schools at Brathay Hall in the Lake District. In June 2018 she was invited to speak to the annual Cancer Survivors' Day at the Guy's Hospital Cancer Centre.

These talks and writings are re-assembled here as an attempt to explore the complexity and richness of our conversations about our own and each other's illness. Something quite special happens when texts are performed. Writing about performance is almost a contradiction in terms; it is the

performance that is the action. Gaby's piece is unusual in this regard; she performed it before she wrote it so her text is a record of the performance rather than a script.

Gaby's talk at the Murmurations launch. 24 November 2017

I'm Liz Day's partner. Many of you know Liz. She's an editor of Murmurations. She has a piece in the first issue called *Picturing the Graig*. The Graig is a mountain in South Wales where she spent a lot of time as a child. Her piece has been very well received, I think because it's deeply personal and beautifully written.



Gaby Charing, Gail Simon, Birgitte Pedersen and Liz Day during Gaby's talk at the launch of Murmurations Journal

It was many years before I discovered I'd married a writer. Liz was always a painter. We converted part of the garage to make a small studio for her. When she decided to do the Professional Doctorate in Systemic Practice at the University of Bedfordshire, she plonked a computer in the studio and said that was where she was going to write. She would disappear for hours and I had no idea what she was doing. Well, that isn't quite true. I guessed, rightly, that there was a lot of Sudoku going on, and the computer game Farmville, and I'd sometimes hear music playing. She bought herself a small fridge to keep milk in – milk for the mugs of tea that fuel the life of the mind. When I looked inside, it was full of beer. One day she appeared and asked, a little aggressively, I thought, "Well, do you want to read it?". It was the first draft. It was extraordinarily interesting, while being moving, personal and beautifully written. The quality of the writing was a revelation to me.

A lot of people have read that thesis. They have been drawn in, fascinated. I commend it to you.

Now we have this piece about the Graig. It is a work in progress. It is, again, beautifully written, and people have found it very moving.

Liz has a passion for landscape, especially mountains. We go to a very special place in the French Pyrenees, and when we're there it's as if she becomes truly herself. She loves the work of Richard Long, who makes art in and of the landscape, and the writers Robert Macfarlane and Tim Ingold. I hear an echo of the melancholy of WG Sebald. But Liz is finding her own voice as a writer.

Those of you who have read *Picturing the Graig* will know that one of its themes is the way our lives have been affected by my illness. In June 2015 I had a local recurrence of a rectal cancer that had been

treated and everyone hoped would never trouble me again. We've known since that recurrence that I'm not going to get better. I'm well at the moment because of one of those wonder drugs, but it won't go on working for ever. I'm scanned every three months. The next scans are on Monday week.

For nearly two and a half years our lives have revolved round my fortnightly clinic appointment on a Tuesday, followed by treatment on the Thursday which takes all day. Every three months there are scans, and we wait a week for the results. If I get through the December scans – if I'm told the treatment is still working and the cancer isn't galloping back – then we'll face the same thing again at the end of February. That is the structure of our lives. It's the space we live in. It's hard.

I use the word space, deliberately. The philosopher Immanuel Kant tells us that time is the form of inner sense and space is the form of outer sense. The space Liz and I inhabit is tightly structured. Our time, on the other hand, is our own. Time isn't linear; it's ours to play with.

Knowing you are going to die before your time is a test of character. It tests your resilience. It tests your intellect and your ability to marshal and control your emotions so that they don't overwhelm you. Reason may be the slave of the passions, but its job is to enable you to navigate your life and your emotions and make sense of what is happening to you. And knowing you are going to die tests your values. In particular, it tests your ability to reconcile yourself to what is going to happen to you. For me, that is a moral imperative.

I managed to grow up without religion in my life, even at school. I have no religious faith, and I don't believe in an afterlife. I believe that when I die, that will be that. But the wisest thing I have read on the subject of suffering and, by extension, death, is the Old Testament Book of Job. Job is sometimes described, wrongly, as patient. On the contrary, he railed against God. But what he did not do was reject God, or dispute God's right to inflict suffering on him. He didn't like what God had decreed for him - boils, ulcers and the rest - but he accepted it. He rejected the blandishments of his comforters.

Those comforters are everywhere. "Don't give up hope". Well of course I don't give up hope. Everyone knows cancer is unpredictable. I shan't object if a miracle comes my way. But I'm not inclined to base my plans on the possibility of divine intervention, or even of very good fortune. A nasty one is, "Surely they can do something?", implying that my doctors have got it wrong. I am having the very best, evidence-based treatment from doctors in whom I have total confidence. When they tell me they have done all they can, I shall believe them. I may exercise my right to a second opinion, but I shall accept medical advice. I will not make Liz's and my lives a misery by chasing hares.

This approach seems to me to be right. Right for me, and right ethically. In fields such as medicine where evidence is central, people who refuse to be guided by the evidence, and choose instead to pursue speculative nostrums, are in my view not just foolish but dangerous.

There doesn't seem to be much point worrying about how long I'm going to live. I know they can't tell me, so I haven't asked. A couple of generations back, I might have been glad to reach my three score years and ten, and think I was doing well to be dying in my mid-seventies. No one has the right to expect to live to a ripe old age. Life isn't like that. Job recognised that life wasn't fair, but knew that God had His reasons. I'm not sure about God and reasons, but I do know this: if you believe that fate ought to treat you kindly, you're deluded, and suffering from a misguided sense of entitlement.

I find I'm enjoying life more than I've ever done. I'm getting on with doing the things I enjoy. The truth is, I can't fully engage with the fact that my life is going to end so much sooner than I expected. When I do think about it, I feel desperately sad.

There's a look of pain that crosses Liz's face. You may have seen it. I saw it the day I had to tell her it seemed I did have cancer (having been told I probably didn't) and that it was quite advanced. I've seen that look many times since. It slices me in half. I can more or less accept what's going to happen to me, but I cannot accept, I cannot even make sense of, what's going to happen to Liz. I cannot understand why the ending of one life has to be so destructive of another. It feels as if someone is trying to take a wrecking ball to Liz's life. It feels as if she's going to be punished for having loved me.

People can be crass, very crass, about cancer. I think we can also be quite crass about bereavement. How often have I been told that someone's wife, husband, partner has died, and I've said, "Oh, how awful", and I may even have written a nice letter; but have I stopped to ask myself, just what does awful mean? If it's someone close to you, you may enter a little into their experience. I think we might all try harder to do that.

A close friend has asked me, twice, whether I'm worried about Liz. I've replied that I'm not. I know that Liz will be all right. She'll suffer, but she'll be OK. She'll grieve in many different ways - although not necessarily in the approved stages: I don't need to be dead for her to get angry with me. She'll suffer, she'll grieve, but she'll come through it. She'll come through it because of her own strength and resilience, because she too is trying hard to make sense of this. We're very different people, but, each in our own way, we're working at the same thing.

Liz has her painting and writing. The two go together. All her writing contains art work. Painting and writing are her ways of processing and giving meaning to her experience. They will help her navigate this. We have a strategy to ensure Liz doesn't get sucked into my illness to the point that it takes over her life. That's something I've seen happen. When the patient dies, the person has gone, and so too has the illness. There's nothing left. That must not happen to Liz. Since she retired, she's built up what is sometimes called a portfolio career, a mixture of teaching on the doctorate at Bedfordshire, co-editing a book on Nonviolent Resistance, maintaining a small therapy and supervision practice, and being involved in our local NHS. She'll keep that going. She is not going to become my full-time carer.

And there is Murmurations. Liz has found it a joy to have created this journal with Birgitte and Gail. The first issue of Murmurations is a marvellous achievement. If you haven't done so already, I urge you to read it.

In the end, it's people who make a difference to one's life. It's people who will be there to support Liz. Liz speaks of you, her systemic colleagues, as her family. It's an honour for me to be here among you, Liz's systemic family. Thank you.

Liz's story

Listening to Gaby tell our story to an audience was hard. I experienced mixed feelings about being the focus of attention. And this was *our* predicament stripped bare and put out there for everyone to see. Did that make it more real? No, nothing could make it more real than it already was.

Although Gaby didn't mention it, we were both acutely aware that two days earlier I had undergone surgery for breast cancer. The physical discomfort and fatigue that day was a constant reminder to me of my own situation. I've come to realise that when I speak about life since Gaby's diagnosis, I don't usually worry about whether what I say affects the people listening; I want them to be moved, to have a sense of how it feels. We are at the centre and other people are around us; some close, some further away. The eye of the storm is a calm place to be but when you step out of it you encounter the ruin and devastation caused by the hurricane.

I wrote this in my notebook on January 2nd 2018, the day before I had my second operation.

This morning, as the bus I was travelling on crossed Waterloo bridge in the direction of Somerset House, I thought about throwing myself into the river. It was a fleeting thought. Not one with any intent. But it was a shock to find it there in my mind.

In October a small abnormality was found in my left breast during routine screening. I was diagnosed with breast cancer and had surgery at the end of November. I recovered well. They removed a small tumour, and the sentinel lymph nodes, which they then tested to see if the cancer had spread. They found cancer in one node and tomorrow they are going to remove all the rest from my left armpit. It's called Axillary Node Clearance. I am terrified. "It will be a wee bit painful", the breast care nurse said, "That doesn't begin to describe it", I thought to myself gloomily.

Ten days later I am feeling grey. Still juggling an assortment of tablets to try to find the right combination to manage the pain. Constantly aware of the fluid-filled swelling under my arm which impedes my movement and makes me feel as if I am wearing some sort of clumsy, inflatable device. I remember as a child how the plastic swimming ring used to rub and pinch the tender bit under my arms. Things gradually improve but it takes a long time and then the healing has to start all over again when I have radiotherapy.

Guy's Hospital Cancer Survivors' Day

In the spring the Chair of the Guy's Cancer Centre User Group invited me, Liz, to speak at the Cancer Centre Survivors' Day celebrations in June. She wanted me to talk about being a carer and being someone with cancer. She'd like what I say to be uplifting. There's a challenge!

It's a scorching hot day and two of us are going to speak immediately before the glitzy upbeat fashion show, modelled by people with cancer. It turns out that the other speaker is a young gay man, an opera singer. This is an opportunity to perform our stories in front of hundreds of witnesses: people with cancer, their families, children, doctors, nurses, other healthcare professionals, and volunteers. I'm very aware of my audience and the need to speak to include everyone there as much as possible.

I'm up first. Just as I'm waiting to go on stage one of the people I know wishes me luck and asks me if I'm nervous. I'm not at all, I want this. I'm *poised*, as John Shotter (2012) would say.

a poised resourcefulness in our own special professional practices, an ability to go out to meet a whole range of contingencies with an appropriate response 'at the ready', so to speak – contingencies to do with human bewilderments, disorientations, puzzlements, feelings, emotions, and many other human disturbances that we can meet in our relations with the others and othernesses around us.

(John Shotter 2012, p.12)

Liz's speech. 24 June 2018

Everyone's story is different and so in telling you mine and talking about how I coped I'm not saying this is how you do it but just that this is how it happened for me. And you may connect to a lot of my story, or some parts of it, or you may not find any connection.

Carers' stories aren't often told. We are less at the centre of things. As a carer, I felt powerless, out of control. I was there to support Gaby and I was part of most of the conversations and appointments, but they were, rightly, about her and not me. But it was happening to me too; it was happening to us. I remember those first days and weeks. The days before any formal diagnosis, while we were still numb from shock, when time stretches like a desert. Wondering how long Gaby was going to live, because we knew that the tumour was large and had been there for some time. We got lots of messages of support from friends. At least Gaby did, I didn't. The messages were of course meant for us both, and Gaby always showed them to me, but I became increasingly distressed, feeling left out and excluded, but thinking I ought not to feel that way because I was OK, I didn't have cancer.

We have been together as a lesbian couple for thirty-three years. We have both been active in the LGBTQ+ (Lesbian Gay Bisexual Trans Queer plus) movement since the 1970s. We don't expect to be treated differently from other couples and we aren't. But each time we meet a new health professional, we have to actively make clear that we are a couple, or they may assume we're family members or supportive friends.

As we became used to the situation, things got easier. Sometimes routines and predictability help you adjust. When the cancer came back it was a shock for us and for the clinicians involved in Gaby's care. Gaby had an intravenous PICC (peripherally inserted central catheter) line surgically inserted into her arm. She went home from each treatment with a pump attached to it. At my request, I was taught to disconnect the pump and flush the line. This meant we didn't have to rely on the community nurses. One day, in the cancer day unit, I noticed how distressed someone was about having to return to the hospital on a Sunday to have the pump disconnected when they lived far away and had a special family event planned. I told the couple that they could be taught how to do it themselves.

This marked a turning point for me. I begin to feel more in control and that I could make a difference. At this point I started wanting to share ideas with other people and think about what might help other carers at the cancer centre.

I think that the time things really changed for me was when I spoke to the Board of Directors at King's College Hospital about being a carer. I wanted to convey how difficult it is when you find yourself with no voice. I had previously been at the height of my career, really pleased with the way life was going, and that had crumbled away overnight. I continued to function and didn't look any different on the outside but now a major part of my identity was defined by Gaby's illness. When I became involved

and felt connected again, I got my voice back and no longer felt helpless. I didn't know the extent to which I had lost a sense of who I was, until I got it back. And of course, I was no longer the same person.

Then I got to see things from the other side.

I was diagnosed with breast cancer. Now I was the one in the patient chair and Gaby was in the other seat. Despite what was happening, I felt strangely in control, because it was about me. I had to remember to include Gaby in conversations where my health was the sole topic. I realised how hard it was to keep eye contact with the doctor and include Gaby.

I had two lots of surgery and three weeks of radiotherapy and I've now begun five years of taking Tamoxifen. I know what a lonely and cruel place the CT and radiotherapy suites are, despite the lovely staff. But suddenly I feel re-energised. I don't think I'd realised what a strain the past months had been; being a carer and a patient at the same time, trying to navigate both roles.

In the middle of the mess and confusion you just have to keep on as best you can. Sometimes you lose your sense of who you are in the storm that rages around you. Getting involved made me feel less helpless in a situation where I knew I couldn't change things or make them better, and gave me back a sense of direction. Gaby is increasingly tired, so we live a pared down version of a normal life. But we do the things we enjoy: seeing friends and family, travelling when we can, looking at art and listening to music.

While I was writing this speech, I realised that maybe the key to being a survivor is something to do with staying connected. The cancer process isolates you, leaves you stranded on some strange bleak shore with no landmarks in sight. When I was having radiotherapy, I posted on social media every day. I checked in to the Guy's Cancer Centre on Facebook and told my friends when I had completed each session. They encouraged me and spurred me on. I felt connected even though I was lying alone in a vast cold room with a space age machine revolving around me. That sense of connection continues to support me so that I don't feel alone. And that's what the cancer survivors' day is all about.

Gaby reflects

Almost my first thought on being told I had cancer was that I, an only child who thrives on attention, was now going to get all the attention I could possibly want. I realised I must rise to the occasion. I must "do" having cancer, perform it, in a way that was, so far as I could manage, dignified and "right". I must also be in charge. If there were difficult decisions to be made, I would make them - in consultation with Liz, whose wishes and needs would almost certainly be my first concern; but it was my body and my illness, and the decisions must be mine.

At the beginning I had a powerful feeling that by sharing my experience I might be able to help others. I wanted to contribute to demystifying cancer. For a year I served as a patient representative on the board of our regional NHS cancer alliance. Not so long ago, I wondered if I should start a cancer blog, something for which there seems to be an insatiable demand. It's taken writing this paper to bring home to me that engaging in that way with the world of cancer isn't what I want to do. The talk I gave at the Murmurations launch, almost a year ago, wasn't about cancer but about living with dying.

I was diagnosed with a cancer that, although caught rather late, was eminently curable. Our future happiness and wellbeing depended on my successful treatment. During this first phase of my illness, Liz's experience was unnecessarily difficult, demonstrating that much needs to be done to improve matters for carers; but neither of us would dispute that I and my treatment were rightly the prime focus. When I had the recurrence, that changed. I recall the meeting with the surgeon – a woman of great kindness and empathy whom I trusted completely. We went through the radiology report in detail. The diagnosis would have to be confirmed by biopsy, but she and the radiologist were fairly sure I had a major local recurrence. I said I knew that meant I was going to die.

Then I launched into a peroration, talking with more or less coherence about cancer, death, people I had known, foolish things people had said to me – it was a stream of consciousness, to which she listened, patiently and attentively. I talked a lot about Liz, and ended by saying that she was now the person who mattered most. The surgeon replied, quietly, "Yes, I can see that". At my request, she sat with me while I telephoned Liz who was in Wales to tell her the terrible news.

I'd understood, instantly, that my terminal diagnosis repositioned us in relation to my illness. I was going to die, and when I died, I'd be gone. But Liz would have to carry on. Her future must now be the focus of our attention. That much was obvious. But through writing this paper I have slowly come to realise that there has been another important change. I no longer want to be in control.

There may be difficult decisions to be made. Increasingly, I want Liz to make them. Nowadays, she's more clear-headed than I am. I may be offered a clinical trial. Will it be worthwhile? I'm not sure I trust my judgment or my ability to understand our needs. The classic decision, of course, is where to die. We read that more and more people want to die at home, and it must be made possible for them to do so. That puzzles me. As long as I receive good care, why should it matter to me whether I die at home or in a hospice? But it may matter a great deal to Liz, and she will have to live with the consequences. She should decide.

My sense of agency is gently receding, and that feels right. I want to put myself and my future into Liz's hands. I have repositioned myself. I'm also withdrawing from active engagement with the world outside. I've given up all my work in the NHS. I'm unashamedly living for myself.

Reflections on the systemic practice context by Liz

This paper can be seen as an exercise in *bricolage* (Lévi-Strauss 1962; Denzin & Lincoln 2005) using autoethnography (Ellis 1995, 2004; Bochner and Ellis 2016) and relational autoethnography (Simon 2013). We talk about our shared experience of living with cancer and show how, through writing (Richardson 2000) and performance (Denzin 2003), we have been able to find ways of going on. But this *bricolage* also creates a rich portrait (Day 2014) of our relationship. These activities of writing, and talking, and talking about what we are writing, are activities of sense-making.

...the outcomes of our inquiries as practitioners are not to be measured in terms of their end points – in terms of their objective outcomes – but in terms of what we learn along the way in the course of the unfolding movements they led us into making.

(Shotter 2012, p.1)

We are using in our relationship the artistry and skill that thinkers and systemic practitioners bring to the table. How do therapists create conversations that navigate complex and difficult situations and life events and give meaning to them? How do we make and retain our connectedness? Adversity doesn't only happen to our clients; it also happens to us. Experiences that cause us pain and distress have the capacity to create resources for us. Learning to steer a way through choppy and treacherous waters can equip us to manage threatening situations with a greater sense of agency. When we are "at sea", we need points of connection to steady things and anchor ourselves. These points of connection can be friends and colleagues, but they are also provided by texts and through mapping the network of theoretical knots and intersections.

Connections and meaning can also be made in work with clients. In the week I returned to work after Gaby's initial diagnosis, I assessed a teenager who was feeling overwhelmed: several of her close family members had cancer, including a young cousin whom she had recently nursed until his death. Now I spoke from a new position of both experience and curiosity, I asked some questions informed by my own local knowledge (Geertz 1983). I recall indicating, without talking about my own situation, that I had personal experience of what the family were going through. Janine Roberts (2005) has written usefully about disclosure for therapists, and makes the point that transparency always involves self-disclosure of some sort.

In a previous paper (Day 2009), I described the powerful therapeutic effect of performance, when a young girl read out loud to me and her father two compelling and moving letters she had written. Her mother had died, and she was grieving that loss. One letter was to her mother, an alcohol and drug misuser who had led a troubled and chaotic life, and the other was her mother's imagined reply, apologising for the hurt she had caused. As she read the letters she inhabited them, in a way that reduced her father and me to tears.

I am also reminded of some therapeutic work I did twenty years ago. I worked with Roya Dooman, a drama therapist, to develop a groupwork intervention for African children who had lost parents and close relatives through HIV; we called the project *The Circle of Life* (Day and Dooman 1998). A key part of the intervention was to help the children develop stories about adversity, support and resilience, and then to create opportunities for each story to be performed within the group. The performance, and the presence of the rest of the group as audience, moved the stories up to a higher level of connection and embodied meaning-making.

A key therapeutic feature of the Nonviolent Resistance multi-parent group (Heismann, Jude and Day 2018) is that parents carefully compose messages to their child and then practise performing them in front of the rest of the group until the performance embodies their love for their child and determination to change things. This intervention has the powerful effect of moving parents into a more connected, empathic and relational space.

Liz and Gaby

Susan Roos (2002) says that chronic sorrow is a natural grief reaction to losses that are not final, but continue to be present in the life of the griever. That is the situation we find ourselves in, yet we are not overwhelmed by sorrow. Sorrow is in the background, but rarely in the forefront of our minds.

In her keynote speech to the 2018 conference of the Association for Systemic and Family Therapy, Jenny Altschuler said, "... acceptance (of an illness identity) equals a greater capacity to adjust

psychologically and better physical functioning". She also suggested that same-sex couples may do better than heterosexual couples because "... shared gender constructs mean that care is more likely to fit with expectations".

An interesting conundrum is the juxtaposition of anger and acceptance in the western literature about anticipatory grieving, bereavement and loss. Anger is often described (Bowlby 1980; Kübler-Ross 1969; Parkes and Prigerson 2009) as one of the stages or phases of a transition towards acceptance; yet we know that in fact the process is complex, convoluted, cyclical and individual.

We rarely feel angry; sometimes frustrated, often saddened, but not angry. It can be easier to accept one's own fate than that of a person one loves. Gaby does at times feel rage at Liz's situation, both her illness and her impending bereavement; but it is an empty, helpless rage that surfaces only occasionally and quickly subsides.

Adversity, sickness, premature death: none of these is unusual. A sense of entitlement is culturally specific. In many parts of the world it would be unthinkable to believe one was entitled to live into old age and that not to do so was abnormal.

In our experience acceptance is part of a healthy response. It is not a passive uncritical acceptance, but one that is informed, pragmatic and thought through.

Final Words

This paper is a description of using writing and performance to help us make sense of very difficult things: of having to live with cancer; having to confront premature death, on the one hand, and bereavement, on the other, and needing to do this in a life-affirming and profoundly ethical way. What interests us is how the story has developed and changed in the process of writing, reading and talking together about the writing. This iterative endeavour has been profoundly therapeutic and new meanings have emerged.

In his final book, John Shotter writes, "... more than the mere solving of immediate problems, one after another, is needed if we are to act within the particular practical situations confronting us in our everyday lives, *prudently*, with *practical wisdom*, with a *sense* of what, overall, it is best for us to do." (2016 p.35) This is practical ethics.

Writing has brought us a sense of calm and focus. We are both surprised by how happy we feel a lot of the time; how strangely satisfied with our lives we are. There is little point in railing against what can't be changed, and it isn't in either of our natures to do so. We are sharing this experience and we need to decide how to live our lives in the time that is left to us. The present feels timeless, but it isn't. Liz is learning to face a future without Gaby and construct an ongoing life for herself.

The experience of writing has been revelatory. We have talked issues over, written and re-written sections, taken things out, and talked again. What we each have to say has been shaped by the process, in ways we did not expect. What we have found ourselves writing has sometimes surprised us. Maybe people facing death and bereavement need this creative relational space to do the talking and reflecting that will help them generate stories of future possibilities.

A challenge for us in writing this paper has been to work out what it is about. That question, which seemed at first to have an obvious answer, has turned out to be not so easy. So, our *final words* are not final at all, but punctuate an ongoing conversation.

Glad and cheerful, let us say, as we go to our rest: 'I have finished living; I have run the course that fortune set for me'. If God gives us another day, let us receive it with joy. The happiest person, who owns himself more fully, is the one who waits for the next day without anxiety. Anyone who can say, 'I have had my life' rises with a bonus, receiving one more day.

(Seneca, Letters, 12.9.)

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