



# Creating Stories of Hope: A Narrative Approach to Illness, Death and Grief

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A narrative approach allows psychosocial teams to stand alongside children who have cancer, or life-threatening illnesses, and their families at critical times and to create stories of agency. Rather than dwelling on stories of loss and despair that potentially enfeeble families, a narrative approach builds on stories of strength that engender hope by asking questions that separate the person from the problem. Developing such stories supports people in taking action against the effects of cancer. It also facilitates the formation of a legacy that can sustain family members, even after the death of a child. This legacy serves as the foundation for remembering the dead, folding their stories into the lives of the living, and constructing lines of relational connection that can transcend physical death. Not only do families benefit from this approach, but the psychosocial team that provides professional and medical services can be uplifted through witnessing practices of strength and love in the face of hardship.

**Keywords:** bereavement, narrative therapy, family therapy, remembering practices, externalising, adolescent, oncology, hope

## Key Points

- 1 A narrative approach to illness, death and grief disrupts stories of despair when facing the death of a child and in the aftermath of these unthinkable events.
- 2 Shifts from certainty (where we are expert) to collaborative conversations (valuing the knowledge of those who consult us) create opportunities for new identity stories.
- 3 Externalizing and mapping questions that address death, illness and grief of a child create agency to explore and expand the gaps in stories that otherwise can paralyze families.
- 4 Hope can be fostered through relational action, not only by optimism about a preferred outcome.
- 5 Remembering conversations fold the legacies of those who have died into the lives of the living.

Working with children and their families when serious illness and death visits, requires special skills that are often learned on the job. This work calls on us to sit with more than just an open heart and the finesse of active listening, but also to think about how to help children and their families find hope when their world is threatened by dramatic changes. This article will offer some new ideas about how those who work with children who are seriously ill and their families can create spaces of hope. The article will also address the upheaval that a death of a child brings to a

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family, and how to support families towards stores of strength and agency at such times. It will bring together strands from narrative therapy with personal experiences of working with death, dying and grief. My hope is to invite readers to notice places of resonance, or perhaps find places of curiosity, that will encourage further delving into narrative counselling.

I believe narrative practice invigorates life, and strengthens the stories that people can live by, while upholding love, even in the face of the unthinkable. While many other theories and practices have provided models for counselling families facing the death of a child, I have found narrative practice a model that personally resonates with my way of thinking and living in. It is based on the use of questions that social workers, counsellors, medical professionals and those in caring professions can use to draw from people's performances of living. These theories can be used to form questions – really good questions – for those whose lives depend on them.

### **The Narrative Background**

Narrative counselling was born in the 1980s in Australia and New Zealand. When White and Epston (1990) wrote *Narrative means to therapeutic ends*, ideas about how to view problems and how to think of people's lives were shifting dramatically. In the thirty plus years since, hundreds of articles have been published, thousands of counsellors have been trained around the world, and many books on narrative practice produced.<sup>1</sup> All of this work has heralded a departure from thinking of people primarily in terms of personality deficits, fractured egos, attachment oddities, or psychological diagnoses such as adjustment disorders or PTSD. Narrative counselling has grown from these beginnings to address many topics and to present a fresh approach to the support of individuals, families and communities facing hardship. We see wonderful examples of a new approach in White's (2007) book, *Maps of narrative practice* that further shifts how problems are thought of and the way in which counsellors can create new conversations with clients even in the face of the unthinkable. The question remains however, how can narrative practice help people make sense of illness, death, and grief? And how in particular is this new way of thinking helpful when working with children and families who are dealing with these challenges?

Narrative practice is strongly informed by a social constructionist philosophy (Gergen, 1994, 1999). This means eschewing the assumptions of modernist humanistic philosophy or empirical, positivist realism. In social constructionism, people's personalities and identities are considered relational constructions organised into coherent narratives (White, 2007). While it seems harmless enough to say that we are relational beings, this view has implications for how we understand where problems might originate and, ultimately, for where we seek solutions (Gergen, 1994, 2009). Narrative practices have embraced the idea that we are always in the process of becoming – that is, who we are is always being constructed in the context of relationships and that these relationships are formed against the cultural backdrops of stories.

Narrative practice is built on the assumption that people live their lives through stories and that they are all multi-storied in their lived experience (Freedman & Combs, 1996; White, 2007). People do not have only one true story, or one single purpose. There are always multiple entry points to the stories about a person that can organise narratives in multiple ways. Gergen (1990) called being 'multiphrenic' a condition of living in the modern world. This perspective allows the flexibility of

shifting from one story to another and not being locked into any single story, say, as a 8-year-old cancer patient. It assumes the possibility of speaking ourselves into existence (Davies, 2000) in new versions of identity stories, for example, as a courageous and loving family member who enriches the lives of siblings and happens to have cancer in his or her life.

Our stories are sequences of events linked over time, not necessarily in a linear or logical trajectory, but in a series (Deleuze, 1990) that lends coherence to who we are becoming. Stories provide us with meaning and shape our sense of identity (May, 2005). Using a narrative approach, we can enquire into how problems have taken on a storied form and are impacting on a person or a family. These enquiries can be made without attributing blame or responsibility to any one individual in a family.

### **A Dramatic Shift**

Narrative practice shifts our position as 'helpers'. No longer must we take up being the expert on another's life. Other people know their lives far better than we ever will. Social workers, counsellors and medical professionals can walk beside others when they are in trouble, without succumbing to the temptation to know what is best for them. People already have skills, competencies, knowledges and abilities that enable them to respond to the problems of life. This is a statement about the politics and ethics of professional practice. It is possible to either use professional power to colonise people or to create opportunities for them to have a say in the governing of their own lives. This assumption shifts the emphasis *away* from knowing best, diagnosing unseen problems, telling people what to do, assigning therapeutic homework and the like, and *towards* being curious, asking questions, and enquiring into the usefulness of existing resources people have available. It means avoiding thinking in terms of deficits, or speaking about 'patients' at staff meetings in objectifying language. It does mean fostering curiosity and engendering collaboration between psychosocial teams and families. Doing this with people who are sick, or dying, or living with grief, creates dramatically different kinds of conversation.

One of the most important principles of narrative practice is summed up in White's (1989) aphorism: 'The person is not the problem, the problem is the problem' (p. 6). This simple expression potentially revolutionises counselling conversations. When we no longer see the person as the problem, we stop looking for the identified patient, or describing an individual as the '16-year-old male with chronic lymphocytic leukemia' (he is always many more things than that anyway), or as the mother who is in denial (who is also much more than this). Nor would we speak about families in pathologising terms as dysfunctional, overly enmeshed, chaotic, or lacking a father figure. We no longer need to reduce people to one simple diagnosis or a single description that limits their possibilities for creating identity stories. The statement, 'The person is not the problem, the problem is the problem', challenges decades of totalising psychological descriptions that are regularly placed at the doorsteps of those who are suffering. Seeing the problem as something that lives in the discourse and is produced in relationships between people, allows us to invite both individuals and families to take a stand against a problem and to explore both the effects of a problem on them and the openings to a counter story in which the power of a problem might be reduced.

An example of a family story will now be used to illustrate these ideas and to show how questions can be used to separate people from problems, and to develop stories of strength.

### **Matt and his Family<sup>2</sup>**

I first met Matt when he was just fourteen. He had been diagnosed with Hodgkin's lymphoma at twelve. I also met his younger sister, Tammy, who was ten, and his parents, Greg and Michelle. Michelle had scheduled a family counselling appointment, hoping I could explain to Matt why he needed to be more careful with his health. The day I visited, I was greeted at the door by Matt's best friend, his German Shepherd, Buddy. Buddy had come into Matt's life when he was undergoing chemotherapy and had stayed by Matt's side and slept in his bed ever since. Matt also had an older sister, Jeanette, who would have been eighteen if she had been alive. Jeanette had died two years earlier at sixteen from Hodgkin's lymphoma. Soon after her death, Matt had been diagnosed with the same illness.

Greg and Michelle had days in which life felt overwhelming. They were consumed by doctor's appointments, treatments, their daughter's death, and their son's illness. They were trying to balance the medicalisation of their lives with the jobs they both had to keep to make ends meet and to maintain health insurance. Michelle worked as a hairdresser and Greg as a fireman. Both worked long hours and adjusted their schedules so someone was always at home with the children or available to take them to an appointment. They were also trying to support their youngest and attend Tammy's school functions and not forget that she wanted ballet lessons. They were naturally highly anxious about what might lie ahead for their son. They felt like failures as parents for 'giving' two of their children cancer, even though no-one else in their extended families had ever had cancer. Terror was nipping at their ankles with the questions: *Would this too be Tammy's future? Would they have to bury all three of their children?*

### **The First Conversation**

I first met them at their home and was greeted at the door by the dog, Buddy. Michelle and Greg had initiated counselling as they could see Matt struggling. He had completed numerous rounds of chemotherapy enduring the usual symptoms. Matt wanted to be outside, to do what he had used to do, to go to the park, to hang out at the movies with his friends, and to 'not feel like a prisoner' in his home. Greg explained there had been 'an incident' last week in which Matt had snuck out late at night. He had walked to a friend's house a couple of miles away, and had not returned home until eight the next morning. His parents had been understandably frantic. They wanted me to explain about the dangers lurking outside their home – the germs and viruses that could prove deadly to Matt's fragile immune system.

In conventional counselling, we might enquire about Matt's feelings. We might ask questions about how he feels stifled, or ask Michelle about her sadness over Jeanette's death. We might even develop concern for Michelle's and Greg's 'unfinished business' of grieving properly, which could be said to be interfering with their relationship with Matt and increasing anxiety. We also might make assumptions about Matt as a young adolescent, despite the cancer, doing the developmental dance

of separation and rebellion. We might come up with a list of ‘homework’ assignments for this overwhelmed family about how to take more time for themselves. Following these conventional lines of practice, however, might blind us to the larger stories of strength and love.

By contrast, the narrative assumption that ‘the person is not the problem, the problem is the problem’, frees up a different line of enquiry. Rather than pronouncing a diagnosis and treatment plan, it might be more respectful to ask simple questions about how the family members see the problems they are grappling with. We can even ask them to give the problem a name.

### **Naming the Problem**

Naming allows us to respectfully join alongside a family to combat the problem that is bothering them (Mann, 2002). It both acknowledges what has been taking place, and also initiates a conversation about how to stand against the problem’s sway. For example, we could ask Matt and his family:

*If we were to call all of this, all of what has been occurring in your family, a name, what would we want to name it?*

Without naming, it is like fighting against something unknown and wrestling the air. Multiple names might arise, so it is important to take time to name the problem as the first step in separating from a problem story. Naming makes it possible for family members to unify against a shared problem without demonising one another. The problem might be objectified as ‘the cancer’ or ‘the illness’, or sometimes with younger children it might become ‘the monster’, or ‘the green stuff’. Sometimes it is simply ‘the problem’ or ‘it’.

Externalising the problem through naming introduces a dramatic difference from conventional counselling about a problem that lives inside a person: Matt’s depression, Michelle’s anxiety or Greg’s unresolved grief. These descriptors construct any emotional response as emerging from an internal need or deficit. Internalising problems understands a person’s responses as indicative of a personal lack, or a misguided guilt, or a dysfunctional family system. Internalising asks people to take responsibility for things they do not control, like cancer, and can easily degenerate into blame when things are not going well.

Asking families to name something problematic might seem a bit odd at first, but most people easily respond to the questions and appreciate the sense of lifting the burden of personal blame or fault. Often names appear easily, almost organically, in the metaphors of conversation. Other times more questions are needed to begin to separate the person from the problem. Matt and his family talked for a bit about what might be a fitting name. They all agreed that the most appropriate name was ‘The Intruder’. This grabbed all of the factors into one – the cancer, the unwanted experiences and associated feelings. The name spoke to each of them and captured the sense of something being unwelcome in their lives for the previous four years.

### **Externalising and Exploring the Effects of the Problem**

Once a problem has been named, its effects on the family can be explored without laying blame at anyone’s feet. *The Intruder* is to blame. Everyone can talk about

how *The Intruder* is producing suffering without stories of personal failure or deficit leading the way. Questions such as the following help flesh out how the problem operates:

- *When The Intruder visits, how do you know it is present?*
- *Do you know what it looks like? Sounds like?*

Personifying the problem gives a sense of how undermining it has become. We might even discover whether the problem has any intentions for them by asking:

- *What do you think The Intruder wants from you?*
- *What plans does The Intruder have for your future?*

*We can also map the effects of the problem on relationships in the family by asking:*

- *When The Intruder is present, does it have you talking differently with one another? How do you notice this?*

Responses to these questions shape the problem story and lead toward acting against the power of problem. Another way to do this is to explore the length of time the problem has been around, the depth of the problem, and the breadth of the problem's reach (Winslade & Monk, 2007). This would look like the following:

**Length:** *How long has The Intruder lived in this house?  
When did you first notice The Intruder coming home with you?*

**Breadth:** *Does The Intruder live in all aspects of your life?  
Are there some places where it lives more than others?*

**Depth:** *Does The Intruder wreak such havoc that there are times when it makes it hard to carry on?*

These questions are different from those asked on the bio-psychosocial intake forms social workers, psychologists and counsellors usually complete. The traditional intake often assumes a linear progression of an illness, mental or physical, and solicits stories of deficit and pathology at the expense of resourcefulness or resilience. Mapping the effects of questions (Mann, 2002; White, 2007) give families a sense of what might be happening in their lives, but also sets the stage for what happens next: the identification of unique outcomes or instances of a counter story.

Matt's family had a clear explanation for how long *The Intruder* had been in their lives – from the first moment five years earlier when they had thought Jeanette had tonsillitis. The day the doctor had told them that what appeared to be a simple illness was in fact a life threatening cancer, *The Intruder* had barged full force into their lives. *The Intruder* had taken up residence in their house, without even paying rent. It had lived there through Jeanette's chemotherapy, through the course of her increasingly stubborn cancer, and ultimately her death. Through their son's diagnosis and treatment, *The Intruder* had continued to live with this family and help itself to their resources. Michelle explained that there were times she could not get out of bed or concentrate at work. Greg spoke about how he felt like he was losing his entire family, first his daughter, now his son's life was on the line, and at times he felt like he had lost his wife as well. Matt felt *The Intruder* was living inside his body. He described it as 'like an alien that had taken him over'. There was no escape, as he saw it, when he looked everyday at the part that had been surgically

placed in his chest, or when he saw his bald head. Tammy was sad to see everyone in her family being so sad all the time. Sometimes she felt this way at school and could not shake feeling so blue. Clearly *The Intruder* was deeply interfering with this family.

If an intake stopped only by understanding the history of the problem and its effects, however, we would be remiss. We still need to find a way to help families cope with what seems unimaginable. We can do this by asking whether people are willing to take a stand against the problem and against the havoc it has been wreaking in their lives. This step invokes a sense of agency by enquiring into family members' preferences. It can be as simple as asking:

*Do you mind The Intruder living with you?*

While it seems almost superfluous, such a question has the purpose of establishing a turning point in the story from a past, in which the problem story has been in charge, *towards* a future in which the family wants to take charge. Most people do object to the problem's intrusion in their lives which allows us to ask why they object. Such questions pull the problem story away from close identification with people. No longer is the problem completely in charge of what is happening. People are now asked to sit in judgement of the problem rather than of each other or of themselves. Enquiry into their dreams and values, besides being a person living with a problem, now becomes possible. They can be asked to construct an image of a future where the problem has less of a hold on them.

*Do you have a different future planned out for your family than the future The Intruder has planned?*

Asking questions cannot, of course, make a problem like cancer magically go away. But they can help people access a sense of agency in how they face the magnitude of the problem. A sense of agency renders people less susceptible to being overwhelmed by problems or to judging themselves as failing. Exploring the effects of the problem can restore agency and potentially return some semblance of control to people's lives. From here, they are in a better position to make sense of significant challenges and to at least be able to put one foot in front of another. Each step into agency lessens the strong grip of the problem and opens to a counter story.

### **Absent but Implicit**

Another way to access a counter story is to listen for the other side of the story – what White (2000) referred to as listening for the 'absent but implicit'. White suggested that we pay attention to what is being negated as well as to what is being stated. We do this by 'double listening' (White, 2000, 2007). Double listening is an advance on the conventional active listening, in which we are trying to tune in to what a client is saying and attending to their feelings. Double listening enables us to go further and hear two stories sitting side by side. For example, a person may be simultaneously experiencing a sense of hurt and rejection especially because they value relationship and connection to the other person. Social workers, counsellors and psychologists can simply focus on the story of hurt, but doing so means clients miss out on a possible pathway out from the pain. Double listening involves hearing both the pain and the valuing of relationship. It involves looking at how something negative stands out

against the background of something positive that it negates. It attends to how a problem story always has a counter story sitting in its shadow. As Cohen (1992) said:

‘There is a crack, a crack in everything. That’s how the light gets in’.

Double listening lets us find these cracks by enquiring more directly about what is absent. We can grow a small moment of difference into a larger narrative. For example, we could ask:

*Is The Intruder always here, or are there times The Intruder takes the day or night off, leaving you alone for a bit?*

The assumption here is that small periods when the problem story is not so dominant can be openings for a new story. In the face of substantial illness, these instances can easily be overlooked. It is my job to pause over these easily overlooked moments in order to grow their significance. Such small oases of difference are what White and Epston (1990) referred to as ‘unique outcomes’.

### **The Pause**

In response to the question, *Is The Intruder always here, or are there times The Intruder takes the day or night off, leaving you alone for a bit?*, Matt reflected on a couple of times when the intruder had been quiet. One was when he’s with his friends. He explained he can play video games and hang out and not think about, or talk about, cancer. This is a small crack that lets light in. It needs to be further developed by expanding the landscape around the action to form stories of identity. Rather than encouraging him to spend more time with his friends, curious enquiry into his stories builds his sense of agency. For example:

- *What difference does it make to hang out with your friends and play video games?*
- *What is it like to have a break from The Intruder?*
- *Does The Intruder ever try to grab your attention back at these moments?*
- *If so, how do you refuse to allow The Intruder to take up space in your thoughts?*

It was not a huge surprise that Matt would speak about how he felt normal when he was free from his medicalised world. What was a surprise, however, was what he said next.

‘Sometimes when I am falling asleep, I talk to my sister Jeanette. She’s kind of with me.’

‘What kind of things do you tell her about?’ I asked.

‘I just kind of update her about stuff, like the doctors and Buddy, or how bored I am at the hospital’, Matt explains.

‘What happens to The Intruder when Jeanette and you speak?’ I enquired.

‘The Intruder gets really quiet then so I can hear her.’

His answer was amazing. In the moment that could easily be overlooked, Matt was calling on his dead sister’s memory to help resist the problem story in his life. Michelle and Greg had no idea this was a part of their son’s experience. In fact, they sometimes thought they should not talk about Jeanette so as not to discourage Matt. It was therefore very significant to hear his words. The moment might have simply



gone by like a blip on a radar screen, had we not spoken about the ways in which they could guard against the problem story.

### **Re-membering**

The practice of re-membering informs how conversations about death and grief are shaped (Hedtke, 2012; Hedtke & Winslade, 2004). The foundations of re-membering can be found in the work of the anthropologist, Barbara Myerhoff (1982, 1986), who researched the impact of stories that surrounded the accidental death of an 80-year old woman in an elderly community in Los Angeles. Her project was captured in the 1976 Academy award-winning documentary, *Number our days* (1978). Myerhoff noted that people's personal sense of self and also their communal sense of belonging were both re-invigorated and revitalised when they actively told stories of those who had died. Myerhoff noticed that they were doing more than reminiscing. They were actively conjuring a dead person's voice and legacy to produce meaning and purpose for those who continued to live on. She even spoke of this act as potentially life-saving:

Re-membered lives are moral documents and their function is salvific, inevitably implying, 'All this has not been for nothing.'

(Myerhoff, 1982), p. 111.

Re-membering conversations stand in contrast to conventional grief psychology that encourages people to say goodbye and find completion in the relationship, prior to the physical death of an individual. The bereaved are commonly expected to progress through a linear series of stages or perform prescriptive tasks in order to move on in their lives and not remain haunted by the pain of loss. This conventional model of death and grief psychology has, to a large extent, governed professional practice around death and grief, but can be often particularly cruel in relation to the death of a child. Many people for good reason resist the injunction to say goodbye to a dying child. They refuse to accept such a death as a reality, if acceptance requires letting go of the ongoing significance to a family of a dead child.

### **What Remains**

In contrast, re-membering conversations strengthen a sense of connection with what is *not* lost, with what gives comfort through being recalled and folded back into the lives of the living. Re-membering affirms the life of the deceased, rather than points to his or her absence. It takes advantage of the sense in which a person can be brought to life again through the stories told about them. Bereaved people often enjoy, and are comforted by, the chance to treasure moments of connection with a dead loved one (Hedtke, 2012). There is no reason such treasured moments cannot be held close for a lifetime to come. Saying goodbye and letting the deceased go would waste the potential comfort their stories can offer, even at times of great pain. Matt's conversations with Jeanette are testimony to this possibility – recalling her words, two years after her death, provided him with confidence for the hard circumstances in his own life.

Re-membering can also generate new meaning and purpose for those who carry forward the stories of the deceased. Most people find this approach a source of comfort that helps them make sense of death. To some degree it can mitigate the pain of loss. It is not that re-membering can completely remove the pain, but it can help

people find sustaining meaning. Re-membering allows people to continue to speak about a beloved child, or an older sister who has died, and celebrate what the child's life meant to them, and also what their lives continue to mean in the lives of those who love them.

As Matt showed, the noise created by new problems of living, (such as what Matt referred to as 'The Intruder'), became quieter so as to not interfere between he and his dead sister. Recalling his sister's encouragement made it easier to cope with what was on his plate. Re-membering conversation that incorporates the voice of the dead loved one can thus become a resource for an identity narrative (Hedtke, 2012). With this in mind, I wondered how Matt's conversations with his deceased sister could be helpful for Matt, and for his family, to draw upon. This might be the crack where the light gets in. Invoking Jeanette's voice from beyond the grave could help Matt and his family resist the problem of The Intruder. Questions that might access such help include:

- *How would Jeanette advise you to resist the effects of The Intruder?*
- *What difference would it make in your life to follow her advice?*
- *What would Jeanette appreciate about how you have not totally given in to The Intruder?*

### **New Identity Stories**

Rather than dwelling on stories of sadness about how much he misses her, these questions invite him to interlace his sister's words with his own identity story. His responses herald no less than a new way of standing up to The Intruder. Such enquiries can help people live with debilitating circumstances by borrowing from the strength of the dead and upholding the relationship between the living and the deceased. Conventional grief psychology too often asks people to do this alone through the series of tasks or stages one is obliged to progress through (Worden, 1991). Re-membering encourages us to do so in company of those we love, even those who are no longer alive. Incorporating the deceased person's stories or words of advice into one's efforts to live through difficult challenges potentially strengthens people's resolve to keep moving forward. Thus, re-membering is not just about the past. It can also carry us into the future.

### **Making the Light Grow Larger**

What about the skills and knowledges that enable Matt to create this moment of internal peace? In the original explanation of the 'problem', Matt's parents had thought he did not understand the dangers of not allowing time for his immune system to heal. They were now witnessing their son talking about his skill at accessing helpful, healing stories. To expand the stories of strength, it was important to ask Michelle and Greg to speak about what they were appreciating about their son's maturity in knowing how to resist The Intruder. They were acquiring new knowledge about how to trust Matt to make good choices.

### **Stories of Strength**

My intention was not to suggest that their lives would be rosy and problem-free. That would clearly not be helpful and could be offensive. Matt's lymphoma might or

might not continue responding to treatment as it had done. Nor did we know whether Tammy might eventually be diagnosed with the same illness. This family was also still fresh with the grief of the death of their eldest daughter. They had understandably been filled with despair. We also needed to find a way to address this despair so that it would not paralyse them or us.

To find a basis for hope they needed to hold on to what might feel lighter, but to talk about what was positive in their circumstances could sound insulting. Neither would conveying an optimistic belief that things would work out for the best be warranted. I too grimace at the unintended cruelty involved when someone living through tragic circumstances is told, 'Everything happens for a reason'. Who would begrudge Matt's family moments of hopelessness after witnessing a child die?

### **Stories of Hope and Despair**

The dominant stories from the world around us can sometimes interfere with access to hopeful stories, particularly when the floodgates of despair have been opened. But the meanings of what we are going through do not lie in the essences of events themselves. We make meanings ourselves through the stories we create about life. Hope and despair can both be emphasised by the choices we make of which stories to use to make sense of our lives. In circumstances like what this family was facing, the movement of hope and despair sometimes needed to be held simultaneously, as if in an intricate dance with one another. Rather than arguing for hope and attempting to exclude the presence of despair, or only focusing on the tragic experience, it seemed more useful to invite the family to experience the fluctuation between them; cautiously developing responses to the despair in order to restore a semblance of agency.

I asked Greg, 'How is it, when you feel like your family is crumbling around you, that you are able to manage all that has been happening in your life?'

He told me how at times in the months following Jeanette's death, he would go to the firehouse and temporarily forget his pain. 'I could concentrate on others who needed me. It felt like I was making a difference in someone else's life.'

'This desire to help others when they are in distress, is that about something you value?' I asked.

He explained, 'It's important for me to help others – to help my family, my kids and my wife, and also to help others. It has been really hard, when it has felt like I couldn't make a difference with my family.'

'So, when you are helping your family, even when you think it might not be making an impact, what would you hope they would say about how it helps them to manage?'

'I'd hope Matt would say he likes it when I take him to his appointments. We kind of hang out and do guy stuff. I read to him while he is getting his chemo.'

'And Tammy, what would she notice?' I asked.

'I went to the 'back to school' night last week. She showed me her desk and a letter she had written to me. She introduced me to her teacher. It was sweet,' Greg said.

'And what would Michelle say?' (I was asking in front of Michelle.)

'We have times where we don't see each other much with all the appointments and work, but at night I will hold her when she cries.'

'And what would Jeanette like about how her father does all of this?'

'She was so full of love – she would just hug me.'

This last question was important, because it continued to give voice to a family member who has died. Jeanette is included in the conversation and her connection to her parents is kept alive.

Hope is often thought of as oriented to the future – to what might happen if a particular future transpires. Often families hold out hope for a cure or for a treatment miracle, only to have hope ripped away from them when what was promised does not come to pass. Hope can turn into a cruel trickster at these times and steal a preferred future in which a child was supposed to be alright. How can narrative practice be useful in this context?

### **Intentional State Versus Internal State Therapy**

Michael White called narrative practice an intentional state therapy, rather than an internal state therapy (White, 2007). Hope or resilience are not to be sought out in the hearts of individuals as states of being. They are not qualities or personality characteristics that some people have and others do not. Neither should hope be reduced to an emotional experience. Rather, it is a theme in a narrative. Narratives contain feelings and emotions but are also much more than them. Narratives are ways of organising feelings, thoughts and actions into meaningful units of living. Therefore narrative inquiry is more likely to ask people about the stories they are living that feature hope, rather than whether they feel hopeful.

Focusing on intentional states, Greg and his family can speak about their responses to hopelessness and despair. This is different from believing counsellors and social workers can give hope to others or empower people. To believe so diminishes people's ability to find agency and strength in their stories, and may actually produce more hopelessness (Madigan, 2007). Instead, we can ask questions to help make sense of life experiences, of the interplay between hope and despair, as they often ride alongside each other. Hope is not a commodity or an essence that lives inside resilient persons. We cannot accumulate supplies of hope or hoard it like wealth or money. We cannot get rich by saving it up, and we cannot steal it from others. We can, however, explore people's responses to despair and seek out stories of agency that, over time, can render hopelessness more tolerable.

### **Hope as a Lived Expression**

Hope is an active verb that refers to a process. It is an expression of agency in the face of significant challenges. It can be unearthed by enquiring into responses to setbacks. For example, we might ask Greg and Michelle what they knew they could count on during times of great challenge, such as when Jeanette died. This question aims to connect them with what is solid in themselves and in their relationships. Such a line of questioning is not an antidote to despair, but offers ballast to help them steer a course through choppy waters. We could also privilege the deceased child's voice to

give direction to the living in the midst of despair by asking which stories Jeanette might want her family to keep close to them.

Michelle spoke about how Jeanette was a protective older sister and would be upset to learn of her little brother's diagnosis. With Matt and Tammy listening, Michelle spoke about how much Jeanette loved them and what she imagined Jeanette would say about this.

'She would want Matt to not let it get to him, even when it is really hard. She would also tell him to take care of himself so he can look after Buddy.'

Hearing his sister's wishes for Matt is potentially far more powerful and motivating than anything his parents or his counsellor might tell Matt about how he should behave.

As Matt listened, with Buddy laying on his feet, the verb *to hope* here served as the counter story to despair, and connected Matt's care for his dog with his sister's encouragement.

'Do you like paying attention to the advice Jeanette offers you?' I asked.

Matt just smiled and said, 'Yup.'

### **Hope is a Practice that People do**

Hope is achieved by taking action, even simple practices like caring for a dog. This idea fits with the emphasis on hope as a verb and, therefore, as a practice. In other words, ways of speaking need to be understood as actions upon ourselves and others that engender behaviour and create meaning. Counsellors can thus help develop actions into identity narratives that can sustain a person through hardship.

Organising pieces of discourse into narratives makes meaning of events, and this meaning is then performed in practice. The idea of practice is much larger than the narrow idea of behaviour. Hope as a practice occurs when Matt remembers his sister's pride in him, while he is having medical treatments and listening to her iPod.

Weingarten (2000, 2007) has argued that hope is not a state of being that people live in, so much as something that they do. It is less a state of being than an action. She goes further and suggests that it is also something people do together, not just something that individuals do. At its best, hope is a collaborative project in a relational context. If it is something you do, rather than primarily a feeling, then it follows that you can sometimes do hope, even when you cannot feel it.

Doing hope is about transforming experiences into possibilities. But feeling hopeful does not alone complete this transformation. Feeling hope may be necessary but not enough. As Freire (1994) says, 'Hope alone does not win' (pp. 8–9). There is no hope in only being hopeful, but it must be anchored in action and uplifted in identity stories.

### **Greg and Michelle's Hope**

Greg and Michelle spoke about the day their daughter Jeanette died. Michelle had kept thinking about that fateful day. In fact, it was hard to get it out of her head.

Jeanette had been out of hospital for a few weeks in home hospice care. She had been sleeping more and seemed comfortable. Her parents had stayed by her side, taking turns sleeping on the cot in her room. All her favourite things were in her room,

including pictures of her as a young gymnast and trophies she had won. Music she liked was played on her computer. They had invited her friends to visit and had taped colourful posters to the wall where her friends could write messages of love for Jeanette. They had kept her snuggled in blankets and fed her ice cream and sips of seven-up soda whenever she had wanted.

The day Jeanette died, they were devastated. Even though they had known that this day was approaching, the pain was excruciating. Greg's parents lived nearby and had come to help look after Matt and Tammy. As they recalled these events, the two years since her death collapsed into the present moment. The pain was palpable – it was still so close, so demanding of them. It was imperative to locate a story that would help them to go on in life or serve as the basis for modest chunks of hope. This happened in response to the following questions:

- *How did you and Greg work together at this time?*
- *What did you do to stay connected with one another?*
- *In the face of such a hard situation, how did you hold on to any small pieces of hope?*

Michele and Greg spoke of having days and weeks of quiet in the house where they did not talk much, but knowing one another was close by seemed to buffer a sense of aloneness. The presence of others who were also suffering somehow comforted them.

Such questions are intended to connect people with knowledge they may have forgotten. It is so easy to misplace hope when death visits. Narrative questions invite forward hope in a sense of connection with others. This is different from asking, *What were you each hoping for?* This question would have thrown them back inside their internal resources rather than looking to each another. It would have also created the inevitable impossible answer that they were hoping for their daughter not to die. Instead, the questions deliberately invited them to locate hope in the relationship between them as parents.

### **Hope is about Making Meaning**

Havel (1991), playwright and politician, writing in Communist Czechoslovakia, made a clear distinction between hope and optimism. Hope, he said, is:

... definitely not the same thing as optimism. It is not the conviction that things will turn out well, but the certainty that something makes sense, regardless of how it turns out (p. 181).

Optimism can be naïve or deny the realities of a situation, but to be hopeful does not require this. While Jeanette was dying, it would be unlikely her family would feel optimistic. Havel is emphasising the postmodern shift to making meaning. Being hopeful involves identifying sustaining meanings, rather than just being emotionally happy (Weingarten, 2007). To be hopeful involves taking up the challenge of making meaning, rather than just accepting meanings that might be made for us. Hope is thus a product of a story that gives someone access to meaning in action.

As they were sharing their account of Jeanette's death, Greg and Michelle spoke about an evening a month later in their living room. Tammy was doing her schoolwork and Matt was helping her with a math problem. Greg and Michelle were holding hands on the sofa. There was nothing extraordinary or profound, but they had turned to each other and said, 'I love you.' They both recalled this two years later as

a sweet moment. It could easily have been washed away by the waves of despair, rather than as an opportunity for keeping Jeanette's legacy present.

*What would this moment have meant for Jeanette?* I asked.

Michelle knew that Jeanette would have loved this family moment.

Folding this moment back into their identity as a family could make the unbearable sometimes just a little bearable. Re-remembering can thus serve as the crack where the light gets in. It does not erase the pain that death can bring, but it does affirm relationship with the living and with those who have died. It can be the space where we do hope, even in the immediacy of the despair.

### A Post-Script

As of now, a few years later, Matt and Tammy are healthy and doing well. Buddy continues to be Matt's faithful friend, and Tammy loves her ballet lessons. Michelle and Greg are continuing to do their best for all three of their children.

Their connections to Jeanette remain and set the stage for continued hope. Her legacy serves as a wellspring of hope to dip into, should the despair again encroach. And, from this place, they all can do hope.

### Endnotes

<sup>1</sup> For an overview of narrative practices around the world and a wealth of articles and resources, visit the Dulwich Centre's website at: [www.dulwichcentre.com.au](http://www.dulwichcentre.com.au).

<sup>2</sup> All names and identifying information has been changed or removed.

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