



Deconstructing Denial: Stories of Narrative Therapy with People Who are Dying and Their Families ¹

Sasha McAllum Pilkington

Counsellor, Hospice North Shore, Auckland, New Zealand

When I was 19 years old, I got a job as a nurse aide in a hospice to pay for my university fees. Elizabeth Kubler-Ross (1969) was my hero and I was broke.

One day I was handing out lunches. I walked into the room of a woman whom I hadn't met before. I had been told this woman was "in denial". She was sitting up in bed stiffly, as if uncomfortable. Her skeletally thin, pale face turned towards me as I entered the room. With some energy she immediately began to challenge me in a loud voice, "I look ugly don't I?" "Don't you think I look disgusting?" "How could anyone think I wasn't ugly?"

She spat out the words angrily.

I didn't know what to say. It seemed apparent from what she was saying that other people had argued and tried to reassure her. That seemed unhelpful somehow so I listened. In fact, I listened with all my might. That afternoon I went home and thought about her. I wondered what it would be like to be so distressed and angry, and dying.

I asked myself, "What could I do", "What could I say". I knew the staff had said she was "in denial". What did that mean I wondered, because it seemed to me she knew exactly what was happening to her and she was very, very, upset.

I went back to work the next morning resolved to try and do something for her, only to discover she had died in the night.

Wonderings of a narrative therapist

Now as a narrative therapist I might wonder how the staff came to understand the woman was "in denial" and where conversations could have gone if there had been another understanding.

¹ This paper was originally presented as a keynote address at the conference "Therapeutic Conversations Norway" in 2016. It is dedicated to Geir Lundby in acknowledgment of his commitment over many years to nourishing Narrative Therapy and in memory of a wonderful dinner time conversation. For inquiries about this paper please contact Sasha at Sasha.Pilkington@hospicenorthshore.org.nz





I might wonder what kind of assault her body had been enduring from the cancer, and treatments she may have had, and how that had been for her.

I might wonder what her understanding was of the changes to her appearance and what meaning she attributed to those changes.

I might want to ask her what was important to her in this, the last phase of her life.

In this paper I will be using stories of practice to illustrate some of the alternatives that Narrative Therapy (White & Epston, 1990) offers to labelling a person's relationship with approaching death as "in denial". The stories I am going to share are representations of therapeutic conversations I frequently have with the people I meet in my role as a counsellor working for Hospice North Shore.

Hospice North Shore provides palliative care for people living with a life ending illness and their families. Palliative care refers to specialist health care services for people with a life ending illness, and their families, that "aim to relieve and prevent suffering in the physical, psychological, social and spiritual domain" (Gaertner et al, 2015).

As I mainly meet with New Zealand Europeans, I am going to illustrate practice that addresses the influence of the dominant Western discourses that permeate many societies and impact on the work I am engaged with. However, our relationship with death is culturally constructed and I want to acknowledge that there are many cultural understandings that can shape a person's relationship with illness and death.

The stories I am going to share illustrate one way a counsellor might respond. They are not the only way to respond. However, my hope is that they will invite you to reflect on your practice and what you might do.

Deconstructing denial.

When a person's response to loss, illness and approaching death is constructed as "in denial" (Kubler-Ross, 1969), further inquiry about their actions and understandings is often shut down. Meaning is imposed and their response may be understood as "a problem to overcome" (Zimmermann, 2007). Judgements that cast a person as "in denial" foist the onus to change onto them, relinquishing those around them from the responsibility to pursue understanding their stance. The issue moves from being one between two people, to a problem one person has (Zimmermann, 2004). The values and experiences that are behind the person's stance remain obscured. At a time when a person is most needing of support they can be diminished and pathologized, robbed of dignity and disconnected from those people that are important to them. Distressed family members lose an opportunity to understand and be understood and there is a real possibility of families remaining fractured at a time when connection is what they wish for.

In the following story I am going to introduce you to Alan and Catherine. Alan had nearly died three times in the 2 months before I met him because he had refused to acknowledge life threatening symptoms of the cancer he was living with. He was also fighting for his life with





huge energy. Such seeming conflicting responses are common in this area of work. They often require a counsellor to traverse with a person, the spaces in-between (see Bird, 2000, p.23) their hopes, and what they value with tremendous care and skill. These conversations demand a commitment to look further than common explanations of a person's response, to persist in searching for what their reactions express, to hold compassion closely and respect closer still, remembering the ongoing traumatic context in which they are living.

The following is the first chapter of a story I wrote called "Travelling on the journey to death" (Pilkington, 2014). It illustrates how I might go about stepping into a conversation with someone and begin to co-evolve with them the meaning of their stance².

Travelling on the journey to death: A story illustrating narrative practice for counsellors. (Pilkington, 2014).

The rain battered the hospice roof. I could see it pelting down on the quarry that my office window overlooked. It had been a busy day for all of us in the hospice community team. I readjusted my gaze and looked down at the new referral sitting on my desk. Catherine had requested counselling because she and her husband, Alan, had been fighting for the past year. The referral described Alan as "in denial." "Whose description was that" had been my first thought. When I telephoned Catherine, she told me she was desperate for the fighting to stop so they could enjoy the last few months of Alan's life. Catherine said she wanted their three young children to have some time with their father, but all Alan did was work. "How does Alan feel about us talking about these concerns you have for the relationship?" I asked her.

Catherine told me Alan wanted to be at our initial meeting but hadn't decided if he would talk. He would just listen and then make up his mind whether he wanted to be part of the counselling or not. As Alan was extremely fatigued we agreed to meet at the family home. A few days later, I drove to Alan and Catherine's house, reflecting on the multiple intrusions families have endured in the health system before they begin to receive care from hospice. I respected Alan's caution about speaking to me. I would ask him about his concerns and address the "bystander" role as the conversation evolved.

FINDING A "WAY"

The inside of the house was in stark contrast to the luxury car parked in the driveway and the affluence of the surrounding area. It was unheated and the furnishings were oddly sparse for the size of the house. Alan sat there on the sofa, as if the weight of his concerns were pressing down on him. He looked shrunken and exhausted, at variance with the deep laughter lines running through his face. His face held no smile now. The yellow colour of his skin hinted at the cancer that had spread throughout his body. I had been warned by

² For another full story illustrating practice with someone who has been positioned as "in denial" see Pilkington, 2016.





Catherine that Alan would refuse to speak of the cancer. I wondered to myself how he had reached this conclusion and why. He would have good reasons for doing so. Catherine's welcome was tinged with apprehension as she asked me to take a seat. She sat on a chair well away from her husband and I moved to sit somewhere midway between them.

"When you were thinking about me coming today, did you have any thoughts about what might be useful for us to talk about?" I inquired, looking at Catherine.

Catherine glanced at Alan nervously. "We have been fighting all year," she explained, "ever since Alan got sick. I want to enjoy this time together but all he does is go and work in his office. He won't talk to me," she said, looking reproachfully at Alan. "I want to get on and do some fun things together with the children, but all we do is argue." Alan, whose restless movements suggested he was becoming increasingly agitated, chipped in, "We wouldn't argue if you were supportive."

Intending to sidestep any invitation to pass judgment on the dispute implicit in Alan's retort, I asked, "Would it be all right if I asked you some questions about your life before all this happened?" I waited. When they both gave a nod I began, "What was it that you enjoyed about each other before the illness came into your lives?" Smiling for a moment before answering, Catherine reminisced, "We were very happy. We've always been a close family. Alan is a great father. He has always been involved with the children. And, as a couple we have been friends, talked, you know. . . ." Catherine's voice petered out and she dolefully looked over at Alan. He remained silent and expressionless. I wondered if he had expected such a favourable description.

I proceeded on this track, uncertain as to where it might lead, "How might you like to be together as a couple, and as a family, at this time in your lives?" Catherine responded readily as if her answer carried with it some seemingly well-rehearsed thoughts: "I want to get on. I want to do things together, and talk. Be close, and share things like we used to." Alan's eyes were downcast as if he were studying the pattern on the carpet beneath his feet. "What do you think Alan's wishes for your time together might be?" I asked. Taking her time over her reply as she contemplated, Catherine, in a barely audible voice, finally said, "I don't know."

"From my experience of speaking to people, a serious illness often brings with it huge challenges that can strain even the strongest of relationships," I said. Intending to make known some of the effects the cancer might be having on their relationship, I then asked, "How would you say the illness has disrupted the way you want to be together?"

Alan, still bowed, now began to pick at the varnish that was peeling on the armrest. Catherine continued in her efforts to communicate to me some of what they had been going through. "We were devastated when Alan got his diagnosis. We were very stressed, tired. I wanted to talk about what was happening but he wouldn't. It's been endless appointments and visits to the hospital." As Catherine talked about all their efforts to rid Alan of the





cancer, Alan started to quietly chip in as if he couldn't help himself. As he started to do this more, I tentatively observed, "I notice you are sharing some of your thoughts, Alan." I broke off, before gently going on. "Would you like to join in the conversation fully, Alan? Or is it more useful to continue from the sidelines as you are?" I paused, not wanting to impose on him. "I don't want you to find yourself talking just for my benefit."

I know the people I meet are often generous to me in this regard, or perhaps feel unable to say what they want. I didn't want him to regret speaking or to come to the end of our conversation without it having been what he wanted it to be.

Alan looked me in the eye. Then, in a voice that held surprising firmness, stated, "I want to talk. Then you can hear my point of view."

Again, I was as tentative as my tone of voice would allow. "Would it be all right if I asked you about your experience of living with this illness, Alan?" I wasn't ready for the enthusiastic response I received. "Living with it!" he exclaimed. "Now that's more like it! Everyone is always. . . . The way they talk to me! But I'm going to fight. I'm going to fight this thing and never give up!"

At times taking a fighting stance can be problematic for people living with terminal illnesses (Harrington, 2012), as it leads to a binary (Bird, 2004) of "winning" or "losing." However, I respected the position Alan had taken up as it was obviously meaningful for him and may have been well thought out. Aware we still hadn't agreed on a name for what he was fighting, I asked "How do you go about this fighting of yours, Alan?"

"Well, they won't give me any more chemo." He hesitated. "I am having vitamin C infusions twice a week. My brother offered to pay for them." Pink colour spread over his face, and he started to pick at the varnish again. "I do all I can." His head dropped, as if he were surrendering something.

"Could you help me to fully understand what you are fighting for?"

In a quavering voice Alan replied, "I am doing all I can to live. I have to live." Alan's voice shook with what sounded like fear as he continued to speak. "Being sick, it has taken everything from me. You know we had to leave our house. We're renting here, though we are going to have to move. To think that I would be in a position of not being able to pay . . . the bills, they just kept coming and I kept thinking I could find a way. I used to earn a lot of money. Did you see my car in the driveway? But now. . . ." Catherine chimed in, "Alan is still doing what he can, though I keep telling him to leave it. He spends all his time in his office pouring over the accounts and doing some work for his old company. He won't let it go. It's all he ever does. He barely spends any time with me and the children. . . ." As her voice became accusatory in tone, she seemed to catch herself and quickly trailed off.

"What is important to you about the work that you return to it, Alan?" I inquired.





"I have to find a way," he said with some urgency.

"What "way" are you looking for?" I asked.

There was a long silence, which Alan finally broke. "A way for them to be okay," he whispered, releasing a long slow breath, and nodding over to where Catherine was sitting. Catherine was startled. She opened her mouth to speak, but Alan continued, fear and desperation in his lowered voice now: "I can't afford to die and leave them like this. I can't afford to die."

I listened to the yearning he had to care for his family.

"So when you retire to your office, what are your hopes for your work?" I asked quietly. "I'm working to try and find some money for them," Alan anxiously replied.

Catherine started to cry silently, the tears sliding down her face freely as if they already knew the way.

"My family are important to me." Alan looked at Catherine for the first time since the conversation began, tenderness in his eyes. Catherine, returning his gaze, rose from her seat, and moved to sit beside him.

We were interrupted by the sound of a child. Their 3-year-old son, Robbie, had woken. Catherine got up and brought him into the room. Without paying his father any attention, he looked at me with interest, before settling down to play beside Catherine. We had stretched everyone's attention and in particular Alan's energy about as far as I thought prudent.

"How has this conversation been going?" I asked them. "Have we talked about the matters you hoped we might, or is there something we have missed?"

"It's been good," Catherine answered. Alan cut in across her, "Better than I thought."

"Is this a good place to stop?" I asked "or is there something else we might speak about today?"

They both agreed there was nothing further for today. "What are your thoughts about meeting up again?" I asked them. They quickly requested another meeting for the following week.





Deconstructing Denial

You may be wondering what influenced Alan to take up such a strong fighting stance and how he came to be positioned as “in denial”.

To consider therapeutic practice with people who are dying, and their families, it is important that we understand how the notion of denial is constructed, if we are to avoid reproducing ideas that pathologize people in the counselling room (Hare-Mustin, 1994).

Western discourses of death have changed shape over time. In modern Western society, dominant discourses of death centre on our increasing faith in science and the progress of modern medicine (Powell, 2011) in its stated journey to “find a cure”. Death is positioned as something to be fought (Powell, 2011) and cancer as a problem to be solved (Willig, 2011). Discourse prescribes “fighting” (Harrington, 2012) disease, evoking a binary position (see Bird, 2004) of winning or losing which is problematic for those people living with a terminal illness. In addition, dominant discourse insists on thinking positively (Willig, 2011) closing down space for people to talk about suffering and their mortality and may have them engaging in aggressive treatment till the end of their life.

In palliative care, discourse has arisen that contradicts the wider social discourse about death. Death is accepted as part of life and is discussed openly. There is a focus on quality of life rather than cure. People receiving treatment in palliative care are engaged in conversations concerning symptom management (Zimmermann, 2007) of, for example, pain, as part of their care. They are invited to participate in advanced care planning so their wishes can be respected concerning how they want to die. From a person’s earliest contact, when a consent form is given to them, open discussion about approaching death is present and is often seen as necessary, in order for someone to have a “good death” (Saclier, 1998; Smith, 2000), though what constitutes “a good death” is being challenged (Clarke, 2002).

Once a person receives the news they are going to die the wider social discourse and the palliative care discourse collide. On the one hand people receive a message that they must take a stand to resist the illness and on the other they are quickly required to consider and discuss dying. Those people who maintain a stance where they continue to “think positively” or resist speaking about dying in the manner or at the time another person requires it, may be positioned as “in denial” (Zimmermann, 2007). In addition, denial may be applied to a person when their actions are interpreted as a hopeless attempt to prolong life, such as when a caregiver feeds someone who is seriously ill. Denial is also a description a person may apply to themselves when they have no alternative discourse available with which to describe not wanting to openly talk about death.

Narrative therapy (White & Epston, 1990) offers a therapeutic alternative to labelling people as “in denial”. It uses practices that privilege a person’s desired relationship with dying while honouring what is important to them in their life.





Let us now reflect back on the conversation with Alan and Catherine, and consider how my understanding of narrative therapy ideas influenced what unfolded.

When meeting with people such as Alan, their dignity is foremost in my mind. I carry with me a sense of our shared humanity, and recognition of the reciprocity in the relationship. Alan gave me a priceless gift when he bared himself and shared his experience. As I positioned myself in the conversation I wanted to honour Alan's efforts towards his life and those he loved. To do so, I was listening for virtue in his intentions. I understood the context of the conversation as a crisis where every aspect of Alan's life may have been disrupted. I was also aware that there may have been no opportunity for Alan and Catherine to talk fully about their experience. Stories such as theirs are usually untold.

When Michael White wrote about attending to trauma, he described psychological pain, "as testimony to the violation of what a person holds precious (2005, p.19)". White (2005) went on to say how day-to-day distress could be considered a tribute to a person's ability, to maintain a relationship, with what they hold precious. Such understanding, directs inquiries towards fully understanding how a person pays tribute and to exploring what is treasured in their life that the illness is threatening.

In my conversation with Alan this was reflected in me asking questions to develop a shared new understanding of how he went about the fighting, and what it represented. We were then able to research what was cherished by Alan that had been violated.

Alan's unfailing dedication to his work, in spite of being seriously ill, was shown to represent a daily tribute of love towards his family. Once this new co-evolved meaning was brought forth Alan could then weigh up the new knowledge of how he was responding to the illness, with how he wanted to show his love for his family. The new shared understandings led us to the possibility of exploring the questions:

- Do Alan's responses reflect, or contradict, what is important to him? And, are his responses the way he would most like to express what he values?

We could then follow through with exploring the implications for his life and how he lived it.

Therapeutic conversations that create space in which a person comes to understand what is behind their response and allow family members access to their good intentions can be very powerful in restoring dignity, accessing love and inviting reconnection of relationships. Let me illustrate this point further.

Restoring Dignity and Connection

The following conversation occurred in the first meeting with an extended family in a story I wrote called "Antidotes to pathologizing ideas" (Pilkington, 2016). Jane had approached me





and requested I meet with her family as they had never spoken about the cancer she had been living with, though she had been unwell for a number of years. Jane was in the last few months of her life and desperately worried about her partner Andrew, and teenage daughter Alice, whom the family understood to be “in denial”. Jane wanted to talk about her illness and dying but they refused to do so. There was enormous tension in the room with family members well aware that they were considered to be “doing it wrong”.

In contrast to beginning by talking about what Jane was worried about, I had began with an inquiry highlighting the family’s commitment to be there to support Jane, even though most of them would have rather not come (see Epston, 2010; 2016). Having heard a little of each person’s loving intentions towards Jane, and noting their generosity in being there, we began to approach Jane’s desire for the family to talk, and belief that it would be better to do so. What follows is a brief snippet of dialogue that occurred 25 minutes into the conversation. I was still moving slowly and carefully, mindful of multiple marginalisation’s this family had been subjected to and wanting to respect each person’s position (See Pilkington, 2016, Antidotes to pathologizing ideas: A story illustrating narrative counselling practice with someone approaching death).

...Andrew, Jane’s husband remained hunched in his dark corner. He had barely moved since I had entered the room. His eyes now stared at the wall as if he was willing me to pass him by. As gently as I was able, I asked, “Andrew, do you have any thoughts you think might be helpful for us to talk about today?”

“No” was his quiet reply.

Andrew gathered himself and looked at me, “The thing is, I don’t believe in emotions”, he pronounced.

I nodded attentively. Then, with as much respect as I could put into my voice I asked, “Would it be OK to ask how you like to do it?”

Andrew uncurled his body looking a little startled.

“I think about things a bit... when I feel like it” he stuttered.

“Would you say you are a thinker?” I checked, offering a possible name for his style, but also to make it clear I wasn’t pathologizing his position.

“Yeah, I’d say that” he concluded.

I noticed his eyes were no longer directed at the wall but now followed the conversation.

As Andrew seemed finished for the moment I stored the new information away intending to return to it at a later point, and turned to Alice. Before I could say anything Alice shook her head. She was still unable to speak a word. Distress seemed to silently pour out of her bowed reddened face.

“Alice and me, we’re in denial”, Andrew explained from the corner.





I wondered if they had been criticised for their stand.

"I find people mean different things when they talk about the idea of denial. Could you help me to understand what you mean when you say you're in denial?" I asked evenly.

He nodded, but before we could go further, Alice stood up and moved to sit on the backdoor step adjoining the room. She immediately lit a cigarette and turned her back to us. Her grandmother Violet jumped up and told her to come back, however I intervened.

I saw Alice could easily hear us, but didn't want to talk, and not wanting to impose on her I said, "Its fine. Alice can stay there and listen or come back if she wants too. These conversations can be very tough and we all respond differently".

"Alice and I are in denial", Andrew confirmed again. "We put our heads in the sand."

"Could you explain to me how you go about putting your heads in the sand?" I asked him curiously.

Andrew paused, allowing me to catch a glimpse of Alice listening intently on the step.

"I don't think about it. I've still gotta work, doesn't do any good dwelling on Jane having cancer. I wouldn't be any use to anyone", he answered me steadily.

"How has it helped you live with this?" I replied, intending to offer validity to the way they had responded to their experience, yet not wanting to impose a name on what "this" was.

"...Meant I could get on with things, carry on. Still gotta make myself useful. There are still bills to be paid", Andrew answered quietly, seeming to chew the idea over.

"May I ask, what is important to you that you carry on and try to be of use?"

Before Andrew could answer Violet interrupted, "He's had a tough life. He doesn't talk about it".

Ignoring this comment, Andrew began to slowly answer, "First time I've been happy....being with Jane...wanted to hang on to it...look after her."

Andrew sat back in his chair, withdrawing into his dark corner. Surprise sat on every face. We all sat for a moment in silence. Jane had only eyes for Andrew. Later, I would hear how rare this verbal expression of love was.

Listening for Virtue

When people have been positioned as "in denial", listening for and identifying "moral virtue" can reveal attributes that may directly contradict the pathologizing story. Moral virtue according to Epston (2015) refers to Aristotelian representations of goodness; courage, justice, kindness, gentleness and wisdom.





In a family where someone is dying, identifying and thickening the narrative (White, 2007) of people acting with virtue can hold immense significance in meaning making. Gathering such stories can reconnect family members and sustain people through the challenges loss and illness may present.

However, in people who have been positioned as “in denial” virtue is often rendered invisible. To make matters harder, as they defend what is important to them against the multiple intrusions that usually occur, they may become angry or react in ways they would rather not. They then have to contend with the losses in their life and the idea they are behaving badly.

An inquiry can create a new lens through which a person can understand their responses. Shame can be replaced with understanding or even pride in what they are protecting. At the same time, revealing the previously hidden purposes of anger, can allow a person to then articulate more clearly, what it is they need, and allow them to respond in ways that honour what they value. Let me illustrate what I mean.

A small hope: A story illustrating Narrative Therapy

I was on my way to a first meeting with Joe and Andrea. Joe was in the last weeks of his life and Andrea, I had been told, was refusing to speak about the possibility of his death. She instructed all health professionals that she only wanted to hear positive news about Joe’s physical condition.

As I drove to the house I reflected on how suddenly and recently Joe and Andrea had been catapulted into news that Joe’s illness couldn’t be cured. For this young couple with 6 year old twin boys it was completely unexpected.

Early in our first meeting I began “Cancer has a way of taking over people’s lives. Would it be OK if I asked you a bit about yourselves and your life before all this happened?” I turned my head towards Joe, who smiled and began to tell me about himself. Andrea had a big reaction to this question making it very clear that she liked being asked who they were aside from the cancer. This question began an inquiry which revealed their love for each other and dedication to the environment. After such a warm beginning we then went on to discuss, quite naturally, how they preferred to live with the cancer. “What do you give weight to in the day as you live with this cancer?” I asked them. Andrea confided that she was afraid that their twin boys would forget their Dad. It was the first acknowledgement of Joe’s approaching death though death was not named. This confidence provided an entryway into us discussing what was important to them that they wanted to be remembered. Together we devised a family charter of values so the boys could know what was important to them as a family being sure to name Joe’s beliefs and hopes.

During the course of the week I heard that Andrea had become angry with any assessment of Joe’s symptoms. Joe’s condition continued to deteriorate and it became evident to the hospice team he was actively dying. It would perhaps be easy for Andrea to be seen as “in denial” and as an “angry person” but inquiry provided a more useful description.





In contrast to these reports, when I arrived Andrea was bright, and told me it had been “a better week”. As Joe was too sick to talk we spoke on our own.

“When you look back on the last week do you have some ideas about what has contributed to this week being better?” I asked using her words.

“I’ve stopped looking ahead” Andrea replied.

I responded tentatively, “May I ask, where do you look when you’re not looking ahead?”

Andrea answered me initially seeming to seek reassurance.

“No one can know exactly what’s going to happen, can they? Now I only think about today and I have some hope” she added.

“Could you help me to understand a little of what this hope is to you?” I inquired. Andrea paused bowing her head.

“It is only a small hope” she said in a little voice as if confessing something. “...To be with Joe, for another day or maybe even a few days.” Andrea looked down again her eyes gleaming with tears. For a moment we sat quietly.

Moved by her humble hope I went on “May I ask what difference this small hope makes to you?”

“It means I’m not crying all the time. I sat by the window and told Joe what I saw outside. We spent some time talking quietly together once the boys were at school. I made him a little something for lunch and we sat together. He told me being together like that was perfect, and he has never said that before.”

“As you look out the window describing what you see to Joe, what does this small hope do, that has Joe finding your time together perfect?”

“I can enjoy the moment and he feels that. It helps me forget what is coming” Andrea explained.

“When you spend these moments that the small hope has given you, what has been made possible, that wasn’t there in the week before?” I asked her as I knew that the week before had been distressing for both of them.

“Close time together. Before we were only fighting we were so stressed” was her reply. Andrea and Joe had spoken about the impact of the stress and its effects with me in our first meeting. Rather than returning to it I responded, “How did you come to find closeness in sharing the view from the window and talking and bringing Joe food?”

Andrea told me with eagerness now edging into her voice “It’s what we’ve always done together, enjoyed the simple things. We like to do those things that money can’t buy”. Andrea continued telling me stories that illustrated what she had said.





“How would you describe the qualities you experience in your relationship in those enjoyable times?” I asked her.

“We are best friends. We have always done everything together” Andrea told me before enlarging on their shared parenting beliefs.

“What else do you do in the day that speaks to the closeness you share as a couple and as parents together and brings you closer to Joe?” I wondered.

“Gardening,” Andrea readily answered, “I feel close to him when I do his vegetable garden and I will keep doing it. I just couldn’t do it before. I was too shocked. Now I have some hope and it gets me through the day”.

“How important is this hope in keeping you close to Joe and getting through the day?” I asked her.

Firmness was in her voice as she stated, “Very, very important. It means I can enjoy some time with Joe and that is the most important thing to me. The time is so precious. And I don’t want to cry every minute”.

It is now easy to see why Andrea might protect the small hope that was helping her savour time with her dying husband. It is by no means a denial of approaching death but rather an embracing of what was most important to her, close time with Joe before he died.

Creating Space for Silenced Stories

As practitioners we know that therapeutic practice embraces complexity and the shades of everyday life. Clean lines and binary thinking are replaced by the “somewhat” and the “both and”. Every story a person tells us has the potential to turn any assumptions or previous understandings we hold upside down, and they often contain more beauty, than we could ever envisage ourselves. With this in mind I want to share with you a final story.

This story illustrates how I might support a couple in their preferred relationship with illness and death where they do not want to openly talk about dying. Such a preference is difficult to hold. People who are seriously ill are given regular injections of information about their health’s deterioration through symptoms, hospital appointments and in their contact with health professionals.

For people not wanting to think about dying, such overwhelming unwanted information can shut conversations down as they defend their position, leaving little room to talk about matters that may be distressing for them. Rather than label people as in denial, let me show you the space that can be created by privileging a person’s own way of talking about their experience.





A loss of faith: A story illustrating Narrative Therapy with someone approaching death.

I picked up the phone one busy afternoon. I had been asked to ring a young woman called Marie. The hospice team had requested that I speak to her urgently, as her partner Andy was very close to death.

“Sasha, I was wondering if I could see you” she said from the other end of the telephone sounding agitated. “I feel so guilty. I’m a failure as a partner. You see, I have lost the faith.”

“Could you help me to understand a little of what this faith is that you have lost?” I responded somewhat surprised by her candour.

“That he’s going to be cured. I keep trying but I just can’t be positive for Andy and keep believing” was Marie’s reply. I could hear her begin to weep with shame on the other end of the phone.

“Would it be OK to ask how you came to lose this belief that he was going to be cured?” I responded when she had quietened.

“He is so sick. He can barely get out of bed. I feel so guilty. I’m letting him down” Marie told me.

We talked a little more and then began to arrange getting together.

“Where would you like to meet?” I asked her. Normally I visit people who are seriously ill at home but I didn’t want to presume.

“It will have to be home as I can’t leave Andy anymore” she replied.

“What will Andy make of me coming?” I checked not wanting to impose on him.

Marie was clear, “He’s OK with it. He said he’d be there to support me but you mustn’t say anything about dying to him. Andy won’t talk about that. We are focused on being positive and getting him better.”

I noted Andy’s care of Marie and his willingness to risk a conversation that could be uncomfortable for him so he could support her. Andy had no way of knowing I would support his chosen stance.

With Marie and Andy

I knocked on a brightly coloured door surrounded by flowers. The door opened, and as I took a step forward, two young girls flew out dressed in fairy costumes. They were followed closely by an older woman, whom I imagined might have been their grandmother. “You must be Sasha” she immediately said, “go on upstairs, they are waiting for you”.

I walked up a light airy staircase calling out “Hellooo.....Hellooo....it’s Sasha”. Marie came out of a door at the top of the stairs to meet me. “Come on up. We’re in here. Andy is just in the bathroom”. I paused at the top of the stairs, and hesitated, not wanting to intrude. Marie





welcomed me into the room again just as Andy emerged. When he saw me standing in the hallway he immediately mumbled, “not much privacy when you’re sick, is there”.

“No indeed. I am sorry. It can be quite an invasion”. Marie beckoned me in, but I remained hesitant. “Would you like to talk here in the bedroom or is there somewhere else you’d rather go?” I asked, looking at Andy. “You’d better come in here” Andy replied curtly. Andy climbed back into bed slowly. Each of his legs moved as if attached to a heavy weight. Marie offered him an arm but he brushed it aside. Andy’s skin was a bright yellow colour that announced a liver overwhelmed with its bodily tasks. It was easy to see he had recently been a strong and fit man in muscles that had been well used, though they could barely support him now. I wondered how he managed such disability at 32 years of age.

We sat down on the bed as he indicated we should. In this intimate space we exchanged some greetings.

“Thank you for seeing me. It’s lovely to finally meet you in person Marie” I began warmly. “How kind of you to see me” I said turning to Andy, remembering Marie’s comment on the phone.

“He’s always very supportive of me” Marie immediately said.

“It’s the least I could do with all she is doing for me” Andy responded stony faced.

I began tentatively, “Would it be Ok to ask you a little bit about your lives before all this happened?” My hand in the air spoke for me as I indicated the illness because we hadn’t agreed on what “this” was.

Marie began to tell me about herself following this invitation and I heard how she was a successful personal assistant, good at organising and managing people.

Andy looked surprised by my question, “I was a welder before I got cancer”. He paused before adding, “Look I’m not any good at talking. I can’t express myself in words. Marie’s the one for that”. He lay back on his pillows shutting his eyes for a moment.

I discovered a little bit more about their jobs before asking them how they spent their spare time. When they had described the outdoor activities they enjoyed Andy began to join in the conversation a little more.

I then began to approach more personal areas of their lives. “Would it be OK to ask how you two met?”

I looked over at Marie.

“Through mutual friends...we were at a party. He came over to me towards the end of the night and just started talking to me” Marie explained.

I turned towards Andy, “may I ask what it was that drew you over to Marie? What made you think she might be worth talking too?” I smiled warmly at him.





"She's such a beautiful kind person" he answered me somewhat gruffly. I risked another question, "Would it be OK to ask how you knew she was kind from over the other side of the room? Was it in her eyes or was there something she did that communicated her kindness...?"

Marie perked up looking at Andy with curiosity.

Andy somewhat bashfully responded, "Well err, I was actually watching her all night"... He glanced at Marie before continuing. "... And I noticed that she talked to this guy in the corner who no one wanted to hang out with and then later there was a bloke beginning to make a fool of himself and she told a joke and diverted attention. I'm pretty sure she stopped everyone thinking he was an idiot actually....and I thought "I've just got to meet this woman" so I went up to her....and well, she was just lovely. But I'm no good at this sort of thing. I can't express my feelings."

"I never knew all that!" exclaimed Marie. "Sure you did" Andy retorted.

"Was there anything in the way Andy crossed the room to talk to you, Marie, that made you think he might have seen your kindness?"

"Actually I couldn't believe that he would talk to me. Andy is so charismatic and everyone likes him" she responded while Andy stared silently at her but remained expressionless.

"Did you see yourself differently in that moment when he picked you out to talk to?" I asked her. A small smile crept onto Marie's lips and I caught Andy looking at her with attention. His face softened.

"He's always made me feel special, though we are totally different. People love Andy and want to be around him whereas I'm more of an "in the background" kind of person".

Andy interrupted gently, "She's the organiser, the planner, the one who makes things happen and she can get close to people. I'm no good at that intimate talking stuff".

I noticed Andy's willingness to speak well of Marie even though he said he found talking difficult.

"We are a team. You make people happy and laugh. Everyone loves you" Marie cut in smiling at him.

"What does Andy do that has everyone loving him?" I asked her.

"He's incredibly loyal to his friends. He looks after the people who are close to him, I mean really looks after them. My parents live with us, and, he takes care of all his family." She looked towards Andy and for a moment I thought I saw the gleam of tears in her eyes.

"Do you mind me asking how Andy shows that care and loyalty towards you?"

As Marie hesitated Andy answered, "It's not just me. We all rely on you to make things work." Andy turned to look at me with expectant attention as if seeking my backing.





However, before I could reply he added, "I just wish I'd been able to tell her what I feel more".

He looked downcast for the first time as the conversation took on a new tone.

Carefully I responded, "May I ask, what you wish you could have said if you'd been able".

"I would have told her what she meant to me" he answered seeming to force the words out.

I reflected that my question may have been too broad and tried to cut it down a size or two,

"Is there a particular time when you would have told Marie what she meant to you if you could have?" I asked him.

"The way she stuck by me when my parents died. And then when it was tough at work and I was a bit of a...well you get the picture. She was on my side always. And then the way she organised our holidays. We've travelled a lot together and she made all this wonderful stuff happen. I've always been able to count on her. She means a lot" he managed to utter.

"What difference has it made to you to have Marie at your side and to know you could count on her?" I asked wanting to give him a chance to express his appreciation of Marie in her presence.

"Well it meant I could get on and do my thing and there she would be kind of organising things behind the scenes, making things work. I wouldn't have been able to support the people I love if it hadn't been for her. She is incredibly kind and generous. I was right about her from the start." Andy looked pleased with himself.

Marie chimed in, "We are a team".

"Would you be willing to tell me a bit about this team-ness? Do you have any stories of you being a team together?"

Marie took the lead and began to share some of the precious times they had spent together. Andy then told a story of his own about a travel adventure they had shared. It was rich and full in spite of Andy's assertion he wasn't able to express himself. I pursued stories of appreciation and they both spoke of their love and value for each other.

Andy finally remarked, "Not that I can travel now I've got cancer."

"Andy may I ask how you go about living with cancer?"

"I look after my health. I'm not into pills and artificial stuff. I've always been very positive. I don't believe in looking ahead. I just live moment by moment."

"What part of your life would you say you are prioritising as you live moment by moment?"

"Time with Marie and the girls I guess" he replied.





"How did you come to decide to live moment by moment rather than letting the cancer take over your life?" I then inquired.

"I still wanted to be a husband and father and live my life. I wasn't going to give in to it. I admit it's challenging at times" he told me.

"When this way of living is challenged, may I ask what you do to reconnect with it?" I asked.

"Marie helps me and I believe. I know I lose the plot sometimes. It's like a bit of metal, if you bend it enough it breaks. But I'm a welder, and I know metal can be welded together again. So I just move on and put myself back together"

I was fascinated by his reply. However, as Andy spoke Marie's eyebrows drew together and her foot started tapping on the floor. She then exclaimed, "I do believe but I also worry about how I might manage. I don't know how I would cope with the girls and looking after my parents. I can't help it, I keep worrying. I'm so sorry Andy... I'm worried I'm losing the faith". Marie began to cry.

Andy looked uncomfortable and concerned for her. He tried to wriggle closer to Marie but weakness prevented that. He then attempted to cover up his inability to move in the bed so, concerned for his dignity, I offered a distraction in the form of a question.

"Do you mind if I ask you some questions about this?"

Marie nodded.

"Would it be OK with you Andy?"

Andy with a rueful smile said, "Sure", and in that moment I gathered he knew what I had done and was perhaps grateful.

"Could you help me to understand a little of what this faith is to you both?" I asked. I steered away from asking about the nature of the faith as I didn't want to take Andy down paths he didn't want to travel, even though I recognised Marie had alluded to him dying indirectly.

"It keeps me going. A good attitude is essential. The diet and the special supplements I am taking are making a big difference. I believe in myself" Andy answered and turned to Marie.

"We have believed all along in him and it has got us this far" Marie told me. "I'm letting him down....losing faith". She looked like she might cry again.

Rather than pursue further what Andy meant by a good attitude and believing in himself I decided to inquire into what was distressing Marie, "Could you help me understand this experience of losing the faith?" I asked her.

"It makes me feel so bad...a failure. I want to keep the faith but stuff that is coming up worries me and I start to think ahead" she explained.





“What is important to you that is reflected in this desire to keep the faith?”

“I want Andy to know I believe in him. Support him... So I know I’ve done everything possible” Marie and Andy looked at each other. Andy softly spoke to Marie,

“You are, love. I know you believe in me. We are just different people. And you are looking after the girls, your parents and me. Making sure we are all Ok.” I noted that he had spoken of the faith as believing in him rather than in his getting well.

Andy reached out for Marie’s hand.

“What do you believe in about Andy?” I asked turning to Marie.

“That if anyone can do it he can, he will do everything that’s possible”. We were speaking about the possibility of Andy dying and I noted he appeared calm. Marie added, “I’ll be here looking after him and the girls no matter what.”

“How do you go about looking after Andy and the girls?” I inquired.

It was Andy who answered, “She organises all my treatments, food and appointments. She’s making sure everyone is going to be OK and I appreciate that”.

Marie looked grateful for this interruption so I continued, “Andy, what does it mean for you, that Marie is taking care of everyone?”

Andy paused looking thoughtful, “Actually, it means I don’t have to worry. It means I can be in the moment. Marie is the planner. It saves me worrying about the family and day to day stuff so I can concentrate on my health.” I noticed Marie began to look a little brighter.

“Marie, may I ask, does taking care of the future and making sure everyone is Ok mean you have lost faith in Andy?”

Marie almost stood up as she exclaimed, “No! I’ve just realised. I haven’t lost the faith and given up on Andy. I am just planning and looking after everyone like I always do!” She laughed and Andy returned her smile. “See love, I told you, we were OK. Someone’s got to do it” he reassured.

I couldn’t help but grin. Marie was way ahead of me!

“If you were to hold on to this recognition that you are planning, and taking care of other people, rather than not believing in Andy, what difference might it make to the way you think about yourself when you fear for the future?” I asked still catching up.

Marie became buoyant. “All the difference! I just need to remember I’m looking after them” she exclaimed. Her relief was palpable.

“What could Andy do to support you in this remembering... so you keep this knowledge in the forefront of your mind?” I continued however Marie changed our direction.

“Andy, you could help practically. Will you speak to Dad about moving?” she replied.





“Sure” he grunted willingly.

“When will you do it?” Marie persisted.

When they agreed that it would have to be that evening or the following at the latest it became clear to me they were now acknowledging that Andy had little time left alive, though death was not openly canvassed.

I could see Andy was tiring and began to bring the conversation to a close.

Andy died 5 days later. When I met with Marie after his death she told me “When I look back I will always treasure those last weeks. We did all we could. In spite of everything, we kept believing till the very end”.

Marie and Andy had preserved the way they wanted to live by not speaking openly about dying (Frank, 1995). I chose to uphold and respect their wishes, making it possible for a conversation to unfold.

Beyond the Veil of Denial

When we cast aside prescriptions of a right way to die we create the possibility of a space to be alongside a family as they contend with some of the struggles that may accompany approaching death.

The stories in this paper illustrate some of the alternatives Narrative Therapy offers to labelling someone as “in denial”. They show how people can be supported and find new meanings in their preferred relationship with loss, illness and death.

When we focus our energy on entering another person’s world with curiosity, bending our attention persistently and compassionately towards trying to understand their experience, we cast aside the veil of denial, and enter a realm of many possibilities.

We may find there loss and suffering, but also more love and virtue than we dreamed was possible. We may find creativity, and the extraordinary in the everyday, or we may be called on to witness distress, and paradoxes that challenge us. However, when we meet people in this realm of their creation, we can join with them; to find chinks of light in dark places, give voice to silenced stories and maybe, find solace in love.





References

- Bird, J. (2000). *The heart's narrative: Therapy and navigating life's contradictions*. Auckland, New Zealand: Edge Press.
- Bird, J. (2004). *Talk that Sings: Therapy in a new linguistic key*. Auckland, New Zealand: Edge Press.
- Clark, D. (2002). Between hope and acceptance: The medicalisation of dying. *British Medical Journal*, 324, 905-7.
- Epston, D. (2015). Unpublished untitled plenary address, Therapeutic Conversations 12, Vancouver, April.
- Epston, D. (2016). In pursuit of children's virtues: The wonderfulness interview. In D. Marsten, D. Epston, & L. Markham (Eds.). *Narrative therapy in wonderland: Connecting with children's imaginations and knowhow (pp27-48)*. New York: Norton.
- Epston, D. & Marsten, D. (2010). 'What doesn't the problem know about your son or daughter?': Providing the conditions for the restoration of a family's dignity. *The International Journal of Narrative Therapy and Community Work*, 1, 30-36.
- Frank, A. (1995). *The wounded storyteller: Body, illness, and ethics*. Chicago: Chicago Press 2nd edition
- Gaertner, J., Waldemar, S., Antes, G., Meerpohl, J., Xander, C., Schwarzer, G., Stock, S. & Becker, G. (2015). Specialist palliative care services for adults with advanced incurable illness in hospital, hospice or community settings – protocol for systemic review. *Systematic Reviews*, 4, 123.
- Hare-Mustin, R. (1994). Discourses in the mirrored room: A postmodern analysis of therapy. *Family Process*, 33, 19-34.
- Harrington, K. (2012). The use of metaphor in discourse about cancer: A review of the literature. *Clinical Journal of Oncology Nursing*, 16, 408- 412.
- Kubler-Ross, E. (1969). *On death and dying*. New York, NY: The Macmillan Company.
- Pilkington, S. (2014). Traveling on the journey to death: A story illustrating narrative practice for counselors. *Journal of Systemic Therapies*, 33, 79-93.
- Pilkington, S. (2016). Stories of narrative practice in palliative care. Unpublished Master's Research Portfolio. University of Auckland.





- Pilkington, S. (2016). Insurance policies for miracle cures: A story illustrating narrative practice with someone approaching death. *Journal of Systemic Therapies*, 35, 71-87.
- Powell, J. (2011). Foucault, discourses of death, and institutional power. *Illness, Crisis & Loss*, 19, 351-361.
- Saclier, A.L. (1976) Good death: responsible choice in a changing society, *Australian and NewZealand Journal of Psychiatry*, 10, 1, 3–6.
- Smith, R. (2000) A good death. An important aim for health services and for us all, *British Medical Journal*, 320, 7228, 129–30.
- White, M. (2005). *Workshop notes*. Retrieved from www.dulwichcentre.com.au/michael-white-workshop-notes.pdf
- White, M. (2007). *Maps of narrative practice*. New York: W. W. Norton.
- White, M. & Epston, D. (1990). *Narrative means to therapeutic ends*. Adelaide Australia: Dulwich Centre Publications.
- Willig, C. (2011). Cancer diagnosis as discursive capture: Phenomenological repercussions of being positioned within dominant constructions of cancer. *Social Science & Medicine*, 73, 897-903.
- Zimmermann, C. (2004). Denial of impending death: A discourse analysis of the palliative care literature. *Social Science & Medicine*, 59, 1769-1780.
- Zimmermann, C. (2007). Death denial: Obstacle or instrument for palliative care? An analysis of clinical literature. *Sociology of Health & Illness*, 29, 297-314.

