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About This Release

We are pleased to tell you of this most recent release of the Journal of Contemporary Narrative Therapy. We highlight two lengthy case stories, one by Sasha Pilkington and another by Kay Ingamells. Sasha was the editor of a previous special release of the journal on death and dying and if you have not read it, I recommend you return to Release 1, 2021 and in particular, Sasha's 'Narrative Therapy with Someone Expecting Significant Loss and Grief: An Illustration with Reflections on Practice, 58-97. especially if you work in palliative care of assisted dying as she does.

Kay's story, entitled 'Wrapped in Care: Narrative Therapy in the Time of Covid' begins: "My nana died from Covid. She died four months ago. I am still crying every day. I'm not getting over it." To my way of thinking, this is one of the most poignant exemplars of Narrative Therapy of a loved one dying under the limiting circumstances of a lock down here in New Zealand.

Sasha's case story, 'Deciding how to Die: Narrative Therapy in palliative care with someone considering stopping dialysis,' begins:

"The referral in front of me had "urgent" written across it in large letters. It was from one of the community nurses at the hospice where I worked.

"Please would you see Mr Fionn Williams as soon as possible. He has end stage kidney disease and is having dialysis three times a week. Fionn is being cared for at home by his son Liam, and Liam's partner Pete. Every week Fionn decides to stop dialysis only to change his mind at the last minute. This has been going on for months and he and his family are very distressed. Fionn describes himself as "tortured" by his indecision. Dr White has discussed stopping dialysis with Fionn and his family a number of times. Fionn knows he doesn't have long to live and his quality of life is very poor, however his indecision continues. Fionn has refused counselling support every time it has been offered but yesterday, he changed his mind. His family are relieved he has accepted counselling and are waiting for your call."

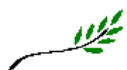
This poignant story is wonderfully augmented in two distinctive ways. Firstly, although Sasha has written it so it can be read without interruption as a story, she has footnoted in considerable detail at every turn of her thinking which then allows for a second stop-and-start





reading. I recommend you approach 'Deciding how to Die, etc' in such a fashion. As well, the eminent scholar/activist/bio-ethicist, Arthur Frank, has added a commentary given Sasha had referenced his theorising of 'rightness' in choosing one's death as compared to moral logic. Art is Professor Emeritus of Sociology at the University of Calgary and currently lecturer in the legendary 'Narrative Medicine' programme at Columbia University(New York). No one I know has closer connections to Narrative Therapy theoretically than Art, especially in his career-long considerations of personal narratives as counter-stories to the medicalisation of the lives of cancer sufferers. See for example A.W. Frank, *At the Will of the Body: Reflections on Illness*(1991; 2002); *The Renewal of Generosity: Illness, Medicine and How to Live*(2004), and most importantly, *The Wounded Storyteller: Body, Illness, and Ethics*(1995; 2013). I also recommend Art's earlier paper, *Notes on Socio-Narratology and Narrative Therapy*, *Journal of Narrative Family Therapy* (now known as *Contemporary Narrative Therapy*), Release 2, 2018, 3-19. As well Kay and Sasha's papers extend upon the special release of the *Journal of Contemporary Narrative Therapy*, 2021 Sasha edited including her paper, *Narrative Therapy with Someone Expecting Significant Loss and Grief: An Illustration with Reflections on Practice*, 58-97. I recommend this paper to be read alongside her above-mentioned paper.

This Release introduces what we hope to be a regular feature: autobiographical accounts of Narrative Therapy veterans and those retiring who were there at the beginning of Narrative Therapy and might be considered to be foundational to it in the late 1980s/1990s. We are grateful to Collin Sanders from Vancouver for pioneering this genre and are hoping that Jeff Zimmerman will follow him in the next release. We would like to think these stories of their engagements with Narrative Therapy will be of interest both to veterans as well as newcomers.





Wrapped in Care: Narrative Therapy in the time of COVID

Kay Ingamells

Private Practice, Aotearoa/New Zealand

“My nana died from Covid. She died four months ago. I am still crying every day. I am not getting over it.”

That’s what the email said. That’s why Harper intended to meet with me. As a therapist I work for various organisations, and Harper’s employer, an Australian-New Zealand company, was one of them.

I don’t like Zoom at the best of times. To me, with my head-and-shoulders only view she looked a small, perhaps even plump young woman, her face rounded like an apple. It was only months later when I met Harper in person that I realised that the five foot three inches was in my imagination. Harper’s face might be applely, but her stature was more that of a Kauri tree: She was tall, solid. She was dressed in Nike, growing towards the light.

Usually, I will begin by enquiring into a person’s virtues (Pilkington, 2018)¹ and I will ask for stories to illuminate them. So often problems obscure from the person themselves the very attributes of their character which will be of most help to them in adversity. The problem weighs in on the person, forcing them to see only their troubles and rubbing their noses in inadequacy. But Harper was alone. Usually, I will ask others to speak for the person because it is so hard for them to do so themselves. For Māori this is likely to be even harder because to speak about oneself, especially with pride, can be inappropriate when the sense of self is primarily a collective one (Hermansson & Durie 1990.) This whakataukī (Māori proverb), speaks to this cultural tenet: “Kāore te kūmara e kōrero mō tōna ake reka”, translated as: “The kumara does not speak of its own sweetness.”

¹ A virtue enquiry is Sasha Pilkington’s adaptation (2018), of David Epston’s term ‘wonderfulness inquiry’ which he invented at a workshop in Boston in 1996, and documented in numerous writings including Marsten, Epston and Markham (2016).





However, Māori see themselves in terms of their whakapapa, described by Te Rito as “a genealogical narrative, a story told layer upon layer, ancestor upon ancestor up to the present day. There are parallel lineages of characters which run vertically side by side, era by era, and incident by incident.” (Te Rito, 2007, p.1). To enquire about Harper’s identity in terms of the genealogy of her character would be to enquire after her whakapapa, to site her character within her lineage. As Swann says, “whakapapa narratives also provide the individual and cultural context from which meaning-making, connection, and shaping of identity emerge.” (Swann, 2012, pp. 8–9 quoted in Swann et al. 2013, p.13).

Sometimes I will interview people about their virtues even if they are on their own. I might ask them to imagine what someone close to them might say. I might have consulted with Harper about whether this would have been something she would like to have done, within the context of her whakapapa had her grief and love for her Nana not filled the screen. Instead, encouraged her to speak of her Nana and what she meant to her, and how they had been separated by distance, then by Covid, then by death.

I intuited that Harper’s relationship with her would offer us our way through in our therapy conversations. Knowing that for Māori, our ancestors are with us in the here and now, that they “go with us” (Russell Smith, personal communication 13th April 2012), I asked her to tell me about her nana: “Harper, would you be willing to introduce me to your nana? Would you be willing to tell me a little about her and her life?”

Harper’s hand went to heart. “Yes, I’d love to. Nana was born in the Hokianga².” She sat up straight in her chair. “She was Ngāpuhi³ and full Māori. She had it hard because Grandad had an affair and left her with seven kids. My dad was the second eldest, and the oldest boy.”

“And what is it that most stands out to you about who she was, Harper?”

² The Hokianga is in the far north of the North Island of Aotearoa New Zealand. It was from here that the descendants of the great Māori ancestor, Kupe made their home.

³ Ngāpuhi (or Ngā Puhī) is a Māori iwi associated with the Northland region of New Zealand and centred in the Hokianga, the Bay of Islands, and Whangārei. (“Ngāpuh,” 2022)





Harper looked upwards, as if consulting the heavens. “Even though she worked three jobs and had all of those seven tamariki⁴ to care for, she always helped others.”

She went on to tell me her nana had had the misfortune to be admitted to hospital in Wellington after a fall. Then diagnosed with Covid 19, she found herself cared for by strangers as the rest of her devoted whānau⁵ waited in lockdown. They were only four kilometres away, but heart-breakingly, hopelessly distant.

Harper was unable to see “the most beautiful woman alive,” whom she had visited every day of her twenty-three years. She had moved away to Australia only six weeks before Covid burst forth into the world. She was stranded by love, lured by a new relationship with Arthur which had begun online. Messaging had turned into long emails, which had turned into daily Zoom calls. Harper and Arthur soon realised that they had to meet and see if their online romance would flourish in the ‘real’ world.

Their first meeting in person was at Sydney airport. She saw Arthur before he saw her, waiting, hands in pockets, fretted brow, chewing a strand of silky black hair to soothe his nervous heart. In that moment, 2D became 3D, pixels became flesh, their love jumped from the screen into the arrival lounge. Arthur’s life had been wall to wall with challenge and worry, but his budding relationship with Harper had kept him afloat. Arthur’s father was waiting for a triple bypass. The mother of his eighteen-month-old son had departed with her boss for the Gold Coast six months before, and his mother had died of cancer two years earlier ago. Harper knew he was barely hanging on, so she stayed. Just like her nana would have done.

Harper told me of the trials of living with Arthurs’s family, how she felt both “homesick, and not at home when I am at home,” her outrage at Arthur’s siblings, and even Arthur himself, for indulging “a complaining old man” who continued to mete out nastiness to all of them, whilst they bowed under the sway of his illness. Nothing new to this family, just a new reason. But in the background hummed the tune of a granddaughter's love for her Nana whom she would never set eyes on

⁴ The Māori name for children

⁵ The Māori name for extended family





again. Love was the bass line, even if grief for her nana had become a superimposed, unwelcome harmony.

She told me of her premonition the week before the world closed its doors and its airport runways:

“I wanted to go home to my nana. I asked myself what if I can’t say goodbye? I wondered if I would ever forgive myself if I chose to be here, over the ditch, with a family that doesn't build me up. Then I got the call from Dad. Nana had tested positive. I just knew. None of us got to say goodbye. We had a full whānau Zoom. She was so happy. Then she rolled over and died. We think she did it then on purpose.

My auntie had a korowai⁶ made by a woman near Rawene. It was arranged five minutes after she passed. We wanted to have the cloak on her so that she felt that we were with her as she began to leave her body, and to leave us. Afterwards the cloak had to go into quarantine. I watched the tangi⁷ on livestream. How weird is that? The last thing I saw was my family hugging her. Of course, only ten of them could go because of the Level 3 Covid restrictions. All I could think was ‘why am I here in Sydney?’ I turned off the livestream and just sat there thinking ‘now what am I meant to do?’ Nothing felt real. The grief didn’t feel real. I was on my own staring at a blank screen. All because someone gave her Covid. Covid robbed me of my nana.”

Grief and love mixed with outrage at the injustice of it all. The injustice of losing “the most beautiful woman alive” to Covid, the injustice of not being able to say goodbye. The injustice of being away from her whānau, her friends. The injustice of having to “zip her lip” at the behaviour of this sullen old man, and the equally nauseating behaviour of a family afraid to name what they see as so many families do.

⁶ A Korowai is the modern term for a Māori cloak in the Awawa tribal domain (Buchanan, Te Awekotoku, Nikora), made with flax and bird feathers through the art of whatu (finger weft-twining). They are given as esteemed gifts to honour relationships and to provide physical and spiritual protection

⁷ Tangi is short for tangihanga, the Māori term for funeral. “The [tangihanga](#) is the enduring Māori ceremony for mourning someone who has died. It is commonly called a tangi, which also means to weep, and to sing a dirge (a lament for the dead)” (Higgins 2021).





Harper had said “unjust” several times. I thought to ask her, “Harper, if you feel you have suffered such injustice, would you say that you are someone who believes in justice for yourself, and also for others?”

“I am about justice. I speak out. I cannot stand things being swept under the carpet.”

How, I wondered, had Harper become an “all about justice” young wahine⁸? It is all too easy to take such insight into a person’s character at face value: to assume that this is just ‘who they are’. But virtues have stories. Perhaps some of it is genetic, but the choice to act on values is embedded in familial and wider culture, and in my experience have a story behind them if I am prepared to search hard enough with people. The story may have begun with the person, or it may have begun generations ago. A person’s virtues are rarely intrinsic to them. The cult of the individual blinds us to the context in which personal virtues and values are handed down to us. And more than that, there are ancestral stories, which for Māori, trace whakapapa. As Love says: “A view of individual selfhood is indivisible from the whanau (hapu and iwi) unit including the temporal and spiritual constituents of these. The boundaries of the self were drawn around the whānau, hapū and Iwi, unit, ancestors and the natural and supernatural world (Love 1999). Te Rito writes about his experience of researching the importance of tracing his own ancestry as he went about his academic research into the importance of whakapapa for identity. He writes: “...it has helped ground myself firmly in place and time. It connects me to my past and to my present. Such outcomes certainly confirm identity and a deep sense of ‘being’.” (Te Rito 2007, p.9). I was thinking of Harper’s whakapapa when I asked, “Harper, how do you guess that you have become someone who “is about justice, who speaks out, and won’t tolerate things being swept under the carpet?”

“It’s to do with my dad and how he has treated my mum all my life. I won’t stand for it.”

“How is it that your dad has treated your mum, Harper, and how have you gone about standing up to your dad’s treatment of her?”⁹ Her presence on the screen

⁸ The Māori name for women/female

⁹ “When someone describes an action that they have taken which expresses a value or way of being that is important to them, I research it with them so that we can distinguish what it is from what it is not. From





seemed to become larger as she said, “My father is a strong, proud, Māori man. He thinks that he doesn’t need to justify anything. Mum said he acts that way because this is how he acts. That is how proud Māori men are. Dad has never been abusive, but he does shut Mum down.”

“Does your commitment to speaking out against injustice extend to others beyond your whānau, Harper?”¹⁰

“I confront my dad, and I confront others, but it’s hard doing this for everyone else.”

It wasn’t just Harper’s love for her Nana that shone from the screen; it was her willingness to speak out on love’s behalf: “Is speaking out one of the ways that you show your love for people?”, I asked her.¹¹

Harper stopped as if putting her foot to the floor at speed.

“Yes, I speak out because I do love people. I don’t want people to feel hurt.” Looking down, she changed gear: “I try to fix things for others, and for myself. Death hurts but I can’t fix it.”

We sat in silence for a moment or two.

“Harper, is this what your nana did? Did she fix things for others?”

The words that followed sounded like the final knell of a church bell :

“My nana used to say, ‘while we are living we have the chance to turn things around.’” Her voice softened, as she confessed: “I don’t respect my dad because of how he is but I do want a better relationship with him. He was always

distinguishing what is, we can detect much that is hidden in the background, that made explicit, can reveal more to them of themselves and what is important to them.” (White 2000).

¹⁰ In asking this question, I am inviting Harper to consider that this commitment to speaking out against injustice may be a significant facet of who she is in the world that may have a broader reach and importance than she may have realised. Questions such as these and the preceding one are designed to story her identity, so that these facets can become more visible to her, and hence can play a bigger part in the story of who she is, both now and in the future.

¹¹ I am suggesting that Harper’s commitment to ‘speaking out’, is an expression of a bigger intention. The way she has responded to her father, potentially becomes part of a larger description of who she is.





physically present, but he wasn't there for me emotionally. I have told him that I want him to be in contact with me more often."

"Harper, are you trying to turn around your relationship with your dad around just as your nana would have done?"¹²

Her closed hand came to rest on her lips. "I realised that I wouldn't be okay if my dad were to die and we were not okay. I told him, 'I recognise that you have your own way of showing your love to me.' He was shocked. He just said, 'I try to make sure that you come along with me to the rugby club, but you just don't want to come.'"

Father-daughter love had been conflated with going to the rugby club. I felt for her even though I realised that this was a father who loved his daughter and was expressing it in the best way he knew how at that time. However, I marvelled that this twenty-three-year-old, aggrieved by her father's treatment of her mother, was willing to take the side of love.¹³

"Harper, even though you say that you do not respect your father because of the way in which he has treated your mother, why is it that knowing him as you do, you reached out your arms in love to him, even if it seems as if he has kept his by his side?"¹⁴

"It's Nana, through and through. She never took sides. I spent a lot of time with her growing up. Dad always used to take me and my brothers to her. It is one of the best things that Dad ever did for me."

My ears pricked. "Did your nana teach you how to take the side of love?" I asked her.

¹² Harper's intentions are being storied alongside her nana's. The story of who she is is situated inside of her whakapapa. This storying of her identity alongside that of her nana's, brings her closer to her nana.

¹³ Even though I have not said this out loud to Harper, I am formulating a counter-story about how Harper has been choosing to 'take the side of love,' in her life. The work of this emerging counter-story is to contextualise Harper's struggles with her family inside of a story that can enliven her and her relationship to how she is choosing to act, leaving her with a fuller version of who she could be said to be.

¹⁴ By investigating the 'why,' I am inviting her to look beneath her actions to find intentions that may not be visible to her. These intentions may story who she has been for herself, and so open up a larger possible sense of self that she can find pride in.





She reached for a tissue as tears began to swell.

“Could you tell me a story which would help me to understand how it is that your Nana taught you to take the side of love rather than to take sides?”¹⁵

“I would get sent there to her place as punishment when I was in trouble. She would sit me down at her kitchen table and tell me stories about her life and the hardships she suffered like ‘having to walk for eight kilometres to school every day after milking the cows and tending to the farm.’ The stories made me realise how I might have overreacted at home, or why my parents did what they did. There were always lessons in her stories, and it always came back to ‘do you know your parents love you? There is a reason why your parents do what they do.’ I was so wrapped up in her care that I didn’t hear it as a lecture.”

“Harper, would you say that your nana taught you to take the side of your parents' love for you, no matter what, and did so in such a loving way that you were able to hear her?”

“Yes. I know she sympathised, but she never said anything against them. She always directed everything back to their love for me.”

“Has your nana taking the side of love rather than your side or your parent’s side inspired you to continue to believe in your father’s love and to continue to reach out to him, even if at times you do not experience that love in return?”¹⁶

“One-hundred-percent,” she affirmed.

“And are there any other ways in which your nana has taught you to love?”¹⁷ For instance, you chose to leave your whānau, to move overseas when you had never even been out of Auckland before to be with a partner with a baby son and a sick father. And you told me earlier that your nana was always there for others even

¹⁵ Calling for a story of how her nana ‘taught her to take the side of love,’ connects Harper to her nana, but more importantly, it explores the whakapapa of the commitment that she has. If this commitment is brought to life with a story, it will live much more powerfully for Harper.

¹⁶ The story of her nana’s love for her and for her parents is now being woven back into the present and connected to how she continues to express her love to her father; The story of ‘taking the side of love,’ is now being told across generations.

¹⁷ This love is not something that has just come to her, it has been taught. By asking for stories of this teaching, the story of being someone who ‘chooses the path of love,’ becomes more substantial.





although she was a single parent with seven children to care for and worked three jobs. Did your nana hand down to you your generosity to others?"¹⁸

"I'd like to think so. Her love was like this river that flowed to everyone in her path. And her love ran through me too. She was me and I was her. Or that is how it always felt to me."¹⁹

All too aware that guilt was likely to be troubling Harper because she had made choices for her own life that took her from her nana not long before she fell sick, I asked her, "even although you were so far away from your nana, how did you make sure that your Nana felt your love for her through her illness?"

"I spoke to her every day on the phone and on Zoom, so she did get to see and to hear me morning and night. I formed a relationship with her head nurse. I remember one day hearing singing as I was joining her online. It was the nurses. They had written out songs and they sang them to her, and they weren't even Māori. They worked out our family tree and knew who each of us was. It nearly broke my heart when I realised that they had done all of this for my nana and for us."

I was suspicious that there was more to this than met the eye. Not every team of nurses would find Māori songs and sing them to a patient, especially if they weren't Māori themselves, and especially during lockdown in a pandemic. Was it Harper and her love for her Nana that had inspired them? "Harper, would you agree that what the nurses did was pretty unusual? Do you think that they also felt your love for your nana and your nana's love for others and got pulled into the river of her love as well?"

"They certainly felt my love for her, and I guess no one escaped her love, even when she was in hospital. I have always believed that I was her favourite, and maybe they realised," she bubbled. She looked up wistfully, and said, "although

¹⁸ By quoting examples of how she has been expressing this 'way of love' that her nana has bequeathed her, I am providing a storied preface to my question which allows the 'story of this commitment so far' to move forwards with us, and further substantiate it. It also allows for Harper to be drawn closer to the nana that she is grieving.

¹⁹ You could say that the story that we are weaving together is a river that runs from her nana to her, and back again, as well as having tributaries that run to others.





the dementia took part of her away, her wairua²⁰ remained just as it had always been. They must have felt her wairua.”

We sat for a few moments in what felt to me to be reverence. Then her brow furrowed. She told me that she had been feeling overcome with anger since she had had a phone call from her auntie.

“I have this righteous anger. My auntie said she heard a rumour that it was a nurse who was sick and didn’t go for a test. Someone made a choice and brought the virus in and caused her death. I keep asking myself ‘what is going to be done about that?’ Then, I was sitting in the walk-in-wardrobe in our bedroom, which is where I go when I need time out, and I heard her voice saying: ‘you are not me.’ I didn’t feel belittled at all.”

“Why not,” Harper? What was it that you heard in your nana’s words that was not a criticism, not belittling in any way?”²¹

“I knew what she meant because she told me this many times. She was letting me know that it was not up to me to seek justice, that I didn’t need to replace her, and it was okay to be angry even although she would feel differently. Sitting there on my bed, I realised that she was giving me permission to be myself, just like she always did. I sat there for a bit and then I realised that I do want to be like her. I so respected my Nana. I can be like her and be me. Then, for some reason I turned on the TV, and on the news there was a clip of Jacinda²² speaking about the New Zealand response to Covid. I felt for her. She has had so much flack. And although what she has done was not successful for my nana, there could have been thousands more deaths. As I watched her, I felt my nana’s presence.”

“What was it about Jacinda that felt so much like your nana, Harper?” She looked up as if taking herself back to the moment.

²⁰ The Māori name for spirit or soul

²¹ This practice of repeating what the person has just said inside of a question, allows for their words to be taken forward into the storying and invites storying in a way that the shorter alternative of, “why not?”, does not. I call these questions, ‘close questions’ because they stay close to the person and to their words.

²² Jacinda Ardern, serving Prime Minister of New Zealand. First elected 2017.





“My nana’s strength came from her love of people and that is how Jacinda is for me.”

I was surprised to hear what she said next. It is one thing to feel a connection, another to act. I wondered whether her nana was also a woman who acted when she felt strongly, and especially if motivated by contributing to another. It certainly seemed so.

“I decided to write to Jacinda. I told her about my nana. I told her about how I believed she loved people in the same way. I told her I didn’t blame her. I didn’t need a reply, and I didn’t expect one, so I was so surprised when one came. She said that she was ‘moved to tears by my letter’ and that ‘she was proud to be compared to my nana.’”

A calm had descended. It is strange that even though we were thousands of miles away from one another I felt it palpably, as if we were in the same room. I also felt as if Harper’s nana was with us. Perhaps she was in the spirit of the way in which she lived: in service of her love for others. Enamoured with the idea that our lives are all ‘peopled’ at all times with those that have ‘gone before us’ (Russell Smith, personal communication, 6th May 2015), I felt the urge to include Harper’s nana in our conversation, and asked a question that I might often ask when I felt that a loved one, no longer present in their physical body, might be knocking on the door, waiting to be asked to contribute:

“Harper, if your nana was looking down on us right now²³, and felt your love for her, what do you think she might say?”

Harper’s eyes widened. She looked up and away, and then answered as if my question was one that she was asked everyday: “She would say, remember that Jacinda is healing her whānau too.”

Harper’s nana had been the matriarch of her whānau, its spiritual leader, its healer. Harper was her most beloved grandchild. I had the sense that Harper’s nana may also have seen in Harper her spiritual successor. This sense, along with the Māori belief that our ancestors walk with us, led me to ask, “Harper, would

²³ The question is borrowed from David Epston (personal communication November 11, 2010)



you say that your nana has passed on her ability to love people to you?"²⁴ The absence of hesitation gave me her answer before I heard her reply:

"Yes. My uncle says, 'you have so much of her spirit and essence', and I feel closer to her when I talk to you."

"And Harper, you said that your nana found her strength in her love of people. Would you say that you do and will find your strength through your love of people also?"

Harper blinked away a tear. Our first meeting had come to an end. We held on for a few moments, and then we both reluctantly pressed 'leave meeting'.

Whilst we are living...

Harper's face popped onto the screen. She mouthed something but the caption told me that her microphone was still connecting. Harper wanted to tell me about the memorial she and her whanau had been planning for her nana. She had put together a slideshow of photographs from her nana's life. The bubbiness which had shimmered on the screen in those first few moments burst, as she told me that the purposefulness of her slideshow-mission had given way the moment she had finished it.

"I just cried. It was the first time that it came home to me that she was really gone. Until that moment, her loss had not fully made its way to my heart. It is so hard to accept that 'that is that.'"

An emptiness sat between us, and then, like a visitor who senses the awkwardness of the moment and attempts to fill it, a suggestion intruded.

Harper said, "I want to write a speech for the memorial."

What could be wrong with this suggestion? Nothing. Of course she would wish to speak of her nana at the memorial. Yet it seemed that at this moment the suggestion was here to fill the pain. I felt the emptiness. Harper had been ripped away from her nana by distance as well as by death. How might I help to bring her

²⁴ By uniting Harper with her nana in this way, I am bringing her closer to her in her grief, inviting her to presence her nana's ways of being in her own life right now.





closer to her nana, even in some small way? How might I help to salve the pain of this chasm even mildly so? The words materialised in the air between us before my reasoning had taken full shape:

“Harper, would you consider writing a letter to your nana rather than writing a speech about her? What if you were to read it to *her* at the memorial?”

Harper’s hand fled to her heart and sat there like a nesting bird.

“Ohh” she exclaimed

There was a moment of silence, and then she said:

“Judging how my heart feels about the idea...”

“And what might you say?” I asked. Harper’s reply delighted me.

“I have no regrets with Nana. She knew how much I loved her. I would like to talk with her about some of the good times, some of the funny times we had together, especially towards the end. I’ll think about what people want to know about her, and what I want them to see about our relationship.”

As a narrative therapist I cannot ever pass up the chance of a story²⁵ so I asked her, “Could you tell me a story about one of those funny times that you shared with your nana?”

Harper’s eyes danced as she told me about how she had to “keep seeing her through dementia...I had to find a new way of seeing that spark in her so that I could see a bit of her, even for a moment. She loved the Silver Ferns²⁶ and she was always very proud of me when I played netball for my school team. One day, I told her that I had been picked to play for the Ferns. It wasn’t true, of course. I said ‘Nana, guess what? I’ve been picked to play for the Silver Ferns.’ She exploded with joy and pride. ‘Really?’ she said. ‘Yes, really,’ I said. ‘What position?’ she asked. I said, ‘Goal Attack (that was that I used to play).’ I was so

²⁵ People’s relationships (with themselves and others), exist for me as ‘stories’, and it is through asking for these stories to be told that we can enter into a landscape together in which these stories can be, embellished, cast aside in favour of previously untold stories, or take different turns leading to new or rarely visited destinations.

²⁶ The New Zealand National Netball Team





surprised when ten minutes later she remembered my fake Silver Ferns selection, and asked me again, ‘what position are you playing?’”

We laughed together. I was touched to be privy to this moment in Harper’s relationship with her nana. “Harper, I would love to see your letter to your nana after the memorial. Would that be okay?”

“Of course,” she said. “When I have finished reading my letter to her, I will blow out the candle that will be lit for her. This signifies that we will be going on without her, but it doesn’t mean that the light needs to go out ‘in here,’” she said, as she laid her hand across her heart.

Another idea crossed my mind: “Harper, do you think you should wear the korowai?”²⁷ She replied with a solemnity worthy of the feathered cloak itself, yet without the expectation that she deserved it.

“Maybe I could ask my uncle. He is the keeper.” She mused, “I would like her to be with me as I read to her. I would be wrapped in the korowai, and it was the last thing that she was wrapped in.”

Harper’s gaze drifted somewhere off screen. A moment passed until her gaze returned. She looked troubled. I waited for her to speak, aware that there was something in the wind that was about to change the direction of our conversation.

Christmas, weddings, births, deaths. All events that bring family together. And with the togetherness come the ghosts. The ghosts of all that has been said, the ghosts of all that has not been said. The ghosts of resentments, the ghosts which carry secrets under their grey gowns. There had been “a lot of family drama around the memorial,” and the winds of these dramas blowing through the whānau had disturbed her and had been “piled on top of my grief,” making it hard to feel, hard to find her nana. Harper wanted to talk with me about how she might navigate her way through this.

²⁷ I asked Harper whether she would like to wear the korowai, not only because it would bring her closer to her nana and offer comfort, but because it appeared that she might be her nana’s successor as the spiritual leader of her whānau.





I knew I would need to understand what was coming to the surface in some detail, and so I asked Harper if she would “tell me the story of these whānau dramas?” A fifty-year saga of ‘black sheep’, drugs, prison, dodgy dealings, cheating, and financial losses at one another’s hands took shape before me. However, the rift that had split the whānau into two very unequal halves, with one of Harper’s dad’s cousins and her brood on the one side, and most of the rest of the family on the other, with a few undecideds wandering around in the middle, had led to a nasty physical fight in which a younger male cousin had been seriously hurt. An allegation had been laid against Harper’s father by Doreen, the young man’s sister. Harper had first heard the rumour a few years before. She had never met her father’s cousin, Doreen, who had been faded out of the family, partly because of the rumours, and perhaps partly because of her “troubles with drink,” but somehow word had gotten around as it always does. In the spirit of her commitment to “speaking out” and “standing up for others,” which Harper had been practising in her father’s company for some time, she had confronted him:

“My dad was so angry, and he refused to answer. He just said that you don’t need to know.

Then one day not long before Harpers’ nana became ill, Doreen rampaged on Facebook. Messages were sent to random family members, including Harper. Terms like “swept under the rug” were used, and “stuff was said about my mum.”

Harper had replied saying: “It’s not my business, don’t talk to me about it,” and Doreen had replied with, “Do you condone physical abuse and violence?”

Harper had blocked her.

And then when Nana became ill, Doreen had made an appearance in person. Harper’s uncle had spoken with her and apologised for her treatment over the years. The views of the other aunts and uncles were that “she needs to get over it.”

Doreen was refusing to come to the memorial because the family had been unwilling to involve her. But she had been close to Nana. Nana had been as important to Doreen in her early years as she had been to Harper. Harper's troubles were double-edged. She wanted Doreen to be able to take her rightful





place at the memorial, to be able to grieve Nana and at the same time she was angry with Doreen and with her father. As she then said to me,

“This is why I don’t respect my dad, quite apart from how he has treated my mum. He hasn’t explained. And I don’t want to get close to him...but if anything should come out of Nana dying it should be restoration.”

Family members often become invaluable co-therapists in therapy conversations and have been especially helpful to me when there has been an impasse. This time, I realised that the person I needed to call upon was Harper’s nana. This was the first time I had asked for a co-therapist to join me who was not physically alive.

Sensing the bridges between what Harper had already told me of her Nana’s way of being in the world: her love of people, the saying “while we are living we have the chance to turn things around,” and now Harper’s conviction that “if anything should come out of Nana dying it should be restoration,” I asked her, “Harper, if your nana was here with us now and you were to ask her what she might wish to do about this whānau drama, what do you think she might say?” She took my unusual request in her stride and her answer came as soon as the last syllable left my lips:

“Nana would tell them ‘It was forty years ago. You all have to get over it.’”

Sensing that Harper needed to hear what her nana would say to her directly, I asked: “And what would your nana say to you?”

I am sure I could see the answer descend as her face stilled, but it was a moment before she shared it with me.

“She would say: ‘your father is a strong, proud Māori man. He won’t ever tell you. He won’t ever apologise. That is the way that he is.’” Harper blinked.

I had a sense that there might be more. “Is there anything else you think your nana would say to you if she were here with us? Would you be willing to close your eyes for a moment and see what comes?”





Harper's eyelids gently lowered. Her cheeks seemed to take on a warmer hue. She waited and then:

"There is something else she is saying to me. She says: 'I want all my whanau there at the memorial, but good luck getting them to hear you. You might just have to let it be.'"

Her now open eyes stared ahead into space. They seemed to say, 'but wait, isn't there more?' A pause, and then Harper announced:

"Anyone can change. I want to believe this. I want to believe that Doreen can change. I don't just see her as an alcoholic. I see her as someone who was hurt. I believe my dad can change too."

It seemed to me that Harper found herself straddling two worlds, two possible paths to restoration: that of 'letting be' and that of being a direct agent of change for others. Her Nana's path was clear. Harper's belief in 'speaking out,' her commitment to justice, her commitment to not allowing things to be 'swept under the carpet,' left her uncertain. Harper's nana had told her "you are not me," she had given her permission to be herself, and yet Harper walked in her nana's footsteps and perhaps had been doing so all of her life, and one day might be recognised as her nana's successor as the spiritual head of the whānau. There was another way, I thought to myself. Nana was Nana, Harper was Harper, but they shared whakapapa,²⁸ their wairua²⁹ was entwined. How might I ask her a question that might help her to discover a path between?

"Harper," I ventured hesitantly, unsure of my footing as a Pakeha,³⁰ and concerned lest I should be culturally clumsy, or just plain wrong, "even if the actions you may wish to take may be different from those your nana would take,

²⁸ "Whakapapa is a taxonomic framework that links all animate and inanimate, known and unknown phenomena in the terrestrial and spiritual worlds. Whakapapa therefore binds all things. It maps relationships so that mythology, legend, history, knowledge, tikanga (custom), philosophies and spiritualities are organised, preserved and transmitted from one generation to the next.

Whakapapa is the core of traditional mātauranga Māori (Māori knowledge). Whakapapa means genealogy." Taonui, R (2015.)

²⁹ Spirit or soul in Māori.

³⁰ A Pākehā is a New Zealander of European descent.





what is it of her wairua that she has handed down to you? What is it that you and your nana shared and always will share?”

Harper put her head in her hands. She pulled her fingers down her face, speaking as they parted: “It is her selflessness. She wanted to help people; I want to help people. She was big on family and wanting to mend things. She came from love.”

I felt as if I were venturing out onto the limb of a tree, although I felt it was a well-rooted one, as I asked: “Is this love for your family trying to be here?”

“Yes.”

Harper’s hands cupped her young face. “I can still love them regardless of their grievances and their stubbornness. I can love them fiercely.”

It’s not my time

I heard the beep of Harper joining the call. I hurriedly snatched my tea bag from the packet, poured the water from the kettle which had just had time to boil between sessions, danced over to my computer and clicked.

Harper had rushed too. There was a faint buzz of excitement. She began, telling me that she was “proud to have stuck to what she believed.” Her family had asked her to make some changes to her contribution to the memorial, and she had refused, but offered an alternative. She said with pride:

“I can say ‘no’ and still honour my nana, and how she would be. I needed to hold my ground and also to remember that these are her children as well. It is not my time to take on ‘being Nana’ in my whānau. I can’t replace her, but I can still be like her. She often didn’t need to say much, and it still said a lot. I believe I can honour her in my own way, in my own time.”

Updating me on the whānau drama, Harper told me that her uncle had “tried to meet with Doreen to apologise, but she had refused to let it go.” Her face froze for a moment on the screen, and her voice distorted to Darlek tones, but I was still able to make out her words:

“Even though she is not prepared to let it go, it came to me that we can.”





She continued this time in tones that rang clear:

“You know, I have realised that one of the reasons why I have cared so much about people being held to account and I felt I had to hold on and have control was because my previous partner used to hit me.”

Harper looked at me with a slightly dazed, yet innocent expression. Perhaps the expression of someone who has spoken the plain truth to themselves and to another for the first time finds themselves in awe of the words that float dangerously in the air before them. I too felt awed. Not only by Harper’s insight and her willingness to speak it, but by being in the presence of something so beautiful.

She looked down. I thought I saw her lip quiver.

“I want to honour my nana, and she always told me ‘Respect your parents: they love you.’ I have been thinking that if I am going to honour my nana then I need to respect my dad.”

Love takes many forms of course. At times, respect can be challenging, even ruthless or accepting. And perhaps, I thought to myself, true love needs to be able to turn on a dime: to express itself in whatever form is needed to do the work of love in the moment. My thoughts shaped themselves into a question which I hoped would speak to Harper’s nana’s expression of love:

“Harper, do you think respect is an expression of love? And do you think acceptance can also be an expression of love?”

As I spoke a Piwakawaka³¹ danced into the house, into the bedroom, and back out again through the front door. I wondered at its meaning.

Harper gazed seemingly into space. All of a sudden, she seemed smaller, like a little creature looking for somewhere to nest, as she spoke:

“Is it okay for me to love my dad just because he is my dad?”

³¹ A Piwakawaka is a bird that is native to New Zealand/Aotearoa. It is also known by many other names, including Tīwaiwaka. The English name is Fantail.





Her words hung between us like a line of spider's gossamer which might just be the first thread in a work of miraculous, yet everyday beauty. There was silence for a moment. But not an everyday kind of silence.

"What do you think?" I asked her. "Could it be okay for you to love your dad just because he is your dad?"

She pondered.

"It would be a relief for my dad. After he watched the slideshow I made for Nana, he called me and he said, 'I am so proud of you.'"

Her face now seemed to widen, just as a few moments before it had seemed to shrink, as she said unbelievably:

"He said it five or six times"

I felt as if we were suspended together halfway across a bridge: a bridge to somewhere worth getting to. I asked a question that I hoped would take us a step or two closer to the other side: "Do you think your dad could be feeling constrained at the moment?"

Zoom is a strange medium. How often 'in real' might you be close enough to someone to see the very beginnings of a tear beginning to form. I saw it. And then another. Harper spoke as her tears fell.

"He may feel hurt that our relationship is like this. He said to me that he was 'too young to understand what happened with his cousin'. He said to me, 'why do you think it is that when your grandad died, we gave Doreen's son our share of the inheritance?'"

I felt it was time to ask Harper's Nana, my co-therapist, to join our conversation again. "Harper, if your nana was with us now, what do you think she might wish to say?"

Harper looked upwards, the trails from her tears glistening like streams running down a New Zealand mountainside. She spoke slowly but surely through closed eyes. "She says, 'your dad has always been pinpointed for his mistakes all his life, and the one thing he doesn't want to make a mistake with is you.'"





There are times as a therapist when my eyes begin to burn with tears. I feel them wanting to find their way out as my therapist's face prepares for them. This was one of those times. We were both silent. I heard the piwakawaka's chirping through the open window. Then I saw it swoop and dance. Some people would say that when a piwakawaka enters a house it is a harbinger of death. Others would say it sometimes signifies a visit from an ancestor.

Harper's mouth opened, then closed, then opened again, as she found her words. "I don't think I need to say anything to him. I just think I need to take a different perspective. I have seen him as this authority figure, and myself as someone who always does wrong in his eyes. I need to change that. As I spoke to Nana, I saw him as a little boy. I wouldn't want him to think that he has made a mistake with me. He says, 'I have a lot of Nana in me.'

"Remember, he always sent you to her."

"Yes", Harper replied. "Maybe he knew what I needed."

Postscript

Four months later...

I emailed Harper after we had last met to ask her whether she would be willing for me to write the story of our conversations, and I had, of course, enquired after her. I was delighted to read her reply a week or so later:

Hi Kay,

I am so sorry I haven't got back to you sooner! Everything was crazy at work after the memorial and I actually resigned from my job and have accepted a position at the Sydney Zoo, which I am really happy about!





The memorial was so beautiful and reading my letter felt so right and I felt so much closure from that day! It is so crazy how much our sessions helped and have helped with things with the family since then!

Also, if you are still keen on using my story for your book I am still more than willing to help. And guess what? I am back in Auckland for the next month, so if there is anything you would like to ask I'd be happy to meet...

Eight months later...

My desk was piled with papers. I had read through my detailed scrawlings from my sessions with Harper numerous times, and intrigued by some unanswered questions, and wanting to know more about how life had changed for her since our sessions, I decided to take her up on her offer to meet.

The autumn sun flitted across the now sun-tired garden of my practice building as I waited for Harper, accompanied by Abigail, my landlady's attention-seeking little cat. I heard steps on the path, and there she was!

There was much I wanted to ask her. I wanted to know how it had been to read her letter to her nana rather than to deliver a eulogy. I wanted to know whether her relationship with her father had altered. I wanted to know in what ways she was continuing to connect with her nana. Harper told me about the memorial: How there had been two hundred people present, who had all joined the whānau afterwards for a hangi³² that had cost all of \$260, partly because of donated meat. It was, she told me, "The cheapest memorial ever!"

"Nana would have loved the hangi but she would have hated the fuss," she continued.

Harper had read her letter to her nana to me at our third and final session, but I was longing to know how it had been received.

"People laughed so much when I read the letter to Nana. They weren't expecting it at all. It was sad and heavy until then. I wouldn't have wanted her to be upset so it was full of jokes and funny stories."

³² Hangi refers to food cooked in an earth oven.





I found myself thinking of how Harper had described her nana “wrapping her in care,” and I found myself asking her, “Did you wrap your nana in care? Not only with how you wrote her letter, but in how you cared for her, especially in her final days, even although you couldn't be by her side?”

Harper’s eyes shone with tears. She smiled as she said: “I was hoping I wouldn’t cry so early on. Yes, I think I did. Even organising the korowai was a mission in itself. I felt she would have known that it would have been killing me and my family not to be there, because no one could visit her at all in her final days. She knew how much we respected her and how much we wouldn’t have wanted her to be on her own. I think the Zoom call was for us. She was singing and talking to her sister in Māori. We all left in such high spirits. It was about her giving peace to all of us. That is what she would have wanted. I heard later that she was holding the hand of one of the nurses as she passed. The nurse had the same name as me, and the head nurse told me that Nana wouldn’t let her out of her sight.”

Abigail had found her way onto Harper’s lap on the garden bench, and her purring filled the silence between us. As if reading my mind, Harper began to tell me about what had transpired in her relationship with her father since what she described as “the big revelation.” “Before I was trying to mould him into being the kind of dad I wanted him to be, and he was always falling short. It has been a journey of acceptance, finding the positives in who he is, and loving him for those things.”

“The biggest thing was after I had been on at him and mum to sort out their wills, because there was a lot of drama after Nana died because she hadn’t written one. Mum loves rings. She has several on most of her fingers. She sent me and my sister a ‘who gets what rings list’, and then Dad said, ‘I want to give you this. I want to give it to you now.’ It was his greenstone, carved with our family emblem. It is the one thing I know is him.”

References

Hermansson, G., & Durie, M. (1990). Counselling Maori people in New Zealand. *International Journal for the Advancement of Counselling*, 13(2), 107-118





Keane-Tuala, K. 'Ngā manu – birds - Birds associated with death', Te Ara - the Encyclopaedia of New Zealand, <http://www.TeAra.govt.nz/en/nga-manu-birds/page-2> (accessed 24 December 2021)

Love, C. M. A., (1999). *Maori voices in the construction of indigenous models of counselling theory and practice*. (Unpublished thesis completed in partial fulfilment of the requirements for the degree of Doctor of Philosophy in Psychology at Massey University).

Malcolm-Buchanan, V., Te Awekotuku, N., & Nikora, L. W. (2012). *Cloaked in life and death: Korowai, kaitiaki and tangihanga*. *Mai Journal*, 1, 50–60. <http://www.journal.mai.ac.nz>

Marsten, D., Epston, D. and Markham, L. (2016). *Narrative therapy in wonderland: Connecting with Children's imaginative know-how*. New York: Norton.

Ngāpuhi (2022). In *Wikipedia*. <https://en.wikipedia.org/w/index.php?title=Ng%C4%81puhi&oldid=1083245240>

Pilkington, S. (2018). *Virtue Inquiries*. Video of Collab Salon, November 2018, Re-Authoring Teaching. www.reauthoringteaching.com (Freely available)

Rawinia Higgins, 'Tangihanga – death customs - Understanding tangihanga', Te Ara - the Encyclopaedia of New Zealand, <http://www.TeAra.govt.nz/en/tangihanga-death-customs/page-1> (accessed 21 December 2021).

Rāwiri Taonui, 'Whakapapa – genealogy - What is whakapapa?', Te Ara - the Encyclopaedia of New Zealand, <http://www.TeAra.govt.nz/en/whakapapa-genealogy/page-1> (accessed 24 December 2021)

Rāwiri Taonui, 'Whakapapa – genealogy - What is whakapapa?', Te Ara - the Encyclopaedia of New Zealand, <http://www.TeAra.govt.nz/en/whakapapa-genealogy/page-1> (accessed 6 January 2022).

Swann, B., Swann, H., Crocket, K. (2013). *Whakapapa narratives and whānau therapy*. *New Zealand Journal of Counselling*, 33, 12-30.





Te Rito, J.S. (2007). *Whakapapa: A framework for understanding identity*. MAI Review, Article 2, 1-10. Available from <http://www.journal.mai.ac.nz>

White, M. (2000) *Re-engaging with history: The absent but implicit*. In Reflections on Narrative Practice. Adelaide, South Australia: Dulwich Centre Publications.



Deciding how to die: Narrative Therapy in palliative care with someone considering stopping dialysis.

Sasha McAllum Pilkington³³

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Abstract

Living with a life ending illness can raise questions where there is no clear “right” answer. The following illustration of Narrative Therapy focuses on conversations with a man who was tortured by indecision as he considered whether or not to stop dialysis. Stopping dialysis would lead to his death. This story of our work together illustrates narrative therapy practices that can help to restore dignity, witness suffering, enhance meaning making and offer a person a sense of agency as they approach death. Accompanying the illustration of therapy are footnotes. The footnotes explain more about my thinking and the ideas behind some of the questions that I asked. They also describe how I have applied ideas drawn from philosophy and Narrative Therapy to practice in palliative care. You can choose to read the story of the therapeutic conversations and the footnotes either together or separately.

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Deciding how to die³⁴

The referral in front of me had “urgent” written across it in large letters. It was from one of the community nurses at the hospice where I worked.

“Please would you see Mr Fionn Williams as soon as possible. He has end stage kidney disease and is having dialysis three times a week. Fionn is being cared for at home by his son Liam, and Liam’s partner Pete. Every week Fionn decides to stop dialysis only to change his mind at the last minute. This has been going on for months and he and his family are very distressed. Fionn describes himself as “tortured” by his indecision. Dr White³⁵ has discussed stopping dialysis with Fionn and his family a number of times. Fionn knows he doesn’t have long to live and his quality of life is very poor, however his indecision continues. Fionn has refused counselling support every time it has been offered but yesterday, he changed his mind. His family are relieved he has accepted counselling and are waiting for your call.”³⁶

I rang Fionn immediately.

Reviving dignity and meaning

The following afternoon I parked my car in the shadows of some large trees overhanging the road from Fionn’s property. The path to the house gave me an uplifting view of native plants and trees surrounding a soothing lawn. I walked up

³⁴ For ideas on how to use stories such as this one to learn or teach narrative therapy see Carlson et al (2018). For additional examples of stories illustrating Narrative Therapy see Epston, 1989; 2004; Heath & Arroyo, 2015; Heath, Carlson & Epston, 2022; Ingamells & Epston, 2014; Ingamells, 2016; Pilkington, 2014; 2016; 2021.

³⁵ Confidentiality and ethical issues have been attended to in writing this story (see Pilkington, 2018b). All names and identifying details have been changed and some composite elements have been included.

³⁶ I often meet with people who are making major decisions around treatment. As a counsellor I may be involved when these decisions are not medical decisions but based on personal preference. For example, whether someone wishes to continue with chemotherapy, intravenous feeding, dialysis (see Russ, Shim & Kaufman, 2007) or turn off a device that keeps their heart going, when there are both benefits and disadvantages. Such decision-making and the timing of it can be enormously challenging and for some people there may be no clear pathway forward. Not only that but different choices are right for different people and their families, and at times, family members may disagree. Sometimes I will help people identify: questions they want their doctors to clarify; what their values and priorities are; or give them the opportunity to identify and discuss what they are weighing up. This story illustrates one way I might step into such a conversation.





to the front door intent on assisting Fionn to search for what might be right for him (see Frank, 2017) in his decision making. I had no idea what that might be.

Fionn's son Liam greeted me at the front door. Liam was a tall lean man, in his thirties I guessed, with a welcoming manner. He invited me into a tidy living room to sit down and then excused himself to let Fionn know I had arrived.

Fionn hobbled into the room leaning on Liam. I stood up to greet him and, as he caught my eye, we exchanged a brief acknowledgement. As Fionn came closer, I could hear him breathing heavily. He was dressed in winter pyjamas and a heavy cardigan despite the warmth of the day. The grey hue of his skin and the care with which he nursed his body through each step made him look older than his 74 years. Unlike Liam who had a deep red beard, Fionn was clean shaven, but it was easy to see that they were father and son due to their similar statures and light blue eyes.

Liam supported his father into the comfortable looking chair beside me that I had carefully avoided sitting in. Fionn gingerly settled back into the chair and looked at me.

"Are you the one who's come to analyse me? I'm quite curious to hear what you make of me," he rasped crisply.

I smiled warmly as I leant forward to shake his hand, choosing to respond to the possibility of humour in his comment and to my hopes for the relationship rather than the crispness of his tone³⁷. "My name's Sasha, I'm one of the counsellors from the hospice. I'm looking forward to talking with you, 'though I'm more interested to hear what *you* make of you and your experience." I was aware that being a fifty-eight-year-old woman with a soft voice and a big smile might have added to this introduction some of the care I wished to convey. I was generally

³⁷ The enactment of compassion can be expressed not only in how we respond but in what we choose to respond to. My decision not to respond to Fionn's irritable tone but rather to search for the best in him, is an intentional action that takes into account his suffering and the possibility that the crispness could carry multiple meanings. See Sinclair et al (2017) on compassion and its differences to empathy and sympathy.





just what people expected when they agreed to see a counsellor working for hospice and that could ease our first moments of getting to know each other³⁸.

Fionn chuckled. Liam turned to his Dad with his eyebrows raised and a slight smile on his face. In a tone of pleasant surprise he said, "I'll leave you to it Dad, so you can have some privacy."

Fionn immediately replied, his voice wobbling as it betrayed the toll even speaking had on him, "No, no, you stay. I haven't got any secrets from you."

Liam responded by pulling up a chair so that the three of us sat around the coffee table. "Alright then but I'll have to leave shortly Dad. I've got a few things to do."

They both then turned and looked at me.

"Would it be Ok to begin maybe, with me asking you a bit about yourselves?", I offered tentatively. Liam nodded and, looking at Fionn, I explained further, "... so that I might know a little of who and what matters to you. I find people are so much more than their current situation."³⁹

³⁸ My colleague Wayne Gates and I have often discussed the difference gender, age, ethnicity, appearance and other factors can have on these initial moments when we visit people in their homes. I find it useful to be aware of the first impressions I may generate; when they are likely to be assisting the relationship and when they may get in the way. These are assumptions to be held lightly though as they may be incorrect.

³⁹ I often begin a conversation by getting to know a person aside from the illness. My intention in doing so is to build a relationship with the person I am meeting where they can have an experience of themselves as more than the illness they are living with, as worthy of respect, and as holding knowledge and wisdom about their life. I take great care and all the time they wish for, to generate what I hope will be a meaningful connection. If we are to have conversations about a person's experience of suffering, we first need to generate a relationship in which such stories can be told.

The way a person expresses their suffering can make building a therapeutic relationship challenging at times. Suffering isn't always communicated in polite and comfortable ways. It may hide what is most endearing about a person. And yet if we are to form a therapeutic relationship in which a person can speak about their experience, we need to find ways of connecting that honour them and bring forward those parts of them they would like to be visible.

Relationships and conversations that bring forward preferred identities matter. Our narratives and the descriptions that we apply to ourselves don't just speak to our past and to whom we think of ourselves as being, they influence our future decisions and what we think is possible for us. Not only that, a good relationship is therapeutic in itself and has been shown to enhance the benefits of medical interventions (Wampold, 2021) that are likely to be important to a person's sense of wellbeing if they are sick.

I ask questions informed by Narrative Therapy ideas (White & Epston, 1990). Underpinning the questions I ask, is the idea that these are sacred conversations, and ones that I approach from a position of our shared humanity. I





Fionn's tone was abrupt. "Sure," he croaked. Before I could respond, Fionn heaved his body forwards gasping at the air as if unable to get enough of its vital oxygen.

I waited, watching until his breathing eased.

Once Fionn could speak again, he explained, "It's like this a lot... very hard to breathe... If I start to cough it's going to interrupt us. Did they tell you it takes a while to settle it down?"

I wondered if the struggle to breathe was behind the severity with which Fionn expressed himself and reflected that he might be anxious or even afraid. Feeling so sick could be overwhelming and here he was risking meeting a stranger on top of everything else.

I spoke with sincerity looking into Fionn's faded blue eyes, "I'm sorry I didn't know that. Thank you for seeing me. If you start to cough, is it Ok if I sit with you or is there something else you'd like me to do? I'd like to do whatever is most comfortable for you."

Fionn's voice softened. "Just wait for me to stop. I do eventually."

"I'm happy to wait. I'm in no hurry. Please take all the time you need to be comfortable without worrying about me," I said warmly, trying to reassure Fionn that he didn't need to consider me.

I reflected that people often have to cope with the responses of others on top of the symptoms they are managing and briefly wondered what Fionn's experience had been.

don't assume I have a right to enter what might be tender or intimate areas of a person's life. I am also mindful that respectful ways of greeting and getting to know one another are culturally constructed and so I will shape the conversation in ways that I hope will show respect to the people I am meeting (see Pilkington, 2018a).

The practice of getting to know a person ahead of the problem (see Epston, 2004;2016; Epston & Marsden, 2010) can be powerful, but is not one that I impose upon a person. If someone is brimming over with a story they wish to share, I will be guided by them and return to getting to know other aspects of their life at a later time.





Liam chipped in with, “Dad has some medication for it but basically nothing can be done. He puts up with a lot.”

Nodding at Fionn in acknowledgement, I considered pursuing what he was putting up with but then thought it might be more useful to come back to it later in the conversation. We didn’t know each other and I wanted to create with Fionn an entryway into a space where his experience of illness and treatment could be spoken about without compromising his dignity⁴⁰.

Fionn helped me out by indicating where his interest lay.

“Yeah...so we were doing some introductions. What do you want to know?”

Guided by Fionn’s question, I reiterated, “Would you mind telling me a little about yourself to start with perhaps?”

Speaking to the floor, he answered, “Not much to tell... haven’t thought about anything much other than trying to get through each day for ages. Let’s see now...well for a start you can call me Finn. It’s what my friends call me.”

I smiled appreciatively, thinking of his generosity in extending me his friendship. “Thank you, Finn. Is that Irish?”

“Yeah. My grandparents came out from Ireland.” He lifted his eyes from the floor and focused on a nearby corner.

“...See that ‘cello over there?”, Finn directed.

I turned my head to look with interest.⁴¹

⁴⁰ For the value of dignity as we approach the end of life see the work of Harvey Max Chochinov (2012).

⁴¹ The philosopher Todd May writes that what a person is engaged with in their life, and if they go about it in ways that express Aristotelian virtues (for example kindness, compassion, courage, determination and love), can give their life meaning across time (May, 2015). May clarifies that an outside audience would need to recognise the person as acting in a way that expresses an Aristotelian virtue. When he refers to a meaningful life May is referring to a person having a sense of living a life that is meaningful *to them*. May states that for these ways of living to give a person a sense of living meaningfully, they need to be a theme in their life. He calls such themes “narrative values” (May, 2015, p. 73).

To live meaningfully does not require ease or happiness. This is important in my practice with people who are dying. I research *how* a person goes about their life, especially those parts of their life that are of particular





Finn lent forward and in spite of his weakness managed to convey a flicker of enthusiasm. “Played it for years. It had a beautiful mellow sound until last year when I went downhill and couldn’t play it anymore.” Finn hung his head with his body seeming to follow as he collapsed back in his chair.

“What a beautiful instrument. How did you come to learn the ‘cello?’”

What could have been a hint of pride entered Finn’s voice as he raised his eyes to meet mine. “My Dad taught me and then I’ve practiced over the years.”

“How old were you when your father began to teach you?”, I asked.

“Just a young nipper. Must have been about seven I s’pose.”

“Gee that’s young. What did your father see in you that made him think he could teach you the cello when you were only seven years old?”, I exclaimed.

significance to them. As I ask a person how they have gone about their life I am listening for expressions of Aristotelian goodness (see Epston, 2016;2018, Pilkington, 2017). I then ask for more stories from their life that illustrate a value or expression of ‘goodness’ we identify together. I listen for themes that are valued by the person. These themes or narrative values can lead to a person rediscovering meaning in their life. When someone has a sense of living meaningfully, it is likely to shape their relationship with their approaching death in ways that can be very helpful.

Researching narrative values can also generate a sense of agency by giving the person possible ways of responding in the future as they manage their deteriorating health. Virtue is not dependant on an able body. When I am having re-authoring conversations (White, 2007) with a person who is seriously ill, I am always listening for alternative stories that track narrative values. This is so that even when a person has been robbed of their physical abilities, the new descriptions produced by the new narrative, generate agency in their current life rather than past identities that can no longer be enacted. I may begin this process from my first moments of meeting with a person. Not only that, I often track how the narrative values in a person’s life show up in previous generations and ask questions about their legacy for future generations (See Pilkington, 2022 for an example). There are occasions when such questioning may shape entire meetings. For example, if I only have the chance of one meeting with a person before they die.

Often, expressions of goodness are not readily available to a person. In order to identify expressions of goodness to build such a narrative, these conversations may require a counsellor to deconstruct old stories and to practise “double listening” (White, 2003, p. 30) as they listen both for what is being said, and what is not being said, yet is implicit in the discussion (see White discussing “the absent but implicit”, 2000, p. 23.). For example, as I listen to Fionn I am curious about what values and qualities might sit behind his music practice.

You may notice examples of conversation with Fionn that reveal attributes that he hasn’t previously noticed about himself or perhaps hasn’t thought about for many years.





Finn furrowed his brow thoughtfully. “I s’pose he knew I’d work at it. I’m not one to take something lightly if you know what I mean. You have to start out young with strings ideally.”

I leant forward to better hear Finn as I asked, “When you say he knew you’d work at it and not take it lightly, would you mind explaining a little more of what you mean?”

“Well...”, Finn hesitated, “Dad knew I’d practice and you’ve got to do that if you want to learn to play... especially with a stringed instrument. You have to make the notes you see. Even when I was a boy if I set my mind to something, I’d keep going with it.” Again, I noted a glimmer of what could have been pride in Finn’s demeanour. My keen interest must have been evident on my face. When Finn caught my eye, he explained further.

“When I was 4 years old, I decided I wanted to ride an old two-wheeler bike and there was just no way anyone was going to stop me trying. Did it too in the end. Just kept going till I did it.” Finn glanced at me again with a small smile transforming his lined face for an instant.

I responded immediately caught up in the picture he had drawn of himself. “What do you call this ability to keep going with something you want to do?”

“Grit, I guess. I’m a hell of a determined kind of fellow.”

“You sure are Dad,” Liam echoed.

“What have you come to respect about your Dad’s grit and determination, Liam?”⁴² Finn peered at Liam while Liam told a story of Finn never leaving a job unfinished even if it became frustrating and difficult. Liam glanced at Finn as he spoke, seeming to check he was listening.

⁴² I ask questions that invite commentary on a person’s virtues, knowledge and abilities from other family members to both give weight to such stories, and bring forward examples that occur in their relationship. Untold stories that are meaningful to families are often shared in these moments.





“Finn has this ability to apply grit and determination shown up in other areas of your life?”

“Yeah, pretty much everywhere. I would have been dead by now if I hadn’t had it. It’s important to do your best at things and not cop out.” Finn’s certainty suggested to me that this was a quality he valued.

“Would it be too much to ask for another story of you giving of your best with grit and determination?” I enquired, aware Finn had little energy and might want to save it for other matters.

Finn began to give me other examples with Liam chiming in and sharing with me his father’s persistence in living with his disease. When we had gathered a collection of stories of Finn’s grit and determination, I returned to another piece of information he had shared.

“You also mentioned your father taught you the ‘cello as he thought you would enjoy music. Do you think your father had some hopes for you in teaching and encouraging you further into a musical world?”

For a moment light danced in Finn’s eyes softening the lines of weariness that marked his face. “Music always gave my Dad joy. He loved it and he wanted to pass that on to me. He did too.”

“Like your father, do you get joy from music?”, I asked. Finn nodded in agreement. “Is this something you are still able to experience even now when you have so much to contend with?”

“Well yeah,” Finn said, sounding surprised by himself. “...Especially if I’m listening to the Bach ‘cello suites... beautiful.”

“What does this ability to appreciate music and to feel joy from listening to it give you day to day, especially at this time when you are living with some serious





health issues?"⁴³ I chose to narrow our focus to day to day living to reduce the size of my question.

"There isn't much that I can do anymore. I used to be a landscape gardener. That's gone, Liam and Pete keep my garden up for me now. I do appreciate what they do. But every month there's another thing I can't do. Listening to music is something that keeps me going I guess." Resignation was thick in Finn's tone.

I tried to imagine Finn's world. "What is it about the experience of listening to music that keeps you going?"

Finn hesitated as he considered. "It takes me to another place."

I was fascinated. "Would it be OK to ask where it takes you?"

Finn dropped his shoulders and his face relaxed. "Ah..... it takes me back to happier times."

I asked Finn about these happy times and he responded readily, sharing some treasured memories⁴⁴. I then returned to an earlier thread of the conversation.

"When did you first notice that you could take yourself to another place while listening to music, even when you were unwell and perhaps had the pain and sickness to draw you back?" I framed my question in such a way that Finn might notice this as an ability and something *he* was doing⁴⁵. I was aware that a person's experience of illness could rob them of a sense of having influence over their life.

⁴³ Rather than introducing battle metaphors, which can position a person as "winning or losing", I will often begin by enquiring how a person goes about "living with" an illness (Pilkington, 2014). This offers the person a wide territory in which they can describe their experience. I then listen for the language they use and will adopt their expressions, checking with them and enquiring about the meaning of the words they chose. If the person's preferred position is one of 'fighting', I will respect their stance and enquire into how they go about 'fighting' and what is important to them about it (see Pilkington, 2014). Such enquiries frequently open up new possibilities.

⁴⁴ This conversation, in addition to connecting Finn to some happy times, could also have evoked a sense of loss. If that had occurred, I would have acknowledged the loss and the conversation might have gone in another direction. Acknowledging loss is almost always important for a person to feel seen and heard. Significantly, there are usually few places where a person can speak freely of loss they are experiencing. Experiences of loss and suffering are often subjugated stories.

⁴⁵ People are often robbed of a sense of agency by the illness. By agency I am referring to a person having a sense of being influential in their own life. They may describe feeling useless and powerless. I hope to give them an





“In the last year or two at dialysis... I couldn’t read... or concentrate... so I listened to music and it made the time better. I got sicker but it was a habit by then and well, I’d done it every time. I was kind of used to it.”

“Used to it?” I queried, half to myself as I reflected, searching for a link to Finn’s increasing skill as he got less well.

“I’d kind of practiced it I s’pose...” Finn explained.

My ears pricked up. “You practiced it? How did you go about that?”

“It’s just what I’ve always done. I started doing it more and more. Certain pieces are better than others. The 1812 Overture doesn’t help pain but if I’m feeling like I need a boost it’s just the trick”, he shared with a small smile.

I furrowed my eyebrows as I reflected on what Finn had just explained. It seemed like he might have developed a number of skills to manage the symptoms he was experiencing and, hoping to draw these possible skills to Finn’s attention, I offered a brief summary for him to consider. “Can I just check that I’ve understood you right?”

I waited for Finn to indicate if it was alright with him for me to proceed. When he nodded with attention I continued, “Have you worked out which music helps you live with this and have even discovered particular pieces of music are helpful to you at different times depending on how the illness is affecting you?”

“Well yeah,” Finn exclaimed, looking pleased and surprised at the same time. He glanced at Liam who gave a firm nod and smiled with encouragement.

“And you said you’d practiced. Could you help me understand a bit more about this practice you’ve been doing?”⁴⁶

experience of agency through the way I frame my questions (see Bird, 2004). It is possible that Finn’s renewed sense of agency could have been significant in what followed.

⁴⁶ Note how I construct this question. I use externalising language to position Finn in relationship to his practising (*this practice*) and I emphasise that the practice is something he does (to highlight his agency).





Liam and I both turned to Finn who looked as if he was enjoying himself. “I found if I knew the piece... well, I was more relaxed, I guess. It was easier to forget the bad stuff and relax... So... I listened to music I liked till I knew every note. It used to help. Not so much now. I’m too far gone now. Listening to music is one thing I can do though. That counts for something. There isn’t much... Liam and Pete sometimes come and sit with me and we listen together.”

“It’s a nice time together Dad. We enjoy spending it with you,” Liam added, as if trying to convince his father. Finn raised his eyebrows and gave Liam a tired smile as if he didn’t quite believe what Liam was saying.

I turned to Liam. “What is it that you enjoy about spending time with your Dad?”

“It’s nice to be together as a family...”, he replied with a sidelong glance at Finn.

“Liam have you learnt anything from your Dad’s grit and determination or his ability to appreciate music and be taken to another place that has been useful to you in your life?”

Liam let out a big breath as if gathering some resolve. “Actually, it’s been enormously important to me. I had a tough time at school. I was bullied a lot. Mum was always supportive which meant the world to me but it was Dad who taught me how to keep going and not give in to it.” Finn looked down and shook his head slightly. Liam turned to his father trying to catch his eye and said, “You taught me how to survive Dad.”

Finn muttered, “Wish I could have done more...I didn’t realise how tough it was for you.”

“Attitudes were different then. You’ve been wonderful since Mum died, having me and Pete here and all. Dad I survived because of you and Mum. Both of you.”

Finn’s eyes glinted with tears as he reached out to Liam. They clasped hands for a moment. A small smile emerged on Finn’s face and his forehead relaxed. Liam lowered his shoulders and released a breath as he looked again at his father.





“Finn, what is it that you wish you could have done for Liam?”⁴⁷

Finn looked steadily at me but his words were for Liam. “Been there for him... understood more...protected him, I guess. Beth was better at it than me.” He turned awkwardly towards his son, moving his chest carefully around until his eyes eventually found Liam’s.

Liam choked up. He managed to croak, “Oh Dad. That means a lot,” before emotion silenced him.

We sat together not speaking as we quietly honoured what had passed between Finn and Liam.

After a few minutes Finn began to cough. Liam touched his back lightly waiting patiently for Finn to settle. When they both looked at me indicating their readiness to continue, I asked Finn, “Is there anything in particular you would have liked to have understood, or maybe protected Liam from that you would like to speak about today?” I was aware that Finn might die at any time and such a question could lead to further acknowledgement and connection that might be helpful for both Finn and Liam.

We continued talking together in this manner. Bit by bit I researched, listening out for what was important to them in their lives, their good intentions, skills, beliefs and hopes. When we encountered acts of kindness, loyalty, love and any virtue they might value, I asked more questions. Finn talked about his wife Beth, fatherhood, the important relationships in his life, and his work.

Twenty minutes later Finn signalled a wish to change the direction of our conversation. “It’s all been taken away Sasha. Bit by bit. I was an active person with a full life. Now all I’m left with is this terrible sickness.”⁴⁸

⁴⁷ Finn’s wish he could have done more for Liam was a significant new story of relationship that could have been lost or remained undeveloped. My intention in asking further questions about his wishes was to enlarge and strengthen this meaningful moment for them both. Such enquiries can bring forward hopes and desires that have previously been unspoken and not been storied in relationships. I am always listening for opportunities to bring such wishes forward.

⁴⁸ When I begin a conversation with an inquiry getting to know a person through identities other than the illness identity, a turning point such as this one usually occurs signaling the person’s readiness to enter into the territory





“Would it be OK to ask you a bit more about this sickness you’re living with Finn? Or is it something you prefer not to talk about too much?” I asked, opening up the space for Finn to describe what it was like for him to be so unwell. In spite of undergoing many assessments in health services I knew that Finn may have had few opportunities to talk about his experience.

Finn seemed to welcome the opportunity to talk. “I’m fainting every day and this pain...” Without seeming to know what he did, Finn held his ribs. He was clearly uncomfortable but carried on speaking though hopelessness seemed to hover nearby as he spoke. “I never have any energy and I feel so sick I don’t feel like doing anything anyway. I’m so nauseated I can’t eat or not much. Nothing tastes good. I can’t even sleep and I’m not nice to be with. Irritable. I want to die. I’ve had enough. I want to die.”⁴⁹

He sighed but the reflective pause was denied him as the next moment he coughed and choked, gasping as his face became greyer with every minute. Liam immediately bustled away to get some medication while I stayed providing companionship as Finn struggled to breathe. It took ten minutes for the medication to settle Finn’s breathing and longer for him to relax.

Once Finn was comfortable again and his breathing had eased, Liam reluctantly explained that he needed to go. There was medication to pick up and other jobs to do. I thought about the extra work and expense that often came along when someone is very sick.

The front door shut noisily a few minutes later. Finn and I were alone in the quietness of the house.

of their lives occupied by the illness. I wait for the person to indicate their willingness to begin talking about their experience of the illness. If they don’t indicate a desire to speak of such matters, I will enquire carefully approaching perhaps how they might want to enter such talk, or if they want to at all.

⁴⁹ Many people I meet with express wanting to die even as they actively take steps to ensure they live. The meaning of such a statement cannot be assumed and requires an enquiry to establish what it means for that particular person.





“You were speaking of how each part of your life is being taken away bit by bit from you and you said you’d had enough and want to die. Would you mind if I asked you a few questions about that?”

“Go ahead,” Finn replied, and I noted the warmth that had become increasingly present in his voice.

“Is there anything in particular that has been taken away that leads to this sense of having enough and wanting to die?”⁵⁰

Finn spoke with energy as he confided, “It’s all of it but mainly that I feel so awful. I wish I’d hurry up and die but I keep waking up every morning and another day starts.”

I tried to convey care in my tone as I responded, “Would you mind explaining a bit more of what you mean when you speak of wishing you would “hurry up and die”?”

Finn sighed. “I want to go to bed and not wake up in the morning. Tonight preferably. Every day is a struggle.”

“Could you help me understand⁵¹ what your day-to-day life is like Finn? Would you be kind enough to walk me through a typical day for you perhaps... so that I can better understand a little of what this struggle is like for you to live with?” I tried to shrink my question about the struggle Finn was experiencing into a more manageable size by offering a time frame so it wasn’t overwhelming.

Finn shared with me his daily routines. As I listened, I could easily empathise with why he might be feeling like he’d had enough. The effects of being unwell sounded exhausting. Hearing about Finn’s day-to-day life allowed me to gather some detail and as he talked, I asked him how he responded to each difficulty or symptom he encountered. I noted how eagerly he spoke to me in spite of the

⁵⁰ I cannot assume I know what causes a person’s suffering and what does not (Chochinov, 2022).

⁵¹ This kind of polite entryway into a question is a practice of David Epston’s (Ingamells, 2015) which I find helpful in conveying care and respect for what a person may be experiencing.





fatigue he was managing and the topic of conversation and wondered if he'd had the chance to speak of his efforts in response to the difficulties.

When a pause occurred in the conversation, I checked with him, "How are we going with this conversation Finn? Are we talking about what you hoped we might or have I taken us off track?"

Finn relaxed back in his chair. "It's actually a relief to talk about it, Sasha. I don't want to worry Liam and it's different saying it out loud somehow." I wasn't surprised by Finn saying that he didn't want to worry Liam. People I meet often want to protect those they love from the worst of their experience.

"Finn, how would you describe the changes you've had to make to your life as a result of this sickness?"

Finn picked at his cardigan meditatively as he considered my question. "It happened gradually. When I first got sick the dialysis really helped. I felt good and I could enjoy being outside and in the garden. I was able to keep working for quite a few years. But now, I feel terrible all the time. It's been all downhill. I can't work of course. I can't do anything. Liam cooks for me and I have help showering. Last week I started falling. That's on top of the fainting. And of course, I have to go out to dialysis three times a week. That's always a huge effort."

"Could you teach me about your experience of dialysis?"⁵² I asked, wondering what it was like for him.

"A taxi comes and picks me up 'cause Liam and Pete are at work. It takes me to the hospital. All the people having dialysis are in a special room hooked up". Finn sighed.

A picture formed in my mind. "Do you get to know the other people there?"

"We don't talk to each other. We just all stay on our beds there. There was one man who would talk to everyone in the room and got people chatting a little but then one day he didn't come back. I don't know what happened to him. People do

⁵² When I ask Finn to 'teach' me I am acknowledging his knowledge about his own life rather than assuming I know about dialysis and thus his experience.





gradually stop coming back but I don't know exactly why. I wonder about them you know.... have they died or did they decide to stop? In the end it's a bit of the same thing I suppose..." Finn sighed and his shoulders sagged. I had imagined the people all sharing their experience and learning about each other's lives, maybe finding some support in being together. Finn's description was a surprise and it contrasted with the stories I had heard from other people. I briefly considered what Finn had told me and thought of asking about the effects of not connecting to the other people receiving dialysis. However, I decided to take another tack which I hoped would be more useful to him.

"May I ask, what were your hopes and intentions when you decided on this routine of attending dialysis three times a week? (Song et al, 2013; Visser, 2009)"⁵³

"I wanted to live! And I wanted to have a good quality of life...I was pretty sick then. I'd been in and out of hospital, had three operations and endless tests. Beth was alive and we wanted to be able to do things together that we'd planned....and support Liam. It seemed a really good solution at the time. I didn't hesitate. I wanted to feel well again. The dialysis saved my life... and if I stop, I'll die."

I nodded solemnly to acknowledge the magnitude of what he was facing and we both paused for a moment. "...Were your hopes met by the dialysis treatment?"

Finn explained, "Yes they were at first. I was able to do things with Beth and I felt good."

"As the years went by did these hopes and intentions you held for the dialysis shift or change in any way?"⁵⁴

Finn answered me thoughtfully. "They changed without me knowing if you know what I mean. I got sicker as my disease progressed. I s'pose I've just kept on going

⁵³ Note how I position him as agentic. Such a question often brings out a previously unspoken narrative.

⁵⁴ I am hoping to create movement in the process, to create a spectrum of possibilities and avoid positioning Finn in a binary of for example "dialysis is either right or wrong" (See Bird, 2004; Wright, 2015). Treatment is complex, with advantages and disadvantages that are different for different people and can change in any given moment or over time.





to dialysis as I don't want to feel so sick. But then there are side effects as well, not as bad as the disease of course, but bad enough, and the visits to the clinic take a lot of time." He paused a moment and frowned. "It's different now. I don't know what to think. I want to die. Every morning I wake up and I think I've had enough. I can't live like this anymore. I'd rather just not wake up one morning."

"You've spoken of wanting to die and wishing you wouldn't wake up in the morning. Do you want to die by not waking up rather than say by deciding not to go to dialysis?", I asked, noting Finn had *not* said he wanted to stop dialysis.⁵⁵

Finn hung his head. "Well...yeah...that's right. I know I should stop dialysis but I can't seem to make the decision. Yesterday I thought I was going to stop but then I couldn't go through with it again. I've been doing it for months. It's awful, not just for me. I'm putting Liam and Pete through it too. I'm letting everyone down. I'm such a coward."

Tears filled his eyes.

I reached out, moved that he would judge himself a coward when such a decision would try most of us deeply. "Would you like to try and figure this out together?"⁵⁶

Finn took out a large handkerchief from a pocket in his cardigan. He dabbed his eyes with the folded hanky before slipping it back into his cardigan. "Yes, yes, that would be good," he responded looking at me with what might have been a glimmer of hope.

I considered what might be a helpful direction to go in. I was tempted to inquire about Finn's idea that he was a coward (White, 1993) but reflected we might first need to carefully research Finn's experience of decision making. Perhaps we could unravel some of the ideas that were leading Finn to feel he was letting people down and 'should stop dialysis'. He might then be able to arrive at some different

⁵⁵ Here I want to acknowledge complexity. We can hold many seemingly conflicting desires at once. I voice what I call a "both and" rather than an "either or" position. Sometimes when I explain this I use a baking metaphor. There are many ingredients that go into the mixture of a cake.

⁵⁶ Note how different this stance of 'doing it together' is from the counsellor being positioned as an expert who knows best.





ideas about himself. “Would it be OK if I asked you about your thoughts about dialysis and what you want?”

Finn nodded.

“I noticed that you said you were thinking that you *should* stop dialysis. Could you help me understand how you came to think stopping dialysis was something you were supposed to do?”

“Lots of ways. Dr. McDonald said he couldn’t do any more for me than what he’s doing. He said there comes a time when the dialysis just doesn’t work so well anymore and the disease has progressed too far. I know he’s worried about me. Last time that I was in hospital some of the ward staff talked to Liam and Pete and said I was so bad that they should try and help me stop. It’s expensive too and I could be taking someone else’s spot. I feel so terrible but I just can’t seem to do it.” Finn’s voice tailed off into a whisper. At the same time a pink flush appeared on his neck and began spreading up towards his face.

“It sounds like people are worried about what you are putting up with and there is quite a tide of thought towards thinking it would be a good idea to stop.....May I ask you though Finn, do you have any thoughts about how you would like to go about this last part of your life?”

“I don’t want to be like this worrying all the time and feeling such a chicken... I don’t know.....” Finn rested his head in his hands and looked down at the floor. I waited as he considered what he might want. Eventually he murmured, “I want to be enjoying my life... spend time with Liam and Pete... Quality of life I suppose. The dialysis gave me that for so long. I wanted it then but it started to change.”

“Can you remember how it began to change?”

“Yeah. It was a few years back and I was admitted to hospital. I started to have a few doubts about it then.”

“Do you remember any experiences or thoughts that led you to having these doubts and perhaps consider that dialysis might not be completely what you





wanted?”⁵⁷, I asked, wanting to acknowledge the mixture of possibly conflicting feelings as we researched the movement in Finn’s thoughts.

“I guess as I started to have some problems and was less well. After Beth died, I had a few doubts. I started to think I might not want to prolong my life but then I had some projects on and time kept passing. As the dialysis worked less well I thought about it more. When I started to feel awful, even though I was having it, I wondered, “what was the point”. Then I got more side effects after each dialysis session. I had to have another operation too and that made me think I might want to stop. But there was stuff to do and it just stayed in the back of my mind.”

“Would it be OK to ask what happened to the idea that it wasn’t completely what you wanted? Did it stay with you unchanged or did it begin to change over time?”

“As I got sicker I thought about it more and more I suppose... now that I think about it. I didn’t know if I could keep going. I got really irritable with everyone...wasn’t nice to live with. I guess I started to think about how bad I was feeling and whether I should keep going all the time.” Mournfully he added, “I want to be able to decide to stop and I can’t.”

I didn’t make any attempt to hide my compassion for Finn from my face or my voice.

“What a terrible position to be in. If you were to describe to someone else this weighing up you have been doing of whether to continue with your life, how big of a decision would they think this was?”⁵⁸

“Huge. It’s the only one I’ve got!” Finn smiled wryly in spite of himself. I nodded in acknowledgement.

⁵⁷ This question with the words “might not be completely” highlights a process of movement in decision making and again avoids a binary position while still leaving space for Finn to not know what he wants. Note Finn’s doubts are externalised. This is an externalising conversation where I use language to position Finn in relationship to ideas and attributes we are exploring. For example; “these doubts”, “the idea”, “this last part of your life”, “this weighing up” (White & Epston, 1990: White, 2007).

⁵⁸ Acknowledgement of the difficulties a person is facing can be very important.





“As you both want to die and at the same time consider whether you can go on with your life what do you take into account?”

“I guess it depends how I’m feeling. Most of the time I feel like I can’t even make it through another day I feel so bad.... I decide I can’t take it anymore and won’t go to dialysis but then I change my mind again like I did yesterday.”

As I listened to Finn, I noticed that the thought of stopping dialysis seemed to be specifically linked to the feeling he couldn’t bear the symptoms he was experiencing. I decided it might be helpful to gather more information. I also wondered if introducing the idea of possible agency in Finn both “deciding” and “not deciding” to go to dialysis might be useful to him. His description of himself as a coward loomed large in my mind.

“Hmmm.... Finn would you mind walking me through how you came to decide yesterday to stop dialysis and then re-considered and decided to continue?”

“Well....I couldn’t eat yesterday the nausea was so bad. I’d been awake a lot in the night and I was feeling so terrible. All I could do was sit in my chair. I’d had enough... It felt like I couldn’t go on. So I decided I wouldn’t go. But then I changed my mind at the last minute again. Made me late...”

Concentrating hard I asked him, “Could you walk me through sitting in your chair to you deciding to go to dialysis?”

“I was sitting in my chair feeling so terrible I wanted to die... and then Sue, the wife of an old friend, came to the house with a cake. I couldn’t eat any of course. Then I sat in my chair. And....half an hour later I thought maybe I’d go.”

“What sort of cake did Sue bring?”

Finn raised his eyebrows. “It was a chocolate cake she’d made.”

I reflected on Sue’s kindness. “Did she make it especially for you?”

The pace of Finn’s speech quickened, “Yeah she did. Nice person. She often pops in with my mate or sometimes on her own with some cooking and we have a chat. She’s a sympathetic woman.”





“May I ask what difference it made to you to have Sue pop in with a cake she had baked especially for you and have her stay for a bit of a chat?”

“I dunno. I guess it felt like life wasn’t so bad maybe.” Finn sat up a little straighter in his chair.

“What was it about your life in that moment that made it seem “not so bad”?”, I asked, collecting more details.

Finn spoke with gratitude, “There are good people around. Kind people who are interested in me I s’pose. Makes me think life isn’t so bad after all.”

“How would you say feeling ‘life wasn’t so bad after all’ influenced the way you felt about going to dialysis?”

“Well... I do wish I didn’t wake up this morning but yesterday, well I felt I could go on, that things weren’t so bad....and... so I went to dialysis,” Finn replied meditatively.

“Do you both want to die and value some of what your life gives you?”, I persisted.

Energy penetrated Finn’s voice, “Well...yeah! I never thought about it like that.”

“Would it be OK if you gave me another example of you re-deciding to continue on with your life?”, I asked intending to examine this idea further.

Finn began to give me examples of him deciding to stop dialysis and die because he felt he could no longer go on and then finding some reason to continue on with his life. Sometimes it was a gift from someone, a kind act, a moment of respite from the symptoms he was living with or even a phone call. I discovered that he was skilled at finding things to appreciate and reasons to continue with his life.

“Finn, do you both want to die and value some of your life?”, I repeated with a smile.

He responded, “Well yeah. It doesn’t sound like it makes sense but yeah!”





“When you start to feel overwhelmed by the symptoms of the illness or the side effects of dialysis what happens to this valuing of your life?”⁵⁹

“I don’t know, I lose it... I feel overwhelmed. Then someone does something nice and I remember it again.” Finn looked up with a small smile on his face. I noticed with admiration his gratitude for the people in his life.

I was tempted to research more about this value Finn held for his life but time was running out and he was starting to look fatigued. I made a mental note to return to it if we met again and instead decided to pursue the way he described himself.

“Finn you described yourself earlier as a coward. Would it be OK to ask you what your understanding of a coward is?”

“Someone who runs away...is chicken and doesn’t face things,” he muttered a bit shamefaced.

Slowly I summarised a little of our conversation. Finn nodded as I recapped, “You’ve talked about wanting to die and deciding to stop dialysis.... but then being reminded of the value you hold for your life by appreciating someone or something, and then re-deciding to continue with your life by going to dialysis. Would you describe this as running away from death, as cowardly, or is it perhaps closer to moving towards living, appreciating it, and being connected to what you hold dear?”

Finn stared at me wide eyed. He managed to stutter, “Well....yeah my life...yeah I’m doing that...not running away...no not running...”

I repeated my question offering a little more for him to consider. “Are you valuing and respecting your life even as you wish to die?” Finn nodded. “Does that valuing perhaps connect you to living and make ‘having a hand’ in the timing of your own death more difficult to contemplate than most of us could possibly imagine?”

⁵⁹ Note that I have externalised ‘valuing’ and positioned valuing as something Finn is doing actively (see Bird, 2004).





Finn nodded again. Tears flowed down his face as he stared at me unblinking. He reached into his pocket for his handkerchief.

“I’m not a coward,” he croaked.

We sat together with Finn mopping his face with his handkerchief. He sat, no longer hunched or downcast but upright, making eye contact with me from time to time as he continued to pat his skin dry. Every now and then his face lightened and a small smile emerged.

In a whisper he repeated to himself as he patted the tears away, “No...I’m not a coward...”.

We were coming to the end of our time together and I noticed Finn was beginning to look weary. After a few more minutes of conversation I finally checked, “Is this a good place to stop?”

“Yeah. It probably is.”

Tentatively I asked, “Would you like to meet again?”

“Oh yes. Can you come back soon? In a few days?”

I was aware that Finn could die at any time or in the next few weeks. Time has a different meaning when someone is approaching death and that meaning has a role in shaping the gap between counselling meetings as well as the length of them. I looked up from my diary and smiled at Finn, “I’ll be back at work on Wednesday. That’s five days. How does that suit you?”⁶⁰

“Yeah, yeah. Come back then,” he answered hastily returning my smile.

Getting curious about fear

Five days later I arrived at the house grateful for another chance to talk with Finn. We had greeted each other warmly and were now deep in conversation as we sat

⁶⁰ Five days is a very short time between meetings by usual counselling standards with someone who is well but not for someone so close to death. As a person begins to get sicker more rapidly towards the end of life, time takes on new meaning.





together, comfortable in each other's company. Finn had greeted me with descriptions of his struggle to live with symptoms of his disease. As I listened, I noticed he looked significantly less well than he had just five days before. The lines etched into his face had deepened, adding shadows to the transparency of his skin, and as he pulled his heavy woollen cardigan about him, I thought he was perhaps even thinner.

"I'm still here," Finn stated ruefully. His voice scratched over the words as he explained, "I knew I'd go for treatment this week. I nearly couldn't get out the door. I was vomiting and it was almost too much but somehow I managed... your hospice doctor visited afterwards and it's better now..."

My speech slowed to match his. "How did you know you'd go for treatment?"

Finn's eyes twinkled. "I pretty much decided after you left last time. I figured I needed a bit more time to work things out."

I gave a small smile in return. "What made you think that it might be helpful to give yourself a bit more time to work things out?"⁶¹

Finn immediately looked serious. "I've been wondering... You must have seen people like me. I feel so bad now... how much worse is it going to get? I'm kind of wondering about what it might be like...you know, dying..." Finn's voice trailed off. His face was drawn and tense. I could see a pulse at his temple moving his papery skin rapidly in and out.

I wondered if fear could be playing a role in making it difficult for Finn to know what he wanted. "Would it be helpful to talk about your wonderings about dying?"⁶²

Finn raised his chin though his voice had a tremor, "Yeah...might be."

⁶¹ I highlight his agency by repeating this is something he is doing in my question.

⁶² A counsellor practising in palliative care is required to be steady about conversations concerning death. I often venture with people into areas that are considered prohibited by dominant Western societal ideas.





“Is it OK to ask which part of dying you have been wondering about?”⁶³ Some people I meet with are more worried about the process of dying while for others their biggest concern may be about how family will cope or what it might mean to be no longer alive. I didn’t know where Finn’s attention was focused.

Finn drew his eyebrows together and shifted in his chair. “The dying part. It’ll all be over when I’m dead⁶⁴. I guess I’m wondering what it’s going to be like...might not be too good...might be painful.” He looked up at me with wide eyes.

I was aware from the hospice doctors that Finn might feel very sick when he stopped dialysis but the medical staff had also spoken of what could be done to help Finn. Dr MacDonald had also told me that this information had been explained to Finn many times. With this in mind I wondered if it might be helpful to draw out the narrative of what could be done to support Finn.⁶⁵

“What did the doctor say they could do to help you should you start to feel sick coming off dialysis?”⁶⁶

“She talked about one of those pumps...that make you relaxed and give you pain relief all the time....” He glanced at me as if checking this was true. I nodded in response.

Finn and I continued to talk. As we spoke, it became apparent that he was now voicing fears and considering the end of his life in a way that until now he had not been able to. Finn repeated to me the information he had been given by the doctor. As we revisited what Finn remembered it seemed to reassure him. It was

⁶³ As I ask this question, I am deconstructing the idea of dying with Finn and examining his relationship to it. Dying is externalised and acknowledged through language as a complex multi-faceted experience rather than as a simple entity.

⁶⁴ The people I meet with have many varying ideas that shape their relationship with illness and death. See Pilkington, 2014; 2016; 2018; 2021 for illustrations of practice with people who hold different beliefs from Finn.

⁶⁵ Sometimes people turn to their relationship with me to verify what they have been told many times by other health professionals.

⁶⁶ I take up a naive enquirer position over health information and resist “knowing” anything. Not only is this important medico-legally, it provides the person with the option to try out ideas, with me alongside them asking questions rather than being yet another person telling them what to do. There are many far more qualified people doing that already.





as if Finn had been unable to consider and absorb the information until that moment he uttered the information himself.

Finn rounded our discussion off with, “I’ve just got to decide and follow through with it... whichever way.”

“Would it be OK if I asked you about this desire⁶⁷ of yours to make a decision and to follow through with it? Have I got that right?”

Finn nodded. “Yeah, that’s right. Sure.”

“What makes it important to you to decide and then follow through?” We both knew he didn’t have long to live regardless of whether he stopped dialysis or not.

I looked over at Finn who was shifting stiffly in his chair. Noticing he had more to manage than just my question I elaborated a little, conveying in my tone as much care as possible. “If you were to die say in your sleep having decided *not to decide one way or another* about going to dialysis how would that sit with you for example?”

Mournfully Finn intoned, “My soul would know. I’d die feeling like I’d copped out and I hadn’t looked after Liam and Pete. It’s hurting them. I have to decide one way or the other. I feel like I can’t live properly while I can’t decide. It’s with me all the time.”

“Mmm...”, I empathised, my complete attention on every word. “What do you imagine it might feel like to have made a decision about what you want to do?”

Finn sighed. “Peaceful...”

“If you were to decide, how would you know if it was a decision that you would want to follow through on? That it was a decision to be acted on?”

⁶⁷ Note I use the language “this desire” (see Bird, 2004) which positions Finn relationally to desire allowing us to research it.





“I guess I would know if it was *my* decision and I thought it was the right thing to do. Not what someone else thought was right but what I thought. I’ve been thinking about what I told you last time.”

“How would you recognise a decision that was yours and right for you?”

“I would feel it in here”, he replied, putting his hand over his heart, “...not in my head. I wouldn’t worry all the time.”

I considered asking Finn if he could envisage any steps that might take him in the direction of deciding but wondered if it might be too hard of a question, which would not be helpful. As I was pondering Finn repositioned himself again in his chair groaning quietly with each movement. “I just feel so bad Sasha. I’m so tired from all this. It’s gone on and on. Everything’s a struggle.” He sighed heavily.

“Which parts of the struggle are you noticing as we talk Finn?”

“It’s the pain. I can’t seem to get away from it today,” he groaned. Rather than ask him about the pain which had already been canvassed in depth by the two of us earlier,⁶⁸ I enquired, “Finn, what keeps you going day to day when you are living with pain that you can’t get away from as well as many other challenges caused by this illness?”

“It doesn’t feel like I’ve got a choice Sasha. I just keep on keeping on like I’ve always done.” I waited as he seemed to contemplate. A small smile crept onto Finn’s face. “There’s one thing though. See those buds there?”, he said, pointing to some bulbs outside the window. “I’m waiting for them to flower.”⁶⁹

⁶⁸ I wouldn’t ask the following question if I hadn’t already acknowledged what he was managing.

⁶⁹ Timing is important. I find that if we construct a space in which a person can speak fully about what they are struggling with, then, in time, when they are ready, they will turn the conversation and often spontaneously offer reasons why they want to continue with their lives or tell me what they are grateful for. I am watchful for the pressure to “be positive” (Willig, 2011) which silences talk of suffering and mortality. There is a distinction between talk that results from people feeling they “should” be a particular way and genuine expressions of what a person finds meaningful. I don’t think Finn would have talked about the buds if I hadn’t already fully witnessed and acknowledged his experience.





“What is it about waiting for the buds to flower that has you keeping on with your life?” I wondered, curious.

“You just never know exactly how they are going to flower and that moment when the petals unfold....so beautiful.” Light crept into Finn’s eyes and his brow relaxed as he talked about the plants he had delighted in nurturing most of his life. I was fascinated by his ability to appreciate beauty and asked him about it. When he had concluded I decided to research further.

“What else supports you to keep going as you manage this disease?”

Apologetically Finn explained “I’ve never watched much TV but Pete and I have been watching Downton Abbey together. We both like it. I keep wondering if Edith’s going to be alright.”

I grinned. I wanted to know too!

As we talked, I reflected that there were many aspects of Finn’s life he had found a way to enjoy. As the list grew longer, I marvelled at his ability to adapt to his circumstances.⁷⁰ If I had guessed at that moment, I would have imagined Finn would decide to continue with dialysis for as long as possible.

I finally asked him, “You have spoken of finding ways of enjoying parts of your life in spite of all that you are managing, of things you are looking forward to and times of companionship. Is there anything you’d like to add that’s important to you in the keeping on going?”⁷¹

Finn screwed up his face concentrating. After a pause he said with generosity, “Well....Liam is important... and Pete his partner. I want them to be happy.”

⁷⁰ Note that I am listening for his abilities and knowledge. Listening for pathology here might position Finn as “in denial” (see Pilkington, 2017; Zimmermann, 2004; 2007).

⁷¹ I often offer small summaries that preface a question asking if there is anything else a person wants to add. One time I might do this is when the conversation seems to come to a natural pause. In response, the person may reflect further and come up with an answer they wouldn’t normally give. These ‘add on’ answers that come after readily accessible stories have been exhausted are often invaluable.





I could see Finn was tiring. He had begun to cough and his speech had slowed. I carefully summarised what we had covered, checking with him as I spoke. We then arranged another time to meet the following week.

As I picked up my bag and got ready to leave, I turned at the door to say a final goodbye. Finn smiled at me. In what could have been a mischievous tone he sent me on my way with, "You know Sasha....I have hope for my life!" His smile became a grin and I left, uplifted by the manner of his good bye.

Deciding to die

Five days later I sat in the morning meeting unable to focus. I heard conversations around me but they passed me by. All I could think of was the news that had greeted me when I walked in the door. Finn was in the hospice inpatient unit. He had decided to stop dialysis. Finn was dying. As the news reverberated through me some of the staff offered their praise. They understood Finn's decision as the right one given his poor quality of life.

"That's good work you've done Sasha. That poor man was suffering so much," a colleague said.

The kind words didn't ease my mind though. Dominating my thoughts was the question, "Was this what Finn truly wanted? Was it right for him?" My internal agitation made its way to the surface and I moved restlessly in my chair. I could hardly believe Finn's swift change of heart. "What had happened? How had he come to decide?"

I had met with many people who were considering treatment options they had been offered by their doctors. I *often* created spaces in which a person could discuss how they wanted to approach the end of their life. What was it that had me quite so unsure this time? Was it the rapid time over which this had all occurred? I thought about Finn saying to me, "I have hope for my life" as I had left his house only the week before. I knew I had held no preference as to what Finn should do, but what effect, if any, had our conversations had on his decision making? I resolved to make sure Finn was doing what he truly wanted.





I almost ran downstairs to my office checking my diary as I went. As I made my way through the hospice inpatient unit, I asked one of the nurses to enquire if Finn would like to see me⁷². When I arrived in my office the answer was already waiting for me on the answerphone. Finn and Liam were keen to meet with me.

I knocked on the door to Finn's room in the late morning. Finn was lying in bed in his pyjamas. His head peeped out of the bedclothes, the white of the sheets drawing my attention to his pallor.

"Hi Finn."

"You found me alright then. Thought you might go to the house...", he rasped. Finn's mouth turned up as he attempted a smile. He seemed to have forgotten that I had arranged this meeting with them only hours ago.

Liam's eyes shone with tears as he explained, "We arrived yesterday morning. Dad's been getting worse every day. He's a bit confused at times. They say he's only got a day or two maybe...".

Tentatively I asked, "Finn do you have the energy to catch me up on events since we last met? Or would it be easier if Liam helped me out here? It seems like a lot has happened..."

Each word was an effort as Finn explained, "After I saw you, I went to dialysis and decided I'd had enough."

My speaking seemed to slow to the pace of his. "How did you know you'd had enough?"

"It was just too difficult." The gaps between each exchange lengthened as we responded to the limits of illness.

"May I ask what it was that became too difficult?"

⁷² I asked the nurse to enquire, as it would be easier for Finn and Liam to say "no" to her. If I had asked them, they would have probably been kind and accommodated me even if they didn't really feel like talking. It is hard to say "no" to health professionals because of the power relationship and people are often generous with their time even when it is to their own detriment.





“Living... when I decided to stop treatment it was like a great relief... as though a weight had been lifted off my shoulders... I was in pain all the time. I’m in the final stages... and I’d had enough. I wanted some peace.”

“What were you hoping for that some peace could give you?”⁷³

“For the last few months I was always in pain, tired and felt sick. I was falling over and I couldn’t breathe properly. I never got a day’s relief...” Finn paused gathering his breath. I remained silent allowing him the time he needed to go on.

“The doctor told me it was harder to stop than to start dialysis... and I started to think about that. It’s easy to start because you think it’ll do you some good. And it does to start with. Then it gets harder and harder... to get some peace you have to feel worse first.” Finn began to cough. I waited quietly, conveying in my stillness and relaxation that I was in no hurry for him to resume the conversation. When Finn had settled, I picked up the thread again, “You’ve spoken to me of the struggle to decide. How did you move towards thinking that some peace might be more important to you than continuing on with your life?”

⁷³Note the construction of this sentence. “What were you hoping for that some peace could *give* you?” Larry Zucker has offered me some valuable insights into questions such as this one that inquire into actions that new identity descriptions might make possible. He explains that “alternative stories in Narrative Therapy matter most because they point the way to alternative actions”. He is always “looking for language that creates lanes for possible actions”. Larry is interested in what a new description might allow/provide/ enable a person to *do* (personal communication, 11th April, 2021). These inquiries that Larry referred to as “meaning-in-action questions”, move the conversation towards how the person might enact the new story of their identity thereby making such actions more possible. They plot possible paths for the alternative story to go forward. You will notice that I take liberties with grammar in order to create some of my questions. For example, I shift nouns and adjectives into verbs and extend the meanings of particular words. Such a play occurs when I externalise “some peace” rather than “peace” and change the meaning of “some” even as I reproduce Finn’s language. I do this with particular therapeutic purposes in mind. “Some peace” avoids a binary (Bird, 2000, p. 20-25; Bird, 2004, p.23) of Finn being at peace or not and creates space for movement in Finn’s experience of peace. It also allows room for other experiences not just peace. Johnella Bird calls this “language for the in-between” (Bird, 2000, p.24). There are many examples of “language for the in-between” in my stories as it a significant language practice I use every day in my conversations with people at the end of life.





“I realised I couldn’t do what I wanted, I don’t have quality of life and I thought a lot about what I wanted... what was important to me...you asked me that....and I thought ‘I want some peace’.” Finn shut his eyes underlining what he had said.

“You had some worries about this time and what it might be like. Are those worries still there or have they changed in some way?”

“They’re different now, not so bad. The staff are helping me.” Finn looked out the door in the direction of the nurses station. “I’ve been thinking about it for a long time and I just thought, ‘this is enough’.”

Finn tried to move up the bed but couldn’t. Indicating with his hands to Liam he didn’t want help, he settled for moving his body onto his side.

Liam answered as he watched Finn struggle but respected Finn’s request to be independent. “It was a shock. It took me a while but I understand. And it was a relief especially when we found out Dad could come into the hospice for care. Suddenly he was the person he used to be. Laughing and joking and poking fun. He was himself.”

Turning to Finn I asked, “Do you feel more yourself?”

Finn answered as if each word was weighted down by the effort it took to utter. “Yes. I was using all my energy in the fight... with the illness. It was a struggle every day. There was nothing left... Just to go to dialysis was so exhausting. It’s a relief... A total relief and now I want peace. I won’t go back to dialysis again...”

I turned to Liam to give Finn some respite from speaking. “Liam what do you think your Dad is prioritising when he chooses peace?”

“Control over himself again. He wanted to take it back. He’s spent so long being sick, going to dialysis, taking so many pills, trying to sleep and dealing with the pain. It’s a relief for him now. And drugs have side effects. He’s more himself now.”

Finn added, “Yeah...it kind of enslaves you....” His eyes closed.





“Liam you said that your Dad stopping dialysis was taking back control and being the person he is. Could you tell me about this person you understand your Dad to be?”

“Organised. He always liked to be in the driving seat. He is a bright active man who always managed everything on his own. He got himself to treatment every week through all these years, did things on his own terms.”

Finn opened his eyes again and echoed, “Yeah and I’m going out on my terms now.”

“Finn, you mentioned that “it kind of enslaves you” earlier. Could you help me to understand more of what you mean by that?”

Finn sighed. “My catheter leaked last night...everywhere. The nurses had to come and we did a big clean up. It’s not just the dialysis. It’s everything. All the problems, the treatment, the side effects. It’s all the time.”

“So much to deal with....”, I murmured.

Finn responded with a long speech for someone so unwell. “I feel free now.... A man came to the dialysis unit for his first treatment when I was having my dialysis the day after I saw you. What ended up being the last one. I watched him come in and I thought, “if it was me doing it again, I would never start”. I was kind of shocked by myself thinking that but I realised it’s true. I wanted to go over and tell him not to do it... but I didn’t of course. And then I thought, “What am I doing here?” and suddenly I knew I didn’t want to be. I thought it would feel like giving up but it doesn’t.....it feels right in here...” Finn moved his hand to his heart. “I am me again...and soon I will have some peace.”

As Finn spoke, I reflected that I might not ever fully understand what had allowed him to decide. I wondered if reconnecting him to a sense of his own worth or to some of his knowledge and abilities had had a role but I would never know for sure. A slight smile emerged on Finn’s relaxed face. In that moment I could see what looked like the peace he had been describing.





I left the room after thanking Finn for sharing so much of himself and his life with me, and teaching me about decision making.

It wasn't the last time I saw Finn though.

Two days later I walked past Finn's room knowing he was now close to death. Finn was alone, lying in his bed and I thought I could hear Liam's voice in the hallway talking to a nurse. Finn invited me in with a look. Speech seemed beyond him. When I sat down by his bedside, Finn reached over to hold my hand. Willingly I offered it to him and he clutched it tightly. We remained silent, though I could feel what I thought of as companionship and warmth between us.

Finn lay sprawled on his back with his eyes closed. His breathing was moist and I thought he was possibly close to death. After a time, I felt a slight pressure on my hand. "Is this it?" he whispered, seeking my confirmation he was dying.

Steadily, gently, and with all the kindness I could fold in, I slowly confirmed, "Yes... This is it."⁷⁴ He seemed to relax then, sinking back into his bed as if soothed. Though his hand still held mine, it had lost its tight grip.⁷⁵

References

- Bird, J. (2000). *The heart's narrative: Therapy and navigating life's contradictions*. Edge Press.
- Bird, J. (2004). *Talk that Sings: Therapy in a new linguistic key*. Edge Press.
- Carlson, T.S., Epston, D., Haire, A., Corturillo, E., Lopez Huerta, A. & Pilkington, S.M. (2018). Learning narrative therapy backwards: Exemplary tales as an

⁷⁴ It is not uncommon for people I have met with to seek my confirmation in this way even though they have been told by their doctors that they are dying. Over dinner one evening I reflected on this with Jenny Freeman. She suggested that a person knows if another person can "show up" or not for such a moment. I agree that people do perceive this. Perhaps, the question, "Is this it?" could have a meaning like, "Can you be present for me with this?"

⁷⁵ Finn died shortly afterwards with his family present.





- alternative pedagogy for learning practice. *Journal of Systemic Therapies*, 36, 94-107.
- Chochinov, H.M. (2012). *Dignity Therapy. Final words for final days*. Oxford University Press.
- Chochinov, H.M. (2022). The platinum rule: A new standard for person-centred care. *Journal of Palliative Medicine*. [http://doi: 10.1089/jpm.2022.0075](http://doi:10.1089/jpm.2022.0075)
- Epston, D. (1989). *Collected Papers*. Dulwich Centre Publications.
- Epston, D. (2004). Joel, can you help me to train Amber to be a guard dog? *Journal of Brief Therapy*, 3, 92-106.
- 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.
- Epston, D. (2016). Getting to know the person ahead of the problem: Wonderfulnesses as expressions of moral character and virtue. In D. Marsten, D. Epston, & L. Markham (Eds.). *Narrative therapy in wonderland: Connecting with children's imaginations and knowhow (npp)*. New York: Norton.
- Epston, D. (2018). In pursuit of goodness. *Journal of Contemporary Narrative Therapy*, 3, p.2-26. www.journalcnt.com
- Frank, A. (2017). Bioethics and "Rightness". *The Hastings Center Report*, 47(2), 53. doi:10.1002/hast.694
- Heath, T. & Arroyo, P. (2015). Spitting the truth from my soul: A case story of rapping, probation, and the narrative practices. Part 1. *Journal of Systemic Therapies*, 34(3), p.77-90.
- Heath, T. Carlson, T. & Epston, D. (2022). *Re-imagining narrative therapy through practice stories and autoethnography*. Routledge.





- Ingamells, K. & Epston, D. (2014). Love is not all you need: A revolutionary approach to parental abuse. *Australian and New Zealand Journal of Family Therapy*, 35, 364-382.
- Ingamells, K. (2015). *From 'learning the scales' to improvisation: A journey to becoming a narrative therapist*. Unpublished paper presented at the Therapeutic Conversations Conference, Vancouver, Canada.
- Ingamells, K. (2016). Wilbur the worrier becomes Wilbur the warrior: A teaching story for narrative family therapists. *Journal of Systemic Therapies*, 35(4), 43-57.
- May, T. (2015). *A Significant Life. Human Meaning in a silent universe*. The University of Chicago Press.
- Russ, A., Shim, J. & Kaufman, S. (2007). The value of "life at any cost": Talk about stopping kidney dialysis, *Social Science & Medicine*, 64, p. 2236- 2247.
- 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.M. (2016). Insurance policies for miracle cures: A story illustrating narrative counselling practice with someone approaching death. *Journal of Systemic Therapies*, 35, 71-87.
- Pilkington, S. M. (2017). Deconstructing denial: Stories of Narrative Therapy with people approaching death and their families. *Journal of Contemporary Narrative Therapy*, 1, 54-75. www.journalcnt.com
- Pilkington, S.M. (2018a). A story illustrating Narrative Therapy in a cross-cultural conversation with someone approaching death. *New Zealand Journal of Counselling*, 38, 39-49.
- Pilkington, S.M. (2018b). Writing narrative therapeutic letters: Gathering, recording and performing lost stories. *Journal of Contemporary Narrative Therapy*, Special Release, 20-48.





- Pilkington, S.M. (2021). Narrative Therapy with someone experiencing significant loss and grief: An illustration with reflections on practice. *Journal of Contemporary Narrative Therapy*, 1, 58-97.
- Pilkington, S. M. (2022). Blossoming in the Storm. In T. Heath, T. S. Carlson, & D. Epston, (Eds). *Reimagining Narrative Therapy through stories and autoethnography*. p. 117-150. Routledge.
<http://doi.org/10.4324/9781003226543-7>
- Sinclair, S., Beamer, K., Hack, T. F., McClement, S., Raffin Bouchal, S., Chochinov, H. M., & Hagen, N. A. (2017). Sympathy, empathy, and compassion: A grounded theory study of palliative care patients' understandings, experiences, and preferences. *Palliative Medicine*, 31(5), 437-447. <https://doi.org/10.1177/0269216316663499>
- Song, M., Lin, F., Gilet, C., Arnold, R., Bridgman, J. & Ward, S. (2013). Patient perspectives on informed decision-making surrounding dialysis initiation, *Nephrology Dialysis Transplantation*, 28, p. 2815–2823, <https://doi.org/10.1093/ndt/gft238>
- Visser, A. (2009). Accepting or declining dialysis: Considerations taken into account by elderly patients with end-stage renal disease. *Journal of Nephrology*, 22, p. 704- 799.
- Wampold, B. (2021). Healing in a Social Context: The Importance of Clinician and Patient Relationship. *Frontiers in Pain Research*. 2, 684768. <http://doi:10.3389/fpain.2021.684768>
- White, M. & Epston, D. (1990). Narrative means to therapeutic ends. Adelaide Australia: Dulwich Centre Publication
- White, M. (1993). Deconstruction and therapy. In S. G. Gilligan & R. Price (Eds.), *Therapeutic conversations* (p. 22–61). W.W Norton & Co. (Reprinted from the "Dulwich Centre Newsletter," 3, 1991, 1–21)





- White, M. (2000). Re-engaging with history: The absent but implicit. In M. White: *Reflections on Narrative Practice: Essays & Interviews* (pp. 35-58) Dulwich Centre Publications.
- White, M. (2003). Narrative practice and community assignments. *International Journal of Narrative Therapy and Community Work*, 2, 17-55.
- White, M. (2007). Maps of narrative practice. W. W. Norton.
- Willig, C. (2011). Cancer diagnosis as discursive capture: Phenomenological repercussions of being positioned within dominant constructions of cancer. *Social Science & Medicine*, 73, 897-903.
- Wright, L. (2015). Brain science and illness beliefs: An unexpected explanation of the healing power of therapeutic conversations and the family interventions that matter. *Journal of Family Nursing*, 21, 186-205.
- 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.





Commentary on Sasha McAllum Pilkington's "Deciding how to die":

What's *Right* for Finn

Arthur W. Frank, Ph.D

When Sasha first arrives at Finn's house, she wants "to search for what might be right for him in his decision making," and to qualify what she means, she cites a short piece I wrote about how people hold a sense of *rightness*. Near the end, Finn uses the same word to describe his decision to cease dialysis and be admitted to the hospice in-patient unit: "it feels right in here." I want to let Finn's story help me to develop what's meant by *right* and then consider how our idea of what counts as being therapeutic might be affected if we think of people holding rightness not as an idea or even an aspiration, but as what I can best call a *telos of alignment*. That's a dense phrase that I will work my way back to.

The article of mine that Sasha cites sought to counterbalance the way that academic bioethics and moral philosophy often imagine moral decision-making, including how people hold themselves accountable for their decisions. Much of bioethics treats people as if they were responsive to arguments phrased in terms of principles. Instead, I imagine people to be making decisions and holding themselves accountable for their actions based on a sense of rightness that is not principled. Rightness is *felt* as something embodied. People express their sense of rightness affirmatively in phrases like "It's just what you do," and negatively in "It's not who I am." Rightness is the unspecified but deeply felt standard that people hold themselves to, and the standard they expect others to follow to varying degrees—whom we expect to act according to our sense of rightness, in which situations, is a subtle, nuanced issue.

People may describe their sense of rightness as being intuitive, and so it feels to them. I understand rightness as a sedimentation of multiple lines of feedback, including hearing both explicit and tacit messages to oneself and to others, as well as experiences of how past acts have worked out. Messages about rightness begin in the first parental responses of "good" and "bad," and such messages proliferate in schools, religious institutions, and forms of what we can call civic education. Crucially, rightness is group specific, reflecting an individual's sense of what people "like me" are supposed to do and find it possible to do. In that



supposed to do, rightness reflects membership: any person maintains membership in a group—families, workplaces and occupational groups, clubs and community groups, affiliations of gender and ethnicity—by doing what counts as right in the eyes of that group. Groups have spokespersons, either self-appointed or formally selected, who express rightness both tacitly and explicitly. The sense of rightness thus becomes deeply inscribed in anyone’s sense of self and self-expectation, but it is not immutable. People seek therapy when their sense of rightness runs up against some reality that is undeniable. That’s a dilemma people need help with—it’s Finn’s dilemma that he needs Sasha’s help with.

To put all this another way: the American Shaker hymn *Simple Gifts* has a line: “And when we find ourselves, in the place just right....” When we hear that being sung, we don’t ask questions. We don’t inquire as to the geographical coordinates of that place or what the local economy is based on. Hymns don’t ask theological questions; they make such questions seem secondary to living everyday faith. The hymn’s line bypasses those left-brain concerns by appealing to an intuitive part of ourselves that has a vague memory of being in a place just right and a hope of eventual return.

I recall the novelist John Fowles writing that for him, what instigates works of art is human memory of an infantile, possibly fetal, wholeness without concern. On Fowles’s account, which many others express in different ways, art works give us a transitory sense of again being there, where nothing needs to be questioned. Wholly absorbed in the painting, or the music, or the poem, we are for that moment in this place just right. Forms of worship may have their appeal by giving us that sense of being in the place just right, which is why the line from the hymn *works*, both on us and for us. The line is what philosophers would call performative: the words themselves enact what they call for (Austin 1965). Instead of imagining some actual if otherworldly place, maybe the place-just-right exists only in the words and music of the hymn, and the closest we will get to this place is when we sing or play or just listen to that hymn, and let it take us there. The aspiration of hospice care is similar: to make dying feel right; if not just right, at least right enough.

To consider Sasha and Finn, I think about how each is situated as an actor. Each is in a place between, a place of uncertainty as to what their respective tasks are. Finn’s situation reminds me of one of the most significant lines I remember in a bioethics case report I read years ago. A woman in the early stage of pregnancy



was informed that ultrasound tests showed her baby had a fetal abnormality. She had to make a decision, based on uncertain information. When she was told all this, she responded by saying that this is *a choice no one should have to make*. Finn faces that sort of choice. Modern medicine has, by offering dialysis, given him some years of living what's called a reasonable quality of life. But that's a time limited offer, which life itself is for all of us, and now that Finn's time has reached its limit, he *must* make a decision. He either perseveres living what has become a terrible quality of life, or he decides to end dialysis. His death will be his decision, rather than what simply befalls him.

Finn's choice fits the parameters defined by Gregory Bateson and his colleagues (1972), at the beginning of the family therapy movement, as a double bind: if he does (x) he loses; if he does (y) he loses; and he can't leave the field, because to make no choice brings about an outcome. If Finn continues dialysis, he suffers. If he ends dialysis, he tells Sasha that he will feel like a quitter or a coward; thus he suffers from the prospect of acting in a way that contradicts his sense of the identity he feels right upholding. And Finn suffers from indecision itself: it becomes difficult to distinguish whether he feels like a coward for wanting to stop dialysis, or if it's his indecision that he considers cowardly. The issues conflate, as one feeds another.

Finn's double bind is produced by an institutionalized technology. Bateson understood families as the source of double binds. For Finn, the double bind began when medical institutions offered him a Faustian bargain: he can have longer life, but he sells his soul in the sense that some day—and that day is when Sasha enters Finn's life—he will have to make a choice that nobody should have to make. We get a sense of how much this bargain has cost Finn when he tells Sasha about seeing a person who is just starting dialysis: "I watched him come in and I thought, 'if it was me doing it again, I would never start.'" That's a sobering line for medical clinicians.

People did not have to make choices that are structured as Finn's choice is—a technologically produced double bind—until the second half of the twentieth century. That has given us only about two generations to develop a moral vocabulary with which we can talk about what we call choices, although that word is seriously inadequate in its implication that individuals make decisions alone in our heads. We make decisions in response to people and situations; we respond to explicit and tacit messages expressing expectations. To make decisions



that others have some stake in—and others do have a stake in almost all our decisions—we need words that can express what’s going on. Words weigh possibilities. We may have to decide we don’t like how the received descriptive terms are directing us, but to do that we need alternative words and phrases.

Finn represents all the people who are put in situations where their moral vocabulary hasn’t had time to catch up to what the situation demands. It’s by linguistic default that Finn gets stuck using a descriptive term like “quitter.” He needs a word that can describe deciding to stop dialysis as an act of managing his life on his own terms. He and Sasha spend considerable time talking around the absence of a word that describes someone who makes an *affirmative refusal* of treatment.

Or, phrased differently, people in Finn’s situation are living a story for which they do not yet have an overarching narrative that gives us a sense of where such a story ought to lead and how it gets there. Sasha’s article is one step in creating that narrative as a cultural resource.

Sasha’s work as a hospice counsellor is complementary to Finn’s situation in its ambiguity or in-betweenness. She is neither a bioethicist, nor is she a psychotherapist in the sense of mental health professional, nor does she advise, although she calls herself a counsellor. In terms preferred by narrative therapy, Finn is not visited by a Problem like bed wetting, or physical abusiveness, or anorexia. Instead, he confronts a dilemma: again, a choice no one should have to choose, a distinctly modern choice, with an inadequate moral vocabulary. Sasha is not trying to work with Finn to control a Problem or get it out of his life. A geographical metaphor seems to fit better. Sasha is working with Finn to get somewhere, which happily is where he ends up: finally able to say, “it feels right in here.” Finn’s dilemma, his double bind, will never be resolved, but it might somehow be surpassed: it might just cease to matter.

Because processes of change are subtle, it’s not surprising that the moment when Finn gets beyond “feeling like I’d copped out” occurs during a gap in Sasha’s narrative. Sasha experiences this gap when she hears that Finn has stopped dialysis and been admitted to the hospice in-patient unit. The gap is where Finn’s sense of rightness shifts; his sense of what he should do, to be who it’s right to be, changes. Sasha’s colleagues congratulate her on her good work, but she feels uncertain. That uncertainty may be where she asks too much of herself and



perhaps expects too much step-by-step continuity in Finn's story. Sasha tries to fill in that uncertainty with reasons for Finn's decision, and Finn cooperatively offers her a few such reasons, but—significantly for my understanding of what's going on—Finn's decision seems underdetermined by any specific reasons. That underdetermination might be a problem for some bioethicists; to me, it's inevitable, and bioethics often goes wrong when it tries to fill uncertainty with moral principles applicable to a category of cases that professionals consider alike.

Finn's situation—his life, not his “case”—requires not a solution but a response, and the response cannot be strictly rational. On my account, vague as it is to put it this way: Finn gets to a point where doing what he did felt right; I call that place a good death, a phrase people use to express their sense of rightness. But Finn did not get there alone. Sasha's non-Problem-oriented work was to get Finn to a place where he could trust that it felt right. The elusiveness of Sasha's work is that at the end all Finn can say is “it feels right in here.” There's no outcome metric, only a feeling.

If Sasha is not doing therapy, her counselling has a therapeutic effect, and she tells us a good deal about how she achieves this effect; in particular, how she phrases questions so as to create *spaces*, as she describes it. Sasha does not follow any map; she follows Finn's leads, cueing him in response to cues he gives her. Her cues direct him to think of himself as ... what? *Capable* is one word, as in capable of agency, even after his physical capacities are seriously reduced. After Finn has made his decision, Sasha asks his son Liam what kind of a person his father is. “Organised,” Liam says. “He always liked to be in the driver's seat. He is a bright active man who always managed everything on his own terms.” Sasha is enlisting Liam as a witness, a role he plays later when he affirms that Finn's stopping dialysis is his way of acting on his own terms.

I will risk an analytic summary of how, or maybe where, the therapeutic happens in Sasha's work with Finn. The therapeutic effect, equally a palliative effect, takes place in Finn's subliminal uptake of potential narratives for his life that Sasha embeds in her questions that are always offered as responses to Finn's lead. Sasha's implied narrative is that Finn has lived a life that has prepared him to know, when he gets there, that he is in the place just right. He just needs to let himself get there, as he will in his own time. Time and space must conjoin, and they will: the place can be just right only at the right time.



Rightness is not cognitive and getting there is not “behavioural” in the sense of changing how one acts. Early in this comment I used the awkward phrase *telos of articulation*. Rightness is an articulation, but it’s not about being articulate in speech. The articulation involved in rightness is the sense of a *fitting together* of time, place, action, and relationships—at least these, but also more than we can list, including a person’s sense of who, present or absent, expects what from them, and what self-expectations they must honour.

This articulation is a *telos* insofar as it’s an end state that life is *felt* to be all about reaching; we describe that feeling with phrases like saying the self is finally *true to itself*. When Sasha asks Finn, “Do you feel more yourself?”, I hear that less as a question and more as the gentlest way of offering permission. Two points deserve emphasis. First, Sasha’s presence during the period of time leading up to this moment has *earned* her the right to offer that permission; it’s earned in real time spent *attending*. Institutionalized medical care often neglects that need to earn in real time. Second, Sasha’s permission still leaves space for Finn to add something else, to want something more before he can feel fully himself. Medical decision-making often wants finalized end points.

Sasha’s work, however skilled as a practice, is simple to describe: she shows up, asks questions that follow what Finn and his surroundings suggest, and in those questions she reflects back to him a version of the person he indicates is most himself. I understand *feeling most yourself* as being another performative act: I am most myself because I pronounce myself feeling that way when I act. The act affirms the self as being most itself, and being that particular self warrants the rightness of the act.

Finn, or any of us, has to earn that pronouncement of feeling himself, and that earning generally takes place within a relationship of mutual response with another person—a witness. That’s the subtlety of it: it’s only words, but I can’t just say it. Saying it requires believing it, and none of us can get to believing it on our own. I have to feel that where I am is the end at which I was supposed to arrive. That arrival is joint, until one person goes on alone, as must be.

In the end, as Finn dies, he takes Sasha’s hand. She is there as his companion and his witness. She is a crucial part of the articulation. Sasha *makes* the place just right.

References



Austin, J.L. (1965). *How to Do Things with Words*. Oxford University Press.

Bateson, G. (1972). *Steps to an Ecology of Mind*. Ballantine Books.

Pilkington, S.M. (2022). Deciding how to die: Narrative Therapy in palliative care with someone considering stopping dialysis. *Journal of Contemporary Narrative Therapy*, 3, 29-68.



My Autobiography with Narrative Therapy

By Collin Sanders

Chapter One: Affinities.

In memory of my dear friend, Garth Thomson (1952-2009), who initiated me into the realm of narrative ideas and therapeutic practices. This autobiographical memoir is dedicated to Noreen Sanders, my mother, and to my partner, Gail Marie Boivin.

I is another – Arthur Rimbaud *I am another now and yet the same* - James Joyce

I have written previously (Sanders, 2014)⁷⁶ my introduction to narrative therapy as espoused by Michael White and David Epston occurred in 1991, when my dear friend, Garth Thomson, presented me with a copy of *Narrative Means to Therapeutic Ends* (1990), insisting I read the book. At the time, Garth and I were working together as part of a team in a new program, Peak House, which opened in 1988, in Vancouver, B.C., Canada. Garth was a family therapist with Peak House, and I was a program coordinator, and would soon become the clinical director. Garth had recently attended a workshop in the town of Duncan, on Vancouver Island, sponsored by the Orcas Society⁷⁷, with Australian family therapist Michael White, and had purchased a copy of Michael and David's book, originally published as *Literate Means to Therapeutic Ends* (White & Epston, 1989), now titled, *Narrative Means to Therapeutic Ends*. Michael and David's reference to *literate* and to *narrative* immediately intrigued me.

At the time I was unaware of the existence of *narrative therapy*, and had no idea who Michael White, or David Epston, were. Garth had been enrolled in the

⁷⁶ For a more thorough, detailed, account of my engagement with narrative therapy, my early reading history, and related interests and influences finding affinity with David and Michael's thinking/writing/practices, see my dissertation (Sanders, 2014).

⁷⁷ The Orcas Society, Duncan, Vancouver Island, sponsored Michael on three occasions, in addition to bringing Lynn Hoffman, New Zealand's The Family Centre, Imelda McCarthy and Noillag Byrne (Fifth Province Associates, Ireland), Insoo Kim Berg and Steve de Shazer, and Luigi Boscolo and Gianfranco Cecchin, formerly of The Milan Team, amongst others, to present new and innovative ideas within therapeutic practice.





M.S.W. program at Vancouver's University of British Columbia some years earlier with Stephen Madigan (2019), from whom he first learned of a distinctive *narrative therapy*. "Here Colin, read this book; I think you will find that these guys talk about some of the writers you have on your bookshelves," Garth remarked. I read the book over that very weekend, intrigued and impressed with how Michael and David co-created a creative therapeutic practice utilizing ideas and concepts from many of the thinkers/writers, as Garth observed, whose books I had on my office bookshelves, and in my home library.

Reflecting back, there existed a counter-cultural thread to narrative therapy that resonated with me, along with a clear challenge to predominant, pathologizing and marginalizing, so-called therapeutic practices. Michael and David appeared to be rebels *with* a cause; their cause being to disrupt the taken-for-granted ideas, concepts, and practices associated with traditional ways of engaging with suffering others, and, to create an alternative to and de-humanizing medical and psychiatric practices. It appeared to me Michael and David's ideas and associated practices offered a lucid, viable, effective alternative perspective, a way of thinking about and reimagining therapeutic practice that I could discover inspiration in.

In reading through Michael and David's first book, their collective thinking certainly aligned and connected with some of my own reading/thinking, dating back to the late sixties. The ecologically minded "Beat" poet, Gary Snyder, now 91, had studied anthropology, and the "Beat" writer, William Burroughs⁷⁸ had studied anthropology as well; both were influences for me in deciding to study cultural anthropology. I completed my M.A. in cultural anthropology in 1979. Cultural anthropology opened a window for me into the thinking/writing of Gregory Bateson, Clifford Geertz, Victor Turner, Barbara Myerhoff, Claude Levi-Strauss, Michel Foucault, and others. I was also introduced, in those early university years, to the philosophical, and literary, thinking/writing of Gaston Bachelard, Emmanuel Levinas, Paul Riceour, Jacques Derrida, Julia Kristeva, Luce Irigaray, Helene Cixous, Jacques Deleuze, Felix Guattari, Erving Goffman, R.D.

⁷⁸ See my references for poets and poetics, and for ecologically minded writers whose work I admire and have reviewed or written about. Also, the documentary film by Trevor Carolan (2015) has a brief interview with me talking about Beat poets Allen Ginsberg and Michael McClure and the ecological threads within their poetry. In 1985, I was fortunate to have spent one week studying poetics with Ginsberg at Hollyhock Farm on Cortez Island, B.C., an event organized by Rex Weyler, who had been the first photographer for Greenpeace, on Greenpeace's inaugural voyage on the vessel, *The Rainbow Warrior*.





Laing, David Cooper, Angela Davis, Ivan Illich, Franz Fanon, amongst others. All of whom, in different ways, contributed to post-structuralist based therapeutic practice, and many of whom were engaged with social activism in regards to structural and systemic racism, the pathologizing and marginalizing of so-called mental patients, and “blaming the victim” practices; many of these authors (e.g., Laing and Cooper) and activists contributed to the critique of psychiatric institutions and dehumanizing practices, providing me with inspiration for the work undertaken at Peak House. In the early 70’s, I had also taken a seminar on the Gospels and social justice with radical Jesuit priest and activist, Daniel Berrigan, and I had attended, and met, R.D. Laing and philosopher Alan Watts, who gave talks at the University of Manitoba (Winnipeg), where I had studied.

Reading and ranging across disciplines was often eschewed and viewed as suspect; and as Kenneth Gergen (2009) observed, “There are also risks for roaming. Scholars who are curious about another discipline are often viewed as alien interlopers by the denizens of the discipline... Academic safety lies in knowing more and more about how to address an ever-smaller community of colleagues” (p. 211). I discovered solace and encouragement in Michael’s (White & Epston, 1990) description of David:

Without doubt, David’s fascinating childhood experiences...and his former career as an anthropologist ideally equip him to traffic in storytelling. In fact, upon reflecting on his unique location in the therapy world, I see that he hasn’t departed from anthropology at all. An anthropological degree has been defined as an “intellectual poaching license” – an apt description of the sort of credential that David would take most seriously. He collects ideas for stories from all over and displays a profound disrespect for ‘disciplinary’ boundaries in his search for helpful metaphors to interpret events in social systems” (p. xvi)

And, as Michael himself once remarked, “I guess I’ve always been more interested in reading outside the boundaries of the profession, rather than inside” (White, 1995, p. 12). Such irreverence was helpful!

I considered Michael and David to be profoundly poetic in their ability to facilitate the emergence of alternative stories with persons’ suffering and struggling under the restraint of debilitating stories and despairing thoughts; I perceived their poetic, narrative, practices as representing an ability to articulate the ineffable,





bringing forth the unsaid, or the not yet said, as proposed by Anderson and Goolishian (1988).

Ultimately, for my relationship with narrative therapy, Michael and David's example evoked a sense of poetry in action, a praxis grounded within literary and philosophical anti-traditions, all of which threads I could relate to, a practice of resistance, and a poetics of renewal. Following Michael's untimely death, David, writing in the Introduction to White's posthumous publication, *Narrative Practice: Continuing the Conversation* (2011), pondered the question where narrative therapy may migrate to, reimagining the adventure of narrative *praxis*, wondering, "Michael, don't you think we have to turn to poetics for this? After all, your words were at times mesmerizing, and it was no surprise to me that you drew upon Bachelard (1958/1994) and the aesthetic metaphor of 'transport' as images for your narrative practice" (Epston, 2011, p, xxvi).⁷⁹ In one conversation, Michael had himself declared, "I believe that through the metaphor of poetics it becomes possible for us to challenge the marginalizing of existence..." (1996, p. 48).

Soon after reading Michael and David's book I attended a two-day workshop with New Zealand's The Family Center and was introduced to the *just therapy* approach to community work and healing, a socially just practice in which Indigenous wisdom and knowledge might be utilized and honored, and ideas regarding the sacred were privileged. In an essay initially published in 1990, offering a description of "a just therapy" practice, the Family Center's Charles Waldegrave (2003) wrote:

'Just Therapy' is a reflective approach to therapy...It is termed 'Just' for a number of reasons: firstly it indicates a 'just' approach within the therapy to the client group, one which takes into account their gender as well as the cultural, social, and economic context. Secondly, the approach attempts to demystify therapy (and therapists) so that it can be practiced by a wider range of people including those with skills and community experience or cultural knowledge (p. 7).

⁷⁹ For further reflections upon Michael's work, his reading of Gaston Bachelard et al, and what I envisage as Michael's affinity with the sacred, see Sanders (2022).





I found this *just therapy* perspective liberating. Just therapy, in conjunction with narrative therapy, would be extremely important in the bringing forth of therapeutic practices at Peak House, some of which practices are described below. Discovering the relational interconnections between The Family Center and Michael and David, and coming to know Tamalie Kiwi Tamasese and Charles Waldegrave personally, enhanced my understanding and appreciation of the thoughtfulness grounding their work.

Soon after my initial encounter with folks associated with The Family Center, I attended a workshop with David Epston, whom I only knew as being the co-creator of narrative therapy. At David's workshop, I met Stephen Madigan. Madigan and his wife at the time, Jennifer Sigman, were in the process of opening Vancouver's Yaletown Family Therapy (YFT) and starting The Vancouver School of Narrative Therapy (VSNT). Madigan and I developed a close personal friendship and professional relationship, both of which lasted for almost three decades. I was a therapist with, and became the Associate Director of YFT, in addition to teaching with the VSNT from 1993-2013. I participated in, and presented my evolving work, in many of YFT's sponsored conferences, including two International Narrative Therapy Conference, and several Therapeutic Conversations conferences.

Through Madigan, I came to know David Epston personally; a friendship David and I have cultivated since 1992. On November 28, 1992, I had just returned from ten days of teaching narrative in relation to substance use struggles at Arctic College, in the Yukon Territories (seeing the Northern Lights was astounding!), with social work students. That evening, my partner Gail and I met up with Madigan, our friend and colleague Heather Elliot, and David, for drinks at The Sylvia Hotel in Vancouver where David was staying. The next day I picked my copy of *Experience, Contradiction, Narrative & Imagination* (Epston & White, 1992), which I had asked David to autograph, in which he wrote, "Colin, I enjoyed your Foucaultian rave at The Sylvia last night, best wishes, David Epston"; one of many conversations we enjoyed over the years relating to Foucault's thinking, and influence upon the early evolution of narrative.

At YFT's first International Narrative Therapy conference, in Vancouver, Canada, I presented a paper, "Narrative Imagination in Evoking a Language of Mind" (1995), a transcript of which that was subsequently published, aptly enough, in a special edition of the *Calgary Participator: A Family Therapy Newsletter*, entitled, *Soul-*



Making. This particular issue of the newsletter was dedicated to the memory of Winnie Tomm (1995), who had died recently; Winnie was a feminist, professor, researcher, and author, who had been married to progressive psychiatrist and professor, Karl Tomm⁸⁰, of the Family Therapy Centre, of the University of Calgary. Karl was good friends with Michael and with David and wrote the Foreword to their first book.

The conference commentator on my paper presentation was Bill Lax, who would become a friend. Bill had at one time worked closely with Lynn Hoffman, and I was introduced to Lynn through her friend Chris Kinman⁸¹. Regarding narrative therapy, Hoffman wrote, "A third break with systems concepts and the modernist methods of therapy that derived from them came with the extraordinary innovations of Michael White and David Epston in Australia and New Zealand. White and Epston's book *Narrative Means to Therapeutic Ends* broke upon the shores of family therapy in 1990, *and the field has not been the same since* (1995, p. xi-xii, emphasis added).

At the inaugural Vancouver narrative conference, I also met Michael and his then wife and business partner, in Dulwich Center, Adelaide, Australia, Cheryl White. Through the YFT sponsored conferences, I would come to meet Jeff Zimmerman, Victoria Dickerson, Karl Tomm, Winnie Tomm, Imelda McCarthy, Noillag Byrne, David Nylund, Julie Tilsen, Rick Maisel, Ali Borden, Johnella Bird, Amanda Kamsler, Jill Freedman, Gene Combs, Alan Parry, Vanessa Swan and Ian Law, amongst others, many of whom remain friends to this day.

I met Chris Iwestel Kinman, musician, poet, photographer, artist, film maker, and therapist, around this time; and, as Chris often reminds me, I turned him on to the thinking/writings of Gilles Deleuze and Felix Guattari, while he turned me on to the enchanting work of Imelda McCarthy and Noillag Byrne, known then as The Irish Team, and, in later years, The Fifth Province Associates. Chris had come to

⁸⁰ Cheryl White (2009) has said of Karl Tomm: "From the time Michael and David met Karl Tomm in the mid 80's they all became firm friends and Karl's influence was significant. Karl introduced their work internationally as well as consistently raising questions and challenges that added to the development of Michael's and David's thinking. They all took every opportunity available to them to meet up, especially in Calgary [Canada], and work together" (p. 60). See also, Cheryl White (2011).

⁸¹ Chris' documentary film celebrating Lynn Hoffman, *All Manner of Poetic Disobedience: Lynn Hoffman and the Rhizome Century* (2013) provides a wonderful genealogy of the theoretical interconnections and lineages connecting thinkers and practitioners Hoffman believed promoted "communal practices".

https://www.youtube.com/playlist?list=PLzbbBmmFIX9zPS3m4ohEP_GQsO6pf1E-S





know of the many practitioners who were moving away from working in traditional ways, becoming more interested in collaborative practice and poststructuralist ideas, through his studies at the University of Calgary with Karl Tomm and Alan Parry, amongst others. Chris and I co-presented our work in various contexts, in several cities and towns, over the years, and I hired him to teach at CityU. Now living in different geographical vicinities of British Columbia, we continue to connect regularly by telephone and email.

Chapter Two.

A. Praxis: The Influence of Narrative Therapy and Social Justice Ideas and Practices at Vancouver's Peak House⁸².

- Narrative Theory and Practices & the Academy.
- Narrative Theory and Practices & Research.

The psychologists do not know everything. Poets have other insights into man [sic]. Gaston Bachelard

A. Praxis.

In 1997 I wrote, "Peak House is a program of the Pacific Youth and Family Services Society, Vancouver, British Columbia, Canada. Peak House is a nonprofit, government-funded program. It was started in 1988 as a traditional chemical dependence treatment program *and has evolved in a narrative direction since that time*" (Sanders, 1997, p. 400, emphasis added). Peak House (www.peakhouse.ca), now in its 33rd year of continuous operation; and as currently configured, is a voluntary, ten-week, live-in, program for young persons struggling with substance use and related dilemmas. At Peak House, I initiated and assumed leadership in the evolution into a narrative therapy orientation and framework, providing theoretical direction from 1989 to 2002.⁸³

⁸² This section of the paper represents a considerable distillation and synthesis of Chapter Seven of my dissertation (Sanders, 2014).

⁸³ In 2013, on behalf of Peak House, I was pleased to accept the B.C. Association of Clinical Counsellors (BCACC) Professional Care Award, which was presented to Peak House in recognition of the unique service provided to young persons struggling with substance use.



Within a brief period of time, I had come to consider the 12-Step philosophy and associated practices, along with the “disease metaphor,” to be of use to some persons, and not much use at all to others. I realized having an entire live-in program constructed around a 12-Step philosophy was entirely limiting. Additionally, within the confines of such a theoretical context, there existed little space for the incorporation of emerging harm reduction practices. Increasingly disenchanted with the hegemony of 12-Step philosophy within the domain of “addiction” studies and practices (Sanders, 1994, 1997, 1998, 1999, 2007), I became receptive to exploring alternative conceptual frameworks for our practices. The narrative therapy of Michael and David opened both a challenging and intriguing space, providing a radical alternative upon which to construct more collaborative, reauthoring, practices at Peak House. Kenneth Gergen’s (1992) observation captured the shift then occurring at Peak House:

...We must relinquish the claim of final authority for any psychological school – psychoanalysis, Rogerian therapy, behaviorism, cognitive therapy, 12-step programs, family systems, structural-strategic models – none will give us objective knowledge, either separately or all together. In this climate, knowledge claims (“we know”) and the authority that flows from them (“You should listen to us because we know”) lose their power of persuasion. (p. 57)

Increasingly, we envisaged our practices at Peak House to be more and more representative of genuine collaboration *with* the young participants accessing the program.

I have written elsewhere (Sanders & Thomson, 1994; Sanders, 1994, 1995) of the evolution of our ongoing attempts to co-create with clients’ counter practices to traditional drug and alcohol “interventions” within the lives of young persons and families. Significantly, the practices we engage in and utilize are practices young persons themselves have had a hand in creating... Our practices are not imposed from above, but instead reflect ideas, solution knowledges’, and wisdom evolving out of consultation with those seeking our services... (Sanders, 1997, p. 401).

Over time, following personnel changes and some departures, I found myself engaging increasingly alongside other practitioners at Peak House who had come to share an interest in narrative and collaborative therapy, and the social justice ideas and practices of Waldegrave (1990), and Waldegrave, Tamasese, Tuhaka



and Campbell (2003). For me, those years were extremely exciting, as we embarked upon new theoretical and practice territory, uncertain as to where we were headed, yet certain of where we had been, and where we did not wish to return to.

Evolving Practices.

Based upon the practice of *externalizing*, (White 1989, White, 2007; White & Epston, 1990; Epston, 2020), participants within the community of Peak House were encouraged to compose documents identifying dilemmas or problems that at times imposed upon them, interfering with their lives and relationships. The experience of “anger” was often a common dilemma participants at Peak House spoke of, an experience that influenced young persons towards actions and activities within their lives and relationships they wished to separate from. One participant wrote the following letter to “Anger”:

Dear Anger:

I can't stop to think what your role in my life is. You push me around, try to control my feelings, and then leave me like a piece of shit because of the actions that you take. I am beginning to understand your game, and I am overcoming the powers you once had over me. Well guess what? I am fed up with all your bullshit and the violence you cause. I think you have no right to make me deal with problems and feelings the way that you do. I am not that kind of person anymore. I used to run my life around you and it made me and others believe that I didn't care about anything. I tried to hide from you by doing speed and other drugs but I have realized that I don't have to hide from you and that you are just a feeling inside that everyone experiences.

While another participant at Peak House wrote the following, to “Heroin”:

Dear Heroin:

Fuck you. You messed me up in so many ways. You bring me to tears almost every night, thinking about you. I wish I could get you out of my life forever. I am hopefully saying “goodbye” to you, and never seeing your lifestyle again. You've taken my dreams, my dad, friends, and family lost trust in me. I wish I never met you. But I did and I have to get over that and change my





life. I hate you so much for the things I have done because of you. You've made me go to jail, hurt my mom and family, and rob people. That's not me, that is you. So stay out of my life, please. I am tired of this shit and the lifestyle. I'm a nice person and I know I've seen my "clean" side, and I know how nice I am. So leave me alone.

Significant shifts in practice began to emerge and to evolve. These more inclusive practices reflected ways of being more aligned with experiences promoting of belonging. For example, when a new participant entered the program, a current participant would be in attendance at the initial conversation and would respond to questions the incoming participant might have, or questions the incoming participants' family members, or referring practitioner, may have.

New participants were initiated into the liminal space of Peak House in a Welcoming Ceremony, a symbolic practice suggested and initiated by Joanne Davis. Inspired by our introduction to the cultural, community, practices of New Zealand's The Family Centre, we realized we were working with a significant number of First Nations young persons and extended families, yet we had initially only employed one First Nations person to work in the program. We were fortunate in connecting with an Indigenous woman, Joanne Davis, of *Gitlaxt'aamiks*, a Nisga'a village in northern British Columbia, who had come to work with us. Joanne was instrumental in introducing us to the cultural significance of ritual and ceremony relating to indigenous practices, and how we might utilize such in our ongoing work. Joanne recently completed a Master's degree, and is currently Manager of Family Support Services for the village of *Gitlaxt'aamiks*.

As originally conceived, in the Welcoming Ceremony, new participants entering Peak House would select a stone from a basket, and the stone they chose would be passed around to all other participants and practitioners present, seated in a circle. Each participant would impart into the stone their hopes and wishes for the new person entering the program. Often, sage would be burned, and drumming, guitar, or flute playing would accompany the ceremony; often, a song would be performed, or a poem read.

When a participant was preparing to depart from the community, a Commencement Ceremony was performed. This ceremony formerly had been called a graduation, but graduation held negative connotations for many of the



young persons' coming to Peak House, based upon inadequate educational experiences.

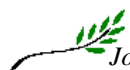
We considered Commencement Ceremony as a context in which a participant who had come to the Peak House community from an external community would celebrate their reauthoring experiences and re-connecting experiences, re-entering the world from which they came; now possessing a different perspective on how to negotiate relationships within their community of origin. Additionally, participants leaving the community were also departing with a new vocabulary, and, invariably, a different way of understanding relational struggles, especially struggles with substances and related dehumanizing experiences. Many departing participants now considered they were not beneath the spell of some sort of disease, recognizing they possessed personal agency that could be used to counter the influence of substances.

This re-entry was highlighted with the passing around of the stone the participant had chosen at their Welcoming Ceremony upon entering the community of Peak House. Again, each person present in the circle was invited to speak to the hopes, dreams, and desires for the person commencing. Often, a participant would read a letter⁸⁴ they had written, illustrating and highlighting what they considered to be of significance regarding their experiences at Peak House. Practitioners working at Peak House would also often read letters to the departing participant.

Inspired by Michael and David's (White & Epston, 1990) incorporation of van Gennepe's (1960) ideas regarding liminality, we imagined the work we were performing at Peak House within this metaphor of *rite of passage* (van Gennepe, 1960). We perceived the experience a participant may go through in their time at Peak House as one of liminality, in that a participant entering (separation) Peak House was no longer the person they had been upon entering the program, and they were not yet the person they may become upon entering back (reassimilating) into the world, following their experience at Peak House.

Further inspired by narrative therapy ideas, the formerly called Chemical Dependency Group became Reauthoring Group. Reauthoring Group became a collaborative, conversational, relational, and dialogical, experience, whereas,

⁸⁴ Many letters written and read by both participants and practitioners at Peak House were inspired by David Epston's concept of "therapeutic letters".





previously, in the Chemical Dependency Group, only the therapists (as experts expounding expert knowledge) spoke, while the youth counsellors' took notes, and the program participants were expected, and pressured, to speak. To a significant degree, hierarchy dissolved, and the content and tone of the group became conversation, not polemical.

We began to explore Norway's radical psychiatrist Tom Andersen's (1991) reflecting group process practices, and Michael's outsider witness groups (White 1995, 1997), in addition to Cultural Witnessing groups (Reynolds, 2002), inspired in part by The Family Center.

We adopted the song "Fight the Power" as a motto, from American hip hop band Public Enemy (1989), and, in time, the alumni community support group at Peak House became known as the Fight the Power group. This particular group provided support for young persons' following their experiences at Peak House, assisting former participants in resisting the influence of substances, sex trade recruitment, exploitation, homophobia, racism, and other injustices and restraints.

Together as a team, and alongside participants in the program, we co-created many other symbolic, ritualized, and ceremonial ways of celebrating small victories over substance use and other dilemmas. We imagined these ceremonies to be performances of new meaning (White & Epston, 1990), considering these ceremonies as a way to highlight the reauthoring of identity participants were experiencing; as such, these ceremonies stood in opposition to dehumanizing practices, referred to as "degradation ceremony" by Garfinkel (1957).

Also influenced by Michael and David's discussion of Rom Harre's critique of "the life of the file," we ceased holding so-called "case" conferences, honouring of the fact that the young persons' at Peak House were human beings, not *cases*.

We ceased reading files sent to us from referring agencies or persons, preferring to first meet the new participant face-to-face for an initial conversation, avoiding presuppositions regarding the participant as described by expert others. We developed a practice of co-authoring accounts and descriptions of participants' experiences in the community of Peak House, thus meeting contractual and regulatory requirements. We then forwarded these documents to the agencies or persons who had first referred the participant. Following Geertz, these thick



descriptions appeared closer to the participants' lived experience, certainly more so than anything reflected in so-called "discharge summaries".

Based upon concerns for safety, initiated by several female practitioners, a separate group was created for the young women participating in the program; and a separate group was created for the young men. The male gender group, most often co-facilitated by myself along with other male practitioners, presented alternative ways of thinking about and performing masculinity, and, based upon the work of Alan Jenkins (1990), discussed the values and ethical behaviours and actions associated with being an honourable person, taking up the challenges associated with Jenkins' ideas regarding "an invitation to responsibility". It was useful to have the older men, the elders, within the program offer illustrations of, and unravel, patriarchal attitudes and behaviours. We were committed to challenging misogyny, and acts of verbal and physical violence towards women, and homophobia.

In the early years at Peak House (I was there from 1989-2002), we were encouraged and heartened by the descriptions participants gave us regarding their experience at Peak House. Participant responses to the ongoing, evolving, practices in the program provided us with confidence that the journey we were on was an effective and respectful one. One participant at Peak House wrote in her commencement letter that Peak House was a "spiritual place", and her relationship with the "grownups" at Peak House had indeed changed her mind about adults, given that she had learned to experience herself as a person, not as a "delinquent".

I experienced such revelations of new learning from participants as being representative of Foucault's (1980) "insurrection of subjugated knowledge" (p. 81); the emergence of knowledge hitherto minimized and ignored; knowledge and know-how the participants had to keep to themselves or share sparingly and cautiously with accepting others.

The following, a letter read out at a Commencement Ceremony by a participant, provides an excellent illustration of the communal support experienced by a young participant while at Peak House.



My Metaphor for Peak House.

I know from my experience I'm always going to think of Peak House as a place where they take wounded birds who cannot fly or fend for themselves, and they feed the little bird and care for it, and nurture it, and most importantly teach it to love and respect. Slowly the bird gets stronger and healthier, until the bird feels ready to fend for itself. After a long period of caring for the bird, Peak House takes the bird and lets the bird fly away. As the bird flies away, Peak House gets smaller and smaller, until the bird cannot see it anymore. For this the bird is sad because that was his home. That's where he met people so special to him that he never wanted to leave. But the bird knows that Peak house will always be in his heart, and he holds that memory, and flies off to success.

Love to you all!

Towards a Narrative Poetics of Resistance.

When it came to writing up our evolving practices, I conceived of what we were as a *poetics of resistance*:

A poetics of resistance will highlight actions and behavior promoting of personal agency, intention, and choice. A poetics of resistance highlights and encourages narratives other than those offered by normative descriptions, diagnoses, and labels, especially descriptions disconnected from sociopolitical, sociocultural contexts [which are] pathologizing of the person. A poetics of resistance always believes a person is always more than the sum of the diagnosis (Sanders, 2007, p. 68).

Specific to practices evolving at Peak House, I wrote:

A poetics of resistance does not participate in the perpetuation of personal pathology and disease metaphor language. A poetics of resistance insists that ideological phrases such as “my addiction” can always be reconceptualized and renegotiated in terms of “the impact addiction has on my life is such that...” or “this relationship addiction has with me...” or “my response to the direction addiction wants for me is...” or “my resistance to the intentions of addiction within my life is such that...” and so on (Sanders, 2007, p. 68).





The concept of a poetics of resistance originated for my thinking with Foucault's proposal, "Where there is power, there is resistance" (Foucault, 1980, p. 95). In June of 2007, in Havana, Cuba, I presented on, "A poetics of resistance: alternative practices within 'addiction' studies", at The Spirit of Community in Cuban Social Programs & Narrative Therapy conference, organized by Michael Kerman of Toronto, assisted by David Epston, who invited many narrative influenced therapists to present their work. My doctoral dissertation was entitled *Narrative Poetics of Resistance: Towards an Aesthetics of Resistance* (Sanders, 2014).⁸⁵

Due to the predominant influence within the domain of substance use theory/practice, what I previously referred to as "addiction mythology" (Kinman & Sanders, 1994; Sanders, 1994), particularly in relation to the common assumption that substance use was brought forth due to genetic influences, I wrote:

[A] poetics of resistance represents a counter story to the story of hopelessness and self-doubt associated with the restraints of a genetic fundamentalism (Schwartz, 1997). Adhering to the idea that so-called genetic disposition toward particular behaviors is directing and ultimately shaping of one's life represents a limited worldview, a restraining perspective that needs to be respectfully questioned. From a sociobiological perspective, genetic fundamentalism represents a dangerous rationale for all sorts of violent, destructive human behaviors. I believe that imagining a Fifth Province domain within therapeutic conversation allows for resistance to the primacy of genetic predisposition in the creation of an "addictive personality." This way of thinking needs to be resisted if space for personal agency and re-authoring possibilities is to emerge (Sanders, 2007, p. 69).

In the early 1990's, when requested to facilitate and present workshops, or, when proposing workshop ideas, I began asking participants in the community of Peak House if they felt safe enough to accompany, and collaborate, with me at workshops and conferences, addressing practitioners in their own words,

⁸⁵ I wish to acknowledge my gratitude and appreciation to Sheila McNamee, of The Taos Institute, for guiding me through the dissertation process while encouraging me in writing up my thoughts and experiences.



regarding their own lived experience. I provided participants who accepted with an *honorarium* for their contributions.

In writing this memoir of my autobiography with narrative therapy, I am extremely pleased with reviewing what we accomplished at Peak House. I once heard Michael White remark that deconstructing is easy to do, while re-constructing alternatives in place of what has been taken down is much more difficult. Such work requires vision, commitment, engagement, perseverance and patience, values I often mentioned when asked about Peak House's evolution. Michael's point was instructive and helpful in realizing it was insufficient to be critical of certain practices without offering viable alternatives. Since I left Peak House in 2002, practitioners at Peak House have continued to be both creative and courageous in evolving the program to meet contemporary challenges.

Part Two: Narrative Ideas in the Academy.

In 1998, my friends Arden Henley and Mary Kean invited me to teach as a professor in the Master of Counselling program they had recently co-created with City University of Seattle (hereafter, CityU), in Vancouver, B.C. This graduate program was practitioner facilitated, and over the years, for the most part, professors teaching in the program brought with them their own lived experience in therapeutic and community work contexts.

Arden previously in his career had been involved with directing innovative programs supporting young persons, and Arden and Mary had an interest in, and remain considerably involved with, traditional Chinese medicine, and related practices (cf. Henley & Miller, 2010).

Arden and Mary are Buddhist practitioners, and Arden has written of narrative therapy and Buddhism (Henley, 1995). Both Mary and Arden are also poets. Together at CityU, we highlighted and promoted narrative and socially just, anti-oppressive, perspectives in the curriculum and within our teaching. Mary had also taught for five years at Naropa University, Boulder, Colorado, where poets Allen Ginsberg and Anne Waldman (with assistance from poet Diane di Prima and composer John Cage) had co-created The Jack Kerouac School of Disembodied



Poetics in 1974. Something about narrative therapy resonated with poets, counter-cultural community activists, Buddhists, and followers of The Grateful Dead!⁸⁶

My partner, Gail, and I had just returned from a vacation in Mexico, the first week of April 2008, when we received two telephone calls from friends with the sad news Michael had died in Los Angeles. Gail and I experienced immense sadness at Michael's death. Not too long after Michael's death, we at CityU organized a memorial honouring and celebrating Michael's many contributions.

Taimalie Kiwi Tamasese and Charles Waldegrave, from The Family Center, were in town, and they both spoke at the gathering, as did Stephen Madigan, Jeff Chang, Garth Thomson, Ninetta Tavano, Mary Kean⁸⁷, Arden Henley, and myself. The memorial was well attended by CityU students, faculty, and community members involved in the narrative community.

I was involved at CityU for twenty years, between 1998-2019. I taught courses for ten years, in addition to coordinating the CityU Community Counselling Clinic (offering free therapy to the community provided by CityU student interns). The focus of my consultations with student interns was considerably informed by narrative ideas. I was particularly influenced by Johnella Bird's (1994, 2004) thinking related to narrative and externalizing conversation, and, especially Johnella's preference for taking a co-visioning position rather than a hierarchical, super-visioning, position (Bird, 2006). I was a Director for an additional ten years.

I encouraged a number of my former colleagues from Peak House to obtain Master degrees from CityU, and, when I became Director, many practitioners in the community who knew of my work with Peak House, and with the nonprofit organization, Rain City Housing and Support Society, applied to our Master of Counselling, CityU program.

When I started teaching at CityU in 1998, in the spirit of Lynn Hoffman's communal practices, and in the narrative spirit of breaking down expert/non-

⁸⁶ Our friendship continues, these days, and I sit on the Editorial Board of the *GTEC Reader*, an online journal of which Mary is Editor, associated with Arden and Mary's Green Technology Education Centre (GTEC), in Vancouver. Subscriptions to the *GTEC Reader* are free, and you are invited to subscribe at gteccanada.ca.

⁸⁷ Mark Kean recently re-read the poem she wrote for Michael, in a conversation with Chris Westel Kinman for his "Communal Practices Project"; see, <https://youtu.be/2kbF4G7VCrw>





expert knowledge practices, I invited young persons from Peak House to attend classes I was facilitating, speaking for themselves to students regarding ways in which they were positioning themselves against substance use, and how they were negotiating experiences of violation, violence, and marginalization, racism, homophobia and other experiences incurred in their brief lives. Many young persons clearly and respectfully articulated to the graduate students counsellor engagement styles they best responded to.

For many CityU students, working in what I would refer to as traditional, medical model influenced, hierarchical programs, the transparency occasioned by having young persons speaking to their lived experience in the room was considerably different from what they were accustomed to. I had taken to referring to this inclusive and transparent practice as representative of the dissemination of “lay knowledge”, following Adorno (1973).

Many graduate students I taught, or whose internships I acted as a consultant for at CityU became intrigued by the usefulness of incorporating narrative therapy ideas and practices into their own relationships and daily lives, not merely within their professional practices. Often enough, students in the Master’s program at CityU experienced their exposure to narrative in personally liberating, transforming, ways (Sanders, 2012). Many went further, studying the more specialized narrative training offered through the VSNT, and attending David’s regular workshops in Vancouver and in Calgary.

Over the years, CityU graduates in the Master of Counselling program would become responsible for introducing narrative therapy influenced therapeutic groups and other related practices into a wide range of medical, psychiatric, mental health, and hospital programs for children and young persons; grief and loss groups, substance use counselling services, employee assistance programs, crisis lines, and school counselling contexts. Arden and Mary are also friends with David Epston, and David visited our CityU offices a couple of times and spoke once to the students in a course I facilitated.

Part Three: Research and Narrative Therapy.

In 2008, I was invited to participate as a Team Leader on an Assertive Community Treatment (ACT) team in a “Housing First” research demonstration project; at the



time, this \$110M project represented the largest research initiative in Canada, organized and directed by the Mental Health Commission of Canada.

The research took place in five Canadian cities, Moncton (New Brunswick), Montreal (Québec), Toronto (Ontario), Winnipeg (Manitoba), and Vancouver (British Columbia).

The research I was involved with was coordinated through the Rain City Housing and Support Society (raincityhousing.org), a nonprofit organization, in Vancouver, British Columbia.

The focus of the research was to demonstrate that, with support available 24/7, formerly homeless persons struggling with substance use and related health concerns and diagnoses, could live in their own apartments and would begin to seek out and access a wide range of supportive services. The research was based upon an established, and substantially documented, practice known as a “housing first” model (cf. Tsemberis, 1999, 2010). Within the different cities, and local sections of the research project, there existed considerable theoretical flexibility. The Rain City research project team was comprised of several practitioners interested in narrative therapy. David Epston visited with our team on one occasion. Stephen Madigan was briefly involved with this Rain City Housing research project, and I stayed with the project as a Team Leader for fourteen months, seeing our component of the research successfully through its first fidelity assessment.

The ACT Team was initially comprised of a peer practitioner, a nurse practitioner, social worker(s), education and career training counsellor, and two psychiatrists. For the most part, all of us had experience working with marginalized persons, and most of us had experience working specifically with persons struggling with substance use; ultimately, our similarities outweighed our differences, and the team we gathered was a compassionate one, and activist in terms of the human rights of displaced, persons, homeless, or, inadequately housed, substance using persons.

Following the “housing first” model, the majority of the work involved community outreach, and engaging with participants within the local community, with limited time spent in the office. The structure and function of this research project differed from many traditional programs in that everyone, regardless of their title



and role, was involved in assisting a participant move into their apartment, stocking the newly arrived in apartment with groceries, furniture, and cleaning supplies, and so on; and everyone performed the same tasks; e.g., which often enough involved unplugging toilets and contending with bedbug infestations.

Four of us on the ACT team particularly shared an interest in weaving narrative ideas into the conversations and practices with persons with whom we engaged. We were fortunately able to consult on a couple of occasions with David Epston regarding our evolving research and participant engagement practices. Amongst other works, as I recall, David recommended we read Denzin's (2003) book, *Performance Ethnography: Critical Pedagogy and the Politics of Culture*.

Two project colleagues, Barbara Baumgartner and Brian Williams, collaborated on the creation of a unique and liberating way of co-facilitating a narrative-based group for participants, publishing two articles describing their narrative groups for homeless participants who had recently moved inside their own apartments (Williams & Baumgartner, 2014; Baumgartner & Williams, 2014). Brian had been a student of mine at CityU and had become a friend. Brian had an interest in anarchist heavy metal music, Buddhism (Williams, 2015), and skateboarding; we continue to connect with one other, these days on the Sunshine Coast where Brian and his family now live, too. Alongside one of the research project participants', they also co-presented at one of the Therapeutic Conversations conference. I hired Sacha Medine (2016), recently interviewed in *The Journal of Contemporary Narrative Therapy* (2020, Release 3), onto the project, and Sacha would later complete a Master of Counselling degree at CityU where I was Director, and, in recent years, Sacha has taught courses at CityU.

In June of 2009, I was a co-presenter⁸⁸ at a session called, "Concurrent Struggles" (my idea for the title, as opposed to "Dual Disorders"!), at a conference of the Mental Health Commission of Canada, At Home/*Chez Soi* Research Demonstration Project, Moncton, New Brunswick. In our session, I introduced narrative concepts, and used Foucault's notion of "the insurrection of subjugated knowledge", to frame stories of resistance, resilience, and survival, as illustrated by participants

⁸⁸ This group presentation included, Kim Markel RN, Dr Verena Strelau, and Dawn Skylus MSW, all of whom were involved with the Housing First research project conducted in Vancouver, B.C.



contending with longstanding homelessness, violation and violence, and chronic substance use.

One encouraging, positive, development following from outcomes demonstrated by the ACT research was that the Province of British Columbia health authorities (Vancouver Coastal Health and Fraser Health) now fund their own hybrid versions of housing first ACT teams.

Chapter Three.

It would be horrible if we were sensible to pain, hunger, injustice, and violence without perceiving the reasons for all this negativity. It would be horrible if we could feel the oppression but could not imagine a different world. It would be horrible if we could dream about a different world as a project but not commit ourselves to the fight for its construction. Paolo Freire.

Reflecting back over three decades, in considering my engagement with the ever evolving, narrative ideas introduced by Michael and David, I have witnessed and observed the creation of numerous innovative, narrative practices, building upon their original work. The narrative therapy literature is vast and considerable and has become articulated in multiple languages. I wish to acknowledge the work of several narrative inspired therapists and community workers, many of whom I have known personally, whose contributions I have learned and benefitted from.

In no particular order, I would note the following. Regarding “anorexia/bulimia”, the work of Maisel, Epston and Borden (2004), Grieves (1997) and Dennstedt (2010) has proved useful in situating and naming cultural influences contributing to struggles associated with body specification; Tilsen’s (2015, 2021) courageous work on engaging with queer youth has been exceptionally informative; Winslade and Monk’s (2000) narrative mediation approach I found of use in my practice and my administration work; Nylund (2007) and Medine’s (2016) work on deconstructing masculinity, I have found considerably useful in therapeutic practice and also in teaching. With narrative and collaborative practices for live-in programs for persons struggling with substance use, the work of Dennstedt (2011) and Dennstedt and Grieves (2004), Reynolds (2002), and Saville (1998) has been significant. The narrative inspired group collaborations, with formerly homeless persons, of Williams and Baumgartner, (2014), and Baumgartner and Williams (2014), remain intriguing. Zimmerman’s (2018; Zimmerman & Carlson,



2020) work combining narrative practice, neuropsychology, and mindfulness meditation offers a novel “neuro-narrative” practice. The narrative witnessing practices of Reynolds (Reynolds et al, 2014), illustrating her work in conversation with survivors of political violence and torture is also unique; while the remembering narrative work of Hedke (2010) has been influential, and the Insider Witnessing Practice (IWP) of David and Tom Stone Carlson, richly described within the pages of this journal, all continue to re-imagine narrative therapy in new directions. All of the above persons have made creative contributions to the field of narrative therapy and community work.

I have long considered narrative therapy not merely as a technique to be utilized in therapeutic practice, but more as a philosophy informing how to be in the world, and as a way of thinking about how stories inform relationships, in all ways. Throughout my professional life, I have been interested in the creation of viable and effective alternative programs, healing practices, and a socially just learning curriculum. I have protested against, and remained disinterested in, reproducing and replicating program structures that were static, hierarchical, oppressive, and promoting of individual pathology. I bear Michael’s reflection in mind, when he was asked to describe how he understood his way of engaging with others: “Well, as I wouldn’t define it as an approach, it is hard for me to really talk limitations in the usual way. Is this work better defined as a world-view? Perhaps, but even then this is not enough. Perhaps its is an epistemology, a philosophy, a personal commitment, a politics, an ethics, a practice, a life and so on...” (White, 1997, p. 37).

Happily retired now from teaching, training, graduate studies program direction, and the practice of psychotherapy, I am aware of what an extraordinary privilege it has been having the freedom afforded life as an academic and as a therapy practitioner. I hold fond memories of enriching experiences associated with collaborating with others in co-creating alternate spaces for healing as well as for collaborative, anti-oppressive, educational learning spaces. I hold fond memories of celebrating changes and transformations, reauthoring moments, experienced by participants and students in contexts I have been involved with.

In considering the future of narrative practices and community work, I often imagine and envisage a more concerted, structured, integral, role for narrative



within education systems, especially with young students. I am aware there already exist some initiatives in this direction and would be pleased to see further developments along such lines.

I reside on the traditional, unceded, territories of the *Shíshálh* (Sechelt) and the *Skw̓wú7mesh* (Squamish) Indigenous people of British Columbia's Sunshine Coast, forty minutes by ferry from Vancouver. Living here, I am acutely aware that provincially, and nationally, many young persons are concerned with the climate crisis, with oil pipeline construction, and associated environmental and ecological considerations. Indeed, as I write these words, our community is experiencing Stage Four water restrictions due to drought, meaning that no outdoor tap watering of any kind is permitted, under this ban. Young persons with climate crisis concerns could benefit from narrative ideas, and an insistence upon inquiring, questioning, and taking no discourse, especially neoliberal media representations, for granted.

The number of forest fires burning this past spring and summer in British Columbia has been incredibly devastating; many creatures have perished and animal habitats have been lost; and many human settlements have been destroyed. Following the wild fires, extensive, destructive, flooding occurred in many regions of our province, and many creatures, and livestock, perished, and people lost their homes. Narrative therapy could offer young students a paradigm for unraveling predominant stories, and a structure for bringing forth new and different stories regarding human connection and ecological concerns. Indeed, Jenny Freeman (2018-2019), assisted by David, recently created a series of narrative question to assist students in their responses to anxiety and concerns with climate crisis.

I also think narrative ideas could facilitate an increasing awareness of, or enhancement of, critical thinking with high school students. Michael himself once reflected, "I don't believe that anything should go unquestioned. I would feel highly uncomfortable if anything I say, write or do, that has the potential to influence others, was to be considered exempt from being questioned" (White 2000, p. 169). In these days when the neoliberal, corporate media, edits and filters what is worthy of news, thinking critically in regards to the so-called "news" being espoused and perspectives being promulgated, is imperative.



These are merely some of my musings; as I realize there are folks performing narrative therapeutic ideas and practices in innovative and novel ways worldwide. Staying local, back in 2013, when I was writing my dissertation⁸⁹, I asked a few friends what occasioned them to take up narrative. Barbara Baumgartner, now practicing social work in Australia, was intrigued by the ways in which the narrative therapy of White and Epston refused to engage in further alienating and marginalizing already suffering others (personal communication, May, 2013). Barbara responded to my research question, “Describe what initially enchanted you regarding narrative theory, as co-created by Michael White and David Epston (1989, 1990)”, writing:

What enchanted me about narrative therapy was ‘the person is the expert’ ethic. I had been working in the area of sexual violence and was reading trauma informed approaches to assessment and counselling; all of which stressed the importance of eliciting a person’s trauma story in a precise and perfect way that did not cause them harm. When I started to read narrative ideas around ‘trauma’, it was a big relief, because [narrative work] didn’t focus on me the counselor knowing it all (personal communication).

Barbara goes on to mention that, upon reflection and the benefit of time, she realized the challenge presented by narrative therapy to counsellor training and educational ideas and perspectives, writing, “In hindsight, I can see that I was also very influenced by the discourse that was circulated in my Master’s program, that a counselor had to be ‘finished’ with all their own personal growth work and their family of origin ‘issues’ before practicing as a counselor.”

Scott Lawrance, a friend, poet, Buddhist, teacher, psychotherapist, and former CityU professor, responding to the same question remarked that “...the ‘story’ metaphor altogether” caught his attention, when initially introduced to the narrative therapy of White and Epston. The “sense of living/enacting life as embodiment of multiple stories, with some (more ‘preferred’) lurking in the shadows cast by the dominant and dominating (more, temporarily, powerful), stories” and, perhaps not surprising for a poet, “the importance of language

⁸⁹ Again, for a more detailed and thorough description of how several narrative inspired therapists responded to my question, “Describe what initially enchanted you regarding narrative therapy, as co- created by Michael White and David Epston” see Sanders (2014).



(words, grammar, syntax) in shaping experience” (Personal communication, May, 2013).

Scott goes on to write about the importance of questions within this process, “and further to that, that questions could be shaping of experience (that possibility richly unfolded further through Karl Tomm’s paper(s) on interventive questioning...[with] Foucault in the background here, shaping and providing context for the discussion and practices – in particular, the options of self-surveillance as articulated by David and Michael’s reflections of Foucault’s use of the panopticon.”

Brian Williams, introduced above, responded to my question, writing,

The best way for me to describe my initial engagement is a sense of relief. I’d been involved with radical activism throughout my 20’s and 30’s in the areas of animal rights, anti-globalization, anti-patriarchy, and community-building work. When I got to grad school I felt like many of my values had to be backgrounded in order for me to feel safe – or at least be accepted. Many of the more individualistic/psychologically-oriented models did not feel like a fit. So when I encountered narrative therapy, with its emphasis on social justice, accounting for socio-political context, and deeply respectful, non-blaming approach, I felt like I could finally engage authentically and be myself within a therapeutic framework (Personal communication, May, 2013).

Both Brian Williams, and Tara Souch, another CityU graduate, have been using narrative ideas in their collaborations with Indigenous communities in British Columbia. Tara has been weaving narrative ideas into her engagement with young indigenous persons from *Ditidaht*, *Ahousaht*, *Tla-o-qui-aht* and *Yuu-cluth-aht*, all regions within the *Nuu-cha-nulth* First Nations, near where Tara lives in Ucluelet, B.C. Brian Williams has been assisting the indigenous community of *Klemtu*, of the *Kitasoo Xai’xais* Nation, on Swindle Island, B.C., integrating narrative into the oral storytelling traditional Indigenous context.

Working together, Scott Lawrance and Tara Souch, have been co-facilitating rite of passage wilderness experiences, in which the reauthoring concept manifests in practice. Scott and Brian have also integrated narrative into their Buddhist practice, and psychotherapy (Williams, 2015).



Michael indicated some time ago, “Narrative therapy, as I understand it, is not associated with some global proposal about how things should be” (White, 2000, p.170), yet it remains clear to me that narrative ideas and practices have benefitted many persons, and, indeed, many communities.

Finally, my initiation into the domain of narrative ideas and practices, and narrative and community practices, arose at a pivotal juncture and turning point within my personal life. At the time I was introduced to the thinking/writing of Michael and David, I had recently departed from a marriage of seventeen years, finding myself within a liminal space, embarking upon a new journey, experiencing shifts in my identity, engaging within a process of *restorying* and *reauthoring*. My partner Gail and I recently celebrated three decades together. We met around the same time I became intrigued with narrative. As the Grateful Dead song goes, “...what a long, strange, trip it’s been,” but what a lovely, marvelous, enriching trip, and one that is far from over. Gail is integrally woven into the tapestry and context of my autobiography with narrative therapy.

Gail worked for many years with marginalized others, persons struggling with severe and debilitating experiences of violence and violation, substance use, homelessness, and discrimination. Gail successfully incorporated narrative ideas and associated practices into community-based work on Vancouver’s Downtown East Side; work that included establishing medical clinics in single room occupancy (SRO’s) hotels and rooming houses, bringing medical services to persons who otherwise were unlikely to access such services. Gail utilized narrative in her engagement with participants in the Opiate Replacement Program she coordinated on the Sunshine Coast, as well as using narrative ideas in mediation and navigating her role as a Manager with Vancouver Coastal Health, which entailed a complex portfolio. Gail also worked as a psychiatric nurse at Insite, North America’s first legal supervised injection site in Vancouver (established 2003), when this harm reduction site first opened. Gail and I met through our work at Peak House in 1991, and Gail was considerably involved with the early narrative community in Vancouver. However, the associated particulars of that experience represent another story, for another time!

I consider my autobiography alongside narrative ideas and therapeutic and community practices to have been, and continue to be, a relational journey



involving many connections, interconnections, relationships, and interrelationships, many now spanning thirty years. The similarities and affinities with others whom I have encountered, including participants within programs and research projects I have worked and experiences with counselling graduate students, have vastly outweighed the differences. I have learned much from this journey, and continue to be educated in novel, narrative, inspiring ways.

At one point some years ago now, struggling with some personal dilemmas and attempting to move through an extremely troubling time, David witnessed the struggle I was experiencing. David thoughtfully and compassionately expressed his concerns and hope for me in a handwritten letter, not an email, which he mailed to me from his home in New Zealand. This consideration speaks to the sense of care and community with others I have encountered.

Finally, as the late poet Robin Blaser (2006) wrote, "I read, walk, listen, dream and write among companions. These pieces do not belong to me" (p.203).

References.

- Adorno, T. (1973). *Negative Dialectics*. Seabury Press.
- Andersen, T. (Ed.) (1991). *The Reflecting Team: Dialogues and dialogues about the dialogues*. Norton.
- Anderson, H., & Goolishian, H. (1988). Human systems as linguistic systems: Preliminary and evolving ideas about the implications for clinical theory. *Family Process*, 27(4), 371-395.
- Baumgartner, B., & Williams, B. (2014). Becoming an insider: Narrative therapy groups alongside people overcoming homelessness. *Journal of Systemic Therapies*, 33(4), 1-14.
- Bird, J. (1994). *The Heart's Narrative: Therapy and Negotiating Life's Contradictions*. Edge Press.
- Bird, J. (2004). *Talk that Sings: Therapy in a New Key*. Edge Press.
- Bird, J. (2006). *Constructing the Narrative in Super-vision*. Edge Press.





- Blaser, R. (2006). *The Holy Forest*. University of California Press.
- Carolan, T. (2015). *Powerground: The life and breath of the world*. Documentary film. Gallus Murus Productions.
- Dennstedt, C. (2010). The interplay of substance use and disordered eating practices in the lives of young women. *The International Journal of Narrative Therapy & Community Work*, 3, 52-63.
- Dennstedt, C. (2011) The interplay of substance misuse and disordered eating practices in the lives of young women: Implications for narrative therapeutic practices. Dissertation. University of Tilburg, NL.
<http://www.taosinstitute.net/christine-dennstedt1>
- Dennstedt, C. & Grieves, L. (2004). Unravelling substance misuse stories: Re-authoring and witnessing practices. In (Ed.) S. Madigan. *Therapeutic Conversations 5: Therapy from the outside in* (pp. 55-72) Yaletown Family Therapy.
- Epston, D. (1992). *Experience, Contradiction, Narrative & Imagination: Selected papers of David Epston & Michael White, 1989-1991*. Dulwich Centre Publications. 33
- Epston, D. (2011). Introduction. *Narrative Practice: Continuing the Conversation*. M. White. Norton.
- Epston, D. (2020). How Michael White Came Up with the Idea of Externalization: An Educated Guess. *Journal of Contemporary Narrative Therapy*, (September Release), 25-33.
- Freeman, J. (2018-2019). Questions for our times: Narrative Responses to Climate Change. Retrieved from *Reauthoringteaching.com*, January 31, 2022.
- Foucault, M. (1980). *Power/Knowledge: Selected interviews and other writings, 1972-1977*. (Translated by Colin Gordon, Leo Marshall, John Mepham, & Kate Soper). Pantheon Books.
- Freire, P. (2007). *Letters to Christina: Reflections on my life and work*. Routledge.





- Garfinkel, H. (1956). Conditions of successful degradation ceremonies. *American Journal of Sociology*, 61, 420-424.
- Gergen, K. J. (1992). The social constructionist movement in modern psychology.
- Gergen, K. (2009). *Relational being: Beyond self and community*. Oxford University Press.
- Grieves, L. (1997). Beginning to start: The Vancouver anti-anorexia, anti-bulimia league. *Gecko: A Journal of Deconstruction and Narrative Ideas in Therapeutic Practice*, 2, 78-88.
- Hedke, C. L. (2010). *Folding memories in conversation: Remembering practices in bereavement groups*. Tilburg University, Netherlands: Prismaprint.
- Henley, A. (1995). Arriving simultaneously with coincidence: Buddhism, phenomenology and narrative therapy. *The Journal of Collaborative Therapies*, 3(2), 33-38.
- Henley, A., & Miller, S. (2010). Possible applications of psychotherapy outcome research to traditional Chinese medicine. *Journal of Complementary and Integrative Medicine*, 7(1), DOI: 10.2202/1553-3840.1146, (June).
- Hoffman, L. (1995). Foreword. *The reflecting team in action: Collaborative practice in family therapy*. (Ed.) S. Friedman. New York & London: The Guilford Press.
- Jenkins, A. (1990). *Invitation to responsibility*. Adelaide, AU: Dulwich Centre Publications.
- Lax, W. (1996). Narrative, social constructionism and Buddhism. *The Journal of Collaborative Therapies*. 4, 9-18.
- Kinman, C. & Sanders, C.J. (1994). *Deconstructing addiction mythologies*. Fraser Valley Education & Therapy Services.
- Madigan, S. (2011). *Narrative Therapy*. American Psychological Association.
- Maisel, R., Epston, D., & Borden, A. (2004). *Biting the hand that starves you: Inspiring resistance to anorexia/bulimia*. Norton.



- Medine, S. (2016) Positive Opposition: Narratives of Anti-Hegemonic Masculinity Performance. Unpublished Master's thesis, City University of Seattle, Vancouver, British Columbia, Canada.
- Nylund, D. (2007). *Beer, babes and balls: Masculinity and sports talk radio*. State University of New York Press.
- Reynolds, V. (2002). Weaving threads of belonging: Cultural witnessing groups. *Journal of Child & Youth Care*, 15, 89-105.
- Reynolds, V. 'Bahman', Hammoud-Beckett, S., Sanders, C.J., & Haworth, G. (2014) Poetic resistance: Witnessing Bahman's resistance to torture and political violence. *International Journal of Narrative Therapy & Community Work*, Dulwich Center, Adelaide, Australia.
- Sanders, C.J. (1994). Workshop notes: Deconstructing addiction mythology. *The Calgary Participator*, 4(1), 25-28.
- Sanders, C.J. (1995). An appreciation of Lynn Hoffman's Exchanging Voices. *Journal of Collaborative Therapies*, 3(2) (January) pp.18-19.
- Sanders, C.J (1995). Narrative imagination in evoking a language of mind. *The Calgary Participator, Winter*, pp.44-49.
- Sanders, C.J. & G Thomson. (1994). Opening space: Towards dialogue and discovery *Journal of Child & Youth Care*, 9(2), 1-11
- Sanders, C. J. (1997). Re-authoring problem identities: Small victories with young persons captured by substance misuse. In C. Smith & D. Nylund (Eds.), *Narrative therapies with children and adolescents* (pp. 400-422). Guilford Press.
- Sanders, C. J. (1998). Substance misuse dilemmas: A postmodern inquiry. In S. Madigan & I. Law (Eds.), *Praxis: Situating discourse, feminism & politics in narrative therapies* (pp. 141-162). Yaletown Family Therapy & Cardigan Press.



- Sanders, C. J. (1999, April). *Workshop notes: The poetics of resistance*. Paper presented at The Centre for Peace, “New Narratives” workshop, sponsored by The Vancouver School of Narrative Therapy, Vancouver, Canada.
- Sanders, C. J. (2007). A poetics of resistance: Compassionate practice in substance misuse therapy. In C. Brown & T. Augusta-Scott (Eds.), *Narrative therapy: Making meaning, making lives* (pp.59- 76). Sage.
- Sanders, C.J. (2010). An inside update on current government initiatives for the homeless and mentally ill. *Insights into Clinical Counselling* (April), (pp.16-18, 40)
- Sanders, C.J. (2010). The Berkeley Renaissance: Its influence in context of the “Pacific Nation,” in appreciation of Robin Blaser’s *The Holy Forest*. In T. Carolan (Ed.). *Making Waves: Reading BC and Pacific Northwest Literature*, pp. 35-65. Anvil Press & the University of the Fraser Valley Press.
- Sanders, C. J. (2012). The use of narrative therapy in the personal transformations of graduate students. *Insights into Clinical Counselling*, (May), 22-23.
- Sanders, C.J. (2012b). Beat Scene Interview. In C. Wagstaff (Ed.). *A poet’s mind: Collected interviews with Robert Duncan, 1960-1985*. North Atlantic Books.
- Sanders, C. J. (2013). An exploration of therapeutic practice as sacred engagement. *Insights into Clinical Counselling*, (April), 16-17.
- Sanders, C.J. (2013). Lew Welch revisited: A “bright-eyed bardic spirit”. *The Pacific Rim Review of Books*, 9(1), 14-15.
- Sanders, C. J. (2014). *Narrative poetics of resistance: Towards an aesthetics of engagement*.
[http://www.taosinstitute.net/Websites/taos/images/PhDProgramCurrentDissertations/Sanders_Dissertation_2014_\(2\)-1.pdf](http://www.taosinstitute.net/Websites/taos/images/PhDProgramCurrentDissertations/Sanders_Dissertation_2014_(2)-1.pdf)
- Sanders, C.J. (2016). Toward an Aesthetics of Engagement. In V. Dickerson (Ed.), *Poststructural and Narrative Thinking in Family Therapy*. AFTA/SpringerBriefs in Family Therapy. Pp. 61-81.
- Sanders, C.J. (2019). Book review: *Falter: Has the human game begun to play itself out?* By Bill McKibben (2019), *GTEC Reader*, 1, (September).





- Sanders, C. (2020). Cultivating the horizon: Considerations occasioned by Barry Lopez's memoir, *Horizon*. *GTEC Reader*, 3, (January).
- Sanders, C.J. (2020). Son of a Genius: Tosh Berman, A life in Art. Book review: *Tosh: Growing up in Wallace Berman's World*. Tosh Berman (2019). City Lights Books. *Pacific Rim Review of Books*. 25, 14, No. 1., 13-14.
- Sanders, C.J. (2020). Peter Orlovsky: In his own right. Book review: *Peter Orlovsky: A life in Words: Intimate chronicles of a Beat writer*. *Pacific Rim Review of Books*. 25, 14, No. 1., 31.
- Sanders, C.J. (2021). Alan Watts and the Re-visioning of Psychotherapy. In P.J. Columbus, *The Relevance of Alan Watts in Contemporary Culture: Understanding Contributions & Controversies*. Routledge.
- Sanders, C.J. (2022). *Notes toward an ethos of the sacred: The praxis of Michael White*. Manuscript in preparation.
- Sanders, C.J. (2022). The Climate Crisis: Reflections in an Existential Emergency. Part One. In Press, *GTEC Reader*, Vol. 2, issue 6 (February 2022). gteccanada.ca
- Sanders, C.J. & Thomson, G. (1994). Opening space: Towards dialogue and discovery. *Journal of Child and Youth Care*, 9, 1-11.
- Saville, S. (1998). *Overcoming the problem of substance misuse: Adolescent experience in a narrative re-authoring program* (Unpublished Master's thesis). University of British Columbia, Vancouver, Canada.
- Tsemberis, S. (1999). From streets to homes: An innovative approach to supported housing for homeless adults with psychiatric disabilities. *Journal of Community Psychology*, 27 (2), 225- 241.
- Tsemberis, S. (2010). *Housing first: The pathways model to end homelessness for people with mental illness and addiction*. Hazelton.
- Tilsen, J. (2015). *Therapeutic conversations with queer youth: Transcending homonormativity and constructing preferred identities*. Rowman & Littlefield Publishers





- Tilsen, J. (2021). *Queering your therapy practice*. Routledge.
- Van Gennepe, A. (1960). *The rites of passage*. University of Chicago Press.
- Waldegrave, C. (1990). *Just therapy*. Dulwich Centre Publications.
- Waldegrave, C., Tamasese, K, Tuhaka, F., & Campbell, W. (2003). *Just therapy – a journey: A collection of papers on the Just Therapy Team, New Zealand*. Dulwich Centre Publications.
- White, C. (2009). Where did it all begin? Reflecting on the collaborative work of Michael White and David Epston. *Context*, Issue 105, 59-60.
- White, C. (2011). Postscript & Acknowledgment. *Narrative practice: Continuing the conversation*. Michael White. Norton.
- White, M. (1989). *Selected Papers*. Dulwich Centre.
- White, M. (1995). *Re-authoring lives: Interview and essays*. Dulwich Centre.
- White, M. (1997). *Narratives of therapists' lives*. Dulwich Centre.
- White, M. (2000). *Reflections on narrative practice*. Norton.
- White, M. (2007). *Maps of Narrative Practice*. Norton.
- Williams, B.D. (2015). The Dharma of harm reduction: Responding to substance use with the compassion of the Buddha. *The Buddhist Peace Fellowship*. <https://buddhistpeacefellowship.org/the-dharma-of-harm-reduction>
- Williams, B.D., & Baumgartner, B. (2014). Standing on the shoulders of giants: Narrative practices in support of frontline community work with homelessness, mental health, and substance use. *International Journal of Child, Youth & Family Studies*, 5(2), 240- 257.
- Winslade, J. and Monk, G. (2000). *Narrative Mediation: A New Approach to Conflict Resolution*. Jossey-Bass.
- Zimmerman, J. (2018). *Neuro-Narrative Therapy: New possibilities for emotion-filled conversations*. Norton.





Zimmerman, J. and Carlson, T. S. (2020). Insider Witnessing Practices, Trauma, and Neuro-Affectional Reauthoring. *Journal of Contemporary Narrative Therapy*. (July, 2020, Release 2), 166-205.