Co-Evolving Meaning with Narrative Therapy: Practices That Preserve Hope and Dignity at the End of Life

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Abstract

The following narrative therapy teaching story focuses on therapeutic conversations I had with a man who was living with cancer and in the last weeks of his life. Although he had only a short time to live, he told me he was on "a journey to wellness" and insisted he didn't want to speak of anything else.

This paper illustrates, and reflects on, how we formed a therapeutic relationship and how meaning was co-evolved so that he could engage with dying in a way that dignified him. Accompanying the illustration of therapy are detailed footnotes that provide a commentary on the narrative therapy practices that informed me and my thoughts about them. These footnotes can be read either alongside the story of our conversations or separately.

A beginning

Tom[2] stood in the reception area of the hospice. He was dressed in a full-length oilskin coat and cowboy hat. His slim frame and angular features reminded me of an athlete rather than a man living with end-stage cancer. As I came into view, Tom strode towards me without hesitation, and we simultaneously reached out to shake hands.

"Hello, I'm Sasha, one of the counsellors here at the hospice."

"Tom," he replied, gripping my hand.

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[2] All names and identifying information have been changed. For information on stories as pedagogy for learning Narrative Therapy, see Carlson et al. (2017) and Heath et al. (2022) and as a therapeutic legacy written with people living with a life ending illness see Chochinov (2012). Baines' (2002) book on ethical wills may also be of interest.

I ushered Tom down the long hallway towards the counselling room, avoiding the usual, “How are you?” that often is used as a greeting in Aotearoa New Zealand. Sometimes to try and put a person at ease, I ask a small concrete question.[3] Not today. Tom kept his eyes focused ahead and walked purposefully in the direction I had indicated. I remained silent.

At the doorway to the counselling room, Tom paused and turned to face me. Speaking with intensity, he declared, “I’m on a journey to wellness. If you can’t join me on it, I don’t want anything to do with you.”

He stated his position with the conviction of someone fighting their way out of a corner.[4]

Looking him in the eye, I solemnly acknowledged his statement. “Okay.”

My reply seemed inadequate to me but was enough for him to walk through the door. We both sat down.

I didn’t know what Tom’s statement meant to him, but with death fast approaching, Tom may have felt he was fighting for his life. I put aside my curiosity and resisted asking Tom to explain more. Instead, I decided to begin by getting to know him. I hoped we might have a more useful conversation about his journey to wellness once we had built a relationship.

[3] For example, an inquiry as to whether they found a car park easily. By a small question I am referring to questions that inquire about short blocks of time, are often concrete, and are easily answered. A big open-ended question such as, “How are you?” is often overwhelming for people with a life ending illness and requires care.

[4] When a person has endured previous imposition or has had to defend their stance, they may respond in various ways. For example, they may be silenced and no longer speak of their preferences or they may pathologise themselves and believe they are ‘doing it wrong.’ Another response might be to turn up the volume of what they want and fight for their beliefs. As a narrative therapist, I start from an understanding that people have good reasons that make sense to them for what they do (see Simmonds, 2018; White, 1986). Such an understanding enables me to be curious about their world without prejudgment. I inquire into what they are taking account of in their decisions, and also what might be restraining them from taking alternative paths. This is in contrast to ideas that state a person should be going about treatment or living with the illness in particular ways and it is up to the health professional to educate and persuade them to take the ‘right’ path. Open inquiries from a position of non-judgmental curiosity invite people to speak their thoughts out loud, sometimes for the first time. Speaking thoughts out loud allows a person to form a narrative from the fragments they hold in their mind. They can then examine the narrative and see if it fits with their values (see Pilkington, 2014, 2017).

On the telephone I had spoken to Tom about my role and the length of time he might expect us to meet. Therefore, once we were comfortably settled, I stepped into the conversation with, “People are so much more than the illness they are living with and their current situation. Would it be OK if we began with me asking you a little bit about your life and what matters to you?”[5]

Tom’s face relaxed and he eased himself into the back of the chair. “Yeah, sure.”

“Would you like me to take a few notes of our conversation? These would be for you rather than the hospice file. Many …” Tom interrupted me. “No. There’s no need.”

I had been going to explain that many people find it helpful to have a written record of the conversation and I could send this to him in the form of a letter.[6] Instead, I asked, “Would you be willing to share a little of your life before all this happened to you?” I didn’t name the cancer because I didn’t know how he wished to speak of it or what language he liked to use.

Instead of answering my question, Tom explained his rebuttal with what could have been pride in his voice. “I don’t need notes. I have an excellent memory for detail. I was identified as a child genius when I was young.”

[5] I step into conversations with great care. I don’t assume I have an automatic right to talk about areas in a person’s life that they may find painful. This question allows me to acknowledge that Tom is more than his illness. It leads me into learning about those areas of his life he values and creates a stepping stone towards building a relationship in which I hoped Tom could feel respected and valued (see Chochinov et al., 2015; Epston, 2018, 2025). When someone is backed into a corner and forced to defend their position, attending to the relationship first can create a context in which their story can be told. It can allow them to come out from having their back to the wall and examine, re-evaluate, and add detail to their own preferred narrative of how they wish to die.

[6] Narrative therapists use letters for therapeutic purposes (see Newman, 2023). “Narrative letters can be used as potent records of therapeutic conversation to underline and consolidate what has been discovered in therapy” (Pilkington, 2018).

I responded to his tone as this information seemed important to him. Dignity can be hard to come by when a person is living with a serious illness.[7] "A child genius. Wow. Would you mind sharing a little more about that?"

"I'm lucky. I've got a really fine mind. I mean I was the brightest kid in my primary school for ten years. I've got an IQ of 145," he explained.

"Would you mind sharing a little of how this brightness shows up in your life?" Before I had completed my sentence, Tom responded, "Basically, in school stuff. I was talking way beyond other kids. I mean I was worrying about the universe as an eight-year-old. Interestingly, my intelligence is much more around creativity and language than maths and science, though I ended up teaching maths and doing a science degree. I mean I used to do shit in my head with maths that other people couldn't do on paper. But when I look back, I realise my creativity and language went way beyond."

Tom went on to share with me that he had done very well at university, had a number of degrees, and had been head of a large complementary therapy institution, a lecturer, and an esteemed practitioner of reiki. "People have recognised my abilities as extraordinary. They came from far and wide to have healing sessions with me," he explained. Tom had also been a schoolteacher and cared deeply for the children he came into contact with. Tom then talked about his current partner and their young daughter, his adult children from his first relationship, and how much they all meant to him. He told me his family was very important to him.

"I am one of 2% of people who are still alive of all those who received the same cancer diagnosis as me two years ago. My oncologist says I'll be dead by the end of October, but we shall see. Very few people have my abilities," he told me, in a tone that suggested he was in no doubt he would be alive for a long time to

[7] Our identity descriptions don't just speak to our past and to whom we think of ourselves as being; they influence our future decision making and what we think is possible for us (See White, 2016). One reason I asked Tom about his intelligence was to underline and potentially expand any ideas he held about himself that might be helpful as he approached death. When Tom described the valued ways he viewed himself, he was also renewing his connection to these ideas about himself.

come. I quickly calculated in my head. The end of October was less than eight weeks away. Tom continued, "I walked up Mt Taranaki.[8] Right to the top. I had to crawl the last bit but I got there!"

"Are you a determined kind of pers—?" Before I had finished my sentence Tom quickly corrected me. "Not determined, I'm focused, and I don't give up. My journey to wellness is a good example of that."

Tentatively and with as much respect as I could offer, I responded, "Would it be OK to ask … how are you going about your journey to wellness?"[9]

Tom talked enthusiastically about his diet and the care his partner was taking to help him. He spoke of his exercise achievements, meditation, and reiki regimes. Tom explained he was having intravenous vitamin C, that he was also taking chemotherapy, and having radiotherapy as prescribed.

"Then there's Crockie. He's reptilian hindbrain. Fight and feed, OK? Crockie is the ultimate survival fighter for me. He's the one who's attacking the cancer cells. At the primal level."

[8] Mt Taranaki has an altitude of 2,518 m (8,262 ft).

[9] This is a deconstructive question (See White, 1991). Deconstructive questions pull apart the threads of an idea in order to make them visible. The person can then examine the ideas that are influencing them and weigh up whether they are going about their life in accordance with their values.
Ideas that have guided a person and have previously fitted with their values may no longer do so following a diagnosis of a life ending illness. For example, if quality of life is an important value and hugging family members is part of quality of life for a particular person, then the idea 'taking pills is a bad thing' that served the person when they were in good health, may not serve them when they are in pain, if that pain prevents them from enjoying touch and hugging (See also Pomfret & Simmonds, 2018). It can be as if the details of *how* a person is required to live according to their values are turned upside down and yet the change is not easily recognisable. In such situations, these kinds of questions can be very helpful.
In my conversations with Tom, you may notice a sequence of deconstructive questions that I ask about his 'journey'. I intentionally spaced these questions out in order to respect his wishes for the conversation. This was the first. I chose to ask Tom this one first as it was the most easily answered. The second key deconstructive question I asked him was when I inquired what wellness was to him. Many more follow as we explore how he can both die and continue on his journey to wellness. The timing of these questions was important and I resisted asking them until Tom indicated he was willing and interested in going in such directions.

I was familiar with people giving their disease a name, but Tom was doing something different. He seemed to be naming a part of himself. Tentatively, I inquired, “How does he go about that? What’s your understanding?”

“If cancer cells are getting bad, he gets in there. He fights. Think of a reptile.”

“Okay,” I reflected, trying to understand. My thought was cut off though by my desire to listen.

“At the moment he’s very, very busy. I went down the track of wondering if I could work with the cancer cells but then I realised, ‘They don’t give a shit.’ When it’s been my survival at stake Crockie is there for me. Sometimes when I’ve been semi-conscious, it’s Crockie who’s been there for me fighting.”

I use language such as ‘living with’ and avoid fighting language when I am meeting with people with incurable illnesses until I’ve learnt what language they prefer. War-like metaphors can create a binary of winning and losing that is usually unhelpful, although this isn’t always the case. Crockie had fought for Tom, but what of the rest of him? As Tom talked, I was listening for vocabulary that fitted with his experience.

Tom conveyed confidence that his abilities would be enough to overcome cancer. I wondered how I could support Tom, as he got sicker, to keep those identity descriptions of himself that he prized. Serious illnesses rob people of so much.

We continued to talk, with me focusing on building a relationship with Tom.[10] He told me he didn't want to discuss the effects of the cancer or loss. "I don't want that analytical stuff. I've done years of counselling already. I'm on a journey to wellness and I'm not interested in talking about anything else." I wasn't going to analyse or pathologise as Tom expected but he had no way of knowing that.[11] I also respected Tom's clarity on how he wished to spend his time with me.

Our relationship took a positive leap when I invited Tom to write this story. He was delighted, and enthused warmly about his previous teaching and writing. This

[10] A good respectful relationship is essential and creates a context in which many difficult or unfamiliar conversations can take place with a therapeutic outcome. A good therapeutic relationship is not only helpful in itself but has been shown to enhance the value of medical interventions and even the placebo effect (Wampold, 2021). It can create a context in which a person may examine how they might want to go about living with their disease and approach death. When someone is positioned as being 'in denial' attending to the relationship is critical. If we wish to discuss and honour stories of suffering and mortality, we first need to generate the kind of relationship in which such stories can be told (see Pilkington, 2017).
Illness and suffering can make building a therapeutic relationship challenging at times. Loss, stress, illness and suffering aren't always communicated in polite and comfortable ways. None of us are likely to be at our best when we are suffering, or our customary way of life is being threatened. People have different knowledge and skills. They have different histories and bring different styles to conversations with health professionals. Not only that, but when people are under great stress, unwell, exhausted, perhaps with their back against the wall as they contemplate their mortality, building a relationship in which stories of their experience can be told may be very challenging indeed. It may also be even more important.
There is huge value in knowing how we can go about building a warm therapeutic relationship when there are challenges that are likely to derail doing so. When we know how we can go about building a relationship and what we can do to be helpful, we can then be intentional especially if the other person's way of responding gets in the way or could take us into conflict. Skilfully practised ways of building relationships offer up pathways when "getting along" or "finding things in common" won't work.
When I met Tom, I intentionally prioritised getting to know him and building a relationship in which we might talk about approaching death. It wasn't easy. Tom had been forced to defend his "journey to wellness" many times and he first needed to be sure he could trust me to accompany him in ways that fitted with his values. He also disliked many counselling approaches and had some particular ideas concerning what he wanted to speak about and how. I chose to try and get to know Tom aside from the cancer he was living with (see Epston, 2004, 2016; Epston & Marsten, 2010; Marsten, Epston & Markham, 2016). If he had preferred another way to begin the conversation, I would have been guided by that. I wanted to find ways of connecting with him that honoured and brought forward those parts of him he wanted to make known. I asked him questions about how he went about what mattered to him and listened for expressions of goodness in his actions. By goodness, I am referring to Aristotelian virtues such as kindness, courage, determination, persistence, and love. Such inquiries bring forward preferred identities and can create an entranceway into previously unspeakable areas of a person's life. Not only that, they can give a person a sense of living meaningfully (May, 2015) which is especially important at the end of life (Pilkington, 2022).

[11] Counselling/therapy conversations are informed by different philosophical ideas and counsellors/ therapists engage with different practices. However, such knowledge is not widely known. In addition, not all counselling experiences are helpful. Tom had previously experienced multiple relationships with counsellors and psychologists that he had found unhelpful. I therefore prioritised our therapeutic relationship and Tom's knowledge of what he wanted and believed would be useful for him during our time together.

led me to ask a question that I hadn't felt able to venture earlier in the conversation.

"Could you help me understand a little of what you mean when you speak of wellness?" (see Namisango et al., 2023).

"Integration," stated Tom. He offered no further explanation and the severity with which he expressed himself made it clear to me he didn't wish to. It was early in our relationship and I didn't want to impose on Tom or take him in directions he didn't want to go. So even though I didn't know what he meant by integration, I remained silent. I would wait until he wanted to talk about it. Instead, I checked with him, "How are we going with this conversation? Are we talking about what you hoped we might, or have I taken us off track?"

Tom assured me we were on a useful path.

"Would you like to meet up again?" I inquired. At Tom's suggestion, we made time to meet again in a fortnight at the hospice. He had a series of appointments at the hospital the following week. A fortnight is a long time when someone is very unwell and so I invited him to call me should he wish to change any part of our arrangement. I then asked about his partner, "How is Cherie doing? Would you like her to join us in the future?"

"She's busy working at the moment and she also has a lot to do for our daughter. Maybe some time in the future we can all meet."

"It would be lovely to meet her," I responded, aware that cancer impacts many people, not just the person who is unwell. It was usual for me to meet couples

together[12], at least for some conversations, and so I had tried to create a space for such a meeting.

Working in a multi-disciplinary team has many advantages. The community nurses who visited Tom at home were also seeing Cherie and would alert me if they were concerned for her or any other members of Tom's family. I was also aware that one of the nurses might be Cherie's preferred support person and, in an organisation like hospice, the family would also have the option of seeing another counsellor.

The following week I received a phone call from Tom.

"I'd like to have a family meeting with you. Would that be possible?"

"Of course. I'd be very happy to do that. Who would you like to bring along?" I inquired.

There was a pause.

"Not that sort of family meeting. I'd like to check in with everyone and see how we're going," Tom explained. I was puzzled.

Tom clarified, "You've met Crockie. I'd like to have a meeting with the whole family." I began to realise that Tom was referring to his internal family.

"Where would you like to have it?" I asked.

"At the hospice like last time," he said. "I'll see you as we arranged."

[12] I may meet with many different constellations of families. When I meet with couples, we may sometimes arrange individual conversations as well. Such a decision is done with great care and respect for even handedness, transparency and attention to what might become problematic. When someone becomes unwell with a life ending illness all those who care about that person will be impacted in some way. I frequently will involve counselling colleagues in supporting family members however, even if a colleague is seeing another family member, I will look to make myself known to the person's partner. It was unusual for me to meet with Tom without ever seeing him with Cherie or other family members.

Entering Tom's world

A fortnight later Tom arrived early. When I walked into the reception area, he was leaning back in the folds of a chair with his cowboy hat tilted forward across his eyes. He could have been sleeping.

"Sasha," he acknowledged me from under his hat.

"Hi Tom," I responded, intentionally infusing warmth into my tone.

I led Tom into a larger room than the one we had used previously. He surveyed the space as we stepped into the room. "Thanks for organizing this. The extra chairs are great," he said, affirming my decision to move to the bigger room. We both sat down.

"How would you like to go about this?" I inquired.

Tom spoke firmly as he instructed, "We will start with me introducing you to the family."

"Thank you for having me," I replied.

Tom looked around the chairs again. "One for each of them," he stated. Tentatively I offered, "Would you like me to help in any way? If you wanted, I could make a name label for each member of the family..."

"Yes, a name label would be good. Put it on each chair as I introduce them. I've told you about Crockie, my primal fighter. He's reptilian hindbrain." I wrote 'Crockie' on a piece of paper and placed it on a chair near Tom. "Next is Wombie, short for Wombat. He's my mammalian mid-brain. I picked up these concepts from Arthur Koestler. Wombie is the emotional, mammalian, love and connection part of me. Crockie got no encouragement when I was a child. Wombie looks after me. He looked after me in the past when the basic message was 'you're not good enough.'"

"May I ask, how does Wombie help you live with the cancer?" I realised as soon as I'd spoken that I'd got ahead of what Tom wanted to do but he hurriedly

continued, “I’ll come back to that after I’ve given you the next bit.” I sat back with a sense of reprieve and listened attentively.

“Next is Rattie. Rattie is my driven side; he came from a character in a science fiction novel. Rattie is driven by anxiety and will constantly ask, ‘what about, what about, what about?’ If you put Rattie down the bottom of a 10-foot-deep silo, he would never stop looking for a way out even if it meant gnawing a foot off. Rattie would sort it out. That’s what Rattie does and he’s very, very good.”

“Is Rattie persistent?” I asked, caught up in Tom’s world.

Tom replied with gusto, “Unbelievable! Beyond persistent.”

“Doesn’t give up?”

“Never. Rattie would argue that I got a bit complacent. Because I got to a comfortable place in my totality, I soothed Rattie down. I had him in his comfortable little house and said, ‘Don’t worry. We’re OK’. That complacency cost me. The cancer got away on us. But we’ll see. The next one is Alby. Alby is my frontal lobes, my intelligence. I’m lucky. I’ve got a really fine mind and when I was young Rattie and Alby between them were protective and they protected Wombie in particular. My childhood was pretty challenging to say the least. The basic message I received was, ‘You’re not good enough.’ Rattie would constantly work at figuring out ways of looking after Wombie, because Wombie as a young child was small and weak whereas now Wombie is very strong.”

“How did Wombie get strong …?”

“By me realising … um let me just think about that for a second … me realising that as I entered adulthood and new relationships and having kids, that my ways of dealing with emotional issues were not working very well.” Tom elaborated further, finishing with, “I grew up basically defending myself against the world.”

Each time Tom introduced a member of the family I wrote their name down and placed it on a chair. I said very little as Tom described his life, pouring out his

experiences and views. I was focused on building a relationship with him and listened with all my attention for what Tom might want me to know about him.

"… When I got to adulthood, I realised I was where I needed to be in terms of relationships. For instance, now my kids have shown me extraordinary love and support. I've been in tears … so many times. Being a parent, you don't expect anything back but when I got my diagnosis the support started coming back."

Tom began telling me stories about his family. As he spoke, I listened for what mattered to him and gave meaning to his life. I noticed how he cherished his relationships with his children and partner. 'It is generous,' I thought, 'to share such precious stories with me, a stranger.' There were times when I was concerned that I wasn't being helpful. I was saying little in the conversation, but I decided to respect Tom's desire to talk and see what unfolded.[13]

"My daughter organized for the family to get together. I was a bit down to it 'cos my energy wasn't that great so I said 'you guys just go and enjoy yourselves' and next thing you know I'm sitting on the bed with my kids and they start treating me … well it was one of the best evenings of my life. Just talking about how life had been for them as kids with me as Dad. Some crazy shit we used to get up to … which was really neat!"

"May I ask, what made that mean so much to you?"

"The clear expression of love. And appreciation for me as a dad and the childhood they'd had. My parenting has been, 'I want to help you all to be the best you can be.' My kids are very different. They're all neat. The stories range from crazy driving shit to chasing possums, to going for walks for hours … We lived in the country surrounded by bush. No one around for miles. It wasn't specifically saying, 'Dad you're great.' It was more, here's the warmth and love and vitality."

"Was it a living breathing love in the relationships as they were there in the room?"

[13] The context of Tom's life expectancy and also his previous counselling experiences is important in this decision.

“Oh, shit yeah! And then I said, ‘Well guys, one of the things I want to address is the nuts and bolts. I’ve already laid out the broad outline of my will. I want to get down to specifics.’”

Tom went into detail, trusting me with the specifics and what the conversation had meant to him. I noted that he was both on a journey to wellness and able to discuss the possibility of his death.

“So, we had this impromptu warm fuzzies and at no point was there any dissension. It was just ‘we’re doing this together.’ And that was extraordinary. I’ve been around helping people work stuff out and never has there been a situation where it was worked out so well.”

“What does it mean to you that as a family you can …”

Tom anticipated my next words, “Pretty much everything … I’m a dad, that’s who I am … but it’s also the kids I taught at Conway about 5 years ago, they’re emailing and they’re wanting to catch up with me.”

“How do you think they remember you?”

“I’m a guy who cared. It’s that simple. It’s just how I am. I volunteered to work in the university creche as an 18-year-old. That was in the day when men did not do that.”

“How come you did that!?”

“I don’t know. I can’t take credit for it. It’s here,” Tom explained, placing both hands over his heart.

Without thinking, I copied him, raising my hands over my heart. “Here,” I echoed.

“If you want to get analytical about it, and I hate doing that. It goes back to the analysis bullshit that I told you about because I suffered for a long time from a lack of care. Life’s not easy. If we can do anything to make it better …”

Tom shared with me some examples of his teaching according to this ethic and how much difference he had made to his students' learning.[14]

"What did the suffering you experienced as a child teach you about the importance of …" I had been going to say 'love and care' but Tom stopped me, "Again, I don't want to get analytical about that. I spent decades exploring and analysing and I've just had enough."

I reflected that I didn't know what Tom meant by 'analytical'. I wanted to clarify its meaning for Tom so I didn't accidentally go there again but first I needed to apologize, "I'm so sorry. I didn't intend to take us in an analytical direction. When you say you don't want to be analytical, so I don't ask you questions that take you to places you don't want to go, would you mind …"

Tom interrupted me, "I see it as unproductive and I know I'm being forceful but I really don't see it as useful. I know that I didn't reach my full potential as a person because of that. Let's try and make the world a better place. It's real simple … and that comes down to looking after one another."

Tom went on to discuss his beliefs. I inquired about his voluntary work at the creche which seemed to please him. However, I still didn't fully understand what Tom meant by 'analytical' and I didn't know how to avoid asking him questions that he was reluctant to answer. I was aware that in many counselling contexts there might have been a focus on topics as they arise and maybe a different way of going about a therapeutic conversation. However, in palliative care it can be different. Time was running out for Tom, and we needed to prioritize what we discussed. I respected Tom's clarity about what he wished to talk about and how. I wanted to ensure the conversation addressed what was most important to him and we needed to build a trusting relationship before I could be useful to him.

[14] I asked Tom if he would mind sharing more stories from his life that illustrated his care. Gathering more stories of Tom's care of others strengthened the identity description of Tom being a caring person. It is helpful to strengthen preferred descriptions a person holds about themselves as the strengthened or new description can offer the person expanded or new possibilities for responding in their life and/or new ways of appreciating themselves (see White, 2007).

I tried again, “Would you mind clarifying what you mean by analytical because I …”

Speaking quickly, Tom replied, “These things happen because I did this. I did that because of that.” He returned to talking about his teaching without elaborating further.

I wondered if some scaffolding, and questions that were less direct might be more helpful as Tom’s understanding of what I was asking seemed to be different to mine. Resolving to listen even harder to what Tom was saying, I finally said, “Sadly, some people are deprived of love and compassion … it sounds like you turned such an experience around and, would you say learnt the value of it …?”

“All I know is it works better.”

I reflected, “It works better.”

Tom sat back in his chair and explained more of his experience as a teacher.

When a pause occurred in the conversation I checked, “How are we going with this conversation? I notice we’ve stopped the introductions to the family. What would you like to do at this point?” I wanted to ensure we were headed in a direction he considered useful.[15]

Tom was clear. “I’d like to finish getting the labels done now,” he said. I readied my pen.

Tom introduced me to JC, who he said was his spiritual side, and to Auntie Lee, Queenie, and Errol, whom he called ‘the triumvirate’.

“These are the three who are involved in my healing side. I trained as a naturopath and osteopath and became head of the Atlantic College. I also had a practice teaching about the body. I developed my skill to the point of holding my hands far above people’s bodies and they ended up having amazing healing

[15] I ask questions that check on how the conversation is going for a person/family as a regular part of my practice. This practice keeps us on track with what the person seeks from our conversation.

experiences.” Tom stretched his hands above his head to show me the extent of his ability. I listened as he shared stories of how the triumvirate came into his life and supported his knowledge of healing.

“So that’s my family and what I’d like to do now is run the family meeting,” Tom concluded.

“Would it be OK to ask what the goals are of the family meeting?”

“Right now, I just want to ask them how they think things are going.”

The chairs were positioned in a semi-circle, and each had a family member’s name on their seat. Tom began to outline some ground rules. “You’re here as an observer. You do not have speaking rights,” he stated, looking me in the eye.

I nodded. “OK.”

“The family meeting is the family. We’re a unit. If one of them wants to talk to you directly, they’ll run it through me. If I say ‘yes’, I’ll then discuss with you what we’re going to do, and then you can have the conversation.”

“OK.”

“If it’s ‘no’, that’s it.” Tom waited for my agreement once again looking intently into my eyes.

“Of course. I want to do all I can to respect how you prefer to go about this. I’m an observer unless you tell me … even if one of them wants to talk to me, it still goes through you.”

“Yes. It still goes through me. I’m the unifying principle,” he explained.

“Thank you very much for having me as an observer.”

“Thank you for saying that” replied Tom, all business, his eyes now surveying the room.

Family meeting

Tom looked at the empty chairs, “OK, guys, so we’re having a family meeting to sort out where we’re up to in the journey we’re on to wellness. And we’re really lucky in that we’ve got Sasha here as an observer and to record this. Just like when Death was here, she doesn’t have speaking rights unless we agree. We’re going to talk about where we are up to and what we do next as we continue on our journey to wellness. What I want from each of you is a score out of ten as to how much you believe we are going to make that magical five-year survival mark which is the benchmark in terms of how well people survive cancer. It’s nearly three years away. I want you to then talk about how and why you came to that score and what we do next, whether we try and improve it or carry on. OK, Crockie, I’ll start with you. What do you think the score is?”

Tom’s tone of voice changed and Crockie spoke, “Ten out of ten. I am not stopping until I have killed every single one of the cancer cells. And I’m going to do it. I’m going in hard. I’m ten out of ten confident we will make the five-year survival mark.”

Tom’s distinctive voice rang out as he replied, “Thank you Crockie. You’re a tough bugger and I love you to bits. Fantastic. OK, next. Wombie.”

In a soft voice Wombie responded, “I’m seven out of ten. That’s because I kind of get worried we get a false sense of confidence. I can feel from the kids that they absolutely love …” Tom interrupted Wombie, “Excuse me … hanky break …” He pulled out a handkerchief from his pocket and mopped tears that were falling unhindered from his eyes. After a brief pause Wombie continued, “the kids love and want me to be around for them and the grandkids … so we can continue to be a family. I don’t want anyone around me who is not committed to us - me - getting well. And I understand that they’re worried. One of the kids wasn’t 100% sure that we were going to make it, so that’s what pulled it down from ten to seven for me. As to what we do about it. We just keep on keeping on.”

Tom directed his comments to me, “Wombie would love to be around for the sake of being with my kids, my grandies, my family … Cherie and Frankie, dear Frankie. Wombie is very clear about wanting to continue and …”

Wombie interrupted, “I want us to continue to keep on going so the faith we all had in making it, is not just repaid by going on living, but we’re here living life well.”

Tom turned to me. “Wombie was really struck when Death visited a family meeting. We asked Death for a bit of advice and Death said, ‘Live well.’”

Awe filled me. “How wise,” I thought.

Tom returned to Wombie, “That for me Wombie, is our answer. Thank you, Wombie.”

Tom spoke aside to me to explain further, “Out of a hundred people who had my diagnosis two and a half years ago, right now ninety-six of them are dead. All that tells me is that the climb is pretty steep. The oncologist says he doesn’t expect me to last past the end of next month.”

Rattie spoke quickly, pushing out the words as if playing a staccato beat on a drum, “I just love being Rattie because I will find a way. I will not stop, and I will, I will get us through. I’m a ten.”

“Thank you, Rattie. You’ve been there all my life, and I’d like to have a lot more life for you to be there for. And I hope next time I have you sitting in a tidy little house that it works … for longer. Cool, OK. Alby.”

Alby’s voice was refined and certain, “Well, I’m not going to give you ten because there are probabilities here. I’m going nine and a half out of ten confident. And … what that’s about is sometimes things happen that we don’t expect. I’d lean to ten except my intelligence has taught me that we need to be aware … It’s nine and a half because I’m a little bit cautious … but I’m looking to how I can shift it up to ten.”

Tom released his brow which had been screwed up as soon as Alby mentioned he was looking for a way to move his score up. “Thank you, Alby. I love the voice of reason. Just a nice complement to the other guys so yes, very cool. Ok … JC.”

Tom asked each of his family how they rated their chances of living for another three years. All were confident. No other family members expressed the hesitation that Wombie had mentioned.

“OK. Thank you, guys. That was fantastic. Is there anything any of you would like to ask Sasha or talk to her about?”

Tom looked at me, “I’ve just had a collective message from all of them just saying thank you for being here and for allowing this process to happen. And from me the same. I’m getting quite blunt now. I’d rather have a family meeting than a counselling session. It was that important for me to have this and to have it in this setting with you is synergistic. With one of my mates or three or five I don’t care. Absolutely precious and magic. You’ve said you’ll do a transcript of the recording. I’d love to talk with you about it next session.”

Tom concluded, “OK guys. Meeting’s over. And thank you. That’s just fantastic.”

Tom addressed me. “I have not had a bad family meeting. Not once. Death has been present twice. I specifically asked Death, ‘Have you any advice for us?’ … and in return I got this love, so much that it almost felt impersonal, it was so huge, overwhelming almost.”

Awestruck, I reflected, “Did you have an experience of Death loving you?”

“Yeah. Death … is not what a lot of people think it is. Death is not to be feared. I could feel a twinkle in the eye. The sense of humour was so far up there. And this voice came down and said, ‘Live well’ and I just thought, ‘Do I need to know anything else?’ And after that I said to Death, ‘Thank you. Do you feel like you should be here?’ and he said, ‘No. That’s all I need to say to you. We’re done. Live well!’ It’s impossible for me to convey the power that that has within me. Okay, I’ll live well,” Tom gesticulated, expansively moving his arms.

I was fascinated. “Wow! What does living well mean to you?”

“It means every one of us[16] must operate as well as we can, so all of us benefit. We all live well, we all integrate, we’re all happy, … and so on … so yeah … In some ways I have been waiting for this for a couple of years … To have you record the treasure that kind of gets created on the spot. It’s preserved, so thank you. You are the first to attend outside the family apart from Death.” Tom paused, and I realised what an honour had been bestowed on me. Tom then concluded, “I can’t think of anything else I want to say right now.”[17]

Tom asked to meet again in a fortnight. Time was passing and I wondered with concern what Tom would make of himself if he got sicker and realised he was dying.

Just before we were due to meet again, Tom telephoned me. “You said you visited people at home. … Could you come to where I’m living tomorrow? I’m not going to make it out of the house.”

Generating a new narrative for dying

Tom sat in the corner of the living room. He was resting in a comfortable reclining chair with his feet up. Large windows surrounded him, giving me a glimpse of the sea off in the distance. As I walked into the room Tom swung his feet to the floor as if he was considering standing up. The movement drew my attention to his legs. Even from across the room I could see they were swollen, his skin unable to contain escaping rivulets of fluid that glistened in the light. After we had greeted each other, he rasped, “I’m not going to be sparkling this morning. I’m in your hands.”[18] He paused, perhaps waiting for me to express shock at his physical

[16] Tom is referring to his internal family.
[17] Tom was described as “in denial” by some whom he met. This story illustrates an alternative to applying such a construct (see Pilkington, 2017; Zimmermann, 2004, 2007). As I enter Tom’s world, his wonderful creativity and resourcefulness become visible and we begin to build a relationship in which dying can be discussed.
[18] Our first two meetings focused on ways in which Tom wished to be known. Tom then indicates to me he is possibly ready for a new direction when he tells me, “… I’m in your hands”. Alert for this change, I begin to draw on further questioning practices and we enter new territory. As Tom becomes fascinated by his responses and the movement in his narrative, our relationship and his engagement with our conversations continues to develop (see Steindl et al., 2023).

deterioration but not wanting to hear it. When I remained calm, Tom seemed to relax back in his chair and lifted his feet, so they were once again on the elevated footrest.

Tom's eyes fell on the paper in my hand, and I saw them focus. I handed him the written transcript of the family meeting and sat down. "That was a fantastic session last time. High energy," he exclaimed hoarsely, as he examined the transcript. After some exchanges about our last conversation, we began to talk more of Tom's journey to wellness.

"Would it be OK to ask you a little more about the journey?" I asked.

Tom responded without hesitation. "All I know is I'm committed to getting well. There's a narrow rocky steep path, but it is there. I have a massive journey ahead in terms of re-integrating myself."

"When I asked what wellness was to you, last time we met, you said it was 'integration.' Could you help me understand[19] what you mean by integration and you re-integrating yourself?" I responded, curious about the meaning of such concepts in Tom's world (Namisango et al., 2023).[20]

Tom readily clarified. "To me, cancer is disintegration. If it keeps going … Well, that's not fucking smart. So, I'm reintegrating to become whole again. And that means spiritually, mentally, emotionally, physically." Tom went on to explain that integration for him meant harnessing his skills of healing, meditation, his high IQ and other abilities along with diet and exercise to achieve unity in one direction. He concluded with, "Biologically, I've got maybe a few billion cancer cells that are

[19] Note the entry into this question; "Could you help me understand …" Polite entryways into questions show respect and emphasise that I don't believe I have an automatic right to inquire into another person's world. Such inquiries seek permission to enter what can be tender or intimate territories of a person's life. The practice of using polite entry ways into questions was developed by David Epston (Ingamells, 2015) who co-founded Narrative Therapy with Michael White (White & Epston, 1990). I noticed that such tentative entryways into questions were helpful in my conversations with Tom and I used them time and time again.

[20] I felt I could ask this question as our relationship had developed considerably since we had first met.

making a nuisance of themselves. I'm trying to focus all of us[21] to work together to get rid of this cancer so we can be integrated and heal."

"Would you mind explaining a bit more of this process of working together towards integration?" I requested, trying to understand more of Tom's world.

Instantly, Tom stated, "I'm not working towards it." His mouth became small, and his eyebrows knitted together.

"Okay. How would you describe it?" I responded, as I internally told myself to 'listen harder'.

Tom replied with increasing energy as he explained. "Allowing the things within me that will enable wellness to happen. Receiving. Like I'm receiving energy from the sea out there. Some people have beaten cancer, but that's not my terminology anymore. Yes, I am talking about destroying the cancer cells - that's Crockie's job as part of us reintegrating. But now I'm into receiving … I feel there is a wonderful shift going on." He eased himself back in the chair smiling.

Intrigued, I asked, "Could you help me understand a bit more about what you mean by receiving and perhaps the shift you referred to?"

As I listened to Tom's reply, I noticed he had referenced a change in his approach. "You've used the words 'receiving' and 'allowing.' I was wondering—"

Tom's tone was short initially. "Well, you've actually drawn it out of me." He looked out the window. "It's … umm … wait a minute … Instead of trying to make the world a better place, which I do want to do anyway, it's just allowing that to happen."[22]

"You described this allowing and receiving as a shift from extending yourself and fighting. Could you speak a little more about that?" The notions of allowing and

[21] Tom's internal family.

[22] When Tom hesitated and considered his answers, it cued me to the possibility he may have been expressing a previously unformed or untold narrative. In other words, he was working out what he thought within our conversation. Whenever such a hesitation happened, I was encouraged that we might be venturing into new territory and therefore sought to explore further.

receiving seemed a new possible way for Tom to be in relationship to his illness. I thought I would pursue this in case it proved helpful.

Tom jumped in smiling. “The world’s a beautiful place. It’s just these little joys, you know. Sitting here looking at the thrush that’s just landed in that tree out there … the swallows yesterday.”

I marvelled at Tom’s ability to appreciate the world even as he was confronted with his mortality. “Is this—”

Tom spoke joyfully, “Spring is sprung.”

“Is there, and this is my word, and I’d like to hear your word, is there a savouring of life and …”

“Oh God, yeah,” Tom enthused.

I continued warmly, “… and gratitude or thankfulness, I don’t know how you would put it[23], in this state of mind of allowing and receiving?”

“Yes … gratitude is not a word I would ordinarily use but I do feel lucky or blessed or words like that.”

I repeated Tom’s words to acknowledge his experience. “Ah … lucky or blessed. In this state of mind of receiving and allowing. … Is there a different experience of life? Does it come into focus differently?”

“Yes. I’ve always been good at enjoying life. It’s harder now because my physical energy is so low and sometimes my emotional energy is low too … such as when I was in pain solidly for two weeks. That started to run me down!”

[23] It is important to check with a person what language fits with their experience. We can do this by asking, or by offering suggestions for the person to consider. This was particularly important to Tom and on occasion, as you may have noticed, I didn’t get my language right. I have shown my errors in order to illustrate how I then responded. We are seeking a new narrative of Tom’s dying. The new story he tells himself is more likely to include language he is comfortable with in describing his experience.

I kept my response brief, aware we were in territory Tom had said he didn't want to enter. "Sure."[24]

Tom laughed without heart as he elaborated, "Headbutting the wall because of pain … I thought, 'Well, this needs to change.'"

I remained solemn. "Headbutting because of pain is up there, isn't it?"

Tom nodded. "Anyway, the pain is sorted. Your hospice people visited. I don't want to talk about that. What were we talking about?"

I responded, wanting to convey my respect for his wishes, "I was just noticing your savouring, your smiling, your focus on life, and asking about any change in focus, and you said you'd always been able to enjoy life."

Tom sounded delighted as he exclaimed, "Shit yes!"

I smiled, enjoying his enthusiasm. "Could you tell me a story of you enjoying life?"

With considerable energy and vitality for a man so sick, Tom answered readily. "Biggest one: birth of my kids! I have been present every single time. I've delivered a couple of them and had tears of joy running down my face. Just … joy and wonder. A transcendental moment. I got this feeling of the power of generation after generation going back. It felt like hundreds of women giving birth. 'Till we get … my daughter. Extraordinary."

"Wow," I gasped.

"What could be more than that! When Frankie was born, she was born with a massive cleft. Did I tell you?" he confided.

"No, no," I murmured.

[24] I am prioritising finding a way that Tom's dying can have meaning that fits with his world and thus allows him to retain his ideas about himself that he values. Most of the people I meet with want to share their experiences of suffering with me. This is not surprising as such stories are often silenced and it is usually harder to suffer alone. Tom did not wish to share such stories and so I respected what he wanted. It is important to note that Tom stopped seeing health professionals whom he felt imposed on by or whom he felt didn't respect his wishes.

"A cleft palate. I delivered her. She came up and onto Cherie's breast and here was this little kid who had no hope of sucking 'cos she couldn't form a seal."

Suddenly, fluid started leaking freely from Tom's legs and onto the floor. It pooled on the wooden floor as if to illustrate the disintegration of his body that he had been talking about earlier.

In a matter-of-fact tone, he asked, "Would you mind getting some tissues? They're in the kitchen."

Willingly, I went to get the tissues and with Tom guiding me, mopped the floor. I knew that the fluid on the floor signalled that Tom's death was close. I refocused on collecting a story for Frankie but also on continuing to search for a way Tom might make meaning of his dying in ways that fitted with his world and preserved his preferred understandings of himself.

I sat down again. "You were telling me Frankie was trying to suck …"[25]

Tom took up his story again. "Yeah … trying to suck and she finally managed a few drops of colostrum …" He paused and began to weep as he relived the precious moment. "… And Frankie's courage and drive … it was … beautiful." Tears flowed down Tom's face. I was entranced, moved by his ability to appreciate his newborn daughter's efforts.

After a moment, Tom roused himself. "Life, life, life! Blimey I love it! There is a rumour going around lately that I'm not immortal. I'm not sure how much credence I put in that rumour … likely to be here!" Tom almost sang as he expressed confidence in continuing his life although the fluid that should have been within his cells continued to leak onto the floor beneath him.

A sense of urgency was growing inside of me. "You've spoken of your mind's abilities and the help it is to you. You've also spoken about some quite different attributes as well …"

[25] I briefly diverted from pursuing a way Tom could die with dignity to gather this story for Frankie.

"Shit yeah!" Tom relaxed back in his reclining chair with a smile on his face and began to talk about 'different ways of being' he had access to.

Time was passing and the end of Tom's life wasn't far away. I decided to take the initiative and see if we could find a way of talking about dying that resonated with him and how he thought about his life.

Tentatively I asked, "I have seen some remarkable things with people who are living with serious illnesses. Can I ask you something, drawing on your knowledge of ways of being?"[26]

Tom nodded contentedly from his chair.

"I have seen some remarkable people dying with extraordinary grace. … Do you think it's possible to reach a state of integration and have incurable cancer?"[27] I spoke as respectfully as I could, aware I now leant on the warm relationship we had been developing. I used the words "extraordinary" and "remarkable" as Tom had used them in relation to his own abilities many times and I wondered if such a description might be one that he could relate to. I was searching for a way that dying could fit into his world.[28]

Tom replied thoughtfully, with a small smile on his face. "That's a really interesting question. Really interesting. Um, my instinct is to say 'probably.' I live in a probabilistic universe. No, probably not! But! And the 'but' is a very big 'but' and often for me … that may be where I end up. I think I'm working on that in the back of my mind. Thank you for that. That's kind of brought it up to my consciousness."

[26] My intention is to show respect and build readiness by asking this permission seeking question first.
[27] I wanted to move away from the idea that Tom could only achieve integration through getting physically well. Moving away from 'either/or' understandings that are binaries and towards 'both/and' understandings like this one can often be helpful (Bird, 2004). Another common example of a both/and is "I want her suffering to end *and* I don't want her to die" instead of, "I want this to end" which is often given the meaning, 'I want her to die' and then leaves people feeling guilty.
[28] The timing of this question was especially important. I also asked it within the context of his world.

I was struck by Tom's generosity and openness in allowing me to ask such a very confronting question. I decided to extend the idea as Tom had indicated he was receptive.

"If I said I've seen some extraordinary … it's almost as if when someone's dying … what do you call it when someone rises above?" I asked, wanting to include his words in the description.

Tom was quick to reply. "Transcendental will do."

Taking a risk, I changed Tom's word a little. "Thanks, yeah, when someone transcends almost, what's going on in their body …"[29] I wanted our language to reflect something a person did and a process with movement in it (Bird, 2004). Such movement would then make it possible for Tom to consider if he was in the process of transcending should this pathway prove useful.

I checked, "Does that fit? You have far more knowledge than I have," as I acknowledged his experience. I wanted to take the utmost care.

Tom's tone was firm as he said, "Yeah. The simple answer is 'yes' because it has happened. My fundamental belief is …" He paused. "Um … I'm just going to have to mull on that. … I quite like the notion of having views that are going to shift over time as part of a process," he added, picking up on the idea of movement.

I continued, "'Cos if we're all going to die …"

Tom contributed, "Yes, yes, something's gone wrong somewhere in terms of the body."

"… If death is part of life. You're the biologist. And yet …" We were speaking in tandem as we moved away from the idea that death was a failure of sorts that Tom had alluded to in previous conversations.

[29] I again raise the possibility of a 'both/and' by speaking of both transcending and not being constrained by the body.

Tom laughed heartily. “Yes. I love it. The world is a contradictory place. We die with grace from cancer, and we have this beautiful experience. And then you’re dead. What? How does this make sense?”

Tentatively I continued, “because death is usually just talked about as …, well people often use warlike language, and I know you’re not, but people are often referred to as losing a battle …”

Tom was all attention, “Yes.”

“It can suggest people as somehow having failed …”

“Yes.” Tom stared at me without blinking.

I kept going, hoping to offer him a possible way of thinking about dying, “and yet, I would suggest that that doesn’t fit …”

Immediately he responded, “No. No. You’re right.” He looked at me waiting for me to continue and so I ventured further.

“There are many ways to die and some of them are extraordinary. Some people show such graciousness and humanity in the way they manage the last part of their life. Do you think that ‘he lost his battle’ is a complete or good description of such a death?” I reflected that perhaps ‘extraordinary’ wasn’t my preferred choice of words, but Tom had described his life and the ways he had battled the cancer as ‘extraordinary’ to me many times. The extraordinary was an important part of his world. I now used his language to see if such a death might be something he could contemplate for himself.

“No, it’s not. And I think that’s pretty magic they can die like that. I often laugh ‘cause I’ve got a mind that tries to figure life out and I know I’ll get the answer the day I draw my last breath. I’ll go, ‘Oh fuck. I’ve got it sussed and now I’m gone’. I find it fascinating.”

I noticed we were talking about dying again which had been forbidden when we first met. I felt honoured to have Tom’s trust for such a conversation.

Tom now continued the topic. “Going back to your thing of dying. Transcendentally and beautifully with cancer …” He paused, looking as if he was thinking.

“Or any way …” I added, thinking of all the people whom I had met and cared for who had died. To me, each of them was special and there was beauty in the ordinary.

“Right. Or that particular version you shared right now of the extraordinary. I’m glad you’ve had that experience or experiences plural. That’s fantastic. I would like …” Tom hesitated. We sat in silence as he reflected before he continued, “… I mean it would be neat if I was able to exit gracefully. I’m not putting that out there because who knows what’s going to happen. Death, we just don’t know. I’ve been a lucky boy all my life and if I’m lucky enough to die gracefully … sometime in the next three or four hundred years.” Tom burst out laughing.

“Three or four hundred years, aye?” I laughed back, matching his tone and allowing him to pace himself when talking of death.

“I love playing with this sort of stuff. If I manage to die gracefully in the next three or four hundred years, I’ll think, ‘You were lucky to have lasted you bugger’. But my journey to wellness is about … I feel that that[30] would be a really good outcome for all sorts of reasons, not just my own journey. My own journey includes those around me.[31] I’ve been having some wonderful conversations with my children and have finally been able to give to them.”

I noted that Tom had returned to talking about his journey to wellness and it now included the possibility of a graceful death sometime in the future.[32] He was also thinking of the impact of the way he died on those he loved. I chose to follow up on this possibly new idea.

[30] Tom is referring to dying gracefully.
[31] Cherie was an important part of his journey with the support she offered around all sorts of aspects of it.
[32] The meaning of what Tom’s journey to wellness entails has changed.

“You used the word ‘finally’ when you spoke of your pleasure in being able to give to your children and I wondered, ‘Have you been able to give more richly to them?’”

“Absolutely! And what’s that about is …” There was a long pause as Tom contemplated. “I’ve looked beyond myself. I’m becoming more attuned.”

We discussed in depth what the giving and developing attunement meant to Tom, which led him to conclude he was indeed moving towards integration. “Maybe this is a possible way to reintegrate. It’s funny, when I was in the depths of the pain and just, ‘I’m doing it hard here’, I connected with JC and he said, ‘You’ll be amazed with how well you come out of this.’”

Tom paused. I waited as he gathered his thoughts.

“… And I am. I don’t know whether JC meant in the short term or whether he meant in the long term. ‘Cause there’s no doubt there is disease progression.”

I thought a chink of possibility seemed to be emerging. Coming out of it well as JC had said was no longer only contingent on physical healing.

“What do you make of there being disease progression and that you are moving closer towards integration?” I asked, seeking to separate getting sicker from any suggestion that it was associated with a lack of ability of Tom’s to integrate himself.

Tom sighed deeply. “I don’t know the extent of the disease progression: whether I have more disease in my spine but not elsewhere or whether the disease is more widespread but somehow with that incredible strength that’s down in me somewhere, I’m just managing to live around it.”

“Could it be that it’s not an ‘either/or’ but a ‘both/and’? That you have disease progression and that you are using the incredible strength within you to live around it?”

Tom was emphatic. “Absolutely.”

My voice was soft as I tried to convey respect in my question. “Could you actually be moving towards integration and some kind of graciousness at the same time as the disease progresses?”

Tom spoke very slowly. “Good question. My preference is that it’s gone … um … but saying that I can be extremely pragmatic. Yeah, paradox is the stuff of the universe. I’m made of steel. I wasn’t always.” I nodded when he said his preference was that the cancer was gone. I also noted Tom’s ability to be in two places at once: on a journey to wellness and pragmatic about being so sick.

Tom and I continued to talk. We spoke of some of the hard times in his life and his current strength. He concluded, “This is not the session I expected but it’s been really nice, thank you!”

We made a time for the following week as he requested. “Please don’t hesitate to reschedule if something else comes up or you don’t feel up to it in any way,” I offered, the unpredictability of what he was living with at the forefront of my mind.

I left reflecting that we had opened the possibility of both dying and integrating at the same time. We had travelled a long way on Tom’s journey to wellness and his ideas of what wellness meant had become significantly broader. I hoped the conversations would contribute to him dying in a way that was settled and meaningful for him and his family.[33]

In a few weeks I was going to fly to Vermont in the USA. I was facilitating a workshop and would be away for two weeks. Tom and I had discussed it.[34] I started to worry about the timing and the possible impact on him.

[33] Tom began preparing for death after this conversation. He organised his own funeral not long after.

[34] It is very important to give good notice about leave or changes in availability to the people we meet with therapeutically, if at all possible. Good relationships thrive on respectful processes. If I have upcoming leave, I will make a plan in a collaborative way with families that ensures they are well supported. This might mean involving one of my counselling colleagues or other members of the multi-disciplinary team.

Co-evolving new meaning

Tom chuckled. “It’s fascinating. I feel like the patchwork man. Bits and pieces of me keep misbehaving and are falling out. I’ve got a mediastinal hernia; I’ve got an inguinal hernia … look at these feet!” Tom showed me his enormously swollen ankles, his skin stretched beyond its capacity. “BUT … I started my exercise program. You know how I used to love having my achievements,” he confided.[35]

It was a week later, and Tom was much sicker.[36]

“I started on the cross trainer, and I did exactly as much as I could without going too far. Sixty seconds!” Tom started laughing. “Sixty seconds! I sent a text to my kids and laughed about it.” Tom started laughing again. He didn’t sound joyful. I remained solemn.[37] “It’s shit. It’s so funny when I compare from back then to now.” Instantly Tom became serious. “I love this whole recalibration thing that’s going on. I told you. I’m just going to be this humble little old guy who just …” He didn’t finish.

“Is the recalibrating giving you anything that perhaps wasn’t so in focus before?”

“There’s my boat. I had notions of rowing it to Great Barrier Island. Nah! The boat is only going to puddle out on the Waitemata harbour. Maybe just offshore, and I’ll lie there and listen to the lapping. I think you could say I’m not particularly driven anymore,” he remarked quietly, sadly perhaps.

We talked for a time about the change in him.

[35] Note Tom’s use of the past tense as he suggests he is changing.
[36] Early in each conversation and then in subsequent appropriate moments, I checked in with Tom as to how the unwellness might impact on the therapeutic conversation and if there were any adjustments we needed to make to respect his energy levels and other symptoms he was managing. I have chosen not to illustrate these parts of the conversation as I have given examples in other stories I have written. Tom remained committed to meeting and wanted to spend the full possible time talking with me in spite of being so unwell. I don’t ever take this for granted.
[37] I only laugh with people when they laugh congruently and are genuinely joyful. I didn’t laugh with Tom as he is laughing at his own expense. It is important to be alert for this. He says he is happy but I note he is referring to his ability to recalibrate, not the loss he is experiencing over aspects of his life that were once a source of pride for him.

Tom then handed me a biography of his internal family. “For your interest or maybe background for the story if you want,” he offered. I handed him a draft of this story. Tom chuckled as he pored over what I had written.

“It was fascinating writing the biographies out. All those bits and pieces that I talked about. Strange to relate. But it’s fascinating. I’ll be really interested to hear what you make of it.” Tom grinned, still with his head in the story.

“I can’t wait to read it. What did you find fascinating in particular?” I responded.

Tom and I talked about the history of his internal family.

“… I’m writing an evolutionary epistemology for you. When are you going to Vermont? Will we be able to meet before you go?”

I was touched by Tom’s enthusiasm. However, his dignity, and how he might die, were foremost in my mind. I therefore moved the conversation soon after to some of the meanings we had been co-evolving.

“Last time … you shared some of your thoughts … would it be OK if we summarised where we got to so we don’t lose any of it?”[38]

Tom nodded.

I was tentative as I gathered up some of the threads of our last conversation. “This is my language, so please tell me what you would say; you spoke of savouring life …”

“Mmm.” Tom nodded.

[38] Summarising can be helpful especially if I haven’t sent a therapeutic letter (White & Epston, 1990; Pilkington, 2018) to ensure key parts of earlier conversations aren’t lost. They also allow me to check we have shared mutually agreed on understandings of what has been said. In this case, the summary also allows me to direct the conversation to an area I hope will be most helpful.

"… and the way that you were doing that and then you talked about integration as wellness … And I put to you a question, 'Do you think that you can get sicker and … at the same time become more integrated?'"

"That's a hell of a good question … and I'm still ruminating on it."

Tom paused. I remained silent.

"It's a really good question. And again, my instinctive answers are the same. I prefer to think 'no'." I nodded in acknowledgement. Tom continued, "Having said that … I have no problem with the notion that in a perfect world you could get sick and be becoming more attuned … it's like there are times when we're in perfect rhythm but there is a certain amount of pain involved … the pain is an integral part of the place where I'm at. Yes, I can see it's possible that getting sicker, whatever that means, may enable the other to be more complete."

"We discussed the idea of transcending …"

"Yeah … and I've had times where … everything is in tune physically, emotionally, mentally and spiritually. And it kind of creates almost a new entity of its own … Ah, a meta entity if you like," Tom reflected, new thoughts seeming to come to him as he spoke.

"Is generating that meta entity reliant on a well body or could there be a well something else?"

"That's where I come back to your question. We tend to think of pain as black and white. Just bad. You've got pain, it's bad, you don't have pain, it's good. I don't quite see it like that. It's information that the body has. What my body's telling me."

"Would you mind explaining a bit more about that? Perhaps sharing an example?"

"I've had moments of, in the dentist chair of all places, of transcendental … where I've gone to another place altogether … which … this is answering your question!

Finally, finally, finally! I could not have gone to another place while in the dentist's chair without that pain there!"

"Ah!" I acknowledged, catching Tom's excitement.

"It kicked me up another level!" Tom's eyes sparkled and his voice rose with enthusiasm.

"Ah," I gasped, smiling back at him.

"Because I wanted to get to a place without pain. It wasn't bad. Plenty of information saying something was going on and, 'Oh my god, it's hurting', but I went somewhere else! There it is!" Tom clicked his fingers as he exclaimed.

"Do you think the sickness can …?"

Tom's words burst out exuding confidence and excitement. "Yes, it can … catalyse it! Finally, finally, finally! It took a long time to get there but the answer is, yes, you can get sicker and still transcend."[39]

In that moment, Tom's journey to wellness evolved into a path with new meaning and possibility. He could transcend and die. He could die with dignity rather than a sense of failure.

His excitement was catching, and I grinned back. "Can you enlarge on that just a bit?" I asked as I sought to add detail to strengthen Tom's realisation.

"Well, I'll just go straight back to me. Without my sickness an awful lot of insights, and opening up of my life, and my kids being near me couldn't have happened! It catalysed this whole bunch of things! So, yeah, the answer's really very simple

[39] The conversations that occurred to reach this point were important. If I had told Tom that he could transcend when we first met, it would not have held the meaning or resonance for him as it did by us traveling together over time to reach this point. The process of me inquiring and Tom reflecting allowed him to develop his own narrative of the meaning of his illness and dying. The steps that occurred and the links of meaning we made over time were a vital part of Tom reaching this understanding. 'Telling' isn't helpful even though it may be tempting at times especially when we as therapists/health professionals think we "know".

when I think about it. It took a long time to get there but the answer is yes … a person can get sicker and still …" Tom paused.

"Become more integrated?"

"Yeah. I'm not sure integrated is quite the word now but certainly … It's getting to a more consciously aware state."

"What could such an understanding offer you?"

"All sorts of things. I'm going to think more about that. Can we meet again?"

Our time together had come to an end and much as I wanted to explore the new understanding that had emerged, I could see Tom was tired and I had another person to see. We arranged to meet again the following week.[40]

Transcending

Tom was sitting in his chair with plastic nappies wrapped around his legs. Sunlight streamed through the windows that surrounded him. His face looked thinner but there was lightness in Tom's demeanor. A smile played at the corner of his lips and his eyes had a sparkle in spite of the heaviness his body conveyed.

We greeted each other warmly and as I sat down, Tom remarked, "A lot's been going on."

I wondered what might have been made possible by the new understanding that Tom could be transcending even as he approached death. Eager to hear what had

[40] When I make another time to meet, I first ask the person, "Would you like to meet up again?" I then ask them how long they would like to leave between appointments. We might have a discussion about the length of time between appointments if one of us is curious or surprised by what is being suggested. I then try and accommodate what the person wants as much as possible for me. Once we have made a time, I invite them to contact me and reschedule should something they would rather do come up or if they don't feel up to a conversation that day. Time is very precious at the end of life and I explain to people I want to support them to spend their time as they most wish to. I also offer people the option of a shorter meeting time if that suits their energy levels better. Even though Tom was very unwell, he expressed his valuing of our conversations through wanting regular meetings and using his scant energy to talk for a full hour with me. It was humbling. Whenever I checked in with him, he was always very keen to continue our conversation.

been going on in Tom's life I asked, "Would you like to begin maybe, with catching me up on some of what has been happening since we last met?"

My curiosity grew as I observed Tom's demeanor. There was a lightness and joy present that I had never witnessed in him. "Cherie and I visited the cemetery. I've picked where I want to be buried," Tom began. "And I've had my birthday. My party was on Saturday." Tom's voice was quiet[41], but his twinkling eyes and upturned mouth conveyed excitement.

"Did you? How did that go?" I asked, smiling.

Tom's words burst out in a rush of joy. "It's part of the story. I had a CT scan on the morning of my birthday. And I said to myself, 'I'm not going to leave this unremarked'. I put a smiley face on the CT[42] scan appointment card!" Chuckling, Tom mimicked an imaginary friend asking, "What did you do on your birthday?" before answering as himself, "Had a CT scan. I've had a million bucks[43] worth of shiny machine looking after me. Beat that! Beat that!" Tom's eyes crinkled upwards.

"What do you call this … making the most of your birthday when you're in a machine?" I stumbled, as I smiled back at him.

Tom was enjoying himself. "Straightforward, mate![44] It's reality … you know" he teased. His eyes swept down to the nappies around his legs as if to underline his awareness of how close he was to death.

"Reality …" I murmured. I thought about him choosing the place where he wished to be buried.

[41] Tom's quiet voice was caused by the difficulties he was experiencing in breathing.
[42] CT is an abbreviation for a CAT scan.
[43] Slang for dollars.
[44] Colloquial language meaning friend.

Tom was jubilant. “Lucky! Lucky, lucky, lucky!” he sang, his gratitude bouncing around the room. Catching some of his mood I responded, “Have you always had this ability to see your luck? Even when many would say it might be hard to find?”

Tom’s eyes traveled out the window to the sea in the distance. “Um … To some extent but not like now … I’ve always had a pretty black sense of humour. It’s the Irish in me. It doesn’t take much looking to see incongruities. Most people just don’t look. I happen to like looking. Curiosity, I don’t know.”

“Curiosity,” I repeated with interest.

Tom nodded, smiling as he sat back in his chair.

“And what do you see as you look around?” I asked, wondering what was Tom’s view of his world.

“Well, incongruities. Death and growth. I remember saying, ‘Paradox is the stuff of the universe.’ Look at all the things going on, oxymorons unite!” he replied, laughing as he referenced our last conversation where we had discussed the possibility of transcending even as he approached death.

“Would you mind sharing with me an example of that, maybe a recent one, so I can understand a little more of what you’re meaning?”

“Yeah. I had a CT scan on my birthday, and I enjoyed it. Even like this,” he said, laughing as he pointed to his deteriorating body. “That’s not bad!” Tom exclaimed, grinning at me. He elaborated further, directing me to think of his response as transcending.

“The ability to enjoy a CT scan … aye? In spite of everything,” I acknowledged.

Full of energy in spite of the lack of power in his voice, Tom rejoined, “Well yeah! We live in days of miracles and wonder. One hundred years ago I would be dead. Twenty years ago, I’d be dead. In fact, on the balance of probabilities, right now I’d be dead!” Tom laughed. “I really don’t see what I’m doing as that

extraordinary. And look, in the last 24 hours I've ended up counselling people!" Tom smiled, leaning back in his chair.

"Who have you been counselling?" I asked, with the intention of collecting more stories of Tom transcending (Ingamells, 2016).[45]

"A friend for a start. One of my ex-students and somebody who I met at the CT scan. It's quite neat actually," Tom replied.

"What part of it do you find neat? Are you giving to people even as you —"

"Well, if I can help people, and make the world a better place, well … who misses out here? Nobody! It's just neat," Tom effused.

Smiling with appreciation, I responded, "Do you even now see an opportunity to make the world a better place?"

Tom lay back in his chair. As if contented he said, "Ah look, I'm pretty lazy. If it happens to occur to me and there's an easy way to do it, I'll do it. Everybody in the CT waiting room had a little chuckle as I walked out wiping the floor … I'd been leaking.[46] The nurses were a bit blown away when I turned up with a plastic bag full of paper towels and plastic bags." Tom sat back with a satisfied glow on his face. He looked happy.

"What do you think it's like for people to see you being so considerate of others? What do you think it touches in them when they witness you so unwell and cleaning up like that?"

Tom was momentarily lost for words. "I … I don't know. I think they appreciate it, well, particularly the staff. I think people take the public health system for granted. I think it is absolutely magnificent. There's a panicky reaction that could occur 'What are you doing, we have cleaners' or 'that's a bit odd.' It could be

[45] I am collecting more stories to strengthen the new narrative of meaning or counter-story (Ingamells, 2016; Paljakka & Stone Carlson, 2025) we have co-evolved. A single thread may easily break whereas a narrative that has been thickened with multiple stories is likely to endure.

[46] Fluid from his cells was leaking out of his swollen legs onto the floor. Tom is representing his efforts modestly. To be so unwell and clean the floor would not have been easy.

anything. I thought, 'I want to do this,' so I did. I don't go down the footpath wiping after myself. Like I said I'm pretty lazy so that honestly wasn't hard. Five seconds to put in and put the paper towels in the bag and away we go." Tom glowed.

"What ideas or values were behind your desire to clean up, would you say?"

Tom beamed. "Well, walking out of there leaving a mess didn't feel right. And to go right back to our conversation about my healing work and transcending. No two ways about it, I could feel a life force, a light going through me, I don't know what you call it. But to feel this extraordinary clean energy passing through me! They're going 'Oh wow,' and I'm going, 'What a privilege for me to be here experiencing this.'"

"Gosh! What are your understandings of such an experience?"

"Well, I got a smiley face out of it!" he responded laughing, as he reminded me of the picture he'd drawn on his appointment card. "It's a bit like tipping the guy down at the bakery. I put five bucks in, and he was blown away. Five bucks is a cup of coffee! Who cares? Meant a lot to him. I knew it did, but it was just that thing of saying, 'Thanks. You make a damn fine mince pie!'"

Tom and I continued to discuss new ways he was responding to the people and events in his life. It had been a week that he had enjoyed. Tom told me stories where he had acted with graciousness and care, and I pursued them. He understood himself to be transcending and I gathered stories of his experience.

"I've started keeping a biomedical type record … the headings you'll love. Exercise, blood pressure, blood sugar, sleep, bowel movements, resting pulse. Very interesting – NOT. But …" Tom paused, as if unsure.

"Are you keeping an eye on your body?" I offered.

“Yeah. On Friday night before my birthday, I was in the shit. Lots of pain and I was having my birthday party the next day. So, I checked in with the family[47] and did a quick score in answer to the question, ‘Am I going to make it?’ Now, implicit in that has always been the five-year survival thing. Crockie’s instant answer was ‘three! Out of ten!’ Tom’s shock reverberated through the room, and Crockie spoke, ‘I’m feeling overwhelmed 'cos liver’s expanding, and this belly is swollen up 'cos of blockage in my guts.’ Tom continued, ‘Wombie, and this hit me like a freight train. One! One out of ten!’ Wombie was not feeling confident at all and how Wombie is, tells me about how I’m feeling. Very shortly after I said to Cherie, ‘Shit! I didn’t realise how tough I’m doing it at the moment.’ Frankie came up and joined us and we had a three-way cuddle. The score went from one to three just like that. I mean literally within ten seconds. Fascinating!”

“What was fascinating in particular to you?”

“It wasn’t what I expected! So quick too. Amazing! Rattie said nine … love him. Alby gave a seven, cos Alby and Rattie work closely together. JC, ten! I checked … Yep. You probably won’t recall but several weeks ago JC said, ‘there’s going to be some quite amazing stuff that comes out in a few weeks.’”

“JC, ten! What do you make of it?” I exclaimed.

“I’m coming to that. The week tells it all.” He paused and lay back in his chair. I wondered if he needed a small moment of respite from talking.

“Would it be OK if we go back to what you said first and just check I’ve understood?” I requested, talking to give Tom a break. Tom nodded. “You spoke of the family’s scores and Crockie felt overwhelmed by some of the physical symptoms of the cancer. And then you described how a cuddle with Frankie and Cherie had made Wombie’s score go from one to three in ten seconds. What was it about the cuddle that created such a change?”

Tom hesitated. “Umm … Wombie … felt loved.”

[47] Tom’s internal family.

“Would you mind saying a bit more about that?”

“Wombie has different priorities from some of the others. Remember he was the one who was taken with Death’s advice to ‘Live well.’ I mean Wombie, one, JC, ten! Doesn’t take much to think that needs looking at.” Tom recounted all the family’s scores. He then shared with me how his birthday party had impacted on the family’s scores as he reflected on what was influencing his wellbeing.

“The party was with my family. They’re still raving about it. People just turned up and had a really, really good time. And towards the end there were calls for me to give a speech. I was to the point. All I said was, ‘You’ve been coming up to me and asking me how I am. You’re asking how my energy levels are. I’m up because you’re here! Thank you.’ That was my speech, and they all got it. … And that just kind of summed it up. And everyone had a really, really good time. Absolutely good loving positive energy. Fantastic. And then there was even a postscript after the party. Robert[48] lit a fire outside and there was just the four of us sitting around it. Cherie, Frankie, me and Rob. So, I had a big family gathering and then my little family gathering. And it was … I don’t like giving 10/10 but it’s hard not to. It was neat because when the whole family is here, they’re very full of life, but the four of us had a little family time and that was really good as well. Wombie went from one to three with the cuddle from Frankie and Cherie, and then to nine with the family gatherings. I’ve never known anything like it.”

“Will those experiences of connection with your family offer you any guidance about how you …”

“Shit yeah.”

“… want to spend your time as you go forward?”

I noticed that Tom’s internal family scores had increased with the love and connection even though he was near death. I asked Tom what he made of it.

[48] Robert is Tom’s father-in-law with whom he and Cherie lived.

"Yeah. It speaks for itself. It's just something I haven't thought of before but now it's there … I felt the love and care. It was extraordinary."

We arranged an appointment for early in the following week. "It'll be our last I think," said Tom. "I doubt I'll be here when you come back." Tom maintained his aura of lightness although his words had gravity. I acknowledged his comment steadily. I would be away for a fortnight, a huge stretch of time for Tom whose symptoms were worsening day by day.

The day before we were due to see each other again Tom rang me. "I'm not going to make our meeting, I'm sorry. There's a small chance there might be something the oncologist can do for me, and I can't pass up the opportunity of seeing her tomorrow. You and I probably won't see each other again so this will be goodbye. Thank you for everything. It's been absolutely fantastic! We've been on quite the journey, haven't we! Good luck for the workshop in Vermont."

I responded with a farewell and my thanks for all Tom had shared with me. I described what I had learnt from him and how it would add to future conversations I had with people at the end of life.[49] Tom responded warmly. "I love passing on my knowledge to make a difference. That's what life is about."

A few days later I sat on the aeroplane waiting for the engines to start. Already feeling cramped and anticipating the many hours of travel, I thought about Tom and the upcoming workshop. To me, it seemed as if I would be taking him with me. The engines roared into life, and we were soon aloft.

[49] When people say goodbye or acknowledge their approaching death it is important to enter into the exchange with sincerity and not to offer false hope or try and cheer them up with optimism. By meeting someone where they are, a space can be created where some important things are often said. The content of my responses is guided by outsider witness ideas (White, 2007, pp. 90-91). Tom's and my exchange was longer than the one represented in this story.

Unknown to me, Tom had died the night before.[50]

> When we focus our energy on entering another person's world with curiosity, bending our attention persistently and compassionately towards trying to understand their experience, we cast aside the veil of denial, and enter a realm of many possibilities. We may find there loss and suffering, but also more love and virtue than we dreamed was possible. We may find creativity, and the extraordinary in the everyday, or we may be called on to witness distress, and paradoxes that challenge us. However, when we meet people in this realm of their creation, we can join with them; to find chinks of light in dark places, give voice to silenced stories and maybe, find solace in love. (Pilkington, 2017, p. 73)

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[50] The conversations I had with Tom were informed by Narrative Therapy (White & Epston, 1990) ideas. They illustrate externalizing conversations (Bird, 2000; White, 1984) that seek out an alternative story/ counter-story to an *idea* that is the problem. For Tom, the problem idea was that "death is a failure". Not all challenges are problems to be solved (for example inevitable death or grief) however the ideas that influence our experience of a difficulty can be highly problematic. This story was written for therapeutic purposes. (For more on the therapeutic value of storytelling and Narrative Therapy at the end of life see Breeze Hospice, 2025).

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