Working with families where a young person is facing death

with
Sara Portnoy, Cristian Pena and James McParland

There is a Buddhist saying, “Grandfather dies, Father dies, Son dies – that is the natural order of things and a blessing for the family”.

How do you summarise the immensity of working with children and young people facing death, we ask ourselves? We decided to reflect together on our work from the Psych-Oncology Team at University College Hospital, and from our work at Life Force, the Community Paediatric Palliative Care Team in North London. Sara and Cristian thought one way to capture these reflections would be through a conversation. James, who also works across these two teams, heard about this conversation and offered to join. He thought about Sabine Vermeire’s suggestion that if you let only one voice speak it can become a ‘new truth’ and having only two perspectives might create a dilemma or dichotomy for the reader (Vermeire, 2017). Offering at least three voices creates *polyphony* and opportunities for multiple realities and perspectives to be shared, which seems appropriate for conversations about death and dying, where there is no *one size fits all* and both expert and local knowledges can be useful.

All that is written in this chapter has been learned on the shoulders of children and young people facing death and bereaved family members. We honour and thank them. Case examples are used throughout to acknowledge where learnings have come from, but these are composites and distinguishing features have been altered to allow anonymity.

We sit together, on a cold winter’s day in Sara’s office in North London and wonder where to begin. Death is somehow always a sensitive topic to cover, we conclude, and many people prefer to avoid the topic altogether. Is it because it reminds us of the fragility of our own lives and our own inevitable end? Like the opening quotation of this chapter states, is there something so incredibly unnatural about parents losing children that it becomes difficult to even think about how to do this sort of talking? How might you begin?

We decided to start with our own beginnings and journeys into this area.

How did we enter this field of work?

Cristian: Sara, you explained that you entered this field of work gradually. Over the years you worked with children who had more and more serious illnesses and then you started your present job working as a locum psychologist on a paediatric palliative care team because you were unsure whether you would be able to do this type of work. The joke is that you have now been working for the same team for fifteen years!

Sara: That’s true. Cristian what drew you to working in this area?

Cristian: If I am completely honest, I think one of the reasons for wanting to be working in this field, is that I was frightened by death and I had a curiosity or need to understand it and maybe even control it. If I worked in the area then maybe I could control it for both my loved ones and myself. I know that sounds ridiculous.

Sara: No, I don't think that is ridiculous. I can only speak from the experience of my Father dying since working at Life Force and I think there was something about knowing more about death and it not being such a taboo, that made it easier to talk about death with my Father, my family and other professionals involved in his care.

Cristian: My background was in CAMHS and working at a torture rehabilitation centre for refugees. Despite the fact that the act of torture is horrendous, I could, as a psychologist, somehow hold on to the fact that when I was seeing them they had their traumas behind them, the future could always be better. Working with people facing death in the future is a completely different scenario. How would I go about working with people facing death? What role would I play as a psychologist?

James: Similarly, I was curious about what we might offer as clinical psychologists in this context due to my previous work experiences. I particularly started to think about liberation psychology ideas, as I had worked with people with different potential constraints to their freedom. I felt personally heartened by the idea that steps towards liberation might be possible when facing the challenge of death, despite significant constraints (physical, emotional, practical, etc). This had begun to emerge through my experience working with young people with chronic health conditions and with children and families in the psycho-oncology service who were facing a life-threatening condition. Then an opportunity came up to join Sara on the Life Force palliative care team. Knowing that someone as experienced and knowledgeable as Sara would be supervising the role gave me confidence to tentatively take steps into an area which seemed quite daunting!

Sara: I did have experience and knowledge, lots gained from my own supervisor! But also, we all bring knowledges both personal and professional to this work, so I hope you felt able to bring them along too James.

James: Yes, and you saying that has made me think about another experience I'd had which was my doctoral thesis. I interviewed older LGB (Lesbian, Gay and Bisexual) people with dementia and their significant others (McParland & Camic, 2016), considering the intersection of a minority sexuality with a significant neurological condition. The people I spoke with were facing significant losses and threats to their identity through their life-limiting conditions. What I noticed was the importance of their significant relationships, partnerships and friendships, as 'safe harbours' allowing them to 'weather the storms' that life was bringing. It made me want to work with relationship networks to help galvanise these 'shelters' and draw on their possibilities as resourceful systems. I also agree with you both about extending our personal stories about death too. I have certain stories, particularly influenced by my cultural and religious background (Irish, Catholic), but have been afforded the privilege of learning about many more.

Cristian: You are so right. The importance of significant relationships really comes up when working with people facing death. I have seen many young people 'weathering the storms' together with others and coping relatively well, while others lamenting that their friends have distanced themselves at a moment like this.

Has psychology any role to play when the outcome is inevitable?

Sara: Cristian, you and I talked about how this work requires our *presence*. I think that when people feel really listened to and heard by someone who is able to be *truly present* in that moment, non-judgmentally without thinking about what they are going to say next – I think that can be experienced as similar to the feeling of being loved/truly held in mind and cared for. Vikki Reynolds (2012) asks us to imagine what our work would look like if love were absent. She also draws our attention to being very careful about our language with clients. I wonder whether instead of love we could use a word like doing it with 'heart'.

It also makes me think about 'Making Now Precious' (Lee, 2012). The title of the paper is helpful in reminding me to stay in the present moment. Although she writes about working with asylum seekers many of her ideas feel relevant for working with parents whose child is dying. Often, I think that it is as much *how* you say the words as the things that you say.

Cristian: This work makes you so humble. You soon realise that it is not about having specific methods up your sleeve, but staying in the present moment and genuinely connecting with the person you are working with is what matters. There is one family that I worked with that I will never forget and that taught me so much. I was asked to help a couple to make an informed decision regarding their daughter. The parents were trying to make an impossible decision about whether to opt for further invasive treatment for their child which would have an uncertain outcome in terms of her quality of life or whether to stop treatment which would lead to their child dying. I had to travel alongside them with humbleness and provide a space for these impossible conversations to take place.

Sara: Keeping in mind the four key themes of relational ethics often holds me steady when I begin these conversations. They are: mutual respect, engagement, embodiment and environment (Bergum & Dosseter, 2005). As Lee (2012) suggests, these take you beyond the spoken or written word.

James: I feel that one of my other roles in these situations is to bear witness to people's stories and experiences. Denborough's (n.d.) 'Draft charter of story-telling rights' guides me in these conversations. Particularly the idea that everyone has the right to have 'their story understood in the context of what they have been through' and 'their skills and knowledges of survival respected, honoured and acknowledged'. I try to hold a space for parents and young people's stories to be told and understood, which means bringing a genuine curiosity and not making assumptions about how people may feel at any given moment. Even when the outcome may be 'inevitable', there are opportunities to hear about how young people or their families respond to this with knowledge and skill; I feel it is important for these responses to be documented. For example, I will create therapeutic documents such as letters about our sessions, or find other ways to hold onto people's stories, such as helping them to write first person accounts and then thinking with them about who they would like to see it, such as other family members or professionals.

Sara: Yes, narrative therapy ideas inform my conversations, including around acknowledgment, documentation and making meaning out of such difficult experiences.

James: My other thought was that when I have worked with young people and young adults who are coming to the end of their lives, part of my work has been about supporting them in moving towards preferred directions, despite the constraints of their medical situation (Afuape, 2011). For example, thinking with young people about how they would like to spend their time in ways informed by their values. This can involve asking questions about their hopes for the next day, week or month, and being curious about whether there are things they would like to talk about or activities they would like to do with those close to them. At other times it has involved more of a supportive advocate role, such as assisting them in asking questions of medical staff which were difficult to put into words during a clinic appointment.

What could you possibly say to a tormented parent whose child is at the end of their lives?

James: I feel it is important to acknowledge this situation really is utterly devastating, difficult to comprehend and contravenes all of the hopes and expectations of parents. At first, I found it tricky to think about how 'hope' could be a part of the conversation in therapy at these times and found myself feeling quite helpless, or worse, useless. Sara, I've found some of our conversations in supervision using Weingarten's (2010) ideas about how 'hope' can be a verb and something you 'do' together, to be very helpful.

Sara: It is a very challenging situation and one which our psychology training does not always allow us to feel prepared for. It brings to mind an experience I had with a parent, who was a medical consultant herself. Her eldest daughter was diagnosed with a brain tumour. From the point of diagnosis there was a poor prognosis because it was staged as a grade 4 tumour. I had worked with this mother and visited her at home for a number of months whilst her daughter received treatment, but her condition was deteriorating. One day, she was overwhelmed with tears, saying "Today I have lost hope". This is a family that will always stay with me because I learnt so much from our conversations. She said, "don't think that when I was given the diagnosis that my daughter had a Grade 4 tumour, I didn't know what that meant. I have given that diagnosis to patients. I knew my daughter would not survive but as a parent my job was to hold on to hope. Until today, I have managed that, but I can't do it anymore." I have held onto this idea. So, when doctors are concerned that a parent may not be being realistic about their child's prognosis I may ask the doctor whether they think it is possible the parent is 'holding on to hope' because it is the best way that they know of being with their child in this situation?

Also, Weingarten's (2010) concept of *reasonable hope* has been very helpful in our work. This is the idea that reasonable hope can sit alongside despair and is different to the more traditional sense of hope as something that is alongside 'wishes'. This has been a more pragmatic sort of hope that parents have been able to discuss alongside distress and despair. There is also an idea like you say James about hope as a verb and something you can do together. This can offer a guide for these difficult conversions in that even when the end is inevitable there are ways of doing 'reasonable hope' together.

James: The story you told is very moving Sara and I'm struck both by the idea of what a parent's 'job' is in this situation and also how our psychology training might have prepared us for these conversations. I think a surprising aspect (for me anyway) is that some of the ways I work have not been that different to how I work in other contexts. There seems to be a story that when 'death' is mentioned, you cannot use more general ideas, but I think you very much can. For example, I have used ideas informed by solution-focused practice (DeShazer & Berg 1997) , such as asking 'If our talking together today was to offer any sort of usefulness to you right now, what might it involve?', 'how would you know that our talking was on the right lines?' or 'where would you be moved to if this had been a helpful conversation?'.

I have found that sometimes people want to use the talking time in therapy to discuss more practical aspects of their experiences and possible other parts of their 'job' as a parent. For example, often parents of children with palliative conditions want to spend time thinking about and planning their funeral. I have been very moved when parents have, with tears in their eyes, asked me if they were 'crazy' for thinking about their child's funeral. At other times their preference has been to discuss how to talk with the child's siblings about what is happening, or to ask for practical suggestions about how to try and relax or look after themselves, to sustain themselves during this difficult time. Throughout the process of these conversations I am informed by 'relational reflexivity' (Burnham, 2005) and check in with clients, through asking 'is this talking comfortable and useful?', and letting them know it is more than OK, it is welcome to tell me if it is not. Some of the feedback has been that the therapy space can be more 'neutral' than such conversations with family or friends where it can be understandably more charged. I am also guided by Fredman's (1997) ideas of 'talking about talking' and not making assumptions about the type of talking that will be helpful to someone at any point, but rather checking out with them which kinds of talking might be of use.

Cristian: I would agree that things come up that you do not expect. Throughout I let clients know that I am here, I am listening, that there is no 'right' way to feel and I attempt to validate their emotional experiences.

James: I was also thinking how alongside curiosity and inviting people to define their own experiences, at points I have found myself 'normalising' emotions. For example, I have shared 'pre-bereavement' as a concept that people can experience a profound sense of loss when they are anticipating a bereavement. Parents I have worked with have let me know it was useful to know this was not abnormal or 'fatalistic thinking'. So sometimes affirming has involved sharing psychological concepts, but doing so in a ‘light’ way, which explicitly invites resistance when something does not fit (Afuape, 2011).

Ideas that have guided us in our work with young people and their families

Sara: One idea that I have found helpful relates to the positioning of a therapist during difficult conversations. (White, 1997a) proposed that therapists remain ‘decentered and influential’; a position where the client’s knowledges are placed in the centre and the therapist provides the conditions within which their stories can be more richly described. I find I am at risk of taking a ‘centred and influential’ position when I am asked for advice, when I am finding the conversation emotionally demanding, or when the story resonates with me personally.

A conversation that comes to mind is when I met with a father on the hospital ward whose daughter was at the end of her life. He was very distressed and he asked me, “How do I tell my eldest daughter, who is sitting her finals at university in a month's time, that her little sister is dying?” It so happened that my eldest son was sitting his finals in a month’s time and my thoughts went to ‘how would I tell Alec that his youngest brother was dying?’ I immediately felt overwhelmed by emotion. I stopped, I remembered to breathe and feel my feet on the floor to try and ground myself. It dawned on me: I had not been asked how I would tell my son Alec. My next thought was, ‘I want to try and help this man. What do the experts say about how to break bad news?’ Then Michael White’s ideas came to mind. I noticed I had unwittingly centred my emotional self, which had led me to grasp for ‘expert’ knowledge. I wondered whether it might be unhelpful to ‘centre’ my knowledge’s at this point. Instead I asked this father to tell me more about his eldest daughter, were there any other occasions where they had held a sensitive conversation and what had helped make that possible.

This made space for him to let me know that one significant time was when he first told her that her little sister had a diagnosis of cancer. Also, he let me know about the times they had spoken about how the treatment was not shrinking her tumour, and he richly described the words he had used and where they were sitting and the expression on his elder daughter’s face.

Cristian: You telling that story brings to mind an image for me of very shaky ground. How, if we try to have conversations on this shaky ground, either us as professionals or our clients, it can start to feel unsafe. It makes me think of the idea of structuring a ‘safe place to stand’ before we begin to talk about problem stories, traumas or challenges and how we can create that safe place through connecting with an individual's skills, abilities and intuitive knowledge. When you connected with this father's hard-won knowledge and experience-based skills, a safer ground was created to hold him during this extremely difficult conversation and it became possible to generate ways forward. You were also able to do the same through giving pause, grounding yourself and connecting with your own *knowings*.

James: It's making me think too about the power of more expert knowledges and discourses, and how it can be easy to be seduced into trying to find one that 'fits' and resolves a client's dilemma. I notice I am pulled towards more expert positions when I feel 'at sea' or on shaky ground too. I think the certainty they can offer is very appealing! I have however found the book 'Death Talk' by Glenda Fredman (1997) to be hugely influential and containing, as it presents the idea that there are multiple valuable stories about death and dying. Some of these stories are professional knowledges, whereas others come from family's experiences, their relationships, religion, culture and broader spirituality. Through remaining curious and decentered as you describe Sara, multiple possibilities for useful conversation can open up.

Sara: I remember carrying 'Death Talk' around in my bag when out in the community when I first started at Life Force! Also, Cristian I'm glad you mentioned the concept of a 'safe place to stand'. Ncube (2006) suggests inviting young people into a 'safe place to stand' through hearing about their lives aside from problem stories, before you then begin to think with them about the challenges in their life. She gives the analogy of a crocodile in a river (which represents the problem) and how you want to get onto the riverbank (which represents your skills, abilities, important people and other sustaining discourses), before you are in a better position to start looking at the crocodile. I think this is often a central intention in our work in this context.

One way of getting to this 'riverbank position' is through narrative therapy ideas using the "Beads of Life" approach, which I initially developed for young people with a diagnosis of cancer (for a full description please see Portnoy, Girling & Fredman, 2013). I begin by getting to know the young person apart from their cancer diagnosis. I ask them about their daily lives, skills, abilities and qualities, important people and the values they have learned from them, and their backgrounds including family customs and culture. This includes asking them about what they enjoy when they are not in hospital or what they enjoyed prior to cancer arriving and they are invited to choose a bead to represent all of these stories. I dare to ask about their hopes and dreams for the future. If someone is near to the end of their life I would ask them about their hopes for the next week or month and also their hopes for family members or friends. As they choose beads, they tell these stories of their lives. We also offer 'Beads of Life' to parents, siblings and other significant people who are travelling alongside a young person in this situation.

James: For me, this brings to mind the idea of 'Hopework' (Moxley-Haegert, 2012), and how through discussion about special achievements and coping or 'survival skills', families engage in this sense of hope as a verb, as something you *do* (Weingarten, 2010). Hopework involves the narrative therapy practice of listening for a 'double-storied' account (White, 2007), which acknowledges both suffering *and* foregrounding those special knowledges that are sustaining a family through hardship. I also think it's helpful as 'hope' then becomes a discourse sustained amongst people, rather than as an individualised concept, which could make people feel inadequate if they do not readily have access to hope themselves in a particular moment. As psychologists we join and hopefully assist families and other relationship systems in their *hopework project*.

Sara: The sense of this being a collective endeavour is an important one with the Beads of Life process. When the young person is telling the stories of their life through beads, we intend to have at least one ‘witness’, as for stories to *live and breathe* they need an audience. I ask the witness, who may be a parent, sibling, friend or professional, such as a nurse with whom they have a close relationship, to give the young person a bead to represent what they have been touched by or what resonated for them when listening to these stories. It can be very powerful for the young person to have an experience of touching someone else’s life in this way. To facilitate talking about the story of hardship, we also invite them to choose beads to represent their medical stories.

Cristian: It's making me think about how a cancer diagnosis really brings so much upheaval and loss to a young person's life, potentially widening the gap between who they thought and wanted to be and who they are able to be in the current circumstances. Many young people I have met with describe and experience periods of resurgent sadness, which Weingarten (2012) terms ‘chronic sorrow’. This non-pathological response to a disruption to their self-narrative has often connected with young people telling me they feel ‘lost’, ‘directionless’ or ‘numb’. It feels important to honour and give space for these stories of loss alongside those of survivorship (Pena & Garcia, 2016). It also reminds me of my work with displaced young people seeking refuge in the Jungle in Calais. They described a similar sense of feeling lost or at times ‘unreal’, as their lives were disrupted and in limbo.

James: A particular framework which has helped me conceptualise this state for young people is the ‘Migration of identity’ proposed by Michael White (1995). This suggests that when people experience a break from life as they know it, they experience a process of ‘separation’ as they depart familiar shores, and enter a ‘betwixt and between’ period. When a young person is diagnosed with cancer, they experience such a moment of separation as they suddenly move away from what is familiar and known, and ‘cross a threshold’ into a different space (Lee, 2020). This includes breaking from familiar structures, such as education or employment as this is often disrupted, or family life as they undergo invasive treatments in hospital. The space young people enter could be viewed as a ‘liminal’ space for identity as they are separated from who they know themselves to be (i.e. a young person without a life-threatening condition), and they may say things like “My world was turned upside down”, “I no longer know who I am” or “It feels like life has been put on pause”.

Part of our work involves being alongside young people in this liminal phase, which is extremely discombobulating and uncomfortable, as they lose the sense of grounding offered by normative structures and expectations, and they manage the uncertainty of a cancer diagnosis. It makes me think about the importance of bearing witness to these struggles through our presence, facilitating discussion where they put words to their experience, inviting them to share any representative images that come to mind and also affirming that they are not ‘going mad’ (Lee, 2020). There can also be liberation in some ways as people enter a realm of new possibilities compared to the pre-existing status quo (Lee, 2020). For example, young people have told me that since their diagnosis they have felt it possible to be more honest about their wants and needs, speak with increased confidence to the adults in their world, experience deeper empathy for those who face struggles in life or have had a realisation about what is important to them. Parents and other significant individuals in young people with cancer's lives experience a similar migration of identity as their world changes.

Sara: I have also witnessed young people taking up opportunities to explore new commitments, such as volunteering. We offer the ‘Beads of Life’ to individuals and as a group workshop. Young people who are interested are invited back to join us as ‘peer trainers’ to help facilitate future workshops as consultants by experience. A number of young people, including those with extremely uncertain or palliative prognoses have joined our workshops as peer trainers. They have offered incredibly rich wisdom, such as hard-earned knowledges about living with cancer and been an inspiration to other young people.

James: The contributions of these young people and the honouring of their skills of living with cancer makes me think of ‘reincorporation’, which is the concluding stage of ‘migration of identity’ (White, 1997b). Reincorporation involves arriving at a new destination in life and connects with the concept of ‘rites of passage’. Many of the young people we meet with miss out on some of the normative rites of passage that their peers experience. For example, they may see friends progress educationally and take further steps towards independence as they leave the family home, while our young people are derailed, delayed, increasingly dependent on parents and/or have to readjust their expectations.

I can find myself in a dilemma requiring thoughtful balance. On the one hand, the uncertainty around prognosis for some can limit how much young people feel able to explore possible futures, so it feels important to stay present to their stories of liminality and allowing them to be *seen* in the liminal space (Lee, 2020). On the other hand, I can feel pulled to celebrate and punctuate life for young people who may have had such opportunities constrained due to health, through finding alternative ways to acknowledge their skills of living and new pathways to a sense of reincorporation (McParland, Khan & Casdagli, 2019). This involves creating opportunities for the new identity stories to be witnessed through ‘communities of acknowledgment’ as young people find ways to *reclaim their lives* from health challenges (White, 1997b).

Sara: A number of different pathways we have travelled towards ‘reincorporation’ are coming to mind. For example, the opportunity for stories to be witnessed in our group workshops, which include a certificate ceremony where we also invite parents or other significant people in the young person's life to bear witness to their skills and abilities. We have also been fortunate to attend conferences talking about our work where young people have joined us to present our projects, including winning a conference award for their contribution, creating further opportunities for new, preferred identity stories to be affirmed.

Cristian: I have been struck by how powerful it has been for people’s preferred identity development when they have had opportunities to ‘give something back’. Many young people have let me know they want to help others and *give back* to the cancer community that has helped them. It also connects to parents too, who have volunteered their time for charities connected to cancer or bereavement, and I wonder if this is a similar experience of reincorporation as they arrive to new destinations in life? I think again about the sense of people re-evaluating what they want their life to stand for in the wake of such an uprooting experience of a health crisis. Similarly, parents may decide to involve themselves with cancer charities or offer peer support to other parents that have experienced bereavement. I have also met parents who completely re-evaluated their lives and involved themselves in different causes. I met one father who became acutely aware of some of the vast inequality in the city, and he decided to join a charity that worked for equality. It may well have been a way for him to channel the sense of unfairness that he was experiencing as a father to a child facing death. In any case, he met a number of people that gave him hope, it gave him a sense of meaning and control, beyond the fear and sorrow that he was experiencing.

Sara: What underpins much of our approach is recognising the possibilities that emerge when you intervene beyond individual therapy. We try to create connections and facilitate opportunities to resist and work against the isolation that a life-threatening condition, such as cancer, can bring to young people, their families and bereaved individuals after death.
In that way I would conceptualise our focus as broadly systemic, appreciating the role of relationships and networks, alongside therapy which may be individual and offers holding and containment.

James: It makes me think about ‘personhood’, which was a specific concept I explored in my earlier research with people with dementia. Kitwood (1997) suggested that promoting personhood is important to counter a state of ‘living death’ when people are faced with significant losses, such as dementia, or I would suggest a life-threatening or palliative condition. The components of personhood are attachment, identity, inclusion, comfort, occupation and what holds them all together: love. This is a social and relational endeavour; personhood is a status bestowed on someone, by others, within the context of social relationships. Through our peer groups and opportunities for family and wider system acknowledgment, we are moving away from seeing psychology as solely ‘internal work’ (Winslade, 2002), finding ways for alternative stories to be interwoven into the lives of others (Morgan, 2000), and trying to do it ‘with heart’ as you beautifully described Sara.

How have bereavement theories helped you in your work?

Sara: This question once again brings to mind Michael White’s ideas about the therapist remaining decentred. It is easy to view well-known theories as *expert* knowledge or even ‘the truth’ and they can then barge in and undermine a bereaved individual’s experiences. In my work I have used theories tentatively, usually when a client says something that resonates with one of them and I have a hypothesis that the theory may help make sense of some of the overwhelming emotions that they are experiencing in relation to grief. I would always ask whether the ideas fit for them, so I centre the young person or parent’s knowledge of whether they have found the ideas helpful.

Cristian: Is this not the problem with diagnoses altogether? In our work with refugees in Calais, Sara, how many refugees' experiences fit into a diagnosis of PTSD, as expected in mainstream trauma psychology? Pain and suffering extends beyond experiencing particular phases or psychological symptoms in the way manuals describe. People experience their suffering multidimensionally; physically, socially, interpersonally, functionally and existentially, as well as psychologically (Patel, 2019). I often hear a particular story or expectation that to process their grief, people need to 'accept the reality of the loss' (Worden, 2009). I remember a bereaved parent finding this a tremendously provocative idea. They said, "I may be able to function with the understanding that my child has died, but I will never accept that it is OK that she died."

Sara: I think that *acceptance* is a difficult word. Is acceptance about saying that it is OK, or is it about not fighting what cannot be changed? 'Accepting the reality of the loss' has been proposed as a *task* of mourning. This fits in that it suggests tasks are *hard wor*k and in my experience and what I have heard from clients, grief is extremely hard work. However, tasks are also things that can be completed, such as 'doing your homework', and accepting the reality of the loss is a task that can take a lifetime. Is it accepted when you lay one less place at the table every mealtime? Or many years later when your youngest sibling celebrates their wedding, accepting your sibling who died is not able to celebrate with you?

James: One model which I have shared and seems to fit for some bereaved individuals is the dual process model (Stroebe & Schut, 1999). There is a suggestion that people move between two coping processes during bereavement: a loss-oriented process which involves more of a focus on facing the death *head on*, with all of the associated sadness, existential questioning and sense of unfairness; and a restoration-oriented process, which includes adjusting to new roles and responsibilities in the aftermath of a death, the completion of day-to-day tasks and a shifted focus from grief. As people describe how they are experiencing these processes and moving between them, I might share the model. This communicates that this *oscillation* is 'normal' and the sense of movement between the two processes seems to offer possibilities for people as they find ways to keep going on with life alongside grief.

Sara: That connects for me with another grief theory that people have told me is a good fit, which involves 'growing around grief' (Tonkin, 1996). Parents who have lost children have helped me understand that their grief has not tended to get smaller over time, but they have found that life has expanded around it, with new experiences and feeling able to notice moments of enjoyment. It seems to fit better as it acknowledges that grief may never totally disappear, and there may be particular times when it becomes more intense such as around anniversaries, but it may become less dominant in someone's life over time. Our conversations in therapy might be about this process, which does not create a sense of disloyalty to the deceased who they forever honour alongside managing to continue with life.

James: Many of the individuals who I have met with in therapy speak about the person who has died still being a part of their life too; these are important relationships that people want to *honour* as you described Sara. ‘Continuing bonds’ is a helpful framework that can create opportunities for people to think about how they might like that relationship to be (Klass & Steffen, 2018). A connected idea from narrative therapy is re-membering conversations (White, 1997a), which involve bringing forth the significant contributions from those who have died to the life of the person that is bereaved. It can also involve asking questions to bring the deceased person more into the present, such as exploring what might the person who has died make of developments in the life of the individual in therapy. These sorts of conversations seem to open up possibilities and ways to live alongside profound grief.

Sara: We also invite families to share special memories at our yearly ‘Memory Day’ for those families that have lost a child who was cared for by the Life Force team, where we celebrate those young people’s lives through a creative memory activity.

James: Another guiding principle is trying to remain open-minded and not assume that a professional is the best person to do *death talking* or have conversations about bereavement with. Therapy can be a space to review different ideas, but it may be that the most usefulness emerges in another context. For example, through conversation with other parents that have experienced a similar bereavement.

Is it all about the present moment..?

Sara: Cristian, you have told me that when you are about to meet the parents of a child who is dying, you wonder what on earth you could say to make them feel better? Then you are reminded of the present moment and that in this moment their child is here; they can still create a precious moment, something they can cherish and remember. This again connects with Lee’s (2012) idea of ‘making now precious’ and exploring how this could be possible with families.

Cristian: Yes, and I learnt this through talking with families. One parent told me that living with a child with a life-limiting illness taught her about the present moment because it was the only safe place to be with her child. The past held bad memories, of difficult diagnoses and hospital appointments. The future is terrifying as it can bring up thoughts of imagining life without her child. If she could find ways to stay in the moment with her son, she could be more comfortable, because this moment involved caregiving, closeness and connection.

James: Parents have also spoken to me about wanting to be more in the ‘now’ with their child. I was pleasantly surprised when having had a discussion about a future imagined funeral, we evaluated the talking, and a parent let me know that this conversation allowed them to put their worry about this to one side and focus more on the now. It also feels important to appreciate how challenging the ‘now’ can be, reconnecting with the earlier ideas around an uncertain and uncomfortable ‘liminal space’.

Cristian: It makes me think about when a doctor says that in their professional opinion there is nothing more they can do for a child and any further treatment will only cause pain and suffering. Parents then have to make a decision about treatment based on the doctor's information. I will always remember a father saying to me, "it's all very well you helping us make this decision, but as a parent, it is impossible for me to say that I don't want my child with me for an extra day".

Sara: It brings to mind the phrase, "Matters of life and death are too onerous, too painful to do alone" (Weingarten, 2000). As professionals, we are offering to bear the unbearable and be a compassionate witness to the chaos of emotions that bereaved or dying people struggle to put into words (Weingarten, 2000). Although our work can involve finding ways to *make now precious* and document responses to challenges, we are also trying to offer a safe place where *any* story can be told. This involves embodying presence and trying to *lean in* to other's stories of distress, as Pennebaker (1997) describes how suffering people who sense their 'listener' is apprehensive about the story they are telling, stop talking.

Cristian: Sometimes the stories we hear might not match up with the stories we are told by other people, for example, a client's understanding of prognosis not fitting with the medical view I have also heard. I remember working with a mother who let me know how her son was her "whole world". From what the doctors told me, I knew that her son was coming to the end of his life, yet she could not contemplate this. It left me with questions about how much should you do a reality check with parents, and how much should you let them hold onto hope?

James: It makes me think about 'denial', which is a story I've heard told about parents who do not seem to be overtly 'accepting' of a poor prognosis. I like Fredman's (1999) idea that 'denial' is a *kind of knowing* that someone is showing in a particular context. An example might be when a parent is talking with a nurse who is administering medication to their child at the end of their life, and they ask questions about whether there could be a different treatment that might help. Fredman suggests that there might be several kinds of knowing, of which 'denial' is one, and which are shown in specific contexts of time and relationship. If we hold a view that there might be several types of knowing, we become freer from needing to remove or identify the 'cause' of the denial. We are also freer from righting someone with 'correct' information, but can instead explore these different *knowings* and who they show them too, including the sorts of opportunities or challenges they create. For example, the same parent may have had conversations with a faith advisor about ideas surrounding the afterlife, which has alleviated some fear for the future, or they may have spoken in therapy about anticipating a time when their child is released from pain, which they anticipate as a relief having seen them suffer.

Sara: Although I agree that denial needs to be unpacked, there is another process at play sometimes which I call 'the protection racket'. Some of the work we do with families when young people are dying is trying to stop 'the protection racket' in its tracks by naming it, speaking about it and examining its tricks and tactics. I've heard that the protection racket tries to talk parents into not sharing difficult information and also their own more distressing emotions with their child. Also, there are some unhelpful prevailing stories that if a young person wants to know what's wrong they will ask; however, many young people will pick up if their audience is uncomfortable about telling them, which can be silencing. Similarly, the protection racket talks children into hiding their questions and concerns from parents. When the protection racket gets going it can cause many misunderstandings and can create emotional distance between children and parents, at a time when they are craving closeness and understanding. I lightly explore whether the protection racket might be operating for people in therapy, letting them know it can be a very common presence. This seems to allow people to examine and evaluate its effects and consider alternatives.

James: I think it's also important to acknowledge the sustaining effect in the present of future hopes and dreams and moving into a future-focused space in therapy also seems to create possibilities, however limiting a prognosis seems. When people have a life-limiting condition, or they are parents of a child with a life-limiting condition, or their child has died, they are in the difficult process of adjusting to the potential for a previously imagined future to become impossible. I would proceed carefully, perhaps inviting feedback on how to phrase questions, e.g. 'should we talk about 'when' or 'if' you have less side effects and can leave the hospital for some time?' Also, hopes and dreams often have a historical context in which they originated, so I may also explore these stories. Moving between the past, present and imagined futures in therapy seems to create reflexive loops that open space for new possibilities, beliefs and stories (Boscolo & Bertrando, 1992).

Working with clients who have a faith

Cristian: When I think about families that I have consulted with who have a religious belief or humanistic belief, I have always found it easier to work with them on some level. I find it gives them a structure and a way to *think about the unthinkable,* such as losing a child*,* or ways for *making meaning* out of their situation.

James: Yes Cristian, I also think about what having a faith offers to people. This can often be a way to make sense of their experiences and offers sustenance to their situation. For example, when asking young people with a palliative condition questions like, 'what effect has having your religious faith had for you?', they have told me "It helps me to understand this is God's way". Or asking bereaved parents, 'what difference has your faith made to how you are living with the loss?', they let me know, "At times it feels impossible, but I know God will send me no suffering I cannot bear, so I keep going".

Sara: I think something that I have learned is that solely knowing a person's religion often tells you little about their unique context, so I have tried to resist making assumptions. I ask questions about their faith, their practices and beliefs. For instance, I remember with a young man who was Muslim, who was feeling so bad that he was experiencing suicidal thoughts, I asked, 'What has stopped you taking the actions that you have contemplated?'. He answered, "Because I can't, it's against my faith" and the clarity about that, the certainty, in that way it helped. Also, I worked with a young Jewish woman who was dying. She did not describe herself as religious, but she did feel her religion offered her a network of people who would be there for her, so maybe you would describe that as her community. For others, the death of their child has made them question their faith and this expression of different personal ideas can lead them to feeling or becoming isolated from faith communities.

James: I agree it is helpful to be open minded and curious about an individual's meaning-making in relation to religion, as this can involve different and sometimes contrasting stories. Initially, I think I was apprehensive, as when people mention religion or 'God' it can feel like a very fixed idea and I did not want to offend or say the 'wrong thing'. However, I noticed that for some people the effects of ideas were quite constraining. For example, bereaved parents would talk about religious guidance they had received about needing to 'move on' or 'reach an acceptance' which they were struggling with and did not seem to fit their emotional experience. The effect of these ideas was that they sometimes felt they were 'lacking' in some way, which compounded their feelings of hopelessness.

Sara: I see one of our roles as to help explore and generate a repertoire of stories and possibilities around death (Fredman, 1997). What that means in practice is not avoiding exploring ideas and discourses, evaluating the effects of these for people and offering an opportunity to explore multiple truths. For example, in many religions there can be more than one story. If I hear that a client is in a dilemma about their emotional response to one religious idea, I might be respectfully curious and say, 'I hear that there is one idea from your Imam about this, might someone else have a different idea?' or 'have you ever heard any alternatives to that position?'

James: I think it can be helpful to allow people to express their views on different beliefs. So I might ask something like 'is that an easy or a difficult religious idea to hold onto?' I think this communicates that all emotional experiences are valid and helps to put words to the dilemmas our clients experience. I like your description Sara and would perhaps call this positioning *respectful curiosity*. I also try to foreground spirituality as another context to be curious about, as sometimes the comfort people experience does not fit within traditional religious frameworks. People often talk about 'signs' or 'messages' they feel are communicated to them by their lost loved ones; I give space, time and affirmation to these stories too.

How does this work impact us as a therapist and as human beings?

Sara: Undoubtedly it has made me appreciate the 'small and the ordinary' in my everyday life. It helps me to be grateful that my 3 children are healthy and when they complain about going to school, how fortunate I am that their lives are so complete they can complain about very normal things. It has also helped me go on learning and seeking new ways of being with families because this type of work was not covered in my training. I am reminded of Vikki Reynold's idea that we learn our work on the backs of clients and I have learned so much from the many families that I have travelled alongside (Reynolds, 2011). In fact, everything that is discussed here is learned from the parents and young people I have worked with as well as the articles and books I have read. And I imagine that those ideas came from the parents and young people those researchers had worked with. It also feels important to mention that learning involves making mistakes; I tread very carefully, sensitively and thoughtfully as the mistakes we make are experienced by our clients, as I have witnessed you both also doing Cristian and James.

Cristian: The work has often led me to question my values. When families have made decisions which may be different from the ones I imagine I might make, it pushes me to remain non-judgemental and try to walk a mile in their shoes. Also, the work challenges me to remain curious and keep asking questions, rather than *knowing* too soon. The not-knowing can be a very uncomfortable place to be, so I have had to learn ways of managing to stay with these feelings. (Anderson & Goolishian, 1992)

James: I would agree Cristian and it has been important for me to let myself off the hook for knowing all the answers, while also continuing to learn, extend my own repertoire of beliefs and stories about death, and keep my work accountable to those who consult with me through continual feedback conversations. The work also makes you think about your own lives, in particular the spirit of ‘making now precious’, encouraging a personal commitment towards celebrating milestones and creating memories.

How do you continue to work in this field and resist burnout?

Cristian: Sara, you have worked in palliative care and bereavement for fifteen years. How have you managed to do this type of work for so long?

Sara: The support I get from my colleagues on the multi-disciplinary team (MDT) and my psychology colleagues have been important factors in sustaining me in this work. The work we do together as an MDT is so much more than the sum of its parts. I very much connect with Vikki Reynold’s concept of “collective sustainability” (Reynolds, 2012). Being part of a team who collectively care helps sustain me and resist burnout. Vikki also reminds us that it is not our clients who create burnout, in fact, our clients usually inspire us. Often it is the injustices that families experience that can lead to a sense of burnout. Alongside the support from my teams, I have been fortunate to have supervision from an inspirational and experienced supervisor, Glenda Fredman, who has enriched my practice through every conversation.

I have also been able to work with families after the death of their child, which has afforded me the opportunity of seeing parents and siblings survive the loss of a child, even witnessing post-traumatic growth for some. It brings to mind a parent I met with before her child died and in the subsequent aftermath. The first time we met after the death, she wept and howled and it was distressing being in the room with so much pain and emotion. At a session 18 months on, she said “I have managed to find a place where I can be with my daughter”. She talked about trying to find some silent moments every day. She also still experienced distressing images of her daughter at the end of her life and the experience that these images did not stay helped her manage them better in the moments when they were present. She has not forgotten her daughter, or ‘moved on’, but has found a way of living and way of being with her daughter who has died.

James: When I reflect on my time with the Life Force team, I also think about the parents who have been bereaved and how they find ways to go on alongside grief. Alongside self-care and use of supervision, I find witnessing their commitment to continuing with life after such a profound loss to be heartening and sustaining to witness. I also think in my clinical practice it has been helpful to release myself from a 'more pain, more gain' discourse in relation to the emotions discussed in therapeutic dialogue (Yuen, 2009). While there will be a space held for processing more painful and difficult emotions, I have let go of the expectation that it will always be the type of talking people want to do. There can be space for another idea of 'less pain, more gain', when you thread through conversations about hopes, moments of joy, celebrations and special memories.

Cristian: I agree with you both. Having the support from colleagues, like you, James; being able to show your weaknesses and fears in supervision, as you have allowed me to do, Sara; as well as having the privilege of being invited by clients to witness their journey; have all given me strength to work in this field. I have learnt that you cannot tame death, you cannot control the future, but you can stay and try to live the present moment to the fullest. I have learned that from my clients.

James: I have found this conversation to be very generative as through talking with you both I have been introduced to even more ideas and possibilities for conversations in therapy, which have been presented with the lightness of touch we aspire to embody in therapeutic encounters. I'm glad we've had this opportunity to share our learnings and offer a polyphony of ideas. As we describe, we do not see one 'right' way to understand or talk about death and dying, so I hope that our readers join us in curiosity and invite them to reflect on how any of the ideas might fit or be of use to them.

References

Anderson, H., & Goolishian, H. (1992). The client is the expert: A not-knowing approach to therapy. In S. McNamee, & K. Gergen (Eds.). *Therapy as social construction* (pp. 25-39). London: Sage.

Afuape, T. (2011). *Power, resistance and liberation in therapy with survivors of trauma: To have our hearts broken*. London: Routledge.

Bergum, V., & Dossetor, J. (2005). *Relational ethics: The full meaning of respect*. Maryland: University Publishing Group.

Boscolo, L., & Bertrando, P. (1992). The reflexive loop of past, present, and future in systemic therapy and consultation. *Family Process*, *31*(2): 119-130.

Burnham, J. (2005). Relational reflexivity: A tool for socially constructing therapeutic relationships. In C. Flaskas, B. Mason & A. Perlesz (Eds.). *The space between: Experience, context, and process in the therapeutic relationship* (pp. 1-17). London: Karnac.

Denborough, D. *Narrative justice and the (draft) charter of story-telling rights*. Retrieved from https://dulwichcentre.com.au/charter-of-story-telling-rights/ [last accessed 30th January 2021]

De Shazer, S., & Berg, I. K. (1997). 'What works?' Remarks on research aspects of solution-focused brief therapy. *Journal of Family therapy*, *19*(2): 121-124.

Fredman, G. (1997). *Death talk: Conversations with children and families*. London: Karnac.

Fredman, G. (1999). Denial: a sort of knowing: Conversations about death and dying. Context, 42: 25-27.

Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Buckingham: Open University Press.

Klass, D., & Steffen, E. M. (2018). Introduction: Continuing bonds—20 years on. In D. Klass & E. M. Steffen (Eds.), *Series in death, dying, and bereavement. Continuing bonds in bereavement: New directions for research and practice* (pp. 1–14). New York: Routledge.

Lee, P. L. (2013). Making now precious: Working with survivors of torture and asylum seekers. *The International Journal of Narrative Therapy and Community Work*, *1*: 1-10.

Lee, P.L (2020). *Chatting about the liminal space during Covid-19*. Retrieved from https://www.narrativeimaginings.com/blog/ [last accessed 30th January 2021]

McParland, J., & Camic, P. M. (2018). How do lesbian and gay people experience dementia?. *Dementia*, *17*: 452-477.

McParland, J., Khan, I., & Casdagli, L. (2019). Marking our journeys alongside young people. *Clinical Psychology Forum, 320*: 35-37.

Morgan, A. (2000). *What is narrative therapy? An easy-to-read introduction*. Adelaide: Dulwich Centre Publications.

Moxley-Haegert, L. (2012). Hopework* Stories of survival from the C.O.U.R.A.G.E program: Families of children diagnosed with cancer. Retrieved from https://dulwichcentre.com.au/wp-content/uploads/2014/08/Hopework_by_Linda_Moxley-Haegert.pdf [last accessed 30th January 2021]

Ncube, N. (2006). The tree of life project. *The International Journal of Narrative Therapy and Community Work, 2006*(1): 3-16.

Patel, N. (2019): Conceptualising rehabilitation as reparation for torture survivors: a clinical perspective. *The International Journal of Human Rights, 23*: 1546-1568

Pena, C., & Garcia, L. (2016). A story of political consciousness and struggle across time and place. In T. Afuape, & Hughes, G. (Eds.). *Liberation practices: Towards emotional wellbeing through dialogue* (pp. 174-184). London: Routledge.

Pennebaker, J.W. (1997). *Opening up: The healing power of emotional expression*. Guilford Press.

Portnoy, S., Girling, I., & Fredman, G. (2016). Supporting young people living with cancer to tell their stories in ways that make them stronger: The Beads of Life approach. *Clinical Child Psychology and Psychiatry, 21*: 255-67.

Reynolds, V. (2011). Resisting burnout with justice-doing. *The International Journal of Narrative Therapy and Community Work, 4*: 27-45.

Reynolds, V. (2012) An ethical stance for justice-doing in community work and therapy. *Journal of Systemic Therapies, 31*(4): 18-33.

Stroebe, M., & Schut, H. (1999). The dual process model of coping with bereavement: Rationale and description. *Death Studies, 23* (3): 197-224.

Tonkin, L. (1996). Growing around grief - another way of looking at grief and recovery. *Bereavement Care, 15*(1), 10.

Vermeire, S. (2017). What if ... I were a king?: Playing with roles and positions in narrative conversations with children who have experienced trauma. *The International Journal of Narrative Therapy and Community Work, 4*: 50-61.

Weingarten, K. (2000). Witnessing, wonder and hope. *Family Process, 39*(4), 389-402.

Weingarten, K. (2010). Reasonable hope: Constructs, clinical applications and support. *Family Process*, *49*(1), 5-25.

Weingarten, K. (2012). Sorrow: A therapist’s reflection on the inevitable and the unknowable. *Family Process, 51*: 440-455.

White, M. (1995). *Re-authoring lives: Interviews and essays*. Adelaide, South Australia: Dulwich Centre Publications.

White, M. (1997a). *Narratives of Therapists Lives.* Adelaide: Dulwich Centre Publications.

White, M. (1997b). Challenging the culture of consumption: Rites of passage and communities of acknowledgement. *Dulwich Centre Newsletter*, *2*(3), 38-42.

White, M. (2005). *Michael White workshop notes*. Retrieved from https://dulwichcentre.com.au/michael-white-workshop-notes.pdf [last accessed 30th January 2021]

White, M. (2007). *Maps of narrative practice.* New York: W. W. Norton & Company.

Winslade, J. (2002). Storying professional identity: From an interview with John Winslade. *The International Journal of Narrative Therapy and Community Work, 4*: 33-38.

Worden, J. W. (2009). *Grief counseling and grief therapy: A handbook for the mental health practitioner*. New York: Springer Publishing Company.

Yuen, A. (2009). Less pain, more gain: Explorations of responses versus effects when working with the consequences of trauma. *Explorations, An e-journal of narrative practice, 1*: 6-16.