Stories of Living and Dying
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This presentation took place on Valentine's day in February 2001. This was a particularly apropos day to speak about death and dying, as Valentine's day is a time to celebrate relationships, connection and love. The stories that I share in the following pages revolve around these same themes. They are stories that celebrate relationships. They are stories of the most tender connections. They are stories of love that truly know no boundaries and blossom even in the face of death.

In this paper I have written about those who have died as well as those who have lived on, carrying the legacies of their loved ones. I have written about people who, in the face of their most trying obstacles, found love and hope and courage to tell significant stories of connection and remembering and community. In sharing with you, the reader, these intimate details of people's lives, I have taken the liberty of changing any identifying information. I have also sought, and attained, the permission of those people whose stories are described here. Sharing their stories is a way that I offer to extend their legacies. Should you like to, you may be able to continue this process by re-telling their stories to others.

Before I begin to relay these stories it is relevant to consider the context of the work that I am involved in. Much of the work I do takes place after a person and their family has been referred to hospice in Tucson, Arizona. Due to the nature of this setting, I generally work with people who have some forward notice about their upcoming death. Aspects of this paper relate to preparing for dying and this is often more possible when we have some awareness that our time may be limited. On the other hand, I believe that the principles that inform the work described in this paper have broader relevance in how we live our lives in relation to death, both our own and those we love. {These principles and practices have also been effectively utilized in circumstances in which people have died a sudden or violent death.}

The broader social context of this work is also relevant to mention, as the issues I discuss in this paper would be very different if the work was occurring in a different country or cultural context. The work described in this paper is occurring in the USA, a predominantly Christian country, in which, despite the profound influence of immigration from around the world, Anglo-European norms and traditions still dominate social discourses of living and dying. {Additionally, individualism strongly influences how social identities are constructed and this in turn has an impact on our attitudes to death.} One of the main emphases of my work is to find ways of preparing for and relating to death that do not prioritise individualism, but instead how our lives are lived in relation to others.

We do not die alone

Within western culture there is a common saying that states that “you’re born alone and you’ll die alone”, and yet I believe this is far from the truth. While I do not deny that in some circumstances, and for some people,
Death is a lonely experience, for many others it can be very different. If the context is right when people die, I believe, they can do so wrapped in a loving blanket of those who matter to them. Many of us can be given our send off to an unknown place, knowing our voice, our stories and our connections can remain with those who love us.

When I ponder “who will take care of me after I die?”, I find it a reassuring thought to know that there is an afterlife. This is not an afterlife that necessarily exists in a physical or etheric or religious sense, but it is an afterlife nonetheless. I know that I will continue to exist within my community of significant others long after I am no longer alive in body. I like this thought – knowing that I matter and that my life will continue to influence those I cherish after my death. When I work with those who are facing their death, I make the assumption that they too will want to know that they matter in their community of loved ones. I believe this is true for us all. We want to know that our life and our lessons and teaching and stories will be present for those we care about, even in our physical absence. As I work with people who are dying and their families, my goal is to help these people to strengthen their important relationships and connections with their communities so that these will continue to have a positive influence after death. I employ narrative practices to bring forward stories of hope and appreciation that can be engaged with in meaningful ways when death is present.

My own background

Let me tell you a story from my own life as way of background. It is one of the multiple stories I could tell about how I started working with death and dying. Six months after my daughter was born, my grandmother became ill. Her cancer, that had been sleeping for more than a decade, had returned. As she and I were very close, I traveled to be with her in California. She hadn’t met her great granddaughter before that moment and it was important to all of us that they have time together.

My grandmother was an amazing woman. She, like myself, had trained as a social worker. Her jobs varied over her career. She worked with Margaret Sanger, the founder of Planned Parenthood in the 1930s, disseminating birth control information. She provided disaster relief in Florida to hurricane victims and worked with social reform for child welfare. My grandmother worked in the Kaiser Permanente Hospital in California until she was over ninety years old. She was a consummate traveler who traveled the world, by herself, ten times over. Two years before she died, when she was ninety-one, she told me that she may have taken her last trip. This was upon her return from China (her second trip there) and I was convinced she was only saying this as a broken neck had inconvenienced her during her trip. In spite of her severe osteoporosis, she walked daily and swam laps a few times a week. My mother’s mother was a spitfire who taught me so much about the world – about service to others, about adventure and about the value of connection. I cherish our relationship.

When she died, I did not want to lose this connection. I wanted my daughter to know her and know her stories. I wanted my young daughter to know she came from a long line of women who worked hard in making the world better. I
did not want my grandmother to be forgotten. Forgetting and moving on from her memory would be far too much of a waste. It has been important to me to carry her voice with me when I work, especially in terms of my commitment to service. When I travel on a long journey, like the one to Adelaide to present this paper, I carry with me her pieces of advice about traveling and how to pack a suitcase. And when I am working with other people, I seek to keep alive their relationships with their loved ones because I know how my grandmother continues to enrich my own life and my daughter’s life.

As I acknowledge the ways in which I carry my grandmother with me, I am conscious of how the work that I do occurs in a context of relationships. These relationships include not only my family but the professional company that I am linked with – an incredible group of clinical practitioners from Phoenix, Arizona. I have been involved with the Institute for Creative Change over many years now. Together we have studied and explored ways to bring new thinking and metaphors into clinical worlds. During the 1980s we were trying to make our own sense of the work of Humberto Maturana, Francisco Varela, Paul Watzlawick, Gregory Bateson, Karl Tomm and Ken Gergen. I still probably couldn’t explain some of their work, but through the explorations I did begin to form new understandings to guide my work with those who were consulting me. When I started to read, with delight, the writings of Michael White and David Epston, I was already interested in how relationship, stories, language and meaning intertwine to form this wonderful adventure that is life. The ideas of narrative therapy led me to experiment with new forms of questions and new avenues for reflective processes in my work in psychiatric and medical hospitals. Often I stumbled, but once in a while I found something that appeared to fit, or I would receive feedback about the significance of a particular conversation. When I then began working in hospices, and my work became more focused on people’s experiences of death and dying, I brought with me the history of all of these different explorations and relationships.

Metaphors of death and dying

I have now worked in hospitals and hospices for over fifteen years, and even so, I still at times feel like an outsider in these arenas. As I practice with a narrative orientation my vocabulary often does not fit with those of medical personnel, physicians and other therapists and social workers. In fact, our ways of thinking and speaking appear quite foreign to each other. I don’t use words like “denial”, “unfinished business”, “end of life issues”, “letting go” or “control issues”. All these commonly used metaphors imply finality, an end and an order in which death should occur. They also privilege the knowledge of people other than those experiencing the death and grief, and imply that these professional others are in a position to stipulate the rightful order of the process. This has many implications, most significantly, those who are seen to be not doing the proceedings in the correct fashion, can become subjected to a critical gaze, or worse.

These metaphors represent the mainstream professional discourse in relation to the world of death and bereavement. Although the hospice movement has succeeded in the remarkable achievement of making death an acceptable topic of discussion and study, dying in hospice still comes with its own constraints and discursive parameters. Hospices are deeply immersed in the
metaphors and classifications of the medical world.

In this paper I want to offer a number of new metaphors - metaphors that have grown from my understanding of social constructionism and narrative therapy. What metaphors can we offer instead of “the need to let go”? I am interested in finding ways to be free from delineated outlines that stipulate how death and grief should occur. In the conversations I have shared with people facing death (either their own or that of a loved one) I have been offered many alternative metaphors, metaphors of remembering, of preparing and leaving legacies, and of carrying legacies forward.

Before exploring some of these alternative metaphors, it seems important to consider some of the effects of the popular western discourse around grief. Here I will discuss just two of the implications that flow from dominant assumptions about death and dying: “cutting our loved ones out of our lives” and “grief equals sadness”.

Cutting our loved ones out of our lives

One of the most powerful effects of dominant attitudes to death involves cutting our loved ones out of our lives. By encouraging the “letting go” of significant relationships, dominant attitudes to grieving reduce the possibilities of remembering. And the opposite of remembering is not just forgetting, I believe it is something much stronger than that. If we cut ourselves off from those we love by “letting go” of their stories and our connections with them, this is akin to an act of ex-communicating the members of our families and communities. In this way, the opposite of remembering is not just forgetting, it is dismembering. It is not unlike cutting off our own limbs, as Delores testifies in the following story.

Delores and I had often talked while her husband was alive (2). I loved visiting them, as I would always come away with the fullest love stories that uplifted me. I felt blessed to be sitting with these warm-hearted people. They had been married for eternity - more than fifty years - when Delores’s husband became ill. Throughout his illness, Delores was the most devoted support. After his death, I was concerned about how Delores was going to adjust to the daily change in her time, as her care-giving efforts were no longer required. I would call her periodically just to touch base. Many times when I phoned, she told me she was fine and in fact, she thought she was doing much better than she had expected. One day when I phoned, Delores asked if we could talk. When I arrived at her house, Delores was obviously distressed and had been crying. She soon relayed what had taken place.

Delores described how, as Christmas was approaching, she had been addressing Christmas cards and had run out of her preprinted return labels. When rummaging through her desk, she found some old labels which had Delores’ name and her husband’s name printed upon them. Thinking that it might make people uncomfortable to receive a Christmas card from a dead man, Delores had taken out a pair of scissors and had begun to cut off her husband’s name from the labels. As she was telling me this she again began to cry and explained how it felt like she was cutting her beloved man out of her life.
This was a powerful metaphor, one that I am always reminded of when I think about the dismembering practices of our culture in relation to death and dying. I wondered about what informed Delores to act in this way. What might produce this belief that she shouldn't have her husband’s name on the Christmas labels anymore? How had she come to know that to cut his name off the cards was the socially acceptable thing to do?

This act of “cutting off” was emotionally painful for Delores because it was an act of dismemberment, the opposite of remembering. Delores told me how wrong it felt to her to cut her husband out. It goes against our grain to cut ourselves off from our loved ones and our communities. But Delores felt constrained to act in this way in anticipation of what other people would think. This is a clear example of how a normalizing gaze can be internalized and influence a person’s construction of relationship. Delores clearly experienced the effects of this construction as very painful. Such constructions of “cutting off” are the cornerstone of mainstream western thinking about bereavement; that is, once we accept the reality and finality of death, we are expected to move on with our lives and accept that the dead loved one is no longer with us. Acts such as sending Christmas cards from a dead person run the risk of attracting pathologising labels. In order to maintain our place in the world of the living, we are told that we must free ourselves from relationships with those who have died.

Grief equals sadness

Many grief narratives float around our culture with implications as to how we are supposed to act when someone dies. Without so much as a manual, we know what is expected of us at these times and what is considered socially acceptable. Not only are we supposed to “let go” and “say goodbye” to the person who has died, but we are invited to understand grief and sadness as in an intricate relationship. This is a second significant effect of dominant cultural constructions of grief. Grief and sadness, in western culture, are a bicycle built for two. They pedal in sync and the tandem association can become self-perpetuating. When people are experiencing grief, it is expected that they will feel sadness. These expectations can lead at times of grief to an encouragement of stories of sadness and loss. Grief begets grief until you can “let go”. {And yet it is uncertain how re-telling painful stories is helpful. It is not a form of expression that invites people to form a new relationship or experience of their grief.}

Multiple stories

This world of these dominant western discourses surrounding grief - those which reduce grieving to “cutting off” and those which depict grief and sadness as synonymous - is not my world. I do not feel at home with these renditions of grief. I am much more interested in knowing all the possible stories that are available to a person as they face death or as they continue to live after the death of a loved one. I prefer not to privilege stories of pain and suffering when other more sustaining stories are possible.

I was asking Shona recently about what she thought was good about her current situation with her partner, Paul who was perhaps only a week or two
away from death. Together the three of us spoke about how precious this time was and how close they felt to one another. Shona shared how demonstrative Paul had recently been and explained that he had not been prone to physical displays of affection throughout their partnership. Had I been focusing on a story of letting go, of how sad it was that Paul was about to die, or how sad Shona might be after his death, they may have missed articulating to each other these sweet nuances in their story. I was sure that these newfound expressions of connectedness were only one aspect of their time together: no doubt there was also sadness. But creating space for the acknowledgement of this sustaining story, of increased connection, was a part of the process of enabling these two people to richly describe their lives together.

There are always many stories of grief available to us. How we want to tell the story matters and we have choices about this. Do we want to tell what good is available in the face of death as well as the stories of sadness? Do we also want to tell the stories of humor? And what about the stories of tremendous relief in situations where a person’s illness has been long or painful? Or the stories of complexity when the person who is dying has brought heartache and sorrow to those they are closest to, as well as intimacy and joy? How do we want to find voice for all these stories? How can we avoid them all being drowned out by the voice of sadness?

An alternative metaphor: to be remembered

There are many ways to fashion death and dying. Not only are there many meanings to be explored in each person’s dying, but there are also alternative metaphors which can inform our experiences of death and grief. One key metaphor relates to how we wish to be remembered.

A man told me at one of my workshops how his partner has already given him specific instructions that one year after her death - on their wedding anniversary - she wants him to have a party in her honour. I suggested that he was married to modest person as I plan to instruct my loved ones that I too want this wonderful kind of remembering after I die, but I want it every month!

Most of us do not want to be forgotten. In fact, I believe that forgetting and moving on is disrespectful to the person who has died as well as to those still alive. With all the beautiful rich life lessons, stories and connection that one person has had the time to live, why would we want to move on and act as if they had not happened? Wherever possible, I try to create a context in which the connections between the living and the dead will be able to be sustained long after death. I want it to be possible for the richness of the person’s life to be celebrated. I want it to be possible for their voice to be brought to life again and again - long after the physical death has occurred.

One man whose partner's death was only hours away, asked me, “How do I write an end to a love story?” My response was quite simple, “You don’t have to”. I went on to invite him to promote his love story and connection with his partner, to cherish it and let it flourish. My hope is that their relationship will continue to grow over the years to come. My questions of
him were designed to generate and encourage practices of remembering, inclusion and on-going relationship. If their relationship is ongoing then the necessity for him to complete unfinished business and “end their love story” becomes redundant.

Working with those who are dying

One of the realms in which narrative influences have been the most dramatic is in my conversations with those who are dying. I do not speak with people about what stage they might be in their acceptance of their own death. I do not want to suggest that death equates with finality, that once we get to the last stage, we mourn without regret and then briefly and efficiently move on to accept the next chapter of our lives. I do not speak with dying people about how much denial is present. I do not even hold in my head an assessment scale against which I can measure how much denial may be taking place as I think to do so would only suggest that I know more than they do and would risk dismembering their relationships long before their death.

But before I relate some stories of the conversations I have shared with those who are dying, I need to make a clarification. Not all people as they are dying wish to speak about death. According to some ways of understanding, not discussing feelings about dying is commonly labeled as denial or is thought to indicate that something is wrong with the person concerned. When I sit with people who don’t wish to discuss death, I assume that this is the correct thing for them. I do not subscribe to a belief that I should in some way pressure people to speak about their death. I ensure that the person knows that I am comfortable and willing to talk about death and dying, but then it is up to the person concerned. Families will often ask - well shouldn’t he/she be talking about dying? The respectful answer I believe is, only if such a conversation is important to the dying person. If the family members wish to talk about their experience then I will create a context for this, but I do not pressure the dying person to have conversations which they are not interested in.

A family that I worked with last year illustrates this kind of flexibility. When I first met Jed, his family asked me to not discuss dying with him unless he brought it up. Jed’s partner, Jane, and their three kids didn’t want this discussion imposed on Jed and were concerned that if it was, that it might encourage him to give up and possibly die sooner. Jed and I would have wonderful chats over the months that I visited. Once he commented as he looked at his window in Tucson, how beautiful Paris is this time of the year. His family would join him in agreeing that it was in fact lovely, not trying to force him to accept reality. With Jane and the children often present, Jed told me stories of his experiences during WWII when he fought at Normandy beach and his early years as an engineer in Michigan. He talked about his joy with his children and how he loved seeing the directions their lives were taking. We didn’t speak about death per se, or about sadness or anger about his terminal brain tumor. We spoke about life and love and connections - the important things that his family would have to hold close as memories.

One day when I visited, Jed told Jane and me about a dream. In his dream, he was climbing a very large mountain. He said that he had to climb it by
himself, but at the top there were two horses waiting for him. He knew that one was for him and the other was for Jane. He told us that he also knew he was to wait there until she could join him on her horse.

Jed died the day after this conversation. When Jane and I spoke later we again talked about this metaphor. I asked her if she thought he was waiting with the horses? She imagined so. She told me that she liked the thought of having him go first - that he had always been something of a trail blazer and now wasn’t any different.

In accordance with narrative ideas, we can create the space for people to story death in ways that fit for them. There isn’t one right way to die. I didn’t meet this family and discuss their denial about death. By insisting that their ways weren’t good enough this would have only robbed them of experiencing what was a wonderful death. Instead we focused on the stories and the legacies that would continue to affirm Jed’s presence for years to come.

There are also many people who do wish to talk about their dying. They very much want to take part in shaping how their lives will be understood in the future and the legacies they might leave behind.

Tending to memories and legacies

One gentleman I sat with, taught me a great deal about dying. David very much wanted to know the details of what was to come. He wanted to speak about death and what it meant and what he thought might happen to him after he died. His death was coming upon him sooner than he thought it would. At fifty-three, he said he hoped that he might yet have a bit more time. I asked David how he would use this time if he were given it. He told me a powerful story about how he regretted never having made it to “The Wall” in Washington. “The Wall” is a large monument that was built for people who died during the Vietnam war that has become a place of connection to the dead.

David had been a soldier in Vietnam on two separate tours and spent about four years there during these times. He told me how he saw many men die and witnessed many horrible events. But, he explained, there were three men, young soldiers who served under him that he felt the worst about. He was with them when they died and for thirty years he had carried the images of their deaths with him. He was hoping that he might be able to go to “The Wall” to the find their names carved into the large granite memorial as he envisaged that this act would be a tribute to them being “good men”. He told me how he had questioned their deaths and how they had constantly reminded him ever since of the preciousness of life. I was curious about this. With all that David had been through, in the face of extreme inhumanity, his life had been powerfully shaped by events that had taken place over a few minutes in time. These few moments had shaped for David a strong narrative of life being precious that had guided him for over thirty years. I asked David if the families of these three men knew of the influence that these boys had had on his life? Would they be surprised to know how their loved ones had touched his life?
We talked about the power of carrying another’s story and how important it is to tend to it. In the course of this conversation David came up with a number of ideas as to how he might be able to continue to “pay tribute” to these men after he died.

These were new thoughts born out of conversations about tending to other people's stories and legacies. They were not pre-scripted, nor did they adhere to a staged process of grief. We spoke about what might happen if he let the families of the three men know of his plans and how he might be able to do this. We talked about the possibility of writing letters to their families. His sister, who had been listening to our conversation, offered to go with a friend of David’s, another veteran, to “The Wall” on his behalf. David said that he would very much like it if she and his buddy would be his eyes and ears to find the names of the young men and to see that the letters he was going to dictate were received by their families.

Before we stopped on this day, I shared with him how moved I was that he had tended to these men's stories with such love for thirty years and that now in his death he was going to continue to tend to them by willing their care to others. I then asked him how he would like his sister to tend to him after his death. If she were to take care of his stories with the same consideration that he had done for these young men, how might she look after him in death? His only answer was that he wanted her to recall the good things. When I asked further about what he hoped she would define as the good things. He only answered, “These times, like now.”

Preferred stories: defining our legacies

If we take seriously the idea of identities and relationships continuing and changing after death, then we open up the possibility of choosing to emphasize some stories ahead of others in the legacy that we leave behind. Those who carry the memories of their loved ones forward can also choose to develop the stories of the deceased that are useful to them rather than feel compelled to restrict themselves to the dominant representations of the person’s life.

Paula was a remarkable woman who was very much involved in creating her own legacy. When she entered hospice she was fifty-four years old. Throughout her life she had been devoted to children. She raised three kids herself while she taught kindergarten at a nearby Catholic Church. Before her illness consumed her energy, she had cared everyday for two of her young grandchildren so that her daughter could work. We met in Paula’s living room to talk with her partner and two of her kids. As we talked, there were numerous children all under the age of five running about. Even her youngest grandson, who was two months old, was contributing to the conversation. As you could imagine, it was a home full of life. We talked candidly about her illness and that she was going to die soon. I asked her to reflect about her grandkids and kids. What did she want them knowing about her over the years? How would they be remembering her a year from then, or five years on, or further? What stories of her life did she want them to know about that had helped her have strength in the face of adversity and that were assisting her in dealing with this present situation?
Paula spoke about the importance to her of being a teacher - she wanted her grandchildren to know this. She wanted them to know how important children had always been for her and how much she loved them. She spoke about her faith as life sustaining in times of challenges and hoped her kids and grandkids would continue practicing Catholicism. I also asked Paula what she might hope her daughters would use from her parenting in how they parented her grandkids? She laughed at this. She thought they would be fine as she could see already how wonderful they were at parenting.

Questions like this may appear simplistic as I was asking Paula to play with images of how life will include her after she is dead. And yet, questions such as these are precise and intentional. In these conversations I want to create a framework that acknowledges how Paula will continue on. I want to give Paula an opportunity to reflect and to voice what she finds meaningful in relation to establishing her legacy. These are questions that resist the cultural practices that threaten to dismember Paula from her family and community as she moves closer to death. To further establish her legacy, I was then interested in creating an audience to witness re-tellings of the stories that mattered to Paula.

Revising relationships in facing death and dying

The two proceeding stories described people who felt all right about dying. David and Paula both wanted to be involved with the conversations about their death. Although they were both relatively young, they expressed a sense that they were not afraid for death to come. They were also in situations in which their primary relationships were in good shape. What about when this is not the case? Can we use a narrative approach to be of service?

If our stories are stronger than our biology, then narrative themes and plots play forth whether particular characters are present or not. Often, when people are facing death there are certain relationships that may have been strained or estranged that they are wanting to come to terms with. This can be a significant aspect of dying.

When I met with Jean-Paul who had struggled with depression throughout his life, I learnt that he lamented how this depression had contributed to him becoming estranged from his son. In listening to Jean-Paul I assumed that the story of him as a depressed person would serve little ongoing value to his son. There are always a multitude of stories about a person's life that can form the basis of the legacies they wish to leave behind. There are always many stories that can be chosen and brought forward. Before Jean-Paul died I was concerned to unearth stories that would provide some alternative territory on which to base a different sort of relationship with his son. Were there alternative stories that his son did not know about him that would help guide his son when he too faced challenges? How had Jean-Paul been courageous in facing times when depression had tried to get the best of him? How had his son, and his hopes for his relationship with his son, contributed to Jean-Paul’s life and the ways he had been able to resist the effects of depression? How could we catch up Jean-Paul’s son on these stories? What might it mean to him to know about these alternative stories of Jean-Paulis life and his contribution to them? And what might it mean to
Jean-Paul to know that his son might come to know him in a different light?

These questions were invitations for Jean-Paul to reflect upon his own life and on his continuing relationship with his son. Embedded within these questions are assumptions that defy finality or letting go. These questions also defy the implied inevitable story of failure and estrangement as the only story that could be told about Jean-Paul’s life in relation to his son. These questions invite Jean-Paul to consider that, despite his imminent death, it is possible that the alternative stories of his life will continue to be available to his son, and indeed future generations. I believe these questions invite hope that a positive legacy will exist. And as the stories are re-told over the years, such narratives might even outgrow the confines of Jean-Paul’s life and the difficult relationship between this father and son.

In situations like this, death sometimes provides opportunities for the revision of relationships. Sometimes it is through death and the rituals that accompany death that people discover that the person to whom they were close was not all that they purported to be. Changes in relationships often occur posthumously when a person who was thought to have trusted member status in another’s life is discovered to have disrespected this trust in some way. Conversely, relationships that have been characterized as troubled or estranged can gradually be re-appraised after death(3). Through tending to the multiplicity of stories that constitute all of our lives, sometimes after death new avenues for understanding and acknowledging the context of a person’s life become available where once this was overshadowed by the difficulties of the everyday relationship. As stories are wonderfully flexible, it is quite common for new stories to develop about relationships after a death has occurred.

Bringing to life the voice of a dead person

In some circumstances, far from “letting go” of the person who has died, it can be of crucial importance to continue to “bring to life” those who have died. The following story illustrates this.

Roberta and Nicolas were very much in love. Nicolas did not want Roberta to die and stated this very loudly. When I would meet with them, she would say, “Nicolas we have to talk about this”. And he always said the same thing, “I don’t want to talk about it”. Being from New York, they spoke in an animated and loud way with one another, which was exaggerated by the fact that neither of them could hear very well. In between gripes about her desire to talk and his desire not to, they would burst into their favorite Frank Sinatra tune and serenade each other with loud and off-key melodies. These conversations were very lively.

Roberta was genuinely concerned about Nicolas. On a number of occasions Nicolas had mentioned that upon Roberta’s death he was planning to kill himself. He couldn't imagine life without Roberta and had decided to shoot himself. The morning Roberta died, Nicolas became agitated and was yelling at the hospice staff. I was paged to the inpatient unit where Nicolas and I talked next to the bed where Roberta’s dead body lay. He told me how he couldn’t go on and how Roberta had brought life to him. “It feels like my
life is over”, he said. I asked him questions to strengthen Roberta’s voice and presence within him. I very much needed for him to have an understanding that he could still have connection with her otherwise I imagined that he might kill himself. For a couple of hours we talked about the times they shared together, the laughter and the disagreements. He told me about how they always said they were only a half of person without the other one Ô that half of her lived in him and half of him lived in her. I took this metaphor as an invitation and asked him many more questions about this. How would the half of her that lives in him want him to carry on? What might the half of her that lives in him say about how he can do well at this? What might the half of her that lives in him want Nicolas to remember about the times they have shared? Nicolas answered by singing another Sinatra tune. He explained that “What are you doing the rest of your life”, was one of Roberta’s favorite songs. I asked, how would she like you to answer that now Nicolas? And he replied, “She’d want me to keep singing”.

How we invite people to tell their stories in times like this matters greatly. If we only invite stories of loss and sadness or tragedy, then not only do we miss out on so many gems of connectedness, but we actually promote injury. By bringing forward the continued voice and presence of our dead loved ones, their positive vision of us can be nurtured. Had I taken Nicolas towards further embellishment of sad stories, and towards metaphors of letting go or how angry he was, I seriously think he wouldn’t be alive today. He would have succeeded in killing himself as this would have seemed the only option of claiming connection to Roberta.

Situations in which I haven’t met the person who has died

There are other times in my work when I haven’t met the person who’s died. Rather, I am learning about them through the eyes of their loved one. In these conversations many of the same remembering ideas apply. I am interested in fostering a sense of ongoing connection and relationship with the person who has died. I am interested in how relationships that were challenging can take on new meaning and possibility. I want the legacies to grow richer over time. I somewhat jokingly tell people about my mother, who has now been dead for over twenty years, and about how she and I have a better relationship now than we ever had when she was alive.

We continue to re-author stories about the relationships we had with people who have since died, and how we do this makes a significant difference. So too does how we bring to life these relationships in the present. Having a sense of my mother’s presence as I have gone through the past twenty years of my life has been a blessing. This was particularly true, as I became a mother. I needed my mother’s stories and guidance close to me. I wanted her membership in my life to continue to be a predominant part of who I am. As my daughter has grown she too has come to have a strong connection with her deceased grandmother. Keep in mind that they have never met in physical form, but only through story. Yet, my eight-year-old daughter speaks about her grandmother as if we just saw her last week. She sings grandmother’s songs, she knows grandmother’s recipes, she knows about her grandmom’s love of animals, and she knows her grandmother’s knack at telling a good joke.
There are so many different ways in which people continue to make meaning out of their connections with those who have died, that perhaps it is best to tell another story as an example. It is a story that describes how particular rituals can act as practices of remembering.

For those families who have experienced the loss of a loved one, regular rituals such as Christmas can be difficult times. One family I know approached their first Christmas after the loss of Romero – their father/husband/grandfather – with considerable angst. The Christmas Eve ritual of opening the stockings had always brought joy to the five children and thirteen grandchildren, and yet this time concerns were expressed that they might feel sad if Romero was not there to open his stocking this year. As we discussed this, they came to the creative solution. They decided to hang Romero’s stocking and in the weeks leading up to Christmas they would place in this stocking slips of paper on which different family members had written notes about what they had appreciated about him. On Christmas Eve, after the others had opened their stocking, they sat down to dinner. One by one, the slips of paper were carefully pulled out and the messages were read out. With each message, another aspect of Romero’s presence was brought to life and more stories came forward! What could have been a ritual of dismemberment, became a ritual of inclusion and remembering.

Responding to other people’s loss

When we hear that someone that we know has experienced the death of a significant person to them, we are faced with the question of how to respond. One common cultural practice is the giving of bereavement cards. I began collecting these cards a number of years ago when a friend asked me if I could pickup a sympathy card for a student of his whose grandfather had died. When I arrived at the stationery store, I found a plethora of cards - those geared for men and those for women, crafted to appeal to certain gender through color and graphic outlay. There were religious cards, and pictures of birds flying into sunsets or maybe sunrises. Words were gingerly sprinkled over the silhouette of a natural scene with etheric wisps of clouds floating by. The often rhyming messages were clear: “Time will heal”; “We’re sorry for your loss”; “Your loved one is in a far better place”; “This is sorrowful/tragic/painful”. The words on such cards spoke poignantly about “separation”, “letting go”, “moving on” and “feeling whole again in time”. 

I was unable to complete my task as I was overwhelmed at how such cards construct the experience of grief. Standing in front of all these cards, I saw before me a mass production of a grief which is characterized by the need to return life to normal functioning as soon as possible & normal functioning being in some way separate from the person who has died. These cards also reproduce the assumption that grief equals tragedy, leaving little room for those who might be experiencing relief that their loved one’s death has freed them from physical pain, or those who have more complex reactions to a recent death.

I would not want to suggest a causal relationship between cards and the modern production of grief. Rather, I think the copywriters of such greeting cards are skilled at reflecting popular discourse about common grief. This
popular discourse has significant effects. In order for someone to have their grief recognized within dominant western thinking, they must be able to sign on to the cultural preference that “I” is more important than relationship. In order for their experience to be embraced by others (including through bereavement cards) individuals must act as if the relationship with the person who has died is somehow of less significance than the “I” that remains alive. According to the popular discourse, what is important after death, is for an individual process of grief to take place. This is prioritised above the relationship between the grieving person and the person who has died. Speaking about a dead partner is quickly discouraged and talking to a dead partner is taboo. Anniversaries, birth dates, death dates go by without acknowledgment or invitation for remembering practices. Bereavement cards for a one-year anniversary or five years beyond the initial period of death are simply not made. Practices of remembering, appreciating and story telling are also not usual. We do not see cards that are preprinted with “I remember a time when...” or “I loved this about your deceased family member”. This change in focus would require cards to incorporate a relational vantage-point and acknowledge an ongoing connection between the dead and the living.

In this context, how we respond to people who have experienced the death of a loved one can be significant. I recently spoke with a Irene whose husband died two months ago. She shared with me the most beautiful of cards that a well-meaning friend had sent her for Christmas. On the cover was an attractive scenic photograph and inside nothing was preprinted. The card read; “I recall years ago we were all together for a New Year’s Eve celebration. Your husband asked you to dance and as he did so he bent over to kiss you. From across the table, I was moved to tears as this moment between you was so love-filled.”

When we spoke of this, Irene actually didn’t recall this exact event, but she said, “Oh, that was just like Jorge.” We spoke at great length about this. I inquired about whether she was surprised by this card and who else might know him to be such a loving husband. As we reflected, we nurtured a wonderful story of remembrance of him as a loving and kind man who adored her. We even spoke about how his loving ways may have influenced others. It was not a pre-scripted moment of sympathy that brought these stories to life, but the simple act of a friend remembering her husband and acknowledging their connection. This act offered to renew Jorge’s membership in a vivid and wonderful way.

If we look to perpetuate relationship, then we must look to find the paths that promote relationship rather than the renewal of individual status. I encourage people to speak about their dead partner, to share stories about him or her, to ask others about what they recall that they enjoyed about them, to actively create rituals and celebrations for holidays and anniversaries. As part of developing the connections further, I invite people to introduce their dead loved one with people who may never have had the chance to know them during life.

What is normal grief?

People often have strong feelings about how somebody should act in their
grief. As with the bereavement cards, popular discourses of grief shape our thoughts and feelings often without our even knowing it. As these discourses produce an idea of what is normal in grief reactions, they also produce the idea of what is “abnormal”.

Some time ago, I consulted with a family who requested that I speak with their mother. The daughter explained that they were concerned as their mom, Lucia, who was grieving the loss of her father. The daughter painted a picture of her mother crying daily, not being able to sleep or eat, and refusing offers to sort through her father’s clothing and possessions “to get the house back in order”. When I did meet with Lucia, I learned that her daughter’s story about her as crying daily and not eating was also Lucia’s story about her recent life. Yes, in fact, she was not sleeping well. And, she really did not want to sort her husband’s things. Lucia told me many touching stories about her life with her husband and how hard she found his dying process. A nurse by profession, Lucia wanted to help him when he was ill and stayed with him around the clock. She recounted stories of rubbing his feet during the night when he was in pain. She slept in the chair next to him so she could stay alert to his needs for medication or attention.

I began forming a new picture, different from that of her daughter’s description during the initial call. Lucia was not only a grieving person but also a loving and devoted partner. And in her current actions she was continuing to express her love of her life-long companion.

As Lucia told me of these events, I became astonished to hear that her husband, whom she had been married to for fifty-three years, had died only three weeks prior to our appointment. It had taken only three weeks before the idea of the need for separation had cut in on the expression of her love. This new information changed my ideas about how I might be supportive to Lucia and her daughter.

Lucia’s daughter truly believed it would be helpful for her mother to move on as quickly as possible from the memory of her dead husband despite the fact that she knew that her parents’ love had been a deep and consistent one that touched many people’s lives. The daughter thought any memory of him would simply be too painful for her mother to bear. The beliefs about how grief should look—that we should all return to “normal” as quickly as possible, put away our dead one’s things and never speak of them again—are prevalently accepted. These unquestioned beliefs guided the daughter’s effort in wanting to help to the extreme that she imagined something must be terribly wrong with her mother as she had been crying for three weeks. Pathologising discourses are very quick to knock at the door.

Lucia’s daughter’s well meaning interpretations had been shaped by discourses that infiltrate our daily lives. She had undoubtedly heard numerous conversations that would suggest moving on as the most efficient method in handling the loss of a loved one. She probably saw titles on magazine covers at the grocery checkout about how to survive a loved one’s death or well-intentioned articles about widowhood and “getting on with it”. She most likely saw many movies and television programs that would have supported and encouraged these actions. She might have even seen the same
television interview that I saw last year of Princess Diana’s bodyguard. Following the release of his book about the car accident and her death, an American news reporter was interviewing him. To start the interview, the reporter, who was informed by the same cultural discourse, asked, “How have you achieved closure since the accident?”

This idea of seeking closure is a prevalent one. The week after Janet’s death, her son, Simon, called me. He was concerned about his stepfather. As we spoke, he told me he was concerned that his stepfather might be overwhelmed by his grief and that this grief would be made worse by living in the large home that Janet and he had shared for many years. Simon further explained that he had looked into apartments where his stepfather might live and have some assistance with cleaning and cooking and the like. He wanted to know if I would speak with him about this suggestion.

I suggested that it might be too soon - Janet hadn’t been dead for even a week and his stepfather might not be in the best place to make any additional life changes. Oh, no, Simon said. I misunderstood him. He knew this week wasn’t a good week to mention a move, but wondered if I could speak to his stepfather next week. I do not wish to fault this young man. He believed he was being helpful in encouraging his stepfather to act in a way that would encourage him to move on and live further away from his dead partner’s memories and possessions. Nevertheless the real effects of Simon’s plan would have been to significantly separate his stepfather from his memories.

People reactions to those who are grieving are bound by cultural discourses about what grief should look like. Therefore, with the best of intentions, people are routinely encouraged to move on, to get busy with other things, and to make new connections rather than “dwell on the past”. And yet, in most situations there are exceptions to these invitations. In most families or friendship networks there are people who are making meanings and connections that are aimed at carrying forward the membership of a deceased loved one in their lives and who are encouraging others to do the same. Exploring these attempts, bringing them into the light, can be significant in itself.

The day I left to come to Adelaide, I spoke briefly with a woman whose partner died last month. She told me that what she found most surprising was how well-intentioned friends and family were trying to keep her busy and that they never brought up her dead partner’s name. To counter this we spoke about her desire to mention her partner whenever possible. I encouraged this.

A gentleman I worked with, as a symbol of maintaining connection with his wife who had died, continued to wear their wedding ring when he remarried. In spite of other people’s discomfort with this practice, he proudly wore two rings on his ring finger and explained to me that removing either ring would have excluded important parts of his life.

After life

Metaphors about afterlife are also important to address when speaking about
remembering practices. Meanings derived from religion and ideas about what occurs after death can produce many varied effects on how people approach their understandings of what will occur after death. Do they believe in an afterlife? What form does it take? Where do your loved ones fit into this picture? Will you be able to communicate with them in some way? Is this communication a one-way or two-way street?

Doug and I shared such a conversation. I knew Doug because he was dying. When I met with him on our third or fourth visit, he was distraught. The night before he had learned that his sister-in-law had been killed in a boating accident. I inquired about Doug’s sister-in-law: could he introduce me to her? He brought to life stories of a kind woman who was warm and bright with a big smile. I was curious if Doug’s brother knew that Doug carried this story of her? He was unsure about this so we discussed ways in which he might let his brother know more about this as a statement of remembering.

Doug was also concerned about the impact of this death on his brother. Knowing he himself had a very short time to live, Doug was worried that two deaths in a short period of time would be devastating for his brother and his family.

“What do you think might make things better for your brother?” I asked.

“If he can remember that Mary is in Heaven”, he said.

“Doug, do you think people in heaven can talk to one another?” I asked.

“Yes, I suppose so.”

I knew from our previous conversations that Doug believed he too was heaven-bound. So I inquired, “Would your brother like it if you were to take a message to Mary from him?”

Yes, he did think his brother would like this.

“What do you think that he might ask you to tell her?”

“That he loves her. That would be the important part.”

We spoke more about the unique position Doug was living in, how he could act as a messenger between worlds, and how playing this part could provide opportunities for the lives of Doug, Mary and his brother to be linked in ongoing ways.

Knowing that a dead loved one now lives in heaven produces particular kinds of conversation and action that are very different from thinking he/she can be found in a garden or in the sound of the wind. A strong belief in reincarnation brings with it different implications for establishing ongoing relationships than a belief system that does not sustain the notion of an afterlife. Different metaphors open different possibilities in relation to incorporating a sense of continuity with those left behind.
Facing death together

Traditional models of grief, woven into our fabric of thinking are unquestionably influential. Without stopping to understand their genealogy, we live as if these theories are fact. We create meanings of events and perform actions based on taken-for-granted assumptions. Finding ways to question that there is a correct way of doing death and grief is one important aspect of my work.

Just as our lives are multi-storied, so too are our deaths. There are many different realms of conversation to explore when someone is approaching death, or when someone has just experienced the death of someone they knew well. So many different factors come into play including whether the death was expected or unexpected, whether it was by accident, illness or by choice, the state of people’s relationships, cultural and religious beliefs about death and afterlife, and so on.

In this paper, I have shared stories from my own life and from the conversations I have shared with many men and women who have courageously reinvented themselves and their relationships in the face of death and grief. These are stories that affirm life, connection and loving relationships. It is my hope that sharing these re-tellings here will invite you, the reader, to consider how the legacies of those we love can be cared for and tended to long after their deaths. It is also my hope that as we further explore alternative ways of relating to death and dying that we may increasingly learn to face death together, joined with those we love, secure in the knowledge that our lives will not be over when we die.

Notes

(1) I would like to express my gratitude to those who created the opportunity for me to speak about my work at the Dulwich Centre Publications international narrative therapy and community work conference. I also want to specifically acknowledge David Denborough’s enthusiastic editing and keen thinking which has spurred on the shaping of the ideas in this paper.

(2) I am conscious that in this paper the stories I tell of people dealing with death and dying involve people within heterosexual relationships and family structures. The experience of death and grief for those whose relationships are not sanctioned by the broader culture present different challenges and possibilities which are not explored here. These implications often include strong revisions of “membered communities” for dying persons where their membership and “life clubs” may have taken on different pathways. Living in a culture that doesn’t acknowledge and make visible membered status to those who chose difference, practices of re-membering those who have died may take different tenor.

(3) It seems important to note that in relationships that have been
characterised by abuse, a death of the perpetrator of abuse can at times bring safety and relief. As always, there are multiple meanings associated with such deaths. Part of my intention with question is to open space for reflection about which stories can affirm life and relationship but not as a way of de-voicing stories of abuse, intrusion and exploitation.

(4) Recently this backfired on me! Addison, my daughter, had been telling me more and more stories, some of which have gotten pretty far fetched. I asked her about a story she was telling me that involved her school catching on fire. She was very elaborate in how she told me the reports of the fire trucks and drama. Surely, I thought if this were true, I would have been notified, and so I had one of those great parenting moments when I said something like, “Are you lying to me?”. At this, Addie kind of twinkled and smiled at me and said, “No mom. I am telling you a good story uh? Just like Grandma would like”.

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This year marks twenty years since the publication of The Tibetan Book of Living and Dying in German. The following are a few stories from people in Germany about how they met the book. Dr. Günter J. Bauer from Berlin and Hamburg writes:

My family’s story — a private matter until now — is that terrible something. Since the incident, I’ve felt isolated by the burden of this story and my sense of obligation to go public with it, but with an unclear aim. Am I raising awareness, in the familiar path of the victim speaking out? And if so, to what end? What will sharing my story really mean for Airbnb? Could the company, with its reportedly $24 billion valuation and plans to go public, do more to ensure the safety of the properties where millions of guests stay each year? As Airbnb rises into a global hospitality behemoth, reinventing not just how we travel but how we value private space, what responsibility does the company have to those who have given it their dollars and trust? Her story about living while dying, growing up fast and realising that she’s worthy of a sex life comes with warmth, energy and belly laughs. BBC Tech correspondent Rory Cellan-Jones went public with his Parkinson’s diagnosis after people noticed his hand shaking on live TV. Since then, the Government have recruited him to their Disability Confident campaign, he has been part of a study and tech innovations designed for people with the condition are being pushed his way. Psychotherapist Mel Halacre, who specialises in disabled people and their mental health, also lends her expertise. Presented by Kate Monaghan and Simon Minty. Produced by Emma Tracey. A transcript is available here. Short Stories Living Dying. People say I’m crazy. Some people even think I’m a “rebel” or a “bad girl.” But I’m not. I’m just living everyday like it’s my last, because sure, I might look back and regret a few things, but I’d never think as them as mistakes, knowing I...