

Disenfranchised Grief

Notes for a National Association of Loss and Grief workshop for students in counselling at the Wellington Institute of Technology.



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Kia ora koutou

Good morning to you, and welcome also to your dead, who you bring with you in your hearts and minds.

This year I was asked to share in conducting the Candlelight Memorial Service, for people who have died of Aids. As I began to prepare, I jotted down the names of people I knew who died of Aids, just to start bringing it all back to me. There were twenty-four names—and there are others whose names I don't remember. That's quite a lot of people in a small city like Wellington, but I have friends who have a lot more than twenty-four names. Most of these people died during a rather short period in the mid and late 1980s. For a gay man at that time, it was a bit like being in a war—but with this difference. In a war those who die are treated by their society as heroes. At the height of the Aids crisis our dead were treated as pariahs. Often their families didn't want to talk about the circumstances of their death—and yet it is talk about the circumstances that is most helpful. And there was a lot of blame and anger, and a fair bit of guilt, too, around these deaths.

It was as a result of that experience that I became a funeral celebrant, starting with some funerals for friends. It was a time when there was a growing demand for non-church funerals, and there were very few people prepared to give them, so for a while my work involved celebrating a huge number of funerals. My typical subject was not someone with Aids, but perhaps a little old grandmother in Miramar. For some years I was doing more than five funerals a week, and I only managed to cut it back by making myself less available while I was training as a counsellor.

One of my specialties has been suicide funerals. The thing that becomes apparent at suicide funerals is the importance of licensing talk, licensing the exchange of stories.

Perhaps this is the time to talk about my most significant professional mistake.

I was asked to do the funeral for a woman who had suicided. Her family situation was complex, and there was a great deal of guilt and blame and anger in the room when I went to see the family. Her body was there, in the casket in the living room, and the people gathered included the woman's teenage son and other, older relations. The son did not say much. The older relations fought. Indeed when it came to discussing pallbearers, it became a physical fight, in the course of which two of them fell across the casket.

The only thing that everyone was agreed on was that nothing was to be said at the funeral about the background to the death. "We all know, of course," I was told, "but we don't want it talked about." In retrospect I ought to have pushed to discuss it out more carefully.

So the funeral made no mention of suicide.

A couple of months later I did a follow-up call—It is very seldom that I do a follow-up call for my celebrancy work, but I was uneasy. When I arrived the son looked depressed, but he made himself scarce pretty quickly. I was told that they were "having problems" with him.

Later I rang his school counsellor, and told her of my connection. The counsellor confirmed that this young man was seeing her, that he was seriously suicidal himself, and that he had not told her that his mother had suicided. She arranged a joint session with the young man and me. At that session I told the story from my perspective.

This young man said he did not know his mother had suicided. Of course he *more or less* knew. He had *sort of* guessed. But it was an unmentionable topic. There was nobody he could talk to about the things that were most important to him. The stories and words which surrounded his mother's death had been seriously inadequate to the situation he faced.

We got him past that point. From time to time I still see him in the street, and we say hello to each other and I get an update. But the bad

instructions, which I had accepted, and the funeral which resulted, nearly killed this boy.

Later, in 1996, ten years ago now, my partner of thirteen years was treated very badly at work. He went into a depression, and suicided.

I was surrounded by friends—including a bunch of friends I had made when we set up the Wellington Branch of NALAG, the National Association of Loss and Grief. Jerome had always called it my “Death Club”.

I remember a couple of days after Jerome died one very kind, very wise woman visited me. I later chose her to be my supervisor for a couple of years. She had benefited immensely from the work of Elizabeth Kubler Ross. I’m afraid at that point she visited me I was grumping around the flat kicking the furniture and kind of chanting “Elizabeth Kubler Ross is full of shit. Elizabeth Kubler Ross is full of shit.”

My other mantra at that time was “It’s waves, y’ know, not steps.”

Waves of grief

- Waves of impact
 - Denial
 - Devastation
 - Disordered thinking
- Waves of negative emotion
 - Guilt
 - Blame
 - Anger
- Waves of seeking
 - Seeking the sequence
 - Seeking the why
 - Seeking the how
 - Seeking the memories
- Waves of healing
 - Moments of acute appreciation of surroundings
 - Moments of a new relationship with deceased
- Waves of a new normality
 - Times of quiet sadness
 - Times of looking backwards
 - Times of looking forward

That was my experience—the inward rush of a wave of realisation of Jerome’s death—a wave, which with immense force pushed consciousness of everything else aside.

And then the wave would recede, and for a time I’d be even more sharply conscious of my surroundings than usual—highly acute to the brilliance of a flower or the beauty of a toddler playing.

And then another rush of realisation.

Irregular but somehow rhythmic waves.

All this, of course, was mediated for me by repetitive talking, stories and explanations, often triggered by friends—a large part of the Wellington gay community. And the crew from the NALAG also played their part for me—it wasn’t their models and their theories that seemed important, however, it was their sensitive inquisitiveness.

Since then, talking to hundred—no thousands—of bereaved people, I’ve discussed these waves with people, and it seems to me possible to describe five rather different kinds of waves—some quite dramatic and quite horrible, others gentler and more benign.

And the whole process of moving from waves of drama and devastation and negativity. to gentler, more benign waves, is most effectively mediated by sensitively inquisitive visitors. Visitors asking about what happened, reminding the bereaved of different aspects of the person who has died, and so on.

This list of kinds of waves doesn’t actually do much for the person who is bereaved. The waves will happen to them anyway—or perhaps in some cases will not happen—I’m not proposing any kind of universal law. But this idea of waves is, I suggest, nearer to the actual felt experience of many people who have been bereaved than most of the theories—closer to the felt experience than the psychodynamic explanations for grief, or the road-maps of the typical course of grief, or any list of the tasks of grief. These all have their professional uses, but there are no grand narratives that explain everything. They are not universal explanations, and they are, I think, not so useful to the person who has been bereaved.

I want to propose that from the perspective of the bereaved the most important psychological theorist of grief is William Shakespeare. I’m thinking of a couple of lines from *Macbeth*.

*Give sorrow words. The grief that does not speak
Whispers the o'erfraught heart, and bids it break.*

Shakespeare, it seems to me, is saying that when grief cannot speak, when the stories are not told, then, instead, grief whispers, insidiously, and has the potential to do great damage.

It is when sorrow is not given words that guilt and blame and anger get out of control.

I suppose that we should not be surprised that the pre-eminent figure of words and stories should understand how important words and stories are in dealing with grief. But still, it is gratifyingly transgressive to understand Shakespeare as a Vygotskyian before Lev Vygotsky and a narrativist before Michael White and David Epston.

But the curious thing is that it is not only “high” culture, not only Shakespeare, who is aware of the power of words and stories in addressing grief. Popular culture also encourages putting words and stories around grief.

What happens when someone dies?

We know in our bones—well many of us know—how to behave when someone dies. We telephone. We visit. We talk. And we ask questions, more or less sensitively.

We ask “What happened?”

And we know to bring to the fore some memory, however slight: “What I remember is how he always liked those peppermints” or “how he mowed the lawn so meticulously” or “how she was always playing that ghastly Country and Western music.” And this encourages other memories to come to the fore. We provide an active audience.

When someone dies, friends and relations arrive, and the events around the death are told again and again. There are lots of cuppas, and there’s lots of talk about the person who has died. It’s a process, perhaps, over time, of saying goodbye. There is an irreducible loss to be assimilated.

But often just as importantly, it is a process of saying hello again. It is a process of taking in the change and making sense of it, a process of

repositioning the person who has died and creating a new and different kind of relationship with them.

Funerals are a part of this. And in fact there is a lot of this telling and retelling in funerals. And perhaps because of the Maori influences, New Zealand funerals are particularly rich in the telling and retelling of the stories—richer, perhaps than Australian, American or British funerals. But it is not just the funeral, or that nameless universal after-funeral social function where the stories are told. The stories infuse all the visiting and the telephone calls.

Grief counsellors should learn, more than from anyone else, from the friends and relations who visit the bereaved.

Words and stories are our most important psychological tools, and there is a wisdom in our culture which encourages their use, their expansion. Old stories about the person who has died are told countless times again, but they are told now from a different perspective than they were told when they were alive. The stories have a different meaning than they had before the death, and they are told in different ways. In the telling and retelling of the stories we adjust slowly to the change that has occurred, we adjust, more or less and over a period of time, to the death.

So our culture has embedded in it many of the techniques of narrative therapy.

Of course there are other contrary streams of culture—discourses of denial of death, discourses of moving on as quickly as possible. Cultures are not homogenous or consistent, but contradictory. But nevertheless there are in our culture many mechanisms of narrative therapy.

But of course that is mostly about franchised grief—about licensed, permitted, authorised grief. We come to the difficulties when grief, for one reason or another, is not permitted, when it is unauthorised or disenfranchised. And the difficulties arise, of course, because when grief is not permitted, we are not permitted, either, to give it words or stories. When grief cannot speak, instead it whispers insidiously to the over-fraught heart, and bids it break.

So the question of disenfranchised grief reduces itself to the question of grief that cannot be talked about, and how to licence the talking.

One of the things main things that gets in the way of grief finding a voice, one of the main silencers of grief, is any major gap in the story, when we don't know the sequence of events—when we don't know what caused the accident, when we don't know what led to the murder.

When we do not know we are tempted to remain silent, so the story remains incomplete and unsatisfactory. However it is often possible to fill in the gap by piecing clues together, and by speculation. And speculation is healthy in making sense of things.

The difficulty of gaps is particularly relevant with suicide, because there are secrets the person who has suicided usually takes with them to the grave. Some of that is dealt with by looking for clues and by speculation. But there is one other thing that can help fill in the gaps in suicide bereavement—looking at the stories of other people who have nearly suicided, to see what elements of their stories might fit.

I'm someone who reads a great deal, and when Jerome died I read a huge amount about suicide. In fact I was not able for some months to concentrate on any reading except about suicide. I have on my shelves 27 books about suicide that I bought and read at that time, and there were others that I borrowed. Basically I was seeking other people's stories—the stories of people who had tried suicide and failed, and the stories of others who have survived the death of someone close to them through suicide. I was wanting to find elements of other people's stories which might, with the appropriate adjustments, fit Jerome and me.

The most useful of those books to me was *Waking Up Alive* by Richard Heckler, in which he tells the stories of a number of people he interviewed who were very nearly successful at suicide. He shows a pattern that, in the days before their attempt, they fitted into.

The pattern described by Richard Heckler involves the experience of a painful loss, with the person as a result starting to withdraw somewhat from the people around them. They put up a kind of façade in the face of the world, and then start to go into a special kind of suicidal trance, in which they might appear normal and carry out the usual interactions of their life. But at an emotional level they increasingly lose connection with the world around them. Ultimately they descend into a state in which suicide is seen as the only way out, and they become blind to any alternative. Heckler uses the metaphor of a suicidal tunnel.

That metaphor of a tunnel, into which someone moving toward suicide descends, was important to me—a tunnel which excludes all connection with the outside world, and in which at the other end, is a beguiling light—the prospect of an end to the pain. That seemed to explain Jerome’s behaviour. And I’ve found since then, talking to those bereaved by suicide, that the metaphor of the suicidal tunnel helps many people to reconstruct what happened in the last days of the life of the person who has been lost.

Suicide, of course, is only one of the kinds of grief that is disenfranchised. I’ve made a provisional list of the griefs that it is often not sufficiently permitted to talk about. It’s obviously a list that would be different in different historical periods and in different cultural settings.

Disenfranchised non-death griefs

1. Identity alteration
 - a. Loss of lifestyle
 - b. Loss of youth
 - c. Loss of independence
 - d. Loss of health
 - e. Loss of employment
 - f. Loss of status
 - g. Loss of family
 - h. Loss of home or homeland
 - i. Loss of anticipated future

(Does this include everyone who consults us?)

2. Loss of other by
 - a. Separation
 - b. Termination of professional relationship
 - c. Illness
 - d. Psychosis
 - e. Coma
 - f. Dementia
 - g. Abuse

Disenfranchised bereavement

1. Secret or “illegitimate” relationship with deceased
 - a. Extramarital relationship
 - b. Gay relationship

2. Culturally under-recognised relationship with deceased
 - a. Abortion
 - b. Still-birth
 - c. Therapist
 - d. Client
 - e. Non-related friend
 - f. Non-married partner
 - g. Same-sex partner
 - h. Pet

3. Ambivalent relationship with deceased
 - a. Abuser
 - b. Alcoholic
 - c. Gambler
 - d. Separated partner
 - e. Unfinished business

4. Taboo death
 - a. Murder
 - b. Suicide
 - c. Abortion
 - d. Aids

5. Traumatic death
 - a. Murder
 - b. Suicide
 - c. Premature death
 - i. Young death
 - ii. Accidental death

6. Postponed death, after
 - a. Psychosis
 - b. Coma
 - c. Dementia

7. Guilty grief
 - a. Abused deceased
 - a. Suicide
 - b. Accident
 - c. Abortion

Often it is possible to push aside the silencers, which get in the way of these various grief situations, simply by acknowledging their existence,

and gently encouraging the talk, simply flouting the different cultural mechanisms that seek to suppress talk. It might not be easy to get the talk going, but it is usually possible, at least in a confidential counselling situation.

Among the characteristics of these kinds of disenfranchised grief are high levels of guilt and blame and anger, and it is necessary to address these feelings directly. It is important to talk about these feelings; I often explicitly license these feelings at a funeral, saying how normal they are in the situation. Guilt and blame and anger are often inevitable, and sometimes even entirely appropriate. Sometimes there is something in the situation that *demand*s guilt or blame or anger.

But actually, guilt and blame and anger are often somewhat misplaced, and so usually it is not so great if extremes of guilt and blame and anger are retained for long. Sometimes it is helpful to unravel the background of the guilt and blame and anger. Sometimes it is helpful to find the details that dispel or reduce the guilt and blame and anger. Sometimes these feelings are the result of gaps in the story—missing facts, which when they are acknowledged reduce the guilt and blame and anger.

The truth is, accidents happen, and nobody is to blame, or nobody is to blame all that much. The truth is none of us is perfect, and sometimes a small slip has disproportionate consequences.

When there is a suicide, the truth is usually that we did everything we could. The truth is everyone else usually did everything they could, too. The truth is that the suicide was the choice of the person who died. Perhaps they have some anger coming to them. But the truth is that they were in enormous pain—so too much anger, for too long, might not be right.

It can be enormously helpful to explore the stories around those truths

Anything which helps give the sequence more context, more reality, leaves less room for too much guilt and blame and anger. Anything that fills out the story helps a movement to gradually more gentle waves of grief.

And that's what most people want.

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