

# Sadness and Chronic Illness: A Conversation with Bruce Perham

Lisa Massingham

Bruce Perham is a social worker and narrative therapist who works at Alzheimers Australia Vic., the peak body representing the interests of people affected by dementia. He previously worked at an adoption agency, the Spastic Society (now Scope), and the Multiple Sclerosis Society. Bruce trained in family therapy in Melbourne and in narrative therapy with Michael White at the Dulwich Centre. Bruce has created an extensive range of written and video resources for people with dementia and MS and their family members. He describes how his family of origin, his resultant personal struggles as an adult, and narrative therapy, have profoundly influenced his work with people with chronic illness and their families, in particular, his approach to sadness.

**Lisa:** Tell me a bit about yourself. How did you start in this field?

**Bruce:** I grew up with my parents and an older sister in Melbourne. My twin sister Leanne died of leukaemia when I was two and a half years old so Leanne was never really in my life, but the impact of her death on myself and my family is important as an influence in both my life and my work.

I've always known that I wanted to work with people, as far back as I can remember. I did an Arts degree and then completed Social Work. My first job with Copeland St Family Services Adoption Agency was as a 23-year-old, working with middle-aged adults desperate for kids. I worked there for about three years and then moved to the Spastic Society, which turned out to be the most amazing work experience. It was overwhelmingly demanding and tragic.

It was during this time, at the age of 26, that things started to fall apart for me personally. I interviewed a mother with a very disabled child, who screamed at me: 'How can you help me?' I knew instantly that in some ways this interview had upset me like no other. It triggered emotional processes in me that, as it turned out, took a long time to come to terms with. Initially I thought

that maybe I was overstressed. I tried some different things, changed jobs, but I just didn't feel right; I didn't feel 'me'. Although I knew that I needed help, I became almost totally dysfunctional before I went to a doctor to obtain some pills to calm me down. The doctor suggested that I needed to talk this through and referred me to a psychiatrist, which I took very badly. I wasn't aware of it at the time, but everything that had happened to me as a child was all there just waiting to be unleashed.

I had always realised the importance of Leanne's death at an emotional level but I had underestimated the full impact of these earlier experiences. If you asked me about what it was like growing up in the aftermath of Leanne's death, I could have told you that it was terrible but I did not connect it with what was happening to me as an adult. I still marvel at how out of touch we can be.

My memory of initially seeing the psychiatrist is just chatting and not really feeling any better for it. Then, one session, he said: 'Tell me about something that's been painful'. I found myself talking about a relationship with a girlfriend that had recently ended. I knew that had hurt me. I was driving home from the session when I suddenly began crying. I could not stop. Julie (my partner then and wife now) drove the rest of the way home. I was an absolute mess and that was really the start. Once he had asked that question, there was no turning back and it took about two years from there living with terrible depression.



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**Lisa:** Sitting in the counsellor's spot, was his question a 'safe' question?

**Bruce:** I would have to say it needed to be asked. I remember a wonderful moment where Michael White talked about 'points of entry' into conversations and how, if you take them, they can open up exploration of emotional experiences. That question was a point of entry but there were some risks attached and clearly the therapist had to be there to assist me to deal with those risks. I don't think the psychiatrist fully anticipated the effect that question was going to have. It was really from then on that I began to explore the impact of Leanne's death on myself and my family. There were to be many more moments of crying for long periods but as time went by, I became more aware of what I was crying for. I would never have understood how a person I never knew could be so much a core of my whole childhood and so influential in everything that happened in my life. That really was the catalyst for my work — searching for the sadness that so often never saw the light of day. After some time, things started to slowly improve. After four or five years, I started to feel that I had survived and that I would not fall back into depression.

**Lisa:** And you believe that you wouldn't have had to go through this experience as an adult, if you had been given an opportunity to talk about sadness as a child?

**Bruce:** I have absolutely no doubt about that. I have no memory of anybody talking to me about the loss of Leanne as a loss for *me*. I knew that she died of leukaemia. I knew how hard it was for my parents, but it was never acknowledged in terms of the impact on me. One of the things that came out in therapy was the shared birthdays. And that I had actually thought a lot about her, she was very present for me as a child, although I had no direct memories of Leanne. I grew up trying to be the mediator, trying to make my mother happy, to compensate for the loss of Leanne and to absorb my mother's depression, which is what I did really. My parents had no counselling or any help.

**Lisa:** So, your parents did not have an opportunity to talk about their sadness? And no one acknowledged the impact of Leanne's death on you or the impact of your mother's sadness about her loss on you?

**Bruce:** From a narrative point of view, there was no creativeness in her loss and there was none of the 'keeping Leanne alive' in a positive way. When I was a kid, there would have been a thousand points of entry to talk about Leanne's death, and if anyone had taken those opportunities I wouldn't have gone into adult life so separated from my experiences as a child. In my work with the MS Society I was reminded constantly that children were often not included or engaged in the 'hard stuff'. Narrative therapy does pick up the 'hard stuff', and children can be included in it. For me, the work that I chose at that time forced me to make the connections with my own family experience.

**Lisa:** So how did you get to narrative therapy?

**Bruce:** I was seeing families at the MS Society but didn't feel comfortable that I knew what I was doing, so I did a family therapy course in 1989–1990. I always had a strong commitment to working with families. I was very aware at that point that I wanted to focus on family discussion about the impact of the disease and for parents to have a better understanding of how MS was hurting their kids. Michael White came to Melbourne for two days as part of the course and what I heard was very connected to the work I was doing, and I knew that this was the type of conversation that I would like to be having.

**Lisa:** Can you remember what struck you about narrative?

**Bruce:** Just the humanness of it and the interest in the person's story and in the person's view of his or her own story. I feel very passionately about some parts of narrative therapy; however, I don't necessarily use all of it. I found the view about the role of the therapist very significant, especially the idea that the therapist does not have to 'fix it'. The therapist does not have to work towards an end point and does not have to be the expert.

In 1994, I attended a week on Narrative Therapy in Dulwich, which was an emotional week for me. In my eyes, Michael White has an unwavering belief that our personal experiences impact and influence our work and that they have the potential to enrich the experiences we can have in our contact with people. It was during that week that I came to realise that maybe my childhood experiences of Leanne's death and subsequent depression would inform my work, and that I no longer needed to feel ashamed of my experience.

**Lisa:** Can you tell more about Michael White's view on the connecting of personal experiences to people's work?

**Bruce:** The connection between our own life and the lives of the people that we sit with is two-way, and we learn from each other. I think that this, for me, is the essence of narrative therapy, the flow between counsellor and the people who ask to see us. The view is that you will be better and richer for hearing the story, no matter how terrible and sad it is. I come to terms with my own experiences, but I don't have to defend myself against the impact of other people's lives on me, because my response is, 'Isn't this interesting, and this is important for me to know and to feel for'.

**Lisa:** And how does it connect to working with families?

**Bruce:** For me, my family relationships have been the most powerful in my life and have been most influential, for good or for bad. The other aspect is the recognition of the value of the story. I mean that there is nothing more precious to us than our life story and experiences. We rarely have a chance to talk about them.

I think that narrative therapy values talking about life more highly than other disciplines. A therapeutic conversation doesn't have to be about a problem, but an opportunity to talk about things that aren't otherwise talked about. Michael White talks about 'hidden experiences' and 'hidden knowledges'. More traditional therapies go towards a cure, or go towards feeling better or go towards 'solving the problem'. Narrative therapy, in a different way, has a similar aim but it emphasises 'Enjoy the ride,

let's not race, let's not be over-focused, and let's not stipulate where we have to be'. I have a quote from Michael White:

If we have no truth, no predestined ending to conversation, there are many possibilities to speak about things that we have never spoken about and to journey to places that we could never have predicted journeying to (White, 2000: 99).

One of the things that narrative therapy does well is the open question. For example, 'What was that time in your life like?' is very different from 'Was that a difficult experience?' which reduces the possible answers.

**Lisa:** So how does this connect to your work on sadness?

**Bruce:** People who take the path of counselling will generally be provided with an avenue to share their sadness. For people who, for whatever reason, may not have access to counselling, it will be far more spasmodic or coincidental that they will have an opportunity to share their sadness. Yet life goes on and sadness has a role in it. It does not go away. Talking does not necessarily provide resolution, but it might open doors for further reflection about life experience.

I recognised I had an opportunity to have these conversations with families that were never going to access counselling. My conviction that these conversations were worth having sprang more from my pain of not having had them myself rather than from theory. I don't see sadness as a problem. I see it as an integral part of life experience. However, my own experience has taught me that if suppressed or ignored, it can have a lethal impact on everything we do and feel. The many conversations this idea has led me into have further strengthened my belief that, as hard as it is, we can unlock the door on sadness outside of a therapy context.

I start from 'You've probably not talked about this to anyone', and 'I'm really interested to know how this has impacted on you'. Often people have just not had the chance to have this conversation. It can be a very slow process so I do not work within a time-frame. For me, 'too long' is better than 'not long enough'. A lot of professional people struggle with that, and when they are watching a tape interview, they can't wait for the 'killer' part. There are no great questions, no moments of 'therapeutic magic', just a rambling discussion about life. But if you watch the tape carefully, there is a sort of 'moving into' talking about things, which I don't do consciously.

I see magical moments everywhere. For example, in one interview, I asked the partner of

a man who has dementia, 'Is there any time that your husband has awareness of his dementia and what it is doing to him?' and she responded that 'There was a moment when he said "My brain is going numb, I'm going" and the next day he couldn't remember that he said it'. She became very tearful and we just talked a little bit about that, without homing in on it. I did shed a tear at this (which this lady noticed). I was so saddened by the reality that this was probably the last moment of connectedness the two of them would share.

Now, what is the therapy in that? That she shared that with me and I heard it and she probably hasn't told anyone else? The therapy is allowing that opportunity to reflect over those moments. Those moments are terribly sad but they are cherished moments in the context of what is happening in a chronic illness.

With progressive illness, the individual is moving from one level of existence to another. For the family watching, this is generally an experience full of pain. Talking about it assists in the coming to terms with the reality of the transition. Often people with chronic health issues do not see the need to come to counselling as their illness cannot be 'fixed', so how is counselling going to help? I have learnt the magic opportunities that a conference paper or a funded project can provide. It puts me in a position to contact people and say 'I am gathering information on families who have this issue, I would be really interested to come and talk to your family because I know that you have been through it'. It does not imply there is a need for counselling but rather that I sense the family have a 'story to tell'. These interviews are always unstructured and conversational in style. The explicit aim is the creation of an educational resource; however, a powerful by-product of this is that provision to the family of the opportunity to talk and to have a lasting record of it. It is hard to explain why this is such a powerful experience for families but I expect it revolves around going public and opening up the life experience for all to see.

For example, I did an interview with a family in which the woman died recently from MS. The partner rang me and said 'Of all the things I have of Rebecca's mum, nothing will tell her more about her mother than that video'. I think that this is what it is all really about.

I have noticed that the more I have become involved in working with people in this way, the less interested I am in the theoretical aspect. The aim is to describe these experiences and the discussions I have, and to show that people can cope

with talking about sadness and that people all over the world deal with sadness and we don't need to be afraid of it. Our own sadness is unique to ourselves but related to everyone else's.

There were many moments when I sat with teenagers around the fire talking about their mum or dad with MS. I saw their sadness. In many ways these children told me no one really wanted to know their sadness and I knew what this was like. Other professionals have expressed concern about the lack of follow-up after these conversations about experiences of trauma, but it hasn't always been possible to provide extensive follow-up. I also have hope that these many children that sat around the campfire with us will always remember the day they touched sadness. The big thing here is that when they touched it they were not alone.

**Lisa:** Are people concerned about the conversations being emotionally 'safe', given that there may not always be a full follow-up?

**Bruce:** I don't minimise that concern and in my own experience, the psychiatrist did need to be there for me. On the other side, the feedback from families has not confirmed the concern. Over the past ten years, there have been some negative reactions by professionals to 'how far you allow people to go'. I always contact people a day or two later and generally people describe the discussion as being most beneficial, even if they had cried all the way through it. If you see sadness as causing harm, then you will think that you better not discuss it.

Maybe in therapy there is some understanding of the enormity of the impact of chronic illness, death and loss on our lives, but I don't think that there is a high level of understanding of this in the general public. Nothing does more damage to a person than emotional pain and yet we often focus totally on the body and practical issues. If you actually talk to people about the emotional experience, the common theme is: 'People don't understand what is happening to me', so that is what I prioritise in my work.

**Lisa:** Do you believe that you need to have gone through your experiences to be able to have these conversations?

**Bruce:** I think it would be hard to be sensitive to these issues unless you have had some experience of grief. You don't need to have direct experience of living with someone with dementia, but some experience of grief. I don't look too far ahead. So I don't have any map, I am not going through any specific 'stages'.

I will never forget a therapeutic moment when I sat with that psychiatrist years ago. I had read about endogenous depression and reactive depression. This article told me reactive depression was curable and endogenous was not. When I asked him did I have endogenous or reactive depression I knew my life hung on his words. I knew I could not live the rest of my life in this state. When he said 'reactive', I felt this surge of hope. It has never left me. I will also never forget how different things could have been if he said 'endogenous'. I guess my belief in talking has held steady from that moment on.

**Lisa:** Can you tell me more about the use of self from the narrative therapy perspective?

**Bruce:** It is almost a mutual understanding, it is the depth and the immediacy of understanding that is conveyed without words and you are much more involved at the emotional level. And sadness in other people's stories does hurt me; I feel it, it hurts by definition. Somehow you have to be able to put it in a life perspective and recognise that it is precious. For my own experience tells me until the sadness is 'tracked', all those other life fulfilling feelings will struggle to really have the influence they are capable of having. Sadness does not exist in isolation and from sadness springs so many things. For me the connection between my passion and sadness was rich in creativity.

**Lisa:** Do you find that the audiotaping and videotaping is another dimension to the therapeutic process? And why is it so powerful?

**Bruce:** The taped interviews with families *are* very powerful. The primary audience is the family and the taping must be valuable to them. If it was useful for them, then it is probably helpful to others and also possibly helpful for other professionals to watch. So it can meet the needs for different audiences. And it is powerful because it is a long-term record of the conversation and it captures a moment of the chronic illness. It is a record of that person and what that experience felt like at that time.

It is an untapped source of knowledge and it provides an opportunity for people to reflect on what they have said, as we don't always remember. It is also a record that can be shared with other people in a way that they may be unable to tell them. For example, 'I can't tell my mum what it is like, but I can show her the video of what I talked about'. It has the capacity to provide insights into the situation that may have previously been

missed. It is a record that can travel in time long after the life is over.

There seems to be enormous resistance to this approach and the only sense I can make of the resistance is that generally people are reluctant to have such conversations because of the possibility that they will be emotional. This work is just sad; this is what it is about and this is what people live with. In my experience, people generally say that no one understands them and they feel misunderstood and isolated. If you have no exposure to ways of talking about sadness, then what are you going to do? How are you going to respond to people who feel that way?

During my depression, I can't really think of anyone who said anything that was remotely consoling. My partner, Julie, really was the only person who had any understanding of the experience. In the past, as a counsellor, I have always had a voice telling me to: 'Keep it moving'. Now I say: 'Why not stay there?' Why must it be kept moving? Why must it be seen as something else other than the conversation that it is? So if we stay there talking about it, what is the problem with that? Yet I think a lot of people have a problem with this approach.

**Lisa:** Can you tell me a bit more about your experience of sadness and how it connected with Michael White's approach to grief?

**Bruce:** Michael's article 'Saying Hello Again' was very influential on my thinking in a vast number of ways. In some ways this article allowed me to come to terms with this whole issue of 'Did Leanne exist or not?' One of Michael White's most significant articles, to me, is about the 'incorporation of lost grief'. He found that sometimes people wanted to hang on and not to let go, and so he had conversations about how to keep the person alive. There was something enriching about bringing Leanne back, as sad as it all was. In a funny sort of way, it has brought her alive. Leanne, who I am never going to remember and do not know, yet has had such an influence on my life, was now more tangible as a sister than a ghost alongside my childhood.

**Lisa:** Thank you for talking with such openness about the connections between your own experiences of sadness and the work that you are doing with people living with chronic illness. And finally, for so clearly articulating how narrative therapy has profoundly influenced your work and your understanding of your own life experiences.

Lisa Massingham

### Resources


*MS: Sharing the Family Experience*, 1994 (can be borrowed from Bruce Perham).

Videos available through the MS Library in Blackburn, Melbourne.

*Living with Memory Loss* [Video], available through the Alzheimer's Australia Vic., Hawthorn, Melbourne.

### References

White, M., 2000. *Reflections on Narrative Practice, Direction and Discovery*, Adelaide, Dulwich.

White, M., 1989. Saying Hullo Again: The Incorporation of the Lost Relationship in the Resolution of Grief. In his *Michael White: Selected Papers*, Adelaide, Dulwich. 

## Good Intentions

The wild cat in the wood-heap  
fought with fierce claws  
as we tried to save the kittens  
from a life like hers.

Another time in a huge storm  
we gave her shelter on the closed verandah.  
In the morning  
broken louvres edged with blood.



**Helen Pavlin**  
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