Bereavement: helping a patient with a learning disability to cope

This case study focuses on 55-year-old Dave Croft, who has a moderate learning disability and has been diagnosed as having bipolar disorder (this is currently in remission). In 1996, after the closure of the old-style residential institution that had been his home for nearly 30 years, he moved to an eight-bed NHS unit for people with learning disabilities/mental health needs and/or challenging behaviour.

While he was on home leave for Christmas six years ago his father died suddenly. His mother organised the funeral ceremony and it was carried out without his knowledge – presumably in the belief that it would be too upsetting for him to attend.

Over the next five years Mr Croft became increasingly agitated at the mention of death. He would occasionally become tearful and inform staff that he was upset because his dad had died. Things reached crisis point in November 2001 when he became inconsolable at any mention of death, whether it was on television or in general conversation.

While staff were sympathetic many became anxious that he was still experiencing difficulty in working through the stages of grieving and was unable to move out of the denial phase as described by Mordia and Chung (1995).

Developing a life event book

Work began on a life event book (Hussain, 1997) for Mr Croft, which we hoped would help him to develop a sense of identity and encourage him to talk about his feelings in a safe environment. He played an important role in developing the book. It took many weeks but gradually began to take on a recognisable format. We started by collecting as many photographs of his family and friends as possible and he then described who they were and how important they were to him.

We ended up with a pictorial history of his life, with brief subtext that enables staff who do not know him to give small verbal prompts. The subtext also means that the book can be used in the future by new staff or friends. We hoped that if Mr Croft could look back at photographs of his father we could encourage him to remember good times and subsequently lessen the pain of his loss.

The book was compiled over several months but when it was finished he still felt unable to use it and became tearful if the subject was mentioned. After discussing the situation in a weekly multidisciplinary team meeting, on the recommendation of the unit’s psychologist, we decided to change the way the life event book was used. We began to record recent events in Mr Croft’s life, such as trips to the theatre or home visits, with the aim of showing him that life moves on and the book, like his life, did not stop when his father died.

We also decided to refer him to a professional bereavement counsellor who had experience working with people who have learning disabilities. It seemed to us that Mr Croft met the criteria for receiving such a service, as described by Elliott (1995) – he was profoundly missing his deceased father and the attachment prior to death had been strong.

Bereavement counselling

Michael Thomas became Mr Croft’s counsellor and after several introductory sessions things settled down to a weekly meeting. It was necessary to determine the extent of his knowledge and understanding of death, and what death education (Hollins, 1995) – if any – had been given. There was no record of any previous work having been done with him on this subject. Mr Thomas had used the life event book as a starting point and asked Mr Croft to name the important people in his life. A lot of the other people who featured in the book had died, and this enabled us to introduce the topic of death without discussing his father.

He then moved on to use a counselling picture book, as advocated by Hollins (1995), which is usually used to help explain death to children. Mr Thomas had used this resource successfully in the past with people with learning disabilities, and while we were all mindful that Mr Croft is not a child, the book was considered to be at the right developmental level for him. At the time this was the only suitable resource available for this purpose, although a number of books and learning tools are now available which address bereavement and unexpected loss specifically in people with a learning disability (Blackman, 1999; Hollins and Sireling, 1999; Read, 1999).

In working with Mr Croft we focused on two pictures from the book: one of a woman in hospital on a heart monitor and the second showing the same woman shortly after she had died. The pictures were illustrations rather than photographs because he was still finding it...
If there is a social gathering after the funeral and Mr Croft is invited, then his choice regarding whether to attend will be respected.

A follow-up visit will be arranged, either to the grave when the headstone is in place, or to the garden of remembrance as appropriate.

Not attending the service

If Mr Croft does not attend the funeral service, nursing staff will make every effort to help and support him through this initial period of bereavement, and ensure that he understands the implications of not attending.

The chaplain will visit and explain what happens next. This will be within one week of the relative’s death, but preferably within one or two days.

A para-funeral will take place as close to the day of the actual funeral as possible, and he will be given the option of whether or not he attends this. A para-funeral is a simple service, using abstracts from the actual funeral service, and is organised for people who are unable to attend the service itself. It can be tailored to suit an individual’s needs, and can be held at, or around, the time of the funeral itself, in a setting most appropriate to the person concerned.

After the para-funeral service has taken place, a follow-up visit will be arranged, either to the graveside to view the headstone once it is in place or to the garden of remembrance.

Conclusion

The articles cited in this case study (Elliott, 1995; Hollins, 1995; Moddia and Chung 1995) are reactive in their approach to bereavement. However, while the exact time and circumstances are unknowable, the death of a loved one is an entirely predictable event.

In providing services for people with learning disabilities we use proactive care plan approaches towards issues such as violence and aggression in an attempt to minimise the negative effects on people’s lives. Perhaps it is now time to take a more proactive approach towards planning for bereavement with our clients. Even if this only involves establishing the extent of individual clients’ knowledge and understanding of death, and how this might be increased, it would be a useful exercise.

While it is generally acknowledged that no one has the right to prevent a person with a learning disability from attending a funeral, in practice they are often not given the opportunity to do so. As in Mr Croft’s case, family members may simply not tell the person concerned when the funeral is to be held – or even that the death has occurred. We hope the arrangements discussed in this article, or something similar, will help our clients come to terms with the loss of a family member, should this arise.

The real test of whether our work with Mr Croft has been successful is whether we have brought about a change in his behaviour. We believe that we have. He is now able to go into a church, say a prayer for his father and light a candle in his memory. That was simply not possible before his counselling.

All names have been changed.

KEYWORDS Learning disability, Bipolar disorder, Bereavement counselling

REFERENCES


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