

supporting individuals with intellectual disability through grief, loss and bereavement...

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Note: This article is a two part series. Part one, focuses on the literature and adult case study whilst part two will focus on a child case study. Part two of this article will be presented in an upcoming edition of the newsletter.

The area of grief and bereavement experienced by people with intellectual disability has historically received little attention, but is now gaining more momentum, thanks to a small group of researchers (Hulbert-Williams & Hastings 2008). People with intellectual disabilities are now living much longer (Paja et al; 2000 cited Dodd et al 2005) and as a result, are experiencing and enjoying many more varied relationships both within their families and in the community at large (Dodd et al, 2005). The place of care has changed from living in large institutions to care out in the community (Bennett 2003).

Almost two-thirds of people with intellectual disability live at home with parents, relatives or foster carers often for many years. This results in the level of care, the degrees of attachment and dependence between a child or adult with an intellectual disability and his/her caregiver becoming very strong. When these close bonds are broken, by the death of the parent/caregiver there can be serious repercussions for the mental health of that individual (Dodd et al 2005). Following a bereavement, if grief is not recognised or expressed by an individual with an intellectual disability complex reactions may occur which prolong the grieving process and are likely to manifest as challenging behaviours (Emerson 1977 cited MacHale & Carey 2002). The research suggest that such grief needs acceptance and normalisation among people with intellectual disabilities.

Participation in mourning rituals helps to convey the finality of death and also helps to facilitate adaptation to loss and the resolution of grief (Read 1999 cited Dodd et. al 2005). Research has shown that exclusion from mourning rituals in an attempt to protect an individual with intellectual disability from possible emotional discomfort places the individual at a

higher risk of developing significant subsequent emotional discomfort and distress (MacHale & Carey 2002, cited Dodd et al 2005).

Yet, often the preparation which a child or adult with an intellectual disability receives about the impending death of a loved one is very minimal. Information about the caregiver's illness, particularly if terminal, is frequently withheld. Time or privacy to grieve is denied and the individual may further excluded from the funeral and other rituals. Raji et. al (2003).

Exclusion from cultural rituals associated with death may result from the caregiver's lack of knowledge and understanding of the bereavement and grief processes experienced by people with intellectual disabilities. Murray et Al, 2000, cited Dodd et. al 2005). Caregivers often hold inaccurate beliefs or lack understanding of the ability of people with an intellectual disability to grieve. Carergivers often believe that people with an intellectual disability have little or no awareness of death or the grieving process therefore feel that it is much better to distract them from the grief until the deceased is forgotten about (Deutsch 1985, cited Dodd et. al 2005). The end result of this can be that the grief expressed by an individual with an intellectual disability will be misunderstood and inappropriately handled either with medication or some kind of behavioural intervention (Hollins & Esterhuyzen 1997, cited Bennett 2003).

A study by Emerson (1977) which explored the incidence of bereavement and the onset of marked behaviour and mood change in adults with intellectual disability (ID) found that caregivers had minimised the significance of the death or had misunderstood the reactions to it. Despite observing a wide range of responses to bereavement when asked, typically commented that there was 'no response to the death' by the person with intellectual disability. Research points to the contrary that understanding the concept of death **is not** a prerequisite for experiencing the emotions associated with grieving (Dodd et al 2005). Absence of the person who has died is the tangible manifestation of his/her death and a person with an intellectual disability will recognise and feel the absence of someone they love. They will grieve for this loss with or without nec-

essarily having the comprehension of the abstract nature of death (Dodd et al 2005).

It is a well known fact that people with intellectual disability are particularly vulnerable to psychiatric illness. Day (1985) specifically examined over 200 new admissions to a psychiatric unit for people with intellectual disability. He found a high incidence of 'reactive depression' and 'anxiety state' in this group with 50% of these breakdowns clearly precipitated by the death or serious illness of a family carer (Dodd et al 2005). Day suggested that the onset of these psychiatric disorders might be viewed as '**bereavement reactions**' A more recent study by Stoddart and colleagues (2002) evaluated the effect of bereavement on a group of 21 individuals with intellectual disability. Scores for depression and scores for anxiety were found to be significantly elevated following the bereavement.

Education programs for people with intellectual disability tend to be around preparation for life in the community with a strong focus on community access activities. There is very little focus on addressing the emotional needs and issues which are common to the wider population (Bennett 2003). Yet studies over the last 15 years have recognised the need for both preparation and support for people with ID who have been bereaved including the right to be told the truth and to grieve (Bennett (2003). Although preparation for loss and change is not an easy topic to discuss, it is one that can lead to increased emotional growth, self awareness and empowerment for the individual concerned. Death is a universal experience that we all must face at some point in our lives (Leick 1991 cited Bennett 2003).

What also needs to be appreciated and understood by those who work and live with people who have an intellectual disability is that when they lose a parent or primary carer they are not just experiencing a single bereavement but often multiple losses. They not only lose their parent and confidant but their family home, possessions, bedroom, pets, familiar routines, neighbours and neighbourhood, day program, school, support services, contact with other family members and friends. When they lose their primary carer they essentially become homeless and maybe hurriedly moved into residential care usually into a group home. They will usually be placed into interim accommodation until a permanent home can be

found. Often they have more than one interim accommodation place and encounter a number of moves. This usually occurs with very little preparation and transition support and they awake to find themselves in completely unfamiliar surroundings with a myriad of new faces around them. One can only imagine how overwhelming this must be. Both interim and permanent placements may often be in a completely new and unfamiliar area,

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with familiar support networks lost. Such extensive losses MacHale & Carey (2002) state only serve to further complicate the bereavement process for individuals with intellectual disability. This is why Crick (1988) identified six areas of best practice to help support individuals with ID through bereavement.

1. Prepare the person for anticipation of loss and bereavement
2. Provide a full explanation of death and dying
3. Ensure there are communication techniques and supports in place to help the person to express their grief.
4. Have an empathetic confidant on hand that they can talk to or feel close to during this time.
5. Acknowledge and recognise the person's feelings and need to grieve
6. Reduce as much as possible the associated multiple losses

The following case study provides a very effective approach for supporting individuals with intellectual disability through grief, loss and bereavement.

Case Study: Vincenza

The following case study illustrates how one family supported their sister and sister-in-law Vincenza through bereavement following the death of her mother early this year.

Vincenza is a 56 year old lady of Italian background. Vincenza has a severe intel-

lectual disability and Turners syndrome. Vincenza has lived with her parents her whole life. Her father passed away more than 20 years ago and that was her first experience of losing a loved one close to her. Vincenza accompanied her mother to the cemetery after her father died for many years and this helped her to gain some understanding of death. Vincenza was cared for by her mother and they had a very close bond. When Vincenza's mother became very ill, the family anticipated that the loss of her mother would be very difficult for her and decided that Vincenza needed to know and to be well prepared that her mother was going to die.

Vincenza's mother started to prepare her by telling her that she was sick and that she was going to die and that Vincenza would go to live with her sister and her family. Vincenza saw her mother slowly deteriorate over the last 2 years and the family believe that she sensed the impending loss and was sub-consciously grieving. Vincenza also became very aware of the change in care arrangements when her mother was no longer able to provide that care to her and Vincenza's sister took over.

The family involved Vincenza in caring for her mother in the final weeks before she passed away. She spent a lot of time sitting next to her mother's bed, would bring her heat bags, rub her back and put her nebuliser away. This active participation in caring for her mother also helped Vincenza to understand that her mother was very ill.

Vincenza was present with her whole family at her mother's bedside when she passed away. At first she didn't quite realise that her mother had passed away. A person with a severe intellectual disability needs a lot more time to process information than the average person. When other family members started to arrive at the house and were crying, Vincenza then understood that her mother had passed away. Seeing the open display of other people's emotions was a much more concrete and visual way of letting Vincenza know that her mother had passed away than by just telling her in words.

The family involved Vincenza in their mourning rituals and customs from the very start of the bereavement. When the funeral directors came to the home to take her mother's body away Vincenza was encouraged by her sister to wave goodbye to her. Vincenza went outside to the back of the hearse and again

waved goodbye to her mother.

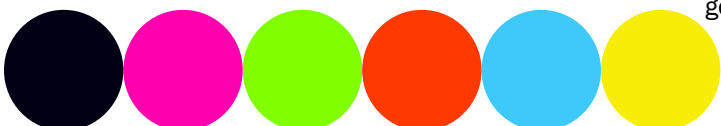
Vincenza accompanied her sister and family to the mortuary for the dressing of her mother's body. Initially it was expected that Vincenza would just sit and watch the process. However she came over and started to touch her mother's leg and her sister did not deter her from doing this. Viewing and touching the body, for someone who has an intellectual disability provides them with the strongest cues to understanding what it means when someone dies. They can see and feel that the person is no longer breathing, talking or moving but lying very still and once again this provides the most concrete experience of death.

In keeping with traditional Italian customs the coffin with her mother's body was kept in the family home for two days before the funeral. Vincenza had many opportunities to view and touch her mother's body. She was encouraged to wave good morning and good night each day.

On the day of the funeral, before the coffin was sealed Vincenza was given one final opportunity to view and touch her mother's body and to wave goodbye to her. At the church service Vincenza walked with her sister and led the coffin into the church and out of the church.

Vincenza was there with her family at the cemetery. Vincenza saw her mother's coffin being placed into the vault and was again encouraged by her family to wave goodbye. This again was a very important part of the process to see exactly where her mother was laid to rest. It is not essential for a person with intellectual disability to understand the more abstract meaning or belief around death for example that the person's soul goes to heaven, there is an afterlife or whatever belief an individual may hold about death. It is important for a person with intellectual disability to physically see where the person's body goes- whether the body is buried, cremated or encryped. This provides a further sense of finality and closure.

In the weeks following her mother's passing the family supported Vincenza in many ways to grieve the loss of her mother and to express her feelings. Her sister continues to take her to the cemetery each week, where Vincenza places flowers and looks and touches the photo of her mother on the vault. Before she leaves the cemetery both Vincenza and her sister wave goodbye to the photo of her mother.



At home Vincenza has been provided with many opportunities to remember her mother. There are special photos of her mother taken with other family members around the house that she can go and look at anytime she feels like. Her sister has kept some of her mother's clothes which Vincenza likes to wear sometimes. Vincenza has also been shown the power point presentation that was shown in the church on the day of her mother's funeral and this has further helped her to understand that her mother is no longer there.

Vincenza, unlike many other adults with intellectual disability was spared the experience of multiple bereavements and losses following the death of her mother. Her family were very mindful of keeping many other aspects of her life constant. Her sister and her family made the decision to move into the family home where Vincenza has been living her whole life. This decision was made so that Vincenza could remain in familiar surroundings and not have to adjust to a completely new environment. She has kept her own room with all her familiar possessions. She has continued to go to the same day program which she has been going to for the past 30 years. This has helped to keep Vincenza in the routine that she has been used to. She also has made many friends and has close ties with staff and other program participants and her family understood how important it was to Vincenza to maintain those connections. The day program also supportive in wanting to help Vincenza through her bereavement. Vincenza continued to attend the day program in the days before her mother's funeral and immediately after which reduced disrupting her usual routine. Maintaining a regular and predictable routine during time of great change is very important particularly for a person with severe intellectual disability as it gives them a continued sense of security and consistency that not everything in their life has changed.

I visited Vincenza at her home and spoke with her sister several weeks after her mother had passed away to see how she was coping with the loss of her mother. Vincenza appeared quite settled and pleased to see visitors coming to her home. She did not appear to show any obvious signs of unresolved grief, emotional discomfort, distress, depression, anger, anxiety or any other behaviours. Vincenza's acceptance of her mother's death can be attributed to how well her family supported her through the process by:-

- Preparing her for the anticipated loss of her mother when her mother first became sick.
- Giving her many opportunities to express and say goodbye to her mother after she had passed away. Each opportunity would have given Vincenza a sense of finality and closure.
- Involving her in all the mourning rituals and in the funeral service from the start.
- Giving Vincenza several opportunities to see and to physically touch her mother's body to help her understand that her mother had died.
- Letting her see where her mother was physically laid to rest.
- Taking her regularly to the cemetery to place flowers and to touch and wave goodbye to her mother's photo.
- Letting her remain in her family home in which she had lived with her mother all her life and to receive continued care from her sister and her family in surroundings which were the most familiar to her.
- Having her sister and other family members as her confidants that she felt close to during that time.
- Being able to see photos of her mother around the house and having access to special mementoes of her mother.
- Maintaining her regular routine and her connections with staff and participants in the day program which she has been attending for many years.

Vincenza's family has clearly shown that her level of intellectual disability in no way determined their decisions as to how much she should be told about her mother's death or how involved she should be in the mourning rituals. Her family afforded her the same dignity and respect to mourn the loss of her mother and to grieve as they afforded to themselves. Her inclusion in every aspect of the bereavement process is what has clearly helped her to accept her mother's passing and to move forward without there being any adverse effects on her mental health and wellbeing. ●

We would like to extend our gratitude and sincere appreciation to Vincenza and her family for being so gracious in allowing for her story to be told in order to help other families to better understand how to support someone with intellectual disability through grief, loss and bereavement.

Thank you

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