

The

Bereavement Buddy

August 2013



Managing Grief Better - People with Disabilities

Understanding the needs of someone with a developmental disability when it comes to loss and grief.

By Professor Sheila Hollins

Part of life is dealing with one's losses and grieving. We have social structures, support systems, teachings and rituals that help us understand and recover from significant loss. It is not uncommon for adults to feel they must protect others from these difficulties, including children, elderly, and persons with disabilities. In fact, strenuous efforts are often made to protect people with developmental disabilities from life's losses and disappointments. The harsh reality of their own and their parent's mortality is a secret they will have been judged too

vulnerable to be told. Their death education has often been nonexistent, so their bewilderment at the disappearance of a loved one should be no surprise. It is imperative that all people be able to access the supports given to understand death and loss. Protecting someone usually results in more problems in that grief and mourning will not be properly experienced, leading to more significant future difficulties.

In trying to understand how the needs of someone with a developmental disability might be similar or different to yours and mine, the context in which they have lived their lives must be considered. A very typical situation, for example, is that of a middle-aged person with a developmental disability living in a dependent relationship with ageing parents. The family is often isolated with few friends and little practical support at home. Their adult son or daughter may have a regular daytime occupation, and be accustomed to staying in a respite care home or hostel from time to time.

Many adult sons and daughters with a developmental disability play an important role in domestic affairs at

home with dependency being very much a two-way matter. When their first parent dies, they may not be told directly of the death. Nevertheless, they will be aware of their parent's absence, of sadness in the family, and of whispered conversations and concern about themselves.

While the rest of the family grieves, emergency admission to respite care or an unexpected holiday with distant relatives may be arranged for the person with a developmental disability. Thus, the person is excluded and kept ignorant of facts that he or she needs to know. Their confusion and fear persists when other family members are coming to terms with their loss. Families comfort themselves with the hope that the person with developmental disability has not noticed or say, "we could not take her to the funeral - she'd be too upset," as if being upset at a funeral was inappropriate.

"Denial" of the loss by the person with a disability at the time is not surprising in these circumstances. The individual's ordinary routines and certainties will have been turned upside down. Prolonged searching behavior and an increase in separation anxiety can be expected. However, angry and aggressive reactions may be delayed to such a degree that, when such behavior does occur, no relationship to the loss is recognized.

A second scenario is seen when the surviving parent dies. The bereaved, dependent person is admitted to emergency care but never returns home. At one stroke, he or she has lost parent and confidante, home and possessions, a familiar neighborhood and routines, and perhaps a pet. Searching for the lost parent and home is difficult unless one is able to explain one's needs and unless a new caregiver is willing to help. In my experience, most caregivers do not recognize emotional needs such as these. A loss of skills, and decreased joy de vivre may lead to inappropriate and difficult to reverse decisions about future living arrangements and opportunities.

There are other loss situations which might be experienced by a resident of a long-term institutional placement. Staff turnover, the discharge of roommates to community care, the end of weekly visits by a devoted parent - now dead - and the death of people one has lived with for many years all go unremarked.

Developmental disabilities is a broad category which encompasses mild developmental difficulties

to profound mental retardation with multiple disabilities. The greater the handicap, the less likely the individual's grief will be recognized. Caregivers tend to ignore or misunderstand the effects of such losses. Research has shown that some people with developmental disabilities will have a delayed understanding of the ageing process. It seems likely that the irreversibility, universality, and the inevitability of death will all be difficult concepts to understand, despite many years of experience as an adult. The capacity to integrate their experiences and to learn from them will be limited unless sensitive help is available.

It is unlikely that the attitudes of a family or of professional caregivers will change in the period between a death and the funeral. There is an important advocacy role for doctors, care managers and social workers who must not be afraid to challenge caregivers and support providers who make decisions to exclude the person with a disability from the full grieving process.

The following recommendations are made to assist persons with disabilities in dealing with death and loss.

Be honest, include and involve

Many caregivers find themselves quite unable to be honest or to include and involve the person with a developmental disability. The person should be offered the choice of whether to attend the funeral or memorial service. If he or she is unable to choose directly because of cognitive limitations, it is usually advisable to involve the person as fully as possible in all the rituals being arranged.

Listen

Be there - Being available to listen and provide support is essential. This must occur immediately after the death, and, most importantly, also in the weeks and months following. Understanding the permanence of death comes slowly, thus the person with a developmental disability may experience delayed grief.

Actively seek out nonverbal rituals

The nonverbal rituals with which most cultures surround death are helpful to many of us. They are particularly helpful to people with developmental

disabilities who cannot find solace in the written or spoken word. Counselling picture books may be helpful in explaining what happens when someone dies.

Respect photos and other mementos

In the early stages of a bereavement it is quite common to avoid pictures and possessions and places which are associated with the person who died. As time passes, such mementos may come to be treasured. Indeed the reduction in avoidance of such cues can provide a useful measure toward resolution of grief. People with a developmental disability should be helped to choose some mementoes, and this choice should be offered again at a later date when some of their emotional pain has subsided. Sometimes people make unexpected choices, but these should be respected.

Minimize change

It is advisable to minimize changes in routine and changes in accommodation or of caregivers at a time of grief. As a rule of thumb, we suggest major changes should be avoided for at least one year.

Avoid assessment of skills

If a caregiver has died, it may seem sensible to assess an individual in order to “fit” him/her into the best service or support system. However, this can be the worst time to assess someone whose behaviour and skills may have regressed because of the emotional energy being expended on grieving.

Assist searching behaviour

By revisiting old haunts and going to the cemetery, caregivers can assist appropriate searching behaviour to support emotional recovery. Hoarding behaviour may suggest that more help of this kind is required. For example, the person who absconds or is found wandering may be trying to find their lost home and family. Mark was asked to leave his “group home” of eight years standing some time after the death of his grandfather from cancer, and his dog in an accident. Despite not being told of the deaths officially, he became slow and uncooperative with ordinary routines and went missing for hours on end. On the second occasion he was found in a distressed state in a wooded park. His carers asked his parents to take him away. Anne moved to a group home after her mother’s death. She went to great lengths

to conceal the small possessions she took from the jackets, purses and bags of visitors to her group home. Staff knew things would have been hidden in her room and tried to make light about her behaviour. It seemed she felt cheated about something as though she was trying to make up for her own loss. This behaviour stopped after some individual bereavement counselling.

Support the observance of anniversaries

Anniversaries must be formally observed. Many religions have formal services a year after someone has died. This is especially true at the time of the anniversary of an important loss.

Seek specialists for consultation if behavioural changes persist

Referrals for consultation with specialists are typically made very late. It is important to make referrals, especially mental health referrals, as soon as any serious grief reactions are noted such as aggressive behaviour, persistent irritability, mutism, loss of skills, inappropriate speech (i.e., asking “where is Dad?” all the time), self-injury, tearfulness and absconding.

Conclusion

People with disabilities have a right to participate fully in the grief and mourning process and in all of society’s support systems and rituals associated with these losses. Concerted effort is needed to offer death education to professionals and to parent organizations so that they may become familiar with normal grief reactions and provide proper supports. Death education can be introduced into the school and adult education curriculum for people with developmental disabilities. Advice is needed to construct guidelines for special agencies to follow when a death does occur. This might include helping professional caregivers rehearse breaking the news of a death. Practical plans to avoid immediate admission to residential care are required. The importance of ensuring that the bereaved person has some mementos of their deceased relative must be remembered and advice on the importance of nonverbal rituals at the funeral may be helpful. Bereavement counselling for persons with a developmental disability should be made available routinely and not just when a maladaptive reaction

has been recognized as grief. Both individual and group work with bereaved individuals may be helpful, particularly if nonverbal approaches, such as the use of counselling picture books, are available.

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Getting Help

Counselling and Support

NALAG Centre for Loss & Grief
Phone: 02 6882 9222

NALAG provides FREE counselling and support for anyone who is grieving. This service is currently only available in Dubbo for face to face individual counselling and support - Phone 02 6882 9222 for information on services closer to you.

Or you can phone the NALAG Telephone Grief Support Line on

Websites

NALAG Centre for Loss & Grief
www.nalag.org.au

The NALAG website provides resources on loss, grief and trauma together with links to other grief related resources.

Scope Disability Services
www.scopevic.org.au

Scope is a not-for-profit organisation providing disability services in Victoria. Scope's mission is to enable each person we support to live as an empowered and equal citizen. Scope provides free resources to support people with a disability.

National Disability Services (NDS)
www.nds.org.au

NDS is the Australian peak body for non-government disability services. Through the provision of information, representation and policy advice, NDS promotes and advances services which support people with all forms of disability to participate in all domains of life.

Other

- Your doctor
- Your local community health centre
- Counsellor
- Psychologist
- Lifeline - Phone 13 11 14
- Australian Psychological Society Referral Service
Tel. 1800 333 497

From the Manager

NALAG Centre for Loss & Grief



Trudy Hanson OAM

*Grief Counsellor & Educator
Manager, NALAG Centre for
Loss & Grief, Dubbo*

This Month is Grief Awareness Month and we have been busy planning activities to commemorate this special month. We conducted a Remembering Service in Dubbo at the St Brigids Church.

Managing grief for people with disabilities is a very important issue featured in this months Bereavement Buddy. Often times is assumed that people with intellectual disabilities in particular are not capable of grieving. This is so untrue and in my experience working with people with intellectual disabilities who are grieving, their grief is real and needs to be acknowledged.

People with disabilities do have a right to participate fully in the grief and mourning process. It is most beneficial for them to play a part in all of society's support systems and rituals associated with these losses. They should be informed of processes such as funerals and given the opportunity to attend and say their goodbyes.

The NALAG Centre is dedicated to further education for professionals and organizations so that they may become familiar with normal grief reactions and provide proper supports for people with intellectual disabilities.

At the NALAG Centre often the grief work is done later after the funeral has happened and we work one on one with clients usually in a creative way so that they can create their own rituals or memories for the person that has died.

I hope you enjoy this issue of the Bereavement Buddy.

Regards

Trudy

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For Your Diary

Education & Training in 2014

1 Day Workshops

- Working Creatively: Children, crisis and Trauma (For children aged 6-12)
- Working Creatively: Adolescents, Crisis and Trauma (Ages 12-18)
- Working Creatively: Improving Self Esteem in Adolescent Girls
- Working Creatively - Children & Anxiety
- Children & Adolescents - Separation & Divorce
- Introduction to Sandplay Therapy
- Advanced Sandplay Therapy
- Attachment Theory
- Suicide Prevention: Children & Adolescents
- Support Adults who Grieve - Basic Loss & Grief Support Skills

2 Day Workshops/Training

- Working with Complex Trauma & Mental Health
- Working with Drawings in Grief Counselling
- Loss & Grief First Aid - Accidental Counsellor
- Psychological First Aid - First Response to Crisis and Trauma
- Seasons for Growth Companion Training
- Blue Healers Depression Stress and Anxiety Facilitator Training

8 Week Training Programs

- Basic Loss & Grief Support Skills Training

Customised Training

The NALAG Centre for Loss and Grief can offer customised education and training in the area of grief, loss, bereavement and trauma. Please contact us to discuss your options or send us an email below.

Registering for a Workshops

Online Registration

Pay online using your credit card or PayPal Account or alternatively opt to pay by cheque or request an invoice.

Early Bird Online Specials

Register and pay online using your credit card by the specified date and receive the discounted rate for any NALAG (NSW) Inc education and training.

Visit www.nalag.org.au for more information.

Bookings & Enquiries

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