

# NALAG News

National Association for Loss & Grief (NSW) Incorporated

August 2013

## Older People Loss, Grief and Carers

Growing old takes much away from us as life becomes a continuous journey of negotiating and growing through losses. This NALAG winter newsletter issue focuses on the loss and grief of older people and their carers. It is an area of grief that is often not recognised very well in our society, although the losses are obvious and are certainly not hidden.

### Inside this issue...

- Loss, Grief and Family Carers of Older People
- Well Being and Loss: The Art of Old Age
- Loss, Grief and Palliative Care for Older People
- Palliative Care for Patients with Dementia: From Diagnosis to Bereavement



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## On the cover

People's hands reflect a life of many stories, many changes, and consequent losses. This issues cover photo was chosen to symbolise the connection between the aged, their family and their carers.

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National Association for Loss & Grief (NSW) Inc

### NALAG (NSW) Inc

NALAG (NSW) Inc President  
Julie Dunsmore AM MAPS

NALAG Centre for Loss & Grief Dubbo  
MANAGER Trudy Hanson OAM

Head Office  
Welchman Street, Dubbo NSW 2830

All Mail  
PO Box 379, Dubbo NSW 2830

Phone: 02 6882 9222  
Fax: 02 6884 9100  
Email: [info@nalag.org.au](mailto:info@nalag.org.au)  
Website: [www.nalag.org.au](http://www.nalag.org.au)

Editorial Team:  
Beate Steller and Paula Hanson  
Design: Paula Hanson

# Loss, Grief and Family Carers of Older People



**Gill Pierce**

**Social Worker and Senior Policy Advisor Carers Victoria**

*Family carers may experience and mourn many losses. Their grief may be complex, and painful: the grieving process varies enormously in duration, and intensity. The completion of grief tasks and the achievability of finding a new equilibrium may also vary.*

*The nature and severity of the disability or illness of the older person, together with differences in its onset and course of development has a significant impact on the grief that carers experience and on the nature of grief work required. Existing theoretical constructs about loss and grief can be reapplied to help explain differences in the grief journeys experienced by different carers.*

## Common losses experienced by carers

A descriptive framework (Pierce & Nankervis, 1998) illustrates the breadth and complexity of loss that may be experienced by individual family carers. It provides a useful way of conceptualising and exploring possible carer experiences. The significance and emotional investment in the losses experienced by carers are highly individual and will vary significantly between family members and friends.

### Losses resulting from the changed functioning of the older person

For carers, the person they care for has changed. The older person may have lost limbs, functions, sight, hearing or speech, sexual functioning, orientation to time and place or the cognitive ability to process information. Carers grieve when confronted with the loss of mobility and capacity for self care of a person with severe arthritis; they experience a great sense of loss at the increased dependency of a person who has suffered a stroke. Family members and others experience a profound sense of loss as the older Alzheimer's sufferer, once vital and healthy, gradually loses physical, mental or social abilities.

Grief accompanies a spouse observing her dementing partner, once an active farmer, compulsively walk around the garden. Grief accompanies a son observing his hemiplegic father

who is unable to actively take part in a fishing expedition or in woodturning. Grief can be a reaction to watching a voracious reader pretend to manage the newspaper, or to seeing a relative's disinterest in the activities of previously loved grandchildren.

### Losses through changes in significant relationships

Illness or disability in an older person can result in a need to redefine significant family relationships.

For spouse carers, there may be partial loss of a lifelong partner and companion. Marriage (or partnership) frequently provides each partner with a way of focusing and framing their personal life, personal identity and place in society. The disability or illness of the older person, especially if it involves cognitive impairment, removes a significant source of identity, support, and self esteem for the carer.

Carer losses may include the loss of intimacy, loss of shared decision-making processes, or loss of usual activities. Partner carers may experience loss in long standing friendships as friends fail to include them either as a single entity or as a couple. In addition, losses can arise from perceived separation from children or grandchildren, a consequence of caring demands.

The spouse carer may feel they are living with a stranger. They must reorient their expectations and skills in an ongoing, radically altered relationship. This may involve saying goodbye to all that the marriage meant and working to build a new

relationship. Some times, when the relationship between partners has been acrimonious, the spouse carer can feel caught or trapped. They may re-grieve the loss of anticipated relationships in the life course. As their parent changes, adult offspring carers may experience the loss of a mentor, a companion, a crisis intervenor, 'listening ear', or playmate for the children.

Particular feelings of loss may arise when a role reversal is required – when an offspring carer needs to feed and bathe a previously independent parent.

## Losses through changes in status and role

Roles, their accompanying status and the personal sense of value they bring are determined in the family, in the workplace and in the community. When a caregiving situation arises, many changes in family roles and responsibilities may be required. These can be complex and painful.

The role of the spouse may change, a role that has been established over many years and is nebulous.

Losses may be symbolic, such as 'loss of the head of the family' or functional, such as loss of the financial manager or home repairer. Alternatively there may be loss in relation to family support and decision-making patterns. Large gaps may appear in usual family functioning. The older person may have been the conveyor of family communication, the family mediator, the organiser of family celebrations, or the person who remembered birthdays and other significant events.

The reorganisation of traditional family roles can be a great cause for grief. The meanings invested in past roles determine the ease or difficulty of handling the changes. Role changes can lead to conflicts and misunderstandings when the expectations by family members of one another are in conflict. For example, assumptions about the division of responsibility for caring may not be shared. Old stereotypes, particularly about the roles of women may emerge.

'Women in the middle' can be caught between changed roles in relation to their disabled parent, their spouse and children, and their brothers and sisters. Each role has different losses as a consequence of caring responsibilities.

## Losses in identity

Caring may occur at very high cost. Generally, the multiple roles a person has in life contribute to their self-concept and sense of well-being. They provide a means of feedback, recognition and validation of the self. Sometimes, carers in high intensity and long term care situations can realise how engulfed they have become in care giving. Their opportunities for interaction through 'outside' roles have been

displaced and greatly reduced. They may feel they have lost their sense of identity, or sense of self.

Other carers can at times feel 'invisible' as social interactions as well as service interventions focus largely on the condition and needs of the older disabled person.

## Loss of expectations

The changes in life expectations that accompany care giving add to the partner carer's sense of loss.

Unexpected illness can destroy retirement plans and the dream of the 'golden years'- individual dreams and expectations that have been developed and anticipated over many years. These may include expectations of freedom from dependant children, or of positive leisure time with the grandchildren. They may include expectations of travel, or opportunities for developing new hobbies, interests and skills.

For offspring carers, radical change to life opportunities may be deeply mourned. These may include the loss of anticipated lifestyle, expectations about career, or future financial well-being.

## Loss of possessions or surroundings

Carers may experience loss in relation to their possessions or surroundings that are of particular emotional significance or symbolism. This can include loss of household aesthetics, as the home becomes hospital-like, or loss of freedom as the home becomes a fortress to contain an older person who wanders. If care giving responsibilities oblige the carer to move in with the person needing care there may be heightened feelings of loss.

Familiar interactions with neighbours and the local community play an enormous role in the sense of identity and connectedness of both the carer and the older person. Their loss can be extremely disorienting and painful.

Doka (2001) emphasises the importance of exploring experiences of family carers and the breadth of losses they experience. This can assist them to express their feelings and can give support to their grief work. Human services workers need to listen to, understand, acknowledge and validate the losses that are experienced by carers, together with their need to grieve.

## Different disease pathways bring different patterns of grief

Components of existing theoretical frameworks can be reapplied to assist in conceptualising common carer differences in loss, grief and mastery. These result from differences in the nature and pathway of



# On the road...



## with Trudy Hanson OAM

Manager of the NALAG Centre for Loss & Grief, Dubbo  
NALAG State Manager & Grief Counsellor and Educator

*Trudy Hanson has over 25 years experience in grief, loss and bereavement support and education. She is the current Manager of the NALAG Centre for Loss & Grief in Dubbo and in her role she travels throughout remote areas of NSW to promote grief and loss awareness and education. She has a special interest in Indigenous grief and the grief experiences of infants and children.*

E: [trudyhanson@nalag.org.au](mailto:trudyhanson@nalag.org.au) Ph: 02 6882 9222 Mail: PO Box 379, Dubbo, NSW 2830

As I write this time I am literally on the road on annual leave, travelling to sunny Queensland with our new caravan in tow.

Since the last time I wrote this column two new grandchildren have arrived, Grace (our first granddaughter) to Paula and Dave, and a grandson Archie to Kim and Jason, this makes seven grandies in total now.

### **Gunnedah Branch**

NALAG Volunteer Sue Ballard and I travelled to meet with Lynn Blundell from the Gunnedah Branch to do some education and support at the Gunnedah Aged Care facility. As you will see from the articles in this issue of the NALAG News, grief and loss is an important issue in aged care. Our efforts were appreciated and we felt it was very worthwhile.

### **Mudgee Branch**

I am delighted to report that the new Mudgee Branch is going very well with member numbers increasing. The NALAG Centre in Dubbo is providing support to clients each fortnight until the Branch is fully functional to provide support. Our partnership with the Benevolent Society continues positively.

Training of local support volunteers in Mudgee is set down for September. More information will be available on our website soon for anyone interested in becoming a grief support volunteer in the Mudgee area. I am looking forward to working with the Mudgee members and the Branch Coordinator Ruth Gobbitt who is doing excellent work for the Branch.

### **Bourke Visit**

In early June I travelled to Bourke to present education on loss and grief for the Meals on Wheels Group Coordinators. It was a great group to work with and further loss and grief education in the future was discussed.

### **Wagga Wagga**

Volunteers Judy Kelly, Shirley Heron and I travelled to Wagga Wagga to present the Working Creatively with Children: Crisis, Trauma and Grief 1 Day Workshop. This was my first trip to Wagga to present education and training for NALAG and we met a great group of people doing great work in the area of loss and grief. Feedback from the workshop was extremely positive and they have asked us to return to Wagga to present more workshops.

This year has been the first year that we have taken our workshops to Wagga with great success. The Working Creatively - Children and Anxiety 1 Day Workshop in May presented by Psychologist Jacki Short was well received and we have Working With Drawings 2 Day Workshop in August and Working Creatively: Improving Self Esteem in Adolescent Girls in September. For more information on these workshops please see our website [www.nalag.org.au](http://www.nalag.org.au)

### **Wellington Support**

The Centre in Dubbo has been working with the Wellington community in a partnership with Burnside Family Services providing Healing Days and recently a presentation on Suicide Awareness and Prevention. I was supported by Dubbo Volunteers and our local