

GRIEF AND LOSS

Grief and loss: the challenge of coming to terms with the changes that dementia brings.

A diagnosis of dementia brings a range of changes for the person with the diagnosis and their partner/whanau and friends. Common feelings at the time of diagnosis are shock, sadness, anger and fear, or for some people, relief at having an explanation for the changes that have been occurring. Actively coming to terms with the changes that dementia brings and the feelings associated with them is an important part of learning to live well with dementia.

With change comes loss. Grief is the word used to describe the feelings of intense sorrow associated with the loss of someone or something important to you. Grieving is the process that takes place as you adjust to a loss. Grief is a natural reaction to any big loss and is not only experienced after a bereavement. Throughout the dementia journey people experience grief in different ways and at different intensities. If grief is avoided, blocked or denied then stress can be compounded.

Grieving is an active process and each individual grieves in their own way. People's experience of grieving will vary according to their culture, past experiences, personality and degree of attachment to the loss. Gender may also affect the way a person grieves. The level of intensity with which grief is experienced tends to change over time.

Grieving is a process that affects the whole person, it may be felt physically, emotionally, intellectually and spiritually. For example, a person may have feelings of being overwhelmed or of hopelessness as well as experiencing changes in appetite, sleeping patterns and thinking processes; many people describe the struggle to "think clearly" or of being more forgetful while they are grieving.

The experience of coming to terms with a diagnosis of dementia involves processing the feelings and coming to accept and adapt to the new situation. A diagnosis of dementia brings many changes which may include; future plans, current social activities, employment, autonomy, finances, uncertainty, relationships and intimacy. The changes and challenges associated with dementia are different for everyone and shift over time.

These changes can feel overwhelming and for some people are made worse by experiencing stigma in relation to the diagnosis which can cause people to focus on disability rather than ability. In coming to accept the new reality of living with dementia, whether supporting someone else or having the diagnosis yourself, it is important that you have the opportunity to express the fears and feelings you are experiencing. When feelings of grief are not acknowledged and worked through, they can become barriers to living well, as peoples' perspective is clouded by what has been lost/changed rather than what abilities and potential still exists. For example, by excessively thinking and worrying about what the future may hold the 'what is' of today is overlooked.

One of the challenging aspects for the person living with dementia and their whanau/friends is the progressive deterioration in functioning that dementia brings. This may cause the person with dementia to become anxious and/or depressed alongside their feelings of grief. Having opportunities to express these feelings is important, as is the need for the person to understand that life does not end with a diagnosis and that with the right supports the person can continue to live a meaningful and enjoyable life. The process of adjusting to a diagnosis of dementia requires letting go of expectations of how things should be or might have been and instead exploring the possibilities, purpose and pleasures that are still available.

For care partners/whanau it may also mean the need for new learning to take on roles and tasks that the person with dementia may no longer be able to do independently. It is important to remember you are not on your own and that a range of supports are available to assist you.

What can help?

Connecting with others who are going through the same experiences. Your local Dementia New Zealand affiliate offers such groups for both care partners and people living with dementia.

- Talking about your feelings with friends, family, a social worker or counsellor.
- Finding inspiration and hope through the stories of others who have walked this journey, there are books and blogs by many inspiring individuals living with dementia and their supporters.
- Accept offers of practical assistance from friends and family.
- Talk to your G.P. if you are feeling anxious, low, or are having difficulty sleeping; it is important to prevent normal feelings of sadness from slipping into clinical depression.
- Remember the importance of exercise and a healthy diet.
- Maintain or re-engage in activities that bring pleasure and meaning.
- Be kind to yourself, coming to terms with, and adapting to changing and unwanted circumstances takes energy and can be exhausting. Give yourself the time you need to process these changes.

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