

former carers

Former carers are partners, relatives, friends or neighbours who have completed their caring role because of the death of the person they were supporting or because the carer no longer has any involvement in caring. Former carers may be of any age.

Q. If the care recipient moves into a residential care facility does the carer become a former carer?

No! This is because there may be continuing involvement in care, including:

- ✓ *a strong sense of responsibility towards the person requiring care*
- ✓ *regular visits*
- ✓ *provision of physical care*
- ✓ *provision of emotional support*
- ✓ *monitoring of care being provided by the facility*

These carers may also experience feelings of intense loss, guilt, sadness, stress and loss of control because they are no longer being the primary caregiver. Placement of the care recipient in residential care is a time when carers may need support to deal with the emotions and other changes.

Q. What issues do former carers face?

Many former carers face common issues regardless of what their caring role involved. These may include:

v Grief/loss due to the death of the care recipient

Most, but not all, former carers will feel some grief after the death of the care recipient. This grief can be very intense and overwhelming. Grief is experienced in a very individual way and each person will deal with it in the way that suits them best. Grief is not something that former carers 'get over' quickly. It may take them many months or years to adjust to the loss of their loved one. Typical reactions to grief are changes in eating and sleeping habits, withdrawal or a need to be around people, a need to keep busy or, alternatively, a feeling of not wanting to do anything and crying. Guilt and anger are also a normal part of the grieving process and are experienced, in particular, by many carers. The grieving process has been described by former carers as like "a big black hole", "a devastating sense of loss" and that they "muddle through life".

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v **Loss of role/identity as a carer**

Being a carer can be an all-encompassing role which takes over the life of the carer. Recent research has shown that carers give up many or all of their activities outside the home due to the demands of caring. As a result, they often lose contact with friends and the community. After the person's death, the former carer who had been caring full-time is unlikely to have a highly structured routine in the way that they may have had while caring. This can leave a huge void in the former carer's life which it takes some time to fill.

v **Isolation/lack of social support**

Isolation is experienced by many carers, particularly those who are housebound. Once the care recipient has died, this isolation is often intensified because contact with friends and relatives has been eroded during the period of caring. Family members may live far away or the former carer may not have any family at all. Former carers may need to make a concerted effort to make new friends and re-establish links with the community once the care recipient has died. They may also require support to do this.

v **Employment Issues**

Because some former carers may have had to give up work to care, their careers have probably been adversely affected. During the time that they have been out of the workforce, changes in technology and industry may also mean that their skills are out of date. Some former carers will also face other barriers, such as age, in their attempt to re-enter employment. Therefore former carers may require assistance in the form of re-training, job search or with the costs associated with returning to work. They should also not be expected to return to the workforce immediately after the care recipient's death. Those on a Carer Payment can receive this for 14 weeks after the person's death.

v **Poor mental or physical health**

The isolation experienced during caring may affect carers' mental health and an intensely physically demanding role may result in injuries or illness for carers. Some carers' health will improve once caring has ended, whereas for others there will be the onset of an illness. Health issues may also affect some carers' ability to re-enter the workforce.

v **Financial disadvantage**

Former carers may have been on low incomes for many years while caring and this may also have affected their ability to save for the future, resulting in low or no superannuation.

v **Fear about the future**

After caring ends, former carers may feel anxious about what the future holds for them. This is a natural reaction to the changes that have occurred and is usually only temporary. For some carers where the care recipient has moved away, carers may be unsure about whether the person will come back and caring will re-start.

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v **Low self-esteem**

Any or all of the above factors can have a severe impact on a carer's self-esteem. Building up the confidence to create a new life needs time, support and other resources.

Q. What supports are available to help former carers adjust to life after caring?

Family, friends, neighbours, support groups and church communities are all important sources of support for former carers. However we should not assume that all former carers have such support networks. Those that do not may require assistance from other sources. These include:

- ✓ *the National Carer Counselling Program;*
- ✓ *former carer groups or courses;*
- ✓ *service providers such as Palliative Care Teams or social workers;*
- ✓ *bereavement support groups;*
- ✓ *general practitioners;*
- ✓ *volunteer groups (such as Legacy); and so on.*

Research conducted by Carers NSW has found that a majority of former carers find the bereavement period difficult, yet that very few ask for help. Thus, former carers need to be provided with information about the existence of services such as those listed above should they want to use them. Service providers and health professionals in contact with carers need to ensure that this information is delivered to them.

Whilst the time after the care recipient's death is difficult for many carers, most of them are able to get on successfully with their lives. Former carers call on their personal coping mechanisms and their faith or religious belief, as well, to help them deal with life after caring. They are usually able to return to a 'normal' level of activity after some time.

It is also important to recognise that support provided to carers during the period of caring (for example respite) may help them to adjust to life after caring more easily. This is because services such as respite may allow the carer to pursue their own interests and activities and maintain links with the community. Having a sense of identity separate from the caring role has been shown to be important in how carers cope both during caring and once they are no longer a carer.

Q. Why does Carers NSW value former carers?

Former carers have a great ability to help others. Their abundance of knowledge and experience is an invaluable resource for carers, Carers NSW, government and service providers. We encourage former carers to maintain contact with Carers NSW and to be proud of their history, what they have contributed, and now, to think about what they may be willing and able to offer to others.

NOVEMBER 2006

Information contained in this fact sheet was supplied by the relevant authorities and is believed to be accurate at the time of publication. Whilst every care has been taken in its preparation, this fact sheet contains only guidelines in relation to its subject matter.

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