Grief and Bereavement

When a person develops dementia, the people closest to them are likely to experience feelings of grief and bereavement not only in the period after the person's death, but also before they die, as the illness progresses. A carer may adapt and come to terms with one stage of the person's illness only to find that their behaviour alters or their abilities decline further and the grieving starts all over again. This fact sheet is for carers, friends and relatives of people with dementia. It looks at some of the feelings that people close to someone with dementia might experience and suggests some ways to cope with them.

Loss

A sense of loss is one of the most powerful feelings that people experience when someone close to them develops dementia. Depending on your relationship with the person and your individual circumstances you may grieve for the loss of:

- the person you once knew
- the future you had planned together
- the relationship you once shared
- their companionship, support or special understanding
- your own freedom to work or to pursue other activities finances or a lifestyle that you once took for granted.

Feelings like these are a normal part of grieving but if you experience them, it is important to realise that you may be under a great deal of stress, and you may need to seek emotional support for yourself.

The ups and downs

Grieving is an up and down process. In the earlier stages of the person's dementia, you may swing between despair and wild optimism that a cure will soon be found. You may even deny that anything is wrong with the person and try to suppress your feelings.

Later, if you have accepted the situation, you may find that there are periods when you can cope well and make the best of things. At other times, you may feel overwhelmed by sadness or anger, or you may simply feel numb. People who care for someone with dementia often feel resentful at times for the restrictions placed on their own life, and may feel unhappy that things have not turned out as they would have hoped. Some people are shocked to find that they sometimes wish that the person they are caring for were dead.

Feelings like these are a normal part of grieving but if you experience them, it is important to realise that you may be under a great deal of stress, and you may need to seek emotional support for yourself.

Tips:

1.1 Talk about your feelings to an understanding professional, to other people coping with a similar situation, to a trusted friend or to supportive members of your family. Don't bottle up your feelings.

1.2 Relieve tension through crying, shouting or punching a cushion.

1.3 However, make sure that the person you are caring for is safe and out of earshot first, or you may distress them.

1.4 Invite friends to drop in for a chat or to phone you regularly. Make sure that you see your GP if you are feeling low or anxious, or if you are very tired and unable to sleep. It is important to try to prevent normal feelings of sadness from slipping into depression, which is much harder to deal with.

1.5 Consider your own needs. If you spend a lot of time with the person with dementia, taking regular breaks can keep you in touch with the outside world and raise your morale.

1.6 Make time for yourself each day. Just relaxing with a cup of tea or having a good chat on the phone will help you recharge your batteries and cope with your emotions.

Long-term care

If the person goes into long-term care you may grieve at another change in Your relationship. The relief which you might feel initially may be replaced by feelings of loss and grief, mixed up with guilt, which can last for a surprisingly long time. You may miss the person's presence. You may experience feelings of emptiness. You may feel very tired, both physically and emotionally.

Tips:

1. Try to take it easy until you feel your energy levels rise again.
2. If your daily routine previously revolved around caring for the person, giving a structure to your day may help you get through the difficult early months.

If you still want to be involved in caring for your relative while they are in care, speak to the staff and explain exactly what you would like to continue to do for them.

Don't fall into the trap of building your life around visiting the person in their new home. You need to build a new life for yourself that includes these visits. Remember that there is no 'right' or 'wrong' way to feel. You experience your own feelings in your own way, and no one has the right to tell you how you should feel.

Final stages of dementia

In the final stages of dementia the person may be unable to recognise you or communicate with you. This can be very painful. Although the relationship seems very nearly over, you are unable to mourn fully because the person is still alive.

Tips:

Holding the person's hand or sitting with your arm around them may be comforting for both of you. There is no right or wrong way through the caring role, take comfort from the knowledge that you have done the best that you could.

When the person dies

Some people who have loved ones with dementia find that they grieve so much during the course of the illness that they have no strong feelings left when the person dies. Others experience a range of overwhelming reactions at different times. These may include:

- numbness, as though their feelings are frozen
- inability to accept the situation
- shock and pain, even if the death has been expected for a long time
- relief, both for the person with dementia and themselves
- anger and resentment about what has happened
- guilt over an incident that happened in the past

- sadness
- feelings of isolation
- a feeling of lack of purpose.

It can take a long time to come to terms with the person's death. Those who have been full-time carers for a long time will be left with a huge void when this role ends.

Tips:

1. Try to avoid making any major decisions in the early months if you are still feeling shocked or vulnerable.

2. Accept that, even though you may generally be coping, there may be times when you feel particularly sad or upset.

3. If you find events such as anniversaries or birthdays distressing, ask friends and family for support.

4. Stay in touch with your GP. You are likely to be more vulnerable to physical illness, as well as to anxiety or depression, following bereavement.

Getting back on your feet

a) Although you may feel very tired after someone close to you dies or goes into long-term care, the time will come when you are ready to re-establish your own life and move forward. Remember that it takes time to adjust, and the length of time will vary from person to person.

b) You may feel very unconfident at first and find it difficult to take decisions, make polite conversation or cope with social gatherings. Don't give up - your confidence will gradually return. Take things slowly, and make sure that you have plenty of support from family and friends, professionals and other people in a similar situation to yourself. If people offer to help, try allowing them to do so - don't refuse straight away.

c) When you feel ready to do so, talk about the person you have lost. Reminisce with friends and family who can also benefit from the opportunity to share feelings and memories.

d) For details of Alzheimer's Society services in your area, visit alzheimers.org.uk/ localinfo. For information about a wide range of dementia-related topics, visit alzheimers.org.uk/ factsheets dementia?

What if I have dementia?

A diagnosis of dementia often comes as a shock. Even if you have been half expecting it, this will be a worrying and upsetting time. It will also be hard for those close to you. You will all need a great deal of reassurance and support.

However, there is much that you can do in the early stages that will help make life easier and more enjoyable - both now and in the future. This factsheet looks at some of the things that you may need to think about at this time.

You will want to remain as independent as you can for as long as possible. Although you will need an increasing amount of help as the dementia progresses, it is important to make sure that other people don't take over your life when you can still manage it. Make sure, too, that you are consulted on all matters that concern you. You should have the opportunity to make your own choices for as long as you can.

Talking things over

You will need to discuss plans for the future with those who are closest to you and with certain professionals. If your family and friends do not already know about your diagnosis, try to tell them as soon as possible. At first, they may not want to believe you if they are very upset by the news. Try to discuss matters in a calm way.

- It will help if you can talk about your own wishes for the future, but try not to ask people to make promises now that may be difficult for them to keep later. You may find it helpful to write your wishes down.

- You may want to talk about your wishes for your end of life care, which may be difficult for you and your family to discuss. Reassure your family that you are not being morbid but want to share your thoughts around what you would like to happen to make it easier for them when the time comes.

- It may help if you can talk about your feelings to someone you trust outside the family.

Putting your affairs in order

Now is the time to make sure that any important documents are in order and can easily be found. These include details of your mortgage or tenancy agreement, insurance policies, bank statements or building society books. Go through all the details with a member of your family, partner or trusted friend.

- Sort out any recent bills, guarantees and regular payments. It might be a good idea to arrange to pay your regular household bills by direct debit, if you are not already doing so. Details of how to do this are given on each bill.

- Look again at your will and make sure that it expresses your wishes, or consult a solicitor about making a new one. Consider making an advance decision. An advance decision allows a person to state what forms of treatment they would or would not like should they become unable to decide for themselves in the future.

- Grant lasting powers of attorney, if you have not already done so. This enables you to appoint someone to manage your legal, financial and health affairs and make decisions on your behalf should you become unable to do this for yourself.

Work

If you are still at work and are finding it stressful, there may be an opportunity to switch to a less demanding job or to reduce your hours.

- Seek expert advice on your pension rights if an occupational pension is due to you. It may be possible to negotiate a lump sum.

- Before leaving work, check whether there are benefits that you or your family may be entitled to, your personnel department or manager should be able to help you make enquiries.

Services

Look at what services may be available to you. Even if you don't need them now, they may be useful in the future. By using the services that you are entitled to you can ensure that those closest to you don't have to take on all the responsibility for helping you. Contact your local social services department for details of services that they can arrange. Find out about getting a community care assessment to assess your needs). Social services departments are listed in the phone book under the name of the county council or metropolitan authority.

Find out what services can be arranged through your GP or consultant. Find out what kinds of services and support are provided by local voluntary organisations, such as Alzheimer's Society.

Health

It is important to take good care of your health. Having dementia should not mean that you feel ill so always check with your doctor if you feel unwell. This is important because any illness can make you feel more confused and forgetful.

1. Try to eat balanced meals.

2. Try to take regular exercise.

3. Enjoy the odd alcoholic drink if you wish - but avoid too much alcohol as it will make you more disoriented.

4. If you are on medication, ask your GP to check whether it is essential, as it can sometimes increase confusion.

5. Poor vision and poor hearing can make you more confused. It is important to have regular eye and hearing checks.

6. Painful teeth, gums or dentures can also make life more difficult. Make sure that you have regular dental check-ups.

Driving

If you drive, you may have to give up doing so either now or in the near future. Anyone who drives and has a medical condition that may affect their ability to drive, such as dementia, must inform the Driver and Vehicle Licensing Authority (DVLA) who will assess every case individually. It is a criminal offence not to inform the DVLA of your diagnosis. Check with your insurance company to make sure you are still covered following your diagnosis.

Memory

If you find it hard to remember things, you may find it useful to follow these tips:

- Don't be afraid to ask questions.

- Don't be afraid to say that you have not understood. Don't be afraid to say that you have forgotten what has been said. Remember, it is not your fault if you can't remember as well as you used to.

- Alzheimer's Society produces free helpcards that help to explain your condition to anyone you might encounter in daily life. Look for practical ways to aid your memory - for example:

- Place helpful telephone numbers by the phone where you can see them.

- Put labels on cupboards or drawers to remind you where things are.

- Write reminders to yourself to lock the door at night, or put out the rubbish on a certain day, for example. Put things you use all the time, such as your keys or glasses, in an obvious place - such as a large bowl in the sitting room.

Managing your routine

You may find it helpful to maintain your previous routine as much as possible:

- As your dementia develops, you may find it increasingly reassuring to do things at the same time each day or each week.
- Nevertheless, try to keep on making the occasional one-off visit or trip, to keep life interesting and enjoyable. Keep up things you like doing for as long as possible - if you find this difficult, try to take things at a slower pace.

Enjoying life

Some of your previous interests may seem too stressful or demanding. But there will be many activities that will still give you satisfaction.

- Try to find things that you still enjoy doing such as listening to music, knitting, playing a game, exercising or talking to a friend.
- Caring for a pet can be very satisfying and reassuring. Taking a dog for a walk is a good way of getting regular exercise.
- Conversation between large groups of people can be hard to follow, so you may prefer friends or family to visit one or two at a time.
- Try to concentrate on what you can still do, rather than worrying about what you can't.

Consider starting a life history book. Use a simple scrapbook or photo album to record details of your past and present life that will be helpful for anyone who may be supporting you. This is something your family and friends can help you with, and it is a great opportunity to share your history, memories and thoughts with those close to you.