What if I have dementia?

Information sheet 518

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.

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. It is essential that you feel able to retain your confidence, dignity and self-esteem.

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 to keep in the future.
- 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.
- Grant lasting powers of attorney, if you have not already done so. This enables you to appoint one or two people to manage your affairs in your best interests if it becomes necessary. (See Factsheet 467, Financial and legal affairs, and 472, Enduring power of attorney and lasting powers of attorney.)

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 on benefits that you or your family may be entitled to (see Factsheet 413, Benefits). If necessary, 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 a community care assessment. 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 the Alzheimer's Society. Social services or your local Citizens Advice Bureau can advise about this. (See 'Useful organisations'.)

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.

- Try to eat balanced meals (see Factsheet 511, Eating).
- Try to take regular exercise (see Factsheet 522, Staying healthy).
- Enjoy the odd alcoholic drink if you wish but avoid too much alcohol as it will make you more disoriented.
- If you are on medication, ask your GP to check whether it is essential, as it can sometimes increase confusion.
- Poor vision and poor hearing can make you more confused. It is important to have regular eye and hearing checks.
- Painful teeth, gums or dentures can also make life more difficult. Make sure that you have regular dental check-ups (see Factsheet 448, Dental care and dementia).

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. (See Factsheet 493, Driving and dementia.)

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. (See ‘Further reading’.)

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 or 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.

(See Factsheet 505, Keeping active and staying involved.)
Further reading

For more information on living with dementia, the following booklets are available for free to people with dementia.

1505, What your diagnosis means for you
1507, Talking to children about your illness

The following may also be helpful:

1540, Memory handbook
1532, Helpcards

All of these are available to order from Xcalibre on 01753 535 751 or alzheimers@xcalibrefs.co.uk

Useful organisations

Alzheimer's Society

Devon House
58 St Katharine’s Way
London E1W 1JX
T 020 7423 3500
0845 300 0336 (helpline open 8.30am-6.30pm weekdays)
E info@alzheimers.org.uk (general information)
helpline@alzheimers.org.uk (helpline)
W alzheimers.org.uk

The UK’s leading care and research charity for people with dementia and those who care for them. The helpline provides information, support, guidance and referrals to other appropriate organisations.

Citizens Advice Bureau (CAB)

Various locations
W http://www.citizensadvice.org.uk/
http://www.adviceguide.org.uk/
Your local CAB can provide information and advice in confidence or point you in the right direction. To find your nearest CAB look in the phone book, ask at your local library or look on the citizens advice website (above). Opening times vary.

Factsheet 518

Last updated: March 2010
Last reviewed: October 2008

Reviewed by: Cathy Baldwin, Dementia Learning and Development Adviser, Alzheimer’s Society