What if I have dementia?

A diagnosis of dementia 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 to 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 gradually need an increasing amount of help 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 matters which concern you. You should have the opportunity to make your own choices for as long as you can. It is essential that you retain your confidence 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. They may not believe you at first because they are so upset by the news. Try to discuss matters in a calm way.
- It helps 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 to someone you trust outside the family about your feelings.

Putting your affairs in order

Now is the time to make sure that any important documents such as details of your mortgage or tenancy agreement, insurance policies, bank statements or building society books are in order and can easily be found. 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 will.
- Make an Enduring Power 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 information sheet, Financial and legal arrangements.)

Work

If you are still at work you are probably finding it stressful. There may be an opportunity to switch to a less demanding job or to reduce your hours. Whatever the situation you will probably need to think about leaving work fairly soon.

- You will need 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. If necessary, your personnel department or manager should be able to help you make enquiries.

Services

Look at what services are available. Even if you don’t need them now they may be useful in the future. Those closest to you should not 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 are arranged through your GP or your consultant.
- Find out what kinds of services and support are provided by local voluntary organisations such as...
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.
• Try to take regular exercise.
• Enjoy the odd 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. Drugs 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.

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 diagnosis of dementia must inform the Driver and Vehicle Licensing Authority (DVLC) at Swansea who will treat every case individually.
You should always check with your insurance company to see whether you are still covered.

Memory
• 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.
• It is not your fault if you can’t remember as well as you used to. Look for ways to aid your memory.

• 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.

Routine
Try to take things at a slower pace. Doing things at the same time each day or each week can also be reassuring. But do try to keep on making the occasional visit or trip.

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

• Try to find things which you still enjoy such as listening to music, knitting, playing dominoes, 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 lots of people can be hard to follow. You may prefer friends or family to visit one or two at a time.
• Try to concentrate on those things that you can still do rather than worrying about those that you can’t.

For more detailed advice see the booklet I’m told I have dementia, available from the Alzheimer’s Society for £3 including package and posting.