This booklet is for you if your doctor has told you that you have dementia. Your doctor may have told you that you have a particular kind of dementia, such as Alzheimer's disease, vascular dementia or multi-infarct dementia. This information, however, is for people with any type of dementia.

It was written with the help of members of the Scottish Dementia Working Group, who all have a diagnosis of dementia. The quotes in boxes are all from people who, like you, have dementia.

This booklet will help you feel less alone.

Sections include:
- About dementia
- Emotional reactions
- Dementia and other people
- Practical support
- Medical treatment
- Staying well
- Tips for coping
- Driving
- Work
- Money matters
- Planning for the future
- Further help

Please carry this dementia helpcard with you. It provides useful advice for you and other people.

www.healthscotland.com
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There is a great deal of information in this booklet. You may find it easier to use this contents list to simply ‘dip in’ and read only the parts you are interested in, rather than reading the whole booklet in one go. For a more detailed contents list, please refer to the back of this booklet.

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Introduction

Who this booklet is for

If your GP or specialist has told you that you have dementia, then this booklet is for you. You may have been told that you have a particular kind of dementia, such as Alzheimer’s disease, Lewy body dementia or vascular dementia. This booklet, however, is for people with any type of dementia.

It was written with the help of members of the Scottish Dementia Working Group, who all have a diagnosis of dementia. The quotes in boxes are all from people who, like you, have dementia.

This booklet will help you understand more about your illness, and about how to cope with its effects and get on with your life. It will show you where you can turn to for help and how to plan for your future. The earlier you start to plan, the more control you will have over what happens in the future.

Three things to keep in mind

Dementia is a serious illness, and it will gradually have more and more of an effect on your life. But there are three things you should know.

1. **There is life after a diagnosis of dementia.** Yes, the illness will change your life. But you and your family can still have a good life, despite the illness. That’s the message from all the people with dementia who helped to write this booklet.

2. **You are not alone.** There are many people who can help you, including:
   - your family and friends
   - other people with dementia
   - health and social workers
   - local and national dementia organisations and groups – see the back of this booklet.

3. **You can help yourself.** This booklet will help you find out about what you can do to help yourself and your family, both now and later on.
• This booklet is for people with any kind of dementia.

• This booklet will help you understand more about your illness and how to cope.

• People with a diagnosis of dementia helped to write this booklet.

• There is life after a diagnosis of dementia – you and your family can still have a full life, despite the illness.

• You are not alone – there are many people who can, and will, help you.

• You can help yourself – this booklet will help you to help yourself, and your family.
About dementia

Diagnosis is important

It is very important to have a proper diagnosis. If you have been feeling forgetful or confused but have not been told by a doctor that you have dementia, you should see your doctor as soon as possible. There are many causes of memory problems and confusion, and some of them can be treated. For example, chest or urinary infections, depression and the side effects of medication can all make some people confused. This confusion can usually be reversed.

If your doctor has not given you a clear diagnosis, visit him or her again. Ask to be referred to a specialist for a full assessment.

‘I think if you learn about the illness, you can start to fight it.’

About dementia

Dementia is an illness which affects the brain. It can affect your memory, thinking and actions. It is progressive, so it will gradually affect you more as time goes on. Up to 66,000 people in Scotland have dementia, so you are not alone.

Dementia is more common in older people – it affects about 1 in 15 people over the age of 65, but as many as 1 in 4 people over 85. It can sometimes affect younger people too, in their 40’s or 50’s or even younger. About 1,600 people in Scotland under the age of 65 have dementia.
About dementia at a glance

- Dementia is an illness which affects the brain.
- Some different kinds of dementia are Alzheimer’s disease, vascular dementia, Lewy body dementia, fronto-temporal dementia and alcohol-related brain damage.
- Dementia progresses gradually and everyone is different.
- You can still carry on with activities you enjoy, and find exciting new ones.
- Usually memory problems are an early symptom. Later, everyday activities become harder to manage without help.
- Ask your doctor to explain more about dementia.
Types of dementia

Dementia is an umbrella term. There are many different causes of dementia. The most common are Alzheimer’s disease and vascular dementia. Other types include Lewy body dementia, fronto-temporal dementia and alcohol-related brain damage. Some people may have more than one type of dementia.

Every person with dementia is different, and even two people with the same type of dementia may have different symptoms and follow a different pathway through the illness.

‘I can remember things from a long time ago, like things that happened when I was at school – but not what I did yesterday.’

Alzheimer’s disease damages individual brain cells, so the brain can’t work as well as it used to. It affects memory and other mental abilities. It generally affects short-term memory first.

With vascular dementia, there are problems with the blood supply to brain cells. The most common type of vascular dementia is caused either by a narrowing of the small blood vessels in the brain, or by a series of small strokes, or a combination of the two. If you are having small strokes (called ‘transient ischaemic attacks’ or TIAs), they damage small areas of the brain. Each time you have one of these ‘mini strokes’, there will probably be a change in how well you are coping. You may feel unwell and more confused for a short time, or you may not notice the strokes at all.

Like Alzheimer’s disease, Lewy body dementia gradually affects your memory and other mental abilities. Sometimes these effects are patchy, and if you have Lewy body dementia, your symptoms may vary a lot from day to day. People quite often have some physical problems too, such as rigidity and stiffness, difficulty starting movements, slowness of movement or tremors, weakness of the arms or legs, clumsiness or falls. Visual hallucinations (seeing things when there is nothing there) are also common. People with Lewy body dementia can also be more sensitive to certain medication.
Some people with Parkinson’s disease may develop dementia, which affects their memory and ability to carry out everyday activities. Parkinson’s disease dementia is related to Lewy body dementia, and similarly the effects may be very variable from day to day.

In fronto-temporal dementia (previously known as Pick’s disease), the areas of the brain at the front and side of the head are particularly affected. You may not have any memory problems until late in the illness, but you are more likely to have changes in behaviour and personality, or language problems.

Alcohol-related brain damage (including Korsakoff’s syndrome) can affect people who are heavy drinkers. It is caused by a vitamin deficiency, because heavy drinkers often do not eat properly and may not absorb vitamins very well. Alcohol-related brain damage particularly affects short-term memory. If you stop drinking it will not get any worse, and may even improve with the right treatment.

There are many other conditions which can cause dementia, such as Huntington’s disease, Creutzfeldt-Jakob disease, and HIV/AIDS. People with Down’s syndrome have a higher risk than other people of developing dementia as they get older.

Is dementia inherited?

Many people wonder if they got dementia because their mother or father had it. Or they may worry about passing it on to their children. In fact, there are only a few, rare families where Alzheimer’s disease is actually inherited. These families usually have a form of the illness that affects people under the age of 65, and they often have already been told that they are affected.

For most people, having a close family member diagnosed with dementia only increases the risk of getting dementia by a small amount.
How dementia progresses

How dementia progresses depends on many things, and it is not possible to predict exactly. Everyone is different, and dementia affects people in different ways. But there is a general pattern.

At first, you may have trouble finding words, finishing thoughts, following directions, or remembering names and other information. You may sometimes get irritable and frustrated. You may feel confused, and your friends and family may notice changes in your personality, mood or behaviour.

You will probably increasingly have problems with remembering and thinking as time goes on. You may also have visual difficulties, such as trouble with judging distances. This is not because there is a problem with your eyes, but how your brain understands what your eyes see. Reading and writing will gradually become more difficult, and it will be harder to take in new information and make decisions.

Later you will find everyday activities difficult. You will begin to have trouble with tasks such as remembering appointments and shopping lists, coping with money and cooking. You may get lost in familiar places and have trouble recognising people. Eventually, you may need help with basic activities such as washing, dressing and eating.

It doesn’t happen suddenly

Remember, these changes are very gradual. You may stay the same for months or years. Although it may become difficult to continue with some of your usual activities, you may rediscover other things to enjoy – for example painting, gardening, sorting out your family photographs or listening to music.
Finding out more

You may want to find out more about your illness. Reading this booklet is a good start. You can also ask your GP or specialist to explain more about dementia. The doctor may have tried to explain some things when he or she first told you about your diagnosis. Perhaps you were too shocked to take it all in. Don’t be embarrassed to go back and ask again. Make a list of what you want to ask about. Taking someone with you can be helpful too. Perhaps you could take some notes or record what the doctor says to remind yourself later.

The freephone 24 hour Dementia Helpline on 0808 808 3000 can also help you find out more.
Emotional reactions

How will dementia affect you?

Having dementia means that you will need to try to come to terms with changes in your life. These gradual changes may be hard for you to think about or accept. But if you know what to expect now, you will have the chance to think about and plan how you will cope in the future.

‘I’d always rather know what’s likely to happen – that way at least I can make plans.’

Reactions soon after diagnosis

For most people, being given a diagnosis of dementia is a shock. You may already have felt that something was not quite right with your memory, or perhaps you were not managing to do things as well as you used to. You may even have suspected that you had dementia. But hearing this confirmed can still come as a blow. On the other hand, for some people, it can come as a kind of relief because it explains what has been happening to them.

You may have very strong emotional reactions after your diagnosis. You may feel angry or frightened, or not believe it is happening to you. Some people feel weepy, emotional, depressed or withdrawn, or lose confidence in themselves. All these reactions are normal. You may feel a range of emotions at different times, and each person has different reactions.

It will take time to come to terms with your diagnosis, but remember that there is life after a diagnosis of dementia, and you are not alone. You can do many things to help yourself, and there are people who can help you.
It is normal to have strong emotional reactions after you are diagnosed.

It may take time to come to terms with your diagnosis.

Try to remember that there is life after being diagnosed with dementia. You are not alone, you can help yourself and there is help available.

Professional counselling may help.

It may be easier to talk things over first with someone you don’t know, such as with the Dementia Helpline on 0808 808 3000.

Support from other people with dementia can be very helpful – ask about groups in your area.

If you find some things make you anxious, upset or agitated, your community psychiatric nurse (CPN) can help you with ways to cope.

Always remember to talk to someone about how you are feeling.

You should be able to keep doing the things that you enjoy, with a bit of help if you need it.
'It really was a very black period of my life – you’re so deep in the mud that logic doesn’t apply. Your sense of worth is destroyed. I couldn’t even say I’ll get up and iron a shirt. I couldn’t see the future. That lasted six months. But I did come through it.'

Getting emotional support

You will probably want to talk to someone about how you feel. Perhaps you can talk to your partner, a close friend, relative or someone else with dementia. Or you may choose to talk to a professional health worker. This could be, for example, your community psychiatric nurse (CPN), doctor, social worker or someone from a local Alzheimer Scotland service. Some people find comfort in their beliefs and their faith, and gain support and comfort from their own faith community.

It can be hard, at first, to know how or where to start. You may find it difficult to talk about things. You may be afraid of other people’s reactions. Will they be afraid or feel awkward? Will they listen to you? Will they support you or reject you?

Many people find it easier to talk things over first with someone they don’t know, with complete confidentiality. There is a free 24 hour Dementia Helpline available on 0808 808 3000 which you can call at any time for information or simply to talk. There is always someone available who knows about dementia, can help you think things through and provide you with information.

As well as the support of people close to you, you may find that professional counselling can help you come to terms with your diagnosis. The Dementia Helpline can help you find a counsellor in your area.
Support from other people with dementia

One of the best ways of feeling better about living life with dementia is getting support from other people with dementia. There may be a local support group you can join, or a course for people with dementia on how to better manage your day-to-day activities. Ask the health professionals you know, or call the Dementia Helpline on 0808 808 3000 for more help on how to find support.

As well as offering and finding support in the community, some people want to campaign to improve services for people with, and attitudes towards, people with dementia. You can join a local group, or the Scottish Dementia Working Group. The Scottish Dementia Working Group is a national group of people with a diagnosis of dementia. They meet to support each other, and to find ways to improve services and attitudes. Their details are at the back of this booklet.

‘My tip is to be positive, and challenge yourself. That’s what I do. And speak to other people with dementia – join a group like I did.’

Some people with dementia wrote a booklet called Don’t make the journey alone – a message from fellow travellers. In it they say, ‘We want to share our experiences to reassure you that you can adapt. There is life after diagnosis. It’s not the same life you had before, it’s a different life. Hopefully one day you will feel able to embrace the change.’ You can get a copy of the booklet from the Dementia Helpline.
Common emotions for people living with dementia

After you have come to terms with your diagnosis, you may find that living with dementia changes your emotional reactions. For example, you may get frustrated when you can’t remember things, annoyed with yourself or embarrassed for making mistakes, or agitated and stressed when things go wrong. These feelings can then make it harder to do whatever it was that upset you in the first place. Be kind to yourself. Don’t blame yourself for making mistakes.

Try to work out what triggers a bad reaction and make plans for how to cope with it in the future. For example, if crowds make you anxious, can you take someone with you? There are useful suggestions in the ‘Tips for coping’ section of this booklet (see page 36).

‘The emotional part of me is much stronger – I’m more sensitive. It’s not what I’m used to. For me the illness has affected my thinking process emotionally. It’s important that my carer knows that my emotional reactions are due to the illness rather than bad temper.’
'Sometimes I feel I don’t believe it, they’ve got it wrong, especially when I have good days. I’ve been back and back asking my doctor, are you really sure? It doesn’t help when my friends say that everyone has ‘senior’ moments – they just don’t get that it isn’t the same as being a bit forgetful.’

It is normal to get anxious sometimes, and it doesn’t mean you can’t keep doing the things you are used to doing. You might just need a bit of support, or to find the best ways to help yourself calm down. If you find some things are making you anxious, upset or agitated, talk to your community psychiatric nurse (CPN). He or she can help you work out ways of coping that work best for you.

It is also common to find it hard to believe that you have dementia. This can be made even more difficult when other people don’t really understand what you are experiencing.
Sex and relationships

Sometimes people with a diagnosis of dementia find their sexual relationships are affected. There may be changes in how you feel about yourself, with your confidence or your sexual desire. If you have a partner, he or she may find that the emotional impact of your diagnosis also has an effect on his or her sexual feelings.

Some people feel that facing dementia together brings them closer to their partner. But other people may have difficulties with sexual issues and with their relationships. If this happens to you, don’t suffer in silence – there is help available. Call the Dementia Helpline on 0800 808 3000 to talk things over in confidence, or ask your doctor or CPN about getting help.
Being positive

A diagnosis of dementia does not mean you can’t enjoy life. You should be able to keep doing the things that you enjoy, perhaps with a bit of help if you need it. For example, if you like golf but have trouble keeping score, ask a friend to look after the score card.

Keeping up your social life is important. See your friends, and keep going out. If a friend seems to find it hard to know what to say to you, don’t let them drift away. Explain that you still need to see them, even if it is awkward at first for them. This isn’t always easy to do, but it’s better than losing contact.

‘It’s not the end of the road… but the beginning of a new route.’

Many people with dementia have taken up new activities after their diagnosis. Perhaps you’ve always fancied going to a pottery class, learning to sing or taking up fishing. Don’t let dementia stop you!
Dementia and other people

Telling people close to you

For some people, the first reaction is to tell someone else, perhaps their partner, or a daughter or son. Sometimes a family member is there when you are first diagnosed, or may even be told before you find out yourself. Other people keep it to themselves, perhaps because they feel there is no-one they can tell, or because they don’t want to upset people they are close to.

It is a good idea to tell your family and friends what is happening to you. If they then notice any changes, they will understand. You could ask your doctor or community psychiatric nurse (CPN) to discuss the effects of your illness with your family.

‘My wife and I had split up because of how I behaved, but when I was diagnosed with Alzheimer’s my daughter told her. We’re now back together, and she’s realised that I’m not a bad guy, it’s the illness.’

You may find it hard and feel reluctant to talk about your diagnosis. For example, some people find it embarrassing, or want to protect other people from upsetting news. If you’re not sure about telling someone, try asking yourself these questions:

- If it was the other way round and they had dementia, would I want to know?
- Would it help them to understand why I might seem different from how I used to be?
- Could they help me, if they knew what’s going on?

Tell your family how you feel about your diagnosis. Sometimes family members feel over-protective and want to take over. Explain what would help you and what support you would like from them.
It is a good idea to tell your family and friends what is happening to you.

Get help from your CPN or doctor if you find it hard to talk to your family about your illness.

Explain what would help you and what support you would like from your family and friends.

Like you, the people close to you may be shocked by your diagnosis, and they may not always react well at first.

Reassure them that although you have dementia you’re still the same person.

Many people make assumptions about dementia, so you may need to explain how your illness affects you.

Just because you have dementia doesn’t mean you can’t keep doing the things you want to do.
The effect on other people

The people you are close to will probably also have strong emotional reactions about your diagnosis. Sometimes all the emotions flying about can affect relationships. Tempers may be short, or people may be withdrawn and unwilling to talk.

It can help if you remember that the people close to you are coping with a shock too, and therefore give them time to come to terms with your diagnosis. It can also help if they know more about what is happening to you. Reassure them that you may have dementia, but you’re still the same person.

Dementia affects families and carers throughout the illness, and at times they may find it difficult and stressful. There is information and support available for them. Call the Dementia Helpline on 0808 808 3000 or see the back of this booklet.
Stigma

Many people don’t understand enough about dementia. They may have ideas about what people with dementia are like, and what they can and can’t do. When someone hears you have dementia they may make assumptions about you.

If you think this is happening, talk to the person and explain how your illness actually affects you – and how they can help you.

And try not to make this kind of assumption about yourself. Just because you have dementia doesn’t mean you can’t keep doing the things you want to do. Ask for help if you need it, and make the most of living with dementia.
Practical support

Get the right support

Your illness means that you may gradually find it more difficult to cope with everyday activities such as shopping, cooking and remembering appointments. But you can still keep active. Do as much as you can, with help when necessary.

Don’t be afraid to ask for support when you need it. This section lists the types of support that are available.

Some people find it hard to accept support at first, but you have a right to help. With the right support, you can remain as independent as you can, for as long as possible. Accepting help does not mean you are giving up, it means you are facing your difficulties realistically.

‘I have vascular dementia, and I can tell you that your life is going to change. But if you get the right support and work hard at it, you can still achieve things.’

It may be particularly hard for you to accept help from outside your family, but your family will probably also find it easier to help you if they are not doing it on their own.

Ask your doctor to refer you to a community psychiatric nurse (CPN) or a link worker from a voluntary organisation. They are specialists in helping with the practical and emotional difficulties you may face. They can visit you regularly to see how you are getting on and to help you get more support when you need it. They will also be able to tell you about support services available locally.
Your illness means that you may gradually find it more difficult to cope with everyday activities.

Do as much as you can, with help when necessary.

Don’t be afraid to ask for support when you need it.

You have a right to receive help and support.

A CPN or a link worker from a voluntary organisation can help you with any difficulties you face.

Don’t be embarrassed to ask for help from family, friends and neighbours.

If you need help, your local social work department can conduct an assessment and provide support services.

The social work department can organise these services for you, or you can organise them yourself.

Finding out more about dementia can be very helpful. There is a list of information sources at the end of this booklet.

In some areas there are courses for people with dementia and their families.
Family and friends

Don’t be embarrassed to ask for help from your family, friends, neighbours and other people. Explain how the illness affects you, and how they can help. For example, perhaps someone could help you remember an appointment by making sure you have it in your diary, or phoning to remind you. If you find you are getting muddled when you go shopping, perhaps you and a neighbour could go at the same time to help you keep track. Perhaps you need your hairdresser to help you count out the right money, or a friend to come with you to play golf.

It may help if you are direct about what you do and don’t want. For example, you might want them to:

- be patient when you forget or repeat things
- do things with you – rather than for you
- not patronise you or do things for you without being asked
- not make assumptions about what you think or need
- not feel that they have to test your memory, or get you to do things they think will help improve your memory.

Community care services

You will be able to get more help as you start to need it. Contact your local social work department to find out what help they can offer. You will find their number in the phone book, under your council listing.

There is a range of support services which may be helpful, both now and later. These are usually arranged by a social worker or care manager. To access these services, you first need a community care assessment. As part of the assessment, the social worker or care manager will talk to you, and your carer if you have one, about what you need. (If you have a family member or friend who is providing you with support or care, they are seen as your carer.) Your carer is entitled to an assessment too.
If you need help or advice on how to get any services, call the Dementia Helpline on 0808 808 3000. They can tell you about help available in your area, including advocacy services. An advocate can help you get your point of view across to service providers.

There may be a charge for some services, depending on your income, but help with personal care is free.

Community care services include:

- home care – help with personal or practical tasks at home, such as dressing, meals or shopping
- day opportunities or home support – one-to-one support to help you with social activities
- day centres – a chance to socialise and take part in fun activities, transport usually provided
- respite/short breaks – time away from home to give you and your carer a break
- equipment – to help you cope and keep safe.

There may also be a local branch of Alzheimer Scotland or other dementia services in your area, which could offer help and support. Call the Dementia Helpline to find out what’s available near you.

**Occupational therapists**

Occupational therapists (OTs) can help you find practical ways of coping with everyday activities, to help you stay as independent as possible and to keep you safe. They know about equipment such as memory aids, and relevant safety devices or technology that can help. You can find an OT through the social work department or through the hospital psychiatric service.
Self-directed support

If you are assessed as needing community care services, one option is for the social worker or care manager to organise this for you. Another option is ‘self-directed support’, also known as direct payments. If you choose this, the social work department provides you with the money that would have been spent on your services. This means that you can pay for exactly the help you need, at a time that suits you. This can be from a service provider such as a care agency or voluntary organisation, or alternatively you can employ your own personal assistant.

Some councils are trying another way of giving people more control over their own support. The council tells each person how much they have to spend (that is, provides each person with an individual budget). People can then arrange their own support services, without having to manage the money themselves.

Arranging your own care means that you have the maximum choice and control over the help you receive. This can help you to live as independently as possible, for as long as possible, by allowing you to personally take charge of the care you receive. You can make sure this fits with what you want, and with the support your family and friends may already provide you.

To get self-directed support, you must be able to arrange the services and manage the funding process yourself, or have someone who is authorised to manage the self-directed support for you. If you have given someone power of attorney (see the ‘Planning for the future’ section on page 54 of this booklet), they can manage it for you – you will still be free to say how you want your funding spent (as long as this is in line with your assessed needs).

There is a support organisation in most local authority areas that can provide information and help for people who choose self-directed support. If you would like more information about this, ask the social work department for the name of your local support organisation.

If the social work department decide that you are not able to manage self-directed support they must explain this in writing. If you disagree you can use the local authority complaints procedure.
Information and courses

Finding out more about dementia and practical ways of managing your condition can be very helpful. There is a list of information sources at the end of this booklet.

In some areas there are courses available for people with dementia and for carers, which cover issues like managing your memory, treatment, getting help, money and legal matters, planning ahead and managing stress. Ask your community psychiatric nurse (CPN) or link worker about these courses. As well as providing you with information and skills, a course will give you the chance to meet other people with dementia.
Medical treatment

Treatments for dementia

There are drug treatments for some kinds of dementia, although there is not yet a cure. Your doctor will advise you on what might be suitable for you. Some people (but not everyone) with Alzheimer’s disease may find their symptoms improve, or progress less quickly, with a type of drug called a ‘cholinesterase inhibitor’ or ‘cognitive enhancer’. These drugs help boost the chemicals in your brain which carry messages between brain cells. They may also help some people with Lewy body dementia or mixed dementia.

If you are prescribed these drugs you may not feel the benefits right away. It may take three to six months to tell whether they are helping, and they don’t work for everyone who tries them. Like all medication, they can sometimes have side effects. When you have just started treatment, the most common side effect is feeling sick. Usually this settles down, but if it remains a problem ask your doctor whether you could try a different drug. Other possible side effects are diarrhoea, vomiting, weight loss, dizziness or leg cramps – talk to your doctor if you have any of these. Sometimes if you change the time of day that you take the pills, or take them after food, it can help reduce these side effects.

Medication to lower your blood pressure, reduce cholesterol, help circulation or reduce the likelihood of blood clotting may help delay the progression of vascular dementia. Your doctor will also have to monitor your ongoing blood sugar and cholesterol levels. It is very important for you to stop smoking.

Always consult your doctor before taking any treatment, including herbal treatments, as they are not suitable for everyone and can have serious side effects.
There are drug treatments for some kinds of dementia, although there is not yet a cure.

Your doctor will advise you on what might be suitable for you.

Always consult your doctor before undertaking any treatment.

It is important to see your doctor regularly. Make a list of what you want to ask before you go.

If you need medical treatment for other conditions, tell staff that you have dementia so that they can be more understanding.

If you are having an operation, tell the anaesthetist you have dementia.

If you are taking medicine, ask your chemist about a pill dispenser with compartments to help you remember.
Reviews

It is important to see your doctor regularly. Your GP, community psychiatric nurse (CPN) or other health professional should give you a face-to-face review at least once a year, to see how you are coping and whether you need help with any problems. But if you are having a problem, don’t wait until your review – ask for an appointment right away.

You may be given a care plan based on an assessment of your needs and what you and your carer think would help you to stay as healthy as possible. If you have a care plan, it will name someone as your care plan coordinator. The coordinator should review your care plan with you and your carer at least every six months.

If you are getting treatment for your dementia, your doctor will want to see you regularly to check whether it is helping you.

Your doctor may ask you to do some tests. These can help the doctor work out how the illness is affecting you, and to see if it is getting worse. They may also help the doctor diagnose which kind of dementia you have, if it is not yet certain. The more your doctor knows about your illness, the more he or she can help you and your family understand any difficulties you have, and how best to tackle them.

Talk to your doctor about what you want to know from your results. Some people want to know if they are improving because of treatment, staying the same or getting worse. Others would rather not know, in case it is bad news. Remember that the most important thing is how you feel you are enjoying life, rather than the results of the tests your doctor might do.

Other conditions

You may need medical treatment for other conditions, such as arthritis or diabetes. It’s best if you tell staff that you have dementia so that they can better meet your needs, and be more understanding and flexible. For example, you may be more likely than other people to get confused, especially if you are in pain or feeling unwell.
'I was very down for two days after getting results showing a decline. After a couple of days I picked myself up, dusted myself down and thought, what’s really changed? Nothing – I’m still the same as I was last week, I can still do the same things.'

Seeing the doctor

To aid your memory, write yourself a list of what you need to tell the doctor, and make notes of what is said. It’s often helpful to take someone with you. He or she can come in to the consultation with you if that’s what you want. Ask for a double appointment each time, to make sure you have enough time to talk with the doctor and to understand all the information.

Having an operation

Some drugs for dementia affect anaesthetics. Make certain you see the anaesthetist in advance, so that he or she can take this into account when planning your care.

One good tip if you have an operation is to ask a friend, family member or someone you know well to be with you beforehand, and again when you come round from the anaesthetic. Looking at familiar photos afterwards can also help you feel less confused.

Taking medicines

Make sure you take any medicines you are prescribed. If you are taking medicine, ask your chemist about a pill dispenser with separate compartments or reminders to help you remember to take it.
Staying well

Look after your health. Like anyone, the healthier you feel, the more you will enjoy life. Feeling unwell or being in pain can make you feel more confused.

Keep active

Keeping physically active helps to improve your mood, and is good for your body and your brain. Walking is very good exercise. If you don’t want to walk alone, ask a friend along or join a walking group – contact Paths to Health (www.pathstohealth.org.uk or phone 01259 218855) to find one near you. Or why not go swimming, dancing or bowling?

‘I go swimming several times a week and I feel much better for it, and not just physically. There’s a real feel-good factor.’

Eat well

Try to eat a balanced diet with at least 5 portions of fruit and vegetables a day. Cut down on salt, sugar and saturated fat. Eat more fish, especially mackerel, salmon or sardines. If it’s good for your heart, it’s good for your brain.

Ask your GP, practice nurse or link worker for more information on healthy eating.

Don’t let yourself get dehydrated, because this could make you confused. Make sure you drink plenty of water, juice or tea.

You can still enjoy an alcoholic drink, as long as you are sensible about it and your dementia is not alcohol-related. But if you’re on any medication, check with your doctor to see if it’s okay to drink alcohol.
• Look after your health.
• Feeling unwell or being in pain can make you feel more confused.
• Keeping physically active helps to improve your mood and is good for your body and your brain.
• Try to eat a balanced diet. If it’s good for your heart, it’s good for your brain.
• Carry on doing things that you enjoy, especially those which keep your mind active.
• Use music, exercise, reading, meditation or whatever helps you to relax.
• Try to make sure you get a good night’s sleep.
• Make sure that you have someone to talk to about your feelings concerning the illness.
Exercise your brain
Carry on doing the things that you enjoy and which keep your mind active – from puzzles and games, to reading or crafts. Consider taking up new things, but don’t force yourself to do things you don’t like or which feel too difficult. Choose activities that suit you and change them to suit your abilities. Mental exercise may not make the illness go away, but it can help you feel happier and more alert.

‘Know your limits, make different plans, and take more time. I used to build model boats but I can’t use the knife anymore. Now I like to paint.’

Relax
Make sure you help yourself relax, especially if you’ve had a frustrating or confusing time. Try music, exercise, reading or meditation.

Coping with tiredness
You may find that you get more tired than you used to. Having dementia can mean it takes more effort and concentration to do things. Being tired makes it harder to concentrate, and you’re less likely to be able to remember things and more likely to feel confused.

Remember to take time out. You don’t have to be busy all the time. Try to make sure you get a good night’s sleep.
'I think people with a diagnosis can still take on new challenges. After my diagnosis, I went to classes and learnt British Sign Language.'

Take care of your mental health

Make sure that you have someone to talk to about your feelings concerning the illness. If you are depressed or have other worrying feelings or thoughts, your doctor or CPN may be able to help. Depression can be treated. Getting help if you’re feeling low can help you feel better and enjoy life again. Call the Dementia Helpline on 0800 808 3000 at any time to talk about how you are feeling – there is help available.
Tips for coping

There are many positive steps you can take to help yourself cope. Remember, changes are not going to happen suddenly. You will have time to adjust your lifestyle and to find help when you need it. You will find out what suits you best. Ask your CPN and other people with dementia for ideas on how better to cope.

These are some of the tips people with dementia recommend.

‘Because my memory was bad I used to buy extra things – huge packs of toilet rolls, a cupboard full of them. Now I always write a shopping list.’

Helping your memory

- Write things down. Make lists of what you need to do, or keep a diary and get into the habit of checking it regularly. Make notes of where things are.
- Put a reminder board on the wall to help you remember things.
- Decide on a place to keep important things like money, keys and glasses. Put them in the same place every time so that you can track them down.
- Ask your family or friends to phone you to remind you about things you need to do.
- If you like gadgets, a mobile phone or personal organiser can act as a diary, plus you can set reminder alarms – for example, to take a pill or catch a train.
Write things down.
• Keep important things in one place.
• Ask your family or friends to phone you to remind you about things you need to do.
• Electronic gadgets such as mobile phones suit some people and can help you cope.
• Be patient with yourself.
• Concentrate on the things you can do.
• Make a routine for yourself.
• Know your good times of day.
• It’s okay to tell people that you have a memory problem.

Use the Helpcard from the back of this booklet to show people, to explain that you have dementia and might need a bit of help.
• Don’t be afraid of asking for help, and accepting it.
• Get other people to help you work out what risks you should or shouldn’t take.
• Don’t let others take advantage. Don’t buy things without talking to someone you trust.
'I have peaks and troughs, I'm much better in the morning. Later in the day I have less energy, and bad reactions.'

People who try to take advantage

Because dementia can affect your judgement, unscrupulous people may try to take advantage of you. Say no to ‘cold callers’ – people who try to sell you something that you haven’t asked for, either door-to-door or by post, phone or email. Don’t buy anything significant without first discussing the deal with someone you trust.

You can reduce the number of phone calls you receive from people that try to sell you things, by registering free with the Telephone Preference Service on 0845 070 0707 or by visiting www.tpsonline.org.uk

To reduce unwanted mail, register free with the Mailing Preference Service on 0845 703 4599 or go to www.mpsonline.org.uk

Ask your computer or internet supplier to install a good spam filter on your computer to cut down on unsolicited emails.

And remember, if an offer seems too good to be true, it probably is!
Communication

• If you’re having difficulty taking in what people are saying – check. Repeat back to them what you think they’ve told you.

• If you have trouble finding words, tell people. They could help by making suggestions, or to give you more time to find the word yourself.

• Make short notes for yourself to remind you what’s been said.

• Remember, communication may be more difficult when you’re stressed or in social situations. Take time-out or ask for help if you need it.

‘I can look as though I’m taking in what people are saying, and I think I am, but then maybe I go to the toilet and when I come back I’ve lost it all. I use a notepad to write down trigger words that help me remember what we’ve been talking about.’
'My wife uses a whiteboard and writes instructions for the day – like what to wear – and puts up post-it notes to remind me to lock the door or how to use the microwave.'

Other people

It’s okay and it’s good to tell people that you have a memory problem. Don’t be embarrassed to ask them to repeat or explain things.

- Ask people to remind you who they are, and where or when you last met.
- Ask people to check what you’d like them to do, and not to take over or speak for you.
- Tell people close to you what causes you problems. For example, some people with dementia find that discomfort, such as being too hot or too cold, makes them more confused.
- Use a Helpcard – it’s a wallet-size card which you can show to people to explain that you have dementia and might need a bit of help. There is one in the back of this booklet, or call the Dementia Helpline on 0808 808 3000 for a free Helpcard.
- Don’t be afraid of asking for help, and taking it.
Managing risk

Having dementia shouldn’t stop you doing the things you want to do. But it might make some things riskier. Of course everyone takes risks in everyday life, like crossing the road. People with dementia need to be able to take risks too. But you may need to do things a bit differently to make sure you minimise the risk.

‘I go out at night, like to see a show. I do get lost, but I know I’ll find my way back in the end. I always keep enough cash for a taxi, just in case.’

The risk depends on you, your illness, and the situation. For example, if you have trouble finding your way, going for a walk alone might be fine if you live in a quiet village where everyone knows you, but not such a good idea in a big city where you could easily get lost.

Judging risk can be tricky because the illness can affect your judgment. Check to see what other people think you can do, and ask for help to keep doing the things you want to do.

‘Nearly every day I disagree with my wife on what I can do on my own – I think I’m probably not safe to judge any more.’
Helping yourself

• Be patient with yourself. If you get frustrated when things aren’t going well, take a break. Blame the illness, not yourself.

• Be positive. Concentrate on the things you can do instead of things that have become too difficult.

• Make a routine for yourself that works for you. You may find it easier to keep track if you have a regular way of doing things and a particular time to do them.

• Know your best times of day – for many people with dementia certain times of day are better than others. Make appointments and save difficult tasks for your good times. Explain to other people which times are better or worse for you.

• Allow plenty of time for things. Don’t let other people rush you.

• If something doesn’t go well, leave it and try again later. If you’re having a bad day don’t be angry with yourself.

• Recognise your limitations – but also remember that making compromises can help you continue to do things.

• Using a sense of humour can help you cope.
‘A couple of weeks ago I cooked my wallet – you either get depressed or get on with it. You have to learn to laugh.’
Driving

In the early stages of dementia you may still be able to drive. But dementia can make your reactions slower and affect your judgement. If you want to keep driving, you need to know you are safe.

The law

The law states that you must tell the Driver and Vehicle Licensing Authority (DVLA) if you have a diagnosis of dementia (see the back of this booklet for details). You must also tell your insurance company. If you don’t do this straight away, your insurance may not cover you.

If you want to carry on driving, tell the DVLA. They will send you a questionnaire and will get reports from your doctor. They may need you to have a driving assessment. If they decide you are safe to drive they will renew your licence, usually for a year at a time.

Driving safely

If you keep driving, be sensible. You will be safer on routes you know well. Don’t drive when you are tired and stay away from busy and fast roads. Driving at night or in wet conditions can also be more difficult.

Deciding not to drive

You may realise yourself that your driving isn’t safe any more, or your family or friends might be concerned. If you decide you shouldn’t carry on driving, send your licence back to the DVLA. If you’re not sure, you can ask your GP to refer you to the Scottish Driving Assessment Service (SDAS), who will assess your driving.
In the early stages of dementia you may still be able to drive.

You must tell the Driver and Vehicle Licensing Authority (DVLA) and your insurance company that you have dementia.

The DVLA may need you to have a driving assessment.

If you keep driving – be sensible.

If you stop driving, send your licence back to the DVLA.

Giving up driving is very hard for many people, and it may feel like you are losing your independence, but there are alternatives.

Family and friends may be able to offer lifts.

People over 60 or disabled are entitled to free bus travel anywhere in Scotland.

You can get cheaper train travel if you buy a railcard.

You could try internet shopping to get your groceries delivered.
‘I became aware I had problems with my driving – once I looked at the speedometer and I was doing 120 mph! I realised I wasn’t safe.’

Many people find giving up driving one of the hardest things to do. You may rely on your car, and feel that driving is an important part of your independence. Without it, your life may have to change, which can be painful and frustrating.

It may help to work out how much your car costs you – by counting the cost of the car, tax, insurance, maintenance and petrol. It can come to a surprisingly high figure. And if you don’t have a car, at least you don’t have to worry about all the things that could go wrong with it!

‘I was a mechanic so I really missed the driving, but since I gave up I am enjoying the sights – I can see more because I can look at the scenery instead of concentrating on the road. Sometimes when my wife’s driving I see something and say, ‘I never knew that was there!’”
Being a passenger

You may need to adjust to being a passenger. Try not to concentrate on the road as though you were still driving. Remember, your judgement is not the same as the driver’s judgement.

‘It helps if people are aware of how I feel when I’m a passenger. If they go too fast I can’t handle it and I don’t feel safe.’
Life without driving

There are practical steps you can take to make the loss of your car less distressing.

- Family and friends may be able to offer lifts. Don’t be embarrassed to ask – most people will be happy to help. Point out that you have an illness that stops you driving, just as if you were losing your sight.

- Get the bus for free. People aged 60 and over or disabled are entitled to free bus travel anywhere in Scotland with a National Entitlement Card. People with dementia may count as disabled for this purpose. If you don’t have one already, apply to your local council. If you need someone to help you when you travel, you can get an entitlement card which also allows you to take a companion, at no charge, on any or all of your trips.

- Get cheaper train travel by buying a Senior Railcard if you are over 60, or a Disabled Persons Railcard. Both give you a reduction on the cost of train tickets. You can apply for railcards at stations and travel agents.
• If you have difficulty using public transport, you can get a **Thistle Travel Card**. If you show it to transport staff they can give you extra help, such as making sure you are on the right bus or train, or telling you when to get off. The cards are available from transport booking offices, council travel offices or call the **Dementia Helpline** on **0808 808 3000**.

• If you have a computer, try using the internet to do your shopping, and get your groceries delivered to your door.

• Ask your local council if it has a taxi scheme – they may offer cheap or free taxi travel for disabled people, which includes people with dementia.
Work

If you are still working, and your dementia affects how you do your job, your employer has a legal duty to make reasonable adjustments to help you. For example, this might include being flexible about the hours you work, changing parts of your job that you find difficult or providing extra equipment. But if reasonable adjustments are not possible, or if they don’t help, you may have to leave your job.

If you are having difficulty with your current position, there may be other jobs you can still do. Many people find that working helps them feel good about themselves. However, in time your illness will make you less able to work. Eventually, you will need to stop working.

Discuss with your employer what arrangements they might have for shorter hours, flexibility, a simpler job or early retirement. If you have an occupational pension, find out how much you will get if you retire early. You may be able to get a lump sum payment. You will probably find it helpful to have someone with you at these discussions – perhaps a friend or someone from your union.

If you can’t do paid work, consider volunteering. You may find that voluntary work is more flexible, especially if you are not able to manage working every day.

‘I volunteer with children. I love working with them – it’s lots of fun and they don’t notice that I have dementia. They love it when I lose at games!’

You can find out what benefits you and your family would be entitled to if you stop work. Your local Citizen’s Advice Bureau will give you information and advice.
• If you are still working, your employer should make reasonable adjustments to help you do your job.

• In time, your illness will make you less able to do your job.

• Ask your employer about shorter hours, flexibility, a simpler job or early retirement.

• Consider voluntary work.

• Your local Citizen’s Advice Bureau will give you information and advice.
Money matters

Extra money

You may be entitled to benefits to help you cope with the extra costs of having dementia. If you are of working age, benefits may help to compensate you if you can no longer work. Your social worker or community psychiatric nurse will advise you on how to apply for them. The Department for Work and Pensions can advise you and fill in your forms for you over the phone. Or if you are over 60, you can ask for a home visit from the Pension, Disability and Carers Service. They can also help people under 60 claim a Disability Living Allowance. See the back of this booklet for details.

The Dementia Helpline (0808 808 3000) or your local Citizen’s Advice Bureau, Welfare Rights Service, Community Law Centre or Money Advice Centre can also advise you on benefits.

If you have applied for a benefit and been refused, seek advice. Sometimes decisions are wrong and it may be possible to challenge the decision, or to apply again if circumstances change.

Some of the main benefits you might be entitled to (depending on your age and circumstances) include an Attendance Allowance, Disability Living Allowance, Employment and Support Allowance, Income Support, Pension Credit, Incapacity Benefit, Council Tax Discount and Housing Benefit.

There is more information on money matters in the booklet Dementia: Money and legal matters – a guide which you can get free from the Dementia Helpline.

Paying bills

You can save yourself the trouble of remembering to pay bills. Ask your bank to set up direct debits or standing orders for all your regular bills such as gas, electricity, rent, and mortgage.
• You may be entitled to benefits.

• Get help from your social worker or CPN, or call the Dementia Helpline on 0808 808 3000.

• Ask your bank to set up direct debits or standing orders for all your regular bills.
Planning for the future

Setting down your wishes

Eventually, dementia will affect your ability to look after your own affairs and make decisions for yourself. It is important that you think as soon as possible about the future and how you wish to arrange your affairs. If you set things in order now, both you and your family will know that what happens in the future is what you wanted.

Make sure that all your important papers are in order, such as your mortgage, insurance, tax details, and bank and building society statements, and keep them all in one place. If you can, go through them with someone you trust.

You should start to make your plans as soon as you feel able to do so. If you leave it too late, you may not legally be able to make these decisions for yourself.

There are three main ways to make sure you have the maximum say in what happens if one day you can’t make decisions yourself:

- **Powers of attorney** – someone you trust can make financial or welfare decisions for you in the future, if you can’t manage it yourself
- **Advance statements** – about what medical treatment you may or may not want in the future
- **A will** – to say what you want to happen to your property after your death.

There is more information in the booklet *Dementia: Money and legal matters – a guide* which you can get free from the Dementia Helpline on 0808 808 3000.
- Make your plans as soon as you feel able to.
- Eventually, dementia will affect your ability to look after your own affairs.
- Make sure that all your important papers are in order.
- You can choose someone to look after your financial or welfare affairs if you become unable to do this in the future. This is called a ‘power of attorney’.
- A solicitor will draw up powers of attorney for you.
- You can write down how you feel about future medical treatment, to make sure your wishes are known.
- Like everyone, you should make a will.
- Discuss with your family what you would like to happen if you become unable to live in your own home.
- Make sure the people close to you know your wishes. Write them down if you can.
Powers of attorney

You can choose someone to look after your financial affairs and make decisions about your welfare, if you become unable to do it for yourself in the future. This is called a power of attorney.

A power of attorney is a document which authorises someone you trust to deal with your affairs. This person is called your attorney. There are two kinds of attorney:

- **Continuing attorneys** look after money and property affairs, such as managing your bank accounts and paying your bills (sometimes called financial attorneys).

- **Welfare attorneys** look after your welfare decisions, such as deciding on your care arrangements or consenting to medical treatment.

You can choose the same person to be both your continuing and welfare attorney, or they can be different people. You can also choose more than one person to be joint attorneys, or have substitute attorneys in case your first choice is no longer able to do it. You can choose family or friends, or you can choose a solicitor (but he or she will charge fees).

It helps if you can discuss who you choose with the rest of your family so that they are aware of your wishes.

A solicitor will draw up powers of attorney for you. It will cost about £150–£400, or sometimes less if you are on a low income. Shop around – ask several solicitors what they will charge.

Whoever you choose as your attorney need not take over your affairs as long as you are still capable of doing it yourself, but you must appoint them in advance. You can only appoint an attorney while you are able to understand fully what you are doing. It is important that you appoint your attorney as soon as you can, to make sure that no-one can claim later on that you weren’t well enough to grant a power of attorney.

You can choose what you would like your attorney to be able to do for you. For example, you might want them to be able to run your bank account, complete your tax returns, sign documents, or buy and sell property for you.
Make sure your power of attorney is registered right away with the **Office of the Public Guardian** (your solicitor will do this for you). They will check that it is valid. If it isn’t registered until later and there is a problem, you might not be able to make a new one.

The booklet **Dementia: Money and legal matters – a guide** covers these arrangements in more detail. See the end of this booklet for how to get a copy.

> ‘I had been doing everything for my Dad and everyone assumed I had his power of attorney. But when it came to light that I didn’t, suddenly I had no rights. So because I now have Alzheimer’s disease, I have got my own power of attorney sorted.’

**Your wishes about future treatment**

You can write down how you feel about future medical treatment, to make sure your wishes are known. The law says that doctors must take your past wishes into account when deciding on treatment.

- An **advance statement** says what kind of treatment you would like, for example, preferences about how you are cared for.
- There is a special kind of advance statement which says how you would want to be cared for, if you are compulsorily treated under the Mental Health (Care and Treatment) Act.
- An **advance directive** (sometimes called a ‘living will’) usually says what kind of treatment you want to refuse. For example, you might feel you would not want artificial feeding or resuscitation if you become terminally ill.
Of course decisions you make now about the future may go out of date, for example if there are new treatments offered. So put a note in your diary to read your advance statement or directive at least once a year, in case you want to change it. Discuss it with your doctor and give him or her a copy for your file.

The **Dementia Helpline (0808 808 3000)** can send you more information on advance statements and advance directives.

### Making a will

Like everyone, you should make a will to make sure that your property and possessions go to the right people when you die. It is very important to draw up your will now, while you are clear about what you want. See a solicitor to help you do this. A simple will costs about £75–£120, or less if you are on a low income.

### Living arrangements

Discuss carefully with your family or friends what you would like to happen if you become unable to live in your own home. Perhaps there is someone you would like to help take care of you while they are able to. But moving in with someone is not always the best answer for you or for them.

Perhaps you would prefer not to involve your family and friends. You might prefer to move into a care home if it should become necessary. You may get help with the cost of a care home if the social work department have assessed you as needing to live there. Speak to the **Dementia Helpline on 0808 808 3000**, or your local Citizen’s Advice Bureau, Law Centre or Money Advice Centre for more information about this.

You may like to talk about the different possibilities with someone who is not personally involved. Speak to your doctor, social worker, nurse or counsellor, or phone the Dementia Helpline.

Make sure the people close to you know your wishes. Write them down if you can. Of course, no-one can know the future, and circumstances may change so that what you decide is no longer suitable. But it will help if your wishes are clear.
Trusts

If you are fairly well-off, it might be to your advantage to set up a trust. This means that trustees take over money or property and administer it for your benefit. Your solicitor can advise you on how best to protect your capital. It may be possible for your solicitor to arrange the trust so that the money doesn’t count as your capital when assessing welfare benefits or contributions to care home fees. However, this would not be the case if you knowingly set up the trust to avoid care charges or to keep benefits. Income from a trust, whether actually paid or not, may be taken into account.

Life story book

You may like to put together a ‘life story book’ for yourself. This is a book about who you are and what is important to you. It is a good way of making sure that people who may be supporting you in the future know more about you. And it can be an enjoyable way of reminding yourself of your life when you look back over it.

It could contain anything you want it to – for example:

- photographs – don’t forget to include a note of who everyone is, and what and when the occasion was
- letters, postcards and other keepsakes
- information about your wishes such as likes and dislikes, or how you want to be cared for
- copies of documents like powers of attorney and advance statements.

Your book could be like a scrapbook of memories, or a practical guide to your wishes, or both – whatever you choose.

‘My life story book is for my daughter. It says this is who I am and this is what I want to be happening to me. If anyone lifts it, they can get the essence of who I am and what I want.’
Prospects for the future

Research

There is a great deal of research going on at the moment into the causes and possible treatments for the different kinds of dementia. In fact, it is one of the most active areas of research world-wide. At present, however, we do not know the causes, and there is no cure.

Be cautious of newspaper reports of research ‘breakthroughs’. These are often exaggerated, so try not to let them raise your hopes until you know the truth. Call the Dementia Helpline on 0808 808 3000 for a realistic assessment of these stories.

Information sheets on current research and what to consider before taking part in research are available from Alzheimer Scotland – see details at the end of this booklet.

Taking part in research

You may be asked to take part in medical or social research. Before you decide whether to go ahead, make sure you understand fully what this will mean. Sometimes people hope that taking part in medical research will give them early access to new treatments. But if you take part in a drug trial, you are just as likely to be given a placebo (dummy pill) as the test drug. And of course, the test drug may not be effective.

All medical research in the UK has to be approved by an ethics committee. There should always be an information sheet to explain the research and what you would be asked to do. You should never be put under any pressure to take part in research. If you do choose to take part, you may not benefit yourself, but you will be helping to increase the information available about dementia and its treatment.

If you become unable to consent, your welfare attorney or your nearest relative might be asked to agree to you taking part in research. Talk to them now so that they know your wishes.
There is a great deal of research into the causes and treatments of dementia.

Be cautious of exaggerated newspaper reports of a research ‘breakthrough’.

If you are asked to take part in research, make sure you understand fully what this will mean before you decide.

Talk to your welfare attorney or your nearest relative so that they know your wishes about taking part in research in the future.
Further help – for you and your family

24 hour Dementia Helpline
Freephone: 0808 808 3000 (24 hours)

For further information, or to talk things over confidentially with someone who understands, call the free Dementia Helpline. The Helpline is open 24 hours a day, every day of the year. Your family and friends can call the Helpline too.

If you get a message about your number being withheld, call again but dial 1470 before the Helpline number. This does not affect your confidentiality.

Alzheimer Scotland
22 Drumsheugh Gardens
Edinburgh EH3 7RN
Phone: 0131 243 1453 (office)
Email: alzheimer@alzscot.org
Website: www.alzscot.org

Alzheimer Scotland is Scotland’s leading dementia charity. They provide services, and campaign nationally and locally to raise awareness of dementia and influence government. They produce information for people with dementia and for carers, and run the Dementia Helpline and local information services. Their website includes a wide range of free information for both people with dementia and carers.

Scottish Dementia Working Group
81 Oxford Street
Glasgow G5 9EP
Phone: 0141 418 3939
Email: sdwg@alzscot.org
Website: www.sdwg.org.uk

The Scottish Dementia Working Group (SDWG) is an independent group run by people with dementia, and funded by Comic Relief and Alzheimer Scotland. Membership is open to people with dementia. The purpose of the SDWG is to campaign to improve services for, and attitudes towards, people with dementia.
Dementia Services Development Centre
Iris Murdoch Building
University of Stirling
Stirling FK9 4LA
Phone: 0178 646 7740
Website: www.dementia.stir.ac.uk

The Dementia Services Development Centre disseminates research and good practice guidelines concerning home and hospital care for people with dementia. They do not provide support services for individuals, but their library and information service is open to the public and offers reading lists, an online catalogue, book loans and photocopies of journal articles (there is a charge for photocopying or postage).

Down’s Syndrome Scotland
158/160 Balgreen Road
Edinburgh EH11 3AU
Phone: 0131 313 4225
Email: info@dsscotland.org.uk
Website: www.dsscotland.org.uk

Down’s Syndrome Scotland works to improve the quality of life for everyone with Down’s syndrome. They provide information, support and advice on Down’s syndrome and dementia.

Department for Work and Pensions
Benefit Enquiry Line for People with Disabilities
Freephone: 0800 88 22 00
Textphone: 0800 24 33 55

Gives confidential advice on the benefits available for people with dementia and carers, and can complete forms for you over the phone.

Pension, Disability and Carers Service
Phone: 0845 60 60 265

Offers home visits for benefit checks and to help with the completion of claim forms for people aged 60 or over.

Driver and Vehicle Licensing Agency
Drivers’ Customer Services
Correspondence Team DVLA
Swansea SA6 7JL
Phone: 0870 240 0009
Textphone: 01792 766 366

Scottish Driving Assessment Service
SMART Centre
Astley Ainslie Hospital
133 Grange Loan
Edinburgh EH9 2HL
Phone: 0131 537 9192
Useful publications

There are several helpful publications, including:

**Don’t make the journey alone – a message from fellow travellers**
A booklet written by people with dementia, for other people with a diagnosis of dementia.

**Coping with dementia: a handbook for carers**

**Dementia – Money and legal matters: a guide**

**Getting help from your doctor: a guide for people worried about their memory, people with dementia and their carers**

**Understanding dementia: a guide for young carers**
For young people aged 12–18.

**I’ll get by with a little help from my friends**
Information for friends of people with dementia.

**What is dementia?**
A booklet about dementia for adults who have a learning disability

You can get these and other booklets free from the Dementia Helpline on 0808 808 3000. Most publications are also available online at www.alzscot.org
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Notes
Notes
This booklet is for you if your doctor has told you that you have dementia. Your doctor may have told you that you have a particular kind of dementia, such as Alzheimer’s disease, vascular dementia or multi-infarct dementia. This information, however, is for people with any type of dementia. It was written with the help of members of the Scottish Dementia Working Group, who all have a diagnosis of dementia. The quotes in boxes are all from people who, like you, have dementia. This booklet will help you feel less alone.

Sections include:
- About dementia
- Emotional reactions
- Dementia and other people
- Practical support
- Medical treatment
- Staying well
- Tips for coping
- Driving
- Work
- Money matters
- Planning for the future
- Further help

Please carry this dementia helpcard with you. It provides useful advice for you and other people.