

# Diagnosed with dementia?

A diagnosis of dementia does not mean sudden illness or dependency on others, or the need to move into a care home.

## Feelings and emotions

Now that you have been diagnosed with dementia, as with any other medical diagnosis, you may experience a whole range of emotions. It will take time to adjust to the diagnosis. These feelings may change as the dementia progresses. None of this is unusual. You are coping with something new and your brain is not quite the same as it was. No-one can tell you how that change will affect you.

You should continue with your usual routine as closely as possible, including getting out and meeting people. This can offer reassurance and provide memory prompts. Some people find that keeping and following a diary helps with day-to-day tasks and routines, and keeping appointments. If you feel that some of your interests or hobbies are now too demanding, you may need to make some adjustments or alternatively, concentrate on other interests that you enjoy. You will find that there are still a lot of activities that can give you satisfaction and enable you to meet new challenges.

## You and your GP

Although there is no cure for dementia - and it's also a progressive condition - you should still visit your GP if you notice changes. You may have other conditions so the changes you have noticed may not be as a result of dementia, it's essential that you get them checked out.

In some cases, your feelings and emotions may be a sign of depression, which can be treated. Before any visit to a GP or health professional, write down questions you want answered - it's sometimes difficult to remember everything at the appointment. If you don't understand anything, ask them to explain and, if necessary, write things down for you. You could also ask a carer or friend to go with you.

## Talking to other people

It's important to talk to someone about how you feel, you don't have to travel your journey alone. This could be your wife, husband or partner, a relative or friend, someone else with dementia, or it could be a professional, such as your GP. This will make you feel less alone and they will also be able to reassure that what you are experiencing is normal.



Talking about things can also make them less frightening and will help you work out ways of coping. OK, it's frustrating that you forget what day it is, but you can always ring someone up and ask them. Or, if going to the shops makes you anxious, arrange to go with a friend. Often a burst of physical exercise can help lift your mood; even something as simple as a walk around the block.

It's important to recognise that your family and friends can provide a fantastic source of support. You might feel embarrassed about asking for help, and explaining why you need it. So try thinking of how you would react if they were the ones asking you for your help. You'd probably be only too happy to help them. Remember, too, that people often prefer it if you tell them exactly what sort of support would help you, rather than them having to guess.

Also, remember that if you genuinely need help and support, then you have a right to it. There is plenty of professional support you can access, from help with personal care and meals, to aids around the house and financial support.



### **Link up with other people with dementia**

An excellent way to feel better about your new life with dementia is to talk with other people who have dementia. You'll find people who have experienced - and are experiencing - exactly the same problems, irritations, anxieties and strange feelings. You'll be able to swap tips and advice - and funny stories - as well as realise you are not alone. You'll also see that they are managing to live fulfilled lives. It's a good idea to link up with other people with dementia. Check out Age UK ([www.ageuk.org.uk](http://www.ageuk.org.uk)) in your area, your library and other specialist organisations, such as the Alzheimer's Society ([www.alzheimers.org.uk](http://www.alzheimers.org.uk)).

Wellbeing Cafés and social events for people with dementia are often free and are a great way to meet other people in similar situations.

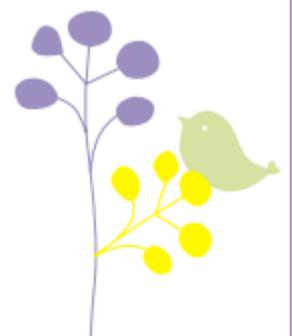
## **Telling family and friends**

**Receiving any medical diagnosis is a shock. Receiving the diagnosis of dementia is no different.**

### **When should I tell them?**

There is no 'correct' way to feel at hearing the news of being diagnosed with dementia. Everybody feels and reacts differently, both emotionally and in the processing of the information. Often a person feels vulnerable and in need of reassurance and support. They look to the closest people to them - which is usually family and friends.

It's a very individual and a personal decision to make about who to confide in, and when. There is no right or wrong way. You might want time to adjust and come to terms with your diagnosis before telling other people. Alternatively, because you have a reason why some things may have become more difficult for you, you might want to tell people quite quickly. This may even bring a sense of relief. Family and friends may also have noticed that things weren't quite right, they may have been worried about you. So seeking support and reassurance from them will not only help you, but you may also find it helps them.



### **How should I tell them?**

There are no hard and fast rules regarding how to tell friends and family of any important changes which may have an impact upon close relationships. It's up to you to choose the best time to tell them.

Don't feel rushed. However, you might want to tell those closest to you sooner rather than later, because of the support they will give you. Also, an early approach could allow additional time to be spent discussing and making plans for the future.

Try and do it calmly. Remember, having a diagnosis of dementia doesn't suddenly mean you or your life will change. You are still 10/11 the same person. The progress of dementia can be very slow, each person experiences it in different ways. Usually, this means there is plenty of time to adjust. You are not suddenly going to be whisked off to hospital or a care home. It's worth remembering that sometimes the best-made plans do not happen as they were intended. Keep an open mind and a flexible approach. Your family and friends may suggest things that you'd never thought of, or someone whom you'd never considered might pop out of the woodwork to offer help.

Remember there is no right or wrong way to behave or lead your life just because you have this new diagnosis. Follow your own thoughts, feelings and wishes. You know best what will suit you and people closest to you.



### **Telling young family members**

When there is a change or difficult situation within a family it is natural to want to protect children and young people. However, it is important to remember that they can pick up on moods and atmospheres extremely quickly. It is often better to be upfront about what is happening so you can explain to them in a controlled way. It can be even more upsetting for children to be aware that there is a problem and not have an understanding or reason for the increased tension within the family.

Children are often relieved to understand why there is a change in a parent's or grandparent's behaviour. They find it easier to accept that the behaviour is due to a condition and not directed at them personally.

### **How should I tell them?**

It is best to be as honest as possible when talking to children. Try to keep sentences short and to the point, be as reassuring as you can. Adapt the information to the age of the child so it is easily understood.

Children welcome honesty and the opportunity to express their own thoughts and feelings on a subject, as they arise. Give them plenty of chances to ask questions, then answer them honestly and naturally. Young children may need to be reminded of things more than once.

### **Coping with their reaction**

Children are individuals and will react to a situation in their own individual way. Each child will require lots of love and reassurance as they may feel grief and sadness.

If you feel that your child is finding his or her situation difficult, you may want to consider speaking with their teachers or a medical professional for advice.

There are some useful books on the subject:

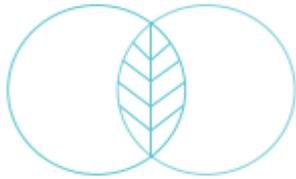
- [Grandma's Box of Memories: Helping Grandma Remember](#) by Jean Demetris
- [Can I tell you about Dementia? A Guide for Family, Friends and Carers](#) by Jude Welton



## Who you must tell

As with other conditions, there are organisations you must tell that you have been diagnosed with dementia and others that it is advisable to tell.

Organisations you must tell and some recommended steps to take.



### Driving

Having dementia does not necessarily mean you have to give up driving. However, if you wish to continue driving you must tell both the Driver and Vehicle Licensing Authority (DVLA) and your insurance company that you have been diagnosed with dementia. The DVLA need to know you are still safe to drive and will send you a questionnaire to assess your medical fitness to drive. This questionnaire is called a CG1 and can be found online and downloaded by visiting the UK government services and information website ([www.gov.uk](http://www.gov.uk)) and searching for CG1. They may then ask you to undergo a medical examination or some form of practical assessment. The DVLA will then ask for your consent to obtain medical reports from your doctor or other consultants relevant to your medical conditions. They will then decide whether or not to renew your driving licence, usually for a year at a time.

You can be fined up to £1,000 if you don't tell DVLA about a medical condition that affects your driving.

You may be prosecuted if you're involved in an accident as a result. Also be aware that your insurance may not cover you if you don't let them know your changed circumstances. Driving without a minimum of third party cover is illegal.

If you decide to stop driving, or are advised to do so by your doctor, inform the DVLA and return your licence to them.

### Financial and legal affairs

Although you may have no difficulty now taking decisions about your affairs - such as house insurance, savings accounts, and medical treatment - it's worth thinking about who you would like to take those decisions in the future when things might become harder for you. Do not assume that your next of kin will have the authority to deal with these matters. You can appoint someone through a Lasting Power of Attorney (LPA) to take decisions on your behalf.

There are two different types of LPA: a property and affairs LPA, who looks after property and financial matters; a personal welfare LPA, who looks after day-to-day matters such as health, care and your home.

You can get LPA appointment forms from the Office of the Public Guardian (OPG). The forms have to be registered, with a fee, at the OPG before they come into effect. You don't need a solicitor to draw them up but you might want to get further advice before signing one.

LPAs replace Enduring Powers of Attorney (EPAs). However, any EPA signed before October 2007 can still be used. One point to bear in mind if you have an EPA is that it only covers finance and property matters. If you'd like someone to look after your day-to-day matters you can appoint, in addition, a personal welfare LPA.

A guide that you may find useful can be found on the website of a legal firm:

Wright Hassall. It can be found by going to their website ([www.wrighthassall.co.uk](http://www.wrighthassall.co.uk)) and searching for 'Complete legal guide to dealing with dementia'.



### Benefits, plus you and your employer

If you are claiming State benefits, such as Income Support, the providers will need to know about the change to your medical status. You may also find you are entitled to additional benefits. Equally, if you are not claiming any benefits you may now be entitled to some. In both cases, you may also be eligible for other forms of financial support, such as Council Tax reduction.

Benefits and financial entitlements are a complex area. You could start by asking for advice at your local Citizens Advice Bureau (CAB) or visiting the benefits section of their website on the following web address: [www.citizensadvice.org.uk/benefits](http://www.citizensadvice.org.uk/benefits)

Other sections of websites you may find useful are the 'Benefits' section of the government website ([www.gov.uk](http://www.gov.uk)) and the 'Benefits and entitlements' section of the Age UK website ([www.ageuk.org.uk](http://www.ageuk.org.uk)).

You should also contact your local council for advice.



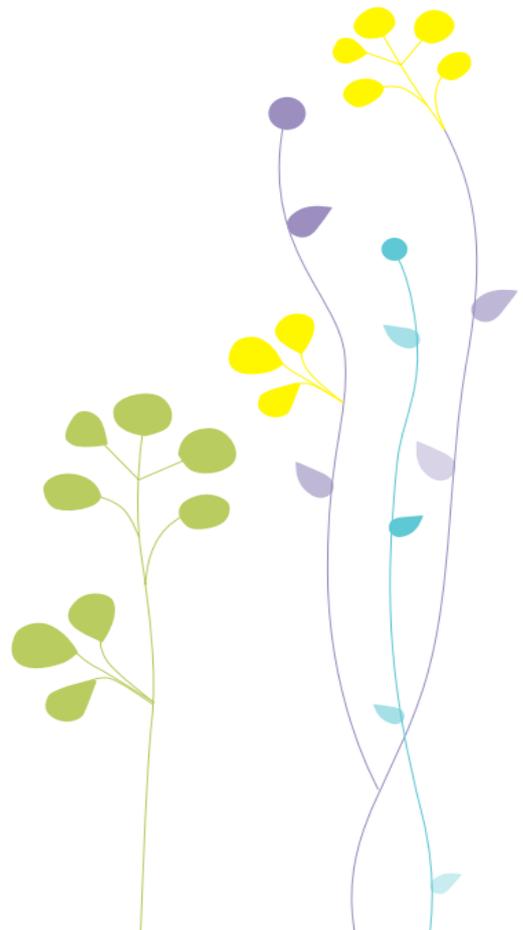
### Employment

If you are working and want to continue, you need to tell your employer of your diagnosis. You both need to discuss how your dementia might affect your work and consider the risks, as well as your capabilities and the advantages and disadvantages of you continuing work. Your employer has a legal duty (under the Disability Discrimination Act) to help you stay at work and to make reasonable adjustments. Discuss these with him or

her. For example, this could include making your hours more flexible, providing any extra equipment to help you, or you moving to a simpler job. Be aware, that if you change jobs, this could mean a drop in income and pension entitlement.

Both you and your employer could get help from the Access to Work Scheme ([www.gov.uk/accessto-work](http://www.gov.uk/accessto-work)). This can provide help towards the costs of any extra help you need, such as equipment or a support worker. For more information, contact the Disability Employment Adviser at your local JobCentre Plus office. For details of your local office visit the Contact JobCentre Plus section on the government website, and use the local office search facility located at the bottom of the page.

If you decide to stop work before you reach retirement age, make sure you get your appropriate pension entitlement for retirement due to ill health. It's a good idea to have someone with you when discussing this with your employer. A union representative would be ideal, or a friend or colleague. You could also get advice from a solicitor who specialises in employment law.



## Support organisations

For more information or advice, please call Dementia Care on 0191 217 1323 and ask to speak to one of our Dementia Guides. They offer free face-to-face support for people with dementia and their families in Newcastle upon Tyne, Hexham and the surrounding areas.

A variety of support groups will exist in your local area. To find out who they are and how to contact them, it may also be useful to contact some of the national organisations listed here:

### Age UK

[www.ageuk.org.uk](http://www.ageuk.org.uk)  
or call 0800 169 2081

### Alzheimer's Society

[www.alzheimers.org.uk](http://www.alzheimers.org.uk)  
or call 0845 300 0336

### The Lewy Body Society

[www.lewybody.org](http://www.lewybody.org)  
or call 0131 473 2385

### Carers UK

[www.carersuk.org](http://www.carersuk.org)  
or call 0808 808 7777

### The Princess Royal Trust

[www.carers.org](http://www.carers.org)  
or call 0844 800 4361

## Concerns regarding financial or other abuse of a vulnerable person

If you have any concerns regarding financial or other abuse of a vulnerable person, you should contact the **Office of the Public Guardian**:

PO Box 16185  
Birmingham  
B2 2WH

Tel: 0300 456 0300 or  
Email: [customerservices@publicguardian.gsi.gov.uk](mailto:customerservices@publicguardian.gsi.gov.uk)

Opening hours:  
Monday, Tuesday, Thursday and Friday - 9 am to 5 pm  
Wednesday - 10 am to 5 pm

