

# Being a Carer

A family member or friend has been diagnosed with dementia

Dementia affects everyone in different ways and it is difficult to say exactly what you can expect to happen and when.



**Within the existing relationship you may have become a carer**

Not only are you having to face the changes occurring to the individual with dementia but also your relationship may now involve being a carer. You may find that you need to take on additional responsibilities, including guiding, supporting and caring for the person with dementia.

It may be hard to consider the changes and be accepting of the additional responsibility. This may include financial responsibility when you are used to the person with dementia being completely independent.

If you have some idea of what to expect or what might happen, it gives you time to think about how you will deal with the changes.

To help you plan ahead, this booklet gives a general overview of what the future may hold for you as a friend or family caregiver. We also give advice and information about resources to help you to support the person you care for and at the same time ensure that you are not forgotten on their journey.

Although it might not seem like it at times, you are never alone. There is a lot of support for you as a carer, from professionals, agencies, service providers, advice centres and carers' organisations, some specialising in support for people with dementia. As a carer you also have carers' rights that are protected in law.

## Recognising there's a problem

**You think that someone has dementia, but you are at a loss to know what to do.**

### **You've started to notice things.**

You think that your friend or family member may have dementia, but how do you get them to admit that they need help?

It may be that they may not want to admit they need help. We all want to keep our independence. Recognising that we have difficulties with our memory and that we are struggling with everyday life is difficult to accept. They may simply be unaware that they are not as alert as they used to be.

Whichever is the case, it's important to be honest and talk to the person about the changes that you have noticed, such as they:

- have difficulty recalling events.
- have difficulty remembering people's names.
- have difficulty working things out.

You are both likely to feel upset and worried that it could be dementia. But, equally, knowing that there is a cause for changes in behaviour - and that support is available - can be reassuring.

### **Encouraging someone to visit their GP**

Their first step should be to visit their GP to get a diagnosis. Don't be tempted to make an appointment for someone. It's important for self-esteem that they keep their independence and remain in control. You may need to persist and gently encourage.

Before the appointment sit down together and write down all the things that are concerning you both. Ask them if they want you to go with them. Take these notes with you when you visit the GP. Suggest that you also take notes during the appointment so that you can both talk about them afterwards.

As well as examining the person, the doctor may find it very useful to ask you questions about the changes that you've noticed. It may be that the doctor makes a referral to a specialist clinic or consultant.

If they are unwilling to go to their GP, keep an eye on things and keep talking to the person, remembering that they will be feeling vulnerable. If they are totally against going to their GP you may ask if you could speak to their GP on their behalf.

The signs that you have noticed may not be dementia, it's important to make this point to the individual. For more information about the signs and symptoms of dementia or what else it may be, read our [Is it dementia?](#) booklet.

### **If dementia is diagnosed**

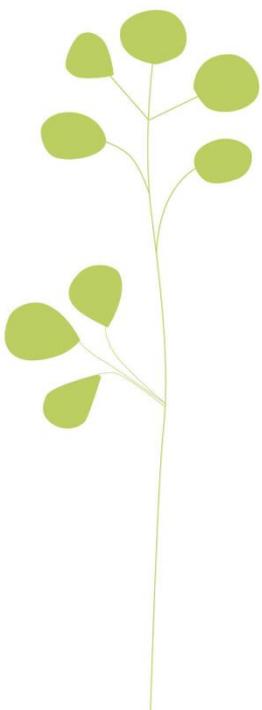
It's very important to treat a person with dementia the same as they were before, and to give them kindness and respect. When you first begin to support someone with dementia, the relationship may start to change because your role has changed. It can be hard to accept and adapt to doing things for the person with dementia.

It is likely that at times the relationship will be tested. You may resent having little spare time for yourself, and you may experience feelings of anger, fear and frustration. The person you care for may also get depressed and angry due to their imposed limitations. Both these reactions are natural. Try always to remember that the dementia isn't their fault; they are still the same person underneath. They aren't being deliberately difficult; it's the dementia that makes them appear so. Remember, it's equally frustrating and confusing for them as they try to cope with what's going on.

### **Your role as a carer**

Knowing what may happen in the future, and knowing that the dementia progresses slowly, gives you time, to think about your options and to make plans. That way you have time to adjust to your possible new future and to put plans in place.

Providing support for someone with dementia can be stressful, frustrating, lonely and tiring. You will experience many different emotions. Helping the person with dementia to cope and continue to enjoy their life can bring you



emotional rewards and satisfaction. To see what your future life might be like, the first step is to understand the condition and how it will impact on the person you care for. We suggest that you have a look at our **Is it dementia?** booklet. You should also read through the other advice and information available in our other booklets (**Diagnosed with dementia?** and **Living well with dementia**) in order to understand things from the perspective of the person with dementia. All the material contained in these booklets can be accessed in the Advice and Information area on our website ([www.dementiacare.org.uk](http://www.dementiacare.org.uk)).

## Looking after yourself

Supporting someone with dementia can be a demanding role.

### Don't forget you

It's essential, just as with any other role, that as a carer you are fit and healthy and have time to relax. You may find yourself juggling more tasks, on top of your usual roles. It is demanding physically, mentally and emotionally when supporting someone with dementia. You can quickly become rundown if you don't actively look after yourself. Research shows that carers are much more likely to experience poor health than those who don't have caring responsibilities.



### Health

Make sure your GP knows you are now a carer. This means they will not only be able to offer advice and support with regard to your caring but also be aware that this could be affecting your health. Don't ignore anything unusual regarding your own health. You may feel you have to battle through and have no time to see the doctor, but get it checked out. If you become ill, you will be in a worse situation.

You may feel increased irritability, difficulty making decisions, poor sleep and tiredness. Don't ignore these signs. Many people find just acknowledging them and then talking about how they feel with other people is a big help.

As a busy carer you should also make sure that you look after your own diet. You can read the Diet and Nutrition section of our Living well with dementia booklet for some advice and useful information or you can access this information through our website.



### Consider joining a carers' support group

Support groups can provide information, practical help, emotional support and companionship.

### Find a carers' support group in your area.

#### Carers UK

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

#### The Princess Royal Trust

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

Realising you are not alone can bring relief. Talk with friends; you might find that when they realise what you are coping with, they offer all sorts of help and support. You could also see your doctor; talking with them might be all that's needed to bring relief.



### Rest and social life

Having a break from your caring routine is vital.

Try and maintain your interests and activities by setting aside regular time for them. This may mean making plans for someone else help whilst you're out. Friends or family might be able to take over. You may also find that the person with dementia could benefit from attending a day centre in your local area, which will also give you time to yourself. Research what is on offer via your local authority. They should have information on their website. Under the Care Act 2014 it is the duty of your local authority to establish and maintain information and advice services relating to care and support for all people in their area.

### If you are struggling

If you are struggling, don't just try to carry on. Find someone to talk to, whether a professional, such as your GP, another carer or friends.

Remember, it's not a failure to ask for support. It's a positive step. Talking about your feelings regarding the possible changes in your relationship, can help you understand why you feel the way that you do.

Equally, just taking some moments for yourself - going for a walk, enjoying the garden, sitting quietly with a cup of tea - just doing something that you enjoy, can help you manage.

Being a carer can also have an impact on other relationships with friends and work colleagues, as you may not have as much time. Let them know what's going on, so that they understand why you may not be in touch as regularly.



## Getting help

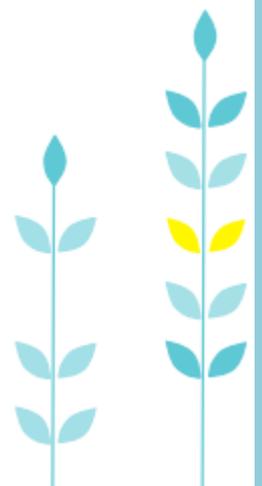
Recognise that you might not be able to do this alone.

### Sharing the care

In the early stages of someone's dementia, the support required may not be huge, but this is likely to change as dementia is a progressive condition. Find out what help you can call on. Also, be realistic about how much care you feel you are able to give to ensure the person will be properly looked after. Asking for help and additional support doesn't mean you have failed. It shows that you care enough about someone's health and welfare to want to provide the best for them. If you have any worries, concerns or anxieties, or you want advice, information or additional support, there are a wide range of professionals and specialists who can help you. These range from people who can help you with medical and health questions to those who can advise on legal, financial and personal care matters. See the **Professional Support** section of this booklet for a list of who they are and what they do.

When caring for a person diagnosed with dementia the care and support needs will increase. At some point the individual's needs may increase to a level where you feel you need additional help to support them to continue to live at home.

Under the Care Act 2014 you may approach your local authority or be referred for a care assessment - both for your needs and for those of the person for whom you care. Depending upon the outcome of the assessment you may both be eligible for services (free or paid for, depending upon financial circumstances), such as home support, respite or day services. Don't feel all the



responsibility is yours. Talk to family and friends about how you can share the care between you. Some may not realise exactly what the day-to-day demands on you are so be specific about where you need help or where you feel others could help. For example, you could arrange a rota of people to call in or take the person out so you can have a break or continue to go to work. With family that lives further away you might be able to organise alternate 'blocks of time' to divide up the caring. It's a good idea to keep reviewing the situation and have regular updates with all those who are helping you, or might be able to help, to keep everyone in the picture.

### **Training and other resources**

Caring for someone with dementia does not require you to be a medical specialist. Having ready access to information and advice on what to expect and how to deal with it may prepare you to feel more confident, and less anxious and isolated. There are organisations whom you can contact listed at the back of this booklet. These all have information on the practical side of caring, such as coping with disturbed sleep patterns, changes in diet and nutrition, daily living skills and activities, communication, incontinence issues, as well as on financial benefits, legal matters and aids to help with mobility or memory issues.

You could also consider taking a training course. There is a web based learning programme run by Social Care Institute of Excellence (SCIE) called 'Dementia Gateway'. This can be studied as an online interactive programme. It is free to access via the SCIE's website ([www.scie.org.uk/dementia](http://www.scie.org.uk/dementia)) and covers the following topics related to dementia:

- What it is and what it isn't
- Living with dementia
- What causes dementia
- Diagnosis and who can help
- Common difficulties and how to help
- The emotional impact of dementia
- Positive communication

### **Learn from other carers**

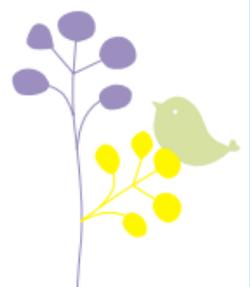
Your biggest source of support could well turn out not to be a trained professional but other carers. These carers are ordinary people, just like you, who have suddenly found themselves taking on a caring role which, in all likelihood, they never expected to be doing. Like you, they are there at the front line, dealing with the sort of problems and worries that you are dealing with, on a daily basis.

Most areas in the UK now have local carers' support groups. See the **Looking after yourself** section in this booklet for information about these groups and how to contact them. You can share hints and tips, and learn from others how they dealt with a particular situation. Sharing experiences also shows you that you are not alone and can relieve some of the feelings of isolation and helplessness. Never assume that the person you care for is the only one to present with a particular problem. It is more than likely that others have been through exactly the same thing.

You might not be keen on joining a group but at least give it a try. Remember, other people are probably looking for someone to chat to, too. And if you don't fancy meeting up with people in person, or are not able to, you could try an online Chat Forum.

### **Carer relief**

A major risk for carers is that you may become socially isolated. Struggling alone increases levels of stress and your ability to cope. It is important to get a break from caring to pursue your own interests and hobbies or visit friends. The break can vary from just a few hours to several weeks. Also, respite breaks may be



needed if you become ill, need a stay in hospital or have other important life commitments.

Many carers feel worried or guilty about taking a break and leaving the person they normally look after. For some people with dementia it is better if the care continues to be provided in their familiar environment of home. If the person does not need support 24 hours a day, then a package of care can be arranged, involving a variety of people such as friends, relatives, social services home care agencies or private or voluntary care agencies.

You might also consider local Day Care Clubs and Centres which can offer both new social opportunities and stimulating activities for the person you care for as well as a valuable break for yourself. These are usually half- or full-day placements, and can be arranged on a regular weekly basis. For longer stretches, respite breaks can be provided by residential care homes and nursing homes. It's a good idea for you to visit a number of places to find the most appropriate environment for the person you care for.

Remember, the person you care for is entitled to a community care assessment to find out what type of care is required. You, as a carer, are also entitled to your own carer's assessment, which will detail the type and frequency of breaks you need in your own right. A financial assessment may need to take place, and in some cases a contribution, classed as a reasonable amount, may be required towards the cost of care.



## Professional Support

If you have any worries, concerns or anxieties, or you want advice, information or additional support, there are a wide range of professionals and specialists who can help you.

### Who they are and what they do

Professionals that can support someone with dementia range from people who can help you with medical and health questions to those who can advise on legal, financial and personal care matters. Here we explain who they are and what they do.

#### General Practitioners or GPs

Everybody should have a named GP, who is local to where they live and looks after their general medical health. The GP is the first point of call for any medical concerns, including memory problems. The GP may make a referral for you to see a consultant. All GPs have to provide an Out of Hours Service, to ensure that any patients in their practice can access medical advice at all times day or night.

#### Dentists

Dentists provide treatment and advice regarding the care of your teeth, oral health and hygiene. They can also do home visits and advise carers on assisting

someone with oral hygiene and oral health maintenance. Dentists provide services both privately and through the National Health Service.

#### Opticians

Opticians specialise in a person's sight, eye health and aids to help people see better - such as glasses and contact lenses. A problem with a person's sight can cause and add to problems of confusion for anyone, and for a person with a diagnosis of dementia it can be of fundamental importance. Opticians usually recommend yearly checkup examinations, and can provide a service at home.

### **Chiropodists**

Chiropodists, or Podiatrists as they are increasingly called, specialise in the health and care of feet, including toenails. By ensuring healthy feet, and freedom from pain, they provide an important service to maintaining a person's mobility. Certain types of dementia do have an impact upon stability and balance, so it is worthwhile to invest in regular chiropody treatment. Chiropodists can be accessed through your GP or privately, and will do home visits.

### **Audiologists**

Audiologists check for hearing problems and can fit a hearing aid if appropriate. Again, it is important for a person with a diagnosis of dementia to have the best level of hearing as is possible, to avoid misunderstandings leading to confusion.

### **Solicitors**

Solicitors offer legal advice, help and information, and carry out legal processes in a wide range of areas. This can include help with, for example, selling your home or drawing up a Will. In some cases you may wish to speak to a solicitor about a **Lasting Power of Attorney (LPA)**. The law can be complicated so it's important to get the best advice you can. A firm of solicitors may offer services in a wide range of legal subjects although more and more solicitors are specialising in only one or two subjects. All solicitors in private practice must hold a practising certificate issued by the Solicitors Regulation Authority, monitored by the Law Society. If you are on a low income or receiving benefits you may be eligible for Legal Aid. You can find out by contacting your nearest Citizen's Advice Bureau or Law Centre.

To find a solicitor in your area, you can use The Law Society website ([www.lawsociety.org.uk](http://www.lawsociety.org.uk)) or call 020 7320 5650.

### **Social Care Workers**

Social Care Workers can be employed by various organisations including Care Homes, Community Service Teams and Home Care Providers. They have a variety of titles such as Personal Assistants, Home

Care Workers and Carers. Their job is to help someone with daily living skills such as bathing, dressing and meal preparation. All staff should be trained in basic skills such as moving and assisting people, first aid, health and safety, and safe-guarding adults. If working with people with dementia, it is preferable that they have dementia specialist training. Their duties are outlined in each person's individual Care Plan, drawn up after an assessment of a person's needs. The Care Plan will have been agreed by the individual together with their family or carer.

### **Social Workers**

Social Workers are part of your local Social Services department. Where an individual meets the eligibility criteria the Social Worker will usually be involved in assessing a person's needs for social care services and arranging its provision. This could include daily visits to help with washing and dressing, or preparation of meals. These services are detailed in a person's individual Care Plan, which will have been agreed by the individual together with their family or carer. Social Workers can often be referred to as Care or Case Managers.

### **Practice Nurses**

Practice Nurses are based at your GP's surgery and can provide help and advice in relation to your health and well-being.

### **Continence Advisors**

Continence Advisors have a nursing background and give advice about any continence issues. This includes the management and care of any continence issues, products that can help, as well as medical advice. The service is always confidential and empathetic.

### **Occupational Therapists (OTs)**

Occupational Therapists advise on adaptations to the home, and any equipment that could allow people to maintain their independence for as long as possible. Occupational Therapists are usually provided by your local health or social services. Contact your GP or Local Authority Social Services department.



### **Dieticians**

Dieticians provide advice and guidance about food, nutrition and issues surrounding poor appetite, weight maintenance, food supplements and vitamins. Your GP or consultant can refer you to a dietetic service if they feel it necessary.

### **Speech and Language Therapists**

Speech and Language Therapists help people who have communication difficulties. They can offer specialist training and exercises to try and improve their communication skills and also advise on relevant communication aids. They can also help people who experience swallowing problems, which then may in turn have an affect on a person's diet and weight loss. You may be able to be referred to a Speech and Language Therapist through your GP, or local health or social services.

### **Independent Mental Capacity Advocates (IMCAs)**

Independent Mental Capacity Advocates (IMCAs) are people who can speak and act on your behalf if you have no family or friends available to be consulted. They support you at a time when you are no longer able to make decisions or find it too difficult. IMCAs can take decisions on various matters including your medical treatment, your care needs or moving from your home to a care home. They are appointed under the Mental Capacity Act. Your local Social Services department can give you local contact details.

### **Adult Safeguarding Teams**

Adult Safeguarding Teams protect vulnerable adults. The team are multi-agency, including social workers, police officers, housing officers, doctors and nurses etc. You can contact your Adult Safeguarding Team via your local council or the police.

## **Specifically focused on dementia**

### **Consultants**

Consultants are doctors who have years of experience and specialised training in a specific area of medicine. Consultants who are usually involved in the treatment of people with a diagnosis of dementia are:

- **Neurologists** - specialists in disorders of the brain and nervous system
- **Psychiatrists** - specialists in a range of mental health illnesses
- **Old Age Psychiatrists** - specialists with further training in mental health issues of older people

### **Admiral Nurses**

Admiral Nurses work for Dementia UK, and offer skilled assessments of the needs of people with dementia, their family and carers. They work with families from the point of diagnosis and throughout the caring journey, providing emotional and psychological support as well as information and practical advice on caring, plus guidance about accessing services.

As well as assisting with caregiving, Admiral Nurses help all concerned to develop and improve their skills, and to develop positive approaches to living with dementia. They work with other professionals and organisations to make sure the correct care is in place. They also enable families and carers to express their wishes and views about the services they receive.

For more information call 0845 257 9406 or visit [www.dementiauk.org](http://www.dementiauk.org).

### **Community Mental Health Nurses**

Community Mental Health Nurses, also known as Community Psychiatric Nurses (CPNs), work within the community in people's homes and at GP practices. They are trained to provide treatment, care and support for people with mental health problems and dementia. The nurses carry out assessments of people at home and can offer advice on how to cope, improve health and quality of life.

## Know your rights

As a carer, you have rights protected in law.

### You have legal rights

With the pressures and demands of caring for someone, you might feel as though you have no-one looking out for you. This is not the case. Knowing what they are could help you get the support that you need.



### Your right to an assessment of your needs

The Care Act 2014 states:

“Local authorities must promote well-being when carrying out any of their care and support functions in respect of a person. This may sometimes be referred to as ‘the well-being principle’ because it is a guiding principle that puts well-being at the heart of care and support.

The well-being principle applies in all cases where a local authority is carrying out a care and support function, or making a decision, in relation to a person... It applies equally to adults with care and support needs and their carers.”

You should contact your local authority Social Services department who should provide you with advice, information and guidance regarding assessment for your needs as a carer. For information online go to the Carers' UK Website ([www.carersuk.org](http://www.carersuk.org)).

### Access to benefits for carers

As a carer, you could be eligible for financial benefits and support to help with the costs of providing care. Make sure you are getting everything to which you are entitled. For more information, visit the Claiming Benefits section of Age UK's website ([www.ageuk.org.uk](http://www.ageuk.org.uk)) or contact your local Citizen's Advice Bureau.

For more information about your rights as a carer, contact:

#### Carers UK

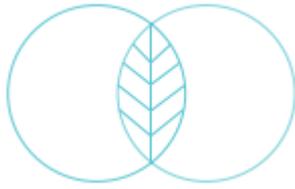
Visit [www.carersuk.org](http://www.carersuk.org)  
or call 0808 808 7777

#### The Princess Royal Trust

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



## Combining caring with work or education



### Balancing work and caring

There is no reason why you cannot continue to work or study while also caring for someone. However, balancing the two demanding roles of work and caring can be extremely difficult. Whilst you may benefit financially by continuing to work, it can take its toll on your health and well-being. It's important that you remain both physically and emotionally well.

### Talk to your employer

As a carer you are not obliged to inform your employer that you also have a caring role but it could be helpful. You may be able to arrange flexible working hours, and your employer may be able to make reasonable adjustments which would enable you to manage both roles more easily.

Remember to talk to work colleagues about your caring role and the difficulties it brings. Three in five of us will be a carer at some point in our lives, and you may be surprised at how much support you will receive.



### Balancing education and caring

Carers often say they would like to learn a skill or study a course but they have no time to fit it in. Or they feel guilty for even thinking about further education opportunities. It is important to remember that by having an activity or interest outside of your caring role you may improve your sense of identity and increase your confidence levels. These will benefit both yourself and the person you care for.

### Talking to your tutor

If you find that you are having difficulty completing coursework or meeting required deadlines on assignments, remember that your course tutor or the college pastoral tutor is available to discuss any personal problems. It is their role to listen and see what they can do to enable you to succeed in your studies.

Your local college will offer a variety of part-time evening or day courses which cover a wide selection of topics. Consider what you'd like to learn, how much time you have available and what level of study you want to pursue. And think about the benefits you'll gain, too. Don't rule out distance and e-learning opportunities.

The carer's role and associated difficulties are well understood by most people. There are a lot of possibilities which could be explored in order to enable you to meet course requirements. For example, you could ask for time extensions for assignments or see if it's possible to study at home through e-learning courses or tutoring. Explain that you may be unable to make all of the set days for the course, and see what alternative arrangements be put in place.

### 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

