

# Carers Road Map

A Guide for Carers of People  
with Dementia





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# Introduction

**Receiving a diagnosis of dementia can be an enormous shock, not only to the person with the diagnosis but also for their close relatives and friends. But it is important to remember that people can live well with dementia and with the right support can stay living in their own home and participating in community life.**

Family and friends play a vital role in supporting and caring for those diagnosed with dementia. While this can be enormously rewarding it can also be quite daunting. The Carers Road Map aims to guide carers through their caring experience and provide practical advice and information to help family and friends who are supporting someone with dementia. Some of the information in the guide may be useful to you early on, when the person you care for is first diagnosed with dementia, and some at a later stage. You may also find it useful to dip into at different times.

The Carers Road Map has been developed from research commissioned by Carers Trust – *A Road Less Rocky – Supporting Carers of People with Dementia*<sup>1</sup>. The research found that although there is no typical caring journey there are ten points in the caring journey where, if carers had more information and support the experience of caring for someone with dementia would have been made a little easier. We have used this research to provide that information and support in the form of this new Carers Road Map.

Although the terminology and legislation referred to in this guide applies to England the general guidance is applicable across the whole of the UK.

<sup>1</sup> Newbronner, L, Chamberlain, R, Borthwick, R, Baxter, M, and Glendinning, C (2013), *A Road Less Rocky – Supporting Carers of People with Dementia* (Carers Trust).

# 1 When dementia is diagnosed

**Having a diagnosis of dementia which explains the changes in the person close to you is important. It means you can work together to put in place strategies to manage the dementia and consider the option of medication which can sometimes help the symptoms and slow the progress of the condition. Unfortunately, there is no cure for dementia at present, however people can live well with dementia for many years.**

## The importance of getting a dementia diagnosis

A timely diagnosis can:

- Open doors to much needed services.
- Give you access to extra finances.
- Allow you and the person you care for time to plan for the future.

Ensure you get the support you need as a carer. While caring can be rewarding it can also be stressful and exhausting. It is vital you take good care of yourself and know where to go when you need support and information.

### Tips

- Get in touch with your local carers service. See [www.carers.org](http://www.carers.org) or tel 0844 800 4361.
- Contact local dementia support services for more information.
- Tell your GP you are a carer.
- Speak to your human resources department if you are in work. They may be able to offer flexible working or carers leave.
- People can live well with dementia.

## Getting a diagnosis

You may find that getting a diagnosis for someone with dementia is not that straightforward. This is especially the case if the person with the condition is reluctant to seek help, or is still quite young. If you are unable to persuade the person you are concerned about to get help, this does not exclude you from doing so. Your local carers and dementia service will be able to offer you support regardless of whether the person you care for has been diagnosed with dementia. Also speak to your GP if you are struggling to manage as they may be able to give some practical advice.

A diagnosis of dementia is most commonly made by a consultant psychiatrist who is a specialist in memory problems. The GP will normally run through some basic tests and if there are any concerns will then refer onto a local memory clinic, these are based in community locations and offer assessment, support, information and advice to those with memory problems and their carers.

## Being involved as a carer

A carer is anyone who cares, **unpaid**, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support.

As a carer you should be given every opportunity to be involved from the start when the person you care for is diagnosed with dementia, particularly regarding their care and the treatment of their symptoms. By involving carers and relatives in this way it can lead to better care for people with dementia.

It is important that:

- You and other family members are consulted about your willingness and ability to care.
- You are given information about the type of dementia and its possible progress.
- You are given advice and information in order to understand and manage changes in the memory and behaviour of the person you care for and make plans for the future.
- You remember that we are all individuals and although there are some common symptoms, dementia will affect each person differently.

As a carer, your experience will give you a certain amount of expertise. Speaking to the GP and consultants regarding the person you care for is important. As a carer you are likely to spend a large amount of time with the person with dementia. This will give you the knowledge and experience of how the dementia specifically affects the person you care for.

Most professionals working in dementia will be only too pleased to consult with carers. However, if you experience problems being heard and consulted, contact your local carers or dementia service for support and advice.

## Confidentiality

Confidentiality is an issue which many carers are concerned about. GPs, consultants and other staff do have to abide by the patient's rights and wishes in this area. However, they must give you enough general information to enable you to care effectively. Professionals also have a duty to let a carer know if the person they care for is at significant risk.

- Confidentiality does not prevent the carer from giving the professional information about the person they care for.
- Confidentiality works both ways so any information you give in confidence should not be passed to the person you care for.

Northumberland, Tyne and Wear NHS Foundation Trust has produced an excellent guide for carers – Commonsense Confidentiality. It is available on its website at [www.meridenfamilyprogramme.com/download/recovery/confidentiality-and-information-sharing/Commonsense%20Confidentiality%20\(2\).pdf](http://www.meridenfamilyprogramme.com/download/recovery/confidentiality-and-information-sharing/Commonsense%20Confidentiality%20(2).pdf).

### Tips

- If you are having trouble getting heard, where possible make a separate appointment for yourself and/or telephone or write to the practitioner concerned.
- Remember, you can give the GP or consultant information, even if they are reluctant to give you any.
- Ask questions if you don't understand (often a lot of medical terminology is used).
- Contact your local carers service for advice and support.

## Access to specialist teams

You might find it useful to get help with navigating NHS and social care services. Ask your GP or local memory service for help to understand what is available in your area, and which organisation delivers each service. The person with dementia may be referred to a number of services that can help, for example:

- Memory service.
- Occupational therapy.
- Physiotherapy.
- Community psychiatric services.
- Local dementia support and activity groups.

These services may be able to help with advice including ways to approach and manage changing behaviour and medication to relieve symptoms.

There are also a number of voluntary organisations which offer support. As a carer you should be offered information and/or a referral to local carers and dementia services. They will be able to help you come to terms with the diagnosis, meet other carers and put strategies in place to help with everyday living, and planning for the future.

### Tips

- Keep a list of the name and contact number of each service you come into contact with.
- Ask what support is available for you as the carer and for the person with dementia.
- Get help with navigating NHS and social care services.

## Advice and information about dementia-related medication

You may find that you take on the responsibility of managing medication for the person with dementia so it is important to get help with this. Where possible, as a carer you should be included in the conversation about choices of medication, potential effectiveness and any side effects. This should not only be restricted to dementia medication but include all medication taken.

Community pharmacies now offer extended services and can be an excellent and easily accessible source of information on medication as well as minor ailments. Your local chemist or pharmacy will have a community pharmacist available to give advice – just ask at the counter to see them. They will have a small consulting room available if needed where you can have a private conversation.

## Tips

- The community pharmacist can give advice on medication.
- When the pharmacy is closed, for advice on any health problem and details of other health services, contact your out-of hours GP or NHS 111. Call 111 if you or the person you care for urgently need medical help but it's not a life-threatening situation. If it is a life threatening situation, call 999 immediately.

## 2 When the carer takes on an active caring role

**Dementia is a complex, unpredictable condition. As the condition progresses, close relatives and friends may find themselves offering an increasing amount of support to enable the person with dementia to manage their everyday life. While caring for someone can be rewarding it can also be challenging and you are likely to find yourself having to adjust your life to accommodate the extra demands put on you. Therefore, it is important to take time out when you can, to look after your own health and wellbeing.**

### Getting information about dementia

It can help to understand more about dementia so ask the health professionals you are in contact with to explain it. The term dementia is used to describe a set of symptoms which can include memory loss, confusion and difficulties with concentration and language. Dementia is caused when there is damage to the brain through diseases such as Alzheimer's or the result of an event such as a stroke. There are a number of different types of dementia and a person can be affected by more than one.

Dementia is more commonly diagnosed in people over 65. It can also affect young people when it is often referred to as early-onset or young onset dementia.

For more information about the different types of dementia contact a UK or local dementia service.

## Tips

- 🟡 Contact your local Carers Trust carers service, see [www.carers.org](http://www.carers.org) or call 0844 800 4361.
- 🟢 Order a free dementia guide from Alzheimer's Society.
- 🟡 Contact your local dementia service. You can get details from Alzheimer's Society.
- 🟢 For information on young onset dementia contact Young Dementia UK.
- 🟢 Ask questions during appointments for you or the person you care for.
- 🟡 Look for other local voluntary organisations that can help, for example Age UK.
- 🟢 Tell your family and friends about the diagnosis of dementia and your role as a carer as they can often be a great support.

## Life doesn't stop with a diagnosis of dementia

People diagnosed with dementia can live well and continue to take an active part in family and community. Putting in strategies to manage the symptoms and forward planning can help you and the person you care for enjoy life.

As a carer you can still appreciate going out and spending time with the person with dementia.

- 🟡 It is important that you still continue taking part in activities that you have always enjoyed together.
- 🟢 Keeping active can help both of you keep physically and emotionally well and prevent isolation.
- 🟢 As the dementia progresses, it can be enormously stimulating for the person with dementia to feel the sensations and hear the sounds outside.
- 🟡 Taking the person you care for to a favourite park or cafe or just sitting in the garden can help stimulate their mind and bring back memories.

The important thing about going out is to just go with the flow and try not to be disappointed if plans have to change. Even if the person you are caring for almost immediately forgets the outing, the moment has been enjoyed and the positive feelings often remain. There are strategies and ideas available which can help with having a good day out and Care UK has produced a handbook which is available on [www.careuk.com](http://www.careuk.com).

## Local and UK support and information services

Making contact with UK and local organisations can be invaluable and can help ensure that you don't become isolated from friends and family. It will give you the opportunity to meet other carers and get valuable information and advice about how to look after yourself as well as the person with dementia.

Carers services often run programmes which cover caring for someone with dementia as well as looking after yourself.

There are many different sources of support and information available to carers and people with dementia. It is important to choose the right support for you.

Carers and those with dementia can access:

-  Helplines.
-  Support and activity groups.
-  Information programmes.
-  One-to-one support.

Talk to your memory service or GP about local carer and dementia services.

## Community care assessment and a carer's assessment

If you are providing, or intend to provide, any level of care for someone it is important you take steps to look after your own needs. Try not to slip into taking on more caring tasks without noticing and make sure you don't neglect your own health and wellbeing.

Carers and those they care for have a right to an assessment of their needs. This is usually carried out by the local social services department. The assessments can either be carried out together, or separately where this is not appropriate. They may also include any other family members either involved or affected by the situation.

-  For the carer this is known as a carer's assessment.
-  For the person being cared for this is known as a community care assessment.

Getting a carer's assessment and a community care assessment early on should give you access to local services. It also ensures that local services are aware of the important role you play in the care of the person with dementia.

If the person with dementia refuses an assessment or service, this does not mean you as the carer are excluded from a carer's assessment and any available services. Carers are entitled to services in their own right.

It is important to ask for a review of the carer's assessment and the community care assessment if things change. As dementia progresses it can create stress points. Your own circumstances can also change, for example, you may have concerns about your own health, employment, finances or other family members.

## Tips

- ❖ Contact your local social care or carers service or talk to the memory clinic to request a carer's assessment for you, and a community care assessment for the person you care for.
- ❖ Don't forget, you are still entitled to an assessment and support even if the person you care for refuses it.
- ❖ The carer's assessment should cover your needs as a carer, including your need to work, and other family and community commitments.
- ❖ If the situation changes ask for a review.
- ❖ Prepare for the unexpected by registering with your utility company's priority service register as a vulnerable household, in case of power cuts. You will be flagged up as a priority for assistance.
- ❖ Talk to Your GP or memory service if you have any concerns.

## 3 Legal and financial planning

**Getting advice on legal and financial issues is essential for anyone diagnosed with dementia and their carer. It is important to get advice before the person you care for has lost the capacity to make informed decisions about the future, or the need for residential care.**

### Lasting power of attorney

Having a lasting power of attorney in place will ensure that if the person with dementia loses capacity, someone they have chosen and trust can look after their affairs on their behalf. To set one up you can either use a solicitor or other trained adviser, or make the application yourself.

There are two types of lasting power of attorney:

- 1.** One covers financial matters and allows the nominated person (the attorney) to make decisions about finances and have access to them.
- 2.** The other covers personal welfare and allows the nominated person (the attorney) to make decisions about where someone should live, how they should be treated medically, what they should eat and who they should have contact with.

If a lasting power of attorney is not in place and the person you care for has lost capacity, it is still possible to get permission to act on their behalf. An application can be made to become a deputy through the Court of Protection. However, this can be time consuming and costly.

### Advance statements and advance decisions (living wills)

As well as a lasting power of attorney the person with dementia can make an advance statement and advance decision. These are often known as living wills.

- An advance decision to refuse treatment is legally binding as long as it fulfills certain requirements. It allows someone to refuse treatment in advance of a time when they don't have the capacity to make a decision for themselves.

- An advance statement is not legally binding. It is a general statement of someone's wishes, and what is important to them. It is usually written down and can contain any information they feel is important for others to know, such as religious, cultural, food and care preferences.

Ensuring that you and the person you care for have these legal documents in place at the earliest possible time will provide peace of mind and sometimes financial security. It ensures the wishes of the person with dementia are respected. You might find it can relieve a lot of stress and anxiety if you are having to make important decisions on behalf of the person you care for.

## Tips

- Plan for the future as soon as possible.
- A lasting power of attorney can only be drawn up while the person still has capacity to understand the process, so don't put this off.
- You will need a lasting power of attorney if you wish to manage someone else's finances and have access to pay for care and other costs.
- You will need a lasting power of attorney that covers health and welfare to make decisions about the medical treatment, social care or housing of the person you care for.
- Contact the Office of the Public Guardian if the person you care for has lost capacity to make a lasting power of attorney.
- Get financial and benefits advice online or from your local Citizens Advice or Age UK.

## Making a will

It is important to make a will regardless of whether you have any possessions or money. A will does not necessarily need to be drawn up by a solicitor. However, unless the will is straightforward it is advisable to seek help. Citizens Advice has some excellent information online or you can visit a local office for one-to-one support.

## Financial and other support

It is important to find out about any financial support you may be entitled to as a carer as caring for someone with dementia can be expensive. You can have a benefits check by a trained adviser to ensure you find out about help you may be entitled to. This includes:

- Carer's Allowance, a benefit for carers.
- Attendance Allowance, a benefit for someone whose ability to keep safe or look after their own personal care is affected by physical or mental illness or disability.
- Personal Independence Payments (PIP), a benefit for someone with a long-term health condition or disability.

There are a number of other financial entitlements which your local authority, or carers, dementia or disability advice service will be able to help you with.

If you are struggling with juggling work and caring:

- Contact your human resources department or manager to let them know the situation.
- Get in touch with your local authority, or local carers service about a carer's assessment for you and a community care assessment for the person you care for.

This will give you the opportunity to explore available support, which could help you stay in work.

### Tips

- Contact your local Citizens Advice or other advice service for information about claiming benefits and ensure you are getting the financial support you are entitled to.
- If the condition of the person you care for deteriorates, you may be entitled to increased support. Ask at your local advice agency.

## 4 When the person with dementia needs more support

**As a carer you are likely to come into contact with a number of different professionals. They may check you have all the relevant information you need but if you are not sure about something, just ask. As the needs of the person you care for change, it is important to get good quality information and support. This will help you keep well and continue to care effectively.**

You can find out more about getting information and advice on legal and financial planning, in the previous chapter.

### Getting advice about coping with dementia

If you are concerned about whether you are doing or saying the right thing when caring for someone with dementia you can get help from your local carers or dementia service or the Dementia UK Admiral Nurse Helpline.

Communicating and stimulating someone who has dementia can be difficult. Memory and concentration are two major areas affected by the condition and loss of these can make a person frightened, confused and anxious.

- Keeping to routines and equipping yourself with some strategies can help.
- There are some simple ways of making your home dementia friendly which can relieve stress and anxiety for you and the person you care for.
- Using memories from the more distant past, creating memory boxes and living in the moment can all help.
- People with dementia tend to remember feelings, better than facts, for example it is better to say “put your coat or you will feel cold and wet”, rather than, “you need a coat it’s raining”.

## How to get support and advice

Support, advice and treatment can come from a variety of sources. Your GP should be able to advise which would be most appropriate. It can be reassuring to have a single point of contact for further support if needed. This can be the GP, dementia adviser or other local contact you have come to trust. It can be helpful when you come in contact with a new person or organisation, to make a note of their name and number so you can easily contact them in the future.

You can access some services directly yourself. These include your local carers service, Alzheimer's Society and Age UK. For some services however, such as community mental health teams, your GP will need to make a referral.

As the dementia progresses you may find it beneficial to receive more information and advice on how to help manage the symptoms and changing behaviour of the person you care for. It can be helpful to repeat information sessions you may have attended at an earlier stage, or get in touch with your local carers or dementia service for ongoing support or speak to an Admiral Nurse.

### Tips

- Call the Dementia UK Admiral Nurse Helpline.
- Try to make your home dementia friendly.
- Equip yourself with information and strategies for everyday living
- Contact your local carers and dementia services.
- Get information and advice from websites about dementia and caring.

## Help with managing household tasks

As well as managing the routine health and care needs of the person with dementia you may find you are increasingly taking over sole responsibility for many of the household tasks or taking on tasks you weren't particularly involved with before. These include banking and other admin, cleaning, gardening and household maintenance, driving and laundry (which may increase if the person you care for becomes incontinent).

If you start to find you are not managing with all the day-to-day tasks alongside caring you can request a carer's assessment or contact your local carers service for advice. This will allow you to explore options for outside support, such as laundry services, or employing a cleaner.

To help with the costs of caring it is important to make sure you and the person you care for are receiving all the financial help you are entitled to. As the person you care for needs more support their entitlement to disability benefits can increase. Talk to your local carers or advice service for more information.

## Getting support when the dementia progresses

As the dementia progresses you may need extra support and regular breaks from caring. Some carers find they reach a point where they are no longer able or confident to continue with the caring role.

If you feel you are becoming very tired or not managing.

- Contact your local social care or carers service about getting more support.
- Request a carer's assessment for you, and a community care assessment for the person you care for. If you have already had one, ask for a review.
- Ask about respite care and carers breaks options in your area.

The more demanding your caring role, the more important it is that you receive support. This may include regular breaks (this is often referred to as respite). Respite can come in many different forms from a few hours weekly, to longer one-off breaks. Breaks can be taken with the person you care for or separately. The important thing is that you get a break from the normal demands of life. The break should primarily meet your needs as a carer although the person with dementia may also benefit.

You may reach a stage where, however much you want to continue to care at home, it may not be practically possible. Stepping back can often have a positive effect on your relationship with the person you care for as a lot of the everyday strain of caring is removed and you can spend time enjoying one another's company. You may want to start thinking about residential care for the person you care for and you will find more information in Chapter 12.

### Tips

- Contact your local social care or carers service to request a carer's assessment and community care assessment.
- Ask for information about local respite options.
- Be honest in your carer's assessment about your own health as it may help you to receive more support.
- If you have already had a carer's assessment or a community care assessment and things have changed, request a review.
- Ask for a referral to the local community mental health team if you are struggling with changing behaviours of the person you care for.
- Don't feel guilty about taking a break, make sure it is the right break for you as the carer.

## Getting help with personal care at home

Understandably, some carers and the person they care for, can be apprehensive about accepting outside help. However, getting support and taking a break will help you to keep well and able to continue to care at home for longer. For some carers, if caring becomes physically impossible to manage, getting outside help is essential.

When the time comes to introduce outside support, it can help to do so gradually. People with dementia have very specific needs and can be particularly sensitive to change, often responding badly to new people and environments. Having information early on will enable you and the person with dementia the opportunity to explore different types of care.

The care and support system and regulations around whether you need to pay for care are complicated. Therefore, it is important to get good information from a UK organisation or a local carers or dementia service.

If you are considering getting help for the person you care for, often known as replacement care, it is important you have confidence in the service. Ask the provider whether the staff have undertaken specific dementia training and if the care staff and timings of visits will be consistent. Carers Trust and Age UK have some excellent guides on choosing care, and what questions to ask. You can also use the Care Quality Commission website or telephone to check availability and standards of care in your local area.

### Tips

- Contact the Care Quality Commission for local information about choosing care.
- When choosing a care provider ask about the standard of staff training.
- Seek help as early as possible.
- Introduce replacement care gradually.
- See the guides to choosing the right replacement care from Carers Trust and Age UK.

## 5 Care options and the cost of care

**Having information and advice on all types of care options, eligibility criteria, and how to access them, will give you the confidence to request the right type of replacement care at the right time. The health and care system can be complicated so it's a good idea to get information about what's available and to start making decisions early on about the best type of care for you and the person you care for.**

### Different types of care options

The main types of care options are:

- Domiciliary, (usually referred to as home care), which can be delivered to the person you care for in their own home.
- Residential care homes, or residential nursing homes, where the person you care for can stay either short term or long term, when it becomes their permanent home.
- Extra-care sheltered housing, which offers more independence than a care home. Residents live in small flat, but meals and care staff are available on site.
- Other options for care and support, including Shared Lives which is family based and small scale ways of supporting adults.

When planning for a move it is important to understand the needs of the person you care for and where they will be best met. For people with young onset dementia, finding a suitable option can be harder and you may have to look further afield. Age UK has some useful information on possible housing options for later in life.

### Paying for care options

Paying for care can be complicated, so it is important to get information and start planning early on. You can contact a local carers or dementia service for advice or look on your local authority website under adult care services.

The two critical points to remember are that:

1. Health costs are met by the NHS.
2. Care needs are met by the local authority and are means tested.

Sometimes, especially with dementia, the lines between health and care support can be blurred. The simplest way to think about it is, care needs include things like washing, dressing and being able to attend social activities. Health care is an intervention which requires a health professional such as a nurse, doctor or physiotherapist to carry it out.

If the person you care for is eligible to have their care all or partly funded then it can be delivered in three main ways:

1. As a service, for example someone attending a day centre, or home care organised by the local authority.
2. As personal care budgets in the form of a direct payment, so instead of receiving a service from the local authority you receive the equivalent in money, which you can use to arrange your own service.
3. As a combination of both a service and a direct payment.

People who are assessed as having to pay for their own care can still choose to have it organised by the local authority.

If a person's medical needs are extremely high NHS continuing healthcare is a package of care arranged and funded solely by the health service in England, it has strict criteria.

Personal health budgets were introduced in 2014 and at present apply to a small group of people, however the government wants to extend this choice to more people in the future.

## Tips

- 👉 Contact Young Dementia UK for younger people with dementia.
- 👉 Plan early for possible future housing options. Download or order a factsheet from Age UK.
- 👉 Contact your local carers service for information on what is available in your area.
- 👉 Ask the GP or consultant what level of care is needed before you look for a residential home.
- 👉 You may want to consider using Shared Lives.
- 👉 If you are caring for someone with complex health needs ask your GP about personal health budgets and NHS continuing healthcare.

## 6 When the carer needs emotional support and/or a break from caring

**You may find that getting emotional support for yourself can help improve your health and wellbeing. Emotional support can be particularly helpful at certain stages as the dementia progresses in the person you care for. It is also important to recognise that your own circumstances as a carer may change, irrespective of the health of the person you care for.**

Emotional support can come from a variety of sources:

- Family and friends.
- Professional counselling.
- Carers groups and programmes.
- Services and forums on websites for carers.

### Getting support from a support group

Some carers enjoy having a break and accessing emotional support together with the person they are caring for as it is a continuation of their everyday life. This can also suit carers who feel too anxious to leave the person with dementia in someone else's care.

People with dementia can become disorientated and frightened in strange places and among people they don't recognise. So having a break together or visiting a dementia cafe for emotional support can be the stepping stone to taking a break on your own.

Carer support groups which you attend without the person you care for, and training sessions on issues around dementia can be invaluable. Here you will meet people in similar situations who have the same mix of feelings that you experience as a carer and will understand what you are going through. Contact your local carers and dementia services for more information.

## Getting support by taking a break

Taking a carers break can bring up a mix of emotions including relief or guilt, and that is normal. But it is important to realise that in order to look after someone else you need to look after yourself and that it is in both your interests that you take a break. A break away from the emotional stress of caring is as important as a rest from the physical demands of the role.

A break from caring can be accessed informally with help and support from family and friends or more formally through a carer's assessment and/or community care assessment for you and the person you care for. Having a carer's assessment will help identify the type of break which will be helpful to you.

If you do not live with the person you care for and find yourself struggling to manage two homes, it is important that you let professionals and family and friends know that you need support and a break.

### Tips

- ▶ Talk to the person you care for and plan for the future.
- ▶ You can take a break and access emotional support together or separately.
- ▶ Some holiday companies have specific breaks for people with disabilities, including dementia.
- ▶ Contact your local carers service for information on breaks and carers support groups.
- ▶ Contact your local dementia service for information on support groups and social opportunities.

## Support for carers to maintain lifestyle choices

If you find yourself having to give up or reduce your work hours, dropping out of community activities and giving up hobbies due to the increasing demands of your caring role, find out what help is available. If you are caring and in employment you have legal rights, including the right to request flexible working and time off for caring responsibilities. Carers and those they care for are also protected by law against discrimination.

Having a carer's assessment is a good way of expressing your wishes and considering what support is needed in order for you to balance caring, work, family and other community commitments. Working or volunteering is a valuable break from caring, and can help with your wellbeing.

## Tips

- Do not give up work or other commitments until you have explored your options.
- Contact your manager or human resources department and discuss your work options.
- Request a carer's assessment for you and a community care assessment for the person you care for, from your local authority.
- Ask a local or UK carers organisation about your rights as a carer.
- Get a free Carers Rights guide from Carers UK and for young and young adult carers, the Carers Trust booklet Know your Rights.

## 7 When the person with dementia loses their mobility

**Many people with dementia will gradually become less able to move about unaided and may stumble and struggle with everyday tasks. It may be that the person you care for already has poor mobility, which is made more challenging due to the dementia. In the later stages of dementia some people may eventually be unable to walk or adjust their position without support.**

### Preparing for loss of mobility

It is important to get information, advice and practical training in assisting someone who has poor mobility. It is key that you do not physically hurt yourself while helping someone else. Decreased mobility can also have a negative effect on the mental wellbeing of both you and the person you care for so try and keep the person with dementia and yourself as active as possible.

There are some straightforward measures that you can put in place to help with mobility and they have no or very little cost. For example, removing things that are easy to trip over, ensuring the house is well lit, and generally making the home more dementia friendly is a good place to start.

If mobility is becoming a concern contact your GP and ask for a referral to an occupational therapist. They will be able to recommend and organise equipment that can help. The earlier you have the right information the less likely it is that an accident or injury will occur. It will also mean you have longer to plan for necessary adjustments in the home or to travel arrangements. It will then be easier for the person with dementia to become accustomed to them.

Find out about local accessible transport schemes and community transport. There are reductions or free access to public transport for people with disabilities in most areas of the UK. This can include bus and train passes, taxi vouchers and hospital transport. Contact your local authority for more information. People with disabilities can also apply to the Blue Badge Scheme.

## Advice and training for carers in lifting and handling

A number of carers organisations offer training for carers which will often include a session on moving and handling as well as general back care. If these sessions are not available or you are finding it difficult to access them, having a carer's assessment could help. Alternatively, ask your GP for a referral to an occupational therapist, they will be able to give advice on equipment and safe moving and lifting techniques.

## Advice on equipment and adaptations

There is a growing selection of equipment which can be used inside and outside the home, to make life easier for yourself and the person you care for. Smaller pieces of safety equipment such as door alarms, and gas and water safety devices can be inexpensive and can help alleviate some of your worries. Most local fire services now carry out free home fire safety checks and install smoke detectors if necessary.

Equipment and adaptations can vary in cost. Ask your local authority for an assessment and they will be able to advise you and may even cover the cost of some of the equipment.

Grants for large adaptations such as wet rooms, lifts or ramps are commonly known as Disabled Facilities Grants and can be applied for through the local authority. You do not necessarily need to own your own home to be eligible. There are also a number of local and UK charities which can give financial assistance, you can find this information at your local library, carers service or from the charity [www.turn2us.org.uk](http://www.turn2us.org.uk).

### Tips

- 🟡 Contact your local carers service or local authority for advice and information on what is available in your area.
- 🟢 Ask your GP for a referral to an occupational therapist to look at possible aids to help.
- 🟣 A few small changes can help make your home dementia friendly.
- 🟤 Look out for small pieces of equipment which can help with everyday life and help prevent accidents.
- 🟠 Explore possible adjustments to your home.
- 🟡 Ask your social services department or local council about Disabled Facilities Grants.
- 🟢 Apply for a Blue Badge for parking and a Radar Key for toilets for disabled people as it can help when going out.

## 8 When the person with dementia has other health issues

**The majority of people who are diagnosed with dementia are 65 or over, therefore it is likely that they will have other medical conditions. Looking after someone with dementia who also has other health conditions can be complex and demanding, particularly when the person with dementia finds it difficult to understand their condition or treatment.**

### Recognition of your role as a carer

If you are caring for someone with multiple health conditions you are likely to come into contact with a number of different health professionals. It is important to recognise that you are a carer and ensure you are given all the information you need about all the health conditions affecting the person you care for. Ask for information about how the condition will develop, effectiveness of any treatment suggested and any possible side effects. This will ensure you feel as equipped as possible to manage the situation. The community pharmacist can be a good source of information on medication and minor ailments.

If the demands of caring for someone with multiple health conditions is having an effect on your own health it is important that you ask for a carer's assessment for you and a community care assessment for the person you care for. If you have both already had an assessment then request a review if the person you care for, or you, need more support. This can open up the opportunity to receive further support, information and advice.

### Managing hospital and GP appointments and admissions

If the person you care for is admitted to hospital your involvement can be key to their care. People with dementia can become easily disorientated and don't cope well in unfamiliar environments. It can be beneficial to be prepared in case the person you care for needs a hospital admission and there are some useful steps you can take to help. Make sure the GP and consultant knows that you are the main carer so that you can be involved in consultations and any decisions made, particularly around discharge planning and end of life care. Age UK and Alzheimer's Society have factsheets with advice.

Some hospitals and GP surgeries have made provision for carers. For example:

- Carer passports which allow you to be easily identified as the main carer.
- Flexible access to appointments.
- A nominated carers champion who you can book an appointment with.
- Encouraging you, if you wish, to be more involved with the day-to-day care of relatives in hospital.
- Enabling you to stay overnight in hospital where the person you care for has been admitted.

The Triangle of Care for dementia is a Carers Trust initiative that can help health services achieve better collaboration between the health professional, carer and the person with dementia. Find out if your hospital has signed up to it and how it can help you. See <https://professionals.carers.org>.

## Getting help from your GP

As the dementia of the person you care for progresses, you may find yourself increasingly taking responsibility for healthcare tasks including making sure the person you care for eats and drinks, and takes their medication. If you need more information or support speak to the GP.

Regular health checks are as important for you as they are for the person you care for. Checks can help pick up any health problems early and prevent further problems or deterioration. As a carer you are entitled to a free flu vaccination and in some areas of the UK health checks are offered through the GP surgery.

### Tips

- Tell professionals you come into contact with that you are a carer.
- Give as much information as you can to health professionals about the person you care for, you are an expert.
- Talk to your local carers service about setting up a carers emergency plan in case you need a hospital stay and can't look after the person you care for, even for a short while.
- Speak to the local pharmacist if you have any concerns about medication.
- Contact your local carers service.
- Don't ignore your own health – talk to your GP surgery about health checks and a flu vaccination.
- Be prepared for a possible hospital admission.

## 9 When the carer has to manage changing behaviour

**During the middle and later stages of dementia the person you care for may struggle to understand the world around them and communicate their feelings and wishes. People with dementia can develop unusual behaviours which may include becoming angry or agitated, pacing, experiencing a different sense of reality to ourselves, repeating themselves and sometimes displaying a lack of inhibition.**

### Positive strategies for managing changes in behaviour

It is important to recognise that behaviour is a form of communication. There is usually a good reason for the unusual behaviour, and understanding why someone is behaving in a certain way can make managing their situation easier.

A change in the behaviour of the person you care for can be an indication that they are not feeling well. Visit the GP to rule out the possibility of other medical conditions. Information on managing changing behaviours is available from the Alzheimer's Society. Local carers and dementia services will be able to give ongoing information, advice and in some areas training. In some cases the GP may refer to the community mental health team for further support.

### Support in managing changing behaviour

Don't be afraid or embarrassed to bring up the subject of difficult behaviours with health professionals involved with the person you care for. They will do what they can to help you continue to care at home if that is what you wish to do. It is always better to ask for advice or extra support early to prevent a difficult situation becoming overwhelming.

As a carer it is important to recognise the emotional impact behaviour changes can have on you and why taking a break can be crucial. Carers groups and the Admiral Nurse helpline can be a useful place to discuss your feelings and pick up invaluable tips.

## Support with night care

Providing care at night and having to manage frequent night time disturbances can be exhausting. It may be worth exploring the options of night time services with your local social services or care services. Get advice on funding the care by asking for an assessment from a social worker. Funding options could include personal budgets, NHS continuing healthcare, and in some areas Admiral Nurses.

Sundowning is the term used to describe the increased confusion and disorientation many people with dementia experience in the evening. It can be particularly difficult for carers to manage as by this time of the day you may be feeling exhausted. For information on sundowning contact Dementia UK or Alzheimer's Society.

### Tips

- Get advice and information on managing changing behaviours.
- Ask for help early, it is always better to be prepared.
- Join a local dementia or carers group for support.
- Find out about local replacement care in your area.
- Speak to your GP to rule out any other health conditions in the person you care for.
- Ask the GP about drug treatments for the person you care for that may help.
- Ask about personal budgets and NHS continuing healthcare.

# 10 When the carer's own circumstances change

**As a carer of someone with dementia you may find yourself caring for a number of years and it is very likely that your circumstances could change throughout the caring experience. Whatever age you are it is important you look after your own health. As a carer you will have your own individual commitments and responsibilities. These can depend on many things, for example your age, family, work or financial circumstances.**

## Looking after your own needs

If you find you need more support to care, get in touch with your local social services or carers service. It is always better to ask for help and advice earlier than you need it to make sure you are prepared.

Having a carer's assessment or review of an existing assessment can give you the opportunity to discuss any changes in circumstances and the impact this is having on your caring role. Use the opportunity to enquire about options for further support.

If you are worried about what will happen to the person you care for if something happens to you, then making a plan and exploring options for replacement care can give you peace of mind. Some local authorities and carers services provide templates and assistance in completing an emergency plan, which will then be held on a central system in case it is needed. Carers are usually then given an emergency card to carry with them.

## Maintaining your own health

It is important that you do not neglect your own health or miss routine screenings and other appointments. As a carer you are entitled to:

- A free flu vaccination.
- In some areas a routine health check.

If you need an operation, therapy or other treatment to maintain your health do not put it off. Ask for support from social services or your local carers service to help make arrangements for replacement care.

Many local carers and dementia services run support groups and training programmes which cover looking after yourself. If you are concerned about your mental health and wellbeing go and see your GP early on.

## Work life balance

If you are working, it is a good idea to let your manager or human resources department know that you are a carer. You can discuss ways of working around your caring responsibilities. Employers are always keen to keep valued staff and adjustments to your working pattern are a better option than the expensive and time consuming process of recruitment.

You can also enquire about any relevant policies the organisation has.

As a carer you have legal rights:

-  To request flexible working.
-  To request time off.
-  To be protected against discrimination.

Many carers find themselves giving up work before other options are fully explored, if your employer is not aware of the legislation there is information on the Carers UK website.

Carers who work part time or are on a low income may be entitled to Carer's Allowance, and other benefits depending upon their financial, family and housing situation. Local advice centres such as Citizens Advice or Age UK will be able to do a benefits check to ensure your family and the person you care for are receiving everything you are entitled to.

## Tips

- ▶ Talk to your human resources department and look at the workplace policies related to caring.
- ▶ Explore how you can balance work and caring.
- ▶ Get in touch with your local carers service for information and support.
- ▶ Request a carer's assessment or a review from your local authority if your circumstances change.
- ▶ Get a full benefits check from a local advice service.
- ▶ Don't put off your own health appointments.
- ▶ Have a flu vaccination and health check.
- ▶ Register as a carer with your GP.
- ▶ Take time to look after your own wellbeing.
- ▶ Make a plan for emergencies.

# 11 When the person with dementia becomes incontinent

**Don't be embarrassed to seek help if the person you care for is having continence issues (toilet problems). Dealing with incontinence can be a big challenge and so it is important to seek advice from the GP early on. It is possible the incontinence is related to a medical condition that could be treated or managed.**

## Planning for possible continence issues

Receiving good timely advice on how to manage incontinence is vital and may help you to continue to care at home. Ask your GP for a referral to the local continence service. It will ensure you are given the right advice on management and products available.

There are some helpful strategies and small adaptations that can be made in the home which can help you and the person with dementia manage continence. For example, always leaving the door open so the toilet is visible, using strong colours to indicate the toilet and thinking about timings and clothing. There are some useful factsheets on managing toilet problems and incontinence available from the Alzheimer's Society.

## Incontinence supplies

It is important to find out about and get advice on appropriate products. There are a large number of personal products available to help, some of which are available on prescription. Before you spend a lot of money, check with the GP or nurse to prevent purchasing unnecessary or incorrect items.

## Tips

- Don't be embarrassed to ask for help – incontinence is not uncommon.
- Go to the GP as there may be a treatable medical reason for the incontinence.
- Ask for a referral to the local continence service.
- Look into strategies and small adaptations that can help.

## Practical help with laundry

Caring for someone who is incontinent can be expensive and time consuming as you may find yourself managing a lot more laundry. Practical help in the home and outside laundry services can ease the pressure. Check you are receiving all the benefits you are entitled to as these can be a useful way of paying for extra household help.

If you are struggling financially and don't have a washing machine and dryer there are a number of local and UK organisations, including local furniture projects, that can provide funding grants and equipment to help. Help may also be available for other essential household items and larger incontinence products such as mattresses and bedding. Charitable organisations may give grants to people who have been employed in a particular field, or have a specific health condition or live in a particular part of the UK.

Some grant applications can be submitted direct from the carer, or person with dementia, however some do ask for a professional referral and your local carers service or Citizens Advice will be happy to help. [www.turn2us.org.uk](http://www.turn2us.org.uk) is an online guide to benefits, grants and charitable organisations.

## Tips

- Check you are getting all the financial support you are entitled to.
- Help with household tasks and outside laundry services can ease the workload.
- Look online or ask the local carers service about grants for equipment to help.

# 12 Considering decisions about residential care

**Choosing residential care for the person you care for can be a difficult decision. You may have mixed emotions about the move, which can include feelings of relief and guilt and this is normal. It is important to remember that as a carer you have been taking on the role of many professionals, often for a long period of time. While this experience can be rewarding it can also be exhausting.**

## Planning or considering residential care

You may have reached a point when caring becomes overwhelming, and either your own health or that of the person you care for is at risk if you continue to care for them at home. A move to residential care does not mean the end of your role as a carer but does mean a change. Many carers choose to regularly visit the person they care for once they are in residential care and continue to give social, emotional and practical support.

Carers of people with dementia often find they start considering residential care at particular stages. These are when the person with dementia is no longer safe at home, when behavioural changes are too difficult to manage, or the person they care for becomes incontinent. Getting help and support around these issues early may help you continue to care at home for longer if you wish. If you are struggling to manage get in touch with your GP or local carers service, they will be able to advise about extra support.

## Planning residential care options

It is important to look into the availability of different residential care options and their cost at an early stage. It is much better if the person with dementia can be involved in decisions about their future care. It is not easy, but it is important to have these conversations early on while the person with dementia still has capacity to contribute.

Most residential care homes welcome visitors, and may have open events for the community, so take your time and have a look around. Staff will be happy to answer any questions about the care home. You can also look online or contact the Care Quality Commission for more information. Making enquiries early can give you and the person you care for time to consider what will best meet both your needs. Preparing early can prevent a crisis and relieve the pressure surrounding any difficult decisions in the future.

For carers of people with rare types of dementia and/or young onset dementia, finding an appropriate residential home can be particularly difficult and it is quite possible there will be no local provision. Therefore, it is important to look for UK as well as local information at an early stage.

## Paying for residential care

Carers are often concerned about the cost of paying for care but it is not the responsibility of the carer to pay for any costs incurred. If the person you care for has been assessed as needing care, they will also be assessed to see how much they can afford to pay towards the cost. They will then pay according to their income and assets. This means they may:

-  Pay all their costs (self-funders).
-  Make a contribution towards the cost, with the local authority also contributing.
-  Have all their care funded by the local authority.
-  Have all or part of their care funded by the NHS.

The regulation around paying for care is complex. You can get information and advice from your local carers or dementia service or online.

### Tips

-  Plan for possible future care needs early.
-  Find out about local provision and cost of care.
-  Visit local residential homes and ask questions.
-  In certain circumstances, care costs are met by the NHS.
-  Explore the care options for people with young onset dementia.
-  Your role as a carer is still important when the person you care for moves to residential care.

# 13 End of life care

**Most people find that talking to someone about dying is not easy. However, planning ahead is important as it can improve the quality of care a person receives.**

## Talking about end of life care

People with a diagnosis of dementia are likely to lose the capacity to make decisions about their care in the future, so having conversations early on is vital. If you are having difficulty approaching the subject, the Dying Matters website has useful resources and information which may help.

For information on lasting power of attorney, advance decisions and advance statements, see Chapter 3: Legal and financial planning.

Carers can play a vital role in end of life care, as you are likely to know the person well and be aware of their needs. If the person you care for has not made provision regarding their end of life wishes and has lost capacity to decide for themselves, it is good practice for health and social care services to include carers and other close relatives or friends in discussions about end of life care.

## Coping with bereavement

Following the death of the person you care for, you may experience different emotions including loss, relief, and guilt and this is normal. Caring will have been a large part of your life and a feeling of loss of purpose is not uncommon. Most carers services can offer support during this time, giving you the opportunity to consider your options for the future. You can also get help from other UK organisations.

Even when your caring role stops it is important that you look after your own health and wellbeing.

For people who need extra support following a bereavement, help is available through Cruse Bereavement Care.

# Useful contacts

## Carers Trust

Carers Trust is a major new charity for, with and about carers. We work to improve support, services and recognition for anyone living with the challenges of caring, **unpaid**, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

We do this with a UK wide network of quality assured independent partners, through our unique online services and through the provision of grants to help carers get the extra help they need to live their own lives. With locally based Network Partners we are able to support carers in their homes through the provision of replacement care, and in the community with information, advice, emotional support, hands on practical help and access to much needed breaks. We offer specialist services for carers of people of all ages and conditions and a range of individually tailored support and group activities.

Our vision is of a world where the role and contribution of **unpaid** carers is recognised and they have access to the trusted quality support and services they need to live their own lives.

To find your nearest Network Partner, call 0844 800 4361 or visit [Carers.org](http://Carers.org).

Carers Trust also supports carers through interactive services on [Carers.org](http://Carers.org), [babble.carers.org](http://babble.carers.org) and [matter.carers.org](http://matter.carers.org).

Tel: 0844 800 4361

Email: [info@carers.org](mailto:info@carers.org)

## Age UK

Age UK is the country's largest charity dedicated to helping everyone make the most of later life.

[www.ageuk.org.uk](http://www.ageuk.org.uk)

Tel: 0800 169 6565

Email: [contact@ageuk.org.uk](mailto:contact@ageuk.org.uk)

### **Alzheimer's Society**

Alzheimer's Society is a support and research charity for people with dementia and their carers. It provides information and support on all forms of dementia.

[www.alzheimers.org.uk](http://www.alzheimers.org.uk)

Tel: 0300 222 11 22

Email: [enquiries@alzheimers.org.uk](mailto:enquiries@alzheimers.org.uk)

### **Care Quality Commission**

Information about choosing care in your area.

[www.cqc.org.uk/content/help-advice](http://www.cqc.org.uk/content/help-advice)

Tel: 03000 616161

### **Carers and disability benefits website**

A website to find government services and information.

[www.gov.uk/browse/benefits/disability](http://www.gov.uk/browse/benefits/disability)

Tel: 0345 608 4321

### **Carers UK**

Information and advice for carers.

[www.carersuk.org](http://www.carersuk.org)

Tel: 0808 808 7777

Email: [advice@carersuk.org](mailto:advice@carersuk.org)

### **Citizens Advice**

Information on benefits, legal issues, housing, making a will and a range of other issues.

[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

Tel: 03444 111 444

### **Compassion in Dying**

Compassion in Dying helps people plan ahead to ensure their wishes will be respected. It works to inform and empower people to exercise their rights and choices around end-of-life care.

[www.compassionindying.org.uk](http://www.compassionindying.org.uk)

Tel: 0800 999 2434

Email: [info@compassionindying.org.uk](mailto:info@compassionindying.org.uk)

### **Cruse Bereavement**

Cruse Bereavement Care offers support after the death of someone close.

[www.cruse.org.uk](http://www.cruse.org.uk)

Tel: 0844 477 9400

Email: [helpline@cruse.org.uk](mailto:helpline@cruse.org.uk)

### **Dementia Care**

Dementia care offers support to people with dementia and their carers. Its website is packed with information, including an interactive dementia friendly house.

[www.dementiacare.org.uk/living-well-with-dementia/i-am-a-carer-or-friend](http://www.dementiacare.org.uk/living-well-with-dementia/i-am-a-carer-or-friend)

Tel: 0191 217 1323

Email: [info@dementiacare.org.uk](mailto:info@dementiacare.org.uk)

### **Dementia Choices**

Information from the NHS for people with dementia and their families and friends.

[www.nhs.uk/conditions/dementia-guide/Pages/dementia-choices.aspx](http://www.nhs.uk/conditions/dementia-guide/Pages/dementia-choices.aspx)

### **Dementia Handbook**

The Dementia Handbook for Carers aims to answer all the questions family members or friends may have about dementia and its symptoms.

[www.berkshirehealthcare.nhs.uk](http://www.berkshirehealthcare.nhs.uk)

Tel: 0118 9605027.

Email: [bht@berkshire.nhs.uk](mailto:bht@berkshire.nhs.uk)

### **Dementia UK**

Admiral Nursing DIRECT is a helpline and email service, provided by experienced Admiral Nurses and is for family and professional carers, people with dementia and those worried about their memory. It gives practical advice and emotional support to anyone affected by dementia.

[www.dementiauk.org/information-support/admiral-nursing-direct/](http://www.dementiauk.org/information-support/admiral-nursing-direct/)

Tel: 0845 257 9406

Email: [direct@dementiauk.org](mailto:direct@dementiauk.org)

### **Disability Rights UK**

Information about the Radar Key and access to toilets for disabled people.

[www.disabilityrightsuk.org](http://www.disabilityrightsuk.org)

Tel: 020 7250 8181

Email: [enquiries@disabilityrightsuk.org](mailto:enquiries@disabilityrightsuk.org)

## **DLF**

DLF is a UK wide charity providing impartial advice, information and training on independent living.

[www.dlf.org.uk](http://www.dlf.org.uk)

Tel: 0300 999 0004

Email: [info@dlf.org.uk](mailto:info@dlf.org.uk)

## **Dying Matters**

Dying Matters is a coalition of members which aims to help people talk more openly about dying, death and bereavement, and to make plans for the end of life.

[www.dyingmatters.org](http://www.dyingmatters.org)

Tel: 08000 21 44 66

## **Innovations in Dementia**

Videos by people with dementia.

[www.innovationsindementia.org.uk/videos\\_walkinggroup.htm](http://www.innovationsindementia.org.uk/videos_walkinggroup.htm)

## **MIND**

A mental health charity providing advice and support to empower anyone experiencing a mental health problem. It also campaigns to improve services, raise awareness and promote understanding.

[www.mind.org.uk](http://www.mind.org.uk)

Tel: 020 8519 2122

Email: [contact@mind.org.uk](mailto:contact@mind.org.uk)

## **NHS Choices**

Health information from the NHS.

[www.nhs.uk](http://www.nhs.uk)

## **Office of the Public Guardian**

Advice if the person you care for has lost capacity to make a lasting power of attorney.

[www.gov.uk/government/organisations/office-of-the-public-guardian](http://www.gov.uk/government/organisations/office-of-the-public-guardian)

Tel: 0300 456 0300

Email: [customerservices@publicguardian.gsi.gov.uk](mailto:customerservices@publicguardian.gsi.gov.uk)

### **Revitalise**

Revitalise is a UK wide charity providing short breaks and holidays (respice care) for disabled people and carers.

[www.revitalise.org.uk](http://www.revitalise.org.uk)

Tel: 0303 303 0145

Email: [info@revitalise.org.uk](mailto:info@revitalise.org.uk)

### **Royal College of Psychiatrists**

Readable, user-friendly and evidence-based information on various mental health problems, treatments and other topics, regularly updated by psychiatric experts.

[www.rcpsych.ac.uk/expertadvice.aspx](http://www.rcpsych.ac.uk/expertadvice.aspx)

Tel: 020 7235 2351

Email: [reception@rcpsych.ac.uk](mailto:reception@rcpsych.ac.uk)

### **Shared Lives Plus**

Information about shared lives as a way of supporting adults.

[www.sharedlivesplus.org.uk](http://www.sharedlivesplus.org.uk)

Tel: 0151 227 3499

Email: [info@sharedlivesplus.org.uk](mailto:info@sharedlivesplus.org.uk)

### **Turn2us**

Turn2us is a UK wide charity that helps people in financial hardship to gain access to welfare benefits, charitable grants and support services.

[www.turn2us.org.uk](http://www.turn2us.org.uk)

### **Young Dementia UK**

Provides specialist support services for younger people with dementia and their families in Oxfordshire and adjoining areas. For people outside the region it offers signposting and telephone support.

[www.youngdementiauk.org](http://www.youngdementiauk.org)

Tel: 01993 776295

Email: [mail@youngdementiauk.org](mailto:mail@youngdementiauk.org)





Carers Trust  
32–36 Loman Street  
London SE1 0EH

Tel: 0844 800 4361  
Fax: 0844 800 4362  
Email: [info@carers.org](mailto:info@carers.org)

[Carers.org](http://Carers.org)  
[matter.carers.org](http://matter.carers.org)  
[babble.carers.org](http://babble.carers.org)  
<http://professionals.carers.org>

 [www.facebook.com/CarersTrust](http://www.facebook.com/CarersTrust)  
 [www.twitter.com/CarersTrust](http://www.twitter.com/CarersTrust)  
 [www.youtube.com/user/CarersTrust](http://www.youtube.com/user/CarersTrust)

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