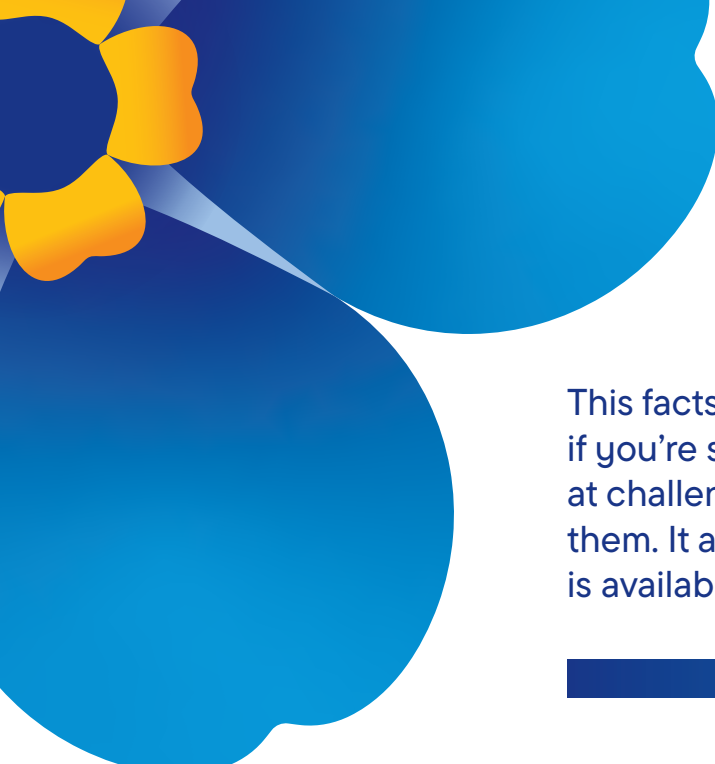


# Carers – looking after yourself



**Alzheimer's  
Society**

Together we are help & hope  
for everyone living with dementia



This factsheet explains ways of looking after yourself if you're supporting a person with dementia. It looks at challenges you might face and how to cope with them. It also explains what help and support is available.

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# 1 Being a carer

If you are supporting a person with dementia you might not see yourself as being their ‘carer’. You might first and foremost think of yourself as being their partner, spouse, family member or friend. But even if you choose not to identify as a ‘carer’ you may still find this factsheet relevant and helpful. It can also be helpful if you use the word ‘carer’ when you talk to professionals because it can help you get the right support.

There are lots of positive things about caring for a person with dementia, including:

- learning new skills
- improving your existing skills
- caring for a person who has cared for you in the past
- strengthening your relationships
- feeling proud of how you are helping
- supporting a person who is important to you.

You can also look for ways to continue to share good times and have positive experiences with the person you are caring for.

However, caring for a person with dementia can also be physically and mentally exhausting. Even when you are doing well with the challenges you are facing, you may not feel you are doing enough. Caring often affects every part of life and it can make people feel isolated, stressed and overwhelmed. It can even make some people feel hopeless or depressed. You also need to look after your own physical and mental health needs. You and other people may overlook these when you are caring for someone else.

Everyone will experience caring in their own way. There may be days when you feel you can cope well and other days when you feel that you can’t. There may be some parts of caring that you can find easy to manage but others that you find difficult. This can change from day to day, which can also be very challenging.

However being a carer affects you, try to learn ways to cope with some of the things you find difficult. The next section of this factsheet looks at some common feelings that carers may have. It then suggests ways you can try to cope with challenges and improve your own health and wellbeing. It also describes different types of help and support available, and how the caring role can change as dementia progresses. You can find advice and information on more topics in booklet 600, **Caring for a person with dementia: A practical guide**.

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**I have gained a fuller respect and appreciation for carers, be it parents, elderly carers, spouse carers, young carers and more.**

Carer of a person with dementia



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# 2 Your health and wellbeing

Caring for a person with dementia can have a big impact on your mental and physical health and your overall wellbeing. That's why it's important that you look after yourself – both for your own sake and so you can continue to care for the person with dementia. Carers often feel a wide range of emotions. Try to understand why you feel the way you do and to accept your emotions as a normal reaction to what may be a very difficult situation.

## Managing your feelings

Remember that you're not alone in feeling the way you do. If you have any negative feelings about the person you are supporting or the situation, it does not mean that you're a bad person. Being aware of your feelings can make it easier to deal with them. For example if you feel frustrated or angry, try to work out why. Are you trying to do too much? Are you not getting the help you need? If you understand why you feel the way you do it will help you make decisions about what is right for you and the person you are caring for.

## Be realistic and kind to yourself

Remember you can only do so much. Everyone who cares for a person with dementia will need help at some stage. Focus on what you can do and try to accept that you may need help with some things.

Try not to compare yourself or your situation with other carers. You may think they are coping much better than you. However, everyone's situation will be different and everyone faces their own challenges. You may struggle with things other people seem to find easy, but they may struggle to do things that you find easy.

## Set out your priorities

Carers often need to do many different things at once. This can be difficult to manage and it can leave you feeling exhausted – both physically and mentally.

Many carers feel torn between their different responsibilities. You might be trying to care for the person with dementia as well as looking after a household, caring for children or going to work. As much as you may want to manage everything, it will not always be possible. It can also be difficult if other people try to help but give you advice that may not apply to your specific situation.

You can't do everything on your own. You also won't be able to please everyone. Work out which things you really need to do and which are less important. Look for tasks that other people may be able to help you with, to take some pressure off you. Don't be hard on yourself about the things you can't manage or feel guilty about asking your family members or friends for help.

### Remember the positives

While you will have challenges to deal with, also try to focus on some of the positive things about caring for and supporting the person with dementia. Take strength from your commitment to them and your fondness for them. Think about your relationship with the person and the fact that you're helping them enormously, even if they may not always seem to know or appreciate it. It can sometimes be hard to see the positive things you are achieving. Writing things down can help – even small things like a joke you shared with the person you're caring for.

When you're having a difficult day, thinking about positive times you've shared can remind you that there are still some better times and about the good that you are doing for the person.

### Talk to other people

Talking about your emotions is often the first step to understanding and dealing with them. It can also help if you talk to the people around you about dementia and your experiences. Tell them what life is like for you and the person you care for. This may help them understand how much you do for the person you are supporting and what help and support you need.

This might help you feel less isolated and stressed. It can also help you put things in perspective. If you don't talk about your feelings or take time to address them, it is likely to make things worse. This won't be good for you and it will also have an impact on the person you're caring for. If you feel like you are struggling, speak to someone as soon as possible.

Talking to and involving your family and friends in your caring role may help you to have breaks and reduce some of your stress. Some carers find that their friends and family members can provide a good range of support. Even if they can't help with day-to-day care, they may be able to look after the person you are supporting for a short time so that you can have a break. Or they might be able to support you in other ways, such as helping you sort out finances.

See 'Getting help and support' on page 9 for more information on talking to other people who can provide support.

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### Asking for help

Don't be afraid to ask for help and support if you need it. Sometimes people don't offer help because they don't know what they can do. Try suggesting specific ways that other people can help. If you've previously said you can manage without someone's help, they may not think to offer again, even when your situation changes. Let people know how valuable their support is and how much it helps you.

If you don't have friends or family members who can help, or if you need a type of support they can't provide, a voluntary organisation or your local authority might be able to help you instead. Find out whether there are services in your local area that can help you or the person with dementia. For more information see 'Getting help and support' on page 9 or call Alzheimer's Society on **0333 150 3456**.

### Dealing with difficult emotions

One of the most difficult things about caring for a person with dementia can be the range of emotions you experience. You may feel frustrated, exhausted or 'burnt out'. You may be angry and wonder, 'Why me?' or feel isolated and cut off from the world. It is common for a carer to feel lonely, especially as your relationship with the person with dementia changes. There may be times when you worry that you are only caring for them out of a sense of duty. Or you may feel you no longer love or even like the person you are caring for. You might also feel grief – like you are losing the person you once knew.

**Everyone will experience caring in their own way. There may be days when you feel you can cope well and other days when you feel that you can't. There may be some parts of caring that you find easy to manage but other things that you find difficult. This can change from day to day, which can also be very challenging.**

These are all very common reactions to caring for a person with dementia. Many other carers will be feeling the same emotions and it's very important not to be ashamed about how you feel.

It is also important to learn to deal with these feelings because they can have a negative impact on many parts of your life. For example they can affect your health and wellbeing. They can also have an impact on the person you are caring for and your family members. See 'Getting help and support' on page 9 for details of support that can help you deal with difficult emotions.

## Feeling guilty

Some emotions you may experience will be normal responses to the situation, such as frustration. Other emotions can be more difficult to deal with and could leave you feeling powerless or 'stuck'.

One emotion that can be particularly hard to deal with is guilt. You may feel guilty for a number of reasons. For example:

- feeling guilty about how you feel – such as angry or frustrated with the person you are caring for
- feeling that you are not looking after the person well enough or that you're doing things 'wrong'
- feeling that you are not coping as well as other carers
- feeling that you've had enough of your role as a carer
- feeling guilty for resenting the impact caring has on your life and that you never 'chose to do it'
- feeling guilty about not having been more patient with the person when their symptoms were developing or about being impatient with them now
- feeling guilty about not making time for yourself, or spending time with your other family members, including children, or friends
- feeling guilty about difficult decisions you make, such as moving the person with dementia into a care home or arranging for them to be cared for by someone else, such as another family member or a paid carer.

You can't stop yourself from feeling these things, but you can learn how to respond to these feelings. For example, remember that you are managing a difficult situation and supporting a person who needs you. Nobody is perfect and everyone gets frustrated at times and makes mistakes. You are helping the person enormously by just being there and caring for them. Dementia is a complex, unpredictable and progressive condition, so caring for a person with dementia is often unlike caring for someone with any other condition.

It is important that you seek support before your feelings reach a crisis point. For example you can call Alzheimer's Society on **0333 150 3456**. For suggestions about support that you may find useful see 'Getting help and support' on page 9.

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## Space for your notes

### Staying physically healthy

Staying physically healthy is an important part of maintaining your mental health too. See page 7 for suggestions about ways to find time for yourself, including support that might be available for you to take regular breaks.

It's not always easy, but try to take care of yourself in the following ways to help you stay healthy.

- Eat a well-balanced diet, with at least five portions of fruit and vegetables every day.
- Exercise regularly. This is again good for both your physical and mental health. You could go for a walk or join an exercise class. Or you could just try to be more physically active during your day.
- Try to get enough sleep. This is very important because sleep helps your brain and your body recover from tiredness. It can be difficult to sleep well if the person you are caring for wakes or gets up at night. If this happens you might find it easier to sleep when the person you care for is sleeping – for example, if they take daytime naps. If you can't get enough sleep, talk to your GP. They may be able to suggest services or techniques to help you, including counselling.
- Stay in touch with your friends or other carers as much as possible – ideally face to face. Seeing friends or speaking to people who are in a similar situation is very important for your mental health and your overall 'resilience' as a carer.
- If you can, spend time enjoying your hobbies and interests. If you find this difficult because of your caring commitments, try to include enjoyable activities in your daily life. For example listening to your favourite music while you are doing household chores or driving to appointments.
- See your GP regularly, so that they can check your general health.

If you are struggling to cope or you feel depressed, anxious or stressed, it is especially important that you talk to your GP. There is help available, such as counselling or extra support services. Speaking to friends or family members can also help. For more information see 'Getting help and support' on page 9.



## Taking regular breaks

It can be difficult to find time for yourself when you are caring for a person with dementia. You might also feel guilty about wanting to spend time alone. However, taking regular breaks from caring is important for your own wellbeing and you will be able to cope better if you make time for yourself. Socialising is also very important for your overall wellbeing.

When you do get time to yourself you could use it to catch up on tasks like housework or managing your finances. Or you may want to have some 'time out', such as meeting a friend for coffee, enjoying a hobby, or doing something else for yourself. Also try to find time to reflect and relax.

Many carers find that making time to do things they enjoy helps them with their caring role. By taking regular breaks you may find you are better able to support the person you're caring for. Having time apart can also be good for both you and the person you are caring for. It can help to ease any tensions or frustrations you have. You don't have to take long breaks from caring. Having a short time to yourself could make a lot of difference.

Try to make time to do something you enjoy every day, whether it is on your own or with the person you are caring for. This could also give the person with dementia a chance to experience new things and to have a change from their routine.

So that you can take a break, ask if someone you know can spend a few hours with the person you are caring for, such as a friend or family member. Or your local authority may be able to help. For example it might have a 'sitting service' or a befriending service. Or it might be able to provide care so that you can take a break. This is called 'respite care' or sometimes 'replacement care'. It could be for an hour or two, or for days or weeks. For more information see factsheets 462, **Replacement care (respite care) in England**, W462, **Respite care in Wales** or NI462, **Respite care in Northern Ireland**.

Other organisations or charities in your local area may also offer respite care. To find support services in your area for people with dementia and their carers you can use our online dementia directory at [alzheimers.org.uk/dementiadirctory](http://alzheimers.org.uk/dementiadirctory)

**Remember that you are managing a difficult situation and supporting a person who needs you. Nobody is perfect and everyone gets frustrated at times or makes mistakes. You are helping the person enormously by just being there and caring for them. Dementia is a complex, unpredictable and progressive condition, so caring for a person with dementia is often unlike caring for someone with any other condition.**

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### Coping with changes

As dementia progresses a person's needs and abilities will change. You'll need to adapt and learn how to cope with these changes. It may sometimes feel like you're starting again with learning how to support the person you are caring for. It can also be very difficult to see them struggle with things they used to be able to do. Try to accept that the changes are happening and focus on what the person can still do. Support them to do those things. For advice about ways to support and communicate with a person with dementia see factsheets 500, **Communicating** and 524, **Understanding and supporting a person with dementia**.

Some of the changes you will need to cope with will be small. However, in the future you may need to make bigger and more difficult decisions about changes. This could include choosing where the person lives. For more information about this see 'Caring as dementia progresses' on page 14.

## 3 Getting help and support

### Space for your notes

When you are caring for someone with dementia you are likely to need support at some point. Carers who get less support are more likely to feel stressed and depressed.

If you don't have friends or family members who can help or give you a break, there are a number of other ways you can get help. This section describes different kinds of support – not every type of support suits everyone. You also might need different types of help and support at different times. Try a few options to find the right services for you. You might have to be persistent and push to get the help you need. This can be frustrating and you may feel you don't have the energy, but it is important to carry on and get the support you need.

There are a range of people and organisations you can turn to for face-to-face support, as well as options for using online services. Some of these include:

- GPs, staff at memory clinics and other health professionals, such as dementia specialist nurses and occupational therapists – these people can support and give you advice on medical issues. For example, ask your GP for advice if the person you're supporting needs your help to move around. They may refer you to a physiotherapist or an occupational therapist or local carers organisations who may provide training about how to lift a person. Contact your local carers organisation, GP or social services to find out what is available in your area.
- Local social services departments who can provide information on registering as a carer and arrange carer's assessments. The GP may also be able to help with this. For more information, see 'Support from local authorities' on page 11.
- Local support groups including your local Alzheimer's Society office, Age UK and Carers UK. These are available in many areas and can be a good source of information on what support is available in your area and how to access it. At the groups you can talk to other carers who understand what you are going through or are in a similar situation. You can share ideas, strategies and advice about caring. For details of local support groups contact Alzheimer's Society (**0333 150 3456**) or Carers UK (see 'Other useful organisations' on page 16), or use our online dementia directory at **[alzheimers.org.uk/dementiadirctory](https://alzheimers.org.uk/dementiadirctory)**

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**We are able to manage by ourselves, but there are some local people from Alzheimer’s Society who call for a catch-up from time to time.**

Partner of a person with dementia



- Online discussion forums – these can give you practical suggestions or simply be a place where you can ‘let off steam’ after a difficult day. You can join online forums at any time. For example try the Dementia Support Forum ([forum.alzheimers.org.uk](http://forum.alzheimers.org.uk)) which is free and is available 24 hours a day, every day of the year. Carers UK also runs a number of forums.
- Talking therapies, such as cognitive behavioural therapy (CBT) – these can help carers who feel anxious or depressed. Counselling can be very helpful because it gives you a chance to talk about how you feel in a non-judgemental and supportive environment. There are many different types of talking therapies.

## Practical support

See our free booklet 600, Caring for a person with dementia, which provides information and advice on many areas of living with, planning and caring for someone with dementia. Other things that can help with everyday activities and your caring role include:

- **Information** – you can get lots of information about caring for a person with dementia. This may include suggestions about strategies to help you deal with difficulties you might be facing. You can also find information about dealing with behaviours that challenge, making decisions for a person with dementia and difficult emotions you may be experiencing. For more information see the full list of Alzheimer’s Society factsheets at [alzheimers.org.uk/publications-list](http://alzheimers.org.uk/publications-list)
- **Adaptations to the home** – you may be able to make changes to the home to make life easier for the person you care for. This could include making adaptations to support their mobility or to help them stay independent. This could also make life easier for you by giving you more time for yourself. For more information and ideas about specific adaptations you could make see factsheet 429, **Using equipment and making adaptations at home.**
- **Technology** – if it is used to help you care for someone with dementia, it is known as ‘assistive technology’. For example you could use the internet on a smart phone, tablet or computer for various everyday tasks. These include online banking and shopping. You can also use electronic devices to reassure you that the person you’re caring for is safe when you’re not with them. For example you could use movement sensors in the home or a ‘GPS locator’ device so that you know where the person is. See factsheet 437, **Using technology to help with everyday life**, for more information about these devices and important things to consider, including getting the person’s consent to use them.

## Support from local authorities

Local authorities including social services departments and health and social care professionals can help people with dementia and their carers. Your local authority may provide some or all of the following:

- homecare visits
- adaptations to the home
- day centres
- respite care (sometimes called ‘replacement care’)
- support from professionals, such as a dementia specialist nurse
- support groups
- counselling
- information that is tailored to your needs.

You might have to pay for some of these services. Ask your local authority social services department for details. Make sure you get all the support you’re entitled to. You’ll find more information in factsheets 532, **Paying for care and support in England**, W532, **Paying for care and support in Wales**, or NI532, **Paying for care and support in Northern Ireland**.

Consider registering as a carer with your local authority. Some local authorities have a Carers Card or Carers Passport scheme. These identify you as a carer and allow you to access support services and other benefits like discounts. Ask your local authority or your GP, or look online for more information.

### Carer’s assessment

Both the person with dementia and their carer are entitled to an assessment of their needs. This is called a ‘needs assessment’. The local authority will use these assessments to decide what support you are eligible to receive. As a carer, your needs can be assessed even if the person you’re caring for chooses not to be assessed. The assessment will aim to:

- assess your abilities and how they affect your caring role
- work out your needs and what level and type of support you need.

There are some things you can do to prepare. For example, before you have a needs assessment, think about your role as a carer. How are you coping and what support do you need? Also think about the difficulties you are having now and what you may face in the future if you continue to give the person the same level of care. This can include:

- feeling stressed, depressed or anxious
- not getting enough sleep

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- feeling tired from spending long hours caring and not getting enough breaks
- struggling to maintain your physical health
- struggling to combine caring with your work or other commitments
- finding it hard to make time for your other interests and hobbies
- difficulty maintaining relationships with your friends and family members
- practical difficulties, such as not being able to drive
- coping with behaviours that challenge (see factsheet 525, **Changes in behaviour**)
- having no plan for emergencies – for example, if you unexpectedly become ill.

For more information on needs assessments see factsheets 418, **Assessment for care and support in England**, W418, **Assessment for care and support in Wales**, or NI418, **Assessment for care and support in Northern Ireland**.

## Legal and financial support

Caring for a person with dementia can affect your legal and financial situation in a number of ways. For example you may be deciding whether to give up work. Check whether you can get support to stay in work, such as flexible working arrangements or help from your local authority. Carers have the right to request flexible working arrangements and employers have to give a good business reason to refuse their request.

If you do give up work but you don't qualify to receive Carer's allowance, you may still be able to claim Carer's credit so that your pension won't be affected. Carer's credit is a National insurance credit for carers. For more information contact the Carer's Allowance Unit (see 'Other useful organisations' on page 16).

Make sure you and the person you are caring for receive all the benefits you're entitled to. Age UK can give you advice about this. Or you can visit an advice centre like Citizens Advice to get a full benefits check. For more information see factsheet 413, **Benefits for people affected by dementia**, and 'Other useful organisations' on page 16.

Think about things that could help you manage your health and finances in the future, such as setting up a Lasting power of attorney (LPA). For more details see factsheets 472, **Lasting power of attorney (for people living in England and Wales)**, and NI472, **Enduring power of attorney and controllership (for people living in Northern Ireland)**.

If the person with dementia receives benefits but they are no longer able to manage this income, you can apply to the Department for Work and Pensions (DWP) to become their 'appointee' so that you can manage this for them. Discuss these options with the person you are caring for.

You might find it difficult to plan ahead. For example it can be upsetting to think about planning for when a person needs long-term care or they reach the end of their life. However, many people find it helpful to find out ahead of time what the impact would be for their home, finances and benefits so that they are prepared.

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## 4 Caring as dementia progresses

### Moving the person into a care home

If a person with dementia moves into a care home it can also have a big impact on the person's carer. You may worry about the care the person will receive, how the move will affect them and whether they will settle in. You might worry about how your relationship with the person will be affected. You might also worry about the impact on your own life, especially if you have been caring for the person for a long time.

Some carers worry that they have let the person down because they feel they should have been able to cope with caring for the person for longer. Some carers may also feel guilty that the person has moved into a care home at all, especially if they had promised the person this wouldn't happen. These emotions can be very difficult to deal with. Remember that because dementia is a complex and progressive condition, a care home may become the best place to meet the person's needs. Try not to be too hard on yourself. Decisions about when and whether a person should move into a care home are often affected by things you can't control. Remember that you are doing what you think is best for the person you are caring for, based on the circumstances you are in.

If the person you are caring for moves into a care home you may begin to question your role and whether they still need you. Some carers find this difficult and they no longer think of themselves as being a carer. This can be similar to feeling that their role changed from being a 'family member' to being a 'carer' when they first began to support the person with dementia.

If you have any of these feelings it is important for you to address them and seek support. For example, speak to your family and friends, a support group, care home staff or a professional, such as a support worker or counsellor. See 'Getting help and support' on page 9 for more information.

If the person you are caring for moves into a care home it is likely to change your relationship. However, it doesn't mean they no longer need you. You should still be able to help care for them if you want to. Speak to staff at the care home about how you can be involved with the person's care and ways you can maintain your relationship. Some carers find their relationship with the person improves when they move into a care home. They can focus on their relationship and positive memories that they share, rather than on the day-to-day tasks and pressures of caring.



## When your caring role ends

Dementia is a life-limiting illness. This means there will be a time when your caring role comes to an end. This can be a very difficult time. You will be grieving for the person who has died as well as coping with the end of your caring role. At this time it's common for people to think about the care they provided and wonder whether they did enough or if they should have done things differently.

You may have lost contact with friends or family members and find it hard to get back in touch with them. Or you may find it hard to adjust to not being a carer anymore because you have thought of yourself as being one for so long.

Some carers therefore find it helpful to think about the future ahead of time, including what may happen when they no longer have a caring role. There are carers organisations that can give you information and support to help you adjust. For more information see 'Other useful organisations' on page 16 and factsheet 507, **Grief, loss and bereavement**. Most importantly, take time to think about yourself and talk to someone about your feelings.

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# Other useful organisations

### **Carer's Allowance Unit**

**0800 731 0297 (8am–6pm Monday–Friday)**

**[www.gov.uk/carers-allowance-unit](http://www.gov.uk/carers-allowance-unit)**

The Carer's Allowance Unit provides information about eligibility for Carer's allowance and Carer's credit to protect your pension if you stop working to become a carer.

### **Carers Trust**

**0300 772 9600 (England)**

**0300 772 9702 (Wales)**

**[info@carers.org](mailto:info@carers.org) (England)**

**[wales@carers.org](mailto:wales@carers.org) (Wales)**

**[www.carers.org](http://www.carers.org)**

Carers Trust works to improve support, services and recognition for anyone who is caring, unpaid, for a family member or friend.

### **Carers UK**

**0808 808 7777 (helpline, 9am–6pm Monday–Friday)**

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

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

Carers UK provides information and advice for carers about their rights and how to access support.

### **Citizens Advice**

**0800 144 8848 (for England, 9am–5pm Monday–Friday)**

**0800 702 2020 (for Wales, 9am–5pm Monday–Friday)**

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

Your local Citizens Advice can give you information and advice in confidence or point you in the right direction.

### **Cruse Bereavement Care**

**0808 808 1677 (helpline, 9.30am–5pm Monday and**

**Friday, 9.30am–8pm Tuesday, Wednesday and Thursday)**

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

Cruse Bereavement Care is a national charity for bereaved people in England, Wales and Northern Ireland. It offers face-to-face, telephone, email and website support.



Factsheet 523

Last reviewed: October 2019

Next review due: October 2022

Reviewed by: Dr Nuriye Kupeli, Senior Research Associate, University College London, and Professor Esme Moniz-Cook, Clinical Psychology of Ageing and Dementia Care Research, University of Hull

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At Alzheimer's Society we're working towards a world where dementia no longer devastates lives. We do this by giving help to everyone who needs it today, and hope for everyone in the future.

We have more information on **Symptoms and treatments**.

For advice and support on this, or any other aspect of dementia, call us on **0333 150 3456** or visit **[alzheimers.org.uk](http://alzheimers.org.uk)**

Thanks to your donations, we're able to be a vital source of support and a powerful force for change for everyone living with dementia. Help us do even more, call **0330 333 0804** or visit **[alzheimers.org.uk/donate](http://alzheimers.org.uk/donate)**



*Patient Information Forum*



Together we are help & hope  
for everyone living with dementia

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