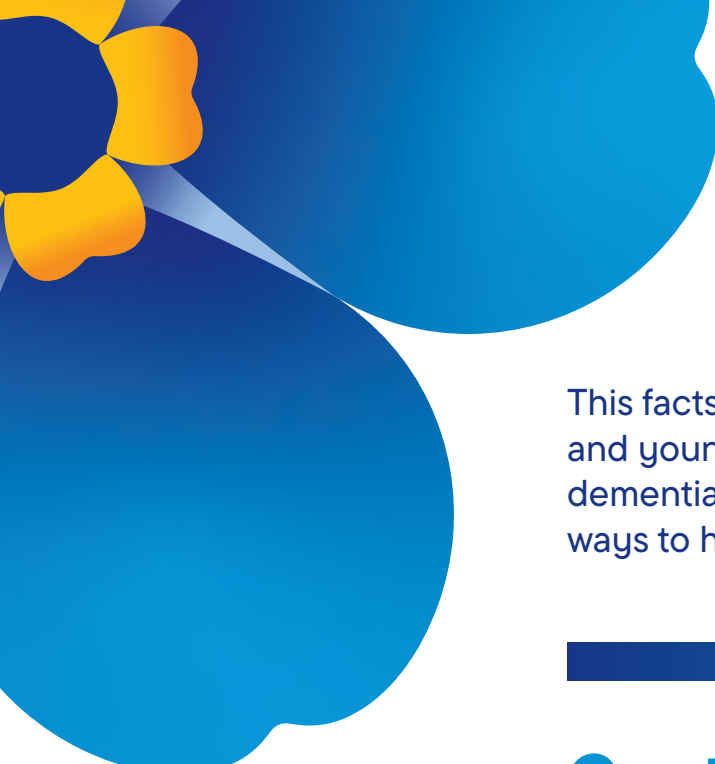


# Supporting children and young people when a person has dementia



**Alzheimer's  
Society**

Together we are help & hope  
for everyone living with dementia



This factsheet suggests ways of talking to children and young people when someone close to them has dementia. It covers how they may be affected and ways to help them feel supported and involved.

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## Contents

<b>1</b>	<b>The importance of talking about dementia</b>	<b>1</b>
<b>2</b>	<b>Explaining dementia to children and young people</b>	<b>3</b>
<b>3</b>	<b>How to involve children and young people</b>	<b>6</b>
<b>4</b>	<b>Coping with common worries and emotions</b>	<b>9</b>
<b>5</b>	<b>Spotting signs of distress</b>	<b>12</b>
	<b>Other useful organisations</b>	<b>15</b>

# 1 The importance of talking about dementia

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Finding out that someone close to you has dementia is difficult for anyone. We all need time to adjust and process our feelings. Children and young people are no different, but it can be harder for them. Children and young people may not fully understand what dementia is. Or they might find it harder to cope with their emotions.

They might also be coping with other things, or changes, in their life that they find difficult, such as:

- starting or moving to a new school, college or university
- moving into a new class or up a year
- dealing with puberty
- preparing for exams
- issues with friendships or relationships
- social media pressure
- comparison with other people's lives.

It is natural to want to protect children and young people from difficult situations. But they are often aware of unusual atmospheres or tensions, even when they don't know the reasons for these. If there are existing problems in the family, then coping with the challenges of dementia can be even more difficult.

It can be reassuring for children and young people to understand what the situation is. If they feel things are kept from them, they may find it difficult to trust what you say to them later. Telling them as soon as you're able to will help them to understand and possibly cope better.

Seeing how people around them deal with difficult situations can help children and young people learn valuable life skills. For example, they can learn how to manage painful emotions in distressing situations.

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Giving clear explanations about dementia can help children and young people to adjust and manage their feelings. By explaining 'why' the person is behaving differently, you will help them to understand the condition better. They may even find it a relief to know that the person's behaviour is part of their dementia.

The person with dementia may be able to talk about their condition with the child or young person. They may need support to do this.

Think about whether it would be helpful for you to be there during the conversation. Children and young people often learn by example. It may help if you speak with the person with dementia in the way you want the child or young person to speak with them. See factsheet 500, **Communicating**.

If you need more information on dementia to be able to explain things there is a lot of information on our website: **alzheimers.org.uk**. Or you can order print publications, for example, factsheet 400, **What is dementia?**

Our magazine **Dementia together** features inspiring stories and ideas from people living with dementia and carers. See **alzheimers.org.uk/magazine**

## 2 Explaining dementia to children and young people

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When you explain what dementia is and what is happening, try to be as clear and calm as possible. Use language and descriptions that the child or young person can understand. Try to get a sense of how much detail they can cope with. Then explore any concerns and worries. It can also be helpful to talk about the type of dementia the person has and how it usually affects people.

Ask the child or young person to share their feelings with you. Listen carefully to what they have to say. This is an important part of supporting them. Listening can sometimes be more valuable than talking.

Allow them time to say how the changes are affecting them. Try to imagine the situation from their point of view. Think about their relationship with the person with dementia. This will help you find out if they are worrying about something specific.

Try to find out what they think dementia is. If they've misunderstood something or taken it the wrong way, try to make it clear for them so they understand it correctly.

You might also find the following tips helpful:

- **Let them know that there is no 'right' way to feel.** Say that they can speak to you whenever they need to, without being judged.
- **Encourage them to ask any questions they have.** Let them know that they can always talk to you. You could also set aside a regular time to talk or do activities together when they can speak with you alone.
- **Acknowledge things that are happening that might seem strange.** This could include the person with dementia forgetting where they are, or not recognising family members. The person may also say and do inappropriate things. The child or young person may have noticed this.
- **Focus on the things that the person with dementia can still do.** Explain the things that are more difficult for the person. Mention any examples of ways you've helped the person to adapt.
- **Try to be patient.** You may need to repeat your explanations on different occasions. The young person or child may take in different information at different times. This will depend on their age, personality and level of understanding. See 'Consider age and maturity' on page 4.

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**My daughter meets him for coffee as well and my son will take him out. They both do it with a sense of humour that he likes.**

**Family member of a person with dementia**

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- **Give them plenty of emotional support.** This can be through caring words or gestures, and hugs where appropriate. Reassure them that they are not alone and that you are all in the situation together.
- **Don't be afraid to use humour if it feels right at the time,** for that person. It often helps if you can laugh together.
- **Use books, online videos and podcasts.** These can help describe what dementia is after you've had a conversation. They can also help explain difficult situations and what the person with dementia may be experiencing. Our YouTube channel is a good resource for this. Go to [alzheimers.org.uk/youtube](https://www.alzheimers.org.uk/youtube)

## Consider age and maturity

Every child and young person is different. Even children of similar ages will vary in their emotional development, understanding, and awareness of situations. They have different experiences, outlooks and personalities. Sometimes a young teenager has more maturity than an older one.

The following approaches give guidance for general development stages and may help guide you in these conversations. However, you are the best person to know how the child or young person close to you may respond when you talk to them about dementia.

### Young children

Young children may not understand the concept of 'dementia'. They may not have heard the word before or may have an incorrect idea about it. For these children, it can be helpful to focus on the things they might have noticed. This could be the person with dementia forgetting their name. You could then use this as an example of how the person is not very well.

Simple videos or pictures can help explain dementia to children at this stage. It is also important to focus on what the person is still able to do and how they are still the same person.

### Older children

Older children might have heard of dementia. They may have some understanding of the condition already. They may even have seen it discussed or portrayed in the media, including social media. It can be helpful to ask what they know about dementia, and whether they have any worries about it. Then give a clear, simple explanation to be sure they understand. They are likely to have more questions than younger children.

## Teenagers

Teenagers will vary a lot depending on their general level of maturity. Their own experiences and what else is going on in their life will form a part of this. This might include exams or starting a new school or university. Life can be confusing and challenging as they become adults.

Body changes, developing romantic relationships and problems with friends can bring strong emotions. These can all affect how they communicate and behave with people around them. This will also affect how you talk to them about dementia.

Teenagers are likely to be able to grasp what dementia is. They might understand how it is affecting the person with dementia and other family members. However, with this awareness, they may need more emotional support than younger children.

Written information can be useful for teenagers. They may read about it themselves on their smartphones. Bear in mind that there is a lot of misinformation online, including on social media. Encourage the teenager to ask you questions about anything that has worried them, or if they have any further questions.

Age-appropriate films, or television programmes about dementia, can also be useful. Although it is often advisable for you to watch them first. It is important to let teenagers take the lead on what information they would like and how they want to receive it.

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**In my experience it's better to be honest and take small steps with information as our children often are more aware than we realise! Linking in with their pastoral/ well-being team at their school may also be helpful when the time is right.**

Family member of a person with dementia

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## Space for your notes

# 3 How to involve children and young people

Children and young people can help the person with dementia. For example, they may like to be involved with the person's daily routine. This may give them a feeling of control. It can help them to cope with a difficult and emotional situation. It can also prevent them from feeling left out when other family members are busy. They may find that there are aspects of caring that are fulfilling.

Make sure that the child or young person knows that you appreciate their help. Show them how they are supporting the person with dementia. This is especially important if the person with dementia finds it difficult to show this appreciation.

Remind them that the person might sometimes forget things or become confused. They may also say things that don't reflect how they actually feel about others. Try to help the child or young person to not take things personally if possible.

Every family and every child is different. Try various ways to involve them. Here are some ideas to help:

- **Let the child or young person know that simply being with the person with dementia**, and showing them love, is one of the most important things they can do. The person with dementia may still be able to connect with them in this way.
- **Try to ensure that the time they spend with the person is pleasurable.** Activities could include walks, playing games, sorting objects, listening to music or making a scrapbook of past events. Try to encourage them to continue doing these things together for as long as they are able to.
- **Talk to the person with dementia about their life and interests with the child or young person.** Encourage them to look at photographs and mementos together and talk about their lives. It's important not to ask the person too many questions as they may feel they are being tested. If they misremember names or places, it doesn't matter. The important thing is to engage them, and the child or young person, in conversation.
- **At any stage of the condition, you can encourage the child or young person to show love and support** by hugging or holding the hand of the person. This must feel appropriate for both the young person and the person with dementia.



- **Children and young people may want to complete a dementia fundraising challenge.** This could be a bake sale or Memory Walk (visit [memorywalk.org.uk](http://memorywalk.org.uk)). It might help them feel they are doing something important to support dementia. This can also give them the chance to talk about dementia with their friends in a relaxed and positive way.
- **The child or young person could speak to their school, college or workplace about Dementia Friends sessions** (visit [dementiafriends.org.uk](http://dementiafriends.org.uk)). Or you could do this on their behalf if they prefer. These sessions can allow their friends to learn more about dementia. For more information, see ‘Other useful organisations’ on page 15.

## When a child or young person is a ‘carer’

Some children or young people may find themselves doing most or all of the ‘caring’ for the person with dementia. This can happen for a number of reasons. For example, if the person with dementia is their parent and there is limited support in the family.

A caring role at a young age can be very difficult, both physically and emotionally. This can have an impact on their health, wellbeing, education and relationships.

Many young people who are carers find it difficult to get the support they need. This is especially true if their family member has young-onset dementia, and if people around them think that dementia only affects older people. This can lead to the child or young person being affected by a lack of understanding or stigma. They can make them feel isolated and alone.

For more information about helping the child or young person, see ‘Ways you can support’ on page 13. Our Dementia Support Forum is an online community where you can read other people’s stories, ask for advice and share concerns. Visit [forum.alzheimers.org.uk](http://forum.alzheimers.org.uk)

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**Mine know that his memory is not so good. That he struggles with some things and we don’t hide things. If he’s going out, they see that I get him ready, shoes socks coat tidy. They take their lead from me and just do the same.**

Family member of a person with dementia

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### Challenging situations that may arise

It is a good idea to be aware of things the person with dementia may find upsetting or confusing. Be prepared to provide reassurance if these happen when a child or young person is present. Talk to the child afterwards if the person becomes upset or confused. This may help them to understand why this happened and to know that it is not their fault.

Young children may need reminding why the person with dementia sometimes behaves unusually. All children and young people may need to talk about their feelings at different times. This may be especially when their relationship with the person with dementia changes.

In certain circumstances, it is best not to leave the child or young person alone with the person with dementia. This could be if they begin to show aggressive or inappropriate behaviour. Try to explain the reasons for this if you can. Make sure the child knows that this is a symptom of the person's condition. Emphasise that this is not how the person with dementia feels towards them.

If the behaviour is violent or sexual, never leave the child or teenager alone with the person with dementia. It is important that the child or young person is kept safe. Share your observations and concerns with a professional immediately. This could be a dementia adviser, social worker or your GP, to get their advice. If this affects how you feel or your wellbeing, talk to your GP.

## 4 Coping with common worries and emotions

A child or young person's ability to understand and cope will be shaped by their lives and their relationship with the person with dementia.

Young people can believe that they are responsible for the way that people around them act. This can include the person with dementia and other family members. This is a common reaction of young people to any unhappy or difficult situation, especially if they do not understand it.

They may also feel this way if they are not given a clear explanation of what dementia is and how it can affect people. Or they might forget. For example, the person with dementia may act in a way that is out of character. The child or young person may then think they have done something wrong to cause it.

It is important to remind them that what the person is doing is due to their dementia, and not for any other reason. It can be helpful to reassure the child or young person and talk about their anxieties. Providing information about dementia and why the person seems different will help.

On difficult days, adults might be short-tempered or not have time for younger people. Or, they may be at home less than before – for example, if they go with the person with dementia to support services. They may also be finding it difficult to manage the practicalities of caring. Children and young people might see this as their fault. All of these changes can make a child or young person feel anxious.

It is very important to reassure children and young people that they haven't done anything wrong. Tell them they're not responsible for the way that others are feeling or acting.

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**He came through and told me that Grandad had said to him “You think you are such a smart \*\*\*\*”. The 9-year-old said to me is Grandad going to say sorry and I said no he won't because he will have forgotten he said it.**

Family member of a person with dementia

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### Getting dementia themselves

A common worry amongst children and young people is that dementia is contagious, and they might catch it. Reassure them that this is not how people develop dementia.

Older children may worry that they or other relatives may get dementia in the future. Especially if the person has a rarer type of dementia with a strong genetic link. For more information on this, see factsheet 405, **Genetics of dementia**. You could explain that research means that better treatments, or even a possible cure, could be found one day.

The child or young person may find our information about dementia and the brain helpful. This includes a series of films. See [alzheimers.org.uk/braintour](http://alzheimers.org.uk/braintour). They might also want to read about ways to minimise the risk of dementia. See factsheet 450, **Risk factors for dementia**.

### Common emotions and reactions

It is important to be mindful of and recognise the needs of children and young people. They can respond in a number of ways when someone in the family has dementia, including:

- **Confusion** – they may be unsure what dementia is and how to respond to it. If the person with dementia is their parent, they may also feel confused about ‘role reversal’. This means feeling the need to be responsible for their parent who used to be responsible for them.
- **Sadness, grief or loss** – they may feel sad about what’s happening to the person they love. They may also feel loss or grief if the person doesn’t seem to be the same as before. Or that they can’t interact with each other in the same way anymore. They might also feel ‘anticipatory grief’ once they know that dementia is a terminal condition.
- **Anxiety and fear** – they may feel nervous about being with the person with dementia. They may be nervous of the person’s changing behaviour and not know how to act around them. Some children or young people may worry about the future. This could include worries about what will happen to the person with dementia and if they will develop dementia themselves. They may also worry if they can go away, for example to university.

- **Anger and frustration** – they may feel angry about the situation and feel it is unfair. They may also feel bored or frustrated at having to answer the same questions. Or they may be annoyed that they can't go out with their friends if they have to be with or look after the person. They may also find it difficult to express other emotions, which can come out as anger or aggression.
- **Embarrassment** – they may feel embarrassed at how the person with dementia behaves. They may also feel they are treated differently at school or amongst friends, as being the relative of a person with dementia.
- **Rejection** – they may feel rejected if other family members are under pressure and seem to have less time for them than before. This can be difficult if they are going through exams or forming romantic relationships and need family support.
- **Responsibility to protect others** – they may feel they can't share worries about feelings or events in their life. This may be to protect family members.
- **Guilt** – they may feel guilty for feeling any of these emotions or thinking negative thoughts about the person with dementia.

Children and young people may be afraid to talk about these feelings and worries. They may see that you and other adults are already under strain and not want to cause any further upset.

Older children and teenagers may feel embarrassed to show their feelings. Or they might distance themselves by becoming uninterested or detached. They may need gentle encouragement to talk about their feelings.

Think about who they would most likely want to speak to. This may be other family members, friends, or professionals such as a therapist or a counsellor.

Dementia is a terminal condition. As the person's condition progresses, the child or young person may think about them dying. They may think about death in general. You may find our factsheet, 531, **End of life care** helpful for these difficult conversations.

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# 5 Spotting signs of distress

Everyone reacts differently to difficult experiences. Distress can come out in a wide range of ways. This is true for children and young people as well as for adults.

A child's or young person's age, personality and stage of development will all play a part in how they react. Some children may not recognise or be able to communicate that they are feeling stress at all. The needs and signs of distress of children and young people can sometimes go unnoticed. This can happen when families focus on the person with dementia, especially as their needs change.

If you are worried about how a situation is affecting a child or young person, these signs may be useful to look out for:

- **Anxiety-related symptoms.** These can include nightmares, difficulty sleeping, or waking through the night. They may be quick to anger or not able to control their emotions. They may also be tense, fidgety or clingy. Unexplained aches and pains are also signs of anxiety. Eating more or less than usual, feeling or being sick, or constantly feeling tired can also be signs that they are anxious.
- **A deterioration in their schoolwork.** Upset children and young people may find it harder to concentrate. They may feel unmotivated to work and their schoolwork or studies may suffer.
- **Appearing unaffected.** A child or young person may appear uninterested or unusually cheerful. They may be bottling things up or putting on a brave face. You can help by encouraging them to talk about the situation and express their feelings.
- **Being sad and weepy.** Some children and young people respond by feeling very upset. They may need a great deal of attention over a long period of time. Even if you are feeling under a lot of pressure, try to give them time each day to comfort them and talk things over.
- **Retreating from the situation.** Older children and teenagers can often seem preoccupied with their own lives. They may retreat to their own rooms or stay out more than usual. They may find the situation hard to handle. This may be because of all the other changes and uncertainties they are dealing with. Teenagers may feel embarrassed to talk about their feelings. However, they still need to know that you love them and understand what they are going through. They may need some time before they are ready to talk about how they feel.

- **Getting too involved in a person's care.** Children and teenagers may want to help in caring for someone they love. But it is important that it doesn't interfere with their own development, studies or health.

## Ways you can support

Children and young people will need plenty of reassurance and emotional support. This will be both now, and as the person's condition progresses.

It is important to let them know that you are there for them and that you are all in this situation together. This will help them feel that you understand the difficulties they face. They need to know that they are still loved even when the adults around them are sad and stressed at times.

The following can help:

- **Let the child know that how they are feeling is normal.** Say that they can talk to you, or others, about their feelings whenever they want. Reassure them that they will never be judged. There may also be a particular family member or friend that they are close to.
- **Help them learn more about dementia.** Websites aimed at children, such as Dementia in My Family, can help. See 'Other useful organisations' on page 15. Suggest that they could explain their relative's changes to their friends. This could be by sharing information or online videos. This will help their friends to understand too.
- **Try to help the child express themselves in a way that works best for them.** They might find it easier to explain how they are feeling by getting involved in arts therapies. This could include creative writing, painting, music or drama.
- **Take photographs of the child or young person together with the person with dementia.** In difficult situations, these can help remind you all of the better times.

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## Space for your notes

### Support services

Think about whether to inform the child's pastoral care team at school, college or university about the person with dementia in the family. Letting them know about the situation will mean they will then understand any relevant difficulties the child may be having.

The team should also keep you informed of any changes they have noticed. They may be able to arrange counselling or other support.

It is important to talk to the child about this before speaking to anyone involved in their education. Include them as much as they would like.

Children at school and young people at university may be able to get extra support or adjustments around exams. They would need to explain their caring responsibilities or family circumstances. Ask about this, if this applies.

If the young person has a job as well as caring responsibilities for the person with dementia, speak with them about how they manage this. Let them know that they don't have to tell their employer about their caring role, but it might help them if they do. Their employer may be able to give them some support.

A wide range of other organisations and services provide support that may be appropriate for the child or young person. This will depend on what is right for them, but suggestions include:

- **Talking therapies** may help as the child or young person can talk about their feelings with a professional. This can be a counsellor or therapist. The GP is a good starting point for this, or you could look for a private counsellor. A teacher or professional who provides pastoral support may be able to help in finding a counsellor.
- **If the child has a religious faith**, consider how this may provide comfort and reassurance. Music, prayers and in-person or online services could be helpful. Some places of worship run support groups for family members of people with dementia.
- **If you or the child or young person would like more support and information**, you can call Alzheimer's Society's Dementia Support Line on **0333 150 3456**. Or you can visit our online community at **[forum.alzheimers.org.uk](https://forum.alzheimers.org.uk)**



# Other useful organisations

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**Alzheimer's Society Youth engagement team**  
**[youngpeople@alzheimers.org.uk](mailto:youngpeople@alzheimers.org.uk)**  
**[alzheimers.org.uk/youngpeople](https://alzheimers.org.uk/youngpeople)**

Alzheimer's Society provides resources for schools, youth groups and universities to support people affected by dementia.

**Childline**  
**0800 11 11**  
**[www.childline.org.uk](https://www.childline.org.uk)**

Childline is a free, private and confidential service where children and young people can talk about any worries or concerns.

**Dementia Explained**  
**[www.alzheimersresearchuk.org/kids/dementia-explained](https://www.alzheimersresearchuk.org/kids/dementia-explained)**

Dementia Explained is Alzheimer's Research's website for children and younger people. It offers age-appropriate information about dementia across three age ranges.

**Dementia In My Family**  
**[www.dementia.org.au/about-dementia/dementia-my-family](https://www.dementia.org.au/about-dementia/dementia-my-family)**

Dementia In My Family is a website that has age-appropriate information about dementia separated by ages, from pre-school to 16+.

**Dementia UK**  
**[www.dementiauk.org](https://www.dementiauk.org)**

Dementia UK have resources for talking to children about dementia, including videos for children on their YouTube channel.

**iSupport**  
**[www.isupportdementiacarers.co.uk](https://www.isupportdementiacarers.co.uk)**

iSupport is an online training and support programme for both adult and young dementia carers. It was developed by the World Health Organization to help carers provide good care and take care of themselves.

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### **The Dragon Story**

**[www.gloriousopportunity.org/thedragonstory.php](http://www.gloriousopportunity.org/thedragonstory.php)**

The Dragon Story is a four-minute cartoon for five- to nine-year-olds explaining dementia and how it can affect family members.

### **Young Minds**

**0808 802 5544 (parents helpline, Monday–Friday  
9.30am–4pm)**

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

Young Minds is a charity dedicated to improving and supporting the mental health of children and young people.



Factsheet 515

Last reviewed: November 2024

Next review due: November 2027

Reviewed by: Dr Joshua Scott, Professor of Ageing and Clinical Psychology/Director, UCL, and Dr Louise Hopper, Associate Professor, School of Psychology, Dublin City University

This factsheet has also been reviewed by people affected by dementia.

To give feedback on this factsheet, or for a list of sources, please email [publications@alzheimers.org.uk](mailto:publications@alzheimers.org.uk)

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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 **Getting a diagnosis**.

For advice and support on this, or any other aspect of dementia, call us on **0333 150 3456** or visit **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**



**Alzheimer's  
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Registered charity no 296645. A company limited by guarantee and registered in England no 2115499. Alzheimer's Society operates in England, Wales and Northern Ireland.