

Children and young people's privacy notice



Introduction

At Dementia UK, we support children and young people whose families are affected by dementia.

Our Consultant Admiral Nurse for Children and Young People is a specialist dementia nurse who works with children and young people. When you talk to the Consultant Admiral Nurse, we will ask for some information about you. This helps us support you and keep you safe.

This notice explains how we use your information when you receive support from our Consultant Admiral Nurse for Children and Young People. It explains:

- what personal information we collect about you
- why we use it
- who we might share it with
- what rights you have

If there is anything you don't understand in this notice, you can ask the Consultant Admiral Nurse or our Data Protection Officer, whose contact details are at the end of this notice.

If you use other Dementia UK services or get involved with us in other ways, please also read our main [▶ privacy notice](#), which explains how we use your information in those situations.

What is personal information?

Personal information (sometimes called personal data) is information about you that could identify you.

This could be your name, a photo of you, where you live, the name of your school or college or information you tell us about yourself or your family.

Some personal information is more sensitive than other information. This includes things like your health, religion, sexuality or ethnicity. The law says we must take extra care when we use this information.



What information do we collect and why?

We need some information about you so that we can:

- give you the support you need
- keep notes about what we talk about together
- help keep you or someone else safe if we are worried that someone might be at risk of harm

The information we collect from you or your parent or guardian will depend on the support you receive from our Consultant Admiral Nurse, but it might include:

- your name
- your birthday or age
- where you live
- your email address and phone number
- the name and contact details of your parent, guardian or another trusted adult
- information about your family and your relationship to the person living with dementia
- notes that we make when we speak to you
- any information you choose to share with us
- information about your health or how you are feeling
- records of your appointments and the conversations we have with you or your family
- information we need to help keep you or someone else safe if we are worried that someone might be at risk of harm

Where do we get your information from?

Most of the information comes from:

- you
- your parent or guardian
- your Consultant Admiral Nurse for Children and Young People



Why do we use your information?

We use your information to:

- understand how we can help you
- provide you with advice and support
- arrange appointments with you
- keep records of what we have spoken to you about
- work with other people to help you if we need to
- protect you or someone else if we are worried about someone's safety or wellbeing
- make our services better
- follow the law

From time to time, we might also ask if you would like to share your experiences to help raise awareness of dementia or support our work. This is always your choice. If you are interested, we will tell you what it involves and ask for permission before using your information.

Why are we allowed to use your information?

The law says we must have a good reason for using your information.

We use what you tell us to understand how we can help you, give you the right support and keep a record of the support we give you.

Some information, for example about your health or how you are feeling, is more sensitive than other information. The law says we can use this information, but we must take extra care with it.

If we are worried that you or someone else may be at risk of harm, the law says we are allowed to use or share your information to help keep you or other people safe.

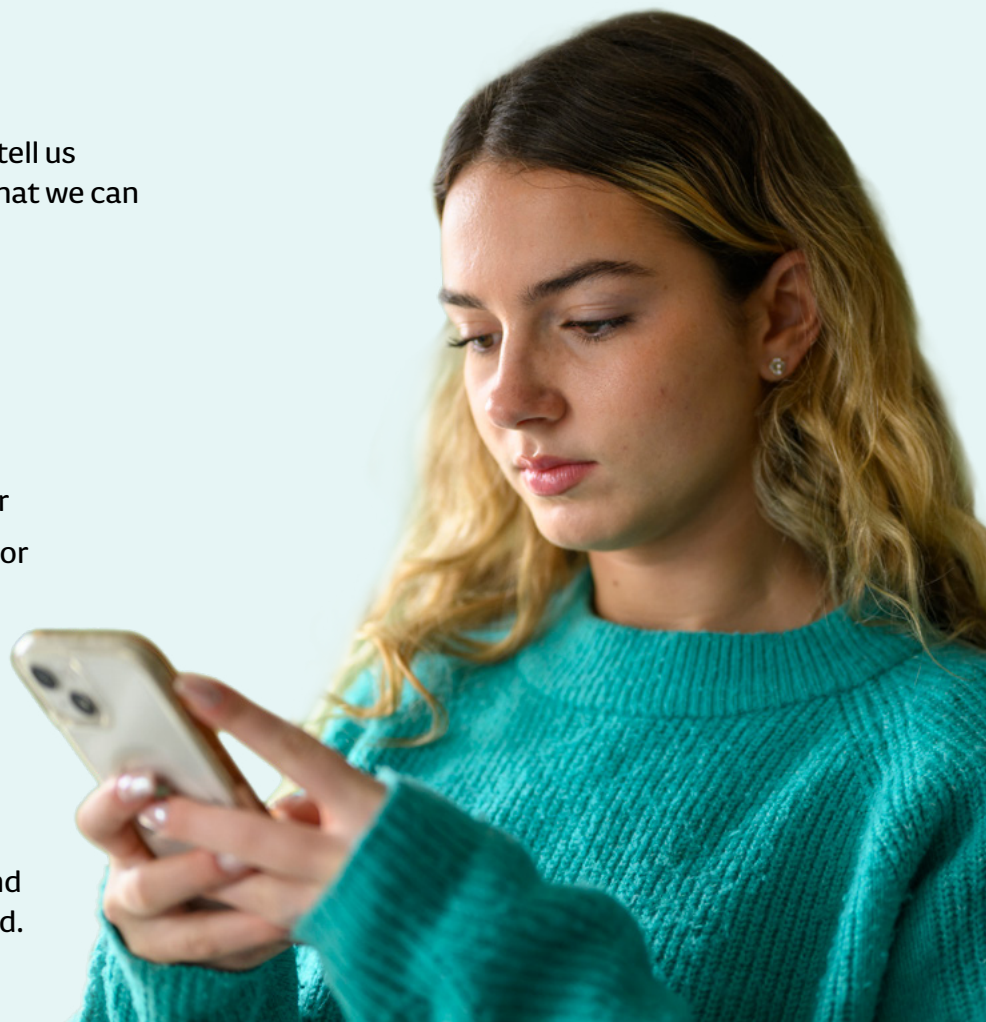
Who might we share your information with?

Sometimes we need to share what you tell us with other people or organisations so that we can support you or keep you safe.

This might include:

- your parent or guardian
- your GP or other health workers
- your school or college
- children's services or a social worker
- other people who help support you or your family
- organisations that help us provide our services (for example the companies that provide our IT systems)

We only share what you tell us with the people or organisations who need it, and we only share the information they need.



Are there times when we might share your information without telling you?

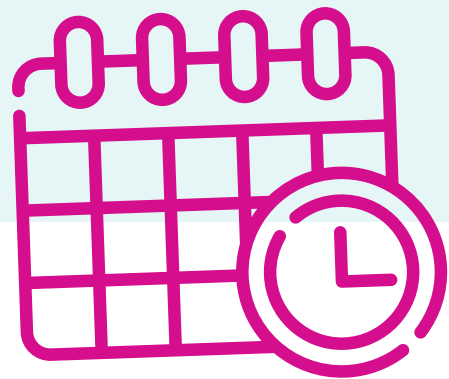
What you tell our Consultant Admiral Nurse is private. We will only share your information if we have a good reason to do so.

Sometimes we need to share information to help keep you or someone else safe, or because the law says we must, for example if:

- we are worried that you or someone else are at risk of harm
- the law says we must share the information

If we can, we will tell you:

- what we have shared
- who we have shared it with
- why we have shared it



How long do we keep your information for?

We only keep your information for as long as we need it.

We keep records about the support we have given you until your 25th birthday. If you are 17 when we stop supporting you, we will keep your records until your 26th birthday. After that, we will securely delete them.

How do we keep your information safe?

We use secure computer systems, and only staff who need your information to do their job can see it. We also have rules and security measures in place to help keep what you tell us safe.



Does your information leave the UK?

Sometimes the companies that help us run our services use computer systems in other countries.

If this happens, we make sure your information is kept safe and protected.



You have rights over your information. This means you can ask us to:

- tell you what information we have about you
- correct information if it is wrong
- delete your information in some situations
- stop using your information for a while in some situations
- send your information to another organisation, if the law allows us to
- deal with any complaint you might have about the way we have used your information

If you are old enough to make decisions about your own information, you can ask us yourself. If not, your parent, guardian or someone acting on your behalf may be able to ask for you.

If you think we have not used your information properly, you can contact us using the details in the 'Questions or complaints' section below. If you are not happy with our response, you can also complain to the Information Commissioner's Office (ICO).



Questions or complaints

If you have any questions about how we use your information, or you think we have not used it properly, please contact our Data Protection Officer.

Email:  dataprotectionofficer@dementiauk.org

We will do our best to put things right.

If you are still unhappy, you can complain to the Information Commissioner's Office (ICO), which is the UK's independent organisation for data protection.

Website:  ico.org.uk

Telephone: 0303 123 1113



DementiaUK

Helping families face dementia