

Family and Friends - *Factsheet*

Dementia web 
Information resource for carers, professionals and you

www.dementiaweb.org.uk



Family and Friends

For some people, a diagnosis of dementia confirms what they, themselves, had suspected for some time. For other people it may come as a great shock, and take some time to seem real. It will be a worrying and upsetting time for you and those closest to you. However, it is important to remember that the support your family and friends can give you will be invaluable to you as they are the people who already know you, and will be able to best support you through the changes.

When should I tell people I have dementia?

There is no right or wrong time to tell your family and friends that you have dementia. It is entirely your choice and you should only do so when you feel ready. You may want to take a little time to consider all the information you have been given and come to terms with what the diagnosis means. People often find that they are able to explain their diagnosis more calmly and clearly, to others, once they have had time to understand it themselves.

If you have had someone with you through your journey up until diagnosis you may wish to discuss with them when is an appropriate time to tell others. They may be able to assist you in doing so. You may also wish to ask the advice of your doctor or caregiver about this. It is important to remember, however, that this is your decision and you should only tell people when you feel ready.

Whom should I tell?

As with deciding when to tell people that you have dementia, the choice of who you tell is also entirely yours. You may decide to tell those closest to you first, those who know you best, and those whom you trust the most. You may realise that some people will have already started to notice changes in you and that the diagnosis will not come as a complete shock to them. Alternatively, there may be other people important in your life that you may not have seen so recently or regularly who may not be so aware of your increasing difficulties.

Telling people other than close friends and family should not necessarily be a priority. However, you may wish to inform other people you see regularly, such as neighbours or other members of a club you may attend. This will help them to understand any changes in you and your behaviour as your dementia progresses and enable them to support you. You could ask close friends or family members to share the news with others if you feel uncomfortable doing so.

Discussing dementia with children and young people

The thought of telling a child or young person that you have dementia may be an extremely difficult one. Your initial feeling may be to keep it from them, as a way of protecting them. However when you feel comfortable in doing so it is extremely important that you discuss your dementia with the children in your family. Children are incredibly perceptive and may have already noticed signs of worry and tension within the family; it may therefore, be reassuring to them to be given some explanation for this and reassurance that they are not the cause of the worries.

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The way in which you share information about your dementia with a child or young person will significantly depend on their age, maturity, and your relationship to them. Very young children may not have noticed any changes in your behaviour and, anyway, may not have already formed definite expectations about usual behaviour. It may be that you will not have to explain anything to children of this age. Older children are more likely to have already noticed changes such as increased forgetfulness or different moods, and will benefit from understanding what is happening. They may be worried that you no longer care as much for them, or that you are angry with them. They can be reassured about these matters and can learn how best to understand your changes and how to help you.

Before you discuss anything with a child or young person, it is important that you involve their parents or guardians in considering the best way to go about explaining you have dementia. You can consider how much detail the child will be able to understand and cope with. It is possible that you or the child's parents will feel that the news is better coming from them; this is fine, as the situation should be dealt with in a way that feels most comfortable to you and your family.

Some useful things to consider when telling a child or young person about your dementia:

- Try to be as honest and clear with your explanations and answers as possible.
- Explain to the child that you are ill and that changes in your behaviour are a result of your illness. Reassure them that it is not their fault and has not been caused by anything they have done.
- Give examples of some of the different types of behaviour you may possibly display in the future, so that children are prepared for this, for example mixing up names.
- Encourage the child to ask any questions they may have, and share any emotions they may feel. Try to make them feel comfortable and confident in doing so. A possible approach to this may be to create a question box that the child can put a question into whenever he or she thinks of it and feels ready to ask.
- Just as you, and other family members, needed time to adjust to the news children will also need time to get used to the diagnosis and will require your patience.
- Where possible try to stay calm when talking to children, if they see you getting upset or agitated it is likely to make them feel the same way.
- Do not be afraid to use humour as a way of communicating with a child especially if they are older - laughter in this type of situation can make everyone feel more at ease.
- Talk to the child about the things you are still able to do, and explain that you will want to continue to spend time with them.

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Every child and young person is different and there is no way to foresee how he or she will react to the news that you have dementia. Inevitably, it will come as a shock, the news will be upsetting, and it will be important for you and other family members to watch out for any deeper signs of distress.

These may include:

- Nightmares or insomnia
- Regularly complaining of feeling ill
- Attention seeking behaviour
- Lack of concentration
- Crying and being sad over a long period

Older children and teenagers may be more likely to seem unaffected by the news, or they may begin to spend a lot of time away from the family in their bedrooms or out with friends. Do not forget that this is normal for most teenagers as they begin to disassociate themselves from their family and focus on their relationships with friends. They may appear distant. Do not read too much into this by pressurising them to talk to you about their feelings.

The most important thing you and your family can do is keep talking, updating and reassuring the children and each other. You may also like to encourage them to talk to friends or teachers about it if they feel more comfortable doing so.

Dealing with unexpected or negative reactions

It might be very hard to predict how family and friends will react to the news that you have dementia. In some cases, family members or friends may seem dismissive because of their lack of knowledge of the disease. Others may seem to distance themselves from you initially because they are not sure how to react, or because they are upset, and do not wish for you to see them that way. Those close to you may also experience feelings of anger, as they do not understand why this is happening to their loved one. You may find that friends or relatives of a similar age to you become distressed at the news, realising that this is something that could similarly affect them. All of these reactions are natural and, in most cases, usually short-lived. Just as it will have taken you time to come to terms with having dementia it may take your friends and family time too, but understanding why they may react in these ways may help you to stay calm and positive in the mean time.

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How can my family and friends support me?

Although you may feel reluctant to ask your friends and family for support, the reality is that they will want to help you in everyway possible and that asking for their support could allow you to continue to live as independently as possible, for as long as possible.

You may wish to remind those close to you that one of the best ways to support you is by continuing to see you as an individual with the same likes and dislikes, and that you will still want to be involved in making decisions and choices. Family members and friends should respect your privacy if you have asked for it and support your choice of whom you wish to tell and whom you do not, at all times.

Help to stay safe and independent

Whilst you are still able to live alone, there are many ways you can ask your family and friends to support you. One of the first things to be affected by dementia is your short-term memory. Keeping your surroundings familiar and creating a routine may help you in continuing to manage well. Therefore, you may wish to ask your family and friends to support you in the following ways:

- Designing and making a daily routine with you and then displaying it somewhere where you will see it, on a fridge or bathroom mirror for example.
- Labelling and placing pictures on cupboards and appliances as a reminder to you of where everything is kept and what it is used for.
- Providing large clocks with the date, placed around the house to help you feel orientated and act as prompts for certain daily activities.
- Programming key contact numbers into your telephone.
- Looking after a spare set of house keys so they can gain quick and easy access to your house if needed, and you can feel reassured that you can ask for them if you need them.
- Telephoning you regularly to remind you of appointments, activities etc.
- Contacting your fuel and water suppliers to ask for information about extra services they provide for disabled customers. This may include regular servicing of your appliances to check they are all working safely.
- Helping you to replace appliances, so that they are more suitable for you, or safer or easier to use.

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- Contacting an occupational therapist who can recommend alterations and adaptations to your home to improve safety or make mobility easier.
- Contacting Adult Services or Health agencies to ensure you can be assessed for any support you need.
- Displaying signs in your window, such as “we do not buy at the door” as well as neighbourhood watch stickers, as these may serve as a deterrent to opportunistic callers.
- Thinking of any other practical ways that you can stay as safe and independent as possible.

Help with Managing your Money

As your dementia progresses it is likely that you will find dealing with your finances more challenging. It will be a good idea to discuss with your family and friends how you would like them to support you with this. Below are some useful ways your family and friends may be able to support you, but the choices are yours and you should do what feels comfortable for you.

- Gathering all your financial information together and keeping it in a safe place.
- Setting up direct debits for your bills, so you do not have to worry about paying them on time or being cut off.
- Making sure that you are receiving all the financial benefits that you are entitled to.
- Appointing a Power of Attorney to manage your affairs when you are no longer able to do so. This should be considered as soon as possible after your diagnosis as your family members will need to think ahead to how they can best support you if you are no longer able to act reliably in your own best interests. Appointing someone to have a lasting power of attorney will ensure that your financial and legal affairs are properly dealt with. (More information about this can be found in our factsheet “Making arrangements to manager your affairs”.)

Help to stay positive

In addition to all these practical ways that your family and friends can support you their ongoing emotional support will be your most invaluable asset. They will not want you to feel alone or distressed and will want to share your good times and those that, inevitably, will be not so good.

Guideposts Trust provides specialist information and care services for people with dementia and their carers. www.dementiaweb.org.uk

Contact the Helpline number: 0845 1204048 available Monday to Friday office hours, answer service at other times or by email at info@dementiaweb.org.uk

Dementia Information Service for Carers

Helpline Number **0845 4379901**

Call in normal office hours. Answer phone at other times.

Email: info@dementiawebwarwickshire.org.uk

Web: www.dementiawebwarwickshire.org.uk

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