



# For Carers, by Carers: Getting a diagnosis



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When someone in your family gets a diagnosis of dementia, it can affect each person differently depending on your relationship with the person diagnosed. Getting a diagnosis can take a long time and require various medical tests, scans and memory testing. It is often the case that the person with dementia, the person closest to them, family and friends notice changes long before a diagnosis is made.

Initial reactions depend on how the person with dementia and you, as a family member, are told and how you may react to a life changing diagnosis. Some experience a sense of relief at finally getting a diagnosis, whereas others have a mix of emotions such as denial, anger, sadness and grief.

What is not often said, or heard if you are distressed, is that people can live well and independently for many years with dementia and do better when they get the right support.



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**Take each day  
as it comes and  
try to focus on  
one thing at a  
time – especially  
the good bits.**

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“People can live independently for many years with dementia and do better when they get the right support.”

#### What carers would like to share with you:

- “It can be difficult to encourage the person to go to the doctor if you have concerns about their memory. It is also unlikely that they’ll get a diagnosis at the first GP appointment. Persevere and speak to the GP alone if you can about your concerns.”
- “Receiving a diagnosis gave us a sense of empowerment, we were finally able to plan our future and get on with our lives, albeit with trepidation.”
- “If you can come to terms with the diagnosis and feel able to talk about it, carers support groups are very helpful to find out how other carers coped with a diagnosis.”
- “When you’re ready and feel able to discuss the diagnosis try to speak to friends and family about it. There is still a stigma attached to dementia that won’t go away if we can’t talk freely about it. It is a medical condition and you and the person with dementia need help and support.”



## Did you know?

1. Dementia is a broad term used to describe a range of brain diseases that can affect memory, thinking, behaviour and daily function. There are many kinds of dementia, but the most common is Alzheimer's disease. Other kinds of dementia include vascular dementia, Lewy body dementia, frontotemporal dementias (including Pick's disease) and alcohol-related dementias. It is also possible to have more than one type of dementia; for example, Alzheimer's disease and vascular dementia. What all these diseases have in common is that they damage and kill brain cells so that the brain cannot work as well as it should.
2. Since 2013, the Scottish Government has committed to ensuring that those diagnosed with dementia are offered a minimum of one year of post-diagnostic support from a Dementia Link Worker. Once a diagnosis is made you are entitled to post diagnostic support. The locality you live in will have different ways of offering this, and you may have to wait.



3. There are a number of welfare benefits available for people with dementia and their carers to help you to cope. It is worth speaking to a welfare rights advisor to find out what is available for you and the person you care for.
4. There may be times when you don't agree with the level of care and support you or the person you care for receive, or you may feel you are not being listened to. NHS Advocacy services are available in most areas.
5. The Carer's (Scotland) Act 2016 will be coming into effect in April 2018. The act is there to support carer's health and wellbeing, helping to make caring more sustainable.

