

Post-diagnostic support for people living with dementia

“Perhaps at one stage, we don’t just want to understand
What we want is to live a normal life.”

This document has been created with The Forgets Me Nots, a group of people with dementia in Kent.

This document is based on a paper produced by the British Psychological Society, but the emphasis has been changed to highlight the needs of people with dementia themselves.

This document is for:

- People newly diagnosed with dementia
- The families and friends of people with dementia
- GPs and other professionals who are giving advice to people with dementia.

Diagnosis is important

“You go to the GP when you’re ill or injured ... you only bring up your memory as an afterthought”

Getting a good diagnosis is key if someone is going to be able to live well with dementia.

- People need fast access to assessment, but the process of getting a diagnosis should not be rushed.
- The diagnosis should be given in a sensitive way. People should be supported throughout the process.
- The person with dementia and their family should understand the diagnosis.

Only once the diagnosis has been received can people with dementia and their families start to adjust to the changes in their lives.

Good post diagnostic support services are key to living well with dementia

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Most people feel alone, confused and frightened after getting a diagnosis. Post diagnostic support services can help people to adjust to living with dementia.

“Families need support and time to adjust – these are big life changes for them as well.”

Post diagnostic support should be available equally to everyone.

Support should be given according to the person’s individual needs and circumstances.

People offering support services should recognise that a person’s needs and circumstances will change.

Access to services after the diagnosis should be automatically put in place as part of care planning.

There are barriers to getting post diagnostic support

“We should be given support with transport and information ... how can people get to any of these groups if there isn't someone to look out for them?”

Many people with dementia and their families do not know what is available or how to access it.

People with dementia and their families may be reluctant to seek support.

Lack of transport is often a big barrier to people getting the support they need.

“I didn't want to go to any of the groups of activities offered to me. Only with encouragement from my family did I end up going at all ... and then I found it really good!”

Information about post diagnostic support is vital

“We need a list of what is available, how to get hold of this kind of treatment, who it is suitable for and who do I ask for advice.”

People with dementia need access to good quality clear information about different types of post diagnostic support.

GPs and other professionals who work with people with dementia need to know what support is available after the diagnosis.

Local information about what services are available, where they are available and how to access them is vital.