

# Clinical psychology in the early stages of dementia

## Key messages

- This is a very brief summary of papers published by the British Psychological Society (BPS).
- The papers covers:
  - What psychology is and what psychologist do.
  - How psychologists can support people before during and after diagnosis.
  - A summary of some comments by people with dementia
- The full documents can be found on the British Psychological Society website:  
<http://shop.bps.org.uk/clinical-psychology-in-the-early-stage-dementia-care-pathway.html>

## A guide to types of appointments

### First visit to GP

This may involve short tests of memory and thinking, and then the GP will make a referral to a memory clinic or other specialist.

**How to prepare:** Information about your background and examples of difficulties you are having. Lists are good!

### Pre-diagnostic counselling

Someone talks through the process and implications of having memory tests.

**How to prepare:** Bring any questions you have about the testing with you.

## Memory clinic assessments

Verbal or written tests may be carried out and any brain scans are analysed.

**How to prepare:** Keep the team up to date with any changes, including physical health and life events.

## Sharing a diagnosis

The professionals share their conclusions about what the tests tell them with the person (and possibly their family).

**How to prepare:** If you don't understand, say so and ask for a break or further appointment.

## Post diagnostic support

Interventions that help people to adjust to changes in their lives and to live well after the diagnosis.

**How to prepare:** Think about what you want, keep lists of questions and don't be afraid to ask.

## Psychologists in dementia services

**Clinical psychologists** help people to understand emotional distress and promote well-being. Many work in NHS mental health services.

**Neuropsychologists** work with people who have a medical condition or injury that affects how their brain works.

**Counselling psychologists** often work with people with depression or anxiety or people who are finding it difficult to adjust to life events.

All psychologists have received specialist education and training.

Psychologists can play a vital role in supporting people going through the diagnosis process and afterwards.

## Pre-assessment counselling

Support before any testing for dementia is called pre-assessment counselling. People and their families may experience changes for some time before speaking to a professional. During this time people and their families may experience distress, conflict, stress, and fear.

Pre-assessment counselling should explain:

- Why assessment might be useful.
- What the process of assessment will be like.
- What the results might be – including a diagnosis of dementia.
- How a diagnosis of dementia might affect other areas of life, eg driving, work, and insurance.

This information will enable the individual to make an informed decision about whether to undergo assessment.

Challenges around pre-assessment counselling include:

- Openness and honesty, including using the word dementia, which can be a very stigmatising word.
- Exploring each person's expectations, fears, and ways in which they have previously coped with difficulties.
- Ensuring that the person understands what assessment involves and what the result might be, so that can make an informed choice. It is important that people know they can change their minds.
- How family or significant others are involved in the process.

## Cognitive assessment

Assessment should not just be about a diagnosis of dementia. An assessment will also provide information about what a person's strengths and difficulties, which will help to build strategies for adjustment in the future.

There are different types of assessment:

- Basic or initial assessment can be administered by GPs and nurses. A basic assessment is less good at detecting the early stages of dementia or less common types of dementia.
- Complex assessments (if they are needed) are carried out by specifically trained psychologists and involve an in-depth examination of personal history and test of different thinking skills.

Assessment may be carried out alongside other investigations such as brain scans and blood tests, and may be repeated after a number of months to see if anything has changed.

## Communicating a diagnosis of dementia

It's important that a diagnosis of dementia is given in a sensitive way that takes into account an individual's needs and wishes, and family situation. Some people find a diagnosis very distressing, but may not be able to tell a professional how they feel. Uncertainty around a diagnosis that is not straightforward can be particularly upsetting.

If a person has a good relationship with a professional, it is helpful for this person to be present when the diagnosis is shared.

Communication skills are important:

- People should be informed about the results of different assessments throughout the process.
- How the specific diagnosis was reached should be explained.
- The person giving the diagnosis should not be too optimistic or pessimistic about the future.
- It is often difficult to remember everything that is told to you at a diagnosis – so written information can be useful.
- Clear language is useful and euphemisms such as 'memory problems' can create confusion.

Time is important:

- People will need time to prepare for the diagnosis appointment.
- Extra time should be made for additional appointments if needed.
- There should be time to talk about support after the diagnosis as well as the diagnosis itself.

Some people don't want to know their diagnosis, but support should still be given to carers and family.

## Post-diagnostic support for people living with dementia

“Once I’d accepted it, life became much easier. I didn’t have to be super-efficient any longer.”

Earlier diagnosis provides more opportunity for people to adjust, resulting in prolonged independence. But a diagnosis without support may not be helpful.

When people get a diagnosis of dementia they may feel shock and grief, while others may feel relief that they have an explanation for their experiences.

Psychosocial support does not involve medication.

Different types of psychosocial support may help people by:

- Supporting their thinking skills (eg cognitive stimulation therapy).
- Helping people improve their emotional lives.
- Giving people ideas for how to be more independent and have control over their lives.
- Supporting people to improve relationships.

Post-diagnostic support should be person- or family-centred with treatments matched to individual needs.

Good psychosocial support can help a person move forwards towards living well with dementia.

Services should offer psychosocial support equally. But some groups such as those who are not prescribed medication, those with a diagnosis of Mild Cognitive Impairment or rarer types of dementia, and people with a learning disability or from black, Asian and minority ethnic communities are less likely to receive this type of support.

“After diagnosis I was put in touch with a dementia advisor. I don’t remember who referred me, or what happened before, but I remember her.”

## Consulting with people living with dementia about the BPS papers

All the papers were written with advice from several groups of people with dementia through DEEP. Comments from these groups were fed back to the authors of the papers throughout the writing process.

“There’s a lot going on that I just don’t know about ... Why isn’t there something being done to bring it all together and raise people’s awareness of what is out there?”

These groups also inspired and advised on the writing of A Guide to Psychosocial Interventions which was produced alongside the BPS documents.

A Guide to Psychosocial Interventions can be found on the British Psychological Society website:

<http://shop.bps.org.uk/publications/condition-and-therapy-guidelines/a-guide-to-psychosocial-interventions-in-early-stages-of-dementia.html>

This guide was created by working with the DEEP groups involved in the BPS consultation

DEEP guides aim to support the involvement of people with dementia. Some are aimed at DEEP groups, others at organisations wanting to work well with people with dementia. They have all been co-produced with people with dementia and will be updated regularly throughout the project. Suggestions for new guides are welcome – contact Rachael Litherland at Innovations in Dementia: email [rachael@myid.org.uk](mailto:rachael@myid.org.uk) or telephone 01392 420076.

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