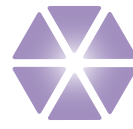




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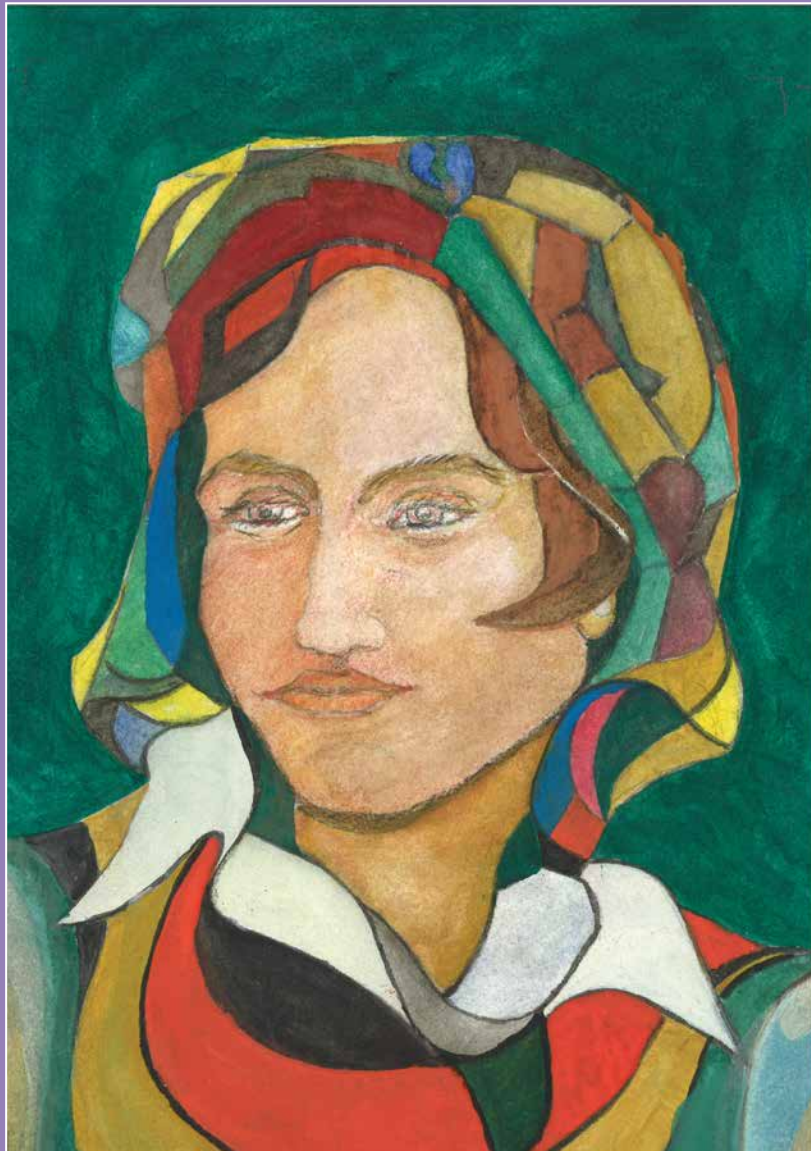


Division of  
Clinical Psychology

## Clinical Psychology in the Early Stage Dementia Care Pathway – Accessible version

Reinhard Guss and colleagues. Collated on behalf of the Faculty of the Psychology of Older People.  
A collaboration of people living with dementia and the Dementia Workstream Expert Reference Group.

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# General introduction

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FPOP have produced a series of papers for professionals working in memory services. This document is a summary of key points and recommendations, intended for the general reader.

The document is divided into six separate sections:

- **Introduction to psychology:** This chapter describes what a psychologist is, and what the different types of psychologist are, who are likely to be involved in supporting people living with dementia.
- **Pre-assessment counselling:** This chapter describes how psychologists can help to support people before they start any tests for dementia.
- **Cognitive assessment:** This chapter describes how psychologists can support people undergoing tests, as well as the types of tests that psychologists can do.
- **Communicating a diagnosis of dementia:** This paper describes how psychologists can help to support people when a diagnosis of dementia is shared, as well as how professionals should share a diagnosis.
- **Post-diagnostic support:** This chapter describes how people can be supported after diagnosis, to enable them to live well with dementia. It discusses how psychologists can be involved in offering support after diagnosis.
- **Consultation with people living with dementia:** This is a summary of some of the comments made by people living with dementia, which informed the writing of this document.

# A guide to types of appointment

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Table 1 explains what different types of appointment with services might be like. It covers five different appointments, each at different stages of the dementia diagnostic process:

- **First GP visit:** GPs refer people to Memory Assessment Services, or Memory Clinics, in order to find out whether their difficulties are due to a form of dementia.
- **Pre-assessment counselling:** Where someone talks through the process and implications before any more testing takes place.
- **Memory clinic assessments:** Appointments in which the necessary tests are carried out.
- **Sharing a diagnosis:** Where professionals share their conclusions with the person who has gone through assessment, and possibly with their family.
- **Post-diagnostic support:** Where a service offers interventions to help with adjustment and with living well after diagnosis.

For each of these types of appointment, the table explains:

- The purpose of the appointment
- What typically happens in the appointment
- Communication skills professionals should have
- Anything the person using the service or their family can contribute to help make the most of their appointments.

Table 1: Different types of appointment

	First GP visit	Pre-assessment counselling	Memory clinic assessments (may be several sessions)	Sharing the diagnosis (one or more sessions)	Post diagnostic treatment and support
<b>What is happening?</b>	You, your family or a professional you know, have concerns about your memory and thinking changes. GP undertakes locally/nationally recommended investigations. GP considers making a referral.	Memory Clinic or other specialist provider talks with you (and your family where appropriate): <ul style="list-style-type: none"> <li>Jointly explore ideas about your difficulties</li> <li>They check out your knowledge to make sure you understand what will happen</li> <li>They provide more explanation about clinic tests</li> <li>Jointly agree way forward.</li> </ul>	The team will arrange standard tests: <ul style="list-style-type: none"> <li>Interview with you and a person who knows you well</li> <li>Short tests of thinking, memory and mood</li> <li>Questions about how you cope at home</li> <li>You may also have brain scan(s)</li> <li>Further medical tests</li> <li>More in-depth cognitive testing</li> <li>Activities of daily living checks.</li> </ul>	The Memory Clinic team will organise an appointment to tell you the diagnosis if this is what you want. A member of the clinical team who has been involved in your assessments should take part/or provide the diagnosis. If more than one session is needed they should offer this.	A Memory Clinic team member will explain treatment and support options and agree a plan with you. The Memory Clinic team/other professionals should continue to explore any questions you have about diagnosis and treatment as time goes on. A Memory Clinic team member will explain treatment and support options and agree a plan with you.
<b>Good communication standards</b>	Sensitive but clear language. Introducing possible diagnoses. Therapeutic optimism. Explain a little about what Memory Clinic does.	Sensitive but clear language. Further exploration of diagnostic possibilities. Clarifying benefits and disadvantages of from your perspective.	Sensitive but clear language. Clear explanations of what is being done and why. Initial indication of how tests are going. Your questions answered.	They should: <ul style="list-style-type: none"> <li>Name the condition</li> <li>Explain how tests have shown this</li> <li>Use sensitive, clear language and check your understanding</li> <li>Ask for feedback from you</li> <li>Begin to explain treatment options</li> <li>Explain/book next steps</li> </ul>	Use sensitive, but clear language. Check your understanding. Ask for feedback from you. Review and monitor agreed treatment and support plan.
<b>What can I and my family contribute</b>	Information about your history and background. Examples of difficulties. Lists are good!	It helps to bring any questions or concerns to the session.	Keep the team up-to-date with any changes you have noticed, including physical health and life events.	If you don't understand say so. If you feel overwhelmed, or unable to concentrate, say so, ask for a break or a further appointment.	Prepare for meetings, keep lists of questions, don't be afraid to ask. Think about what you want.

# Introduction to psychology, psychologists and the role of psychology in dementia services

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'Psychology is the scientific study of human mind and behaviour: How we think, feel, act and interact individually and in groups.'

Definition of psychology by the British Psychological Society

Psychology is both an academic subject and an applied practice. This means that psychologists are concerned with studying the human mind and behaviour, and with using the knowledge gained to help solve problems and make positive changes.

In general, there are three types of psychologists who are likely to be involved in dementia services.

## Clinical and counselling psychologists

Clinical and counselling psychologists bring scientific knowledge, theory and professional experience together to help understand, prevent and overcome emotional distress and promote wellbeing. They may work with people with a diagnosis of depression or anxiety; people who are finding it difficult to adjust to life events; and other complex issues. When working with people living with dementia, clinical and counselling psychologists might provide a space to talk through some of the emotional and relationship difficulties that make adjustment more challenging. Many work in mental health services, often as part of the National Health Service (NHS). They can be responsible for assessment of psychological problems, as well as helping people overcome those problems through therapy. Clinical and counselling psychologists might also be involved in research, as well as training, teaching, supervision and consultation with other workers in the health services and social care.

There is a great deal of overlap between clinical psychologists and counselling psychologists. The main difference between them is the type of training they undergo.

## Neuropsychologists

Neuropsychologists work with people who have a medical condition or injury that affects how their brain works. Dementia is one such condition. Many neuropsychologists are also clinical psychologists and vice versa. However, neuropsychologists have also studied how the physical structure of the brain relates to thinking skills and behaviour. Neuropsychologists are likely to be involved in testing for dementia, and are able to work with people to make the most of their individual strengths.

All psychologists have received specialist education and training. Psychologists working in the NHS need to be recognised as being qualified by the British Psychological Society and by the Health and Care Professions Council.

# Early and timely intervention in dementia: Pre-assessment counselling

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Timely diagnosis and intervention in dementia can help people to find support, and to make decisions about the future.

This section covers how services can offer support before any testing takes place. This support is called ‘pre-assessment counselling’.

Pre-assessment counselling can help people to prepare for the possible results of their tests. It also allows people to make an informed choice about whether they wish to take the tests in the first place.

### What do we mean by timely diagnosis?

A timely diagnosis is one which is given at a time most suitable for the person receiving the diagnosis.

## Recognising early signs: The journey to help seeking

The time leading up to the first contact with services can be extremely challenging, for both the person experiencing possible dementia and their families. Furthermore, the experience of each family is unique.

Research suggests that, on average, people experience changes for at least two years before speaking about them to a professional. While the individual and their families may notice that something is different, there are a number of things that may stop them from seeking help, including:

- The fact that changes happen very gradually, and putting these changes down to normal ageing
- Seeing changes as being caused by other health problems
- Underestimating the impact of symptoms
- The stigma of dementia
- The attitudes of the individual’s culture towards dementia.



Alternatively, good relationships with health care professionals, or having previous experience of dementia with another family member, can lead to making contact with services sooner.

During the period between noticing changes and seeking help, individuals and their families may experience distress, conflict, stress, fear for the future and fear for themselves and others.

First contact is usually with the family doctor or GP. It is therefore vital that these professionals have the knowledge and skills needed to make early referrals to memory clinics.

Pre-assessment counselling can help individuals and their families to talk about their concerns. Psychologists are well placed to help with pre-assessment counselling, and are trained to take into account all parts of each family's unique experience.

Pre-assessment counselling also ensures that individuals are fully aware of the process and possible diagnosis, enabling them to make an informed choice over whether to continue.

### Principles of practice in pre-assessment counselling

Pre-assessment counselling allows full explanation of:

- Why assessment might be useful
- What the process of assessment will be like
- What the results of the assessment might be, including a possible diagnosis of dementia
- The effects a diagnosis might have on other areas of life, including driving, work and insurance.

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

Pre-assessment counselling also aims to reduce the stigma associated with dementia.

Pre-assessment counselling provides an opportunity for individuals and families to discuss their experiences and any concerns they might have. This helps services to tailor support to their specific needs and wishes.

Pre-assessment counselling should be person-centred. This means that professionals place the rights and wishes of the individual and their loved ones as central to the process.

There are a number of challenges associated with practice in pre-assessment counselling:

1. Honesty and openness, including using the word 'dementia'
2. Expectations, fears and coping strategies
3. Informed consent
4. The involvement of family members.

Each of these issues is addressed below.

### **1. Honesty and openness, including using the word ‘dementia’**

The stigma associated with dementia can put people off undergoing assessment. However, research suggests that most people with dementia wish to be told their diagnosis. People may experience a conflict between wanting to know more, and wishing to avoid thinking about the future or having too much information. There may also be differences between family members. Pre-assessment counselling can bring these issues out into the open to be discussed.

Research has found that many health care professionals are careful with the words they use, and are likely to use vague phrases such as ‘memory problems’ rather than using the word ‘dementia’. However, people with dementia have reported that they find vague terms upsetting and confusing. Using the word ‘dementia’ early on allows people to make an informed decision, and helps to reduce stigma.

Discussions about the possibility of dementia should happen at a pace suitable to the individual. There should be a focus on strengths and positives, as well as challenges.

### **2. Exploring expectations and experiences, fears and previous ways of coping with difficulties**

Each person will have different expectations, fears and coping strategies which will affect whether they choose to undergo assessment, how they experience assessment and how they experience a diagnosis of dementia. Pre-assessment counselling can provide space for all of these issues to be discussed. This can inform professionals and allow them to tailor their practice to the needs of individuals and their families.

Pre-assessment counselling can also address the following issues that may arise during the diagnostic process:

- Uncertainty and worry while waiting for assessment or diagnosis. It is important to clarify that a diagnosis may take some time. It is also important that individuals and their families are kept fully informed throughout the diagnostic process.
- Expectations that brain scans will give a certain diagnosis, when this may not be the case. Pre-assessment counselling can also raise the issue of ‘diagnostic uncertainty’, the fact that assessment may not give certain answers.
- Expectations that there will be a way to ‘cure’ the cognitive changes through medication or other treatments. While some medication and therapy has been found to slow the progression, there is currently no cure for dementia.

Addressing these expectations helps to reduce the frustration of not having them met.

Previous life events and coping styles inform how an individual and their family experience a diagnosis. Knowledge of these can help professionals to tailor their services to meet specific needs. Professionals can also help people to build on their coping styles to help with adjustment. Psychologists are able to recognise coping styles and have been trained to help people build on them.

Pre-assessment counselling can also help to identify people who may find dementia particularly challenging, and would find specialist psychological support helpful in the process of adjustment.

### **3. Informed consent**

It is the right of every person to express their opinion and have choice and control over their own lives. It is therefore vital that an individual thinking about undergoing assessment fully understands what assessment involves and what the result might be. This enables informed choice and consent.

Informed consent should be made at every point during the diagnostic process.

Pre-assessment counselling is an opportunity to discuss what assessment involves and what the result might be. It should involve full discussion of what options are available. Information should be provided on what treatments might be available should a diagnosis be made. The person should also be asked if they would like to know their diagnosis, and with whom they wish this information to be shared.

More than one appointment may be required to allow an individual to fully consider all issues and options.

A person should be given the opportunity to change their minds at any time throughout the process.

It is necessary that people who refuse assessment know that they are able to return to the process at any time.

### **4. Involvement of family or significant others**

Cognitive difficulties affect those close to the individual experiencing them. Loved ones may experience changes in relationships and roles. Psychologists are able to discuss these relationships, and offer support when people find changing relationships difficult.

Families and friends may also notice changes before the individual does. It is important to include family members or significant others in the process of assessment and diagnosis, when appropriate.

Engaging family members in services requires the consent of the individual experiencing cognitive changes.

Family members can often provide additional information which will help professionals reach a diagnosis.

Pre-assessment counselling gives family members space to discuss their own expectations, needs and concerns. This helps services to tailor support to their needs.

Pre-assessment counselling can also help family members to understand the changes associated with dementia. It can also help to identify the person's strengths and to use this information to inform the way forward.

## Conclusion

Adjustment is a different process for each individual, and needs change over time. Pre-assessment counselling can help people to begin the process of adjustment at an early stage.

It is important to recognise the needs of individuals and their families, which may differ.

Information given should be tailored to individual needs and wishes.

Good pre-assessment counselling enables individuals to make informed choices about the process.

Psychologists, with knowledge of relationships, coping styles and different thinking skills, make vital contributions to pre-assessment counselling.

A person centred and family centred approach, and a service that is flexible and responsive to needs, can significantly help people towards adjustment and living well with dementia.

# Cognitive assessment of people who may be developing dementia

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## Key messages

- Assessment should be supportive and informative
- There are many different tests, each with their own strengths and weaknesses
- Training, experience and supervision are needed at all levels of staff practice
- Clinical psychologists and neuropsychologists have the most expertise in cognitive assessment
- Good services ensure that people have the best type of assessment to meet their needs
- Good services take steps to reduce the potential harm of inaccurate assessment

## Introduction

Assessment should be supportive and informative. Not only should it inform a diagnosis, it should also provide answers around what a person's strengths and difficulties are. This helps to build strategies for adjustment in the future.

### Quotes from people living with dementia

'I fought it to the end because I didn't believe it. No one pressured me into doing the tests though, and I came to terms with it.'

'Assessment should be collaborative. They should tell us what tests they're doing and why they are doing these tests.'

### What is cognitive assessment?

The word 'cognitive' refers to thinking and thinking skills. Cognitive assessments, therefore, are tests which are designed to test a person's thinking skills.

## Types of cognitive assessment

- There are several different levels of assessment, ranging from basic to complex.
- All cognitive assessments have their own strengths and weaknesses.
- Cognitive assessments should be carried out alongside other investigations, such as brain scans and blood tests.
- Basic cognitive assessments can be administered by GPs and nurses with specific training. They are often used as ‘initial assessments’ and can inform early decisions.
- Basic assessments are less good at detecting early stages of dementia or less common types of dementia. There are a number of other reasons why basic assessments may be inaccurate, including other physical or mental health problems.
- When basic assessments give uncertain results, people need a more complex assessment. These more complex assessments usually involve an in depth examination of personal history, and test different thinking skills more thoroughly.
- More complex assessments should be carried out by specifically trained psychologists. This is because psychologists have in depth knowledge about different thinking skills and how these thinking skills affect day-to-day life. Psychologists are also able to take into account a person’s history and circumstances when interpreting test results.
- Assessments may be repeated after a number of months or years to see what (if anything) has changed in that time. If early assessments show unclear results, they can be used as a baseline for future tests to see if anything has changed. It may take a number of years to be sure about what the results mean.
- More complex assessments should be carried out only if they are needed. A person-centred approach is necessary when choosing the right cognitive assessment to meet the needs of each individual.

### Quotes from people living with dementia

‘Support, correct pacing, clear feedback and information, for me, are all essential to enable me to give the assessor a clear picture.’

‘I really wanted to score as highly as possible, and put a lot of effort into the tests. They were quite exhausting but I appreciated the time being spent to make my assessment accurate.’

# Communicating a diagnosis of dementia

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## Authors

**Sue Watts**, Consultant Clinical Psychologist, Head of Psychology of Older People, Greater Manchester West Mental Health Foundation Trust.

## Key points

- Recently, the UK governments have been encouraging services to reach diagnoses of dementia earlier and for more people. However, it is also important that professionals share a diagnosis in a way that helps individuals to adjust.
- Insensitive sharing of a diagnosis can be very distressing. It can discourage people from seeking professional support in the future.
- Professionals should give time to help individuals prepare for the diagnostic appointment.
- The needs and wishes of the person receiving a diagnosis, as well as those of their family, should inform how the diagnosis is shared.
- A key professional who already knows the individual should be present when a diagnosis is shared.
- Language use should be sensitive to the preferences of the individual.

Research suggests that, when sharing a diagnosis, it is important that professionals:

- Take into account each individual's needs and wishes
- Have good communication skills
- Talk about support after diagnosis, as well as the diagnosis itself
- Take into account each individual's family and social context
- Consider how dementia itself affects how people experience a diagnosis.

Information given at the point of diagnosis can be difficult to remember later. Written information can be a very useful memory aid.

While it is vital that professionals share a diagnosis sensitively, it is also important that they provide the right amount of information for each individual.

Professionals using euphemisms (such as 'memory problems') can create confusion and lack of clarity.

## Recommendations

- The results of assessments should be shared and explained throughout the process of diagnosis.
- Professionals sharing a diagnosis should explain clearly how the specific diagnosis was reached.
- Extra time should be made for additional appointments if needed.
- People should be followed up after the diagnosis is shared, to see how this information has affected them.
- It is important that professionals take individuals' needs and wishes into account when sharing a diagnosis.
- People receiving a diagnosis may find it difficult to remember all the information that was given. Written information can be a useful memory aid for later.
- People do not always feel able to tell professionals if they find the diagnosis too distressing to cope with.
- Professionals need to avoid being overly optimistic or too negative about the future.
- Professionals should use sensitive language.
- If there is a professional with whom the person receiving the diagnosis has built a good relationship, this person should be present when the diagnosis is shared.
- Sometimes a diagnosis is not straightforward. Services need to take into account that uncertainty can be extremely upsetting.
- Some people may not wish to know their diagnosis. Support should still be offered for family and carers.
- Psychologists have studied communication, understanding, emotion and family relationships. This means that clinical psychologists can help the diagnosis to be shared in the best possible way.
- Psychologists can also support staff in the difficult task of sharing a diagnosis.
- Psychologists have training which allows them to evaluate the quality of services. This helps to ensure the best possible experience for people using these services.
- Psychologists are able to support staff who are responsible for sharing diagnosis. They can do this through their knowledge of:
  - Communication
  - Memory and other thinking skills
  - Emotion.

Psychologists are also likely to be directly involved if the person has a rarer type of dementia, or if they have more complex needs. In these cases, it is often useful to have them in the diagnostic appointment itself.



# Post-diagnostic support for people living with dementia

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## Authors

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## Quotes from people living with dementia

'When they told me [the dementia diagnosis] it felt hopeless. [The advice] just seemed to be about getting your affairs in order... I could hardly talk afterwards!'

'...they shouldn't be focused on what pills to give us; they should be focused on feelings! They should ask, "Are you coping?"'

## Introduction

There is currently a national focus on earlier diagnosis. This is because earlier diagnosis provides more opportunity for people to adjust, resulting in prolonged independence.

However, the support that is offered after diagnosis varies across the four nations of Britain. Few services provide a range of support options. Some services offer very little post-diagnostic support. People who are not prescribed medication for dementia are at a higher risk of being discharged without receiving support.

Diagnosis without support may not be beneficial, and in some respects may be harmful.

## Quotes from people living with dementia

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

'Then, after some time, I was offered peer support. That worked for me. It changed my life.'

## What does 'psychosocial' mean?

Psychosocial means to do with the mind and social interaction. A psychosocial intervention is one that does not involve medication. Specific examples include psychotherapy, peer support and cognitive stimulation therapy, among others (see *A Guide to Psychosocial Interventions*, 2014).

More generally, psychosocial approaches:

- Support thinking skills, through 'exercising' them (e.g. cognitive stimulation therapy) or by helping people to use their strengths to make up for some of the limitations of dementia (e.g. cognitive rehabilitation)
- Help to improve people's emotional lives, either by increasing positive experiences or by helping people to manage negative emotions
- Help to give people more independence and control over their lives
- Help to improve relationships.

To accomplish these goals, psychosocial interventions work with a person with dementia and their family through activity that is meaningful and important to the individual, and through good social relationships.

## Good quality psychosocial support

Different people react differently to diagnosis. Some may feel shock and grief, while others may feel relief as they at last have an explanation for their experiences. Research suggests that most people would want to know if they had dementia, as it enables them to make adjustments for the future.

Support can best be provided by a professional who knows the individual, their family and their circumstances. For this reason, it is often most helpful to have contact with the same professional(s) throughout the process.

### Quotes from people living with dementia

'Being told I had dementia was like a door re-opening after a difficult time in my life – new challenges, new opportunities... I want people to understand that dementia isn't an end, it's a new beginning where you do things differently. While some things change forever there is a lot you can still do.'

'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.'

'There is 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?'

'Everyone's diagnosis is different; there's got to be something that suits everyone.'

There are many psychosocial treatments available for people living with dementia. *A Guide to Psychosocial Interventions* was written alongside this document, and provides summaries of a number of these.

While there are many psychosocial treatments available, not all are widely offered. The treatments that are available vary across the country. As every person's needs are different, a range of treatments should be offered.

There are several groups of people less likely to receive post-diagnostic support, including:

- People diagnosed with Mild Cognitive Impairment (MCI), rather than dementia
- People who have not been prescribed medication for dementia
- People with rarer types of dementia, such as fronto-temporal dementia
- People with a learning disability and dementia
- People from ethnic minority communities

It is important for services to offer post-diagnostic support equally.

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

Psychologists can be particularly helpful in supporting people to live well after diagnosis, due to their knowledge of how change affects the way people think and feel, as well as their knowledge of how individuals, families and social groups cope with these changes. They can do this either directly, for example by providing therapy, or indirectly by supporting and advising other professionals as part of a larger team.

Good post-diagnostic support will help an individual to move forward towards living well with dementia. Different people need different types of support or therapy. The Faculty therefore recommends that all memory services should offer a broad range of options of therapies and support after diagnosis.

# Consultation with people living with dementia

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The previous chapters were written with advice from several groups of people living with dementia. These groups are:

- **The Forget Me Nots**, from East Kent
- **Al's Café and Friends Together**, from Redditch
- **The Scottish Dementia Working Group**, from Glasgow
- **EDUCATE**, from Stockport

The expert advice of people living with dementia informed each of the four chapters in this report: pre-assessment counselling, cognitive assessment, communicating a diagnosis of dementia and post-diagnostic support. These groups also inspired and advised on the writing of *A Guide to Psychosocial Interventions*, which was produced alongside this document and covers a range of support options for people who have recently received a diagnosis of dementia.

Comments from service users were fed back to authors throughout the writing process and influenced the language and the content.

**We are very grateful to the service user groups and the organisations supporting them for sharing their expertise and enabling this project.**







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