

# Living well while waiting for a memory assessment



# Making the wait for a diagnosis easier

The wait for a memory assessment can be a worrying and uncertain time. You might not know where to turn to learn more about what might happen next, or whether you can get any help in the meantime. This can leave people feeling alone and confused.

This booklet has been created to help you to live well while you're waiting for an assessment, however long or short that time may be.

On the following pages, you'll find information and advice, as well as some exercises you can complete yourself to help you decide on what's right for you.

## What's inside

You can work your way through the whole booklet, or skip to a particular section of interest. These are:

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What if I'm diagnosed with a form of dementia? (Page 24)

# Preparing for a memory assessment



## About memory assessments

If you have been referred for a memory assessment it is common to want to know more about the process. This might include wait times, what the difference between a virtual and in person appointment is, what to expect on the day, and who you will see when you are there.

This section of the booklet has been created to help you know what to expect and to prepare for the appointment. It is not mandatory to do anything in particular, but you might find that some preparation could help put your mind at rest. There is variation between how individual memory clinics operate, so this is a general guide and may not match your exact experience. If you have any questions it is best to contact your GP or memory clinic to discuss your individual circumstances.

## Wait times

Memory clinic waiting times are longer than normal due to the impact of the Covid-19 pandemic, and vary from place to place. If you are struggling, or feel like your or your loved ones condition is worsening or becoming difficult to manage, contact your GP or memory clinic for advice.

## Ways in which you might be seen

There are a number of options available for how you have your memory assessment. Some considerations are set out below to help you in making your decision. All the options mentioned below may not be suitable for everyone.

The nurse or doctor you are working with may look at all the information and decide with you which type of assessment is best for you.

	Pros	Cons
<b>Phone</b>	<ul style="list-style-type: none"><li>No risk of infection (coronavirus)</li><li>No internet needed</li><li>No need to travel to an appointment</li></ul>	<ul style="list-style-type: none"><li>May be difficult if you are hearing impaired</li><li>May need an extra appointment for physical checks such as blood pressure</li><li>May need a few telephone calls, rather than one appointment</li></ul>
<b>Computer or tablet</b>	<ul style="list-style-type: none"><li>No risk of infection (coronavirus)</li><li>No need to travel to an appointment</li><li>Extended family members are able to join the appointment using video conferencing</li><li>Support may be available to help you use the technology</li><li>Once set up, video assessments are very straightforward</li></ul>	<ul style="list-style-type: none"><li>May be difficult if you are hearing or sight impaired</li><li>Carer, friend or family may be required to support with some parts of the memory assessment</li><li>Requires a good internet connection and access to a computer, iPad or tablet</li><li>May need an extra appointment for physical checks such as blood pressure</li><li>May require a few phone calls afterwards</li></ul>

	Pros	Cons
<b>Face-to-face at home</b>	<ul style="list-style-type: none"> <li>Health professional able to complete physical checks such as blood pressure on the day</li> <li>No internet needed</li> <li>No need to travel to an appointment</li> <li>May not require additional support from carer, friend or family member</li> </ul>	<ul style="list-style-type: none"> <li>Risk of infection for patient and carer, friend or family (coronavirus)</li> <li>Health professional needs to wear a face mask which could be a barrier to communication</li> </ul>
<b>Face-to-face in a clinic</b>	<ul style="list-style-type: none"> <li>Health professional able to complete physical checks such as blood pressure on the day</li> <li>No internet needed</li> <li>May not require additional support from carer, friend or family member</li> </ul>	<ul style="list-style-type: none"> <li>Risk of infection for patient and carer, friend or family (coronavirus)</li> <li>Health professional, patient and carer, friend or family member needs to wear a face mask which could be a barrier to communication</li> <li>Need to travel to appointment</li> </ul>

If you would like some support to help you decide how you would like to receive your memory assessment, contact your memory clinic or GP.

## What will happen during a memory assessment?

During your assessment, there are a number of different ways your nurse or doctor may choose to make a diagnosis. Each one will depend on your individual situation so you may not have all of the below.

**Taking a history:** The nurse or doctor will take a detailed medical and family history. The aim of this is to gather information to understand what might be causing the problems you, or those around you, might have noticed. As part of this, you will be asked about your personal history and your current difficulties.

It helps if someone who knows you well is also with you, as they can help describe any changes or problems they've noticed.

**Mental ability tests:** People with symptoms of dementia are given tests to check their mental abilities, such as memory or thinking.

Although these tests cannot diagnose dementia on their own, they may show there are memory difficulties that need further investigation.

Most tests involve a series of pen-and-paper tests and questions, each of which carries a score.

These tests assess a number of different mental abilities, including your short- and long-term memory, concentration and attention span, language and communication skills, and awareness of time and place.

**Brain scans:** Brain scans are often used once the simpler tests have ruled out other problems.

Like memory tests, on their own brain scans cannot diagnose dementia, but are used as part of the wider assessment. Not everyone will need a brain scan, particularly if the tests and assessments show a likely diagnosis.

**ECG test:** An electrocardiogram may be done to understand how your heart is functioning.

## Who will I see on the day?

There are a number of different people who may be involved in your memory assessment. Here are some explanations of what they do.

**Old age psychiatrists:** Psychiatrists who specialise in the mental health of older people, and also dementia. They may sometimes offer support to younger people with dementia.

**General adult psychiatrists:** Specialists in diagnosing and treating a wide range of mental health problems, as well as dementia. If you are under 65 years of age, you may be referred to one of these psychiatrists to help with the diagnosis.

**Geriatricians:** Specialists in the care of older people, including physical illnesses and disabilities. You may be referred to one of these specialists to see whether your symptoms are due to a condition other than (or as well as) dementia.

**Neurologists:** Specialists in diseases of the brain and nervous system. Some neurologists have particular experience in diagnosing dementia. They tend to see younger people and those with less common types of dementia.

**Consultant:** The consultant usually works alongside a number of doctors at various stages of training in that particular speciality. Although you may not always see the consultant, they are responsible for your case and will discuss it with the doctor you see.

**Memory nurses:** Professionals who coordinate the journey through the memory clinic assessment and providing support and advice, alongside the assessment.

**Psychologists:** Professionals who help people understand emotions and promote well-being.

**Occupational therapists:** Professionals who help people to remain active and independent.

**Social workers:** Professionals who advise on how to get help at home, or what support or benefits you're entitled to.

**Dementia advisors:** Professionals who provide information, advice and guidance to people with dementia and their families.





## Exercises

### Getting the most from your appointment

We all need to get the most out of appointments about our health. It's really important that the information we are given makes sense to us. That way we can make the best decisions about our care, our health, tests and treatment.

On the following pages, we have collected three exercises that can help you to prepare for your memory assessment appointment.

#### **Exercise 1: Recording your appointments**

You might have multiple appointments as part of the memory assessment process. To help you keep track, we've produced a template you can complete with information about the appointments as well as any notes about what you found out.

Print out the table on page 10 and complete it as you need.

#### **Exercise 2: Questions you want to ask**

You should feel comfortable asking any questions you need answering at your memory assessment.

Preparing a list of questions in advance might help, so you don't forget anything important.

Print out the table on page 11 and fill it in with your questions. You can take it with you to your assessment to help you remember what you want to ask, and to record information.



### **Exercise 3: Recording your symptoms**

The more information the people at the memory clinic have about your experience, the easier it will be for them to provide you with answers about your health.

Print out the table on page 12 and use it to record your symptoms. You can do this as many times as you choose over the time you have before your appointment. You can take it with you to your assessment to provide the people at the memory assessment with information.

### **Exercise 4: Thinking about decisions**

During and after your memory assessment, you might need to make decisions about your health, care or treatment.

We all make decisions and process information differently. That's why it's important that the information you need is presented to you in ways that you can understand, and that you are able to communicate your wishes.

The decision-making exercise provides a way for you and those around you to think about how you make decisions. Once you've completed it, you might choose to use what you have thought about to ask the memory assessment staff for information to help you make decisions you need to make.

You can also print it out, complete it and take it to your memory assessment to show the professionals there. By doing this, it will be easier for them to support you.

## Appointment tracker

Date	With who?	Purpose	Notes / follow up

## Questions I want to ask

Question	For who?	Answer

## Symptoms tracker

Date	Symptom noted	How often	Notes

## Making decisions

<p>How I like to get information</p>	
<p>How to present choices to me</p>	
<p>How people can help me think through the decision</p>	
<p>What is the best time for me to make decisions?</p>	
<p>When is a bad time for me to make decisions?</p>	

# Taking care of your wellbeing

Waiting for a memory assessment can be a difficult time. You may be experiencing strong emotions, or be worried about your appointment. However, there are some practical ways you are able to take care of your well-being during this time.

You may also find the experience of waiting frustrating, and mood changes and symptoms can affect relationships with those closest to you. Some people find that the different experience for you and your family member or friend may cause tension. Taking part in activities together, being able to share your worries or concerns with a friend or family member, and supporting each other can help.

This section explains different ways to take care of your well-being during this waiting period.





## Tips for taking care of your mental well-being

**Sleep well:** Making good quality sleep a priority is a great way to support your wellness. Taking time to unwind before bed without screens can help, replacing screen time with activities such as reading a book. Sticking to a regular routine for bedtime and waking up can also help.

**Spend time outside each day on a walk:** Taking the time to go outside and walk is a great way to clear your mind and is also great for your well-being. You might even have a local healthy walks scheme you can link up with to make some new friends or find some new places to walk.

**Maintain your connection to loved ones:** When you're feeling stressed, sometimes the last thing you want is to see people. Nevertheless, maintaining your connections to family and friends who can provide support and an ear to listen can be a great way to look after your mental well-being.

**Continue making time for the things you enjoy:** What makes a good day for you will be totally different to what a good day is to the next person. You may find it useful to make a list of the things you enjoy doing, so you can plan activities to create more good days.



## Exercises Looking after your well-being

On the following pages, we have collected two exercises that can help you to think about your well-being and what you might want to improve in your life.

### **Exercise 5: Create your visual life map**

We don't always take the time to think about our life in a holistic way, or to consider what areas we might want to work on. A visual life map is a simple tool to help you see – at a glance – the areas of your life that you are satisfied with and that you might want to change. During an uncertain time, such as while you are waiting for a memory assessment, this can help you to take positive steps for your emotional well-being.

Print out the table on page 17 and fill it in as per the instructions. You can take it with you to your assessment to show the professionals how you are currently feeling about your life.

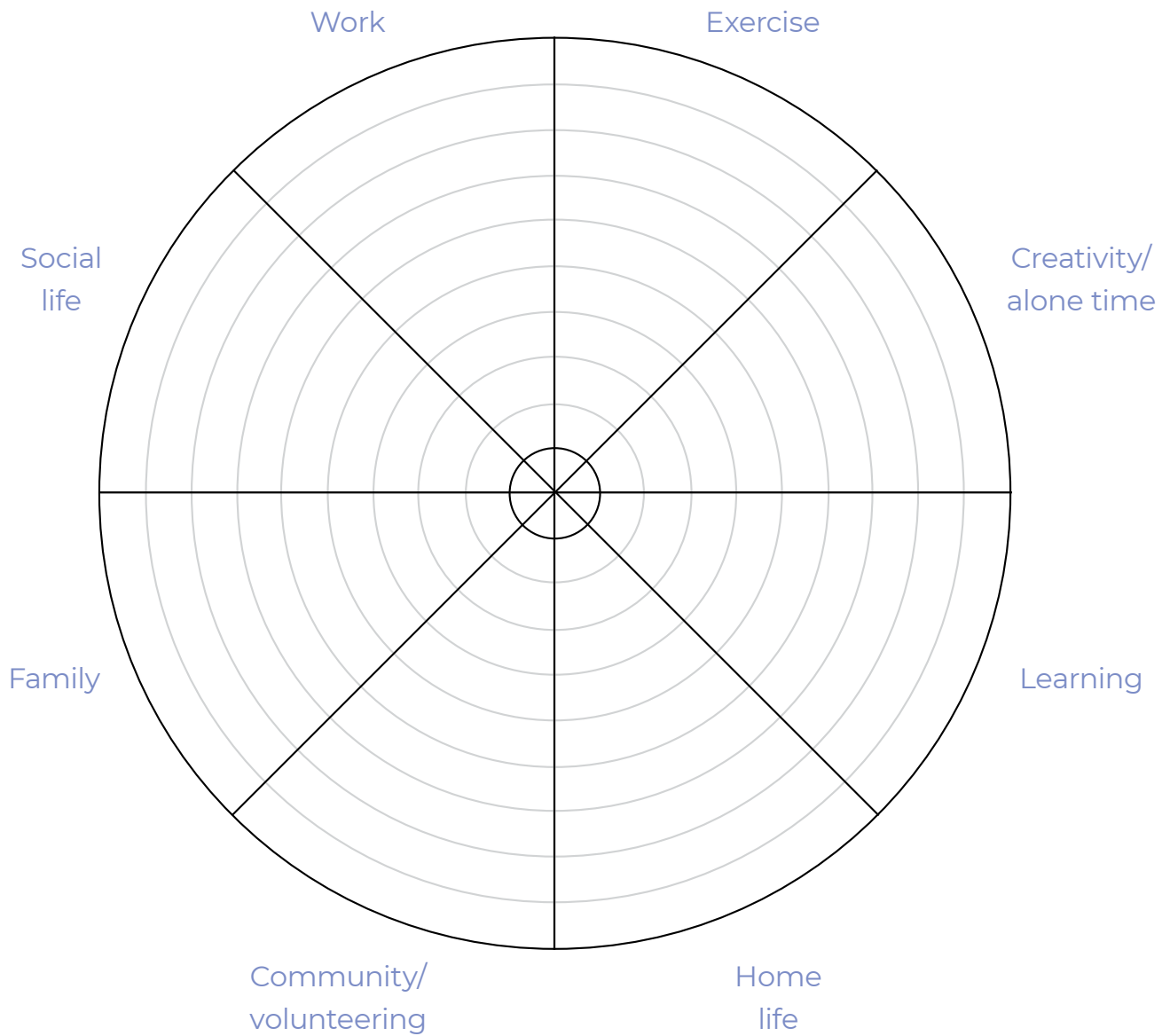
### **Exercise 6: Review what's working and not working**

You can go into further detail by specifying what is and isn't working in relation to different areas of your life. This can give you the information you need to make positive changes, too.

Print out the table on page 18 and complete it as per the instructions. You can then use the information you gain from doing the exercise to decide what steps you're going to take next.

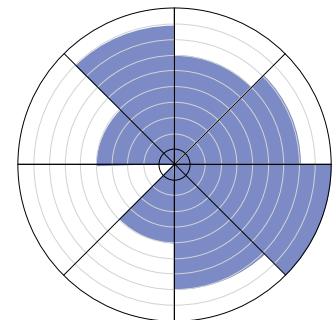


## My visual life map



### Instructions:

Rate each area of your life from one to ten and colour in the segments accordingly, with the outer circle being 'fully satisfied' and the inner circles being 'unsatisfied'. An example can be seen to the right.



## Working/not working

What's working in my life?	What's not working in my life?

What would I like to change after doing this exercise?

# Exploring available support



You don't need to wait until you have a diagnosis from a memory clinic in order to access help and support. If you are struggling now, there are organisations that can help.

In this section, you'll find some questions to help you think about the kind of support you might need, as well as a list of organisations you can contact to get it.

## What support might you need?

There are different types of support available. Here is an overview of some of the most common types.

**Practical support:** This includes things like help for getting to and from your appointments, support with finances, day-to-day tasks around the house, and support managing your symptoms.

**Emotional support:** This relates to mental health and things you can do to support your emotional well-being.

**Clinical support:** This includes anything related to your health for which you may need to go back to your GP or memory clinic.

**Social support:** This includes maintaining your connections to your family, friends and community, and ensuring you're able to continue doing the things that matter to you.

## Who can I contact for support?

While you are waiting for your memory assessment, these organisations will talk through your current worries or difficulties and help you access information.

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### Alzheimer's Society

Practical, emotional, social, clinical

The Alzheimer's Society are able to provide factsheets to learn more, or offer practical support with things like driving and assistive technology. You can also call their helpline for more specific advice, or join the 'Talking Point' online forum where you can speak to other people who are waiting for a memory assessment.

You do not need to have a diagnosis of dementia to access support from Alzheimer's Society.

Contact Alzheimer's Society on 0333 150 3456 or by visiting [alzheimers.org.uk](http://alzheimers.org.uk).

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### Age UK

Practical, social, emotional

Age UK run memory support services. They can also help with social support and help you meet other people. Their helpline can provide practical support and advice.

Contact AgeUK on 0800 055 6112 or by visiting [ageuk.org.uk](http://ageuk.org.uk).

## **Independent Age**

Practical and social

Independent Age has a range of factsheets to help with financial and legal queries. They also run a number of online and face-to-face initiatives that can support people. They can link people to communities and peers for social interaction, and also offer befriending services for those who need support accessing things in the community or are feeling socially isolated.

Contact Independent Age on 0800 319 6789 or by visiting [independentage.org](http://independentage.org).

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## **The Silver Line**

Social

Silverline run befriending programmes and can help support people to get out in their community. This can be a great way to build up your social support network and help you spend time doing things you enjoy.

Contact The Silver Line on 0800 4 70 80 90 or by visiting [thesilverline.org.uk](http://thesilverline.org.uk).

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## **Social Prescribing Link Worker**

Emotional, social

A social prescribing link worker can be accessed through your GP. They are aware of all of the groups and activities in your area and can help you find things to do that match your interests and to meet other people in your community.

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## **Advocacy services**

Clinical

If you feel like you'd like to have support at appointments to make your feelings better known, and to ensure you are being listened to and having your questions answered, you can have an independent advocate attend with you. This can be accessed through your local council.



## Exercises

### Exploring available support

On the following pages, we have collected an exercise to help you think about what support you might need to live well while waiting for your memory assessment.

#### **Exercise 7: Thinking about what support you might need**

We have put together a few questions to help you think about the kind of support you might need while you are waiting for your memory assessment.

Print out the table on page 23 and complete it to think this through. After completing it, you can contact one of the organisations listed above to discuss what you need.

## What support do I need?

<p><b>Emotional support</b></p> <p>What does a good day/bad day look like for me? What activities do I enjoy that I want to keep doing? Would I like to take someone to my assessment for support? Would I like to talk to other people who are in the same position as me?</p>	
<p><b>Clinical support</b></p> <p>Are there any other health needs I need to discuss with my GP? Are any of my symptoms worsening or becoming unmanageable? What questions do I want to ask at my memory clinic appointment? Are there any communication needs I can tell my GP/memory clinic about to help me during my appointment?</p>	
<p><b>Social support</b></p> <p>What groups or activities are there in my local area, that I could attend? What does my support network look like? Who would I see more of if i could? Are there ways I could connect online more with friends or family members?</p>	
<p><b>Practical support</b></p> <p>How will I get to my appointment? What do I need to do for a remote appointment? What's working/not working for me at the moment? What helps me make decisions? Are there any adaptations I need around the home to help me stay independent? Would any assistive technology, or memory aids help me?</p>	

# What if I'm diagnosed with a form of dementia?

Being diagnosed with a form of dementia isn't the only outcome of a memory assessment appointment, but it is a possibility.

People have told us they can feel relieved to have an explanation for their symptoms. Others are left feeling shocked, upset and angry by their diagnosis. It's important to know that whatever you feel is completely normal, and you are not alone.

A diagnosis of dementia means you can access more support, you may be prescribed medication, be able to attend cognitive stimulation therapy, or be able to take part in research studies.

The following organisations have resources, advice, and information about what to expect post-diagnosis. They can also help you adjust to your diagnosis, and live well with dementia:

**Alzheimer's Society:** 0333 150 3456 or via [alzheimers.org.uk](https://www.alzheimers.org.uk).

**Dementia UK:** 0800 888 6678 [dementiauk.org](https://www.dementiauk.org)



**This booklet has been produced as part of the 'Next Steps' initiative. An online version can be found at [nextsteps.org.uk](https://nextsteps.org.uk).**

The Next Steps initiative has been created to help people to find the right support, at the right time, while waiting for a memory assessment appointment.

NextSteps has been created by the Dementia Change Action Network (DCAN), a collaboration between Alzheimer's Society, NHS England & Improvement, and the Coalition for Personalised Care.

DCAN is an open, diverse, action-focussed network. We work in partnership with people with dementia, their families and carers, and professionals, bringing together the worlds of dementia and personalisation.

Learn more about DCAN and join the network at [dcan.org.uk](https://dcan.org.uk).

