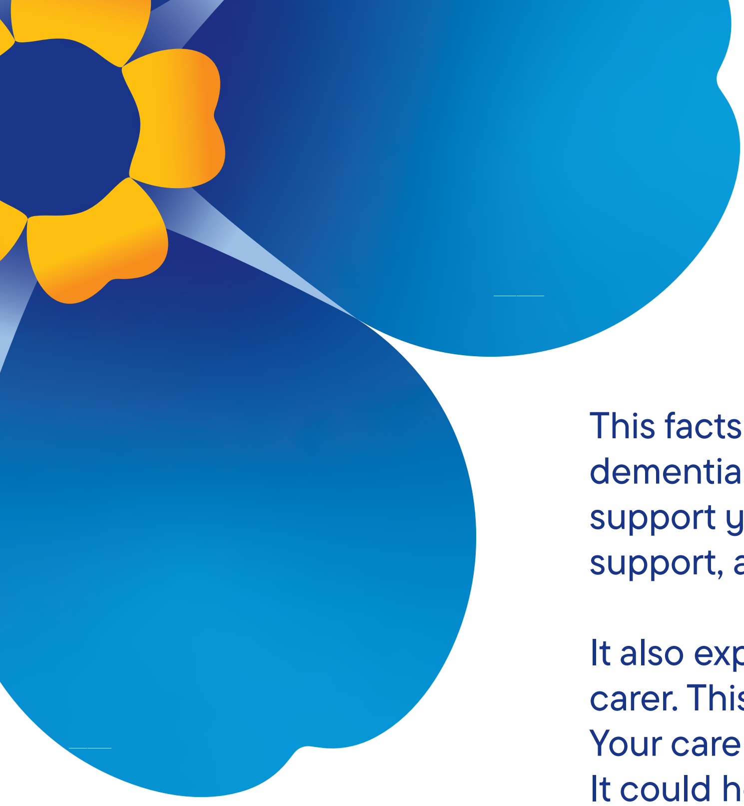
GP support after a dementia diagnosis

Alzheimer's Society
It will take a society to beat dementia



This factsheet is for people with a diagnosis of dementia. It explains how your GP practice will support you. This includes health and wellbeing support, annual reviews and planning for the future.

It also explains how your GP can involve your main carer. This is often a family member or close friend. Your carer may find it helpful to read this factsheet. It could help them to support you with your GP and get support for themselves too.

Contents

1 Support after your diagnosis

When you have had a diagnosis of dementia, your local memory service and GP practice will help you to stay as well as possible. Your GP practice includes your doctor and other health professionals that can support you.

Most people with dementia are diagnosed at a local memory service. They can help you adjust to your diagnosis during the first few weeks.

For most memory services, this should involve:

- getting your medication right if you've been prescribed any
- cognitive stimulation therapy (CST) to help with your memory and thinking skills
- talking therapies to help you to adjust emotionally. This is if you, or your family, are struggling to come to terms with your diagnosis.

After this, your GP practice will take over responsibility. They will be the main source of support to help you to stay as healthy and well as possible.

Your GP can:

- help you to manage other health conditions if you have any
- discuss if it's safe for you to drive
- tell you about local support groups
- support you and your family to make plans for the future when your dementia gets worse
- help you to access financial and social care support
- prescribe medicines if they can help with your symptoms.

Other healthcare professionals at your GP practice

Clinical pharmacists

They can help you to easily manage your medicines and make sure you are only taking the ones you need. You should have a medication review at least once a year.

Space for your notes

> **I want to talk to my GP about what medication can help me and if I can still drive.**
>
> Person with dementia

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Care coordinators

They can be a regular point of contact for you at the GP practice. They'll check in with you to make sure you're keeping well. They can also tell you about local sources of support for people living with dementia.

Social prescribers

They can link you to local activities and therapies to help you stay active and involved, if you want to. These can be local music or art groups, dementia cafes, or types of physical activity that suit your needs.

Nurses or paramedic practitioners

They can do many of the tasks that GPs do, such as seeing patients with new symptoms and prescribing medications. They give vaccinations and in certain cases visit patients in their homes. They also run clinics for people with long-term conditions.

All these health professionals should be able to spend more time with you than a GP can. They're also more likely to be the same person each time you visit. This means that you can get to know them, and they can get to know you.

Dementia Champions

Many GP practices have a Dementia Champion. These people have special training in dementia care. They try to make sure that patients with dementia get the best possible service. Ask if your practice has a Dementia Champion and what they can do to make appointments easier for you.

2 Accessing treatments and therapies for dementia

There isn't yet a cure for dementia. But there are medicines and therapies that can help you to stay as well as possible. These can help to reduce the impact of dementia on your daily life.

If you have dementia caused by Alzheimer's disease, you may be able to take medicines to help improve your memory and thinking. If you have Lewy body dementia, these medicines may also help with some of your symptoms. However, they don't work for people who have other types of dementia, such as vascular dementia.

A GP can sometimes prescribe medicines for other problems, such as depression or anxiety. They may also prescribe medicines to keep your heart and blood circulation working as well as possible.

If you have any problems taking these medicines, tell your GP or ask to speak to the clinical pharmacist.

Therapies and activities like singing or walking groups can help you to feel better and stay active. Some types of therapy can help you to keep skills for longer.

You can ask your GP or care coordinator to find out what's available in your area. Or you can ask your local dementia support, such as an Alzheimer's Society Dementia Adviser. Call our Dementia Support Line on **0333 150 3456**.

If the free therapies in your area don't suit your needs, private options may be available. These can offer greater choice for those able to pay themselves. When looking for a therapist, make sure they are a registered professional. They must have experience helping people with dementia.

Seasonal vaccinations

GP practices and pharmacists provide vaccinations to help you stay well. Diseases such as flu, coronavirus, pneumococcal disease, shingles and RSV can be serious, particularly in older people. Ask the GP if you are eligible for these vaccines. Your carer should be eligible for flu vaccinations to help them stay healthy too.

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3 Your appointments

Sometimes, dementia symptoms can make it harder to organise a visit to your GP, and to get the most out of an appointment.

Below are some tips that can help you. You can share these with your carer, if you want them to support you.

Making an appointment

You can make an appointment at your GP practice in the following ways:

- **Online** – using the online booking form on the GP practice's website, or through an app on a smartphone, such as the NHS app. If you use the internet, booking online can be quick and easy to do.
- **By phone** – calling your GP practice and answering their questions over the phone. There may be a wait of several minutes or more to get through during busy periods.
- **In person** – going into the GP surgery and talking to the receptionist.

When making an appointment online, by phone or in person, say that you have dementia. Your GP practice can then make sure you see the right person and have enough time with them.

Many GP practices now offer patients with dementia:

- double appointment slots so you don't need to rush
- text or phone call reminders to you or a carer, to help you remember to attend
- the chance to see a GP who knows you already.

You should be offered either a telephone or a face-to-face appointment. Telephone appointments can be quick and convenient, but some people prefer to see a doctor in person. You should be able to choose the option you prefer.

If you find the noise of a busy GP waiting room difficult, you can ask for an appointment at a quieter time of day. If you struggle to communicate in English, you can ask for an interpreter in advance.

To prepare for your appointment, it can help to:

- make a note of the appointment on a calendar that you can see easily
- set a reminder on a phone or ask a family member or friend to remind you on the day
- arrange for someone to take you there, if you think you'll need help getting to the GP practice. See 'A companion for your appointments' below (page 5)
- write down some notes in advance about what you want to discuss. It can be difficult to remember everything when you're there.

Our booklet 923 **My Appointments** can help you to organise your GP appointments and make notes. The booklet can be sent to you free of charge – call our Dementia Support Line on **0333 150 3456** or email **orders@alzheimers.org.uk** to order.

At your appointment

Most GP practices will ask you to check in at reception and then take a seat in the waiting area.

If you have difficulties with hearing or vision, ask for someone to help you get to the consultation room when it's your turn.

When you see the GP, ask them to explain anything you don't understand in simpler terms. If you think you might forget something they say, make some notes. You can also ask the GP to write things down for you.

Ask the GP if there's anything they need to know about you to help them understand your needs better. This could include your faith or other personal beliefs. This can help the GP offer the right care for you.

A companion for your appointments

Having dementia can make appointments more difficult. You might not always want to go, or you may feel the appointment isn't needed. Once you're there, things like long waits or noisy waiting rooms can feel overwhelming.

Having someone with you at your GP appointment can really help. They can support you by:

- explaining things if you're finding it hard to communicate
- telling the GP any issues or questions you may have forgotten
- asking the GP if they need to know more about you to help their care
- writing down important information for you
- bringing a list of your medication and your current symptoms

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> **“Dad wants to register me as a carer so that I can attend medical appointments with him.**
>
> Family member of a person with dementia”

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- reassuring you if you feel anxious or stressed
- reminding you to wear your hearing aids and glasses, if you need them
- supporting you during tests, like having your blood pressure checked or giving a blood sample
- asking for a longer appointment so you feel less rushed
- asking to see the same GP to help you feel more comfortable.

It can help if you ask the GP to make a note of your companion as your main carer. This can help you, and them as a carer. You can also ask for your carer to be copied into important information, like appointment times, if that would be helpful.

Staying involved in your care

It's important that you're included in conversations about your health and care as much as possible. Even if your dementia is more advanced, people should still speak with you directly. They should not talk about you as if you're not there. If someone needs to speak to the doctor privately, they should make a separate appointment.

When your dementia progresses

Over time, your symptoms will make things more difficult and confusing for you. You may not understand that you have a health issue and therefore not want to see a doctor.

If this happens, your carer can call your GP practice to explain that you're not well and need help. It's then up to the GP to try to balance your rights and preferences with the need to keep you well. Planning ahead can help makes things easier for you and your carer. See 'Planning ahead' on pages 9–10.

GP home visits

Most GP practices won't send someone to your home unless you physically can't get to them. For example, this could be if you are unable to move from your bed.

If your dementia symptoms make it hard to travel, a telephone appointment may be a good place to start. If the GP still needs to see you in person, ask if a carer, friend or family member can help you get there.

4 Your annual review

An annual review is a chance to have a more detailed conversation with your GP about your dementia and how you're getting on.

You should have at least one review a year. If annual reviews are done well, they can help to keep you living as well as possible with dementia.

Your annual review should be done face-to-face rather than by telephone. It should not be rushed. It's your opportunity to ask questions about your dementia and raise anything that concerns you.

During the conversation, the GP may ask you about your:

- **symptoms** – such as any changes over the past year
- **mood** – if you're feeling low or anxious
- **difficulties** – if you're struggling to do things that you want to
- **medications** – checking that your current medicines are working for you
- **goals** – what's important for you, and what support you need to do it
- **activities** – how you are staying active and involved
- **staying well** – checking that you're able to eat, drink and move well, and getting vaccinations that you need
- **relationships** – how things are with family and friends
- **carers** – making sure the people who support you are coping OK
- **plans** – making or updating any plans for when your condition worsens.

Some GP practices are better at doing annual reviews than others. If you feel that you've not had a good experience with a review, let them know. Tell them that you would like to have a follow-up conversation, perhaps this time with a different person.

Your annual review can also be a good time for your carer to talk to the GP about how they are coping. They can say if they need more support. The GP can then refer them to social services. Social services can arrange for care workers to help with your care, or for your carer to have some caring breaks. See 'Support for your carer' on page 12.

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> **“I didn't know that I should have a yearly review, it's been two years at least.**
>
> Person with dementia”

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Your care plan

Your GP team will have created a care plan for you following your diagnosis. A care plan is a summary of how your GP practice is going to be supporting you with your dementia. This is based on your needs, your general health and what you've said is important to you. It should include the name of a person who is responsible for coordinating your care. Your care plan should be updated as your needs change over time. You can ask your GP practice for a copy to be printed off or sent to you.

5 Planning ahead

There will come a point when you'll find it hard to make decisions for yourself. This is because the symptoms of dementia get worse over time. By planning ahead, you can make sure your wishes for care will be respected in the future. This is called 'advance care planning'.

It can be difficult to plan ahead when you're not sure what's going to happen or what you need to plan for. But your GP practice can help you with this in your annual review.

They can:

- guide you through common situations that people with dementia often face later on
- talk about how you want your other health conditions to be managed – for example, if you've had cancer, what you would prefer to do if it comes back
- discuss the options available to you – for example, how you feel about going into hospital or staying at home
- show you how making decisions in advance can make things easier for you and your family later on.

This way, you get to decide what happens to you, rather than other people who may not know you very well. Any decisions you make are documented and can be updated as often as you like.

It's a good idea to make these plans early, while you still have the ability to do so. This is called having 'mental capacity'. For more information, see factsheet 460 **Mental Capacity Act 2005**.

Examples of advance care planning

Advance decision to refuse treatment

This is when you say that you don't want to have certain kinds of treatment in the future. These wishes have to be respected by health professionals. One example of this is a ReSPECT form. This sets out what you want to happen to you in a medical emergency if you're not able to express your wishes at the time. You can complete this with your GP.

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> **“I need to talk to my GP about what I can put in place for the future – I want my daughters to be able to help me and support my wishes.**
>
> Person with dementia”

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Advance statement

This is a record of how you would like to be cared for in the future. It is not legally binding, but it must be considered by doctors, family members, or anyone else making health or care decisions on your behalf. For more information, see factsheet 463 **Advance decisions and advance statements**.

Lasting power of attorney for health and welfare (England and Wales only)

This is where you choose someone you trust to make future health and care decisions for you when you aren't able to. For more information, see factsheet 472 **Lasting power of attorney** (England and Wales).

To find out more information on ways to plan ahead following a dementia diagnosis, see booklet 1510 **Planning ahead**.

6 Can the GP discuss my medical care with my carer?

All your conversations with health professionals are confidential. They cannot be shared without your permission. This also applies to your medical records.

You can tell the GP practice if you want someone else to be involved in your healthcare. This can be a family member or friend. Most practices will ask you to sign a short form to confirm your wishes.

It's up to you who you want to share your information with, and in what situations. But it can be helpful for you to have a trusted person who can talk to your GP. This can help them understand how best to care for you.

They can:

- book your appointments
- help you to manage your medicines
- get clinical advice if you're unwell
- deal with anything you're struggling with
- have discussions directly with your GP (which your GP may share with you).

If at some point you can no longer provide your consent, the GP may discuss your healthcare with your carer. This is if they think it is in your best interests. They should still try to involve you as much as possible.

Your GP may share your information with other professionals if it helps prevent harm to you or someone else.

If your carer feels they need access to your medical information, they can explain their reasons to the GP. If there's a disagreement, it might be necessary to go through PALS or the NHS complaints procedure. See 'Giving feedback and raising complaints' on page 14.

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7 Support for your carer

As well as supporting you, your GP practice can also support your carer's health and wellbeing. Your GP can register them as your main carer. This will give them priority care, such as:

- information about local support groups, day centres and respite care
- seasonal vaccinations
- more flexible appointment booking
- being asked about their own health and wellbeing in your annual review
- sharing of your medical information with your consent
- help with advance care planning, such as setting up Lasting powers of attorney
- support with carer's assessments. This can help them access care training, home adaptations or help from professional carers
- support when applying for benefits, such as Carer's allowance or Blue Badge disabled parking.

Carers have a right to their own needs assessment. This is separate from your needs. For more information, see our **Assessment for care and support** factsheets 418 (England), NI418 (Northern Ireland) and W418 (Wales).

Talking about how caring affects them can help. They can speak to a friend, family member, GP, or a professional like a counsellor or Dementia Adviser.

You or your carer can also call the Dementia Support Line on **0333 150 3456**, or join conversations with other carers on the Dementia Support Forum at **forum.alzheimers.org.uk**

For more information, advice and tips for carers, see factsheet 523 **Carers – looking after yourself**.

8 Changing your GP practice

You may prefer to use a different GP practice that suits your needs better. Speak to staff at reception and ask if they can make the change. You don't need to explain why you want to change practice.

It's a good idea to visit the new GP practice first, before you switch. Check that they are accepting new patients and that they are easy to get to. You can also ask if they have a Dementia Champion, or someone with a special interest in dementia.

Your carer can change your doctor if you no longer have mental capacity to make this decision yourself. It helps to have a Lasting power of attorney (LPA) for health and welfare in place.

If you live in England and want to find GP practices in your area, visit the NHS website **nhs.uk**. You can also ask your local Healthwatch.

If you live in Northern Ireland, visit **nidirect.gov.uk**. If you live in Wales, visit **111.wales.nhs.uk**

Citizens Advice should also be able to provide information about GPs in your area, wherever you are in the UK. See 'Other useful organisations' on pages 15–16 for more contact details.

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9 Giving feedback and raising complaints

If you, or your carer, have experienced a problem with your GP practice, the first step would be to speak to them. You can call them, visit in person, or send an email or letter. This will help to discuss the issue. Most practices will want to know if something has gone wrong and how they can improve things.

If you're not satisfied with their response, you can complain to the practice manager. They should try to resolve the problem quickly. Most GP practices have a complaints form. This is to tell them what's happened and how you would like it sorted.

If this doesn't resolve the problem, then you can make a formal complaint through the NHS complaints procedure. You may also do this if the issue is very serious.

If you live in England, you can contact the Independent NHS Complaints Advocacy service in your area. The GP practice, Citizens Advice or the NHS website can provide details. If, after doing this, you are not happy with the outcome, contact the Parliamentary and Health Service Ombudsman.

In Northern Ireland, you can contact the Patient and Client Council. If you are not happy with the outcome, contact the Northern Ireland Public Services Ombudsman.

In Wales, you can contact Llais Wales with the complaint. If this doesn't resolve the problem, contact the Public Services Ombudsman for Wales.

For more information and contact details, see 'Other useful organisations' on pages 15–16.

Other useful organisations

Citizens Advice, various locations
0800 144 8848 (Adviceline England, 9am–5pm Monday–Friday)
0800 702 2020 (Advicelink Wales, 9am–5pm Monday–Friday)
www.citizensadvice.org.uk

Your local Citizens Advice can provide information and advice in confidence or point you in the right direction. To find your nearest office look in the phone book, ask at your local library or look on the Citizens Advice website. Opening times vary.

Healthwatch England (and locally)
03000 683 000 (8.30am–5.30pm Monday to Friday)
enquiries@healthwatch.co.uk
healthwatch.co.uk

Healthwatch is an independent and impartial organisation that helps to improve health and social services by listening to your feedback.

Llais Wales
02920 235558
enquiries@llaiscymru.org
www.llaiswales.org

Llais Wales works to give the people of Wales more say in the planning and delivery of their health and social care services.

NHS
www.nhs.uk
www.nhs.uk/service-search (for searching clinical commissioning groups in England or other services)

The NHS website provides information about NHS services in England to enable people to make choices about care and treatment.

NHS 111 Wales
111
www.111.wales.nhs.uk

NHS 111 Wales provides advice and information for when someone is feeling unwell, but the problem is not a medical emergency.

nidirect
nidirect.gov.uk

nidirect is the official government website for Northern Ireland residents, providing access to information and services.

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Northern Ireland Public Services Ombudsman
0800 34 34 24 (10am–12pm Monday–Friday)
nipso@nipso.org.uk
www.nipso.org.uk

The Northern Ireland Ombudsman's role is to investigate complaints where local resolution has not been possible.

Parliamentary and Health Service Ombudsman
0345 015 4033 (9am–4pm Monday–Thursday,
8.30am–12pm Friday)
www.ombudsman.org.uk

The Parliamentary and Health Service Ombudsman's role is to investigate complaints about the NHS in England where local resolution has not been possible.

Patient and Client Council (Northern Ireland)
0800 917 0222 (9am–4pm Monday–Friday)
info@pcc-ni.net
www.pcc-ni.net

The Patient and Client Council provides an independent voice on health and social care issues, and offers help and advice to someone making a complaint about health or social care services in Northern Ireland.

Public Services Ombudsman for Wales
0300 790 0203 (10am–12.30pm and 1.30pm–4pm
Monday–Friday)
www.ombudsman.wales

The Public Services Ombudsman for Wales is an independent body whose role is to investigate and consider complaints where local resolution has not been possible.

Factsheet 425
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Reviewed by: Dr Amer Sana, GP, Taverham Surgery, Norwich and Dr Helen Terrell, GP with extended role in frailty, West Kent Primary Care

This factsheet has been reviewed by people affected by dementia.

To give feedback on this factsheet, or for a list of sources, please email **publications@alzheimers.org.uk**

At Alzheimer's Society we're working towards a world where dementia no longer devastates lives. We do this by giving help to everyone who needs it today, and hope for everyone in the future.

We have more information on **Symptoms and treatment**.

For advice and support on this, or any other aspect of dementia, call us on **0333 150 3456** or visit **alzheimers.org.uk**

Thanks to your donations, we're able to be a vital source of support and a powerful force for change for everyone living with dementia. Help us do even more, call **0330 333 0804** or visit **alzheimers.org.uk/donate**

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**Trusted
Information
Creator**

Patient Information Forum

**Alzheimer's
Society**
It will take a society to beat dementia

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London EC3N 2AE

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