GPs and GP practice staff (including practice nurses) have an important role in supporting people with dementia and their carers. It is important that people with dementia and carers have regular check-ups with their own doctor (at least once a year). They should see them as soon as possible if they have any concerns about their health.

This factsheet looks at the different kinds of support available from a GP for a person with dementia. It also explains how they and their carer can access them.

Contents

- When to see the GP
- What support can the GP give?
- Accompanying the person to the GP surgery
- Can the GP discuss concerns with carers?
- Changing doctors
- Making a complaint
- Carers’ needs
- Other services
- Other useful organisations.
How the GP can support a person with dementia

When to see the GP

A person with dementia should see their GP for a review at least once a year. They should also contact their GP practice as soon as they feel unwell or have concerns about their health. They should also see their doctor if they suddenly become more confused or agitated, or if there are any worrying changes in their behaviour, as this could be a sign that they are ill. Many physical conditions, including chest and urinary tract infections (UTIs), infected leg ulcers, and constipation, can lead to the person feeling more confused and distressed. These conditions can usually be treated.

Other reasons for seeing the GP include if the person feels anxious or restless, or unhappy for a long period of time. Similarly, contact the doctor if there have been changes in their sleeping or eating patterns, or if they become very withdrawn. Any of these can be a sign of depression, which is common during the early stages of dementia. The GP may consider prescribing antidepressant medication, counselling or other forms of support. For more information see factsheet 444, Depression and anxiety.

Seeing the GP

Some GP practices may be quite busy and it may take time to arrange an appointment. However, it is important to see the GP in these situations.

If at any time the person with dementia or their carer feels that a specialist opinion is needed, they can ask the GP for a referral. The GP is usually the only person who can refer someone on to a specialist. Everyone who sees a GP is entitled to request a second opinion, and can do so even if the GP doesn’t see the need.

The person may find it easier or prefer to speak on the phone with the GP. A carer could also write to the GP to list their concerns.
What support can the GP give?

GPs and the practice team (e.g., nurses and healthcare assistants) can offer a range of support to a person with dementia, including:

- general advice on ways of preventing illness and promoting fitness
- support with care planning for the future
- medical advice and treatment
- referrals to specialist help and other services
- continuity of care (the GP will remain a key contact point for the person with dementia and those around them as the dementia progresses)
- support with managing any other conditions the person may have, e.g., diabetes or Parkinson’s disease.

If you think that you, or someone you know, may have dementia but it has not been diagnosed, see factsheet 426, *Assessment and diagnosis*. The GP can also support the person with dementia in the specific ways outlined below.

**Diagnosis**

Often the GP will be the first person that someone goes to if they (or someone close to them) are worried about their memory. For many people, their doctor remains the main point of contact as dementia progresses.

GPs will often be involved in the process of a diagnosis, either directly making a diagnosis themselves or by referring people to specialist services.

When a person goes to see the doctor because they are worried about their memory, there are certain steps a GP will take. They should record notes about the person’s medical history and anyone who accompanies them, if appropriate. They may also ask the person to complete a brief memory assessment – e.g., drawing a clock from memory, or remembering three words. They are also likely to perform a blood test to rule out other possible causes. In some cases the GP may be able to make a diagnosis based on the outcome of this process. If not, they will refer the person on to a specialist service, such as a memory clinic (a service that assesses people who have memory problems, especially suspected dementia) or
neurologist (a doctor who specialises in disorders of the brain and nervous system for a diagnosis.

Getting a timely diagnosis is important because it can help the person to make decisions about what they want for the future, and to plan their care with those supporting them and the health and social care teams.

**Medication**
If the person has been diagnosed with Alzheimer’s disease, or mixed dementia where Alzheimer’s disease is the main cause, they should be offered drugs to help manage the dementia. The drugs that can help with this are:

- donepezil
- rivastigmine
- galantamine (known as cholinesterase inhibitors)
- memantine.

These drugs should only be given by a health professional with the appropriate knowledge and skills. This could be a specialist such as a psychiatrist or neurologist, or a GP, nurse consultant or advanced nurse practitioner who has specialist knowledge of diagnosing and treating Alzheimer’s disease. If the person is started on drugs for Alzheimer’s disease by a specialist, the GP will often take over responsibility for ongoing prescriptions of the drugs, once the person is taking the medication at the right dose for them. For more information see factsheet 407, *Drug treatments for Alzheimer’s disease*.

The GP or a pharmacist can advise on any medication the person needs to take. It can help to ask the GP or pharmacist:

- what each drug is for
- how and when it should be taken
- what the effects are likely to be
- whether there are any side effects to watch out for.
If any drug appears to be having a side effect, contact the doctor straightaway. They may need to change the drug or the dose.

**Next steps**

The GP should talk to the person about next steps following a diagnosis. This should include talking to them about driving. If the person is driving and the GP has diagnosed them with dementia, they should inform the person that they need to notify their insurer and the DVLA (DVA in Northern Ireland). For more information see factsheet 439, *Driving and dementia*.

The GP can also make the person aware of planning for the future. They can talk to the person and those supporting them about the care and support that they might want in the future, including at the end of life, and can support this care. Talking about wishes for the future is especially important for people with dementia, and those around them, as they may not be able to make decisions for themselves later on.

The person may want to set up an advance decision, advance statement and Lasting Power of Attorney. For more information see factsheets 463, *Advance decisions and advance statements*, and 472, *Lasting power of attorney* (in Northern Ireland see factsheet NI 472, *Enduring power of attorney and controllership*).

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The GP should talk to the person about next steps following a diagnosis. This should include talking to them about driving.
Behaviours that challenge
If the person with dementia behaves in ways that challenge them or their carer – eg if they are agitated or restless – it will be helpful to see the GP. The person may be communicating a need when they behave in this way, and the doctor should be able to rule out any physical causes such as an infection or pain that could be contributing to the behaviour. They may also be able to offer information and support around the behaviours or refer them on to a specialist service if appropriate – eg a community mental health team. This is a group of mental health professionals such as social workers, community psychiatric nurses and occupational therapists who work in the community to support people’s mental health.

Local support
The GP and practice staff can also give information to the person and those who care for them, about support that is available in the local area. This includes support from social services and local organisations. For more information see ‘Other services’ below.

Helping the person stay well
The GP will also be able to help with general wellbeing and advice, and support the person to manage any other health conditions. Treating even what seem to be minor complaints can make a big difference to a person’s wellbeing.

The GP and practice staff can provide support for carers as well. For more information see the section on carers below.

How can a GP practice support a person with dementia and their carer?
GP practices are an important part of a dementia-friendly community and there are many things a GP practice can do to support people with dementia and those caring for them. Many GP practices are already dementia friendly. It may be helpful to ask the practice if they provide extra support for people with dementia and carers – many do.
The following suggestions may help a person with dementia and their carer.

- A note on the file to ask the person if they need any extra support when visiting the practice.
- A reminder system for appointments – eg a phone call an hour before the appointment to remind the person.
- Longer appointments so the person has time to say what they want to.
- Staff who have had dementia awareness training.
- Asking the GP practice if they have a dementia champion.
- Making sure the person sees the same GP each time (if they want to). If the person is over 75 they should have access to a named GP.
- Providing regular health checks and an annual flu jab.
- Asking the person to identify their main carer. This means the carer can be offered support and they can discuss plans for emergency care.
- Notifying carers of relevant information, where appropriate. For example, dates and times of hospital appointments the person with dementia has been referred for.
- Offering the carer a regular health check.
- Referring both the person with dementia and their carer to other organisations for information and support, eg local Alzheimer’s Society or Age UK.
- Adapting the environment to be more suitable to a person with dementia. This could include improving lighting, adding signs (eg for the toilet or to the consultation rooms) and having a ‘quiet’ area for people to wait in.
Accompanying the person to the GP surgery

Some people with dementia like having someone attend GP appointments with them. The person who goes with them can offer reassurance and may be able to help describe symptoms or any problems the person is having. They can also make a note of what was said, if necessary. The person with dementia may find it reassuring to have someone with them if they need to have any investigations or tests (eg blood pressure, blood test, urine sample). It may also be helpful for the GP if you can help explain things when the person is unable to remember or cannot speak for themselves.

Tips for carers

If the person wants you to go with them to the doctor or nurse appointment, the following tips may be useful.

- Before going to the surgery, write down all the points you would both like to discuss with the GP. It can be difficult to remember everything you want to say during a consultation.
- It may help to write down all recent changes or concerns as a list on a small card (eg a postcard or record card). This is helpful as the GP can type straight from this onto their notes, which can leave more time to discuss how they can help the person.
- Ask for a longer appointment with the GP or nurse.
- Make a note of anything important the doctor says. For example, you might want to write down any medical terms that are used.
- If there is anything you do not understand, ask the doctor to explain in simpler language.
- If the person comes from a different background or culture from the GP, mention any relevant customs, attitudes or beliefs. This can help the GP to decide on appropriate treatment and services.
- If English is not the person’s first language, they have a right to ask for a translator when they see their GP.
The conversation should always involve the person with dementia. It is important not to talk to the doctor over the person’s head as though they weren’t there. If you feel you need to talk to the doctor on your own, make a separate appointment.

Ask for the GP to make a note of you as the main carer, and to copy you into any important information (e.g., dates and times of appointments), if appropriate.

At the end of the appointment, offer to leave the room so that the person with dementia can speak with the doctor alone.

Keep a record of communication with the GP. This can be useful for showing other health professionals.

**Can the GP discuss concerns with carers?**

Sometimes carers or those supporting the person with dementia want to speak to the GP about the person. For example, someone might want to talk to the doctor about their husband or wife’s memory problems.

The General Medical Council (GMC) produces clear guidance on confidentiality. This guidance states that a doctor should not refuse to listen to someone who is close to the patient on the grounds of confidentiality.

They should listen to concerns that carers, relatives, friends, and others close to the person have, because this information may help their patient – the person with dementia. However, the doctor should make it clear that they may tell the patient. The doctor is also responsible for considering how the person might feel about others sharing concerns and information with the GP.

It can help if people have had a chat with their GP previously about information they would like shared, with whom, and in what circumstances. This way everyone has a clear idea of what the person wants.
Can the GP share medical information with carers?

Whether or not the GP can share medical information about the person with dementia to those supporting them will depend on whether the person with dementia has capacity – the ability to make decisions for themselves. For more information on capacity see factsheet 460, Mental Capacity Act 2005.

If a person has capacity to make decisions about their health and related matters it is up to them to decide whether to share this information and who to share it with.

Their doctor should only share information about them with other people in certain situations. In particular, they can share information when they think the benefit to the public or another person is more important than the public interest or patient’s rights in keeping the information confidential. For example, if not sharing the information may result in a crime being committed, or another person being harmed.

If someone doesn’t have the capacity to consent to their information being shared, the GP should make sure the person with dementia is their main concern and support them to be involved as much as they want and are able to be. They should take into account any views the person has previously expressed.

The GMC guidance on confidentiality (mentioned above) states that if the person does not have the capacity to consent to their information being shared, the doctor should assume that they would want those closest to them to know about their condition, unless they have indicated this is not the case.

If the person with dementia doesn’t have capacity, there may be either a Lasting power of attorney (LPA) for health and welfare or a personal welfare deputy in place. In these cases the GP should disclose information to this representative, and they can make any decisions that the person would have made for themselves (eg consenting to treatment).

If someone objects to their information being shared, but they do not have the capacity to give consent, the doctor can still share relevant
information with carers, relatives or friends if they think it is in the person’s best interests. The GP may also need to share some information with relatives, friends or carers to determine what is in the person’s best interests. However, this doesn’t mean the person has a right to general access of the person with dementia’s medical records or any other medical information that is not relevant – eg about past healthcare.

The GP may be reluctant to share information about someone who lacks capacity. If you (as a carer, family member or friend) think it is not in the person’s best interests for the GP to withhold the information from you, explain this to the GP. It may help to give clear reasons and mention the GMC guidance. If you can’t resolve the situation you can ask the surgery for a copy of their complaints procedure (see below).

**Changing doctors**

The person with dementia or their carer may want to change GP. Sometimes it’s possible just to make appointments with other GPs in the practice – however, people may wish to change the GP they’re registered with. If you want to be registered with another doctor at the practice speak to staff at reception and ask them if you can change. It might help to explain why you would like to change. For example, is there a GP with a special interest in dementia or a GP of the same gender? It is generally helpful for everyone involved to try and build trust with the same GP.

The person may want to change GP surgery rather than just switch from one doctor to another. If so, the person should visit the GP surgery they want to move to and ask to be registered as a new patient. Be aware that the surgery may not be accepting new patients.

The person doesn’t need to specify why they are changing GP surgery. It can help to speak to reception staff and ask if the surgery has doctors who have a specialist interest in dementia before they make a decision. In some areas it may be quite difficult to change doctors. If you live in England your local clinical commissioning group (CCG) can advise you. The GP surgery or Citizens Advice Bureau should have the contact details. Alternatively, you can look on the NHS Choices website (see ‘Other useful organisations’ for details).
12 How the GP can support a person with dementia

If you live in Wales the local health board can assist. The GP surgery or local Citizens Advice Bureau should have contact details. Alternatively, contact NHS Direct Wales, or look on their website.

The Health and Social Care in Northern Ireland Gateway will be able to provide you with advice and a full list of GP contact details if you are in Northern Ireland (see ‘Other useful organisations’ for details).

As a carer, you may wish to change the doctor of the person you care for. Whether you can do this depends on the person’s capacity. If they have the capacity to make this decision for themself, then it is their decision to make. If they are not able to make this decision for themself, you may be able to make the decision. Generally, it will be the person’s attorney under a health and welfare Lasting power of attorney, or the person’s deputy for personal welfare, who will make this decision and arrange it. For more information see factsheet 472, Lasting power of attorney.

Making a complaint

There may be times when you or the person wish to make a complaint about the person’s GP. Someone making a complaint in England can access support from the Independent NHS Complaints Advocacy service in their area. Their surgery, the local Citizens Advice Bureau, or NHS Choices can provide contact details. If after following the complaints procedure you are still not happy with the outcome you can contact the Parliamentary and Health Service Ombudsman.

In Wales, the local Community Health Council can help with complaints, and NHS Direct Wales can provide you with contact information. If after following the complaints procedure you are still not happy with the outcome you can contact the Public Services Ombudsman for Wales.

In Northern Ireland, you can access support with a complaint through the Patient and Client Council. If after following the complaints procedure you are still not happy with the outcome you can contact the Northern Ireland Ombudsman (see ‘Other useful organisations’ for more details).
Carers’ needs
Caring for someone with dementia can cause a lot of physical and emotional stress. Try to dedicate some time for yourself and don’t neglect your own health and wellbeing. You should see your own GP on a regular basis (at least once a year or when they need to) to check up on your health and discuss any problems you may be experiencing.

Many GP surgeries have a carers’ register. It can be helpful for carers to join this as it means that GPs are aware they have caring responsibilities. It may also mean that carers are called in for health checks, sent out newsletters and other relevant information, and signposted to sources of support and information. Ask your GP surgery if they have a carers’ register and if you can be registered. For more information see factsheet 523, Carers: looking after yourself.

Other services
The GP can also refer people to other health and social care staff, for example community nurses or occupational therapists. For more information on other help and support available from the NHS see factsheet 454, How health and social care professionals can help.

Advice about other services is available from your local social services department. Examples of services include day care centres, replacement care (sometimes called respite care or short breaks) and personal care (eg help with cooking a meal or washing) at home. If you have not already done so, ask for an assessment of your needs by social services. The person with dementia and their carer are both entitled to their own needs assessments. The GP can refer you, or you can contact social services directly. Their number will be in the local telephone directory under the name of your local council, or you can find their number online via the government website under the name of your local council – www.gov.uk/find-your-local-council.

For more information see factsheet 418, Assessment for care and support in England; W418, Assessment for care and support in Wales, or NI418, Community care assessment (specifically for Northern Ireland).
Other useful organisations

Citizens Advice Bureau (CAB)
Various locations

www.citizensadvice.org.uk

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

Health and Social Care in Northern Ireland Gateway
www.hscni.net

Provides information and links about GPs, community care and health care services in Northern Ireland.

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

Website providing information about NHS services in England to enable people to make choices about care and treatment.

NHS Direct Wales
0845 46 47
W www.nhsdirect.wales.nhs.uk

Provides information and advice about health, illness and health services in Wales.
Northern Ireland Public Services Ombudsman
0800 34 34 24
nipso@nipso.org.uk
nispo.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 (8.30am–5.30pm weekdays)
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
info.pcc@hscni.net
www.patientclientcouncil.hscni.net

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
ask@ombudsman-wales.org
www.ombudsman-wales.org.uk

The Public Services Ombudsman for Wales is an independent body whose role is to investigate and consider complaints where they have not been resolved locally.
Factsheet 425LP

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This factsheet has also been reviewed by people affected by dementia.
A list of sources is available on request.

Alzheimer’s Society National Dementia Helpline
England, Wales and Northern Ireland:
0300 222 1122
9am–8pm Monday–Wednesday
9am–5pm Thursday–Friday
10am–4pm Saturday–Sunday

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