

Factsheet 425 How the GP can support a person with dementia

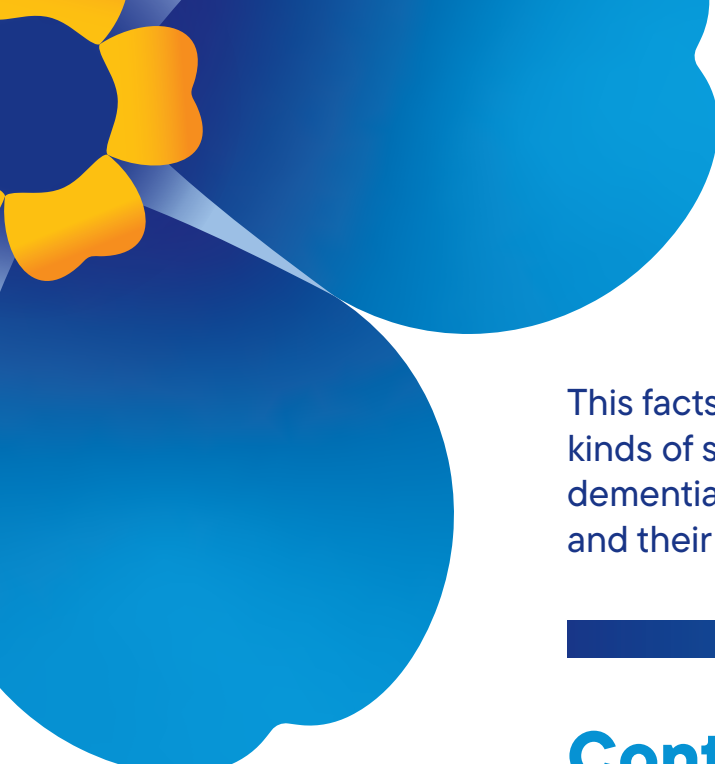
August 2020

How the GP can support a person with dementia



**Alzheimer's
Society**

Together we are help & hope
for everyone living with dementia



This factsheet is for carers. It explains the different kinds of support available from a GP for a person with dementia. It also explains how a person with dementia and their carer can access this support.

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1 The role of the GP

GPs and their practice staff have an important role in supporting people with dementia and their carers. People with dementia and carers should have a check-up with their doctor at least once a year. They should also see them as soon as possible if they have any concerns about their health.

If you think that someone you know may have dementia, but they have not been diagnosed, talk to your doctor. GPs will often be involved in the process of a diagnosis, either by making a diagnosis themselves or referring a person to specialist services.

Seeing and talking to the GP

Some GP practices may offer video or telephone appointments. If you don't think these types of appointments will benefit the person you care for, speak to the GP practice about a face-to-face appointment.

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2 After a diagnosis of dementia

GPs are an important source of support for people diagnosed with dementia and their carers. The person's doctor can help them to manage the condition, and to live well after a diagnosis of dementia. Following a diagnosis, the GP should make sure that the person understands what this means, and talk with them about what to do next. They may also tell the person where they can get further information, and share any local sources of support.

The dementia guide

Booklet 872, The dementia guide: Living well after your diagnosis provides helpful information for anyone recently diagnosed with dementia and for those taking on a caring role.

If the person with dementia currently drives, the GP will tell them that they must notify their insurer and DVLA (DVA in Northern Ireland). For more information see factsheet 439, **Driving and dementia** and booklet 1504, **Driving**.

The GP should also talk to the person about planning for the future. This can include the types of care and support they would like, and end of life care. Family and friends may be included in this discussion. Talking about the future is especially important for people with dementia, as they may not be able to make decisions for themselves later on. For more information see booklet 1510, **Planning ahead**.

The GP may take the contact details of a carer, family member or friend of the person with dementia. This person will be a key contact, and the person with dementia may allow the doctor to share relevant medical information with them. For more information see 'Can the GP share medical information with carers?' on page 10.

Sometimes, after a diagnosis of dementia, the person may not understand or accept their diagnosis. There can be many reasons for this, including memory problems. The person may be in denial, or have what is known as 'lack of insight'. Even though the person may not acknowledge their diagnosis, their GP can support them. It may still be possible to talk about planning ahead and future care. Tell the GP if the person won't accept support and this means that they or someone else is in danger. For more information see factsheet 533, **Understanding denial and lack of insight**.

3 Support and services from the GP

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A person with dementia should see their GP at least once a year for a check-up, called an annual review. This is an important part of their care. They should also contact their GP practice as soon as they feel unwell, or if they are worried about their health.

Delirium

If you notice a sudden change in the person with dementia (over hours or days), it could be delirium, which is a medical emergency. You should make an urgent appointment with the GP or call the NHS 111 telephone service. Delirium can be triggered by an untreated health condition. It can cause people to become confused, drowsy or distressed. Most of the causes of delirium are treatable, such as constipation, dehydration or infections.

The GP can provide support if the person feels anxious or restless, or is unhappy for a long period of time. Contact the doctor if there have been changes in their sleeping or eating patterns, or if they have 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, **Supporting a person with dementia who has depression, anxiety or apathy.**

As well as an annual review, GPs and the practice team (for example, nurses and healthcare assistants) can offer a range of support to a person with dementia and to those caring for them, including:

- advice on how to prevent illness and how to maintain fitness
- medical advice and treatment
- support with managing any other conditions the person may have, for example diabetes, high blood pressure or Parkinson's disease
- referrals to specialist help and services, such as:
 - talking therapies with a counsellor, or help to look after their mental health
 - a gym or physiotherapist to help with fitness and movement
 - a speech and language therapist to help with communication.

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Some practices have Social prescribers (also known as ‘link workers’) who can recommend local support in the community. They can suggest local services that will help the person to manage long-term or complex conditions, and that can help them feel less isolated in the community.

If the GP feels that you, or the person with dementia, needs some practical support, they may make a referral to social care staff. You can contact a social care team yourself if you feel you need some help or support. Your local social services department can tell you what services are available, for example:

- occupational therapy assessment (to assess how to make living at home easier with daily living aids, or adaptations)
- day care centres
- replacement care (sometimes called respite care or short breaks)
- personal care at home (for example, help with cooking a meal or washing).

If you have not already done so, ask for an assessment of your needs by social services. Carers are entitled to their own needs assessment. 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 authority (council). You can also 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 (for Wales) or NI418 (for Northern Ireland).

4 Annual reviews

Even if the person with dementia feels well, they should still see the GP for an annual review. This is a yearly check-up and an important part of their care. The appointment should include the topics in this section, although GP practices may have different approaches to annual reviews. If it's helpful, you could take this factsheet with you to make sure the GP includes everything.

The GP will check that the person with dementia understands their diagnosis. They may confirm which type of dementia they have (for example, Alzheimer's disease, vascular dementia or another type), and what this means.

To make sure everyone is safe and well, the GP may check whether the person with dementia or you are at risk of harm, or of not looking after yourselves properly. They might also check if there is anything causing the person or you to feel stressed or uncomfortable.

The GP may also ask the person with dementia about:

- their hobbies, interests or how they are managing daily activities
- what living well means to them
- what support they need to continue to live well.

Before the annual review, think about any support the person needs or any questions you may wish to ask. It can help to take notes with you so you can talk to the GP about this in the appointment.

The GP should check that the contact details of the person's carer, family or friends are up-to-date. If you are a patient at the same GP practice, you should be offered a carer's assessment and review of your own.

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One time I was invited into 'an annual GP review'. The doc saw Mum for a while then came to see me... 'But how are YOU managing?' It was the kindest/nicest thing anyone had said to me for years! And totally unexpected. Of course, I collapsed in a heap of tears and poured my heart out...'

Family member of a person with dementia

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Treatments and support, including the medicines review

At their annual review, the GP will talk to the person with dementia about how they can maintain their abilities and skills. For example, the doctor might refer them to a physiotherapist to keep them mobile, or consider medicines to help with changes in their behaviour.

The GP may have already prescribed medicines depending on what type of dementia the person has. There is no known cure for dementia, but medicines can help with some symptoms. If a specialist starts a course of medicines, the GP will often take over responsibility for ongoing prescriptions. This is once the person is taking the medicines at the right dose for them. If any medicine appears to be having a side effect, contact the doctor straightaway. They may need to change the medicine or the dose. For more information see factsheet 407, **Medicines to help memory and thinking**.

Part of the annual review is talking about any medicines the person is taking for dementia or any other conditions they have (for example, high blood pressure). The GP will check they aren't taking any unnecessary medicines. If they recommend new medicines, it can help to ask:

- what each medicine is for and how it should help
- how and when it should be taken
- whether there are any side effects to watch out for.

New symptoms and changes in behaviour

The GP may ask if there are any new symptoms since they last met, and how these are affecting the person and those supporting them. The GP may suggest treatment, or, if the symptom cannot be treated, they may discuss ways to manage it.

As dementia progresses, the person will experience changes, and this might include behaving differently. This may cause them or you discomfort or challenges – for example, if they are agitated or restless. This could mean they are distressed, or indicating a need they can't communicate. They may not even be aware of the need when they behave in this way.

The GP should be able to rule out any physical causes, such as pain or an infection, that could be contributing to the behaviour. They may also offer information and support about their behaviour, or refer them on to a specialist service – for example, a community mental health team. This is a team 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.

Advance care planning

During the annual review, the GP may discuss advance care planning. They may describe what could happen in the future, if the person no longer has capacity to make decisions about treatment and care – and particularly the following options:

- **Lasting power of attorney (LPA)** for England and Wales, or **Enduring power of attorney (EPA)** for Northern Ireland allow a person to appoint someone else to make medical or financial decisions for them, when they are no longer able to make those decisions themselves in the future.
- **Advance decisions** for England and Wales or **directives** for Northern Ireland are legal documents that allow a person to refuse, in advance, specific medical procedures or treatments. Like LPAs, advance decisions are legally binding. This means health professionals have to follow these decisions if they can.
- **Advance statements** allow a person to explain what they do and don't like, and set out preferences for the future. Unlike LPAs and advance decisions, advance statements aren't legally binding, but they must still be taken into account.

For more information see factsheets 472, **Lasting power of attorney** (for England and Wales), NI472 **Enduring power of attorney and controllership** (for Northern Ireland) and 463, **Advance decisions and advance statements**.

Thinking about future and end of life care can be distressing. It can also be reassuring to know that the person has done what they can to record their decisions and preferences in advance. It can allow them to then focus on the present. Don't be afraid to ask the GP about any of the subjects in this section. Being open will help them provide the best support for you and the person with dementia. For more information see booklet 1510, **Planning ahead**.

Support for carers review

During the annual review, the GP might talk about your needs as the person's carer. You should feel supported too. You have a right to a carer's assessment, which is separate from the person with dementia's needs assessment.

For more information see factsheet 418, **Assessment for care and support in England**, W418 (for Wales) or NI418 (for Northern Ireland).

The GP can let you know where to access support such as local groups for carers. They should ask if you want to register as a carer. See section 7 'Carers' needs' for more information.

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My husband seems much more reassured after chatting to the GP, who by the way is new to our surgery and is so approachable and had a lot of patience. He wants us to return in a week for a check up.

Partner of a person
with dementia

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5 Going to see the GP

GP practices can be busy and confusing for some people with dementia to visit. Sometimes it is difficult to get a GP appointment in the first place, and sometimes getting the person with dementia to go to the practice can be difficult. It may be helpful to ask the practice if they provide extra support for people with dementia and carers – many do.

The following tips may help make visiting the GP easier:

- If the person with dementia is reluctant to visit, calmly explain why it is important and how it will benefit them.
- If the noise of the waiting room is distressing, ask for an appointment at the quietest time of day, or a telephone appointment.
- Ask for a longer appointment with the GP or nurse. See if you can book double appointments for the person with dementia, so they don't feel rushed.
- Ask to see the same GP where possible, so that the person with dementia can see someone who they already have a relationship with. This may mean they are less reluctant to go.
- If the person with dementia will be visiting alone, ask for a telephone or text message reminder so they don't forget to go.
- Ask if the GP will collect them from the waiting room if they are hard of hearing or visually impaired, or are prone to getting lost. They may miss their appointment if they can't see or hear the announcement, or can't find the right room.
- If possible, help the person to take their medicines with them. This can help to avoid confusion or misunderstandings.
- Before the appointment, write or email the GP with a list of your concerns. It can help the doctor to be aware of the situation, if the person with dementia is likely to not mention it, or to forget. The doctor will decide whether they use these concerns as part of the appointment, and they don't have to share the outcome with you.

Tips for accompanying the person to the GP practice

Some people with dementia like having someone with them when they attend GP appointments. This person can offer reassurance. They can also make a note of what was said, in case the person with dementia needs a reminder after the appointment.

The person with dementia may find it reassuring to have someone with them if they need to have any investigations or tests (for example, blood pressure, blood test or urine sample). If the person is unable to remember or has difficulty communicating, the person attending with them can help explain things to the GP.

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 GP practice, write down all the points you would both like to discuss with the doctor. It can be difficult to remember everything you want to say during an appointment.
- It may help to write down all recent changes or concerns as a list on a small card (for example, a postcard or record card). This is helpful as the GP can read and type straight from this onto their notes, which can leave more time to discuss how they can help the person.
- 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 an interpreter when they see their GP.
- Make a note of anything important that the doctor says. For example, you might want to write down any medical terms that are used, or changes to medications.
- If there is anything you do not understand, ask the doctor to explain in simpler terms.
- The conversation should always involve the person with dementia. It is important not to talk to the doctor about the person as though they weren't there. If you feel you need to talk to the doctor on your own, make a separate appointment.
- Ask the GP to make a note of you as the main carer, and to copy you into any important information (for example, 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 the appointment and any issues you discuss with the GP. This can be useful for showing other health professionals.

We produce a booklet to help people with dementia keep track of medical appointments. You can order a free copy of 923, **My appointments** from our website – go to [alzheimers.org.uk/form/order-free-publications](https://www.alzheimers.org.uk/form/order-free-publications)

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Can the GP discuss concerns with carers?

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

The General Medical Council (GMC) helps to protect patients and improve UK medical practice. It 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 any 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 person with dementia. The doctor is also responsible for considering how the person with dementia might feel about others sharing concerns and information with the GP.

It can help if the person has already had a chat with their GP about information they would like shared, who to share the information with, and in what circumstances. This way everyone has a clear idea of what the person with dementia wants.

Can the GP share medical information with carers?

Whether 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 the person with dementia has capacity to make decisions about their health and related matters, it is their decision whether to share this information and who to share it with.

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 (for example, agreeing to treatment).

If someone doesn't have the capacity to consent to their information being shared, the GP should only share information about them with other people in specific situations – for example, if not sharing the information may result in harm to them, or another person. The person with dementia is their main concern, and the GP should support them to be involved as much as the person wants and is able to be. They should take into account any views the person has previously expressed.

The GMC's guidance on confidentiality covers advice for when the person does not have the capacity to consent to their information being shared. It recommends that the doctor should assume that the patient would want the people closest to them to know about their condition, unless they have indicated this is not the case. If you think it is not in the person's best interests for the GP to keep 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 GP practice for a copy of their complaints procedure.

For more information see 'Other useful organisations' on page 15.

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6 Changing doctors

As the GP often plays an important role in supporting a person with dementia, it is helpful for everyone involved to try and build trust with the same GP. However, the person with dementia, or their carer, may want to change GP. They may prefer a doctor with a special interest in dementia, or a GP of the same gender. If they want to be registered with another doctor at the practice, they should speak to staff at reception and ask if they can change.

The person may want to change GP practice, rather than just switch from one doctor to another. If so, they should visit the GP practice they want to move to, and ask to be registered as a new patient. Be aware that the practice may not be accepting new patients. Before making a decision, it can help to speak to reception staff and ask if the practice have doctors who have a special interest in dementia. The person doesn't need to explain why they are changing GP practice.

In some areas it may be quite difficult to change doctors. If you live in England, your local integrated care board (ICB) can advise you. The GP practice or Citizens Advice should have the contact details. You can also look on the NHS website.

If you live in Wales, the local health board can help you. The GP practice or local Citizens Advice should have contact details. Alternatively, contact NHS 111 Wales, or look on their website.

If you live in Northern Ireland, the nidirect website will be able to provide you with advice and a full list of GP contact details.

For more information see 'Other useful organisations' on page 15.

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, then it is their decision to make. If they are not able to make this decision, you may be able to make it for them. 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**.

7 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. Booklet 600, **Caring for a person with dementia: A practical guide** includes tips to help you. You should see your own GP on a regular basis (at least once a year, or when you need to) to check up on your health and discuss any problems you may be experiencing.

Many GP practices have a carers' register. You might want to join this as it means that the GP is aware you have caring responsibilities. It may also mean that you are called in for health checks, sent newsletters and other relevant information, and signposted to sources of support and information. Ask your GP practice if they have a carers' register and if you can be registered. For more information see factsheet 523, **Carers – looking after yourself**.

Support for carers

Talking about the impact of caring can help. Talk to a friend or family member, your GP, or a professional such as a counsellor or dementia adviser. Call Alzheimer's Society's support line on 0333 150 3456 or talk to other carers on our Dementia Support Forum (forum.alzheimers.org.uk)

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We've been issued with an Carer Alert card so that if OH [other half] or I are involved in an accident (or whatever), the card will alert whoever checks my purse or OH wallet, and start a chain of events to ensure Mum is not abandoned.

Partner of a person with dementia

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8 Making a complaint

There may be times when you or the person with dementia wishes to make a complaint about the GP. Someone making a complaint in England can access support from the Independent NHS Complaints Advocacy service in their area. Their GP practice, the local Citizens Advice or the NHS website 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, you can access support with a complaint from Llais Wales. 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 Public Services Ombudsman.

For more information see 'Other useful organisations' on page 15.

Other useful organisations

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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.

General Medical Council (GMC)

0161 923 6602 (9am–5pm Monday–Friday)

gmc@gmc-uk.org

www.gmc-uk.org

The GMC helps protect patients and improve UK medical education and practice by supporting students, doctors, educators and healthcare providers.

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.

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nidirect **nidirect.gov.uk**

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

Northern Ireland Public Services Ombudsman **0800 34 34 34 (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 (8.30am–5.00pm 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@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)** **ask@ombudsman.wales** **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: Antony Bayer, Professor of Geriatric Medicine at Cardiff University and Louise Robinson, Director, Newcastle University Institute for Ageing and Professor of Primary Care and Ageing

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

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We are reviewing this publication. If you would like to give us any feedback, you can email us at publications@alzheimers.org.uk or call us at 020 7423 7455

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 treatments**.

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**



Patient Information Forum



**Alzheimer's
Society**

Together we are help & hope
for everyone living with dementia

Alzheimer's Society
43-44 Crutched Friars
London EC3N 2AE

0330 333 0804

enquiries@alzheimers.org.uk
alzheimers.org.uk

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