



DementiaUK

Helping families face dementia

After a diagnosis of dementia: next steps checklist



When someone is diagnosed with dementia, it can be difficult to know what to do, who to tell, what decisions need to be made, what support is available and what happens next.

This guide lists the next steps to take after diagnosis. You may not think all of these are necessary at this stage, but it is useful to consider them as soon as possible to minimise stress later on.

1

Ask about follow-up appointments

Find out if there will be further appointments with healthcare professionals.

If yes, who with? How often will these appointments take place? How do you book them?

Who is the main point of contact for coordinating health and social care?

2

Ask about medication

Find out what medication (if any) will be prescribed and how it should be taken. Make yourself aware of any possible side effects and what to do if they occur.

Ask if a repeat prescription can be issued to make the reordering process easier. If it would be helpful, ask the pharmacy if the prescription can be supplied in a dosette box (a pre-filled pill organiser) and delivered to home so you don't have to collect it.

See more about medication and dementia in Sources of support on p11.

3

Tell family and friends

It can be difficult to tell friends and family about the diagnosis – but sharing the news will help them understand what is happening and what to expect, and to offer support.

People with young onset dementia (where symptoms develop before the age of 65) may need to break the news to their children. You may also need to explain the diagnosis if a grandparent is living with dementia.

While these conversations may be upsetting, it is important to be honest about what is happening.

4

Arrange a lasting power of attorney

A lasting power of attorney (LPA) is a legal document that nominates one or more people (usually family or close friends) to make decisions on behalf of a person with dementia if they lose the mental capacity to make these decisions themselves.

There are two types:

- health and welfare
- property and financial affairs

It is important to register both types of LPA as soon as possible to ensure that the wishes of the person with dementia are respected in the future, and that decisions are made in their best interests.

For more information on mental capacity and LPA, please see Sources of support on p10.

5

Inform the DVLA and vehicle insurance company

People with dementia are legally obliged to inform the Driver and Vehicle Licensing Agency (DVLA – or DVA in Northern Ireland) of the diagnosis.

This does not necessarily mean they will have to stop driving straight away (although be aware that this is a possibility) but they may be asked to take a driving assessment and/or be issued with a shorter licence for up to five years.

It is also compulsory to inform the vehicle insurer of the diagnosis.

For more information about driving and dementia, see Sources of support on p10.

6

Inform the employer about the diagnosis

If you are diagnosed with dementia and still working, it's advisable to tell your employer. This will enable them to take steps to support you in your job and will also ensure that you are legally protected against discrimination.

In some professions – such as healthcare, the armed forces and jobs that involve driving or operating machinery – there is a legal duty to inform the employer of a dementia diagnosis.

If you care for someone with dementia, it is a good idea to tell your employer so they can support you to keep working around your caring responsibilities.

For more information on employment and dementia, please see Sources of support on p10.

7

Discuss plans and wishes for the future

Planning ahead will ensure that family and friends know about and can follow the person's wishes if possible, and can reduce conflicts later on, particularly in crisis situations when decisions have to be made quickly.

You might want to discuss the person's wishes about:

- future care, eg where they would like to be cared for and by whom
- future medical treatment
- their involvement in activities such as work, socialising, hobbies, support groups and holidays

It may also be useful to write an Advance Care Plan: a document that outlines a person's future wishes for their care and medical treatment. Please see Sources of support on p10 for information.

8

Apply for a Carer's Assessment

People with caring responsibilities are entitled to a Carer's Assessment by their local authority.

This looks at the impact of caring on the person's everyday life and identifies what support is needed, eg respite care for the person with dementia; help at home; gym membership or exercise classes to relieve stress; or access to support groups.

For more information, please see Sources of support on p10.

9

Apply for a Needs Assessment

This is similar to the Carer's Assessment but looks at the needs of the person with dementia. The assessor may recommend support such as practical help from a paid carer; equipment or adaptations to the home; access to day centres; and help with childcare if there are young children at home.

Financial help may be available to help with the cost of these recommendations.

You can apply for a Needs Assessment through the local authority – see Sources of support on p11 for details.

10

Apply for benefits and financial support

It is important to make sure you and/or the person you care for are receiving any benefits and financial support you are entitled to. This may include:

- Attendance Allowance (if the person with dementia is over 65 years old)
- Personal Independence Payment (if the person is under 65 years old)
- Council Tax reduction or exemption
- Carer's Allowance
- Disability Premium
- Personal Budget (to contribute to/pay for social care)
- Blue Badge (for disabled car parking)

For more information on financial sources of support, please see p10.

11

Make the home safe and comfortable

There are lots of simple, practical steps that can be taken to help a person with dementia live safely, comfortably and independently at home for as long as possible. Please see Sources of support on p11 for our guide.

12

Look into local services and support

Ask your GP, local authority, social worker, and other people you may know who have a family member with dementia whether there are services for people with dementia and their carers in your area.

These could include support groups, memory cafés, activities for people with dementia, day centres, volunteer befrienders, home help, and ‘meals on wheels’.

Make a note of services here:

13

Keep up with health appointments

To ensure you and/or the person with dementia stay healthy, it is important to attend regular sight and hearing tests, dental appointments, podiatry/chiropractic appointments, and any other health appointments that are offered, such as medication reviews, breast screening and cervical screening (smear tests).

Last eye test	Date
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Last hearing test	Date
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Last dental check-up	Date
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Last podiatrist/chiropractic appointment	Date
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Screening appointments	Date
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Any other appointments

Date

Notes

For more information on staying healthy with dementia,
please see Sources of support on p10.

Other notes

Sources of support

For more information on next steps after a dementia diagnosis or any other aspect of dementia, please call our Helpline on **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December) or email helpline@dementiauk.org

To book a phone or video call appointment with an Admiral Nurse, please visit dementiauk.org/book-a-clinic-appointment

Dementia UK resources

Young onset dementia: next steps after a diagnosis
dementiauk.org/young-onset-dementia-next-steps-after-a-diagnosis

Emotional impact of a dementia diagnosis
dementiauk.org/emotional-impact

Staying healthy with dementia
dementiauk.org/staying-healthy

Driving and dementia
dementiauk.org/driving

Practical guide to getting the most from GP and other health appointments
dementiauk.org/practical-guide

Resources for parents
dementiauk.org/parents

Resources for young people
dementiauk.org/young-people

Lasting power of attorney
dementiauk.org/lasting-power

Mental capacity and decision-making
dementiauk.org/capacity-decision-making

Employment and dementia
dementiauk.org/employment

Advance Care Planning
dementiauk.org/advance-care-planning

The Carer's Assessment
dementiauk.org/the-carers-assessment

Financial and legal sources of support
dementiauk.org/sources-of-support-and-advice



Making the home safe and comfortable for a person with dementia
dementiauk.org/safe-comfortable-home

Medication and dementia
dementiauk.org/medication-management

Blue Badge parking and dementia
dementiauk.org/blue-badge-parking-and-dementia

Other resources
Apply for a Needs Assessment
gov.uk/apply-needs-assessment-social-services

Find local authority Adult Social Care services
nhs.uk/service-search/other-services/Local-Authority-Adult-Social-Care/LocationSearch/1918

DVLA (England, Scotland and Wales)
gov.uk/government/organisations/driver-and-vehicle-licensing-agency

DVA (Northern Ireland)
nidirect.gov.uk/contacts/driver-vehicle-agency-dva-northern-ireland

Benefits calculator
gov.uk/benefits-calculators

The information in this leaflet is written and reviewed by dementia specialist Admiral Nurses. We hope you find it useful. If you have feedback, please email feedback@dementiauk.org

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We want to ensure no one has to face dementia alone – and we can only do this because of our generous supporters. If you would like to help, please consider making a kind gift.



To donate: call **0300 365 5500**,
visit dementiauk.org/donate-to-support
or scan the QR code.

Thank you.



If you have questions or concerns about any aspect of dementia, please contact our Admiral Nurses.

Helpline: **0800 888 6678** or helpline@dementiauk.org

Virtual clinics: dementiauk.org/book-a-clinic-appointment



dementiauk.org • info@dementiauk.org

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