

After a diagnosis of dementia: next steps checklist



2 Dementia UK

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 outlines 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 so you are well prepared for the short- and long-term.

While the advice in this leaflet applies to people of all ages, we also have a separate guide to the next steps to take after a diagnosis for people with young onset dementia (where symptoms develop before the age of 65). Please visit [▶ dementiauk.org/young-onset-dementia-next-steps](https://dementiauk.org/young-onset-dementia-next-steps)



Checklist after a diagnosis of dementia

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?

Our leaflet on getting the most out of GP and other health appointments has a section for notes: please see Sources of support on p18.

2

Ask about medication

Find out what medication (if any) will be prescribed, what it is for and how it should be taken, including whether the dose will be increased over time and how often it should be reviewed. 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 – you can then request repeat medication through the NHS app or GP surgery.

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 do not have to collect it.

For more information on medication and dementia, please see Sources of support on p18.

3 Tell family and friends

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

You may need to explain the diagnosis to a child or young person if a parent, grandparent or other person close to them is living with dementia. While these conversations may be upsetting, it is important to be honest about what is happening.

Please see Sources of support on p19 for information on supporting children and adolescents when a parent has young onset dementia.

4 Arrange a lasting power of attorney

A lasting power of attorney (LPA) is a legally binding document that enables the person with dementia to nominate one or more trusted people, known as their attorney (usually family or close friends) to make decisions on their behalf if they lose the mental capacity to do so themselves. There are two types:

- **Health and welfare**, which covers matters such as daily living, care options and medical treatments
- **Property and financial affairs**, which covers matters such as banking, bills, benefits, investments, and buying and selling property

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.

Please see Sources of support on p18 for more information.

5

Inform the DVLA and vehicle insurance company

People with dementia are legally obliged to inform the Driver and Vehicle Licensing Agency (DVLA), or Driver and Vehicle Agency (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. This includes the insurer of a company vehicle.

For more information on driving and dementia, see Sources of support on p17.





6 Inform the employer about the diagnosis

If a person who is working is diagnosed with dementia, it is advisable to inform the employer. This will enable them to take steps to support them in their job and will also ensure that the person is 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 own employer so they can support you to keep working whilst meeting your caring responsibilities. For more information on employment and dementia, please see Sources of support on p18.

7

Discuss plans and wishes for the future

Planning ahead will ensure that family and friends know about the person's wishes for their future and follow them as far as possible. It can also reduce stress and disagreements later on, particularly if the person becomes less able to communicate; and in 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 that they do/do not want, including life-sustaining treatments like cardiopulmonary resuscitation (CPR)
- their involvement in activities such as work, socialising, hobbies, support groups and holidays
- their wishes for the end of life

This information can be recorded in 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 p17 for more information on advance care planning and our template.

8 Make a Will

It is important for all adults to have a Will to ensure that after their death, their money and possessions will go to the people and causes close to their heart. If the person with dementia has not yet made a Will or needs to update an existing Will, they should do so as soon as possible.

Please see Sources of support on p18 for our guide to making a Will and details of our no obligation free Will writing offers.



9**Apply for a carer's assessment**

People with caring responsibilities are entitled to a carer's assessment through 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 on carer's assessments and how to request one, please see Sources of support on p17.

10**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 p19 for details.



11

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 p18.

12

Make the home safe and comfortable

There are lots of practical steps that can be taken to help a person with dementia live safely, comfortably and independently at home for as long as possible. These include minimising safety hazards, identifying changes that will make the person's home easier to navigate, and providing assistive technology and living aids to maintain their independence.

The adaptations you make may need to evolve as the person's dementia progresses, so you should continue to review the situation over time and make any changes as necessary.

Please see Sources of support on p18 for our guide to making the home safe and comfortable for the person with dementia.



13

Look into local services and support

Ask the GP, memory clinic, social services, charities and voluntary organisations about any local services for people with dementia and their family 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. Our website includes details of services specifically for people with young onset dementia: please see Sources of support on p19 for details.



Make a note of services here:

Name of service

Location

Contact details

Opening hours

Name of service

Location

Contact details

Opening hours

Name of service

Location

Contact details

Opening hours

Name of service

Location

Contact details

Opening hours

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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

Notes

Next appointment

Last hearing test

Date

Notes

Next appointment

Last dental check-up

Date

Notes

Next appointment

Last flu/Covid vaccination

Date

Notes

Next appointment

Last podiatrist/chiroprapist appointment

Date

Notes

Next appointment

Screening appointments

Date

Notes

Next appointment

Any other appointments

Type

Date

Notes

Next appointment

For more information on staying healthy with dementia, please see Sources of support on p18.

Sources of support

If you are living with dementia or caring for someone with the condition, register for our free online sessions, ‘Dementia: what next?’ at [▶ dementiauk.org/dementia-what-next](https://dementiauk.org/dementia-what-next)

To contact our free Dementia Helpline, call **0800 888 6678** (Monday–Friday 9am–9pm, Saturday and Sunday 9am–5pm, every day except 25th December) or email [▶ helpline@dementiauk.org](mailto:helpline@dementiauk.org)

If you prefer, you can book a phone or video call with an Admiral Nurse at a time to suit you: please visit [▶ dementiauk.org/book](https://dementiauk.org/book)

Dementia UK resources

Advance care planning

[▶ dementiauk.org/advance-care-planning](https://dementiauk.org/advance-care-planning)

Advance care plan template

[▶ dementiauk.org/advance-care-plan-template](https://dementiauk.org/advance-care-plan-template)

Attendance Allowance

[▶ dementiauk.org/attendance-allowance](https://dementiauk.org/attendance-allowance)

Blue Badge parking and dementia

[▶ dementiauk.org/blue-badge-parking-and-dementia](https://dementiauk.org/blue-badge-parking-and-dementia)

The carer’s assessment

[▶ dementiauk.org/the-carers-assessment](https://dementiauk.org/the-carers-assessment)

Driving and dementia

[▶ dementiauk.org/driving](https://dementiauk.org/driving)

The emotional impact of a dementia diagnosis

[▶ dementiauk.org/emotional-impact](https://dementiauk.org/emotional-impact)

Employment and dementia

➤ dementiauk.org/employment

Free Will writing offers

➤ dementiauk.org/write-or-update-your-will-for-free

Financial and legal sources of support

➤ dementiauk.org/financial-and-legal-sources-of-support

Getting the most from GP and other health appointments

➤ dementiauk.org/getting-the-best-out-of-gp-and-other-health-appointments

Guide to gifts in Wills

➤ dementiauk.org/request-free-gifts-in-wills-guide

Lasting power of attorney

➤ dementiauk.org/lasting-power

Living aids and assistive technology

➤ dementiauk.org/living-aids-and-assistive-technology

Making the home safe and comfortable for a person with dementia

➤ dementiauk.org/safe-comfortable-home

Medication and dementia

➤ dementiauk.org/medication

Mental capacity and decision-making

➤ dementiauk.org/capacity-decision-making

Staying healthy with dementia

➤ dementiauk.org/staying-healthy

Supporting children and adolescents when a parent has young onset dementia

➤ dementiauk.org/supporting-children-and-adolescents-when-a-parent-has-young-onset-dementia

Young onset dementia: next steps after a diagnosis

➤ dementiauk.org/young-onset-dementia-next-steps

Young onset dementia support groups and services

➤ dementiauk.org/find-support

Other resources

Benefits

➤ gov.uk/browse/benefits

Benefits calculators

➤ gov.uk/benefits-calculators

DVLA (England, Scotland and Wales)

➤ gov.uk/dvla

DVA (Northern Ireland)

➤ nidirect.gov.uk/contacts/driver-vehicle-agency-dva-northern-ireland

Find local authority adult social care services

➤ nhs.uk/service-search/other-health-services/local-authority-adult-social-care

Getting a care needs assessment

➤ nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/getting-a-needs-assessment

**To speak to a dementia specialist Admiral Nurse
about any aspect of dementia:**

Contact our Helpline:
0800 888 6678 or [👉 helpline@dementiauk.org](mailto:helpline@dementiauk.org)

Book a virtual appointment:
[👉 dementiauk.org/book](https://dementiauk.org/book)

**Our charity relies entirely on donations to fund our
life-changing work. If you would like to donate to help us
support more families:**

- Call **0300 365 5500**
- Visit [👉 dementiauk.org/donate](https://dementiauk.org/donate)
- Scan the QR code



Thank you.



DementiaUK
Helping families face dementia



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