



# Immediate post diagnosis support guidelines

## Living well with dementia

Authors: Living Well with Dementia working group, London Dementia Strategic Clinical Network  
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## Immediate post diagnosis support guidelines

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## Introduction

This guidance has been produced primarily for professionals working with people with dementia in health and social care settings; however it may also be useful to commissioners.

All support should be tailored to the individual's needs and wishes in order to provide a personalised approach. Not all information below will be appropriate for everyone and it is the diagnosing clinician's decision what to discuss. It is unlikely that all topics will be covered in one meeting; it is anticipated that support will be offered over a series of meetings as necessary.

All areas should use these indicators as a guide to ensure that everyone receives the same level of post diagnosis support regardless of postcode.

This guide also signposts to free advice and other documents which may be of use to the professionals using this document. A useful source of information on support available is [Dementia Connect](#), an online directory of dementia services searchable on proximity to a postcode.

This document supports NICE guidance that all memory assessment services should provide a range of assessment, diagnostic, therapeutic and

rehabilitation services.<sup>1</sup> In addition to a diagnosing clinician, services should include professionals from other disciplines relevant to the needs of their patients. These might include a specialist nurse, occupational therapist and clinical psychologist. Services should also have access to a dementia advisor or equivalent. It should be acknowledged that the resource to provide the early follow up meetings and counselling can have implications for commissioning the service.

It is important for dementia advisors to work closely with the service and to be involved in the diagnostic process (for example sitting in with the patient and carer when the diagnosis is being given) to offer immediate post diagnosis support and signposting.

Once the diagnosis has taken place, a structured person-centred care plan should be written summarising the issues discussed and who to contact in the event of patient or carer needing further advice and support. Any follow up plans should also be written in this care plan. The care plan should be sent to the patient (and with the patient's consent to the carer) and GP. In some cases (for example when the patient declines consent) it may be appropriate for the carer to have a separate plan.

Following the diagnostic review, correspondence should be sent to the GP in a timely manner so that there is an early review in the primary care for the patient if necessary. This could focus on a review of medications to optimise medical management with a particular focus on vascular risk factors.

## Confirming diagnosis including type of dementia

During the initial assessment phase it is good practice to ask the patient and carer if they would like to know the details of their diagnosis.

Tell the patient (and carer or family member if present) that they have dementia, the type of dementia and the stage of the disease, e.g. mild, moderate or severe.

It may also be helpful to go through any scans and tests with the patient and their carers.

## Explaining prognosis

Give an indication of how the disease is likely to progress (bearing in mind that dementia is different for everyone and is dependent on the type of

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<sup>1</sup> NICE Dementia Pathway, <http://pathways.nice.org.uk/pathways/dementia/dementia-diagnosis-and-assessment#content=view-node%3Anodes-specialist-assessment-services>

dementia). It may also be necessary to give advice on life expectancy and deterioration.<sup>2</sup>

It may be useful to refer to the '[Priorities of Care for the Dying Person](#)' when discussing prognosis. Even if you cannot be certain about the prognosis, it is important to acknowledge if the person with dementia wants to know. Ask if there is a specific reason they wish to know, for example timing of a certain decision or events. It is also important to acknowledge the challenges of coping with the uncertainty around life expectancy but as the illness progresses this question can be revisited.

Provide information about symptoms including cognitive, behavioural and physical as well as information on complications of dementia with an explanation that symptoms are likely to change over time depending on the individual and the stage of their dementia. It is important that people are prepared for the wider global impact of a dementia diagnosis and the physical elements so that they understand dementia is not just about memory loss.

It is also important to maximise the patient's physical health, for example suggesting they have eyesight and hearing checks and assessment for fall risk if appropriate.

## Discussion of medications

It is important to carry out a review of existing medications either with or by primary care to avoid clinical risks. This is especially important for those drugs which could have an adverse effect on cognitive function; for example opiates, anticholinergic drugs, sedative antihistamines and tricyclic antidepressants. It is essential that arrangements are made for future reviews where appropriate.

An important source of information on medicines is the Patient Information Leaflet (PIL) that comes in the original pack with the medicines.

If trusts have signed up to [www.choiceandmedication.org](http://www.choiceandmedication.org) then this is also a good source of information on medicines.

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<sup>2</sup> For more information: 'Life Expectancy in Alzheimer's Disease' by Zanetti, S Solerte SB, Cantoni, F, Archives of Gerontology and Geriatrics, (. University of Study of Pavia, School of Geriatrics, Medical Department, ASP S. Margherita, via Emilia12, 1-27100 Pavia, Italy, Volume 49, Supplement, Pages 237–243, 2009 )

Some trusts also produce their own information on medicines. Specialist pharmacists may also be available to help provide information, discuss options and provide ongoing support.

## Drugs to treat the symptoms of dementia

Where appropriate, discuss the use of dementia drugs with the patient and carer. An appropriate risk assessment should be conducted prior to initiation of medication; for example, bradycardia or heart block in case of cholinesterase inhibitors or assessment of the estimated Glomerular Filtration Rate (eGFR) for Memantine. Clinicians should follow NICE guidance to select an appropriate treatment. The patient and carer should be provided with written information.

### Donepezil (Aricept), Rivastigmine (Exelon) and Galantamine (Reminyl)

These drugs are all cholinesterase inhibitors and work in similar ways. They can be used in the treatment of Alzheimer's Disease which may temporarily improve or stabilise symptoms. One may work better for an individual than the others, taking into consideration the different side-effects. NICE guidance states that the most cost-effective drug should be tried first (see the NICE guidance for more information).

Before starting medication the clinician needs to rule out significant bradycardia, significant arrhythmias, uncontrolled asthma, GI ulcers etc. A baseline ECG may also be helpful.

Most common side-effects:

- Loss of appetite
- Nausea
- Vomiting
- Diarrhoea

Other side-effects

- Stomach cramps
- Headaches
- Dizziness
- Fatigue
- Insomnia

People who start on a lower dose for at least one month may be less likely to experience side-effects. The patient and carer also need to know what to do if they develop side-effects that they cannot tolerate, who to contact if they are concerned about a side effect, where to get advice about whether to stop the medication or if they need medication to manage the side-effects.

## Memantine (Ebixa)

This drug works in a different way from the drugs mentioned above.

Before starting the medication, the clinician will need to ensure renal function including eGFR exclude history of epileptic fits, significant constipation and hypertension.

The side-effects of Memantine are less common and less severe than those of cholinesterase inhibitors. Side-effects are:

- Dizziness
- Headaches
- Tiredness
- Increased blood pressure
- Constipation

## Assessing carer needs and support

Carers have a legal right to an assessment of their needs. It is important that they are empowered to seek reviews and support. Carers may require access to both practical and emotional support. It is the duty of the local authority to provide an assessment, but different services may have slightly different processes with regards to assessment and referral. The key point is that clinicians in memory assessment services have a responsibility to identify carers, explain to them their right to an assessment, and refer on for more formal assessment and interventions where appropriate. Carers should also be able to self-refer for an assessment.

A useful document for carers is the [‘Carer’s Call to Action Booklet for Carers by Carers’](#). Other documents which professionals need to be aware of are the [Care Act 2014](#) which contains important information relating to both people with dementia and carers and the [Triangle of Care](#) which was written by the Carer’s Trust. This is a useful framework for commissioners and organisations looking to improve their organisation’s approach to supporting the needs of carers (links to all of these documents are available at the end of this guidance).

## Signposting to voluntary and statutory organisations (including to social and community support)

At the time of diagnosis or soon after it is vital that a practitioner works with the person with dementia and their carer to identify current and future needs, to set up an agreed care, plan and to provide information about local services relevant to the individual.

Each package of care, support or intervention will be different as it will address specific individual need. Below is a list of agencies and services who may be involved in provision of that care.

- **Local authorities** vary in the number and variety of services they provide, some are moving towards a primarily commissioning function, and in their level of integration with memory assessment/mental health services. However, as a general rule in most areas, social services are directly involved in the provision of carer's assessments (see above), in advising carers regarding respite services, day care, and longer term residential placements, carrying out financial assessments in relation to these placements, and co-ordinating local safeguarding services to protect vulnerable people.
- **Occupational therapy** offers assessment and modification of physical environment, including advice and information on assisted living technology.
- **Telecare** or assisted technology (gadgets) are devised to help with everyday living, ['Assistive technology – devices to help with everyday living'](#) is a useful guide.
- **Fire service** Contact with local fire service should be made to check fire alarms and carry out a fire safety check.
- **DVLA**. Driving with a diagnosis of dementia should also be discussed as part of the advance care planning discussions so that people have time to think about how they will manage when they are no longer able to drive.

As well as providing written information on diagnosis and medications the service should also provide written information on signposting and other useful information (either printed and/or electronic), including:

- Contact details for support groups
- Alzheimer's Society – helpline, local guides, [The Dementia Guide](#)
- Dementia Advisor, if not already in touch
- Admiral nursing direct

There may be an opportunity at the point of diagnosis to signpost to activities and interest groups, for example local music, sport and art groups.

## Post diagnostic support/counselling

A follow up meeting should be offered, preferably within 2-3 weeks of the diagnostic meeting to continue discussion of the management or care plan formulated during the diagnostic meeting. Preferably this has input from the

MDT staff. It is particularly important to be aware of people who live alone and how they access support.

It is recommended that the person with dementia and carer is allocated a named care coordinator who is a central point of contact for the person with dementia and their carer for the rest of their lives. The care coordinator should also coordinate other necessary services. Many memory services have dementia advisors who are attached to the service who can act as coordinators and should follow up with the patient immediately following the diagnosis.

## Considering co-morbidities and secondary prevention advice (for example vascular risk)

Give advice on the optimal management of identified vascular risk factors, for example high blood pressure, cardiac problems like arrhythmias, diabetes, high cholesterol, obesity, inactivity, smoking and excessive alcohol intake.

Factors which could increase the risk of developing vascular dementia are often the same as the factors involved in the risk of cardiovascular disease (e.g. smoking).

Further advice:

- Medication compliance (use of dosette box or other concordance aids as necessary).
- Regular monitoring of blood sugar and blood pressure
- Regular reviews by the GP
- Advice about diet and exercise

## Community Services

Community health services play an important role in the care of a patient with dementia. The GP and primary care team can refer for district nursing, continence services, nutrition services, end of life care and a range of other services if needed. Community services also offer services aimed at carers.

## Red flags: Future identification of delirium and prevention

An explanation of increased risk of delirium and ways to prevent delirium should be given.

Discuss the common features suggestive of delirium beyond general fluctuations and when to seek medical help; for example rapid disorientation over hours or days, impaired attention, increasing confusion, change in

behaviour, aggression, visual hallucinations, misinterpretation). If there is a concern contact a GP straightaway or seek other urgent medical advice.

Common causes of delirium are:

- Urinary Tract Infections (UTIs)
- Chest infection,
- Transient Ischaemic Attack (TIA) or stroke
- Constipation

More information on delirium is available in [‘Dementia – guidance on content of delirium policies’](#).

## Research: consenting & recruitment

Ask the person with dementia and the carer if they are interested in any local or national research programmes. Provide appropriate information and signposting guidance to them. Careful consideration should be given to capacity and consent.

The Department of Health has funded an initiative called Join Dementia Research, which is supported by the major dementia charities. Essentially this is a website which helps researchers find people for research, and helps service users access a wide choice of projects around the country. In order for it to work, dementia services need to ensure that all people with dementia and their carers know about this and are supported to register if they are interested. More information on Join Dementia Research can be found on the website.

## Financial and legal advice

### Lasting Powers of Attorney (LPA)

A person with dementia can appoint someone on their behalf who can make decisions for them if they lose capacity. This formal process requires filling out forms and then registering them with the office of the public guardian. A fee applies but financial help may be possible to support this if appropriate. It can take some time to register so this needs to be completed proactively rather than at crisis point.

Someone can be appointed to be an LPA for two types of decisions:

- Property and affairs
- Health and welfare - this allows them to make decisions about medical treatments including refusing treatment but it does not allow them to insist upon treatment).

An LPA needs to be completed when people are still able to express their wishes. It is a legal requirement that the person with dementia has mental capacity on several specific points when applying for this. It gives the appointed person the right to be included in medical decisions where they represent the views of the person with dementia. In the absence of an LPA, family will still be invited to be involved in discussions and decisions but they do not have a legal right to decision making.

## Advance care planning (planning ahead) and end of life care

People respond to a diagnosis of dementia in different ways. Some people may want to think and plan for the future. Others may want to focus on taking each day as it comes. Everyone should be offered the opportunity to talk about their future and their wishes and preferences if they would like to. This may be at any stage of their illness. These types of conversations about the future are often referred to as advance care planning (ACP). ACP can cover a range of issues such as financial issues, medical choices or place of care. ACP means people thinking about, discussing and recording their wishes and decisions for future care. It is about planning for a time when they may not be able to make some decisions themselves. This is why it is very important to people with dementia.

People may need support to make advance care plans. This support could come from family, friends, care staff or doctors.

ACP discussions with a person with dementia will take time. It is unlikely a one-off conversation or meeting will cover everything. People in the early stages of dementia should be supported to make as many decisions as possible to ensure their future care and support best matches what they want.

Remember people can change their minds about any aspect of their care at any time.

Subjects people with dementia and those caring for them may wish to talk about include:

- Knowing what to expect as things progress and how it may affect them.
- Managing finances in the future – lasting powers of attorney, making wills etc.
- Place of care - Where to live if more help should be needed
- Wishes and preferences about how to be cared for. A good example for recording wishes is the "[This is me](#)" document.
- Planning for emergencies.
- Social aspects, for example who will look after you/the person with dementia in an emergency?

- Medical – who do I call if he/she becomes unwell e.g. delirium, out of hours
- What to expect and how to respond when someone is nearing the end of life.
- Wishes and preferences regarding funerals and remembrance.
- Donating organs or bodies for research or to help others.

There are 3 parts to ACP:

- Making statements about future need and wishes
- Advance decisions to refuse treatments
- Lasting powers of attorney

## Further information

### General guidance

[Memory Service National Accreditation Programme \(MSNAP\) guidance](#)

[NICE guidance – Dementia Supporting people with dementia and their carers in health and social care](#)

[Alzheimer's Society](#)

[Care Act 2014](#)

### Guidance on symptoms and side-effects

[NICE guidance on delirium](#)

[London Dementia Strategic Clinical Network SCN 'Guidance on content of delirium policies'](#)

[London Dementia Strategic Clinical Network 'Managing pain for people with dementia'](#)

### Medications

The Choice and Medication website offers people information about medications used in the mental health setting to help people make informed decisions about medication, more information at [www.choiceandmedication.org](http://www.choiceandmedication.org)

### Living well

[The Dementia Guide - Living Well with Dementia, published by the Alzheimer's Society](#). This guide is for anyone who has recently been told they have dementia. This could be any type of dementia, such as Alzheimer's disease, vascular dementia or mixed dementia. It will also be useful to close friends and family of someone with dementia, as it contains information for anyone taking on a caring role.

[Resource produced by the Health Innovation Network to promote peer support opportunities for people with dementia.](#)

'Evidently Better' a document produced by the North of England Dementia Strategic Clinical Network as a guide to post diagnosis support [INSERT LINK]

[DanceFit Prime: A Dance Based Physical Activity and Nutritional Intervention for Primary Care - A Feasibility Study.](#)

[ThinkingFit: pilot and feasibility study for a randomized controlled trial.](#) A complex multimodal activity intervention to reduce the risk of dementia in mild cognitive impairment

Social Care Institute for Excellence, '[Keeping people with dementia active and occupied](#)'.

[The Faculty for the Psychology of Older People \(FPOP; formerly PSIGE\)](#) provides a forum for Psychologists with an interest in work with older people.

The British Psychological Society, 'Clinical Psychology in Early Stage Dementia Care Pathway and A Guide to Psychosocial Interventions in Dementia' [insert link]

## Carers

[Care Act 2014](#)

[Carer's Call to Action Booklet for Carers by Carers](#)

[The Triangle of care: Carers included: A guide to best practice for dementia care.](#)

## Research

[Join Dementia Research](#)

## Financial and legal advice

[Age UK, 'Powers of Attorney: Help with making decisions about your health, welfare or finances'](#)

## **Planning ahead and End of life**

[The Preferred Priorities for Care \(PCC\) document is designed to help people prepare for the future.](#)

['Planning your future care: A guide'](#)