



Checklist for communicating a dementia diagnosis

This checklist provides a comprehensive listing of points that are ideally included when communicating a diagnosis of dementia.

The checklist operationalises the NICE guideline [NG97] Dementia: assessment, management and support for people living with dementia and their carers

In terms of early post diagnostic support, there is considerable variation in the UK as to who and how this is provided. Some memory clinics will diagnosis and transfer the person straight back to their GP, others will provide follow up care. Regardless of which applies, it is very helpful for the person and their family to meet up with the GP early after diagnosis to discuss future care.

See www.forwardwithdementia.org/en/

Preparation

- Note cultural, patient and family views around being told the diagnosis.
- Ensure next of kin is invited, with the patient's permission.
- Ensure you have the Forward with Dementia Patient Information Resource (take home information) pad so you can complete and give to patient.

Introduction

- Give your name and role.
- Explain purpose of appointment (e.g. to give test results and explore options).
- Ask patient if they understand reason for tests and what they are hoping to get out of today's appointment.

Giving the diagnosis

- Give the diagnosis of dementia, including type of dementia if known. Use the words 'dementia' and 'Alzheimer's disease' 'vascular dementia' 'fronto-temporal dementia' etc. unless the patient has indicated a preference not to know.
- Address the patient directly. Talk to next of kin only when relevant.
- Pause to allow time for the diagnosis to sink in.
- Ask the patient their reaction (e.g. thoughts, feelings).
- Explain test results (e.g. scans, cognitive tests, history) which support the diagnosis.
- Explain more about the dementia, tailoring based on patient's reactions, type of dementia and level of understanding.
- Ask if the patient and carer have any questions about diagnosis.
- Address prognosis.

Management

- Discuss as applicable.
 - Some points might be discussed at a follow up appointment if available or refer to patient's GP.
- Emphasise that people live full lives with dementia, and treatments and supports are available.
 - Medications.
 - Acetylcholinesterase (AChE) inhibitors (donepezil, galantamine and rivastigmine)
 - Memantine
 - See NICE guideline [NG97] Dementia: assessment, management and support for people living with dementia and their carers <https://www.nice.org.uk/guidance/ng97/chapter/Recommendations#pharmacological-interventions-for-dementia> for specific guidelines
 - Driving - Discuss driving safety and driving assessments, your responsibility to report to local driving authority (as applicable), as well as contingencies if the person stops driving.
 - Lifestyle recommendations – discuss exercise, staying cognitively and socially active, limit alcohol, stop smoking, 'Mediterranean' diet, nutritional supplements,
 - General health - management of medications, optimal control of blood pressure, cholesterol and blood glucose via GP.
 - Psychological Support – psychology referral via the GP
 - Support with cognition, communication and function – referral to occupational therapy, physiotherapy, speech and language therapy (SALT), psychology.
 - Education and information - Provide the website forwardwithdementia.org/uk, <https://www.alzheimers.org.uk/> and Alzheimer's Society helpline number 0333 150 3456.
 - Managing work or usual activities – discuss issues as relevant.
 - Legal and financial planning – discuss will, Lasting Power of Attorney for health and welfare; and for property and financial affairs, advance decisions to refuse treatment, advance statements and advance care planning.
 - Carer support – refer to local carer support services or to Alzheimer's Society

To finish

- Ask if patient or carer has questions.
- Explain timing of next appointment or who they need to make follow-up appointment with (e.g. GP).
- Complete any referrals.
- Give a written summary of diagnosis and recommendations on the Forward with Dementia Patient Information Resource (take home information).