

Menu of Care and Interventions for Dementia

Specialist Older Adult Clinical Academic Group (SOACAG)

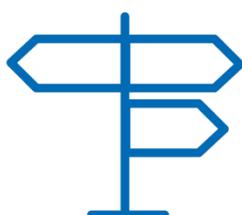


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1. Aims and Objectives

The intention behind this document is to outline evidence-based assessment, treatment and care for people living with dementia. This is not a standalone document but should be considered in relation to Clinical Advisory Group (CAG) core standards of care, cluster-based care packages (see Figure 1), and the Trust's clinical strategy and policies. The core standards specify the nature of care and care approach that all people should expect to receive when being in the care of the Trust. The cluster-based care packages describe the types of care that we offer in relation to patients' needs. This includes more detailed guidance on assessment, care planning and providing continuity of care for someone receiving care in the Trust.

The menu of care and interventions identify evidence-based bio-psycho-social interventions for particular mental health conditions that should help to inform care pathways. A care pathway refers to an individual's journey through the service, drawing down from the menus of care and interventions and underpinned by care packages and the core standards. The menu of intervention has been drawn from the combination of clinical research, NICE guidance, local and national drivers, the preferences of people who use our services, and clinicians' experience. The recommendations developed by CAGs are therefore co-produced, drawing on patient, carer and family member expertise in addition to the expertise of clinicians and researchers and backed with the latest published evidence. An individual's care pathway will be collaboratively developed within a care planning process; agreed between the patient and their care team, and involving family/ friend or formal carers where appropriate.

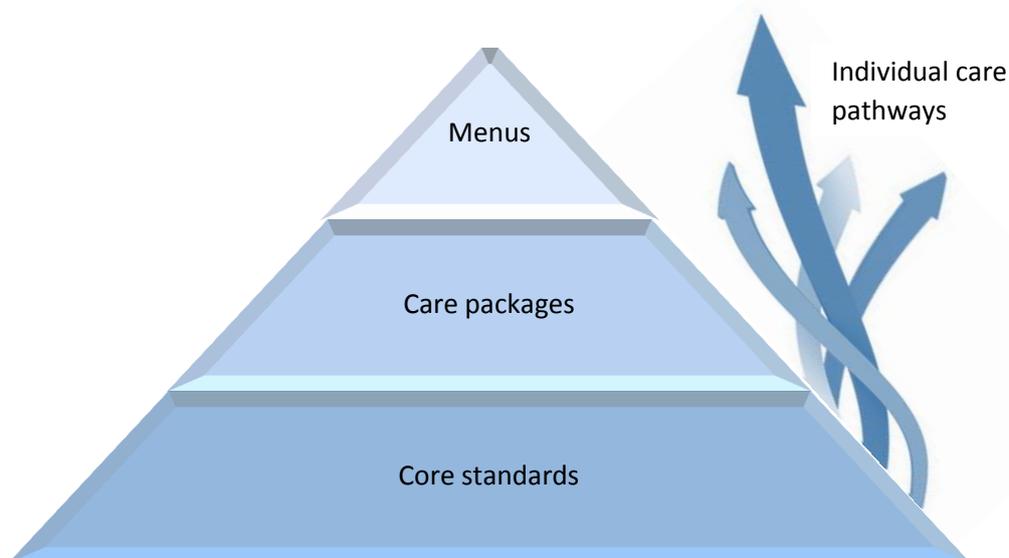


Figure 1: Relationship between patient, menus of care and interventions, cluster-based care packages and core standards.

The menu of care and interventions for dementia has been developed by a multi-disciplinary group of staff including nurses, pharmacists, psychologists, occupational therapists, and

psychiatrists, working alongside people with lived experience of dementia. It specifies the range of evidence-based, NICE-consistent care and interventions that can help people of any age, who have been diagnosed with dementia and their family/friend and formal carers to live well with dementia¹, whilst taking account of resources available.

People may enter the pathway at different points, dependent upon their needs and the needs of their family/friend or formal carers. The pathway is based on a person-centred, multi-disciplinary approach to working collaboratively with people with dementia and their family/friend and formal carers to enhance their wellbeing. Care and interventions are described from diagnosis through to end of life care across biological, physical, psychological, occupational and environmental domains. Care and interventions are not defined in terms of professional group involved, as this recognises the wide range of skills many of us have to work across these domains (with additional training and supervision where necessary).

Dementia and mental health problems are not mutually exclusive and there is a subset of the population living with both². In many cases there will not be a straightforward fit between a person's needs and a single menu of care and interventions. As such, our aim is not to fit the person to a menu, but rather to fit the menu(s) to the person; following a comprehensive assessment, identification of presenting difficulties and formulation. Care planning will be vital to ensure that needs are appropriately addressed, in order to provide continuity of care and an individualised care pathway.

2. Primary Care Assessment

Before referring into specialist services for a dementia assessment, an initial assessment should be undertaken by the referrer. The referrer should screen for treatable conditions that may be either causing or contributing to confusion and distress, such as infections, pain, seizures, vascular events, diabetes, constipation, thyroid disturbance, poor sleep, sensory loss, alcohol misuse and negative impacts of any medication e.g. some statins causing agitation, Parkinson's medication causing disinhibition. This includes being able to exclude delirium. If it has not been possible to establish whether a person has delirium, dementia or delirium superimposed on dementia, the referrer should treat for delirium first. For guidance on treating delirium, see NICE guidance Delirium: prevention, diagnosis and management 2010, updated 2019 (CG103)³. The referrer should also screen for other mental health conditions such as psychosis, depression and anxiety⁴. If no other physical health or mental health issues have been identified the referrer should proceed to cognitive screening assessment such as the Mini Mental State Examination (MMSE) or Six Item Cognitive Impairment Test (6-CIT) in the early stages of dementia or the DiADeM tool for people living

¹ Dementia: Assessment Management and Support for People Living with Dementia and Their Carers (NG97) NICE (2018) (<https://www.nice.org.uk/guidance/ng97>) and Department of Health (DoH) (2009) Living Well with Dementia: A National Dementia Strategy

² The Interface Between Dementia and Mental Health: An evidence review (2016) Mental Health Foundation

³ Delirium: prevention, diagnosis and management (CG103) nice (published 2010, updated 2019)

⁴ Living Well with Dementia: A National Dementia Strategy (2009) DoH

in care homes, if the referrer suspects that the person is in the later stages of dementia. Cognitive assessments at primary care level are essential, but have limited ability to distinguish between dementia and other causes of poor cognitive performance, or between different forms of dementia, particularly unusual initial presentations. These assessments can overestimate cognitive decline in people who have sensory impairments, a limited education, a learning disability, poor physical or mental health, past or current substance misuse, come from a different culture or with a different language. Conversely, in a person of very high lifelong intellectual ability, change may be underestimated. Accurate classification can be particularly difficult in the early stages of dementia when pressure for a quick diagnosis can lead to error⁵. Appropriate caution should therefore be taken with interpreting these screening measures and referral to secondary mental healthcare should be made to establish diagnosis and differential diagnosis where necessary. GPs, if confident, can diagnose and start treatment without referral.

Referral should be made for specialist diagnostic assessment when reversible causes of cognitive decline have been investigated, the referrer is not confident to make a diagnosis and dementia is still suspected. Specialist diagnostic assessment can be provided either in primary or secondary care by Memory Assessment Services.

3. Memory Assessment Services

Before considering which menus of care and interventions are most relevant, a comprehensive assessment should be carried out. Assessment should always consider the legal framework of care, (notably the Mental Capacity Act, the Mental Health Act and Safeguarding), should be person-centred, respectful of diversity, suitably multidisciplinary and lead to a clear holistic formulation. It would generally be considered good practice to involve nominated friends and family members in this process – with the patient’s consent, where possible.

4.0 Diagnosing Dementia in Specialist Memory Assessment Services

Services should be mindful of the potential for benefit and harm when assessing cognition and should strive to maximise the positive outcomes for the people being assessed by the selection of assessment tools, and their careful application by properly trained and supervised workers⁶.

When a referrer requests a diagnostic assessment this should be provided in a timely way⁷ and should consider the following:

- Pre-diagnostic counselling which includes the benefits of having a diagnosis, the opportunity for the person and their family/friend/carer to discuss the potential

⁵ Clinical Psychology in the Early Stage Dementia Pathway (2014) Faculty of The Psychology of Older People (FPOP)

⁶ Clinical Psychology in the Early Stage Dementia Pathway (2014) FPOP

⁷ NCCMH The Dementia Care Pathway 2018 (https://www.rcpsych.ac.uk/docs/default-source/improving-care/nccmh/dementia/nccmh-dementia-care-pathway-full-implementation-guidance.pdf?sfvrsn=cdef189d_6)

impact of having a diagnosis and to consider how they would like to be informed of the outcome of their assessment⁸.

- Comprehensive history taking from the person and their family/friend/carer.
- An assessment of the person's mental health and wellbeing.
- Clarification of the person's own perceptions and concerns.
- The person's environment and social circumstances, including accommodation, family/friend/carer involvement (and changes that have occurred), and other social networks and supports.
- Physical health investigations such as chest x-ray or ECG.
- Cognitive screening assessment using standardised measures such as MMSE, Montreal Cognitive Assessment (MoCA) or Addenbrooke's Cognitive Examination (ACE-III).
- Use of brain scan to rule out reversible causes of cognitive decline and to assist with subtype diagnosis.
- Diagnosis of dementia subtype using international standardised criteria such as⁹:
 - International consensus criteria for dementia with Lewy bodies
 - International FTD criteria for frontotemporal dementia (primary non-fluent aphasia and semantic dementia)
 - International Frontotemporal Dementia Consortium criteria for behavioural variant frontotemporal dementia
 - NINDS-AIREN criteria (National Institute of Neurological Disorders and Stroke and Association Internationale pour la Recherche et l'Enseignement en Neurosciences) for vascular dementia
 - NIA criteria (National Institute on Aging) for Alzheimer's disease
 - Movement disorders Society criteria for Parkinson's disease dementia
 - International criteria for Creutzfeldt-Jakob disease.
- Use of neuropsychological assessment where it is unclear:
 - whether or not the person has cognitive impairment or
 - whether or not their cognitive impairment is caused by dementia or
 - what the correct subtype diagnosis is.
- Occupational therapy assessment such as an Assessment of Motor and Process Skills (AMPS) or similar functional assessment.
- Impact of any current medication on cognitive functioning

4.1 Information Provision

When a person has been assessed, but is not diagnosed with a dementia, they should be provided with information about where to get appropriate help and support, should they need it, from other services.

When the assessment indicates a dementia diagnosis, this should be shared with the person and (where appropriate) their family/friend/carer, in accordance with best practice guidance¹⁰. Time should be allocated for questions and opportunity to discuss concerns. Verbal and written information in a suitable format that is relevant to the person's

⁸ Communicating a Diagnosis of Dementia (2018) FPOP

⁹ Dementia: Assessment Management and Support for People Living with Dementia and Their Carers (NG97) NICE (2018) (<https://www.nice.org.uk/guidance/ng97>)

¹⁰ Communicating a Diagnosis of Dementia (2018) FPOP

circumstances and the stage of their condition should be provided, to enable them to make informed decisions about their future care. This should include¹¹:

- their dementia subtype and the changes to expect as the condition progresses
- which healthcare professionals, social care and third sector teams will be involved in their care and how to contact them
- if appropriate, how dementia affects driving and that they need to tell the Driver and Vehicle Licensing Agency (DVLA) and their car insurer about their dementia diagnosis¹²
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- their legal rights and responsibilities
- their right to reasonable adjustments (in line with the Equality Act 2010) if they are working or looking for work
- information about opportunities to participate in research studies
- discussing the benefits of planning ahead
 - lasting power of attorney (for health and welfare decisions and property and financial affairs decisions)
 - an advance statement about their wishes, preferences, beliefs and values regarding their future care
 - advance decisions to refuse treatment
 - their preferences for place of care and place of death.
- how the following groups can help and how to contact them:
 - local support groups, online forums and national charities
 - financial and legal advice services
 - advocacy services.
- advice on staying well
 - if appropriate Trust information for carers on sleep hygiene related to people living with dementia (see: <https://www.sussexpartnership.nhs.uk/node/6225/attachment>)
- if appropriate Trust information for carers on managing challenging behaviour (see: <https://www.sussexpartnership.nhs.uk/node/1599/attachment>)
- information on the medicines they are likely to be prescribed so they can make an informed choice . (see: <https://www.choiceandmedication.org/sussex/>)
- information regarding local support for carers including accessing carers assessment, local carers support groups, online forums and national charities.

If it has not been documented earlier, ask the person for their consent for services to share information, which people they would like services to share information with (for example family members or carers) and what information they would like services to share.

¹¹ Dementia: Assessment Management and Support for People Living with Dementia and Their Carers (NG97) NICE (2018) (<https://www.nice.org.uk/guidance/ng97>)

¹² Driving with Dementia or Cognitive Impairment (2018) Royal College of Psychiatrists

¹³ DVLA website [Psychiatric disorders: assessing fitness to drive](#) 14 February 2019

4.2 Post Diagnostic Interventions

There is still no cure for dementia therefore adjustment to diagnosis is often complex and an important stage in offering help to live well with the condition. While many people are able to adjust, the impact of the diagnosis is often profound and underestimated, therefore post diagnostic support must be person-centred to each individual as opposed to a standard pathway.

Non-pharmacological interventions¹⁴ promote well-being by minimising and alleviating distress and facilitating adjustment. These interventions can also enable people with dementia and their family/friend carers, to continue to live meaningful and independent lives. The range of interventions should include:

- Psychologically informed interventions for the person with dementia individually or in groups, which may include more in depth education about dementia, support with emotional adjustment to diagnosis, strategies to manage changing cognition and options for cognitive stimulation therapy.
- Psychosocial interventions for carers, couples and families which may include adjustment to diagnosis, carer groups offering support and education, individual carer support.
- Formal psychological therapy such as Cognitive Behaviour Therapy for the person with dementia or for their family and friend carer, if appropriate.
- Cognitive rehabilitation to maintain skills and maximise independence
- Assessment of safety and risks to self and others.
- Signposting access to activities which are meaningful to the person and maintain social inclusion including work and recreational hobbies and interests.
- Referral for driving assessment if appropriate.
- Liaison and joint work with other specialists as required, e.g. learning disabilities services, neurologists, geriatricians and social workers (if services are not integrated).

Pharmacological interventions are based around the three cholinesterase inhibitors, donepezil, rivastigmine, galantamine, and the NMDA receptor antagonist, memantine, which are currently the only effective licensed treatments for dementia. They are thought to be largely symptomatic agents and although effects on the underlying disease process have been proposed, there is no convincing evidence that they modify the disease process in Alzheimer's or any other type of dementia¹⁵.

¹⁴ Clinical Psychology in the Early Stage Dementia Pathway (2014) FPOP, A Guide to Psychosocial Interventions in Early Stages of Dementia (2014) FPOP

¹⁵ NICE (2018) Dementia: Assessment Management and Support for People Living with Dementia and Their Carers (NG97) (<https://www.nice.org.uk/guidance/ng97>).

Guidelines on the use of anti-dementia drugs in people living with dementia¹⁶

- Patients with mild to moderate Alzheimer's disease should initially be offered treatment with an acetylcholinesterase inhibitor.
- The initial acetylcholinesterase inhibitor offered should usually be donepezil tablets as these are quickest and easiest to titrate to maximum dose and have the lowest acquisition cost. However it may be appropriate on an individual basis to offer an alternative choice after taking into account the most prominent symptom, the adverse effect profile of the medications, concurrent medications and possible interactions, expected patient adherence and medication dosing regimens.
- Patients with moderate Alzheimer's disease who are intolerant or have contraindications to treatment with acetylcholinesterase inhibitors should be offered treatment with memantine.
- Patients not established on an acetylcholinesterase inhibitor with severe Alzheimer's disease should be offered mono-therapy with the NMDA receptor antagonist memantine.
- The decision to offer initial treatment of Alzheimer's disease with either an acetylcholinesterase inhibitor or memantine should only be undertaken on the advice of a secondary care specialist (consultant, associated specialist, geriatrician, neurologist) or other healthcare professional who has expertise in diagnosing and treating Alzheimer's Disease (GP, nurse consultant, advanced nurse practitioner, non-medical prescriber).
- Once a decision has been made to start an acetylcholinesterase inhibitor or memantine, the first prescription may be provided by primary care, but if a specialist is seeing the patient they should initiate treatment to avoid delay.
- Patients with moderate or severe Alzheimer's disease who are already taking an acetylcholinesterase inhibitor should be considered for treatment with memantine in addition to their other treatment.
- Where patients have an established diagnosis of Alzheimer's disease and are already taking an acetylcholinesterase inhibitor, primary care prescribers may start treatment with memantine in addition to their other treatment without taking specialist advice.
- The pharmacological treatment of Alzheimer's disease should not be stopped on the basis of disease progression or disease severity only.
- Patients with non-Alzheimer's dementia should be offered the following treatments:
 - Patients with mild to moderate dementia with Lewy bodies should be offered treatment with donepezil or rivastigmine,
 - Patients with severe dementia with Lewy bodies should be considered for treatment with donepezil or rivastigmine
 - Galantamine should only be offered in the treatment of dementia with Lewy Bodies if donepezil or rivastigmine are not tolerated.
 - If acetylcholinesterase inhibitors are not tolerated or are contraindicated, consider offering memantine in the treatment of dementia with Lewy bodies.
 - Patients with mild to moderate Parkinson's disease dementia should be offered treatment with an acetylcholinesterase inhibitor.

¹⁶ NICE technical appraisal TA217 - Donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease (review) (2018) (<https://www.nice.org.uk/guidance/ta217>).

- Patients with severe Parkinson’s disease dementia should be considered for treatment with an acetylcholinesterase inhibitor.
- If acetylcholinesterase inhibitors are not tolerated or are contraindicated, consider offering memantine in the treatment Parkinson’s disease dementia.
- Patients with vascular dementia should only be offered treatment with acetylcholinesterase inhibitors or memantine if they have co-morbid Alzheimer’s disease, dementia with Lewy bodies or Parkinson’s disease dementia.
- Patients with frontotemporal dementia should not be offered treatment with acetylcholinesterase inhibitors or memantine.
- Patients with cognitive impairment caused by multiple sclerosis should not be offered treatment with acetylcholinesterase inhibitors or memantine.
- Patients with mild cognitive impairment should not be offered treatment with acetylcholinesterase inhibitors as current evidence suggests they do not reduce the risk of developing dementia, and that they are ineffective in the treatment of mild cognitive impairment whilst also increasing the risk to the patient from adverse effects. There are no studies to support the prescribing of memantine in mild cognitive impairment.
- GPs should be asked to review patients after a maintenance dose has been achieved and if treatment is well tolerated and there are no complications; continue the treatment long-term.
- When reviewing patients with dementia, concomitant anticholinergic medications should also be reviewed and discontinued or switched to an alternative where possible. Anticholinergics with effects on cognition or the additive effect of multiple anticholinergic medications (anticholinergic burden) may worsen the symptoms of dementia, and counteract the potential benefits of acetylcholinesterase inhibitors.¹⁷

Transition back to primary care should commence once assessment is complete and agreed interventions have been delivered. There should be a clear transfer plan, developed collaboratively with the person with dementia and their family/ friend and formal carers. This plan should include a summary of any medication, list of interventions delivered and any identified risks and safety plans. Services should ensure that people living with dementia and their carers know how to get more information and who from, if their needs change.

5. Non-cognitive changes

The symptoms of dementia make it harder to participate in activities and engage socially, to maintain independence, to communicate effectively, to feel in control and ultimately, to care for oneself. Experiencing symptoms of dementia has consequences, such as loss of confidence or tensions in family relationships, which compound the original disability. All of this can profoundly threaten a person’s sense of identity and security, especially where the person’s environment is not well-adapted or the surrounding community is not inclusive, and can

¹⁷ Guidelines on the use of Antidementia Drugs in People Living with Dementia (2019) Sussex Partnership NHS Foundation Trust

impact on the ability of families to provide care. There is potential for people with dementia to live meaningful and satisfying lives and to experience a good quality of life, but this requires support both to promote inclusion and to manage disability.

In recent years a growing social movement has focused on changing public attitudes, inspired the creation of dementia-friendly communities¹⁸ and promoted inclusion of people with dementia and awareness of the rights of people with dementia, for example through the development of peer support and advocacy groups. Involvement can provide enormous benefits for those people with dementia who wish to engage in this way.

Alongside this, there has been an increasing focus on enablement through providing interventions suitable for the stage of dementia and tailored to personal needs and preferences. A wide range of interventions has been proposed with these general aims in mind. Engaging in enjoyable, creative and health-enhancing activities offers a means of promoting well-being, maximising independence and sustaining positive relationships. It is essential to seek the views of people living with dementia and their family/friend and formal carers about the kinds of interventions they consider to be feasible and acceptable. This will ensure that interventions are personalised and based on an understanding of that individual's unique set of life experiences, circumstances, preferences, strengths and needs¹⁹.

The majority of people living with dementia are likely to experience the development of behavioural and psychological distress at some point during their illness. It has been suggested that these behaviours may be present in up to 90 per cent of people living with Alzheimer's disease. Such behaviour includes occurrences of hitting, kicking, nipping, screaming, apathy, pacing, non-compliance, urinating in inappropriate places and disinhibition as well as confusion, calling out, repetitive questioning, toileting difficulties, misidentifications and sexual challenge. It is important to remember that many of the behaviours identified as challenging are not symptoms of dementia, rather that they are symptoms of human distress, disorientation and misperception. As such, it seems counterproductive to frequently treat such behaviours through tranquilisation and sedation without first attempting to deal with the distress and cognitive confusion²⁰.

Referral to secondary mental health dementia services may be needed when the person develops more significant problems looking after themselves and is at risk of self-neglect/harm to others. The person may be experiencing high levels of anxiety, distress, depression or psychotic symptoms and their behaviour may pose serious challenges to themselves or others. They may be at increasing risk of their care arrangements breaking down. They will need support to maintain wellbeing both for themselves and the carer/family/support network around them. Care will be co-ordinated with risk enablement, otherwise known as positive risk taking²¹, which understands the individual's personal choices and helps family/friends to make decisions in difficult situations.

¹⁸ DoH (2012) The Prime Minister's Challenge on Dementia

¹⁹ Dementia: Assessment Management and Support for People Living with Dementia and Their Carers (NG97) (<https://www.nice.org.uk/guidance/ng97>) (2018) NICE

²⁰ Alternatives to antipsychotic medication: Psychological approaches in managing psychological and behavioural distress in people with dementia (2013) FPOP

²¹ "Nothing Ventured Nothing Gained": Risk Guidance for People with Dementia (2010) DoH

5.1 Care Planning and the Role of Lead Practitioner

The assessment/review process will inform care planning and the development of an individualised care plan for the person concerned. This will include, but is not limited to, appropriate care and interventions from the dementia menu, remembering that the intention is to fit the menu(s) to the person and not the other way around.

Where a lead practitioner is allocated, they will be responsible for developing the care plan and care pathway with the patient and/or their family/ friend and formal carers; involving them in decision-making, encouraging and enabling people living with dementia to give their own views and opinions about their care²². The lead practitioner will collaboratively oversee the implementation of the care plan and care pathway, monitoring and reviewing progress and amending as necessary. They will also play a crucial role in providing continuity of care. Please refer to the Trust Care Programme Approach (CPA) policy for details of this process.

5.2 Non-pharmacological Interventions for Non-Cognitive Changes

The government commissioned a report to review the use of antipsychotic medications for people with dementia²³. The report concluded that the use of antipsychotic medication for people with dementia needs to be reduced in order to limit the risk of harm associated with these medications in this frail and vulnerable group of people due to the high risk of serious side-effects. Before starting any non- pharmacological or pharmacological treatment, good practice guidelines highlight the importance of a structured clinical and environmental assessment to determine the cause of distress. This should include an assessment of a person's physical health (such as vision, hearing, NEWS, blood screening, ECG, nutrition and hydration, constipation, infection, delirium and pain) and an assessment of their physical and social environment.

NICE (2018) recommend non-pharmacological interventions as the first line approach to reduce distress. The Faculty of the Psychology of Older People's work describes the evidence-based alternatives to antipsychotic medication for people with dementia²⁴, they recommend a staged approach, (that is, a stepped care approach) which will increase access to these interventions and therefore reduce reliance on antipsychotic medications. This is further explored by James and Jackman 2017²⁵, see figure 2 below.

²² NICE (2018) Dementia: Assessment Management and Support for People Living with Dementia and Their Carers (NG97) (<https://www.nice.org.uk/guidance/ng97>).

²³ The Use of Antipsychotic Medication for People with Dementia: Time for Action (2009) Professor Sube Banerjee

²⁴ Alternatives to antipsychotic medication: Psychological approaches in managing psychological and behavioural distress in people with dementia (2013) FPOP

²⁵ James and Jackman (2017) Understanding Behaviour in Dementia that Challenges

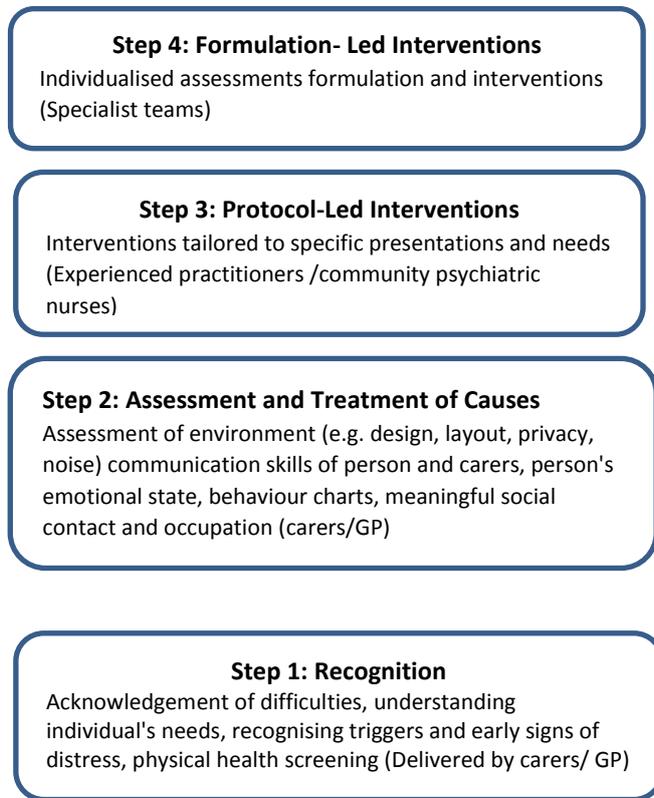


Figure 2 Stepped Care Approach

The stepped care model reinforces the need to ask ‘why the behaviour is occurring?’ and ‘who is it distressing for?’ (i.e. doing a good assessment). This places the behaviour in the context of the person’s life history and the social and physical environment in which they live, and shapes the intervention required.

Steps 3 and 4 apply to community and inpatient secondary mental healthcare services as the assessments and interventions require specialist training to safely and effectively deliver them.

At Step 3, the use of structured protocols such as TREA²⁶ (Treatment Routes for Exploring Agitation) BANGS²⁷ (Breathe; Assess, accept and agree; Never argue; Go and let go; Say sorry), RAM²⁸ (Reduce emotion, Assess need, Meet need), DCM²⁹ (Dementia Care Mapping) and ABC charts, along with a systematic review of information from Step 1 and Step 2, helps clinicians to interpret distress and formulate plans of intervention.

²⁶ Alternatives to antipsychotic medication: Psychological approaches in managing psychological and behavioural distress in people with dementia (2013) FPOP

²⁷ Macaulay (2015) B is for Breathe in BANGS

²⁸ James and Jackman (2017) Understanding Behaviour in Dementia that Challenges

²⁹ Brooker, D & Surr, C (2005) Dementia Care Mapping: Principles and Practice. Bradford: Bradford Dementia Group

At Step 4 clinicians will build on information gathered at Steps 1, 2 and 3. They will make use of specialised assessments, interventions and frameworks to understand the individual's experience and needs. A key part of understanding the experience of a person with dementia is to consider the “Enriched Model of Dementia” (Kitwood 1997)³⁰. The enriched model of dementia looks at neurological impairment, health and physical fitness (including pain, mental health issues and side effects of medication), biography (life history), personality and social psychology (interactions with staff and others, engagement in activities and the environment that are helpful or unhelpful to the person).

A multidisciplinary approach is often required in order to develop a biopsychosocial formulation and a set of interventions which are tailored to the person with dementia, their formal and informal carers and their environment³¹.

Another psychosocial model – the Newcastle Model – builds on the enriched model and provides a framework and process to understand behaviour that challenges in terms of needs which are unmet. It suggests a structure in which to develop effective interventions that keep people with dementia central to their care.

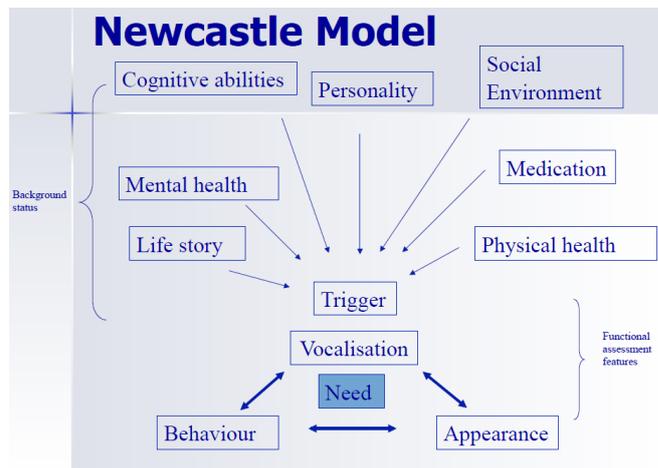


Figure 3 Newcastle Model³²

A thorough clinical assessment leads to the development of a comprehensive formulation (see figure 3). This will support care teams to identify individually tailored interventions for the person and their formal and informal carers.

There are many non-pharmacological approaches but few have a good evidence base. They can be distinguished as preventative approaches which are designed to promote a positive therapeutic milieu and positive wellbeing and formulation led interventions which are strategies developed post formulation in response to identified need.

Examples of preventative strategies include:

³⁰ Dementia Reconsidered: The Person Comes First, Tom Kitwood (1997), Dementia Reconsidered, Revisited. The Person Still Comes First. Tom Kitwood, edited by Dawn Brooker (2019).

³¹ Alternatives to antipsychotic medication: Psychological approaches in managing psychological and behavioural distress in people with dementia (2013) FPOP

³² James and Jackman (2017) Understanding Behaviour in Dementia that Challenges

- Cognitive Stimulation Therapy (CST)
- Cognitive Rehabilitation
- Life Story work i.e. 'This is Me' and more detailed life story work
- Toolbox approaches, i.e. creating individualised boxes for each person to facilitate communicate between them and their formal and informal carers
- Reminiscence Therapy
- Validation Therapy
- Psychomotor and Exercise Therapy
- Multi-sensory Stimulation i.e. light, sound, touch, massage
- Aromatherapy
- Bright Light Therapy
- Music Therapy
- Animal Assisted Therapy
- Doll Therapy
- Assistive Technology
- Creative Art Therapies
- Environmental manipulation i.e. signage, environmental cues, appropriate building layout
- Positive Approach to Care (PAC)
- Prevention and Management of Violence and Aggression (PMVA)³³

Examples of formulation led interventions which can be delivered to the person with dementia and /or their friend/family and formal carers individually or in groups, include:

- Behaviour Therapy
- Positive Behaviour Support
- Standard Psychotherapies such as CBT and family interventions

5.3 Pharmacological Interventions for Non-Cognitive Changes

Pharmacological treatment should only be considered if there is psychosis, depression or behaviour that is significantly distressing or harmful to the patient or others. Where possible, this treatment should be short-term and must be kept under close review³⁴.

Pharmacological interventions are targeted to the problematic behaviour of the person with dementia and include the use of antidepressants, antipsychotics, mood stabilisers and drugs to modify sleep patterns.

Antipsychotic medication should only be offered to people living with dementia who are either at risk of harming themselves or others or are experiencing agitation, hallucinations or delusions that are causing them severe distress. Before commencing any antipsychotic

³³ Positive and Proactive Care: Reducing the Need for Restrictive Interventions. London: Social Care, Local Government and Care Partnership Directorate (2014) DoH

³⁴ Dementia: Assessment Management and Support for People Living with Dementia and Their Carers (NG97) (<https://www.nice.org.uk/guidance/ng97>) (2018) NICE

medication, the potential benefits and negative impacts must be discussed with the person and their family/ friend and formal carers (as appropriate).

People with dementia with Lewy bodies or Parkinson's disease dementia, may experience a worsening of the motor features of the condition, and in some cases experience severe antipsychotic sensitivity reactions. For more guidance, see the advice on managing delusions and hallucinations in the NICE guideline on Parkinson's disease.

For people living with dementia experiencing persistent distress where there is risk of harm to the patient or others and which has not responded to non-pharmacological approaches, the antipsychotic of choice is risperidone, which is licensed for BPSD. The use of any other antipsychotic, is an 'off licence' use of the medicine. This drug (or any other antipsychotic) must be used with extreme caution as all antipsychotics have been shown to increase risk of CVA. Before prescribing antipsychotics consider risk factors for cerebrovascular disease such as previous history of stroke or Transient Ischaemic Episodes (TIAs), hypertension, diabetes, smoker, and atrial fibrillation. An ECG should be completed (caution if long QTc or AF identified) and blood pressure monitored. The starting dose is 0.25mg b.d. adjusted on alternate days to not more than 1mg b.d. Patients must be regularly reviewed and treatment beyond 6 weeks should not occur without full, documented review of ongoing clinical need.

Also note that use of antipsychotics in older people increases risk of pneumonia by up to 60%.

To reduce CVA risk, ensure that the patient remains well hydrated and maintains mobility (where possible).

Other medication options:

- Memantine is also a potential treatment option for moderate to severe Alzheimer's Dementia.
- Depression: Do not routinely offer antidepressants to manage mild to moderate depression in people living with mild to moderate dementia. Consider an antidepressant only in cases of severe clinical depression. Citalopram (up to 20mg) is first choice if not contraindicated. Sertraline, mirtazapine and trazodone are alternatives. All may help restlessness / agitation.
- Anxiety: Should respond to an SSRI antidepressant longer-term, ie. citalopram or sertraline, (not fluoxetine). Benzodiazepines should be avoided other than in extreme cases when short-acting lorazepam or oxazepam are less likely to accumulate. Review regularly and monitor closely for worsening confusion, ataxia and falls.
- Poor Sleep: Improve sleep hygiene. If needed, try short-term use of zolpidem.

Stop treatment with antipsychotics if the person is not getting a clear, ongoing benefit from taking them and after discussion with the person taking them and their family/ friend and formal carers, as appropriate³⁵. When reducing or stopping psychotropic medicines, only reduce or stop one at a time. Consider reducing or stopping anticholinergic drugs (e.g. procylidine), tricyclic antidepressants, drugs for urinary incontinence (e.g. oxybutynin) antihistamines (e.g. promethazine), opioids, Parkinson's drugs (e.g. Sinemet), GI drugs (metoclopramide, ranitidine, hyoscine). Acetylcholinesterase inhibitors themselves may

³⁵ Dementia: Assessment Management and Support for People Living with Dementia and Their Carers (NG97) (<https://www.nice.org.uk/guidance/ng97>) (2018) NICE

sometimes cause agitation. If newly prescribed consider reducing or stopping them to see if behavioural problems resolve³⁶.

6. Outcome Measures for use as part of an assessment and ongoing review

The Five Year Forward View for Mental Health (FYFV)³⁷ was published in October 2014 and proposed 58 recommendations for meeting the needs of the increasing numbers of people using mental health services. It outlined a vision for a comprehensive set of evidence-based treatment pathways to be in place by 2020/21 and the need for mental health services to be able to demonstrate how they deliver evidence-based treatment. The FYFV also set out the need for a leading role for people with lived experience (and their families) in assuring that services are assessed based on quality and the outcomes that are valued by the people who use them. It is important to ensure that evidence based outcome measures are used as part of any clinical assessment and review. The tools below have been recommended by the Trust Specialist Older Adult (SOA) Clinical Academic Group (CAG), any other tools that clinicians feel would be appropriate would need to be approved by the SOA CAG.

- Mini Mental State Examination (MMSE)
- Addenbrookes Cognitive Examination III (ACE-III)
- Montreal Cognitive Assessment (MOCA)
- Diagnosing Advanced Dementia Mandate (DiADeM)
- Health of The Nation Outcome Score (Honos)
- Bristol Activities of Daily Living Scale (BADLS)
- Neuropsychiatric Inventory (NPI)
- Health related quality of life QOL-AD
- Carer quality of life C-DEMQOL
- Behaviour charts i.e. ABC charts
- Malnutrition Universal Screening Tool (MUST)
- Waterlow risk assessment tool for bed sores/ulcers
- Abbey pain scale
- PAIN-AD
- Cornell Scale for Depression in Dementia (CSDD)
- Challenging Behaviour Scale (CBS)
- Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSUIID)
- Zarit Carer burden (ZBI)

³⁶ Responding to Behaviours That Challenge (BPSD) in Older People and Those With Dementia. Sussex Partnership NHS Foundation Trust, Drugs and Therapeutics Group. (2007, updated 2015)

³⁷ The Five Year Forward View for Mental Health (2014) NHS England and NHS Improvement and Delivering the Five Year Forward View for Mental Health: Developing quality and outcomes measures (2015) NHS Improvement Guidance

- National Early Warning Score (NEWS)
- Friends and Family Test

7. Staff Training

Secondary care dementia services should be provided by multi-disciplinary teams that are appropriately trained and skilled. The Dementia Training Standards Framework sets out the essential knowledge and skills necessary for all staff involved in dementia care³⁸.

8. People Participation Strategy

We should actively engage with people with lived experience of dementia to support the ongoing strategic development of high quality services. We encourage the expansion of roles such as Experts by Experience and Peer Support Workers to further enable collaboration and participation. Our services should be reviewed in response to any feedback so that we can collaboratively work to improve the care we provide.

³⁸ Dementia Core Skills and Education Framework (2018) Health Education England (HEE), Skills for Health and Skills for Care