

POST-DIAGNOSTIC SUPPORT AND FOLLOW UP IN DEMENTIA

A Literature Review and Discussion

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Executive Summary

The term Dementia describes a range of conditions caused by physical and chemical changes to the brain, which lead to a decline in memory, communication, reasoning and the ability to carry out routine tasks of living. The most well known of these is Alzheimer's disease. Dementia can occur at any age, however it is far more common in the elderly

This report explores the evidence relating to:

1. Medical follow-ups (MFU) for people with dementia
2. Post-diagnostic support (PDS) models for people with dementia and family carers

PDS and MFU for people with dementia is of particular importance to commissioners as:

- Feedback from patients and carers consistently raises this as a key area in need of improvement, both in terms of access and quality
- There is an evolving evidence base showing that effective PDS can help to prevent unplanned/non-elective admissions to secondary care, and can help to delay admission to long-term/residential care
- PDS is of importance not just to patients, but, crucially, to their carers as well – many of these may also be older people with significant medical history.

A key element of the questions asked in this report must be to consider:

- **What are PDS and MFU trying to achieve?**
- **What outcomes do we want to commission?**

Quality of life outcomes centre on having access to normal activities and patterns of life in ways that maximize feelings of choice and control and encompass social, physical and emotional needs. Service-process outcomes are concerned with the desired impacts of service delivery'.

Commissioning cycles begin with an analysis of the need that commissioned services should be able to address. In the case of people with dementia, these needs can be broadly classified as:

- Clinical
- Functional
- Social
- Learning and Educational
- Crisis
- Palliative Care

In order to address these needs, PDS and MFU might, **from a commissioning and provision perspective**, be broadly classified as follows:

- Clinical
- Social
- Advocacy and opportunity to influence services
- Safeguarding

Commissioners should approach the cycle of commissioning PDS and MFU by beginning to match needs to packages of care beginning with the simple framework above. In addition, any question posed in relation to designing, commissioning and providing PDS for people with dementia should be considered in the context of multimorbidity. Any opportunity to better identify and manage comorbidities without delay should be embraced. This may also engender greater collaboration and promote the integration agenda through clinical specialties, in particular holistic characterisation of patients, minimising contact burden and confusion.

Summary of Published Guidance relating to PDS and MFU

- Patients who continue on treatment with AChEIs/Memantine should be reviewed regularly
- People newly diagnosed with dementia and their carers should receive written and verbal information about their condition, treatment and the support options in their local area.
- People with dementia should have an assessment and an ongoing personalised care plan,
- Carers of people with dementia should be offered an assessment of emotional, psychological and social needs and receive tailored interventions identified by a care plan
- People with dementia should be assessed in primary care to identify and plan palliative care.
- People with dementia should be enabled, to take part in leisure activities during their day

- In order to do proper follow-up, GPs and practice nurses should have the same level of knowledge and confidence as those who assess patients and commence treatment.
- Systematic follow-up is needed, but not necessarily in a specialist hospital clinic.
- Patients with vascular dementia discharged after diagnosis as AChEIs are not indicated must not lose touch with support agencies and they may feel very alone in their predicament
- There is a need for control strategies against vascular disease and unhealthy lifestyle habits
- Patients should be seen at least every 6 months to evaluate for functional/cognitive change
- Voluntary organisations may be an essential source of information.

Summary of Published Research Evidence relating to PDS and MFU

- High level, randomised evidence on PDS and MFU is sparse.
- Limited RCT evidence finds no evidence memory clinics are better than GPs with regard to PDS/MFU, and that costs of care for moderate dementia are higher than for mild dementia.
- Informal care is a non-cash item saving expenditures for professional care
- Community-based dementia care and support to carers needs to be further developed.
- There is much to be done in service development and provision, GP training and education,
- There is some evidence that case management is beneficial at improving some outcomes at certain time points, both in the person with dementia and in their carer
- People with memory problems undergoing assessment often have unmet information needs, especially patients with a diagnosis other than Alzheimer's disease and those who do not receive a diagnosis.
- Wellbeing Cafes can be a valuable community resource for both patients and carers

It is crucial to recognise that the Voluntary and Third Sector occupies an enormous role and bears a significant responsibility in supporting people with dementia and their carers. It would not be possible to consider dementia in the context of strategic and operational planning without explicitly acknowledging and incorporating activity from this sector.

Recommendations

- 1. A region wide audit should be undertaken of processes and activity relating to offers of PDS and referrals to the Alzheimer's Society or like organisations on receipt of diagnosis.**
- 2. The SCN should work with the Alzheimer's Society to begin to build a system whereby every patient, upon receipt of diagnosis, is automatically seen either on site at the time by a Society representative or receives a referral immediately**
- 3. Clarity should be developed specifically in relation to post diagnosis processes and the PDS and MFU offered to those people who do not have Alzheimer's Disease**
- 4. The SCN should lead a piece of work with commissioners identifying packages of PDS that relate systematically to defined circumstances of need**

Introduction

The term Dementia describes a range of conditions caused by physical and chemical changes to the brain, which lead to a decline in memory, communication, reasoning and the ability to carry out routine tasks of living. The most well known of these is Alzheimer's disease. Dementia can occur at any age, however it is far more common in the elderly. One in six people over 80 and one in 14 people over 65 will have a form of dementia. Of particular importance, therefore, is the fact that, as the numbers of elderly people in the population continues to grow, so will the number of people with dementia. As a direct result of this, the costs of caring for people with dementia can be expected to rise in tandem, and there is a pressing need for robust forward planning, both to design effective and efficient services, and to make fiscal allowances for the resources that will be required.

This report was commissioned from Bradford Metropolitan District Council Public Health External Development by Yorkshire & Humber Strategic Clinical Networks, with the aim of producing a comprehensive, referenced summary of the evidence base for two areas of related practice to support effective commissioning of services for people with dementia and their family carers. These are:

1. Medical follow-ups (MFU) for people with dementia
2. Post-diagnostic support (PDS) models for people with dementia and family carers

This summary to include the following:

- Reference to effective service delivery models such as Admiral Nursing and Dementia Advisors (or similar)
- Impact on patient and carer outcomes (where available)
- Cost-effectiveness of different models/approaches
- Consideration of organisational aspects of care found to have an impact on effectiveness e.g. integration between NHS and 3rd sector services
- Examples of good practice identified within the literature

PDS and MFU for people with dementia is of particular importance to commissioners as:

- Feedback from patients and carers consistently raises this as a key area in need of improvement, both in terms of access and quality
- There is an evolving evidence base showing that effective PDS can help to prevent unplanned/non-elective admissions to secondary care, and can help to delay admission to long-term/residential care
- PDS is of importance not just to patients, but, crucially, to their carers as well – many of these may also be older people with significant medical history.

This report is targeted specifically at Clinical Commissioning Group (CCG) and Local Authority (LA) commissioners with responsibility for commissioning dementia care and related support services.

It is important to consider that PDS can cover a broad range of activities and services throughout the care and social environment, however for the purpose of the report we are considering specifically those services or aspects of services (e.g. provision of information) that are commissioned, and whose main focus is provision of support for people who are living with dementia and their family carers.

Key Reference Figures ⁽¹⁾

- The total age-standardised 65+ population prevalence of dementia is 7.1%
- This equals one in every 14 of the population aged 65 years and over.
- There will be an estimated 850,000 people with dementia in the UK in 2015.
- Compared to 2007 estimates, current prevalence estimates are higher for the youngest (65–69) and oldest (90+) age bands and lower for intermediate age groups (80–89).
- The total number of people with dementia in the UK is forecast to increase to over 1 million by 2025 and over 2 million by 2051 if age-specific prevalence remains stable

Growing numbers of people with dementia are being admitted to hospital. It is estimated that up to 25 per cent of hospital beds at any one time are occupied by people with dementia ⁽²⁾. About one in three people with dementia admitted to hospital from home are discharged into a care home ⁽³⁾ increasing the cost pressures on health and social care budgets

On the societal level, dementia is a stigmatized disease surrounded by influences of ageism. Patients and caregivers often deny dementia symptoms, experience difficulties in accepting the diagnosis, and react to the disease with social withdrawal and depression ⁽⁴⁾. They have a lack of disease specific knowledge and of information on regional support and counselling services. This lack of knowledge is often shared by their GPs, who have a tendency of tabooing cognitive impairments and have difficulties in telling bad news – especially disclosing a diagnosis of dementia ^(5, 6).

Background

Policy context

The National Dementia Strategy

In 2009, the Department of Health published “Living Well with Dementia”, the first ever national dementia strategy for England ⁽⁷⁾. The strategy sets out 17 recommendations that the government intended the NHS, Local Authorities and others to take on in order to improve dementia care services. The recommendations are focused on three key themes of:

1. Raising awareness and understanding
2. Early diagnosis and support
3. Living well with dementia

The Prime Minister’s Dementia Challenge

In March 2012, the Prime Minister set a challenge to deliver major improvements in dementia care and research by 2015. Three “Champion Groups” were set up to focus on the main areas for action, these being:

1. Driving improvements in health and care
2. Creating dementia-friendly communities
3. Improving dementia research.

In February 2015 the Prime Minister launched the next phase of the Dementia Challenge, with a five year vision for the future of care, support and research, which follows on from the existing Challenge. The overall ambition set by the vision is by 2020 for England to be:

- The best country in the world for dementia care and support and for people with dementia, their carers and families to live; and
- The best place in the world to undertake research into dementia and other neurodegenerative diseases.

The key aspirations are that by 2020 there should be:

- Improved public awareness and understanding of the factors, which increase the risk of developing dementia and how people can reduce their risk by living more healthily. This should include a new healthy ageing campaign and access to tools such as a personalised risk assessment calculator as part of the NHS Health Check.

- In every part of the country people with dementia having equal access to diagnosis as for other conditions, with an expectation that the national average for an initial assessment should be 6 weeks following a referral from a GP (where clinically appropriate), and that no one should be waiting several months for an initial assessment of dementia.
- GPs playing a leading role in ensuring coordination and continuity of care for people with dementia, as part of the existing commitment that from 1 April 2015 everyone will have access to a named GP with overall responsibility and oversight for their care.
- Every person diagnosed with dementia having meaningful care following their diagnosis, which supports them and those around them, with meaningful care being in accordance with published National Institute for Health and Care Excellence (NICE) Quality Standards. Effective metrics across the health and care system, including feedback from people with dementia and carers, will enable progress against the standards to be tracked and for information to be made publicly available. This care may include for example:
 - Receiving information on what post-diagnosis services are available locally and how these can be accessed, through for example an annual 'information prescription'.
 - Access to relevant advice and support to help and advise on what happens after a diagnosis and the support available through the journey.
 - Carers of people with dementia being made aware of and offered the opportunity for respite, education, training, emotional and psychological support so that they feel able to cope with their caring responsibilities and to have a life alongside caring.
- All NHS staff having received training on dementia appropriate to their role. Newly appointed healthcare assistants and social care support workers, including those providing care and support to people with dementia and their carers, having undergone training as part of the national implementation of the Care Certificate, with the Care Quality Commission asking for evidence of compliance with the Care Certificate as part of their inspection regime. An expectation that social care providers provide appropriate training to all other relevant staff.
- All hospitals and care homes meeting agreed criteria to becoming a dementia friendly health and care setting.

- Alzheimer's Society delivering an additional 3 million Dementia Friends in England, with England leading the way in turning Dementia Friends in to a global movement including sharing its learning across the world and learning from others.
- Over half of people living in areas that have been recognised as Dementia Friendly Communities, according to the guidance developed by Alzheimer's Society working with the British Standards Institute. Each area should be working towards the highest level of achievement under these standards, with a clear national recognition process to reward their progress when they achieve this. The recognition process will be supported by a solid national evidence base promoting the benefits of becoming dementia friendly.
- All businesses encouraged and supported to become dementia friendly, with all industry sectors developing Dementia Friendly Charters and working with business leaders to make individual commitments (especially but not exclusively FTSE 500 companies). All employers with formal induction programmes invited to include dementia awareness training within these programmes.
- National and local government taking a leadership role with all government departments and public sector organisations becoming dementia friendly and all tiers of local government being part of a local Dementia Action Alliance.
- Dementia research as a career opportunity of choice with the UK being the best place for Dementia Research through a partnership between patients, researchers, funders and society.
- Increased investment in dementia research from the pharmaceutical, biotech devices and diagnostics sectors, including from small and medium enterprises (SMEs), supported by new partnerships between universities, research charities, the NHS and the private sector. This would bring world class facilities, infrastructure, drive capacity building and speed up discovery and implementation.
- Cures or disease modifying therapies on track to exist by 2025, their development accelerated by an international framework for dementia research, enabling closer collaboration and cooperation between researchers on the use of research resources – including cohorts and databases around the world.
- More research made readily available to inform effective service models and the development of an effective pathway to enable interventions to be implemented across the health and care sectors.

- Open access to all public funded research publications, with other research funders being encouraged to do the same.
- Increased numbers of people with dementia participating in research, with 25 per cent of people diagnosed with dementia registered on Join Dementia Research and 10 per cent participating in research, up from the current baseline of 4.5 per cent.

Improving Care for People with Dementia

In 2013 the Government launched the policy “Improving Care for People with Dementia”⁽⁸⁾. This is directed towards improving health and care services, creating more dementia-friendly communities and making dementia research a priority. There is an aim to increase diagnosis rates by making sure that doctors give 65-74 year olds information about memory services as part of the NHS health check programme, and refer them for assessment if needed.

NHS 5 Year Forward View

In October 2014, the NHS has published the Five Year Forward View setting out how the health service needs to change over the course of the next Parliament to meet the needs of the population and take advantage of new science, technology and innovation⁽⁹⁾. The document was positioned by NHS Chief Executive Simon Stevens not as a detailed plan but a ‘longer view’ for the NHS and how it can meet the healthcare needs of the future. The document stipulated that, for those that are diagnosed with dementia, the NHS’ ambition over the next five years is to offer a consistent standard of support for patients newly diagnosed with dementia, supported by named clinicians or advisors, with proper care plans developed in partnership with patients and families; and the option of personal budgets.

NHS Mandate

The Government provides direction and ambitions for the NHS/NHS England through an annual document called the NHS Mandate. NHS England must try to achieve these ambitions and the Secretary of State for Health holds them to account for improving care. The 2015/16 NHS Mandate includes directives to improve diagnosis, treatment and care for people with dementia as well as to put mental health on a par with physical health and support people who fall into crisis.

Aims of this Report

This report is designed to explore the evidence relating to PDS and MFU for patients with dementia. It was agreed at the outset with the commissioners of this report that it should be placed in the context of a “real-world” exploration of the place that the evidence found actually takes in the design, commissioning and provision of services for people with dementia. As such it was agreed that the work should not be restricted solely to the confines of formal literature review and critical appraisal frameworks, and so in addition to standard literature searching techniques, broader sources were used to garner important information including the author’s electronic library of dementia research which contains in excess of 600 published papers, with studies selected on the basis that that would help to grow understanding of the subjects in question. The underpinning aims were as follows:

- 1. To describe evidence based, clinically effective and cost-effective methods providing post-diagnostic support to people with dementia and their carers.**
- 2. To describe evidence based, clinically effective and cost-effective methods of follow-up of dementia patients following diagnosis.**

Methodology

A locally developed evidence-search tool which has been in use for over ten years was used. This uses a broad range of sources, including guideline sources, commercial and government evidence search tools and standard libraries such as MEDLINE and PsycINFO.

Search terms used were as follows

- Dementia
- Follow-up
- Review
- Support
- Postdiagnostic
- Postdiagnosis
- MATS
- Effectiveness
- Cost-effectiveness

The following standard evidence hierarchy is used:

1. Guidance/Guidelines
2. Literature Reviews
3. Randomised Studies
4. Non-Randomised Studies

Only studies published in English were included.

No time/ year limits were placed.

Findings are outlined below.

Literature Review

Evidence-Based Guidelines

1. NICE/NHS/DoH produced Guidance

NICE Clinical Guideline 42 – Dementia ⁽¹⁰⁾

- Memory assessment services that identify people with MCI (including those without memory impairment, which may be absent in the earlier stages of non- Alzheimer's dementias) should offer follow-up to monitor cognitive decline and other signs of possible dementia in order to plan care at an early stage.
- Following a diagnosis of dementia, health and social care professionals should, unless the person with dementia clearly indicates to the contrary, provide them and their family with written information about:
 - The signs and symptoms of dementia
 - The course and prognosis of the condition treatments
 - Local care and support services
 - Support groups
 - Sources of financial and legal advice, and advocacy
 - Medico-legal issues, including driving
 - Local information sources, including libraries and voluntary organisations
- AcetylCholinesterase Inhibitors and Memantine:
 - Patients who continue on treatment **should be reviewed regularly** using cognitive, global, functional and behavioural assessment.
 - Treatment should be reviewed by an appropriate specialist team, unless there are locally agreed protocols for shared care.
 - Carers' views on the patient's condition at follow-up should be sought.

NICE Quality Standard 1 – Dementia ⁽¹¹⁾

(NICE quality standards are a set of specific, concise statements and associated measures. They set out aspirational, but achievable, markers of high-quality, cost-effective patient care, covering the treatment and prevention of different diseases and conditions. Derived from the best available evidence such as NICE guidance and other evidence sources accredited by NHS Evidence, they are developed independently by NICE, in collaboration with NHS and social care

professionals, their partners and service users, and address three dimensions of quality: clinical effectiveness, patient safety and patient experience).

List of statements

- Statement 3. People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local area.
- Statement 4. People with dementia have an assessment and an ongoing personalised care plan, agreed across health and social care, that identifies a named care coordinator and addresses their individual needs.
- Statement 5. People with dementia, while they have capacity, have the opportunity to discuss and make decisions, together with their carer/s, about the use of:
 - Advance statements
 - Advance decisions to refuse treatment Lasting Power of Attorney
 - Preferred Priorities of Care.
- Statement 6. Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs.
- Statement 7. People with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, are offered an assessment at an early opportunity to establish generating and aggravating factors. Interventions to improve such behaviour or distress should be recorded in their care plan.
- Statement 8. People with suspected or known dementia using acute and general hospital inpatient services or emergency departments have access to a liaison service that specialises in the diagnosis and management of dementia and older people's mental health.
- Statement 9. People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.
- Statement 10. Carers of people with dementia have access to a comprehensive range of respite/ short-break services that meet the needs of both the carer and the person with dementia.

NICE Quality Standard 30 - Supporting people to live well with dementia ⁽¹²⁾

List of quality statements

- Statement 1. People worried about possible dementia in themselves or someone they know can discuss their concerns, and the options of seeking a diagnosis, with someone with knowledge and expertise.
- Statement 2. People with dementia, with the involvement of their carers, have choice and control in decisions affecting their care and support.
- Statement 3. People with dementia participate, with the involvement of their carers, in a review of their needs and preferences when their circumstances change
- Statement 4. People with dementia are enabled, with the involvement of their carers, to take part in leisure activities during their day based on individual interest and choice.
- Statement 5. People with dementia are enabled, with the involvement of their carers, to maintain and develop relationships.
- Statement 6. People with dementia are enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing.
- Statement 7. People with dementia live in housing that meets their specific needs.
- Statement 8. People with dementia have opportunities, with the involvement of their carers, to participate in and influence the design, planning, evaluation and delivery of services.
- Statement 9. People with dementia are enabled, with the involvement of their carers, to access independent advocacy services.
- Statement 10. People with dementia are enabled, with the involvement of their carers, to maintain and develop their involvement in and contribution to their community.

NHS England - Dementia Revealed – What Primary Care Needs to know – A Primer for General Practice July 2014 ⁽¹³⁾

- Patients with MCI need yearly follow-up and the same advice and support as for Subjective Cognitive Impairment.
- In order to do proper follow-up, GPs and practice nurses should have the same level of knowledge and confidence as those who assess patients and commence treatment.
- Changing and stopping drugs requires just as much knowledge and skill as starting them.

- An identified weakness is that **patients with vascular dementia are generally discharged after diagnosis because AChEI drugs are not indicated**. It is easy for these patients and their families to lose touch with support agencies and they may feel very alone in their predicament

Follow-up:

- **Systematic follow-up is needed, but not necessarily in a specialist hospital clinic.**
- Follow-up needs to be initiated by the practice and patients who do not attend should be contacted and offered follow-up at home.
- The patient should have a simple care plan that includes the diagnosis, a treatment and review plan, and sources of information, including where to find local support groups.
- If an AChEI has been initiated, the first follow-up contact with the patient and carers will be to establish whether there are any significant side-effects. It is useful to do this before the second prescription is due, so an interval of around three weeks is about right.
- The second follow-up should be about three months later when the patient should be assessed for response to treatment.
- A cognition test may be done but, especially in more advanced dementia, an assessment of well-being and functioning is more important.
- It is helpful to **offer information about support organisations at every contact** as people's receptiveness may be different at different times.
- An occupational therapy assessment may be helpful at any stage.
- Further follow-up may include periodic assessment of cognition, as in a memory clinic, but should be omitted if it upsets or intimidates the patient. Overall functioning, medication issues and carer views will constitute most of the review.
- Follow-up is well within the remit of a practice nurse with knowledge of dementia and its problems, and who is trained in cognitive testing.
- There needs to be a regular MDT meeting with the lead GP.
- Patients whose risk is causing concern may need to be referred to a CPN, social services, or to the practice's Virtual Ward, or its equivalent resource.

2. Journal based guidance

BMJ Best Practice – Alzheimer’s Dementia, Follow-up Recommendations ⁽¹⁴⁾

(BMJ Best Practice is a tool which aims to assist health professionals in making decisions about treatment and diagnosis. It uses an evidence-based, patient-focused approach and is used to identify UK or international guidelines and evidence-based synopses).

- Patients should be seen at least every 6 months to evaluate for functional and cognitive change. Issues such as daily medication use, functional status, comorbid illnesses, new signs and symptoms, carer burden, and need for future respite care or nursing home placement should be discussed.
- Medication continuation may be discussed if the disease progresses without apparent symptomatic benefit or plateau.
- Home safety risk assessment should be made at every visit.
- Driving status should be reassessed at least every 6 months.

3. Other reputable sources

Medscape Jan 2015 – Alagiakrishnan – Vascular Dementia Follow-Up ⁽¹⁵⁾

(Medscape is a web resource for physicians and health professionals using peer-reviewed original medical journal articles, a customized version of MEDLINE and drug information)

- Regular follow-up every 4-6 months is recommended to assess the patient's general condition and cognitive and noncognitive symptoms.
- Frequent visits may be needed for patients with behavioral problems and patients who are on specific therapies such as neuroprotective agents.
- Treatment of risk factors such as hypertension, hypercholesterolemia, and diabetes mellitus require special attention.

Medscape Jan 2015 - Chawla – Vascular Dementia Follow-Up ⁽¹⁶⁾

While waiting for effective drug therapies and first-level evidence data, healthcare professionals should be encouraged to improve early diagnosis of cognitive impairment and activate control strategies against vascular disease and unhealthy lifestyle habits.

Literature Reviews

A Canadian literature review undertaken by CADTH in 2014 posed two questions ⁽¹⁷⁾:

(Canadian Agency for Drugs and Technologies in Health (CADTH) provides decision-makers with the evidence, analysis, advice, and recommendations they require to make informed decisions in health care.

Funded by Canada's federal, provincial, and territorial governments, CADTH is an independent, not-for-profit agency that delivers timely, evidence-based information to health care leaders about the effectiveness and efficiency of health technologies)

1. What is the clinical evidence regarding the need for psychiatrist-led care for patients under age 65 with dementia and a psychiatric diagnosis in long-term care settings?
2. What are the evidence-based guidelines regarding the management of patients under age 65 with dementia and a psychiatric diagnosis in long-term care settings?

The search was limited to Health Technology Assessments, systematic reviews, meta-analyses, randomized controlled trials, non-randomized studies and evidence-based guidelines

The authors reported that No health technology assessments, systematic reviews, meta-analyses, randomized controlled trials, non-randomized studies, or evidence-based guidelines were identified regarding psychiatrist-led care of patients with dementia and psychiatric disorders in long-term care settings.

No relevant literature was found regarding psychiatrist-led care of patients with dementia and psychiatric disorders in long-term care settings; therefore, no summary can be provided.

Bunn 2012 ⁽¹⁸⁾

This Systematic Review analysed the qualitative evidence about how patients and carers adapt to a diagnosis of dementia, and which type of post-diagnosis support is perceived as most helpful. The researchers used robust search techniques to identify qualitative studies exploring the experiences of community-dwelling individuals around diagnosis, and the transition to becoming a person with dementia, or becoming a carer of a person with dementia.

Using “thematic analysis”, (a way of synthesizing the results of qualitative studies, they identified three recurring and dominant themes around the diagnosis of dementia.

1. Pathways through diagnosis

Many studies explored the barriers to seeking a diagnosis, such as stigma, normalization of symptoms, and lack of knowledge. They also reported that in some cases doctors are slow to recognise symptoms, and that even when people have been referred to memory services the process may be slow, with long periods of waiting.

Once a diagnosis was made, as you would expect it could have enormous impact on identity, as well as roles and relationships, with spouses especially having to make big adjustments in roles and communication, and in wider social networks.

2. Resolving conflicts to accommodate a diagnosis

The review found that the variation in people’s previous experience and knowledge about dementia before a diagnosis was given led to a big variation in how a diagnosis was reacted to and then accommodated by patients and their carers.

3. Ways of living with dementia

This theme covered the common strategies adopted to cope with the disease which included practical strategies such as using reminders or prompts, social strategies such as relying on family support, and emotional strategies such as using humour or finding meaningful activity.

The review revealed a need for greater support from professionals after diagnosis, including advice, social and psychological support, access to community care, and respite.

Koch 2010 ⁽¹⁹⁾

This systematic review of barriers to the diagnosis and management of patients with dementia in primary care was published in BMC Family Practice in 2010. Publications up to August 2009 relating to barriers to the recognition of dementia, were identified using electronic databases MEDLINE, EMBASE, and psycINFO. Exclusion criteria included non-English language, studies about pharmacological interventions or screening instruments, and settings without primary

care. Eleven empirical studies were found: 3 quantitative, 6 qualitative, and 2 with mixed methodologies. The main themes from the qualitative studies were found to be:

- Lack of support,
- Time constraints,
- Financial constraints,
- Stigma,
- Diagnostic uncertainty,
- Disclosing the diagnosis.

The authors concluded that much still needed to be done in the way of service development and provision, GP training and education, and the eradication of stigma attached to dementia, to improve the early detection and management of dementia.

Shaw 2014 ⁽²⁰⁾

This 2014 systematic review and meta-analysis published in the *Annals of Internal Medicine* investigated the effects of Nurse-Managed protocols in the Outpatient management of adults with chronic conditions. Although not specifically investigating patients with dementia (the study looked at adults with diabetes, hypertension, and hyperlipidemia), many of the themes and concepts explored are potentially generalisable to people with dementia and the findings are pertinent to this report.

The authors used MEDLINE, the Cochrane Central Register of Controlled Trials, EMBASE, and CINAHL from January 1980 through January 2014. The search, appraisal and meta-analyses are robust and clearly set out.

The authors concluded that a team approach that uses nurse-managed protocols may have positive effects on the outpatient management of adults with chronic conditions, with nurse-managed protocols in the studies examined having a consistently positive effect on chronically ill patients.

Reilly Cochrane 2015 ⁽²¹⁾

This 2015 Cochrane review evaluated the effectiveness of case management approaches to home support for people with dementia, from the perspective of the different people involved (patients, carers, and staff) compared with other forms of treatment, including 'treatment as

usual', standard community treatment and other non-case management interventions. Standard Cochrane methodologies were used and will not be explored further here.

13 RCTs involving 9615 participants with dementia were included in the review. Case management interventions in studies varied. There was a low to moderate overall risk of bias, with 69% of studies at high risk for performance bias.

The authors concluded that there is some evidence that case management is beneficial at improving some outcomes at certain time points, both in the person with dementia and in their carer. However, there was considerable heterogeneity between the interventions, outcomes measured and time points across the 13 included RCTs. There was some evidence from good-quality studies to suggest that admissions to care homes and overall healthcare costs are reduced in the medium term; however, the results at longer points of follow-up were uncertain. There was not enough evidence to clearly assess whether case management could delay institutionalisation in care homes. There were uncertain results in patient depression, functional abilities and cognition. Further work should be undertaken to investigate what components of case management are associated with improvement in outcomes. Increased consistency in measures of outcome would support future meta-analysis.

Randomised Studies

Meeuwsen ⁽²²⁾

This randomised controlled trial has been published in the BMJ compares the effectiveness of treatment and care provided by memory clinics and GPs. The aim was to see if it was worth the extra time and expense to send patients on to memory clinics, rather than simply care for them in primary care. Memory clinics have been shown to be effective as diagnostic facilities, but are they also effective for post-diagnosis treatment and care?

The study took place in the Netherlands where 175 community-living patients with a recent diagnosis of mild to moderate dementia were randomised to receiving care either from a memory clinic or from their GP.

The outcomes of interest were:

- Quality of life
- Burden of care

The researchers found that:

1. The quality of life of the patients in the memory clinic group was 0.5 (95% confidence interval -0.7 to 1.6) points higher than in the GP group
2. Caregivers' burden was 2.4 (-5.8 to 1.0) points lower in the memory clinic group than in the general practitioner group

The authors concluded that no evidence was found that memory clinics were more effective than general practitioners with regard to post-diagnosis treatment and coordination care for patients with dementia. Without further evidence on the effectiveness of these modalities, other arguments, such as cost minimisation, patients' preferences, or regional health service planning, can determine which type of dementia care is offered.

The study is well conducted and robust, but has a number of weaknesses worth noting:

- They recruited patients only from memory clinics so the study population may not be representative of the general population

- The study involved Dutch patients, so professionals in other countries may feel that the results are not generalisable to their own healthcare system
- The follow-up was only 12 months long, which may have missed many outcomes that develop more slowly over time with dementia
- The 'pragmatic' trial was not double-blind

Schwarzkopf ⁽²³⁾

This cluster randomised study assessed the financial impact of informal care amongst community-living dementia patients, the main objective being to analyse whether family counseling is an appropriate strategy to delay nursing home placement. The study observed over a two-years period 383 home-dwelling individuals with mild to moderate dementia in Germany . Participants were recruited via general practitioners

Taking a societal perspective, the authors found that dementia care for a home-dwelling patient amounts to around €47,747 per year, with non-cash item informal care covering 80% of this sum (health insurance expenditure totaled around € 13,400). Informal care costs rose disproportionately as disease progressed - in moderate dementia the corresponding amount exceeded the one in mild dementia by 69.9%, whereas costs for formal health care services differ by only 14.3%

The authors concluded that, due to valued informal care, costs of care for community-living patients with moderate dementia are significantly higher than for patients with mild dementia. Informal care is a non-cash item saving expenditures for professional care. To relieve social security system and family care- givers as well as to allow dementia patients to stay at home as long as possible, concepts fostering community-based dementia care and support to family caregivers need to be further developed.

Garand 2014 ⁽²⁴⁾

This 2014 randomised study published in the American Journal of Geriatric Psychiatry sought to evaluate the mental health effects of problem-solving therapy (PST) designed for caregivers of individuals with a recent diagnosis of MCI or early stage dementia. 73 caregivers were randomly assigned to PST or a comparator intervention (nutritional education).

The authors found that, relative to nutritional education, PST led to significantly reduced depression symptoms, particularly among early dementia caregivers. PST also lowered caregivers anxiety levels, and led to lessening of negative problem orientation.

The authors concluded that enhanced problem-solving skills, learned early after a loved one's cognitive diagnosis (especially dementia), results in positive mental health outcomes among new family caregivers.

Marshall 2014 ⁽²⁵⁾

This 2014 pilot randomised controlled trial compared changes in quality of life for participants with recently diagnosed dementia who were randomised to attend either a 'Living Well with Dementia' 10 week group therapy intervention or a waiting-list control.

Memory clinic staff with limited previous experience of group therapy were trained to lead 'Living Well with Dementia'. Fifty-eight participants, all of whom had received a diagnosis of Alzheimer's disease, vascular or Lewy body dementia within the previous 18 months, were randomised to receive either the intervention or treatment as usual (waiting-list control). Data collection occurred at baseline, within two weeks after the intervention finished and at 10-week follow-up.

For the primary outcome, measure of quality of life in Alzheimer's disease (QoL-AD), and secondary outcome, self-esteem, there was some evidence of improvement in the intervention group compared to the control group. There was, also, evidence of a reduction in cognitive functioning in the treatment group compared to the control.

It should be borne in mind, however that these results were obtained in the context of a pilot and not a definitive study and as such should be treated with caution.

Menn 2012 ⁽²⁶⁾

This cluster randomised trial (extension of Schwarzkopf above) analysed the effectiveness and cost impact of three management strategies for dementia care in the general practice setting. 390 community-dwelling patients aged 65 years or older with mild to moderate dementia and their caregivers were enrolled via 129 general practitioners in Germany. The division into arms (A, B and C) was as follows:

Step 1 - Training of GPs in dementia care. To ensure that patient inclusion did not differ systematically across intervention groups, GPs in all study groups A, B and C participated in a

training course on dementia diagnosis that covered basic information about dementia, anamnesis and physical examination, laboratory diagnostics, and psychometric tests. GPs were then informed to which study arm they had been randomised.

Group A - Control. In Group A, drugs and nonmedical treatment options were not part of the training, and so this level of knowledge served as a proxy for the general status quo. This group served as a control group in which patients received usual care.

Groups B and C - Recommendation of support groups and family counseling. In addition, GPs recommended caregiver counseling beginning either at baseline (study arm C) or after the 1-year follow-up (study arm B).

The primary study end point was time to institutionalisation over 2 years. Secondary end points included cognitive functioning, activities of daily living, burden of care-giving, and health-related quality of life after 2 years.

After 2 (4) years, 12% (24%) of the patients were institutionalised and another 21% (35%) died before institutionalization. No significant differences between study groups were observed with respect to time to institutionalisation after 2 and 4 years (P 0.25 and 0.71, respectively). Secondary end points deteriorated, but differences were not significant between study groups. Almost 80% of the health care costs were due to informal care. Total annual costs amounted to more than €47,000 per patient and did not differ between study arms.

Non-Randomised Studies

Abley 2013 ⁽²⁷⁾

A 2013 qualitative study designed to explore patients' and carers' views on what constitutes high-quality communication and information provision during diagnostic assessment in memory clinic services in three areas of England (Lead researcher is a Nurse Consultant). Interviews were undertaken with 27 people with cognitive impairment (13 with confirmed dementia) and 26 carers (20 matched pairs). Comparative analysis of interview transcripts was undertaken on a constant rolling basis.

The authors found that people with memory problems undergoing assessment often have unmet information needs, **especially patients with a diagnosis other than Alzheimer's disease and those who do not receive a diagnosis**. Patients wish to be kept informed about both the assessment and its outcomes. Some have unrealistic expectations of the process (expecting assessment and diagnosis to be complete in two weeks) and some experience what appear to be long delays (over 12 months) in receiving results. Most appreciated clear and honest communication about any diagnosis. Post-diagnostic groups, organised by local memory services, afford opportunities to learn practical strategies and gain informal peer support. **Voluntary organisations may be an essential source of information.**

Manthorpe 2013 ⁽²⁸⁾

This 2013 study published in the British Journal of General Practice aimed to increase understanding of the experiences of people developing dementia and of their carers, to inform practice and decision making. The authors undertook both retrospective and prospective qualitative interviews with participants recruited from four memory clinics in London, the Northwest and the Northeast of England. 27 individuals with memory problems and 26 supporters and carers were involved. Interviews explored referral pathways, assessment processes, disclosure of the diagnosis, experiences of being prescribed medication to help with symptoms, and issues of risk and decision making.

The authors found that **few participants experienced the process of memory assessment as patient-centered**. Where assessment processes were lengthy and drawn out, participants experienced considerable uncertainty. Many experienced tests and assessments as distressing,

sometimes in settings that were perceived as alarming or potentially stigmatising by association. Information provision and communication were variable and practitioners were not always thought to help people to make sense of their experiences.

The authors concluded that the transition from the early stages of cognitive impairment is not straightforward, with much uncertainty and waiting. **Primary care practitioners may be better able to provide tailored support to individuals and their carers during this time if they are aware of what patients are anticipating and are informed about the diagnostic ‘journey’ by the insights of those who have experienced it.**

Pimouguet 2014 ⁽²⁹⁾

This 2014 study published in the journal *Alzheimer’s and Dementia* reflects the fact that, although early dementia care has been hypothesised to benefit both patients and carers, evidence-based benefits are lacking and so they undertook to investigating benefits for newly demented persons according to their pattern of accessing to care in the “real life”.

The authors examined the relation between initial pattern of accessing care and survival of people with dementia in a large prospective population-based cohort of incident dementia cases. They assessed patterns of accessing care for cognitive complaint at the early beginning of dementia when incident cases were screened, classifying patients into three categories:

1. No access to care
2. General practitioner consultation
3. Specialist consultation.

The authors then assessed the association between category and mortality, adjusting for socio-demographical and clinical characteristics.

Two hundred and fifty-three incident dementia participants were screened at the 2 year or 4 year follow-up, split across the three categories as follows:

- 87 patients had not consulted a physician for cognitive problems.
- 86 reported a cognitive problem only to their GP
- 80 had consulted a specialist.

Mean duration of follow-up after incident dementia was 5.1 years, during which 146 participants died. After adjustment on potential confounders, participants who had consulted a specialist early in the disease course presented a poorer survival than those who did not consult any physician. There was no significant differential survival profile between participants who

accessed their GP and those who did not access care, suggesting that **neither accessing a specialist or a GP improved survival of new dementia cases.**

van den Bussche 2011 ⁽³⁰⁾

This 2011 German case-control study published in BMC Health Services Research set out to analyse the referral processes from general practitioners to specialists and between specialists for dementia patients in the time periods before, during and after diagnosis.

1,848 people with incident dementia aged 65 years and above and 7,392 matched controls were compared over a 2 year period covering pre-diagnosis, diagnosis and post-diagnosis.

The authors found an increase in referrals of 30% in the diagnosis period, mainly from general practice to neuropsychiatry and from there to radiology. Referrals to clinical chemistry and other disciplines for dementia- specific reasons were negligible. 34% of incident cases had at least one contact with a neuropsychiatrist during the year of incidence, and the majority of them visited this specialist repeatedly during that year. Only a minority (13.5%) of patients were referred to radiology for imaging. Referrals to other specialists declined whereas self-referrals did not increase.

The authors concluded that referral rates to relevant were are far less frequent than proposed in applicable guidelines and that the forthcoming increase of the number of patients with dementia will need a more structured and more effective interface of primary and specialist care and the corresponding referral and co-treatment processes. Helpfully, they also suggest that guidelines should not only deal with diagnostic procedures and therapeutic options but also consider questions of applicability in daily clinical practice and propose effective organizational models of care provision.

Wellbeing Cafes

Originally pioneered by Dr Bère Miesen in the Netherlands in 1997, the dementia café model is a setting in which *“people with dementia and their carers can come together in a friendly and comfortable place to socialise and get information and support”*. In his dealings with people with dementia and their families, Miesen observed that talking about the condition/illness, even between partners or within a family was a taboo subject. Making dementia discussable and providing information about it and its consequences is very important for the acceptance of the condition. Miesen recognised that it would be good if all those involved could meet each other

in a relaxed forum to exchange experiences and talk about dementia ⁽³¹⁾. A broad range of people can attend the cafes – people with dementia, their families, relatives, friends, health and social care professionals, paid carers, students and volunteers. The cafés can cover a range of activities including the more formal element such as presentations or informal elements of music, refreshments and socialising.

There is a limited amount of literature available on the Alzheimer Café model which in turn is mainly descriptive in nature ⁽³²⁾. Mather (2006) asserts that the cafes are particularly beneficial to people in the early stages of dementia ⁽³³⁾. The theory suggest that by encouraging people to find strategies to manage the cognitive changes of dementia, people with early stage dementia are encouraged to regain contacts within their community and to take up activities that they had previously enjoyed or to try new activities.

Further variations on the model have emerged and are described in the literature, for example Sweeting describes a ‘café event’ where a once off, whole day event was organised around the theme of “every day matters”. It involved a very broad range of inclusive and participative activities highlighting the value of everyday life and the enjoyment that is to be had ⁽³⁴⁾. In Southampton, funding was secured for a dementia café which was renamed the Woodside Supper Club. The club offered the person with dementia and their carer the chance to enjoy dinner together ⁽³⁵⁾.

It is clear from the literature that the frequency and nature of meetings varies but the monthly interval is the most popular choice. The timing also varies –with some held during the day, others in the evenings, some at weekends, others on week days.

There are many other ‘support group’ type models reported in the literature, with a growing number of user-led groups. These models share elements of the Alzheimer café model in terms of their philosophy of addressing the challenges of living with dementia as well as looking at people’s need for socialising with support.

Discussion

Summary of Key Findings from Evidence Review

Guidance

- Patients who continue on treatment with AChEIs/Memantine should be reviewed regularly
- People newly diagnosed with dementia and their carers should receive written and verbal information about their condition, treatment and the support options in their local area.
- People with dementia should have an assessment and an ongoing personalised care plan,
- Carers of people with dementia should be offered an assessment of emotional, psychological and social needs and receive tailored interventions identified by a care plan
- People with dementia should be assessed in primary care to identify and plan palliative care.
- People with dementia should be enabled, to take part in leisure activities during their day
- In order to do proper follow-up, GPs and practice nurses should have the same level of knowledge and confidence as those who assess patients and commence treatment.
- Systematic follow-up is needed, but not necessarily in a specialist hospital clinic.
- Patients with vascular dementia discharged after diagnosis as AChEIs are not indicated must not lose touch with support agencies and they may feel very alone in their predicament
- There is a need for control strategies against vascular disease and unhealthy lifestyle habits
- Patients should be seen at least every 6 months to evaluate for functional/cognitive change
- Voluntary organisations may be an essential source of information.

Research Evidence

- High level, randomised evidence on PDS and MFU is sparse.
- Limited RCT evidence finds no evidence memory clinics are better than GPs with regard to PDS/MFU, and that costs of care for moderate dementia are higher than for mild dementia.
- Informal care is a non-cash item saving expenditures for professional care
- Community-based dementia care and support to carers needs to be further developed.
- There is much to be done in service development and provision, GP training and education,
- There is some evidence that case management is beneficial at improving some outcomes at certain time points, both in the person with dementia and in their carer
- People with memory problems undergoing assessment often have unmet information needs, especially patients with a diagnosis other than Alzheimer's disease and those who do not receive a diagnosis.
- Wellbeing Cafes can be a valuable community resource for both patients and carers

Defining and Describing Post-Diagnostic Support and Follow-up

What do we mean by Post-Diagnostic Support?

Many patients and carers complain of a feeling of being left hanging once a diagnosis of dementia has been made ^(x). In addition, the nature of the diagnostic process of itself can have a fundamental role in determining the type and extent of support required. Formal and scheduled follow up of patients has a broad crossover, and follow up appointments give patients the opportunity to express concerns and needs, as well as asking questions

Before considering and defining PDS and MFU, we should consider both:

1. The **need** that leads to their provision
2. The **outcomes** that we want to commission

Defining the Need

What generates need?

NICE Quality Standard 1 – Dementia ⁽¹¹⁾ outlines sources of need in dementia as follows:

'Individual needs' arise from:

- Diversity, including gender, ethnicity, age (younger or older), religion and personal care.
- Ill health, physical disability, sensory impairment, communication difficulties, problems with nutrition, poor oral health and learning disabilities.
- The life story and preferences of people with dementia and their carer/s (where possible) including diet, sexuality and religion.
- Maintaining independence.
- Information needs.

For the purposes of this report, a simple framework is presented below. Ideally PDS and MFU would be designed, commissioned and provided in a way that can satisfy this range of needs as they arise in a defined population (e.g. a primary care practice or CCG area).

Framework for Defining Needs Felt and Expressed by People with Dementia

Clinical Needs

- Psychological/Psychiatric
- Physical - Pain
- Risk reduction (need to take medication, secondary prevention in vascular dementia)
- Access to specialist care - mental health, physical health, occupational therapy, physio. etc.

Functional Needs

- Communication – of need, distress, happiness, love
- Nutrition
- Hydration
- Taking medications

Social Needs

- Needs assessment
- Named contact
- Schedule of support
- Daily living - social and physical activities to prevent social isolation, depression or anxiety
- Risk reduction
- Financial
- Legal/POA Assessment of decision-making ability
- Cultural and Spiritual
- Advocacy needs
- Access to specialist care

Learning and Educational Needs

- Range and location of support available
- Prognosis and other important clinical information
- Who to contact and when

Crisis Needs

Crisis care - in a crisis situation, receives respite care in an environment that is familiar to them, wherever possible.

Palliative Care Needs

- Advanced Care Plans
- Rapid diagnosis of palliative needs
- Rapid access to generalist and specialist palliative care

Defining Outcomes

One of the key elements of the changes in health and social care over the last five years has been a firm sharpening of the focus on *outcomes* as opposed to process and activity measures ('outputs'), largely underpinned by the realisation that to deliver truly patient-centred care we must focus on what matters most to the patient and their carers.

In theory, outcome based commissioning should focus not on activities and processes but on results. For example, rather than aiming to ensure that *"our MATS service sees 50 patients per week"*, we could aim to have *"50 people diagnosed with dementia, given appropriate advice and support and have management plans agreed and communicated to the person's GP"*.

So, the point of an outcomes-based approach is to shift the primary focus from how a service operates (what it does) to the good that it accomplishes (what it achieves) – being careful to maintain the quality of the processes as we do so.

The publication of three key outcomes frameworks for health and social care has demonstrated the national commitment to commissioning outcomes. The three outcomes frameworks are:

- The Public Health Outcomes Framework
- The Adult Social Care Outcomes Framework
- The NHS Outcomes Framework

The outcomes frameworks set out high level areas for improvement, alongside supporting indicators, to help track progress without overshadowing locally agreed priorities. They will help to ensure that common challenges are highlighted at the local level across the health and care system, informing local priorities and joint action, whilst reflecting the different accountability mechanisms in place.

The three outcomes frameworks are together intended to provide a focus for action and improvement **across the system**. Each of the outcomes frameworks include the main outcomes that represent the issues across health and care that matter most to all of us.

So, in this respect, a key element of the questions asked in this report must be to consider:

- **What are PDS and MFU trying to achieve?**
- **What outcomes do we want to commission?**

What are the key outcomes in Dementia?

A key study by Bamford and Bruce in 2001 defined outcomes important to people with dementia as follows ⁽³⁶⁾:

‘Quality of life outcomes centre on having access to normal activities and patterns of life in ways that maximize feelings of choice and control and encompass social, physical and emotional needs’.

- Access to social contact and company Having a sense of social integration
- Access to meaningful activity and stimulation
- Maximising a sense of autonomy Maintaining a sense of personal identity Feeling safe and secure
- Feeling financially secure
- Being personally clean and comfortable
- Living in a clean and comfortable environment.

‘Service-process outcomes are concerned with the desired impacts of service delivery’.

- Having a say in services
- Feeling valued and respected
- Being treated as an individual
- Being able to relate to other service users.

More recently, in the National Dementia Declaration for England, people with dementia and carers described seven outcomes that are most important to their quality of life, many of which echo common themes from other research ⁽³⁷⁾. These outcomes are perhaps best viewed as underpinning themes that should be reflected in the process of commissioning and providing services, with service specifications and contracts reviewed to assess their ability to deliver them.

The outcomes are:

1. I have personal choice and control or influence over decisions about me.
2. I know that services are designed around me and my needs.
3. I have support that helps me live my life.

4. I have the knowledge and know-how to get what I need.
5. I live in an enabling and supportive environment where I feel valued and understood.
6. I have a sense of belonging and of being a valued part of family, community and civic life.
7. I know there is research going on which delivers a better life for now and hope for the future.

Given this framework of need and desired outcomes outlined above, PDS and MFU might, **from a commissioning and provision perspective**, be broadly classified as follows:

- **Clinical**
 - Scheduled
 - Unscheduled
 - Crisis
 - EOLC
 - Information
- **Social**
 - Scheduled
 - Unscheduled
 - Crisis
 - EOLC
 - Information
 - Socialising with others
- **Advocacy and opportunity to influence services**
 - Commissioners
 - Providers
 - Health and Wellbeing Boards
- **Safeguarding**

Informal Care

In many respects, the “Elephant in the Room” here is that the large majority of PDS is not provided by commissioned services, but by informal carers, predominantly family members.

Dementia costs the UK economy £23 billion per year, with the single greatest burden (£12.4 billion per year) being met by unpaid carers⁽³⁸⁾. Informal care is estimated to involve 1.5 billion hours per year of unpaid care provided to dementia patients living in the community.

The German IDA study referenced above found that informal care costs rise disproportionately as disease progresses – costs in moderate dementia exceeding those in mild dementia by 69.9%, whereas costs for formal health care services differ by only 14.3%⁽²³⁾. This further emphasises the importance of Statement 6 of NICE Quality Standard 1 - that carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs, and also Statement 10 – that carers of people with dementia have access to a comprehensive range of respite/ short-break services that meet the needs of both the carer and the person with dementia.

The Bunn review⁽¹⁸⁾ outlines in detail the enormous impact that a diagnosis of dementia has on family members and carers, with Manthorpe’s study emphasising the importance of a high quality process of diagnosis in empowering carers to undertake what can be new and confusing roles⁽²⁸⁾. There are a number studies investigating methods of improving the coping skills and quality of life of carers of people with dementia, with Garand’s randomised study describing an effective approach to improving carer coping skills through problem solving techniques⁽²⁴⁾.

We should also consider the fact that, although family members who care for relatives with dementia perform an important service and save the healthcare system a considerable amount of money, many do so at substantial cost to themselves. Carers have a higher rate of depression, anxiety, impaired health, and mortality than adults without this caring role⁽³⁹⁾ - a 2010 systematic review of the published research on factors determining the impact of care-giving on caregivers of elderly patients with dementia found that depression occurs in one in three of caregivers and it occurs more frequently in those who care for patients with dementia than in caregivers of patients with other chronic illnesses⁽⁴⁰⁾.

In respect of broader health and wellbeing, research estimates that up to 80% of informal carers of people with dementia have at least one chronic illness, with 60% reporting 2 or more⁽⁴¹⁾. In addition, carers were more likely to be older and unemployed⁽⁴¹⁾.

Follow-up

The key questions being posed currently in respect of formal Follow up of people with dementia are:

- Where the formal process should take place
- How often follow up is required
- By whom it should be conducted.

The Meeuwsen study described above is perhaps the definitive UK study at the moment, being a robust randomised study with a core health economic component ⁽²²⁾. The authors are forward in their conclusion that no evidence was found that memory clinics were more effective than general practitioners with regard to post-diagnosis treatment and coordination care for patients with dementia. In the absence of such evidence, they pragmatically defer to other decision-making arguments such as cost minimisation, patients' preferences, or regional health service planning, to determine which type of dementia care is offered. It is to be expected that all three will take a prominent role in planning over forthcoming years.

NICE Clinical Guideline 42 ⁽¹⁰⁾ makes recommends that memory assessment services that identify people with MCI should offer follow-up to monitor cognitive decline and other signs of possible dementia in order to plan care at an early stage. This feels a rather thin recommendation in the wider context of dementia follow up. The guideline also recommends that patients who continue on AChEI treatment should be reviewed regularly using cognitive, global, functional and behavioural assessment, with treatment reviewed by an appropriate specialist team, unless there are locally agreed protocols for shared care.

The NHS England guidance "Dementia Revealed" ⁽¹³⁾ states that in order to do "proper" follow-up, GPs and practice nurses should have the same level of knowledge and confidence as those who assess patients and commence treatment. Interestingly, this guidance states that an identified weakness is that patients with vascular dementia are generally discharged after diagnosis because AChEI drugs are not indicated, thus losing touch with support agencies and they may feel very alone in their predicament. This suggests that AChEI follow up may currently be the default and bedrock of FU for dementia itself.

The NHS England document makes a number of further specific statements on follow up, including that, “systematic” follow-up is needed, but not necessarily in a specialist hospital clinic, and that it should be initiated by the practice and patients who do not attend should be contacted and offered follow-up at home. This strongly points towards a primary care based model of MFU, with referral to specialists as required, although within the local constructs of AChEI monitoring protocols.

Perhaps the most important statement within the NHS England document is that **“there needs to be a regular MDT meeting with the lead GP”**, this feels an excellent aspiration for a scheduled, needs-led FU process.

The BMJ Best Practice report ⁽¹⁴⁾ recommends that patients should be seen at least every 6 months to evaluate for functional and cognitive change, with issues such as daily medication use, functional status, comorbid illnesses, new signs and symptoms, carer burden, and need for future respite care or nursing home placement should be discussed. This is also the only report that has highlighted driving safety, recommending that driving status should be reassessed at least every 6 months.

Within the peer-reviewed literature, the review by Koch ⁽¹⁹⁾ cites lack of support, time constraints, financial constraints, stigma and diagnostic uncertainty as barriers to the diagnosis and management of dementia in primary care. If a primary care based system of MFU is to be pursued, these will need to be addressed robustly. Last year’s study by Pimouguet ⁽²⁹⁾ observed that equal proportions of patients receiving a diagnosis of dementia either did not consult a clinician, consulted a primary care clinician or consulted a specialist. Mean duration of follow-up after incident dementia was 5.1 years, during which 146 participants died. After adjustment on potential confounders, participants who had consulted a specialist early in the disease course presented a poorer survival than those who did not consult any physician and there was no significant differential survival profile between participants who accessed their GP and those who did not access care, suggesting that neither accessing a specialist or a GP improved survival of new dementia cases. Given that this is an observational study, it should be viewed as informative rather than directive, nonetheless its findings are revealing.

New research across all disease areas is posing the question of whether the most productive visit after certain surgeries or procedures is one in which the patient, by design, doesn't show up

at the doctor's office. For example, one study reported that patients with open hernia repair or laparoscopic cholecystectomy patients who followed up their surgery with a phone call instead of a doctor's visit had the same rate of complications of those who attend outpatients, with almost all patients who did their follow-ups by phone saying they were very satisfied with the experience ⁽⁴²⁾. Most of them, given the option, asked for phone calls over personal visits. Physicians recommended that the strategy should be limited to any visit where a doctor would not be expected to have to see or touch a patient to ascertain his or her condition, it is difficult to consider dementia in this context, particularly as the conversation is likely to be with a carer.

The Importance of Multimorbidity

Clearly, dementia is a disease occurring almost exclusively in older people. There are also a great number of additional diseases which are characterised by having an increased incidence and prevalence, sometimes markedly, in the older years. Common sense dictates, therefore, that we should consider how these diseases ('comorbidities') occur in patients with dementia where their impact is likely to be significant due to the commonality of age.

As people get older, their probability of being diagnosed with multiple diseases ('multimorbidity') rises considerably. A recent large UK study found that the prevalence of people with more than one disease increases substantially with age and is present in most people aged 65 years and over, the age at which dementia is most prevalent ⁽⁴³⁾. In the UK the number of people with three or more long-term conditions is predicted to rise from 1.9 million in 2008 to 2.9 million in 2018 ⁽⁴⁴⁾. Set alongside the projected increases in numbers of people with dementia, we can start to see the potential for significant multiple comorbidities to occur in people with dementia in Yorkshire and the Humber. This is of importance not only to people with dementia and their carers, but to health and social services as well, particularly as there is good evidence that the number of conditions can be a greater determinant of a patient's use of health service resources than the specific diseases involved themselves ⁽⁴³⁾.

Given the issues and evidence outlined above, it is clear that, as we consider PDS and MFU, we should give consideration to the needs of people with dementia and their carers in the context of all of their medical needs, not just those relating specifically to their dementia. It is important to reinforce here that NICE Clinical Guideline 42 ⁽¹⁰⁾ recommends that *"at the time of diagnosis of dementia, and at regular intervals subsequently, assessment should be made for medical comorbidities and key psychiatric features associated with dementia, including depression"*.

From a practical perspective, when considering PDS and MFU, it is important to think of the effects that comorbidities have on people with dementia and their quality of life, particularly in respect of those impacts that lead to deterioration in health or hospital admission. Research conducted on the impact of comorbidities in people with dementia has found that symptoms and health risks caused by comorbidities are common and wide ranging. Studies have found, in particular:

- Undernutrition and weight loss ⁽⁴⁵⁾
- Urinary incontinence ⁽⁴⁶⁾

- Urinary tract infection ⁽⁴⁷⁾
- Hearing and visual impairment ⁽⁴⁶⁾
- Pain ⁽⁴⁸⁾
- Falls ⁽⁴⁹⁾

There is some evidence that certain comorbidities may be underdiagnosed in people with dementia, in particular depression which is a growing problem among older people.

Implications for this report

This section throws an important light on a key issue in the important area integration of care to address the health and social care needs of people with dementia and their carers. It is important to understand that dementia will affect how their other long term conditions are managed and this needs to be taken into account by primary care commissioners and providers as these patients can be 'missed' or 'exempted' by the Quality Outcomes Framework as they are house bound with poor access to service.

Any question posed in relation to designing, commissioning and providing PDS for people with dementia should be considered in the context of multimorbidity. Any opportunity to better identify and manage comorbidities without delay should be embraced. This may also engender greater collaboration and promote the integration agenda through clinical specialties, in particular holistic characterisation of patients, minimising contact burden and confusion.

People with multimorbidity can also have more difficulties with fragmentation of care as much specialist care is focused on treatment of one disease. They are also likely to be prescribed several drugs, each of which is recommended by a disease-specific guideline, with overall drug burden difficult to manage and potentially harmful ⁽⁵⁰⁾.

Ideally, each patient would have a named clinician responsibility for **care coordination**, with both pharmacological and nonpharmacological management including optimal intervention and risk factor modification simultaneously for all diseases.

Clinical pathways and systems of care for people with dementia should develop to reflect the fundamental ubiquity of multimorbidities.

Epidemiological Considerations

The overall prevalence of dementia (i.e. diagnosed plus undiagnosed) in the over 65 population in the UK has previously been thought to be 8.3%, however this estimate has recently been reduced (using newer information from the key study that gave the initial estimate) to **6.5%** ⁽⁵¹⁾. If we apply this figure to the over 65 population in Yorkshire and the Humber it would suggest an overall prevalence (i.e. diagnosed plus undiagnosed) of around **21,000** cases across the District.

One important caveat with these estimates is that it should be recognised, however, that the observed fall in prevalence in the study was driven by non-care settings and was not noted within people in care settings, where prevalence actually increased ⁽⁵²⁾. The prevalence of dementia within care settings was estimated to have increased from 56% to 70%. This implies that the observed reduction in prevalence nationally will not have been transferred into the care service sector locally. The authors of the report suggest that the observed reduction in prevalence may be due to people living generally more health lifestyles as time progresses.

Undiagnosed Dementia

As with any illness, there can broadly be thought to be two groups of people, those who have been diagnosed with the illness, and those who have the illness, but have not yet been diagnosed. This is the case with dementia, where a number of key issues are relevant:

- The early and accurate diagnosis of dementia is essential for optimal disease management. Early detection increases the likelihood of initiation of pharmacological and behavioural interventions, and the identification and management of the treatable cardiovascular factors underpinning vascular dementia.
- Those people who have dementia but are undiagnosed may not therefore be receiving support and treatment. This threatens their quality of life
- The longer the duration between onset of symptoms and diagnosis, the poorer their response to eventual treatment and care is likely to be
- It is recognised nationally that diagnosis rates are too low¹⁾, with less than half of people living with dementia in the UK having a diagnosis, and large differences between diagnosis rates in different areas. This issue is addressed below

- People with undiagnosed dementia are more likely to ^(53, 54):
 - Be older
 - Live alone
 - Be less likely to have a spouse caregiver
 - Perform better on cognitive testing

Ethnicity

People from Black and Minority Ethnic Communities tend to access dementia services later, which can have a negative impact on families as they may have struggled for longer without support ⁽⁵⁵⁾.

NICE Guidance on Dementia clearly emphasises that health and social care staff should identify the specific needs of people with dementia and care plans should record and address these needs ⁽⁵⁶⁾.

It is noteworthy that 6.1% of all people with dementia among BME groups are early onset, compared with only 2.2% for the UK population as a whole ⁽⁵⁷⁾.

It is broadly acknowledged that ethnic minority group status can negatively impact upon the uptake of services for both people from ethnic minority groups and younger people with dementia ⁽⁵⁸⁾. However, a recent English study of the impact of ethnicity on health seeking behaviours found that health seeking behaviour did not vary by ethnic density ⁽⁵⁹⁾.

Dementia Subtypes

Dementia diagnostic subtype, the presence of cognitive fluctuations and some neuropsychiatric symptoms (psychosis and mood disturbance) did predict carer stress (all at $p < 0.01$) but age, gender and severity of cognitive impairment did not (all $p > 0.33$). Carers of people with dementia with Lewy bodies (DLB) and Parkinson's disease dementia (PDD) experienced more stress than those caring for patients with Alzheimer's disease and vascular dementia. Carer stress was associated with higher levels of psychosis, mood disturbances, daytime sleep and cognitive fluctuations in the person with dementia ⁽⁶⁰⁾.

The Voluntary and Third Sector

The Voluntary and Third Sector plays a crucial role in providing PDS through dementia services in the community. Some organisations serve a specific dementia client group and, although they may make a charge for their services, they are non profit-making.

It would not be possible here to explore the panoply of services available, rather the largest and most influential of these services in the UK, The Alzheimer's Society, is described to exemplify the nature of voluntary support and services available in the community.

Alzheimer's Society

The Alzheimer's Society is the primary voluntary sector organisation offering services to people with dementia primarily living in the community, as well as carers, families and professionals.

The aim of services is to:

- Through the Dementia Advisor service - ensure all people newly diagnosed with dementia, their carers and families get access to independent information about their condition, what services are available and what things they should consider in planning for the future. Referrals are usually made directly to the service at diagnosis by a Consultant.
- Through the Dementia Support Worker service - ensuring people get continued access to information and support as required through an allocated casework system. Typically enquiries would include strategies for coping with behavior changes, dealing with stress, signposting to partner agencies or back into statutory services and identifying and referring to specific support packages such as respite and daycare.
- Through the Peer Support service - provide activities and groups such as singing groups, cafes and discussion groups in order to provide both enjoyment and the opportunity to develop friendship and support networks with people in a similar situation. At the time of writing the service is looking at increasing its activity based on the finding of a council commissioned report into peer support activity carried out by the Society. At the time of writing all activities are free of charge or accept a voluntary nominal donation.
- Through the Dementia Friendly Communities project - to ensure that the public are better informed about dementia and that local communities are encouraged and

equipped to better support people living with dementia, carers and families to stay active community participants.

- There are also training courses offered to carers that run throughout the year. These are
 - CrISP 1 (Carers Information and Support programme) - a programme for carers of people diagnosed with 12 months, this is an in depth continuation of the information provided by the Dementia Advisor Service.
 - CrISP 2 – which is for carers of people in which the condition has progressed beyond the initial stages and looks at the issues this raises, available support and planning for the future.
 - IPSAF (Information Programme for South Asian Families), this is similar to CrISP 1 but information is delivered a culturally sensitive way using appropriate examples.

Services are funded through a mixture of fundraised income from the society and grant and income from commissioners.

There is a rich wealth of Voluntary and Third Sector services supporting people with dementia and their carers. It would not be possible to describe all of them and what they provide here.

Clearly the Voluntary and Third Sector occupies an enormous role and bears a significant responsibility in supporting people with dementia and their carers. It would not be possible to consider dementia in the context of strategic and operational planning without explicitly acknowledging and incorporating activity from this sector.

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