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Dementia – post diagnostic support

Introduction, contents and context

Introduction

This document aims to provide local commissioners with an overview of post-diagnostic support for people with dementia and their carers including examples of good practice, resources to support local organisations and sources of further information.

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The context

The current estimated prevalence of dementia in the north is 190,000, of whom 115,000 have received a diagnosis. The prevalence of dementia is expected to double in the next 30 years and as many people with dementia also have a family or carer needing support, it is vital that high quality, effective services are organised to cope with this increasing demand.

There is no cure for dementia but care is important and access to post diagnostic support, not just for the person with dementia but also for their families and carers, is essential. Care needs to be ongoing, not simply in the immediate post-diagnosis period, and must be able to adapt to the changing needs of the person as the disease progresses.

The evidence base for the clinical and cost effectiveness of this support is growing which includes psychosocial interventions such as cognitive stimulation therapy, medication for Alzheimer's disease and carer support interventions (BMJ 2013; 347).

This map sets out what we currently know about current dementia care, support and research across the country.

Post-diagnosis support

"Joined-up, or integrated, services are still the exception, rather than the norm. Dementia care and support is still too focused around structures and systems, rather than the individual needs of the person and their carer. We recognise the importance of spreading best practice of integrated dementia care and support, as well as being a continuing priority across health, social care and wider local government."

Prime Minister's Challenge on Dementia: Year Two update

Post-diagnosis there are a range of simple things that can be done in primary care to help support patients and their carers during regular reviews and as the need demands:

- Signposting – practices should have an up to date directory of locally available services.
- Reviewing medication
- Advising about driving
- Advising about power of attorney arrangement
- Using strategies such as appointment reminders, alerts for reception to offer additional assistance and other practical adjustments (e.g. helpful signage)
- Considering referral for advice regarding benefits
- Ensure accurate coding of the dementia diagnosis
- Consider allocating a named GP
- Documenting the contact details of carers and next of kin and establishing if there is consent to discuss the case with any of these individuals. Who should be the point of contact for arranging appointments or giving information over the telephone?
- Advanced care planning
- Establishing consent for potential future vaccinations including flu
- Discuss carers support (including opportunities for carers education/training and respite)

CCGs may wish to consider the following three steps that will help support people with dementia and their partners or carers, these are:

1. developing a CCG dementia strategy (either stand alone, or part of the CCG strategic plan);
2. encouraging staff, patients and the public to become dementia friends; and
3. the CCG and its practices actively participating or establishing a local Dementia Action Alliance.

Developing a CCG dementia strategy

Integrated support for a person with dementia to live well should be managed within primary care, with specialist services advising and intervening as required. Managing dementia in specialist memory services alone can result in a fragmented, less responsive service.

People with dementia have the right to expect a certain standard of care which has been summarised in the following Dementia Action Alliance (DAA) statements:

- I was diagnosed early
- I understand, so I make good decisions and provide for future decision-making
- I get the treatment and support that are best for my dementia and my life
- Those around me, and looking after me, are well supported
- I am treated with dignity and respect
- I know what I can do to help myself, and who else can help me
- I can enjoy life
- I feel part of the community and I'm inspired to give something back
- I am confident my end of life wishes will be respected. I can expect a good death.
- I had the opportunity to take part in research

Commissioners might want to consider how their dementia strategy will help to deliver each of these expectations.

CCGs taking a strategic approach to dementia will help ensure that the appropriate range of services are being commissioned, that practices are clear about the local dementia pathways including the care and support that can be offered both immediately post-diagnosis, and on an ongoing basis.

The CCG need not have a stand-alone dementia strategy, the strategic approach could be described within the CCG's overall strategic plan.
Joint working with social care and the voluntary sector is essential to deliver comprehensive, joined up ongoing care. A clear strategy allows partner organisations and care providers to align with the CCG's intentions to ensure care is coordinated across a locality.

CCG Dementia Strategies

The key elements of a CCG dementia strategy might include:

- A needs based analysis for the local population
- Describing how services for patients will be coordinated and managed effectively within primary care, calling on specialist services for advice and interventions as required. Details of available evidence based services for onward referral.
- Committing to provide a named contact to provide one to one support to patients throughout their dementia. The CCG approach should define roles, such as dementia advisers, primary care community advisers, admiral nurses, or eldercare facilitators, and how they will work within a system to provide well managed care. People with dementia and their carers are too often left alone to manage with dementia and miss out on quite simple opportunities for information and peer support.
- Defining minimum standards for access to memory services and other relevant specialist services
- Guidance on the prescribing of dementia drugs
- A CCG strategy may wish to free up memory services from medication reviews and focus on the role of non-drug therapies and education. A post-diagnosis "living with dementia" group could be a routine part of the post-diagnosis offer and Cognitive Stimulation Therapy is a NICE-recommended non-drug treatment for mild / moderate dementia.
- Detailing the support on offer to help people to live well with dementia. This could be provided in an information prescription – see examples here

This support might include:

- 'dementia friends' sessions for family and friends;
- understanding and awareness in the community and universal service providers (libraries, shops, bus drivers...);
- help to stay safe and secure (things like doorstep crime and fire prevention, as well as gas escape and falls detectors etc);
- a well-being offer of creative / therapeutic activities (eg. singing groups, creative arts to maintain communication and social skills);
- advocacy at an early stage of the journey; planning around finances, wills, lasting powers of attorney including advance directives;
- carer support and breaks, and peer support.

The strategy should describe how the elements listed above will combine with the one to one support for people with dementia and their carers.

Resources to support the commissioning include:

- a commissioners checklist from London SCN
- Guidance for commissioners describing excellent provision in dementia care (from the South West SCN)

This is an example of a well structured CCG dementia strategy from Birmingham and Solihull.

Whilst this example is of a stand-alone dementia strategy, the strategic approach to dementia could also be described within the CCG's overall strategic plan (and reflected in Better Care Fund plans).

Dementia friends and Dementia Action Alliances

Encouraging dementia friends and dementia friendly communities

CCGs can take an important role in encouraging staff, patients and the public to become dementia friends. The Dementia Friends initiative is led by the Alzheimer's Society. Anybody can become a Dementia Friend. It involves understanding a bit more about dementia and the small things that can be done to help people with the condition. Dementia Friends also have a role raising awareness among colleagues, friends and family about the condition. To become a dementia friend people just need to watch this short video or join an information session in their area.

A dementia-friendly community is one in which people with dementia are empowered to have aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them.

CCG and Practices to form or join Local Dementia Action Alliances

The Dementia Action Alliance is a movement that aims to bring about a society-wide response to dementia. It encourages and supports communities and organisations across England to take practical actions locally to enable people to live well with dementia and reduce the risk of costly crisis intervention.

Regional Dementia Action Alliances have been developed to support more local dementia friendly communities and organisations. All organisations are able to join a Regional Alliance and support is on offer to help establish local Dementia Alliances where they do not already exist. For details of existing local Alliances and how to establish a local Alliance see the dementia action website.

Local examples

The following are examples of current practice in the north that may be of interest to commissioning colleagues to help stimulate local thinking on how post-diagnostic care might be delivered what would work best locally.

Dementia Strategy Group, Bradford

A city-wide Dementia Strategy Group has helped to shape a joined-up approach across health and social care commissioners and providers. A joint strategy has been developed, based on a thorough local needs assessment. Each organisation has a senior (Board/SMT level) champion for the dementia strategy. The Bradford strategic approach includes the following elements:

Dementia advisers (DA), commissioned from the Alzheimers Society to give information and support and help with planning with recently diagnosed people and their carers. People are referred at diagnosis (in primary, secondary or community care) to the Dementia Advisers who then make contact with patients and carers. After the DA visit people can access a Dementia Support Worker service for on-going support as required that can cover information, listening or support to access services, sort out issues and signposting to other organisations.

A multi-disciplinary **crisis intervention team** has been set up across Airedale, Wharfedale and Craven to work with people at risk of hospital admission or A&E attendance, including care planning and support.

Support to establish and raise the profile of **dementia friendly communities** in which people with dementia and their carers work alongside organisations, local community volunteers, shops, businesses and other stakeholders in a local area. People come together to identify what community support can be offered so people can continue to live in their own homes. They develop local initiatives to ensure the community is accessible, has an understanding of dementia and the needs of people in their area.

A **self care booklet** has been produced for people with dementia. It can be printed out from GP systems and given to patients at diagnosis and reviews, the booklet also details support available locally. Plans are also in place to establish a **website detailing local support services and groups.** For more details on self-care and prevention contact Tina.Butler@bradford.gov.uk

A 5 week **training programmes for carers** is offered across the district. There is good uptake for the course, with 6 courses having being run this year (each with approx. 15 people) by the Alzheimers Society.

There are a number of **peer support groups** such as dementia cafes (including a specific South Asian group) and an evening café for younger people with dementia, singing groups and a carers support group - incorporating a reminiscence session for their relatives. There is also a Relate **counselling service on offer for dementia carers**.

For details on Bradford's strategic approach contact simon.baker@bradford.gov.uk

Examples to stimulate local thinking

System One templates have been developed (following NICE) that guide Bradford GPs through the clinical pathway from diagnosis onwards, to link to the local directory of services and then signpost appropriately – including initiating advanced care planning discussions with patients/carers. The Yorkshire and Humber SCN have generic versions of the templates that can be adapted for other localities. **Contact:** Penny.Kirk@nhs.net and nicola.phillis@nhs.net

The Alzheimers Society also provides opportunities for people with dementia to influence the services they receive based on their experiences. **Contact**: Paul.Smithson@alzheimers.org.uk

Dementia Collaborative, Harrogate

All partners within the Harrogate area have worked together (under the umbrella of the Harrogate Dementia Collaborative) to improve service provision for people with dementia.

Improvements were targeted at areas identified by all the people involved in the work (health and social services staff, third sector representatives, patients and carers) at an initial workshop. The work resulted in better collaborative working between staff, better morale and measurable positive changes in all aspects of the dementia pathway.

Headline achievements include:

- Average waiting time for memory clinic appointments reduced from 74 days to 28 days.
- A 50 per cent reduction in the time from referral for assessment, for domiciliary care to start.
- Reduction in average length of stay for people with dementia admitted to acute hospital from 19 to 10.7 days.
- Shared care protocol initiated for dementia follow-ups which has resulted in 780 appointments being moved from secondary to primary care, freeing up capacity in the memory clinic.

Further detail of the improvements made and their outcomes can be found here

Contacts:

Dr Richard Sweeney, GP and CCG Governing Body Member, rick.sweeney@nhs.net

Belinda Goode, Project Manager Harrogate Dementia Collaborative, belinda.goode@nhs.net

Examples to stimulate local thinking

Community support model, Scotland

The Scottish Government has provided a guarantee that people receiving a diagnosis of dementia would be offered one year of post-diagnostic support based on an 8 Pillars Model established by Alzheimer Scotland.

The guarantee provides those newly diagnosed with early stage dementia with support in adjusting and managing the likely impact of the illness, both emotionally and practically. It puts people in the best possible position to manage their symptoms and the practicalities of their lives for a period of time, with access to low-level forms of support and signposting, until their condition progresses to a point where they begin to need other services. The 8 Pillars Model then provides a coordinated approach to supporting people to remain at home for as long as possible.

The eight pillars of community support are:
Pillar 1: The Dementia Practice Coordinator
Pillar 2: Therapeutic interventions to tackle the symptoms of the illness
Pillar 3: General health care and treatment
Pillar 4: Mental health care and treatment
Pillar 5: Personalised support
Pillar 6: Support for carers
Pillar 7: Environment
Pillar 8: Community connections

The 8 Pillars Model combines health and social care to provide a coordinated response to each aspect of the illness. It promotes independence, citizenship and the right to participate as fully as possible in society. It avoids duplication by providing a structured joint health and social care approach.

More examples to stimulate local thinking

Practice briefing, Bury CCG	Bury CCG have developed a 'dementia briefing for practices' to ensure they are aware of the latest developments, local pathways and available services for patients. The document provides a brief overview, explaining the roles and responsibilities of practices and the support available to GPs.
Dementia handbook for carers, Berkshire	The dementia handbook for carers aims to answer the questions carers you may have if a family member has dementia, it includes: • what to expect in the future • how to support people when their memory is failing or their behaviour changes • who to turn to for support and advice. The handbook provides information about services available locally, it could easily be adapted with local information by other organisations as a resource to be shared with carers following a dementia diagnosis.
Memory protection service, Sunderland	The Memory Protection Service complements existing dementia services by improving access to early specialist treatment and diagnosis. Alongside comprehensive assessment and diagnosis, the memory protection service offers: support and advice to people and their families about coping with a memory difficulty; treatment including medication when appropriate; access to a range of support groups; a personal information pack with relevant information; access to other services able to provide help and support; and contact for further assessment, information, help and support as needed.
Carers support videos, Yorkshire and the Humber Strategic Clinical Network	Yorkshire and Humber SCN have developed a series to films to help support carers for people with dementia. The films, showing the experience of others, are free to download (use link above and click on 'Teabags in the fridge: learning resources'). Based on information gathered from over 100 carer interviews, the films use clips of real carers talking about what helps them.
Proactive elderly care team, Lancs Teaching Hospital	A hospital based Proactive Elderly Care Team (PECT) whose main role is to screen patients for dementia and delirium. The team has excellent feedback and saw a reduction in length of stay of 13.5% and a reduction in the readmission rate of 23%. Hospital staff are now working with GPs and commissioners to expand the team into the community. Appointments are routinely available in primary care centres with home visits offered to those unable to attend a clinic. More details in the GM Journal and here

Resources

Strategic Clinical Networks

Strategic Clinical Networks (SCNs)are an important source of advice and support for CCGs seeking to improve care for people with dementia, their families and carers. Contact details for the mental health SCNs in the north can be found at section 9.

Dementia: a General Practice Primer

This document, endorsed by NHS England, DH and RCGP aims to support GPs to develop their capabilities to assess, detect and treat dementia and its common causes.

We need to expand the capabilities of primary care. In the future, some diagnoses will have to be made in primary care if we are to avoid neglecting those who do not engage with an outside service. This booklet is an attempt to gather information that seems most relevant to GPs, de-mystify it and put it into one place.

Dementia diagnosis & management for general practitioners

Described as a brief pragmatic guide for general practitioners this resource has been produced to help GPs contribute positively to the needs of dementia patients. Endorsed by Alistair Burns, the National Clinical Director for Dementia, NHS England. It is neither a guideline nor a protocol, but a pragmatic document intended to offer practical advice.

The process of reading this resource pack, running the dementia data quality toolkit to find missing dementia patients, reviewing notes and cases and reflecting on the management of dementia is ideal material for GP appraisal.

Commissioning for Carers

NHS England has published 'Commissioning for Carers: Principles and resources to support effective commissioning for adult and young carers', to help CCGs better identify and help carers to stay well. The 10 principles outlined in the document will help CCGs deliver the best outcomes for carers, with a self-assessment questionnaire for commissioners to identify where they can provide further support.

The voluntary and not for profit sector

Charities and not-for-profit organisations

The not for profit and voluntary sectors have an important role in delivering integrated dementia care and support. They can be a valuable source of local support, advice and information for people with dementia, their families and carers. Key national organisations include Alzheimer's Society, Dementia UK and Age UK . They may provide the following services locally or have access on how to access them:

- dementia advisers /support workers
- specialist dementia nurses
- dementia support groups
- dementia cafés / day centres
- befriending
- singing groups
- advocacy services
- telephone helplines / discussion forums
- information – online and in factsheets or booklets.

Alzheimers Society, the dementia guide

This guide is for anyone who has recently been told they have dementia (of any type). It will also be useful to close friends and family of someone with dementia, as it contains information for anyone taking on a caring role. Copies of the guide can be ordered from the Alzheimers Society website.

A post-diagnosis next steps guide for patients and carers is also available.

The Alzheimers Society also publish an interactive map of local services

Dementia UK - Admiral Nurses

Admiral Nurses are specialist dementia nurses, working with family, carers and people with dementia, in the community and other settings. Working collaboratively with other professionals, Admiral Nurses use a range of interventions that help people live positively with the condition and develop skills to improve communication and maintain relationships.

Admiral Nurses are available to support families throughout the dementia journey. They provide family carers with the tools and skills to best understand the condition, as well as emotional and psychological support through periods of transition. Admiral Nurses can also help to join up different parts of the health and social care system and enable the needs of family, carers and people with dementia to be addressed in a co-ordinated way.

Map of current Admiral Nursing services and referral arrangements.

Websites, key documents and contacts

Useful websites

Dementia roadmaps: examples of the local services available in Durham and Darlington, and South of Tyne

Join Dementia Research, makes it easier for people to take part in dementia research.

Information prescriptions for dementia are available here.

The Dementia Gateway helps people to understand dementia better: what it is, what it means for daily life, and what support might be required.

Dementia Carers talk candidly about what helps, what to do, and finding support.

Key National Documents

Improving Care for People with Dementia (DH)
NHS Choices Treatment for dementia
NICE dementia pathway
NICE dementia quality standard (QS1)
NICE quality standard for living well with dementia (QS30)
NICE support for commissioners of dementia care
NICE resource for carers and care providers on supporting people to live well with dementia

Contacts

Strategic Clinical Networks are a good first point of contact for CCGs seeking advice or information:

- Cheshire and Merseyside mental health Strategic Clinical Network
- Gt Manchester, Lancashire and South Cumbria mental health Strategic Clinical Network
- North East mental health Strategic Clinical Network
- Yorkshire and the Humber mental health Strategic Clinical Network

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