Dementia: Post Diagnostic Support Project

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What outcomes are we ultimately trying to achieve?

1. I have personal choice and control or influence about the decisions that affect 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 knowledge and know how to get the support I need
5. I live in an enabling and supporting 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 that there is research going on that will lead to a better life for me now and how I can contribute to it

Person diagnosed with dementia, carers and family

The ‘I’ Story Framework
Adapted from ‘A Call to Action: the National Dementia Declaration’
Dementia ambition – a framework of care and support for people diagnosed with dementia and their carers

- A timely diagnosis of their condition and a diagnosis so that they can access the right care at the right time
- Someone who can help and advise who will support them and their carer to access the services they need
- A plan of care that will be tailored to their specific needs
- Support so that they can remain independent for as long as possible after diagnosis
- Access to high quality personalised information that will help them understand and manage their condition
- Access to services such as reminiscence and counselling, that will support them and their carer to live well with dementia
- Co-ordinated care towards and at the end of life
- Timely access to support for carers
- Seamless care with health and social care professionals working together to provide the best care and support

Anna Shears, DH Dementia Care & Support Project
• **Post Diagnostic Support (PDS)**

“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 : Two Year update

• **Person diagnosed with dementia / Carer Perspective**

“Agencies should work together on each case to ensure the person diagnosed with dementia and carer are presented with clear, consistent information.

They should not be the go-between between agencies.
They should not have to find a way to bridge gaps in processes and services – these should be seamless.”
Prime Minister’s challenge on dementia 2020

Supporting better provision of post-diagnostic support

• Commitment that everyone, including people with dementia will be supported by a named GP, with overall responsibility and oversight for their care, from 1st April 2015

• By 2020 we would wish to see GPs playing a leading role in ensuring co-ordination and continuity of care for people with dementia, as part of the above commitment

• 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 NICE Quality Standards. Effective metrics across 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 PDS 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 throughout 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
  — Through the Care Act 2014, local authorities have a responsibility to assess carer’s eligible needs for support. This will mean that more carers are able to have an assessment, comparable to the right of the people they care for, and a support plan setting out how their needs will be met. This is supported by NHS England’s Commitment to Carers, which offers carers a health check, information and support.
Dementia: PDS Project

**Purpose**
To create an understanding of dementia post diagnostic support services across the West Midlands region in health and social care, and other supporting agencies, and identify and communicate best practice across the West Midlands to improve outcomes for people to help improve outcomes for people diagnosed with dementia and their carer.

**Objectives**
- Gather staff, person diagnosed with dementia and carer input in West Midlands geographies – scoping the services offered, identifying best practice, issues and service gaps
- Identify post diagnosis support best practice and key issues in the West Midlands from this information to support agencies to identify gaps in services. Identify best practice from outside the West Midlands that will provide additional stimulation to dementia services in the West Midlands, particularly around addressing the key/common issues
- Communicate best practice amongst the West Midlands geographies through report, website and knowledge sharing event(s)

**Outcomes**
To provide a clear way forward and improve post diagnostic support for dementia across the West Midlands through delivering:
- An understanding of dementia PDS services in place, key issues and service gaps across the West Midlands
- A shared set of best practice dementia PDS services in the West Midlands
- A shared set of best practice dementia PDS external to the West Midlands that will help address the key issues in current West Midlands PDS services
Dementia: PDS - Project Scope

Proposal

- Project scope plans to look at PDS from point of diagnosis and the support currently available to people diagnosed with dementia and their carers.

- Initial information gathering will be done by an online survey for each Clinical Commissioning Group and for each Local Authority across the West Midlands, with three different surveys from three different perspectives:
  - Commissioners of health and social care, and wider wellbeing services that impact dementia.
  - Groups of people with dementia and their carers, including representative groups e.g. Local Alzheimer’s Societies.
  - Providers who routinely signpost people with dementia and their carers to services e.g. Memory Assessment Clinics, Advice and Support services.

- Responses will be collated and results discussed at an ADASS network meeting in June 2015.

- Results and good practice examples will be highlighted and shared at a regional event planned for September 2015.

In scope

- PDS in dementia services from point of diagnosis onwards.

- All geographical areas in the West Midlands, including Shropshire & Staffordshire (who may not fall under the West Midlands SCN in the future).

- People diagnosed with dementia and their carers either individually or groups.

- As well as health and social care services, other community-based services that contribute to PDS to people diagnosed with dementia.

Out of scope

- End of life PDS for dementia.