NHS
South East
Clinical Delivery and Networks

Younger Onset Dementia Services

Dementia care is a key priority for the Wessex region. When we think of dementia, we tend to think of people aged over 65. However, dementia also affects people much younger than this bringing specific challenges to equitable care provision.

The Clinical Network invited Fiona Chaâbane, YOD Nurse Specialist from the Wessex Neurological Centre at University Hospital Southampton to discuss the opportunities and challenges in YOD care.

Younger onset dementia

Dementia is often thought of as a condition affecting older people and often considered only in people over the age of 65. Young onset dementia (YOD) is the term used to describe the condition when it presents in younger people.

YOD population in Wessex

There are estimated to be over 48,000 people with YOD in the UK with over 2,000 living in Wessex. Due in part to some of the challenges outlined in this paper, the official figures of recorded diagnoses (shown below) are considered to be an underestimate of the true prevalence.

Nov 19	Dementia register (All age)	Dementia register (age 65+)	YOD dementia register (aged <65)
Dorset	8,525	8,285	240
HIoW	16,890	16,399	491
Wessex	**25,415**	**24,684**	**731**

Challenges

Dementia presentation in a younger age group has specific challenges in terms of health and social care. These include:

Health care challenges

- Presentation is unexpected and frequently atypical
- Unclear pathway for YOD assessment
- Wider range of potential co morbidity requiring assessment and care
- Higher potential for hereditary disorder has implications for children and siblings
- Post diagnostic care is variable depending on local expertise
- Generally, there is a lack of support and appropriate information for individuals and carers
- Disengagement from outpatient-based clinic review seen in some YoD groups; difficult to reach without review at home as an option
- YOD results in longer admissions to psychiatric care following crisis
- Low expectation of recovery with no formal service or carer support

.. a small patient cohort with specific health and social care needs which can be addressed in an equitable and sustainable manner by working at a Wessex level

Social care challenges

- Cognitive and behavioural challenges are often highlighted at work resulting in performance management and dismissal with no income or pension. With earlier intervention people can be supported to apply for medical retirement on health grounds thus protecting their pension rights.
- Likely to be paying a mortgage or have financial obligations
- Likely to have parenting responsibilities
- Carer likely to be in employment and attending clinic is difficult

Solution 1: Building a Networked approach to YOD services

Peer Review and Discussion

The Dementia Strategy Group comprises experts working along all parts of the Wessex dementia care pathway. They understand the commissioning and care needs of people with dementia (and carers) and look to identify creative solutions to meet both opportunities and challenges. Their individual roles enable them to affect change in their own areas and to work as a group to support system change.

The group acknowledged the difficulties raised in the provision of dementia assessment and care for younger people and discussed the following:

Population and awareness

Anecdotally there has been an increase in GP referrals querying YOD perhaps due to greater primary care and societal awareness. However, this remains a small patient cohort with specific needs.

In general, people with YoD and their carers find it difficult to make their needs understood. Social care and benefits services do not have relevant skills training and awareness of the condition and resulting care needs. People with YOD often do not fit social care referral criteria.

Social care input is often vital in this group and a breakdown in the system results in an increase in health care needs.

Pathway

Diagnosis can be challenging in a younger person. Need a balance of memory and neurological expertise to support the person with transition between services.

In memory clinics people with YOD are usually assessed and diagnosed by consultants but then follow the pathway for older people. This may not be appropriate where the higher levels of behavioural issues presented require longer follow up. Frailty associated comorbidity is less of a factor as physical health is often maintained for longer. However other complex health care needs can be present, and age-appropriateness of services remains an issue.

In older age dementia assessment, testing is heavily focussed on memory loss. In YOD this may come later in disease progression, and as a result the person is discharged with no diagnosis or follow up.

In contrast, some forms of YOD can progress particularly rapidly reducing time from diagnosis to care home admission, usually to manage behavioural issues rather than frailty.

Post diagnostic care can be challenging and often needs to consider the wider family. Taking time from work (for caring duties or appointment attendance) where one income may have disappeared due to the YOD can be challenging.

People with YOD can fall between services. Physical health needs are often not addressed as concerns are put down to the underlying YOD. Physical health care pathways e.g. cardiac care and diabetes pathway do not recognise the importance of YOD.

The challenges of supporting people with YOD have been recognised locally both in the Dorset Services Review and within Southern Health. As a result, Dorset are developing care navigator roles and SHFT are moving to a needs-based (rather than age based) pathway. The IoW run a membership scheme so that patients are not discharged from the pathway. UHS facilitates needs-based contact with Clinical Nurse Specialist on an ongoing basis but facilitates integration into local services where possible.

It may be useful to compare YOD to disability services rather than MH services. On IoW the Down Syndrome pathway aligns clinical and social care.

People with YOD need a range of health and social care services (e.g. childcare, SALT, social care etc). The pathway needs to be flexible such that the right team is accessed at the right stage.

Some aspects of dementia post diagnostic care are not age dependent e.g. driving, POA support. There may be opportunities to use existing systems addressing these issues in a targeted way to optimise support for people with YOD?

A peer support group for carers at is held at UHS and attended by carers from across Wessex (Dorset, Basingstoke, Chichester) suggesting that they can’t get support closer to home.

Workforce and peer support

Recruitment to roles with YOD expertise is challenging, resulting in gaps. YOD roles could be contractual but alongside recruitment challenges this is unlikely to resolve our challenges. There are further difficulties with identifying the reimbursement structure for employers with a broad geographical spread of patients.

Not all staff with experience in YOD work in the same Trust or service.

Care staff have low expertise in this group

This is an emotionally challenging group for health and social care workers, and adequate support and appropriate supervision is required.

The Dementia Advisor services support people with all dementia to navigate local services. They report that they could offer more support to this group if they had better knowledge themselves. Patients report that dementia advisers google YOD specific information in front of them affecting trust and confidence.

Solution 2: Maximising digital technology for greater impact

Wessex opportunities presented

A number of opportunities have been identified which could maximise current expertise and provision to provide a joined up, sustainable and equitable YOD service. These were presented to the group for discussion.

- Across Wessex a wide range of clinicians from all disciplines have been identified who are interested in progressing pre and post diagnostic care pathways and support for patients and families dealing with YOD.
- Multi-disciplinary clinical support network for YOD is being established. A conference in September 2019 leading to the development of a YoD network sharing expertise and working to develop better care pathways and service reviews.
- Expertise in rare or atypical dementias is available but not all in one Trust – the Network will support cross boundary working but a regional/virtual team is entirely possible to support local services.
- Wider development of clinical nurse specialist roles to provide clinical management, support and information for patients and families at home who are dealing with long-term neurodegenerative disorder.
- Close working with families to develop 'rescue' treatments and strategies in managing declining cognitive function/neuropsychiatric disorder at home - admission avoidance.
- Virtual and face-to-face support for carers including use of Skype, WhatsApp, telephone or email access to advice, carer support groups - supervision for clinicians – cancer care model.
- Development of 'My Medical Record' to support self-help and access to information including for carers/family members
- Development of care navigator role for younger people with dementia and their families

Next Steps

We do not wish to fragment existing services or create niche cohorts of small numbers, but do want to ensure equity of service for this group of people.

Grow and support the YOD Network

A Network approach provides the opportunity to join up expertise across STP areas to provide equitable and sustainable services?

Networked colleagues

- Maintain their local knowledge of services but also gain YOD expertise
- Provide opportunity for training and support upskilling staff and sharing best practice
- Can share knowledge with voluntary sector colleagues who have an important role to play but often have little health care knowledge.
- Can support their own local care homes and CHMT teams to understand YOD better

Action 1: **The next YOD Network meeting is being planned for March 2020.**

Colleagues from mental health services, speech and language therapy services, physiotherapists, social workers, community nursing and medical staff, commissioners and third sector support agencies are invited to examine and develop

- a way forward in younger onset dementia referral pathways,
- aspects of diagnosis and post-diagnostic pathways
- feedback on research in the Wessex region

Members are requested to promote and support this through their own organisations. Information will be circulated nearer the time and via the Clinical Network.

Expand use of digital tools

WhatsApp and text messages are successfully being used to link and support people. These are well received by people with YOD and their carers/families.

My Medical Record (MyMR) is a new online patient platform for people with YOD. This has the potential to share expertise and use across region

Expanding the use of digital tools minimises geographical and organisational obstacles.

Action 2: **The next strategy meeting will explore the developing My Medical Record digital tools and plans for expansion.**

Members are asked to consider how they can

- **promote MyMR use for staff delivering YOD care**
- **support patient sign up to MyMR**

The Wessex Dementia Strategy Group is hosted by the Wessex Clinical Network. Members include local experts in the commissioning and delivery of dementia services with the aim of ensuring that

Care, for those with dementia in Wessex, **is Excellent**

If you would like any further information on the group, please contact Rachel.chappell2@nhs.net