Young Onset Dementia Service (YODS) Doncaster

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24 May 2023

Young Onset Dementia Service numbers

Population of Doncaster is about 308 100 people [1]

- 19.4% over age 65 (59 771 older adults).
- 41.6% age 34 and under.
- 120 159 working age adults (age 35 to 64).

92 YODS per 100 000 age 30 to 64 year old adults [2]

- This equates to about 110 YODS people in Doncaster (recently with 117 on caseload).

1   Office for National Statistics census data 2021, Doncaster
https://www.ons.gov.uk/visualisations/censusareachanges/E08000017/

2   Dementia UK
https://www.dementiauk.org/about-dementia/young-onset-dementia/about-young-onset-dementia/facts-and-figures/

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1. How is care organised to a support timely diagnosis/immediate post-diagnosis service?

High volume, low technology, purposeful assessment and treatment

- Use of NICE NG 97 [1] for carer history, patient history, cognitive testing (ACE-III), structural brain imaging (CT brain) against ICD-10 F00.0 diagnostic criteria [2]
- Pragmatic diagnosis (history, ACE-III, CT scan, against ICD-10 criteria).
- Referral to treatment of 6 weeks (except with CT scan delays)
- Home visit, 0 DNA rate
- Post diagnostic support that week
- Palliative care team, bed based services (neuro rehab, psychiatry, Intermediate Care).

1   NICE NG 97 Dementia https://www.nice.org.uk/guidance/ng97
2   WHO ICD-10 https://apps.who.int/iris/bitstream/handle/10665/37108/9241544554.pdf

F00 – F09
Organic, including symptomatic, mental disorders

Dementia

G1. There is evidence of each of the following:

(1) A decline in memory, which is most evident in the learning of new information although, in more severe cases, the recall of previously learned information may also be affected. The impairment applies to both verbal and non-verbal material. The decline should be objectively verified by obtaining a reliable history from an informant, supplemented, if possible, by neuropsychological tests or quantified cognitive assessments. The severity of the decline, with mild impairment as the threshold for diagnosis, should be assessed as follows:

Mild. The degree of memory loss is sufficient to interfere with everyday activities, though not so severe as to be incompatible with independent living. The main function affected is the learning of new material. For example, the individual has difficulty in registering, storing, and recalling elements involved in daily living, such as where belongings have been put, social arrangements, or information recently imparted by family members.

Moderate. The degree of memory loss represents a serious handicap to independent living. Only highly learned or very familiar material is retained. New information is retained only occasionally and very briefly. Individuals are unable to recall basic information about their own local geography, what they have recently been doing, or the names of familiar people.

Severe. The degree of memory loss is characterized by the complete inability to retain new information. Only fragments of previously learned information remain. The individual fails to recognize even close relatives.

(2) A decline in other cognitive abilities characterized by deterioration in judgement and thinking, such as planning and organizing, and in the general processing of information. Evidence for this should ideally be obtained from an informant and supplemented, if possible, by neuropsychological tests or quantified objective assessments. Deterioration from a previously higher level of performance should be established.

The severity of the decline, with mild impairment as the threshold for diagnosis, should be assessed as follows:

Mild. The decline in cognitive abilities causes impaired performance in daily living, but not to a degree that makes the individual dependent on others. Complicated daily tasks or recreational activities cannot be undertaken.

Moderate. The decline in cognitive abilities makes the individual unable to function without the assistance of another in daily living, including shopping and handling money. Within the home, only simple chores can be performed. Activities are increasingly restricted and poorly sustained.

Severe. The decline is characterized by an absence, or virtual absence, of intelligible ideation.

The overall severity of the dementia is best expressed as the level of decline in memory *or* other cognitive abilities, whichever is the more severe (e.g. mild decline in memory *and* moderate decline in cognitive abilities indicate a dementia of moderate severity).

G2. Awareness of the environment (i.e. absence of clouding of consciousness (as defined in F05.–, criterion A)) is preserved during a period of time sufficiently long to allow the unequivocal demonstration of the symptoms in criterion G1. When there are superimposed episodes of delirium, the diagnosis of dementia should be deferred.

G3. There is a decline in emotional control or motivation, or a change in social behaviour manifest as at least one of the following:

(1) emotional lability;

(2) irritability;

(3) apathy;

(4) coarsening of social behaviour.

G4. For a confident clinical diagnosis, the symptoms in criterion G1 should have been present for at least 6 months; if the period since the manifest onset is shorter, the diagnosis can be only tentative.

Evidence Based Medicine in post diagnostic support

- No use of formal Cognitive Stimulation Therapy (CST) [3]
- First home visit is for assessment (about a month from referral).
- Second home visit is for sharing diagnosis and post diagnostic support (a week later).
- Care Plan support based on the person's needs and preferences (work, pool, swim).
- 1:1 band 6 RMN, 1:1 Support Worker, 2 days of group work (bungalow, community).
- Formalised processes (DVLA notification, LPAs, ReSPECT [4]).
- Regular reviews, we have to do (cluster allocation, risk assessment, s117 MHA 1983).
- Regular reviews, purposeful (titration, monitoring, patient initiated follow up).
- Carer support (staff, People Relying On People (PROP group) peer support,

DonMentia [5], monthly Doncaster Dementia Forum, YODS dementia friendly services [6]).

3   CST https://www.england.nhs.uk/wp-content/uploads/2018/01/dg-cognitive-stimulation-therapy.pdf
4   ReSPECT https://www.resus.org.uk/respect/respect-healthcare-professionals
5   DonMentia https://donmentia.org/
6   Doncaster dementia services https://donmentia.org/wp-content/uploads/2021/06/Dementia-directory-2021.pdf

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2. Can you provide some background to how your model was developed?

Drivers:

- ICB discussions [7], identified gaps (by patients, providers, VCF SE, NHS provider), National Dementia Strategy, Prime Minister's Challenge (dementia care navigators).
- Interested nurse and Consultant Psychiatrist, sessional time for a YODS service.
- Vocal local YODS patients, engaged in regional research [8]
- Local YODS patients, engaged with commissioners, authoring the local strategy [9]
- Local YODS media presence, e.g. DonMentia, patient OBE nomination[10]

7   JCPMH https://mentalhealthpartnerships.com/publisher/joint-commissioning-panel-for-mental-health/
8   Patient voice universities https://www.bradford.ac.uk/news/archive/2013/experts-by-experience-take-part-in-teaching-dementia-studies.php
9   Dementia strategy https://www.yhscn.nhs.uk/media/PDFs/mhdn/DementiaStrategyforDoncaster2015-2017FINAL.pdf
10   Mr Dennis Jubb OBE https://www.yorkshirepost.co.uk/news/recipients-region-order-british-empire-1972051

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3. What are the benefits and outcomes of the model of care)?

Benefits and outcomes:
- Clinical: Cognitive stability, beyond clinically expected durations (ACE-III).
- Clinical: Sustained ADLs (employment, driving, stay where ordinarily resident).
- Performance: Meet (with CT scanning) NHS England stretch target of 6 week referral to treatment target, for 85% of patients referred.
- Performance and finance: Reduced admission rates, very short admissions.
- Process: Continuity of care (process, CPA, Your Opinion Counts, RCPsych MSF).
- Reputation: Positive patient, carer, GP, NHS provider organisation feedback.
- Finance: Reduced permanent care home placement, reduced Out of Area specialist placements (Local Authority funded band 7 Social Worker, budget holder, in the team).

4. What data and analysis did you provide to secure support for your model of care?

Support:

- Patient (data on unmet need, with Alzheimer's Society support).
- GP (data on contacts and on unmet need).
- Acute NHS provider (data on Emergency Department contacts and on unmet need).
- Local Authority (data on crisis presentations, on care packages, on OoA placements).
- Police (s136 MHA 1983, petrol pumps, police monthly meetings RCRP [11]).
- Clinical outcomes (duration from diagnosis to first/permanent care home placement, psychiatric hospital admission rates, occupied bed days, use of PICU).
- Patient experience, proxy indicators and YOC forms, formal patient feedback reports.

11 Right Care, Right Person
https://www.college.police.uk/support-forces/practices/smarter-practice/right-care-right-person-humberside-police

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5. How could NHS England or others support commissioning for young onset dementia?

Support:

- Challenge ICBs on expected prevalence, vs numbers of diagnosed patients known.
- From these identified gaps, challenge on how adjustments can meet some needs (e.g. in Learning Difficulties services, Parkinson's Disease services, End of Life care provision).
- Young onset dementia gaps reduce when inclusivity increases (e.g. banks, shops, repeat medications [12]), same benefits for autism, Learning Difficulties, Asperger's syndrome.
- Parity of cancer patient vs dementia patient research.
- Parity of cancer patient vs dementia patient NHS and Local Authority resources.
- All age vs ageless vs age specific services; commissioned pathway requirements.

12   Dementia friendly community
https://www.dementiafriends.org.uk/WEBArticle?page=dementia-friendly-communities#.Y-E0Z3bP2Hs

6. How did you involve patients and families?

Involved in generating the content of the service offer:

- Determination of how assessments were done (home visits, clinic, GP surgeries).
- Determination of what assessments were done (duration and content of assessment).
- Role and presence of carers in conversations, in assessments, and post diagnosis.
- No CST, so blank page generation of their model of post diagnostic support.
- Determination of the role of the service with a focus on patient experience, not just clinical outcomes, and meaningful objective benefits (work, relationships, residence, ADLs).

Involved in ongoing delivery of the service:

- Monthly all age Doncaster Dementia Forum, research (PRAs)
- Involved in all interviews (appointing unqualified staff, manager, psychiatrist).
- Attended commissioner "Deep Dive" workshops, and pathway review/change, now attending dementia commissioning workshops (out to tender, again).

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7. Limitations and how might it be improved?

Limitations:

• Purpose: Provide a neurodegenerative young onset dementia service.

• Reality: Provide a cognitive assessment service for all working age adults.
A limitation is retaining fidelity to the commissioned (and resourced) model.

Improvements:

• Patients suggested increased support workers follow up; current action from our ICB.
Information resources (dementia care navigator role, one team, continuity of care).

• Clarity and hard decisions on inclusion and exclusion criteria (e.g. stroke damage, alcohol related brain injury, Parkinson's disease dementia, Intellectual Disability psychiatry patient cohorts, neurorehabilitation and brain trauma vs progressive dementia).

8. Challenges or opportunities in ICSs

Current experience:

- Pace. Get it right, vs get it good enough. Local variance vs a standardised model.
- Impact. Enthusiasm, agreement, but modest latitude to effect significant change.
- Inequality. Service offer inequalities between physical and mental health.
- Focus. Much less time to discuss local detail of service offers vs centralised assurance.
- Financial risk. Invest to save, opportunistic health promotion, anticipatory care planning.

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9. Communicate local commissioning models?

Communication of information:
- Emails. Great for sharing information/data to read, think over, learn, or reflect upon.
- Presentations. Great for communicating information/data with explanations.
- Formal papers. Great at visualising structures and pathways proposed.

All were unhelpful at early stages, and at review stages, when discussions were necessarily focussed on understanding, to then develop options, rather than decisions.

Communication for understanding:
- Microsoft Teams. Great for wide audience discourse, across geographical and organisational boundaries.
- Face to face. Far and away the best approach to develop understanding, relationships, trust/confidence, and inclusion, enabling trusted decisions and consequent implementation.

10. Best practice models of care in England?

Partnerships:

•   Kent & Medway NHS & Social Care Partnership Trust, face to face visit with RDaSH staff, with patients, and with carers visiting them.

•   5 Boroughs Partnership NHS Foundation Trust and Mersey Care NHS Foundation Trust, face to face visit with RDaSH staff visiting them.

•   Bradford District Care NHS Foundation Trust, face to face visit with RDaSH staff.

•   NHS England Yorkshire and Humber strategic clinical network for dementia, commissioner, NHS provider, VCF SE, patients and carers [13]

Presentations generating feedback from others. Strategic clinical network, commissioners, Wolverhampton, Germany, New Zealand.

13   NHS England Yorkshire and Humber strategic clinical network https://www.yhscn.nhs.uk/dementia

Young Onset Dementia Service structure

YODS resources

- Initially commissioned for 26 patient referrals a year, then 39 patients a year (200).

The commissioning was resourced with

- 1.0 wte band 7 Team Leader (50% clinical, 50% managerial) (Recently lost to QIPP)
- 2.0 wte band 6 NMP RMNs (assessment, prescribing, post diagnostic support)
- 3.0 wte band 3 support workers (post diagnostic support, outreach)
- 1.0 wte band 3 admin
- 0.1 wte Consultant in Old Age psychiatry

Office base, daytime activities (house, bungalow)

Young Onset Dementia Service limitations

YODS inclusion

- Neurodegenerative dementia in Doncaster residents of working age.

YODS exclusion

- Alcohol Related Brain Injury (Addictions psychiatry, Local Authority)
- Stroke (stroke team, stroke and neuro rehabilitation outreach team)
- Learning Disability patients (Intellectual Disability psychiatry)
- HIV dementia (sexual health service)
- Parkinson's Disease dementia (Parkinson's Disease service)

(Mis)used as a cognitive assessment service, to exclude dementia, or subtype dementia.

Young Onset Dementia Service pathway

Referral to our Single Point of Access

- Probable diagnosis of a progressive neurodegenerative disorder.
- Referrals from GPs, Neurologists, Consultant Psychiatrists.
- Watchful waiting.
- First contact (band 6 RMN), telephone, triage, explanation and signposting.

Accepted referrals

- CT brain requested
- Second contact, face to face, Band 6 RMN home assessment with family/carer.
  History, MSE, ACE-III. Care Act 2014, FACE risk assessment, cluster tool.
- Diagnostic MDT within a week.
- Third contact, face to face, Band 6 RMN home visit, formulation and treatment plan.

Young Onset Dementia Service outcomes

On gaining a diagnosis

- NHS England target, 85% referral to treatment in 6 weeks.
- NMP for initiation and titration and monitoring, then GP Shared Care prescribing.
- Support Worker post diagnostic support (groups, one to one).
- Carers (nurse visits, YODS carer support group , DonMentia, Doncaster Dementia Forum, Admiral Nursing).
- Practical support (Social Worker, DVLA notification, LPAs, ReSPECT).

Statistically, we have 100% of Doncaster YODS population found.

3% to 7% of referrals in a year have a YODS diagnosis, service may be too accessible? Diagnosis predicated on GP, patient, carer history, ACE-III and structural brain imaging.