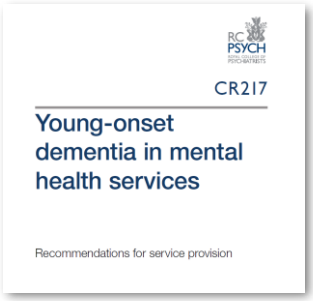

October 2018

Support professionals in Mental Health Trusts to:

- Set-up services for YOD
- Maintain existing services

YOD College Report

- Alzheimer's Society
- Young Dementia Network
- YPWD (Berkshire)
- Patient and carer groups
- Royal College of General Practitioners
- Neurology expertise and Royal College of Nursing
- Royal College Psychiatrists
  - Old Age, Neuropsychiatry & Intellectual Disability
  - Members: Old Age Faculty survey
  - Trainees - Old Age Psychiatry Higher Trainees survey
- Vicky Cartwright, Deputy Programme Manager, MSNAP, RCPsych
- Louis Thackray, Dementia & Neurology Intelligence Network, Health Intelligence Division, Public Health England

Conflicts of interests / methodology

- Biases!
- Limited systematic evidence and research
- Not evidenced based guidelines (eg like NICE) nor systematic review
- Consensus statement about best practice
  - informed by evidence, practice and opinion.

Endorsed by;

Professor Wendy Burn President, Royal College of Psychiatrists
Dr Amanda Thompsell Chair, Faculty of Old Age Psychiatry
Jeremy Hughes CBE Chief Executive, Alzheimer's Society
Tessa Gutteridge Director, YoungDementia UK and Chair, Young Dementia Network
Dr Jonathan Leach Joint Honorary Secretary, Royal College of General Practitioners

- Guide to future practice
- Stimulate more research to improve evidence
- Achieve better outcomes

Why now?

- Last College Report (joint Alz Soc) – 2006
  - Pragmatic / recognises a range of service models
- Changes since:
  - National Dementia Strategy / PM Challenge / NICE 2018 / CQC / ICS
  - Awareness of dementia
  - NHS and non-statutory service changes
    - Memory services / large mental health / MSNAP
  - Young Dementia Network and other charities
  - Refinements in diagnostic toolkit, understanding dementia and therapies
  - International perspectives

Why now?

Clinical practice, policy and research needs of younger people with dementia less visible, developed and concerns about their needs continued to be unmet.

"*A danger that the high prevalence of dementia in later life can overshadow the importance of its occurrence in younger patients*" (Rossor 2010)

College Report sections

1. Access to a specialised service
2. Job planning for psychiatrists
3. CPD, resources and training
4. Research and strategic developments

References

Key messages

People with YOD have needs that are best met in a dedicated, specialised service.

Focus – mental health services.

Recognition of the complex needs of people with YOD – extend into many NHS services – wider integration / alliance essential.

Dedicated service best placed to integrate.

Key message centred on specialised service

- Whilst younger people with dementia will undoubtedly share experiences with older people with dementia, there are important clinical and personal differences that can impact uniquely or disproportionately in younger people.
- Taken together - inform why specialist services for YOD are needed.
- Convergence – clinical, genetic, psychological, family, employment, societal and service.
- Services need to ensure they are organised and delivered to meet these needs.

Key messages centred on specialised service

- A **clear** referral pathway
- **Multi-disciplinary professionals** with specialist training and expertise
- **Links to wider clinical and social networks**
- **Named clinical lead** for YOD within Mental Health Services
- **Continuity of care / needs-led** – named key worker
- Model of **long-term support** - patient & family at the centre

Key messages centred on specialised service

- Trusts name a **senior manager** – development/design/commissioning and integration
- Access to **genetics/specialised neuroimaging/CSF analysis**
- Links with **neurology/neuroradiology**
- Links with **commissioners, clinical strategic networks and clinical research networks**

YOD: why is expertise important?

- Prevalence of YOD:
- Diagnostic rates:
- Diagnostic accuracy:
- Diversity of clinical diagnoses:
- Variations in clinical presentation:
- Prognosis and natural history:
- Higher prevalence of genetic and familial risk factors:
- Delays and difficulties in accessing diagnosis and support:
- Application of new biomarkers for subtyping dementia diagnosis
- Pre and Post diagnostic support and information.

Prevalence and clinical practice

- Nationally
  - 42,000 UK (Alz Soc, 2014)
  - 5% PWD
  - 50 400 by 2025 (Carter et al 2018)
  - Prevalence (all causes) 45-64 range **approximately** 100 per 100,000
- Mental Health Trusts
  - 500-1.4m
- GP
  - 9300 practices:
  - 3.4 per 10,000 registered general practice population (NHS dementia profile data)

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Dementia Intelligence Network
NHS Digital

YOD:

CCG
Local authority
STP

Table 1 Young-onset dementia indicators

Indicator	England value	CCG value
Dementia: crude recorded prevalence per 10 000 (aged under 65 years)	2.99 per 10 000 (2.94 to 3.04)*	*Lowest* Camden 1.12 per 10 000 (0.8 to 1.6)*
		Highest Cumbria/North East: 7.15 per 10 000 (6.1 to 8.3)*
Dementia (aged under 65 years) as a proportion of total dementia (all ages) per 100	3.2% (3.2% to 3.3%)*	*Lowest* Eastern Cheshire 1.3% (1.1 to 2.3)*
		Highest Bradford City 10.4% (6.0 to 14.0)*

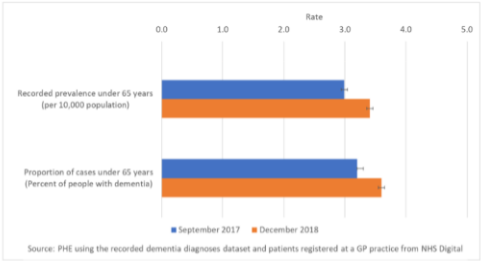
Indicators developed by the Dementia Intelligence / Digital data (April 2017).

Prevalence using GP data

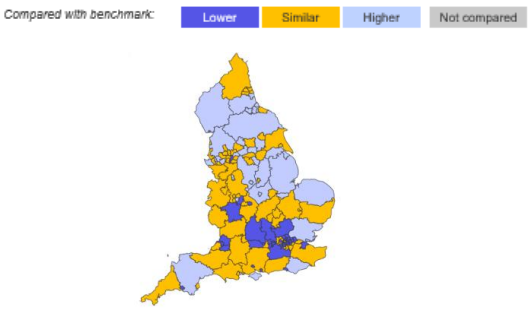
- For early onset dementia, the crude prevalence rate (2018)
  - 3.4 per 10,000 registered general practice population aged under 65 years.
- Total : 16,730 people aged under 65 with dementia
  - ,2,500 more than in 2017.
- Between 2017 and 2018 the proportion GP practices submitting data where no people with dementia under the age 65 years were recorded decreased from one-third to one-quarter.

https://www.gov.uk/government/publications/dementia-profile-april-2019-data-update/statistical-commentary-dementia-profile-april-2019-update

Prevalence using GP data



https://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia/data#page/8/gid/1938132811/pat/6/par/E12000004/ati/102/are/E06000015/iid/93026/age/279/sex/4



Dementia Profile: prevalence of YOD in your area

Dementia: Crude Recorded Prevalence (aged under 65 years) per 10,000 2016

Crude rate - per 10,000

Export table as image Export table as CSV file

Area	Recent Trend	Count	Value	95% Lower CI	95% Upper CI
England	–	16,733	3.41	3.36	3.46
East Midlands region	–	1,862	4.55	4.35	4.76
Derby	–	108	4.36	3.62	5.27
Derbyshire	–	306	4.84	4.32	5.41
Leicester	–	163	4.42	3.79	5.15
Leicestershire	–	238	4.20	3.70	4.77
Lincolnshire	–	393	6.56	5.94	7.24
Northamptonshire	–	197	2.99	2.60	3.44
Nottingham	–	111	3.20	2.66	3.86
Nottinghamshire	–	340	5.28	4.75	5.88
Rutland	–	6	2.08	0.95	4.54

Source: NHS Digital

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Diagnostic practice

- Mis-diagnostic rates 30-50% (Carter 2018)
- Complexity:
  - MCI in younger people
  - psychiatric co-morbidities
  - Intellectual disability
- Under diagnosis – variation (Dementia profile data)
- Over diagnosis – depression / alcohol (Salem 2012, 2014)
  - Incomplete diagnostic work-up
  - Referrals of younger patients increasing but memory clinics moving to episodic care

Diagnostic differences

- Alzheimer's disease (AD) contributes less to the cause of YOD than later in life: approximately one third of diagnoses.
- Fronto-temporal dementia (FTD); 2nd commonest form of degenerative dementia in YOD
- Age-related variations in the type of vascular pathology:
  - Conditions such as cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy (CADASIL), amyloid angiopathy and cerebral vasculitis are more commonly found in younger patients than in older people.

Variation in presentation:

- Clinical phenotype of AD in younger people can be different than older people.
  - Non-amnestic presentations can be more prominent, including dyspraxia, visuospatial and language dysfunction, as can neurological changes, such as myoclonus.
  - Posterior cortical syndromes are more common in younger patients with AD, and can present with apparent visual difficulties that are related to visual agnosia

Rarer causes

Approximately 1 in 3 people with YOD have a rare or uncommon underlying cause. This includes dementia associated with:

- Huntington's disease and rarer genetic disorders;
- movement disorders (e.g. progressive supranuclear palsy, corticobasal degeneration, multiple system atrophy);
- prion diseases (e.g. Creutzfeldt-Jakob disease-CJD);
- inflammation (e.g. cerebral vasculitis, limbic encephalitis);
- metabolic encephalopathies;
- CNS-infections (e.g. HIV-related, syphilis, Lyme disease, Whipple's disease);
- demyelinating disorders;
- certain intellectual disabilities (e.g. Down's syndrome);
- head injury and trauma;
- types of brain cancer;
- alcohol-related brain damage (ARBD) which includes Korsakoff's syndrome, cerebellar syndrome and frontal lobe dysexecutive syndrome.

Genetic causes

Examples include;

- CADASIL (*NOTCH3*),
- Huntington's disease (*HTT* gene CAG trinucleotide repeat)
- FTD (primarily *MAPT*, *GRN*, *C9orf72* expansion)
- AD (*APP, PSEN1, PSEN2*).

YOD: why is expertise important?

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- Diversity of clinical diagnoses:
- Variations in clinical presentation:
- Prognosis and natural history:
- Higher prevalence of genetic and familial risk factors:
- Delays and difficulties in accessing diagnosis and support:
  - longer / more contacts / cumbersome
- Application of new biomarkers for subtyping dementia diagnosis:
  - training in rarer dementias, interpretation of neuroimaging, use of new diagnostic markers, genetic testing

YOD: why is expertise important?

- Pre and post diagnostic support (see YDN)
  - practical, emotional, health, ethical, legal, family, employment, financial needs
  - pace / adjustment to untimely diagnosis
  - continuity important
- Accessing support – high levels of unmet need
  - Cared for at home longer / daytime activities / social / intimacy / communication / mobility / information
- Personal and family context and implications.
  - Use services differently / barriers inc affordability, flexibility and age-appropriateness / lack of tailoring (Draper 2016)
- Employment and driving.
- Palliative care needs and support with later stages of dementia.
- Staff training and awareness.

Current services: examples of excellence but…

- YOD services – see YDN - still the exception and not the rule around the country
- MSNAP data 56 memory services UK (2016) - 5 standards inc x1 mandatory for accreditation
  - 89-100% reported standards met
- Services for patients with YOD with co-morbidities, such as intellectual disability, substance misuse and people from minority groups, have historically been underdeveloped.

Current Services

- Rodda and Carter (2016) surveyed members of the Young Dementia Network, old age psychiatrists, neurologists and members of MSNAP re YOD services.
  - 189 old age psychiatrists, covering 76 UK trusts
  - > 50% of trusts had no specialist consultant lead for YOD and limited access to age specific post diagnostic interventions
- For this report, surveyed 100 consultants working in England, Wales, Northern Ireland and Scotland.
  - no multi-disciplinary YOD service in 71% of localities.
  - A third - services for YOD have reduced and/or moved into generic memory services or mental health services for older people.
  - Only 6% had seen expansion.

Core features of YOD service

Named local lead
Named key worker and multi-professional care
Patient centred
Networked
Continuity and long term support
Leadership

Core functions of a specialised team

Comprehensive dementia diagnosis: including full history; physical and mental state examination; cognitive assessment; relevant investigations including neuroimaging and CSF
Assessing role of mental and physical health co-morbidities
Assess and managed associated physical symptoms
Genetic testing
Comprehensive needs assessment and management
Pre, peri and post diagnostic support with tailored information
Care planning, review and co-ordination

Prescribing cognitive enhancers
Non-pharmacological interventions for people living with dementia
Managing non-cognitive symptoms
Supporting informal carers including information, skills training and support accessing interventions
Providing advice on legal, employment and financial issues
Support advanced care decisions
Palliative care: care towards and at the end of life
Audit and quality assurance
Supervision of team

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References

•Thank you

Standard*	% meeting standard
Service planning and commissioning Health and Social Care Commissioners, in consultation with local partners, people with dementia/suspected dementia and carers, This includes specifically a pathway for young onset dementia, people with learning disabilities and people with rarer types of dementia where diagnosis is more complex and likely to be delayed	93%
Staffing for the memory service There is a named lead within the team for people with young onset dementia.	89%
The processes of assessment and diagnosis** The service has access to in-depth assessment of occupational functioning and neuropsychological assessment as required (e.g. for young onset dementia, complex or abnormal presentations).	96%
Care management The service can refer on to specialist services for rare or young onset dementia and/or complex care needs (e.g. regional/ tertiary neurology/ neuropsychiatry services)	100%
Psychosocial interventions The team signposts younger people with dementia to structured activities such as work, education and volunteering	96%