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YOUNG ONSET DEMENTIA

Current Struggles and Recommendations



Acknowledgements



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Care England, the voice of care and registered charity, is the most diverse representative body for independent providers of adult social care in England.



Dementia Forward is the leading dementia charity for North Yorkshire and York. They provide support, advice and information to anybody affected by dementia across the county, and have developed a comprehensive range of services, including specialist support for people living with young onset dementia.



Wellburn Care Homes created 'The Manor' project, which currently has two homes, one in York, with the other in Gateshead. Both represent their own regions' first ever dedicated home for those living with young onset dementia; two of only a handful nationwide.

Introduction

Care England has created the following report on Young Onset Dementia (YOD) with the help of Dementia Forward and Wellburn Care Homes in order to bring greater awareness to the struggles faced by people experiencing YOD, and advocate for them to receive improved care and support from Government.

YOD develops in individuals under the age of 65. There are over 70,000 people in the UK currently diagnosed, which is around 7.5% of all people living with dementia. Dementia cases are expected to double by 2040. YOD presents unique challenges, unrecognised and uncatered for in our current system and significantly affects individuals and their families on multiple fronts.

The main struggles of people living with YOD:

Delayed Diagnosis: General Practitioners (GPs) often fail to recognise early signs of YOD. Symptoms are more varied than those in older adults, manifesting as changes in behaviour, language, or personality rather than memory loss. Further barriers can be the mirroring of symptoms to other more common ailments such as menopause, depression, B12 deficiency or heart problems. Whilst each of these is investigated and wrongly treated, time passes. This time is precious as much cognition can be lost during this period. Medical practitioners investigate all possible avenues so as not to misdiagnose such a devastating condition. However, without an early diagnosis, patients continue working while the condition progresses, which can lead to personal and professional crises.

Economic Hardship: People with YOD are typically working-age adults, who are often still economically active, supporting families (children and ageing parents) and paying mortgages.

Once diagnosed, the loss of income from the individual is compounded by their spouse often reducing working hours, or leaving their job entirely, to provide unpaid care. The person living with dementia is more commonly asked to leave work, or may be fired, before diagnosis is reached or even sought. This is another impact of delayed diagnosis; eliminating any responsibility for an employer to make necessary and reasonable adjustments to enable people living with dementia to remain in work as an economically active member of society. The financial toll is devastating, as many are unable to access the retirement social support and pension systems available to older individuals.

Lack of Community Support: Many families affected by YOD experience increased isolation, both socially and emotionally.

The stress of managing care and the progressive nature of the disease strains familial and social connections. Community services tailored to YOD patients are scarce and opportunities to connect with others facing similar challenges are limited, leaving both patients and their families feeling isolated. Evidence gathered by Dementia Forward shows that tailored support for both the person with YOD and their carers can reduce isolation and improve wellbeing. Lack of appropriate provision leads more quickly to crisis situations with people living with dementia expressing frustration, aggression and/or paranoia which in turn can lead to sectioning and higher costs of care.

Lack of Appropriate Care: Respite and long-term care facilities for people with YOD are severely lacking. The need for age-appropriate care, both in the short- and long-term, is critical, but current systems are underfunded and ill-equipped to meet this need. This also includes the Learning Disability Community. For people with Down's Syndrome, the risk of dementia increases from 10% at age 40/49 to around 54% between the ages of 60 and 69.

The presentation of YOD differs from dementia in older adults. The types of dementia commonly seen in younger people tend to have symptoms affecting behaviour, social skills, language and the processing of visual information – such as affecting spatial awareness and objects not being recognised. Younger individuals have higher physical energy, necessitating more active and movement-based care. Yet, care facilities and services are often geared towards people of older ages, creating a mismatch in care provision. Care options that cater to younger individuals, with more physical energy, are largely unavailable, and specialised long-term care is almost non-existent often resulting in inappropriate placement within older people's services.

The social aspect of care is just as important as the clinical. Providers more accustomed to providing care to older people may miss cultural points that younger people living with dementia identify with, such as a more modern diet or music taste. A younger person with dementia is less likely to identify as a person needing care, so communication and avoidance of an 'us and them' culture is of high importance. There are other aspects to consider, such as opportunities to spend time as a family within the care setting, as they may have younger children, and care homes are often not set up for this.

CURRENT CARE PATHWAY

The key challenges for a person with young onset dementia.

1

Incorrect Data

Because there is no single code for YOD, GPs often do not code YOD cases correctly, leading to a lack of accurate data.

2

Gap in Knowledge

There is a general gap in knowledge of YOD among primary care professionals, which leads to misdiagnoses or delayed referrals to specialist services. Furthermore, the lack of public awareness may mean individual's affected don't seek the help they need.

3

Long waiting times

Long waiting times for specialist diagnosis services exacerbate patient and family stress and delay access to any potential care and support.

4

Limited Community Support

Community and post-diagnostic services tailored to people with YOD are scarce. Opportunities to connect with others facing similar challenges are limited, leaving both patients and their families feeling isolated, increasing the likelihood of crisis.


5


Absence of long-term care facilities


The absence of specialised long-term care facilities, tailored to YOD patients, leaves families without options for comprehensive, sustainable care solutions. Secondary care providers also often lack the training to effectively manage the unique needs of YOD patients, limiting the quality of ongoing care.


Government Recommendations

To improve the quality of life for those living with YOD and their families, we urge the government to take the following actions:

-  **Increase Research and Data Collection**

There is an urgent need to improve data accuracy and to provide research funding to better understand the prevalence and progression of YOD. Ensuring there is a specific code for YOD for GPs to correctly code cases will facilitate accurate tracking and research.
-  **Enhance Knowledge and Awareness in Primary / Secondary Care**

Training programs for health and social care providers in both primary and secondary care should be developed to increase awareness and early recognition of YOD. This will lead to earlier diagnoses and better treatment planning and outcomes. Subject to funding and support, Dementia Forward is creating a National Young Onset Centre of Excellence which will provide provision for all sectors, and allow them to share their successful model of support.
-  **Public Awareness Campaign**

Build on the significant achievements of Dementia Forward's U&ME Campaign and develop a rigorous public awareness campaign to reduce the stigma associated with YOD, improve understanding, and encourage earlier diagnosis and intervention. Public understanding can help people spot symptoms early and plan for the future, helping them stay in work and active in society for longer. It can also significantly reduce isolation for families and ensure broader societal support. Part of this should be to consult organisations who already provide successful support and seek their advice in policy making and service delivery design, alongside a wider cohort of advisors.
-  **Develop New Local Authority (LA) Payments Framework**

Introduce a revised payments framework that reflects the true costs of caring for people with YOD. Age-appropriate care solutions must be considered in funding allocations, ensuring financial relief for families.

Expand Respite and Long-Term Care Facilities

There is an urgent need for specialised care facilities that cater to the physical and emotional needs of YOD patients. The government should provide funding to create small, tailored respite and long-term care facilities, adapted from models for working-age adults, like Wellburn Care's The Manor at St Catherine's, developed in consultation with Dementia Forward.

Invest in Local Communities and Support Networks

Local authorities need funding to develop age-appropriate services for YOD patients and their families both in the community and within health and social care services. This includes support groups, tailored exercise programs, mental health services, and learning engagement opportunities. Dementia Forward has a working model to share.

Encourage Collaboration with Existing Organisations

The government should work closely with a wide-spread variety of organisations who have experience of providing specific support for people with YOD, to see successful support models in practice and co-develop new respite and long-term care models.

Age-Appropriate Environments

Support and encourage the development of care environments that integrate exercise, mental engagement, and social connections, specifically tailored to those living with YOD. These environments are crucial for maintaining quality of life and slowing cognitive decline.

Parliamentarians who wish to take supportive action should consider:

- **Tabling an adjournment** or Westminster Hall debate about challenges in Young Onset Dementia care.
- Members of the Health & Social Care Select Committee may elect to **conduct an inquiry and publish a report** into the state of YOD care and highlight good practice, through speaking to organisations working in the field, outside of the national charities.
- **Writing a letter to the Secretary of State for Health and the Chief Executive of NHS England**, expressing your concern about the urgent need to improve data accuracy and research funding to better understand the prevalence and progression of YOD. Making it possible for GPs to correctly code cases of YOD will facilitate more accurate tracking and research and generally poor access to primary and secondary health for residents of care homes, inviting other Care Home Parliamentary Network members to be signatories.