

## **Diagnosis and support for people with young onset dementia and their families**

### **Summary of recommendations from the Young Dementia Network Steering Group**

#### **Summary**

This document brings together the experience and expertise of people affected by young onset dementia and the people who work with and support them. It highlights that the impact of dementia can be very different depending on your stage of life and that because of this, services must be tailored to meet those needs. Currently, this is rarely the case and which means that a younger person can take twice as long to be diagnosed than an older person. Once they receive this diagnosis they are often left with no appropriate support and no one with specialist knowledge to guide them through the journey ahead.

From first contact with a GP to end of life care, that journey can be very different for a younger person. They are likely to be in work, have a mortgage and dependent children. They may have a rarer form of dementia which means they are part of an even smaller minority. A dementia diagnosis is always devastating. But for a younger person, that diagnosis means that life changes beyond recognition.

Together we have identified a series of recommendations which are designed to meet those different needs. These recommendations will guide policy makers, commissioners and practitioners in designing and delivering services. Most importantly, we hope they will empower younger people with dementia and their families to demand the services to meet their needs.

#### **Recommendations for policy makers and commissioners**

- Commissioned services must be designed to address the specific needs of younger people with dementia and their families. This means that providers must be able to demonstrate how their service is adapted for younger people. In particular addressing the poor provision of local age-appropriate and meaningful day care, respite care and residential care.
- Dedicate commissioning to developing and supporting existing services to allow sustained clinical experience and development of continuity and co-ordination across different service providers.
- Appoint a dementia lead in the Clinical Commissioning Group responsible for identifying needs of younger people with dementia.
- Review current arrangements for management of younger people with dementia and implement a local protocol across primary care and specialist services, including social care.

#### **Recommendations in detail**

- Positive contact with my GP which reduces the time taken to receive the correct diagnosis
  - GPs to have an awareness of young onset dementia and the variety of symptoms with which it can present including atypical ones. This could improve recognition by GPs of key symptoms that may indicate a referral to specialist services is required.
  - Clear referral routes from the GP to specialist diagnostic services.
- A clear and collaborative diagnostic process which is young onset specific
  - Ensure a defined local care pathway for younger people with possible cognitive

impairment.

- Provide access to a specialist with expertise in the diagnosis of young onset and rare dementia, to improve standards of assessment and diagnostic accuracy.
- Specialist support and information which meets our changing needs
  - A key worker who has specialist knowledge, training and experience of young onset dementia and its impact on the person with the diagnosis and their family.
- Living with young onset dementia
  - For the key worker, clinicians, social services and charitable organisations to work closely together to provide a comprehensive service for the person with young onset and their families.
  - Access to age-appropriate and meaningful activities which enable younger people and their families to remain engaged in their communities, retain and develop relationships and social connectedness. Age-appropriate means that the content, location and timings of activities are designed to be beneficial and accessible for younger people.
  - Advice which enables the person to plan for the end of their life.
  - Access to age-appropriate and local respite and long term care, based in their own home or in residential care depending on the person's wishes and needs.

### **Recommendations by role**

We recommend GPs should

- a) Be aware of young onset dementia and have a low threshold for referral of younger people suspected of cognitive impairment.
- b) Be aware of referral routes to specialist services.
- c) Be aware of the young onset dementia specialist lead for their area.
- d) When the person has received a diagnosis, ensure that they are linked in to local support services. This is especially important when a diagnosis was given in a regional or national centre.

We recommend clinicians based in diagnostic services should

- a) Have a named young onset dementia lead.
- b) Have knowledge of the varied impact of a diagnosis of young onset dementia on the person and their family.
- c) Have access to the full range of assessment, investigations and personnel necessary to make a diagnosis and provide ongoing post-diagnostic support.

We recommend the key worker role should

- a) Have specialist knowledge, skills and experience of the impact on young onset dementia. This will include a knowledge and understanding of rarer forms of dementia, as well as the impact of a diagnosis at a younger age for the person diagnosed and their family.
- b) Provide information, practical and emotional support for family members, as well as connect them to others for mutual support.
- c) Provide continuity of support, and enable the person living with young onset dementia to understand their condition and actively engage in their care plan and journey.
- d) Act as a coordinator of services, organisations and people, helping to connect the person living with young onset to local groups, networks and support services. They will also act as a liaison between clinical services and the person's community and home.
- e) May be delivered through a variety of organisations depending on local infrastructure and funding arrangements. For example (but not limited to) primary care, voluntary sector or be based within local mental health teams or neurology services.



This document was produced by the Young Dementia Network Steering Group, a collaboration of people and organisations. Details of our Steering Group along with the full version of these recommendations can be found at [www.youngdementiauk.org/young-dementia-network](http://www.youngdementiauk.org/young-dementia-network). Contact us via email [network@youngdementiauk.org](mailto:network@youngdementiauk.org)

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