Young onset dementia service

Doncaster
**Introduction**

The following procedures and protocols will govern the operational working and function of the Doncaster Young Onset Dementia Service. The impetus for the development of this service has rose from a needs-based assessment that clearly identified a gap in service provision for people of working age with dementia.

**Ethos**

Based on the principles of person-centred care, the Young Onset Service will collaborate with both users and carers / partners in all aspects of their care, service delivery and planning.

**Size and description of the patient group**

It is estimated that there are approximately 67 cases of dementia per 100,000 people aged between 30 and 64. Adjusting for the age structure of the Doncaster population, approximately 161 people of working age with dementia would be expected within the metropolitan borough. This is likely to be a conservative estimate, as local research suggests that there are high levels of alcohol, vascular and trauma-related dementias, which are suggestive of lifestyle and socio-economic factors. In addition, 1% of the population are from ethnic minority groups who are at increased risk of developing cerebrovascular disease, which is now known to increase the risk of dementia. In order that the service is targeted at the defined group, clear eligibility and exclusion criteria for access to the service has been identified.

**Service specification**

The Young Onset Dementia Service is a borough-wide multi-professional, community-based service and is made up of the following personnel:

**Core team:**
- Team secretary
- Consultant psychiatrist - dedicated time
- Team leader
- 2 x Community mental health nurse
- 3-6 Support workers - dedicated s/w time.
Sessional basis:
- Clinical psychologist
- Access to specialist occupational therapist.

Aims
- To provide a comprehensive, diagnostic assessment and management service to people under the age of sixty-five, diagnosed or suspected of having a degenerative dementing condition, utilising the best available evidence
- To provide information, education and psychological support to the person with dementia, their carers and wider support network
- To ensure that patients and carers have their wider needs assessed, met and evaluated, utilising the Care Programme Approach (CPA) in conjunction with other agencies
- To enable the development of a comprehensive service able to address identified unmet needs of the user, carer and wider support network
- To ensure that the service facilitates equitable access to both ethnic and cultural needs, as well as locational boundaries
- To conduct high quality clinical research aimed at improving the quality of the well-being of people with dementia and their carers.

Consultation only criteria
It is not envisaged that the service will be able to assess and manage the total care of people experiencing the following difficulties:
- Dementia due to brain injury
- Younger stroke sufferers
- Huntington’s Disease
- Human Immunodeficiency Virus (HIV) and Creutzfeldt-Jakob Disease (CJD) related dementia
- Delirium or toxic confusional states
- Cognitive impairment due to functional psychiatric disorder
- Dependency on alcohol and / or illicit drugs with cognitive impairment
- Learning disability, with or without degenerative dementia.

The service will, however, provide assessment of memory and cognitive functioning and offer advice / education to assist in the
management of these difficulties to other services who will retain care co-ordinator responsibility.

**Boundaries**

**Neurology**
Neurology services will continue to have primary responsibility for the psychiatric management of Huntington’s Disease and dementia secondary to acute brain injury, stroke and Prion Disease. Patients with these conditions would, however, have access to services provided by the core team if these would best meet their needs.

**Liaison psychiatry and hospital medicine**
Medical services will have overall responsibility for HIV-related dementia.

**General adult psychiatry**
The Young Onset Team will provide diagnostic expertise for those referred with suspected degenerative dementia. Primary responsibility for the ongoing care of patients with chronic mental health problems and cognitive impairment will continue to reside with working age adult psychiatry, until such time as the cognitive impairment over-rides the mental health problems.

**Alcohol services**
Specialised alcohol services will continue to have primary responsibility for substance abuse problems. The team will provide secondary assessment specific to memory and cognitive functioning.

**Learning disabilities**
Up to 15% of cases of dementia in younger people occur in those with learning disabilities, the main association being between Alzheimer’s Disease and Down’s Syndrome. The majority of these patients already have considerable support services, and the primary responsibility for care will continue to reside with the learning disability team.

**Older adults**
The service will not normally accept new referrals for patients over the age of sixty-five. However, in the case of some of the more uncommon forms of degenerative dementia, the service may provide advice via the core team to older adult services, if this would best meet patient need. It is not envisaged that patients will be transferred to older adult services on the basis of age. However, transfer would be appropriate if these
services would better meet patient and carer need after all assessments and care needs have been reviewed through the Care Programme Approach.

**Accessing the service**

The service will accept written referrals for assessment, which should be directed through single point of access at Cherry Tree Court, to facilitate a clear care pathway. Access to the service will be via an open pathway. However, the client and their family doctor must be aware of the referral.

**Access by family doctor**

A family doctor can refer to the service directly, if a progressive dementing condition is suspected in a younger person following full physical screening, including blood tests (as per management of dementia and depression in primary care guidelines).

**Access by hospital specialists**

Referral by hospital specialists (neurologists, neuropsychiatrists, psychiatrists or physicians) will generally follow a series of cognitive and physical tests, including neuroimaging, indicating the possibility of a progressive dementing condition in a person of working age. Appropriate assessments should be conducted to exclude functional psychiatric disorder or organic conditions related to medicine and neuropsychiatry, such as: epilepsy; Huntington’s Disease; delirium; ongoing substance abuse; non-progressive brain damage due to head injury or stroke, which would be more appropriately dealt with by other services.

**Referral process and care pathway**

Following receipt of the written referral, all referrals will be discussed at a weekly team meeting, at which the most appropriate assessment pathway will be decided, and a team member will be allocated to make the initial contact for assessment.

**Inpatient assessment**

The provision of a community based, multidisciplinary team should minimise the need for inpatient admission.

Patients requiring inpatient assessment will initially be admitted to existing Mental Health Service for Older People beds.
Follow-up
Once the initial diagnostic assessment has been completed and the patient and carer have received a diagnosis, further management will be focused on their normal living environment.

Lead professional
Following initial assessment, each patient will be allocated a lead professional. This will normally be the nurse who carried out the initial assessment.

Dimensions of care
Home setting
- Monitoring of cognitive, behavioural and psychological symptoms
- Counselling / psychological support for the person with dementia
- Advice on services, benefits and employment
- Family and carer education, training and support
- Cognitive rehabilitation
- Continuing assessment of functional ability
- Liaison with the primary care team and wider support network
- Maximising social and recreational opportunities
- Information, advice and prescribing of cognitive choices if assessed as required
- Regular formal cognitive testing.

Social / health care services
Assessment of individuals for the full range of social and/or health day care or respite care services will be conducted in the patient’s home. This will be holistic, person centred assessment, focusing on the day-to-day needs of the individual and their carer, where appropriate. Emphasis will be placed on social inclusion, with services provided in the least restrictive environment.

All services planned or provided as a result of this assessment will be discussed and agreed with the lead professional, in order that the overall package can be monitored and evaluated with the service users concerned.
Key partnerships

Integrated working and the development of care partnerships to provide a range of support and treatment services for older people of working age with dementia, will provide a whole systems care approach to include day and home support, respite and appropriate residential services. This will materially improve the current service provision, which often sees younger people with dementia being cared for in settings that also care for older people with dementia. One of the key recommendations from the Royal College of Psychiatrists (1998) is that specialised day care, respite care and long stay provision are virtually essential, as younger patients are often physically robust and do not integrate easily with frail, elderly people.

The key relationships of the service will be the internal NHS partnerships with neurology, Mental Health Services for Older People and general adult psychiatry, whilst integrating with primary care services. Relationships with social services and care partnerships with a wide range of providers in the voluntary, private and charitable sectors such as Alzheimer’s Society, CRUSE, private nursing homes and hospices are essential for overall effective care delivery.

Evaluation of the service

It is recognised that this is a developing service that will need to be evaluated on an ongoing basis. Evaluation of the service will be undertaken from a number of perspectives, and will be underpinned by improved outcomes of care for people of working age with dementia. This will be carried out through clinical audit, consultation and evaluation from all stakeholders, which will include patients, carers and other service providers and partners.
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