

## Young onset dementia; examples of post diagnostic support across London

### Background

In May 2018 the London Assembly Health Committee held an investigation into young onset dementia in London. The key findings included: there is a lack of accurate information on the number of people living with young onset dementia; younger people living with dementia may face different challenges to older people, and there is little support to help people to continue living well after diagnosis. The Health Committee's recommendations to the Mayor of London included actions for sectors under his remit, such as dementia awareness training for Transport for London staff. Other recommendations included: the need for greater inclusion of young onset dementia in wider discussions on dementia and a stronger evidence base to inform a truer understanding of need and to help to make the case for action in other policy areas. In response to the recommendations the London Dementia Clinical Network was asked to bring together good examples of post-diagnostic support across London and consider how support could be offered routinely across London in a sustainable way.

### Gathering information

A letter co-signed by the Mayor of London and Dr Daniel Harwood (Clinical Director, Dementia Clinical Network) was circulated to health commissioners, local authority commissioners, memory services, dementia GP leads, local Dementia Action Alliances, voluntary sector organisations and other community groups (via the Alzheimer's Society). The letter asked for information on post diagnostic support including: the description of the service provided, feedback from service users, information on evaluation or outcomes of the service and information on funding and costings. The letter was circulated on 23rd January, with information collected until 6th March 2019.

### Information received

11 services submitted information:

- Cognitive Disorders Service, National Hospital for Neurology and Neurosurgery
- Camden and Islington Memory Services
- Salvation Army
- Hounslow Cognitive Impairment and Dementia Service
- Bromley Memory Service
- Cognitive Neurology Service, St George's Hospital
- Age Exchange
- Havering Memory Service

- SweetTree Homecare Services
- Imperial Memory Service
- Alzheimer's Society Merton Dementia Hub

The information from the services was reviewed and five key areas emerged: Cognitive stimulation therapy, Admiral nursing, structured groups, individualised support and therapy and training and education.

### Cognitive stimulation therapy

Cognitive Stimulation Therapy (CST) consists of 14 sessions of structured 45-minute group therapy sessions. It aims to improve cognitive skills and quality of life for people with dementia through activities such as categorisation, word association and discussion of current affairs.

Two memory services stated that they offer CST, but not specifically for younger people. One of the services reported they are keen to explore developing a specific group for younger people across three boroughs.

One memory service has adapted CST for younger people, developing resources for people with expressive language challenges, perceptual and movement issues. The multidisciplinary team runs this intervention and they are currently working with their third cohort of patients.

One service had experience of running a self-funded CST programme costing £490 for two sessions per week over seven weeks (including lunch). The service reported that the attendees evaluated the programme highly and felt that socialisation was key. From an organisational perspective, it was difficult to get the group together due to geography and cost.

The 2018 NICE dementia guideline<sup>1</sup> states that people living with mild to moderate dementia should be offered CST. The NICE 2018 dementia resource impact<sup>2</sup> estimates that staff costs per session for CST are £80.41 for an employee on NHS Agenda for Change band 6 and £52.36 for a band 4. There are likely to be additional costs in running separate CST for younger people; therefore, it would be a sensible approach for smaller boroughs to run CST jointly for younger people to ensure adequate numbers. The location of cross-borough CST would need to be carefully considered to support people living with young onset dementia to attend.

### Admiral Nursing

Admiral Nurses provide specialist dementia support to families, giving them one-to-one support, expert guidance and practical solutions. Most Admiral Nurses work in the community for the NHS, others work in care homes, hospitals and hospices. Admiral Nurses receive ongoing training, development and support from Dementia UK.

One memory service provides one to one person-centred interventions via a clinical psychologist, occupational therapist and an admiral nurse. This includes supporting people living with young onset dementia and their families for end of life care.

In January 2019 one service collaborated with Dementia UK to develop an Admiral Nurse Service based in a neurology out-patient clinic. This will facilitate streamlined therapeutic support from diagnosis through to bereavement and positive responses are already being received about the service. Their model is also helping people without family support who require therapeutic interventions (traditionally the Admiral Nurse Model works with families).

Within the NHS, the typical Admiral Nurse employment cost is £59,628 per annum. (based on London Agenda for Change band 7) and a typical community case load is 40-50 people. Admiral nurses receive ongoing training and development support from Dementia UK.

## Structured groups

One memory service has developed a peer support group; they have been able to keep costs down by using low cost rooms at a hospice and running the events in the evening and recently on a Saturday. Staff from the hospice and the memory service volunteer their free time to run the events. The events are well attended with approximately 40 people and they receive positive feedback, e.g. *'It's nice to meet others in a similar situation, I don't feel as isolated now'*.

This memory service has also worked with their local sports development team to pilot a gym-based group for people living with young onset dementia, which was made possible with charitable funds. An occupational therapist was present for the sessions to advise on adapting activities. Another group is being planned elsewhere in the borough and the memory service plans to evaluate the sessions. Positive feedback has been received, e.g. *'after the group my husband seems more alert and confident'*.

Another peer support group is funded by a hospital charity which enables it to be professionally facilitated and meet monthly at the hospital. Typically about 30 people attend, consisting of people living with dementia and their family carers. The group has been developed in co-production with people living with young onset dementia and their families and provides an opportunity to talk about the challenges of living with dementia, to share ideas and remain up to date on practical issues and scientific developments. Recent monthly topics have included assisted technology and IAPT (Improving Access to Psychological Therapies). The feedback received demonstrates the significant positive impact this group has had e.g. *'we no longer feel alone'*, *'everyone here is feeling empowered'*. The benefits of the group being run in the evening has also been highlighted. The cost of this group is £9,000 per year (facilitation and refreshments).

Part of an NHS-funded support service includes meetings for people living with rare dementias, talks from dementia researchers and telephone support. They also run groups dedicated to carers. The service is part of a wider post-diagnostic support offer which is described further below.

One peer group run by the voluntary sector provides a monthly peer support group for people living with young onset dementia and their carers including sharing personal stories and receiving practical support and information. The group is run in the evening to support attendance.

One group uses a Reminiscence Arts approach to improve the wellbeing of people with dementia and meets every other week. It supports people in adjusting to their changed life circumstances and gives an opportunity to maintain practical, cognitive and social skills. The Reminiscence Artist uses a creative approach to exploring memories, for example making a tie dye T-shirt to represent a story. The group currently has 20 members. The group has received positive feedback with 91% of people saying attending the group has helped them. The yearly cost of the group is £10,200 and is currently half funded by the local borough and half funded through external donations/funders.

Most of these groups are run through charitable funds and/or the generosity of staff volunteering; the sustainability and transferability of these models across London needs to be considered. Any new services should consider evening groups as this has been shown to support attendance.

## Individualised support and therapy

One service offers a nurse-led information and advice service including a telephone help line between appointments and following discharge to local services. Psychological interventions are also available for patients and carers where appropriate. They have also developed links with other services such as speech and language therapy which has improved access.

One memory service offers one to one input from occupational therapy, psychology and admiral nursing providing person centred interventions including: vocational rehabilitation and job retention, supporting voluntary work and supporting end of life care.

Three other memory services support people living with young onset dementia and their families with one to one support via general memory service review appointments, access to psychology and psychoeducation for carers. One service pointed out that they are reliant on being informed that people have been diagnosed with young onset dementia in their area, as they are not a diagnostic service for this client group.

The 2018 NICE dementia guideline states that carers of people living with dementia should be offered a psychoeducation and skills training intervention. The above examples demonstrate that this can be provided via a group setting specific for young onset dementia or on an individual basis. Services that do not specialise in young onset dementia will need to ensure that any carer training encompasses age specific topics such as employment.

## Training and education

One care home provider has a dementia specialist nurse who provides training and guidance to support workers and the wider team with young onset dementia (specifically rarer dementias such as Posterior Cortical Atrophy). This has enabled the support workers to be aware of age appropriate approaches and interventions.

One charitable organisation has rolled out Dementia Friends sessions to all of their volunteers and supports people living with dementia to become volunteers.

## Reflections and summary

Despite wide circulation of the letter only 11 services provided information; this could indicate that there are limited specialist post-diagnostic support services for people living with young onset dementia and their families.

CST and psychoeducation for carers are recommended in the NICE guideline and should be offered regardless of age. Services need to ensure that these are age appropriate either through individualised sessions or specific young onset dementia group sessions. Due to the relatively low numbers of people with young onset dementia it would be more sustainable for boroughs to run these jointly.

Peer support groups are being run in some areas of London at low cost through charitable support and volunteers. These models and funding mechanisms should be shared across London to ensure that everyone living with young onset dementia can access a peer support group; boroughs working jointly to achieve this will help with access and sustainability.

Several services that specialise in young onset dementia offer ongoing support through various means, including follow up appointments and telephone or email advice channels. Currently, people living with dementia are typically discharged from memory services soon after diagnosis; therefore, there needs to be consideration of how people can receive long term contact from a service with expertise in young onset dementia.

The impact of dementia can be significantly different for younger people, they are more likely to have a mortgage, they are more likely to be employed and they are more likely to have children to care for. Services therefore need to ensure that they can meet the individual needs of younger people with dementia and their families.

In summary, in order to ensure that the requirements of the NICE dementia guideline are met and interpreted appropriately for people living with young onset dementia, commissioners and service providers should ensure that every person in London diagnosed with young onset dementia has access to:

- age appropriate CST
- age appropriate psychoeducation for carers
- ongoing access to advice from a service with expertise in young onset dementia

We would also recommend that people living with young onset dementia have access to a peer support group due to the positive feedback these groups have received and that they can be provided at a relatively low cost

We would like to thank the services who took the time to submit information for this survey.

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1 National Institute for Health and Care Excellence 2018. Dementia: assessment, management and support for people living with dementia and their carers (NG97)

<https://www.nice.org.uk/guidance/ng97>

2 National Institute for Health and Care Excellence 2018. Resource impact report: Dementia: assessment, management and support for people living with dementia and their carers (NG97)

<https://www.nice.org.uk/guidance/ng97/resources/resource-impact-report-pdf-4897901485>