

Imperial College London Young Onset Dementia service A report for the Andrée Griotteray White Charitable Trust

Dementia UK is extremely grateful to the Andrée Griotteray White Charitable Trust for your extremely generous donation of £54,000 last year, which funded the creation of the new Young Onset Dementia Service at Imperial College London. We are delighted to provide you with this short update report to outline how the project is progressing, and the support it has already begun to provide for families since it started in January 2019.

About the service

Dementia can affect a person at any age but it is more commonly diagnosed in people over the age of 65 years. A person developing dementia before age 65 is said to have young onset dementia and affects an estimated 42,000 people in the UK. Young onset dementia can cause additional challenges for families and there are few services available to meet these needs. For example, the diagnosis is often unexpected and the loss of income (sometimes double as a partner may give up work to care for their family member) can be difficult to manage. Social isolation is a significant cause of distress which can affect the whole family and the person's children may be younger and also have to take on caring roles as the condition progresses.

In partnership with Imperial College NHS Trust's specialist assessment centre for southern England, this project aims to support families in the clinic at the difficult time of diagnosis and as the illness progresses. The Senior Admiral Nurse works with families to understand the diagnosis, and provide ongoing specialist support, practical solutions and tools (including support for any children and helping families access what services are available locally). As the lead expert, they will also support, mentor and train healthcare colleagues.

Setting up the service

The Young Onset Dementia Service at Imperial College Healthcare NHS Trust (ICHT) is unique in that it is based in a neurology out-patients clinic and specifically supports people with young onset dementia (YOD) and their families. The Admiral Nurse recruited into the role, Amy Kerti, has extensive background in Mental Health and Cognitive Neuroscience and has been an Admiral Nurse since 2013.

Since launching in January 2019, the main focus of the Young Onset Dementia Service has been to develop clinics for people with dementia and their families. The service is based in West London and referrals come from across the country. As well as distance, employment, parenting and care demands mean that it is not easy for people to access face to face clinics, so the Senior Admiral Nurse has developed additional "virtual clinics", using video calls and telephone, allowing for greater flexibility and more frequent support if necessary.

Caseload and support

To date there have been 54 referrals to the service (from the neurology out-patients clinic):

- Thirty had significant difficulties associated with young onset dementia such as employment challenges, impact on children, financial difficulties, and relationship stressors.
- Three required liaison with Admiral Nurse Services in other regions to sustain support.
- Three of the referrals with the most prominent needs were related to genetic conditions where there were children in the family.
- Eight referrals constituted typical Admiral Nursing criteria: two needed to develop skills to care for the person living with dementia; one carer was struggling to adapt to diagnosis; four had complex family dynamics; one carer was struggling to care for their own needs.
- One was because the person living with dementia and the carer were struggling post-bereavement.

The Senior Admiral Nurse can work either with the person living with YOD, or with the family carer(s) - or both depending on needs identified. Of those referred so far:

- The carer required greater support than the person living with dementia in 25 of the referrals.

- In 13 referrals all family members (the person living with dementia and the carer(s)) required similar levels of support.
- The person living with dementia required more support than the rest of the family in five of the referrals.
- Two people living with dementia had no carers.

Although it is too early in the project to provide a detailed case study, examples of the support the service has provided already include:

Family carer support:

A family carer of a loved one with a rare form of YOD is in a state of distress trying to juggle work, their own poor physical health, exhaustion, anxiety and depression - but is unable to recognise this themselves. The person with YOD has been unwell for many years and the carer's own poor physical health is deteriorating as a result of managing the caring role while working. There is an increased potential for care home admission due to the number of difficulties the family faces and behaviours resulting from the complex presentation of this particular type of dementia.

The Senior Admiral Nurse is working with the carer to make sense of their grief, increase their understanding of the condition; adopt strategies for increasing caring abilities as well as how to look after their own health and the need for rest. The Senior Admiral Nurse is also liaising across services to ensure joined up working and provide education and management strategies to other healthcare and public sector services involved with the family.

Support for people living with YOD without family support:

In just 13 weeks in post, the Admiral Nurse has worked with more than one individual who has expressed a desire for assisted suicide. These individuals are struggling with a loss of identity.

The Senior Admiral Nurse is working intensively to assist them to reclaim and redevelop their identity, develop adaptive skills to undertake tasks that were previously easy, incorporate new and different goals and purpose while also working with the individual through the grief and loss experienced.

Other activities and future plans

The Senior Admiral Nurse is working with people living with YOD to create post-diagnostic support groups which focus on living well with these conditions, therapeutic support for the individual and/or the family and introductions to others in similar situations. The Senior Admiral Nurse and people with YOD are working with other organisations to create long-term groups. The aim of these groups is to help sustain a positive support network to increase well-being and reduce the impact of challenging symptoms and caregiver distress to try and keep families well and together for longer.

Networking across organisations and services is a large part of the Admiral Nurse role, so that services can work together to identify any gaps in needs and what is working well. They also look at how best practice can be adopted by the Admiral Nurse service at ICHT to complement other services. The Senior Admiral Nurse is working to strengthen pathways between other Admiral Nurse Services so that they do not overlap and so that people with young onset dementia and their families receive the most relevant support.

The Senior Admiral Nurse has also worked on a number of other projects during this time. She:

- Participated in an initiative created by The Mayor of London and the London Dementia Clinical Network to identify services for YOD within the London area.
- Has joined a Working Group for YOD created by Dementia UK to pull together expertise and inform best practice on a national level.
- Is presenting at the annual national Dementia Congress in order to help influence the practise of others working with people with YOD. Education and support for other services coming into contact or supporting people with YOD is an important part of her role.
- Planning a potential piece of work to explore the difficulties faced by children in families of YOD. Research and support in this area is limited and it is not only important to understand the effects of these conditions on children, but also to develop supportive interventions that enhance the current and future well-being of children in families with YOD.

Conclusion

The support of the Andrée Griotteray White Charitable Trust has been the most significant contribution to the creation of this vital new service, which is already helping families to cope with the demands of caring for a loved one with Young Onset Dementia. We would like to thank you very much once again, and look forward to providing you with further updates about the work Amy is doing, as this important and innovative project progresses.

Thank you very much