

# Young-onset dementia multidisciplinary team meetings

## Why do we need multidisciplinary team (MDT) meetings?

Diagnosing young-onset dementia (YOD) can be complex, leading to longer waits for a confirmed diagnosis. People with suspected YOD can experience disjointed diagnostic pathways and sometimes unclear post-diagnostic support pathways. Due to the rarity of YOD, clinical expertise in this area is spread thinly.

## Why YOD is challenging to diagnose

The London Assembly Health Committee recently held <u>an investigation into young-onset dementia</u> (YOD)<sup>i</sup>. It found:

'People living with YOD report significant frustration engaging with services – including health and care services – which do not recognise or accommodate their specific needs. Even getting a diagnosis can be a significant challenge, particularly for those with more "atypical" symptoms such spatial or language problems which can be confused with other conditions.'

There is a stark difference in time taken to diagnose young-onset dementia (YOD) compared with late-onset dementia (LOD). Research has highlighted that the duration from symptom onset to the diagnosis of YOD exceeded that of LOD by an average of 1.6 years (2.8 versus 4.4 years)<sup>ii</sup>.

NICE clinical guidance<sup>iii</sup> states that if the diagnosis of Alzheimer's disease is uncertain, clinicians should consider either cerebrospinal fluid examination or FDG-PET. It is essential that people with suspected YOD can access these investigations, which are not currently available to the vast majority of memory assessment services (MAS). Consequently, an MAS patient might be referred to neurology as the quickest way to access relevant expertise, with consequent duplication of clinical activities.

Monthly MAS and neurology MDT meetings are a simple and relatively inexpensive approach to ensure accurate and timely diagnosis and avoid unnecessary duplication of clinical assessment.

### **Elements for successful MDT meetings**

To ensure MDT meetings are as high value as possible, the following areas should be considered:

## **Commissioning**

- Clinical sessions for monthly meetings should be formally commissioned. This will help to ensure frequency and attendance. It is recommend that 1PA (3.5 hours) per clinician per month is commissioned (for face to face meeting and preparation / administration time).
- If meetings are held through local clinical relationships and not commissioned, services may wish to consider rotating attending staff to minimise individual impact.

#### **Attendees**

- Memory service staff and a neurologist with a special interest in cognition should attend meetings. Where possible, a neuroradiologist should also attend.



# **Imaging**

- If neuroimaging has not taken place at the meeting host site, scans will need to be transferred to the host site via the image exchange portal. This should be requested at least one week before the meeting.

# **Clinical information**

- Services may want to share other clinical information (for example, reports and cognitive tests) prior to the meeting via a secure process, such as nhs.net email.

# **Meeting structure**

- It is suggested that meetings last for 90 – 120 minutes to enable sufficient time to discuss each case, review imaging, and agree assessment / investigation and post diagnostic support plan.

### **Evaluation**

- When starting these meetings, services may want to consider using a plan, do, study, act (PDSA) approach to maximise the outcome and benefits of meetings.
- Services should consider collected information on the outcome of the meeting (for example, number of clinical decision changes, number of duplicate assessments avoided) to monitor the effectiveness of meeting.

## **Summary**

Diagnosis of YOD can be complex, and specialist investigations are sometimes required. Monthly MAS and neurology MDT meetings are a simple and relatively inexpensive approach to ensure accurate and timely diagnosis and avoid unnecessary duplication of clinical assessment.

<sup>&</sup>lt;sup>i</sup> London Assembly Health Committee, *Young-onset dementia*, <u>link</u> (2018).

<sup>&</sup>lt;sup>ii</sup> Van Vilt, et al, *Time to diagnosis in young-onset dementia as compared with late-onset dementia, link* (2013).

iii NICE, NG97 - Dementia: assessment, management and support for people living with dementia and their carers, <u>link</u> (2018).