

Commissioning person-centred support for people in Trafford living with cognitive impairment.

Why is pre-and post-diagnostic support vital for people living with dementia or mild cognitive impairment:

Growing evidence suggests that supporting lifestyle alterations for people with a mild cognitive impairment (MCI) and dementia could improve the health of their brains, their physical health and wellbeing; and it could even slow down the progress of cognitive decline, enabling them to stay independent for longer. Early intervention and support is essential to help people maintain independence, purpose and belonging, despite dementia. Therefore, the support and advice people receive pre-and post-diagnosis, is crucial for their wellbeing, disease prognosis and ability to continue to live independently for as long as possible.

How does Trafford address this need?

Age UK Trafford has been supporting people with dementia and their carers for nearly 30 years. Initially this was through day care and later included a Dementia Advisor service commissioned by Trafford PCT (now CCG) and Trafford Council.

However, in 2017, a new contract was drawn which included additional funding to support people with Mild Cognitive Impairment (MCI). This added value to the existing service, and ensured that the GM [Recommendations for MCI were implemented in Trafford](#).

The local pathway is novel, since it encourages GP's and the local MATs team to work closely with AgeUK as a post-diagnostic support provider, sharing patient information and referrals.

The service is jointly commissioned by Trafford CCG and Council, and the current contract runs from 2019 until 2024 (including extensions). The service is made possible by CCG/Council funding to the sum of £116,000 per-annum, alongside significant support and additional resources from the local AgeUK team who see dementia and MCI support as a key part of their service provision.

The service:

- GPs refer patients with cognitive impairment and memory problems to Trafford MATS.
- Upon receipt of a complete referral, the MATS team refers the patient **immediately** to Age UK Trafford Memory Loss and Dementia Advisory Service (i.e. pre-diagnosis). This allows rapid access to information, advice, and person-centred support for people with memory issues and their families or carers during a worrying time.
- MATS will confirm the outcome of investigations and any treatment/care plan in due course and discharge the patient to the care of their GP.
- The person living with dementia or MCI will continue to access a range of post-diagnostic support in the community via Age UK Trafford and community partners.

Presently (2020) there are approximately **2000+ people** with dementia or MCI on AgeUK's dementia service database and they receive on average **70 new referrals per month**, on average the service has **contact with 300+ people each month**.

Implementation:

An important facilitator for this service is a data sharing agreement between AgeUK and Trafford MATS. This is an opt-out agreement, meaning that **every patient referred to the MATS team will be referred on to AgeUK for pre/post-diagnostic support unless they request not to be**.

This agreement was facilitated by the CCG (PCT) and local mental health Trust GMMH (under its previous name GMW) as part of a contractual arrangement. Data was originally transferred by fax,

directly to the dementia service administrator’s email. **This was improved about 4 years ago by introducing NHS email addresses for the dementia service staff.** Data is now transferred securely via this route. The MATS team obtains consent to share data with AgeUK Trafford by writing to the patient, providing 7 days to opt out by responding to the initial letter sent by MATS. Alternative methods have been trialled (for example opt-in) but these were not successful.

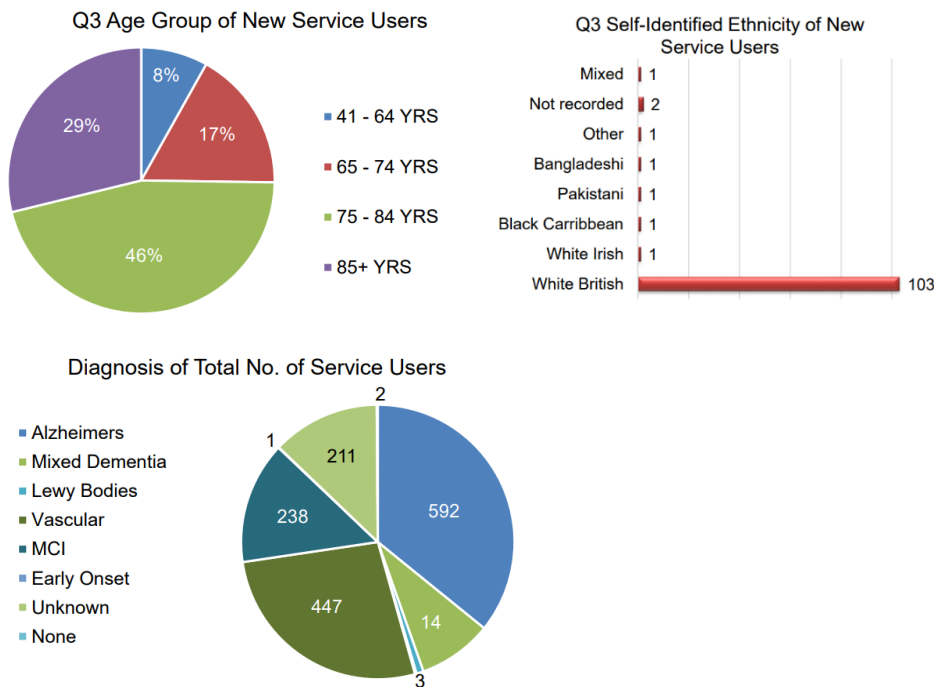
Staffing and sustainability:

- Staffing: two x 32hr dementia advisors, one x 14hr MCI community connector and one x 25hr administrator
- Management: ongoing management is carried out by the Service Development Manager and Chief Executive, this support is in addition to the funded roles and managed through AgeUK.

Patient support offered includes:

- Dedicated telephone helpline, email and bi-monthly newsletter
- Named advisor makes initial contact. Support prior to diagnosis
- Support from adviser is ongoing throughout their dementia journey
- 4 monthly ‘Hub’ meetings and drop ins for people with dementia and carers in locations across borough
- Weekly MCI session
- Support offered with financial and legal planning.
- service users have regular reviews (3-6 months or when needed)
- awareness events, training and social events
- Dementia specific day care service available
- Links to social prescribing.

Key outcomes, demographic (data collected in Q3 2021):



Key outcomes, service user Feedback:

“Thank you so much for persuading me to have a benefits check. I now receive an extra £80 per week, which has made such a difference to the quality of our life”

“Without Age UK Trafford, I would be really struggling. After my husband was diagnosed your service has been invaluable”

“Thank you so much to the team at Passion for Life, without you my dad wouldn’t have been able to live as well and for as long as he did in his own home”

“We were more than delighted to be granted Attendance and Carer’s Allowance, so we send you our most sincere thank you”

“Thank you for your productive visit to us, your guidance and advice was amazing”

Key messages:

- Co-working alongside clinical teams, in this case an opt-out and data sharing agreement with Trafford MATS, is essential to ensure patients receive the support they need pre-and post-diagnosis.
- CCG and Council commissioned support is required to ensure capacity is sufficient to support all those with a diagnosis.
- This service is provisioned via an organisation who see dementia as a strategic priority and are willing to commit their own time and resources to ensuring success.