Greater Manchester Health and Social Care Partnership

A GREATER MANCHESTER APPROACH TO YOUNG ONSET & RARER FORMS OF DEMENTIA

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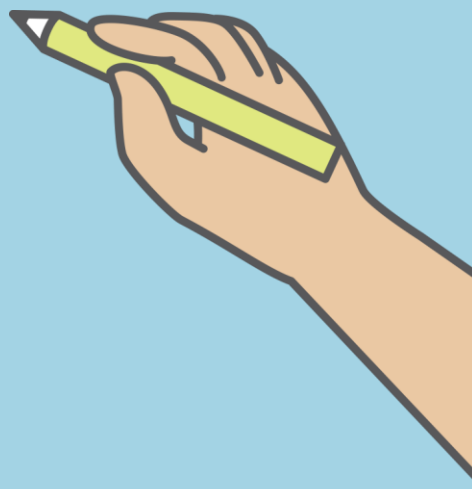

GMCA GREATER MANCHESTER COMBINED AUTHORITY

NHS in Greater Manchester

In collaboration with:

NHS Greater Manchester and East Cheshire Strategic Clinical Networks

Dementia United

Purpose

This document has been created following a 2 year consultation and information exchange with a task and finish group, locality multi-disciplinary teams and experts at the Cerebral Function Unit (CFU) in Salford.

The purpose of this document takes this work forward to describe additional recommendations that would enhance a person-centred pathway for those suspected of or diagnosed with young onset dementia (i.e. under 65 years of age) or a rarer form of dementia e.g. frontotemporal dementia (FTD) across Greater Manchester (GM). It purposefully does not describe who and where the recommendations might be delivered, as this may vary between localities, aligned to local commissioning arrangements. It is also recognised that further work is needed to look at potential capacity and demand issues.

Background and evidence

We have been working across GM to understand the needs of people with a young onset or rare dementia and those that support them. As part of this journey we have spoken to people with dementia, their family members and staff within health, social care and the voluntary sector across GM. We have consulted research and policy in this area. We found examples of good practice but also found considerable variability in provision.

Services were often configured around the needs of older people and those with more common dementias such as Alzheimer's disease or vascular dementia, with pathways into service via 'memory clinics'. Service providers and people with dementia told us that a range of conditions challenged these service models. Diagnosis could often be complicated and protracted: dementia was not expected at a younger age; those with atypical or rarer dementias did not always present with memory problems but with changes in behaviour and language; in some instances dementia occurred alongside a progressive neurological condition or a learning disability; for others dementia arose in the context of alcohol dependency. There was not a clear pathway into services, with multiple routes potentially occurring via working age adult mental health, memory clinics, older people's mental health or neurology services. Referrals from one service to another extended the time to diagnosis.

Once a diagnosis was given then post diagnostic support was not always suitably tailored to need. Advice did not take account of life stage, with those younger needing advice about work and financial issues such as impact on pensions and mortgages. A family centred approach was needed to take account of the effect on children, in some instances still of school age. Advice was required for a wide range of cognitive symptoms. Adapting to a diagnosis of dementia at a young age was psychologically challenging but this was made worse when people with dementia and their family members found themselves grouped with much older individuals. Family members had questions about genetics which required considered and specialist responses. For those with a progressive neurological condition, community neuro teams managed physical and cognitive changes well but were not always geared up to dealing with significant behavioural changes.

Diagnosis

After an NHS England led initiative, the dementia diagnosis rates for those over the age of 65 largely retains its target of **67%** across England. However this initiative failed to include those under the age of 65 and consequently there has been no encouragement of primary care to consider a young onset dementia diagnosis. The estimated prevalence of young onset dementia in England is 35,626 (derived from the UK figure of 42,325 - Ref: Dementia UK, 2nd edition 2014, Alzheimer's Society) but the recorded diagnoses are 16,353 (NHS Digital) giving a diagnostic rate of **45.9%**.

It is likely someone with undiagnosed young onset/rare dementia will first present to their GP. However GPs are not always taught to recognise the red flags for young onset/rare dementia, which may be different to those with dementia over 65. After this first hurdle, it is often not clear who the GP should refer this patient to. For example, in some localities a person must be over 65 to be referred to the memory service with the aim to receive a diagnosis within 12 weeks. However if the patient is under 65 they are referred to the mental health access team (even if the GP strongly suspects dementia), potentially leading to several referrals starting within working age adult mental health, including different screening appointments and scans until they eventually get a diagnosis.

In Greater Manchester, we are fortunate to have the Cerebral Function Unit (CFU) based at Salford Royal, which specialises in the recognition and diagnosis of young onset and atypical neurodegenerative dementias. They have access to essential investigations (e.g. structural imaging, both CT and MRI, PET scanning and CSF sampling), and access to genetic testing as recommended in NICE guidelines. However referrals proportional to the young onset dementia cases in each locality vary across Greater Manchester with Bury, Stockport and Trafford referring more than Bolton, Salford and Wigan. There may be multiple reasons for these differences, but further exploration is needed to ensure there is equitable access to the CFU's specialist expertise, in practice and research, and the potential impact on accuracy of diagnosis.

Research indicates that chaotic care pathways, under referral from primary care and complexity of diagnosis contribute to the prolonged average delay to diagnosis, estimated at 4.4 years in younger people compared to 2.2 years for older age dementia [Van Vliet et al, 2013]. This diagnostic delay is not only distressing but leads to an inequality in access to post diagnostic support. For someone under 65 post diagnostic support needs to take account of matters relevant to their stage in life including advice around work and financial commitments such as mortgages and pensions and family centred advice as they may be carers of young children or older parents. Timely advice around such matters is crucial.

After a diagnosis is made, there is then the issue of coding and accessing this diagnosis. When recorded in GP records, there is currently only a code for those with young onset Alzheimer's Disease and no other subtype of young onset dementia. Rarer dementia codes can be inadequate and do not stipulate diagnosis under the age of 65, which for rarer dementias is often the case. Finally if someone is diagnosed with young onset dementia and then turns 65, they should still be considered to have this diagnosis with its unique requirements. This is often not appreciated either. Inadequate coding hinders services to appropriately plan and provide support for this target audience.

Post Diagnostic Support

Between 5% and 15% of people living with a dementia have a rare dementia (Rare Dementia Support). This can bring with it a unique and complex set of challenges, including difficulties with language, vision, movement and behaviour. However, there is a widespread lack of understanding and often, a shortage in the resources needed to support those affected.

It is well documented that access to appropriate and timely post diagnostic support has a positive impact following a dementia diagnosis however a lack of specialist clinical support and relevant social support in the community is often the reality that faces these groups.

In our discussions with localities we found that staff did not always feel confident in their understanding of when younger onset and rarer dementias might be hereditary. There was a lack of confidence in performing appropriate diagnostic genetic tests and in managing patient and family expectations regarding referral for genetic counselling.

Next Steps

So what can be done to address diagnostic and post diagnostic support issues for those with young onset and rare dementia and their carers? These steps are based on the work of Young Dementia UK and at a Greater Manchester level, Dementia United:

Diagnosis

1. The Young Dementia Network has developed a GP decision-making guide which includes a series of leaflets and posters to aid the recognition of the symptoms of dementia in younger people, which has been endorsed by the Royal College of GPs. These could be publicised via GP networks as a reminder that it is not just those over 65 who get dementia.
2. As part of the dementia diagnosis rates initiative, review the GP dementia diagnosis coding used for young onset and rare dementia diagnoses. Investigation at a local level to ensure consistency by both staff and systems entering diagnosis codes. Consider codes from NHS agreed lists to be included in correspondence to GPs from services confirming the diagnosis.
3. Ensure that family members/carers are involved in the diagnostic process where appropriate. This is to ensure an accurate history is taken from different perspectives and needs assessment takes a broader perspective to include all those supporting the person with potential dementia.
4. Consider rebrand of “Memory Clinics” to “Brain Health Clinic” or “Healthy brain and support service”. Memory loss is not the only symptom of dementia, especially for those with young onset and rare dementia.
5. Memory Clinics to work with working age adult mental health services to agree what would warrant an appropriate referral to memory clinic for a suspected young onset or rare dementia e.g. in particular, if this is the first time a patient is presenting to mental health and they have red flags for young onset/rare dementia, they may be a reasonable candidate for a memory clinic referral.
6. Improve links with the Cerebral Function Unit (CFU) across Greater Manchester. It is understood memory clinics may have expertise to diagnose young onset and rare dementia in house. However ideally there should always be at least one person in every Greater Manchester memory clinic who leads on young onset and rare dementia with a direct link to the CFU so those patients can be jointly managed where appropriate. This would improve communication between services and also maximise any research opportunities.

   NOTE: It is important that any referral that is made to the CFU where a young onset/rare dementia diagnosis is made, the patient is referred back to the referring memory clinic so the patient can access appropriate local post diagnostic services. The CFU are open to memory clinic “young onset and rare dementia leads” shadowing the CFU staff so they can familiarise themselves with the service on offer and decide how they can best work together.

   In December 2020, Dementia United hosted a Young Onset/Rare Dementia Diagnosis masterclass with case studies presented by the CFU. 70 people attended from Greater Manchester secondary care mental health services with 100% of attendees who provided feedback (38) consequently felt more aware of the issues pertinent to diagnosing young

onset and rare dementia. It may be worth considering hosting a similar event for primary care..

Post Diagnostic Support

1. Education for staff working in services providing support within health and social care and the voluntary sector to facilitate more appropriate and personalised care for those with the diagnosis and their families. By increasing awareness of dementia in people below the age of 65 and rarer forms such as frontotemporal dementia (FTD), this will emphasise the need for support which differs from that associated with traditional pathways. The Young Dementia UK website has some great resources including this dementia adviser checklist to help ensure support is age appropriate. The dementia adviser is not expected to be able to cover all areas but should be able to signpost as necessary. Rare Dementia Support are also available to offer remote support across the UK. Follow the link to be directed to Pennine Care's FTD videos hearing from clinical and carer experts.
2. Family members should be offered a carer's assessment. Additional information may be required as younger onset family members may not perceive themselves as 'carers'. These carers should be added to the carer register at the GP practice and signposted to relevant peer support groups in their locality, across Greater Manchester (GM) and national online groups.
3. For those with progressive language disorders referral to speech and language therapy should be considered so that tailored support for communication can be offered. Therapists themselves can contact their professional body RCSLT and ask for advice from an adviser in dementia care to support their own learning if needed. Together with Pennine Care we have created a film on Primary Progressive Aphasia and the role speech and language therapists can play.
4. Referral to an Occupational Therapist and other Allied Health Professionals in the community should be considered to support individuals to adapt to their diagnosis and remain as physically and socially active as possible.
5. Existing community teams (including learning disability and community neuro teams) to work more closely together to better support those presenting with more complex/bespoke commissioning needs and enable relevant referrals into specialist mental health colleagues for assessment and risk mitigation.
6. Localities to review their community services for people with young onset or rare dementia to establish the current baseline and identify gaps and opportunities to enhance support both within the locality and by working with neighbours across GM.
7. A GM collaborative service approach led by commissioners and dementia leads within the localities could enable a 'pooling' of existing resources for these groups which are lower in numbers than those over the age of 65. A partnership way of working or memorandum of understanding between localities will promote equity of access to post diagnostic support, sharing of good practice and a more efficient way of working.

In February 2021, Dementia United hosted a Young Onset/Rare Dementia post diagnostic support webinar. Jan Oyebode spoke about the Angela Project, Ronnie spoke about his personal experience of living with young onset dementia and we hosted a panel between different Salford, Manchester and Stockport post diagnostic services as well as Oldham commissioning. The feedback suggested that 70% of attendees currently thought support

for this audience was inadequate. It also highlighted that the main thing that attendees took away was the desire to network and learn more about young onset and rare dementia services available across GM to facilitate shared learning, joined up practice and better support.

8. Investigate the inequalities for the eligibility and use of personal budgets in GM which is variable by locality. There are positive examples of where utilisation of personal budgets have been successful in supporting these groups, however current inconsistencies mean not everyone in GM is able to benefit. Promotion of the Personal Budgets Leaflet drafted by the Task and Finish Group along with service users in Stockport will support those diagnosed and/or their families/carers to start the application process with their local service provider. This can be found on the Dementia United Website Resources Page (scroll down to "Young Onset and Rare Dementia")
9. Localities have a nominated staff member with the appropriate training, knowledge and experience to facilitate appropriate diagnostic genetic testing. Alternatively localities need a pathway for onward referral to a service that specialises in this aspect of younger onset and rarer dementia management (such as cognitive neurology or clinical genetics teams)
10. Input and contribution to the Dementia United priority workstream of Post Diagnostic Support to ensure the needs of people with young onset and rarer forms of dementia are fully embedded into any subsequent pathways or guidance.

Impact and evaluation

1. Increase in dementia diagnosis rates for those with young onset and rare dementia to better inform requirements for post diagnostic services and improve access.
2. Shorter duration to receive a diagnosis of young onset and rare dementia so people can access support quicker and reduce the devasting impact on their personal, family, financial and professional circumstances.
3. Better links with the CFU supporting good quality referrals across GM to increase the accuracy of young onset and rare dementia diagnoses and access to investigations as recommended by NICE.
4. Evidence of enhanced partnership working across GM in the delivery of services via a memorandum of understanding or other arrangements

References:

- **The Angela Project** - Good Practice in Young Onset Dementia - Improving diagnosis and support for younger people with dementia
- **Young onset dementia care pathway - Young Dementia UK**
- **2020 Action on Young Onset Dementia – Report and Recommendations** (**Peter Watson**, Dementia Programme Board, Member Young Dementia Network, Trustee YPWD Berkshire CIO, former carer of person with young onset dementia; **Tessa Gutteridge**, Director – Young Dementia UK, Chair Young Dementia Network; **Janet Carter**, Senior Clinical Lecturer Old Age Psychiatry UCL, Consultant Old Age Psychiatrist NELFT, Member Young Dementia Network; **Jacqui Hussey**, YPWD Berkshire CIO; **Jan Oyebode**, Professor of Dementia Studies, Centre for Applied Dementia Studies, University of Bradford; link to BPS Faculty of Psychology of Older People, Member Young Dementia Network

2020 Action Report on YOD 30-09-19.pdf

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