

Beyond the Diagnosis

Young Onset Dementia
and the Patient Experience

November 2017

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Definition of terms and acronyms

MMHSCT - Manchester Mental Health and Social Care Trust, the previous provider of mental health services in Manchester prior to the transition to Greater Manchester Mental Health NHS Foundation Trust in January 2017.

GMMH - Greater Manchester Mental Health NHS Foundation Trust, also referred to as the Mental Health Trust.

Later Life Mental Health Services - Services from the Mental Health Trust that provide psychology, counselling and mental health occupational therapy services to people in later life experiencing psychological and emotional difficulties specifically associated with ageing or age-related needs. This includes Dementia and Young Onset Dementia.

Young Onset Dementia - Dementia is considered 'Young Onset' when it affects people under 65 years of age. It is also referred to as 'early onset' dementia. Although younger people can experience similar symptoms to older people with dementia, the impact on their lives is significantly different. Younger people are more likely to still be working when they are diagnosed. Many will have significant financial commitments such as a mortgage. They often have children to care for and dependent parents too. Younger people with dementia also tend to be more physically fit and active.

Ring & Ride - Ring & Ride provides short local trips to eligible residents of Greater Manchester. If you are a registered user you may travel to any location within 6 miles of your home address within Greater Manchester.

Executive Summary

Recent transformations of Later Life Mental Health Services by the Mental Health Trust have put a greater emphasis on improving shorter duration urgent and crisis support, and safer discharge from inpatient or A&E units to prevent relapses and reduce the number of readmissions. Some of the longer term wellbeing services (such as access to the dementia garden at Victoria Park) were thus reduced or are no longer provided by Later Life Services. At the same time, the number of dementia friendly activities and social groups in the community remains few and far between, leaving people living with dementia and their carers very few options to stay active and engaged in the community.

To achieve a truly integrated health and social care system in Manchester, statutory services need to build up stronger links with individual grass-roots organizations. Commissioning bodies need to have a holistic overview to balance the capacity and demand for both NHS services and their associated voluntary sector services.

Recommendations

More can be done to help people living with dementia and their carers find the support they need in Manchester, enable them to maintain a sense of wellbeing, stay active and remain supported in the community. To achieve this, the Mental Health Trust needs to develop stronger links with local dementia groups. Barriers of access to statutory services need to be reduced. Information sharing in the community through local groups should also be looked at.

Here are our recommendations based on the findings from this report:

1. Users who don't have a formal diagnosis of dementia can find it difficult to access support from statutory NHS services and can be cut off from essential updates and information until their condition deteriorates much further. By working with voluntary sector dementia groups, the Mental Health Trust can better identify and provide better support to people with Mild Cognitive Impairments or early forms of dementia to help people remain independent for longer.
2. Local grass-roots dementia groups want to have a stronger link with the Mental Health Trust and a single point of contact who is able to provide regular updates and help with referrals to memory assessments and other mental health services. Not all GP practices specialise in dementia care. Providing more innovative referral pathways in the community can also reduce the burden on primary care.
3. Dementia Support Advisors should be given enough resources to increase their coverage and maintain regular visits to local dementia groups. Some local groups supporting dozens of families affected by dementia have never met and did not know how to contact the Dementia Support Advisors.
4. The three dementia cafes run by the Admiral Nurses should remain open to all users with different levels of dementia without special referrals, including those that are not yet "known to services". This would improve the sharing of best practices for providing dementia care at home and help the trust identify families who are not yet in touch with mental health services.
5. With the advent of the New Models of Care, Commissioners need to ensure that there is enough investment in the community to fill the gap left by the redesign of NHS services. "Day Care" type dementia services in Manchester that were primarily aimed at promoting social interactions and reducing isolation are no longer provided by the Mental Health Trust. At the same time, there are very limited activity groups in the community to help people remain active, especially for people living with Young Onset Dementia.

6. In addition, with more services being commissioned in the community out of clinical environments, Commissioners need to enable GPs to do more social prescribing. People are often not told about what dementia support services are available in the community, this has to change.

7. Transport remains a big challenge for people living with dementia trying to access services in the community. This needs to be a top priority in any discussions on forming a dementia strategy for Manchester. Ring & Ride provides an important service but is currently not able to meet the needs of people living with dementia.

8. Alzheimer's Society's Dementia Connect database for dementia services need to be more widely promoted to encourage new services to add themselves to the database.

9. More black and ethnic minority dementia groups are needed in Manchester. Information on dementia in other languages and information that specifically target BME communities is still quite limited.

1. Introduction

1.1 Healthwatch Manchester (HWM) published a project summary report in 2015 that looked into users' experience with dementia services in Manchester [1]. Our survey found that referrals to dementia assessments and diagnosis times varied hugely across different parts of Manchester. It was also a common experience amongst the carers and patients that we spoke to that very limited information on local support services (such as dementia cafes, peer support groups, activity groups) was given by health professionals during or post diagnosis.

1.2 HWM fed back the findings and recommendations from this work to the local Dementia Action Alliance (DAA), the Later Life Services team at the Mental Health Trust, and to the commissioning team at the Manchester City Council that were developing the Manchester Dementia Strategy [2]. HWM also joined the Manchester DAA and continued to monitor the delivery of dementia services.

1.3 In the past two years, Dementia services in Manchester have been changing as part of the Later Life Mental Health Services redesign initiated by the then Manchester Mental Health and Social Care Trust (now provided by the Greater Manchester Mental Health NHS Foundation Trust - GMMH) [3].

1.4 During this period, users had raised concerns with HWM about some of the service changes, especially around Young Onset Dementia Services.

1.5 HWM carried out some research work to explore these concerns. This report includes our findings from this work and aims to highlight some of the challenges that people living with dementia and their carers can still face today when trying to find and access the support they need in Manchester.

2. Background & Rationale

2.1 Service users with Young Onset Dementia reported to the Manchester DAA in August 2016 that the service redesign at the Victoria Park day centre had quite an adverse impact on them. There are very few support services in Manchester that cater for people living with Young Onset Dementia.

2.2 Following this initial feedback, similar concerns and individual cases were also reported to Healthwatch Manchester (HWM) through our Community Champions who visit local dementia cafes and community groups.

2.3 During this period, the Mental Health Trust in Manchester transitioned from the old Manchester Mental Health and Social Care Trust into a new provider the Greater Manchester Mental Health NHS Foundation Trust (GMMH). The process completed in January 2017.

2.4 At our initial meetings with GMMH, HWM mentioned the concerns about the lack of Young Onset support services. The hope was that services may be organised differently under the new provider. HWM reinitiated this work in 2017.

3. Methodology

3.1 HWM got in touch with the Manchester Later Life team at GMMH in early 2017 to discuss the concerns about the lack of Young Onset Services and to get the latest updates on dementia services in Manchester. A site visit to the Victoria Park Day centre was arranged in April 2017.

3.2 Our volunteers carried out some research to map out the availability of local dementia support groups in Manchester by using Alzheimer's Society's Dementia Connect online database (see Appendix I).

3.3 Our volunteers also used the 2011 Census data from the Office for National Statistics to map out areas of Manchester that have higher numbers of residents that are aged 60 and above who are more at risk of having dementia as an age group (see Appendix II).

4. Key Findings

Dementia services in Manchester were transformed in the past two years under the Later Life Services redesign by the Mental Health Trust. Here are the key findings based on our discussions with staff from the Later Life team and feedback that we have received from service users and local voluntary sector dementia support groups.

4.1 Most statutory dementia services offered by the Mental Health Trust are only available once a user has a confirmed diagnosis of dementia. Users have to be "known to services" for most types of referrals.

- Users who don't have a confirmed diagnosis of dementia can thus find it difficult to access any services (and therefore don't receive the relevant updates on services) until their condition deteriorates much further. Users also get very limited information from their GPs about what dementia support groups are available in their community.

4.2 This includes the three dementia cafes that were provided by the Admiral Nurses (in North, Central, and South Manchester). These groups offered a safe environment where users and carers could meet each other, socialise, seek advice from professionals, and were the main sources of information for most families caring for someone living with dementia. These groups can now only accept users that are known to the Mental Health Trust.

- There are a number of voluntary sector dementia groups in Manchester (See Appendix I). However, GPs and other health professionals are often unaware of these services or are reluctant to refer users to non-statutory services.
- Users without a formal dementia diagnosis are often left on their own until they hear from a friend about one of the local support groups in their area.
- Within Manchester, there are fewer dementia friendly activity groups in the north and some locations in the south such as Wythenshawe (see Appendix I, Table 3). These locations have higher number of residents that are aged 60 and above compared to central Manchester, and are more likely to have higher demand for dementia services (see Appendix II).
- For Black and Minority Ethnic (BME) users, there are even fewer groups that are able to meet their cultural and language needs. Users travel from other parts of Greater Manchester such as Bury, Oldham, Middleton, and Prestwich in order to attend some of the BME dementia groups in Manchester.

4.3 An additional service pathway for Mild Cognitive Impairments has been developed by GMMH that offers earlier interventions to users that are at higher risk of getting dementia.

The pathway offers early dementia risk assessments, memory skills training, and the opportunity for users to be involved in research trials. The aim is to help users manage their memory conditions and slow down the process of deterioration.

- This additional pathway fills an existing gap in dementia services for users who are experiencing memory difficulties but can't yet get a formal diagnosis of dementia. This new pathway was welcomed by all the users and dementia groups that we have spoken to. It helps to address the issue described in 4.1 above.

4.4. Statutory dementia services offered by GMMH now mainly focus on urgent and intensive interventions over shorter periods, and no longer provide "Day Care" type services (i.e. services that aim to promote social interactions and reduce isolation). Access to the dementia garden situated at Victoria Park Day Centre is still an option but only for up to 8-10 weeks.

- Users found this part of the service redesign most difficult to adapt to, especially for Young Onset users who are physically able and want to remain active. Regular access to the dementia garden and support group at the Victoria Park Centre provided a supportive social environment for the users. When the services were changed, users were left with no alternatives.
- People living with Young Onset dementia have very different needs to their Later Life counterparts. Although many voluntary sector groups also welcome Young Onset users, there are very few groups that specifically cater for the needs of Young Onset users.
- Some Young Onset users have turned to social services (through the Local Authority) for physical care support in order to keep themselves active. However, the support offered on a one-to-one basis is more limited and lacks the social element which is crucial to the wellbeing of people living with dementia and their carers.

4.5 Transport remains a big challenge for many users when trying to access dementia services in the community.

- Many users find it difficult to get to services. Ring & Ride in Manchester only help to some extent. Users can book time slots with Ring & Ride but this doesn't guarantee that they will arrive or be picked-up at a specific time. This can be problematic if there is no one to watch over the person with dementia whilst they wait for transport. Most dementia groups don't have the capacity to support multiple users this way before or after the event.
- The bookings with Ring & Ride are also subject to availability (some users were able to get to services but find it difficult to book return journeys to get home).

4.6 Information about what dementia support services are available in the community is still not being given to all patients and their carers during or post diagnosis.

- Dementia Support Advisors are now actively taking up this role.
- However, many grass-roots dementia groups in Manchester still have no links to the Dementia Support Advisors and some have not heard of them. Dementia Support Advisors are also not currently represented at local dementia action groups such as the DAA.
- Alzheimer's Society has put together an online database for dementia services called Dementia Connect. However, not many users are aware of this database. Many users also struggle to access online information on their own and rely on the dementia group they attend to offer such support.
- The Dementia Connect services database needs to be more widely promoted. In our research work, some local services did not show up on Dementia Connect. It was also difficult to limit search results to a specific postcode (see Appendix I).
- Information on dementia in other languages and information that specifically target BME groups is still quite limited.

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4.7 The link between local voluntary sector dementia groups and the Mental Health Trust is currently quite weak. Local groups find it difficult to get updates or to put people into contact with NHS mental health services.

- The Dementia Lead for Manchester from GMMH does attend the local Community Explorer meetings. However, local dementia groups don't have any formal links to the Mental Health Trust.
- To refer a deteriorating user, the only current option is to ask the family to take the user to their GP to get a referral for a memory assessment.
- Some families may be reluctant to contact their GP as they see dementia as a sign of old age rather than a health condition. Dementia can also be a taboo subject in some cultures.
- Local dementia groups have reported that the Mental Health Trust used to have a worker who was able to visit local groups to carry out initial assessments and help with referrals. This is no longer available.

5. Conclusion

Dementia services in Manchester were recently transformed under the Later Life Services redesign by the Mental Health Trust. Whilst the new services aim to respond more rapidly to urgent and crisis care and aim to provide safer discharge and reduce readmissions, longer term wellbeing services were reduced or are no longer provided. People living with dementia have to look for alternatives in the voluntary sector to stay active but the number of dementia friendly activities and social groups on offer in Manchester is still quite limited. Groups that cater to those with Young Onset Dementia or BME users are especially lacking.

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Local groups can play a bigger role in helping to identify and refer users with early signs of dementia, and can help to communicate best practices and share information. Local dementia groups want to have stronger links to the Mental Health Trust, and want to have a key worker who is able to visit local groups to carry out initial assessments and help with referrals.

The new service pathway for Mild Cognitive Impairments was welcomed by most users and carers that we have spoken to. This additional pathway fills an existing gap in dementia services for users who are experiencing memory difficulties but can't yet get a formal diagnosis of dementia.

One of the main challenges for people with dementia to access services is (dementia friendly) transport. This needs to be a top priority in the dementia strategy for Manchester.

Appendices

Appendix I. Dementia support groups near Manchester by postcode areas

Dementia Connect is an online database provided by the Alzheimer's Society for searching dementia services in local areas. Using this database, HWM looked into how many dementia support groups there were in Manchester.

The areas were classified as follows:

Where	Postcodes
North	M8, M9, M40
Central	M1, M2, M3, M4, M11, M12, M13, M14, M15, M16, M18
South	M19, M20, M21, M22, M23, M90

Table 1: Areas of Manchester by postcode.

To filter the search results, the following criteria were used:

- Services within 5 miles of each postcode (this is the smallest area filter on Dementia Connect).
- Whether the group indicates that they are targeting older people specifically (i.e. not suitable for Young Onset).
- Excluding day care and care homes.
- Excluding services for carers ONLY.
- Excluding helplines and online forums.
- Excluding transport services.
- Excluding services that do not offer advice, socialisation or support (e.g. 'books to go' or professional services such as solicitors).

Where	Postcode	Number of services (within 5 miles of each postcode area)	Services open to people living with Young Onset Dementia
North	M8	36	30 <i>*Note - Nothing specifically for young onset*</i>
North	M9	27	23 <i>*Note - Nothing specifically for young onset*</i>
North	M40	31	27 <i>*Note - Nothing specifically for young onset*</i>
Central	M1	34	29 <i>*Note - Nothing specifically for young onset*</i>
Central	M2	41	35 <i>*Note - Nothing specifically for young onset*</i>
Central	M3	44	37 <i>*Note - Nothing specifically for young onset*</i>
Central	M4	34	28 <i>*Note - Nothing specifically for young onset*</i>
Central	M11	34	29 <i>*Note - Nothing specifically for young onset*</i>
Central	M12	33	28 <i>*Note - Nothing specifically for young onset*</i>
Central	M13	39	35 <i>*Note - Nothing specifically for young onset*</i>
Central	M14	39	34 <i>*Note - Nothing specifically for young onset*</i>
Central	M15	45	40 <i>*Note - Nothing specifically for young onset*</i>

Central	M16	41	36 <i>*Note - Nothing specifically for young onset*</i>
Central	M18	41	37 <i>*Note - Nothing specifically for young onset*</i>
South	M19	32	29 <i>*Note - Nothing specifically for young onset*</i>
South	M20	38	35 <i>*Note - Nothing specifically for young onset*</i>
South	M21	42	38 <i>*Note - Nothing specifically for young onset*</i>
South	M22	25	25 <i>*Note - Nothing specifically for young onset*</i>
South	M23	29	28 <i>*Note - Nothing specifically for young onset*</i>
South	M90	11	11 <i>*Note - Nothing specifically for young onset*</i> <i>*Note - real lack of services here in particular*</i>

Table 2: Number of dementia services within 5 miles of each postcode area.
There were no groups specifically for Young Onset Dementia in any of the postcodes.

**Note-* not being able to further filter the search results into smaller areas on Dementia Connect means that there can be a lot of overlaps, with the same services counted multiple times. The actual number of services in each area is small.

Our research further sorted the search results to look at how many of the groups were activities and social groups for people living with dementia. A social group must be a place where people living with dementia can socialise (e.g. not just an advice service).

To filter the search results for Table 3, the following criteria were used:

- Excluded services for carers.
- On Dementia Connect, excluded advocacy, care homes, care or support in the home, online services/helplines, and transport services.

Where	Postcode	Other services (within 5 miles)	Social Groups (within 5 miles)	Social Groups within each postcode area
North	M8	10	24	1
North	M9	9	18	1
North	M40	13	19	3
Central	M1	14	23	0
Central	M2	15	24	0
Central	M3	16	26	0
Central	M4	11	20	0
Central	M11	13	22	2
Central	M12	13	19	0
Central	M13	14	22	1
Central	M14	13	23	0
Central	M15	16	27	2
Central	M16	14	26	2
Central	M18	18	14	0

South	M19	15	18	0
South	M20	17	24	3
South	M21	15	25	1
South	M22	10	17	2
South	M23	7	18	1
South	M90	3	8	0

Table 3: Number of activities/social groups for people living with dementia by postcode area. Note that the number of groups in each area is small.

Findings:

1. The search result showed no specific Young Onset groups in any of the postcodes.
2. However, some Young Onset Services did come up on a web search that were not on Dementia Connect. More needs to be done to promote the database to local groups.
3. Four of the groups were specifically targeting 'older people' and would be less suitable for people who are living with Young Onset Dementia.

Limitations with Dementia Connect:

- Difficult to filter/lack of specificity when searching. We had to manually exclude services for carers etc.
- Not able to filter search results within less than 5 miles.
- Some service don't indicate if it is free to attend or if there is a cost.
- Some service don't show their opening times, we had to call them up to enquire.

Appendix II. Postcode areas in Manchester with the highest number of 60+ residents based on 2011 Census data

The 2011 Census data from the Office for National Statistics [4] showed that there are more residents that are aged 60 and above living in the north, south, and east regions of Manchester (see Figure 1) compared to central Manchester. The risk of having dementia increases with age and this age group represents the biggest proportion of people living with dementia.

As shown in Appendix I, there are also fewer dementia friendly activity or support groups in North Manchester and in some parts of South Manchester such as Wythenshawe. There seems to be a mismatch between where services are needed the most and where they are located at the moment. Without having access to free and reliable dementia friendly transport, people living with dementia would struggle to get to most of the services.



Figure 1: Areas of Manchester with the highest number of residents that are aged 60 or above. A darker shade indicates a higher number. Google Earth is a free mapping tool that was used to show the 2011 Census data.

Postcode areas with highest number of residents that are aged 60 or above:

Where	Postcodes
North	M9, M40
Central	M11, M18
South	M22

Table 4: Postcode areas with highest number of residents that are aged 60 or above.

References

1. Patient & Carer Experience of Service Access Post-diagnosis for Dementia, Healthwatch Manchester, November 2015.
2. Living Well with Dementia in Manchester - A Strategic Statement 2016 - 2018, Manchester City Council.
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