Dementia United

NHS in Greater Manchester

Dementia Post-Diagnostic Support in Greater Manchester

Mapping Report

June 2020

Context

Before the COVID-19 pandemic there were an estimated 30,000 people in Greater Manchester living with dementia, around 75% of whom had received a clinical diagnosis. Many people living with dementia have one or more people who cares for them, usually a family member. Although there is no cure for dementia, there is a range of service for people living with dementia and their carers, which come under the umbrella term of post diagnostic support, and is intended to offer advice, support them living well, through social activity, and provide community and respite for carers. We also know that social stimulation and regular face to face contact helps people living with dementia to feel secure, improves anxiety and mood whilst also helping them to maintain basic cognition, communication and to maintain independence (Alzheimer's Society June 2020). The feedback that Dementia United received from the Care Pathway events, held with people affected by dementia, in February and March 2020, highlighted how important getting a timely diagnosis was, as well as the value in accessing timely post diagnostic support.

The COVID-19 pandemic has meant that social contact between people outside households has been minimised or eliminated. This is especially true for people with existing health conditions who have been asked to shield themselves; many people living with dementia have multiple comorbidities and fall into this higher risk group. Many post-diagnostic support services have been significantly curtailed or wholly ended.

The COVID-19 pandemic has meant that Community Hubs have been established across GM, in all 10 localities to provide support for the most vulnerable. These hubs coordinate support for those who do not have any other way of sourcing food and medical supplies. The likelihood is, that these Community Hubs will have been receiving requests for assistance from people affected by dementia and that these Hubs may not be connected into the wider post diagnostic support network in their locality.

Rationale

Dementia United (DU) set out in May - June 2020 to map the current landscape of post-diagnostic support services for people living with dementia and their carers. The mapping exercise had two core goals:

1. To collate the post-diagnostic support currently on offer and how it differs from previously.
2. To understand the outlook for recovery of these services with regards to:
    a. Returning to normal pre-COVID-19 services.
    b. Expanding and establishing new services to match or replace those previously offered.
3. To scope out a road map to link in with work being undertaken across GM in terms of future role for the Community Hubs.

Method

A master list of known services in Greater Manchester was compiled from existing sources, with the ability to add further services as they are discovered. These services ranged from commissioned organisations with full-time staff to non-commissioned volunteer groups, but excluded services directly provided by the memory assessment services.; as this has been undertaken as a separate scoping exercise.

Each locality was assigned to an individual member of the team to contact the services in that area. By using multiple DU team members we could undertake more calls in a shorter time, yet still allow a single person to have an overview of each area.

The locality lead for each area was contacted before the mapping exercise began to make them aware what would be done and ask for any further information they could provide and linking in as needed with escalating any issues or concerns. Each group was contacted initially be email as an introduction to the exercise then, if agreed, followed up with a telephone conversation. A single script was used by members of the team to guide the telephone conversation and ensure that key points were covered:

1. Offer from the group pre-COVID-19.
2. Current support offer from the group.
3. Issues which have arisen due to changes in the group's activities and the broader situation
4. Sustainability of the group with regards to current offer, expanding that offer, and returning to business as usual.
5. Good practice which has emerged.

Any issues or concerns were fed through Dementia United's governance and in to wider GM HSP as appropriate.

The information that we have presented in this report, reflects the picture as was reported to us, up to 12 June 2020. We appreciate that this information may have changed, in the weeks since we last spoke to some of those groups, mid May 2020.

Overview

Almost 50 groups responded to our requests for information and a telephone conversation. Further groups are known but either did not respond to our requests or were unable to be contacted in time for the first 'working version' of the report. The groups ranged in size from 10 people to over a 100 weekly contacts (some carer's groups have contact lists in the thousands, but only a fraction of these are caring for a person living with dementia). The majority had between 20 and 50 members, thus the total population regularly served by these services is approximately 1,500 people.

Most groups included both the person with dementia and their carer in some form. Those which did not were services specifically for carers. The majority of groups were open to everybody with dementia. A few were focussed on BAME communities, and others intended for those at different stages of the disease. A number of groups specifically said that no diagnosis of dementia is needed and that they welcome anybody with a memory or cognitive problem.

The groups were a mixture of both commissioned and non-commissioned services. Some were entirely voluntary and volunteer-run. The services offered Pre-COVID-19 were wide and varied, but fall into a few categories:

Type of Service	Examples
Formal/Statutory	Carer’s assessment, help claiming benefits, social service referrals
Information/Training	Advice, guidance, signposting, carer training, talks, leaflets
Support/Therapy	Cognitive stimulation therapy, counselling, peer support, helpline, and respite.
Social Activities	Coffee meetings, singing, dancing, arts and crafts, cooking, meals

Service Changes

Almost every group contacted had significantly altered the services they offered after the outbreak of the COVID-19 pandemic. Examples of typical changes to services include:

- Establishment of welfare calls to known members or contacts. These can range in frequency from daily to fortnightly. Some larger groups have created lists of higher risk people for more frequent calls.
- Establishment or extension of telephone helpline for members. This may simply be publishing the mobile telephone number of an organiser or diverting existing helplines to staff mobiles. Extended hours in evening and weekends are also being offered.
- Creation of groups on digital platforms (Facebook, Whatsapp) to facilitate communication between members and with group organisers.
- Arrangements for regular video calls/groups on digital platforms (Whatsapp, Zoom) with structured or semi-structured activity, such as singing.
- Garden visits to allow for face-to-face contact while still maintaining a safe distance.
- Organising and delivering food parcels, activity packs, newsletters (some on a weekly basis), or other important items to members who are unable to leave their home.

Not all groups have made the alterations above. Many services have simply stopped with no attempt at replacement. This is especially true of smaller groups focussed on social activities.

Issues

Changes to the services offered have come with potential costs to people living with dementia, carers, staff, and volunteers. Issues raised by groups include:

- People living with dementia (PLWD) may not be engaging in the same level of physical activity as before and may be losing physical condition.
- PLWD are not receiving the same level and quality of social interaction as before, leading to potential disengagement and deterioration of skills. There is also the risk of an increase in challenging behaviour.
- Carers are at risk of social isolation without opportunities to spend time with others or the possibility of respite. Feelings of being overwhelmed; mental and emotional distress is worsening.
- Carers can feel or be disconnected from the support which is available.
- General lower level of digital skills and equipment for PLWD and carers.
- Groups do not have enough capacity to make calls to all members.
- Telephone calls may not allow the caller to pick up on issues as easily as face-to-face contact, plus they are most likely to speak to the carer and not the PLWD

- Volunteers may find it difficult to deal with some issues they encounter on calls. Concerns that they may be giving out incorrect information.
- Staff and volunteers may experience anxiety and helplessness over the wellbeing of the people they support.

Sustainability

There is a mixed possibility of groups continuing to offer the current services, expand on that offer, or return to business as usual:

- **Funding:**
  - Current services they are providing may bring new costs, such as the provision and delivery of meals at home, or volunteers spending their own money on telephone calls, postage, and printing.
  - Some groups noted that funding for the future of their service was a concern. They may need to bid for money from public bodies and do not feel confident about describing future services or that they would be successful.
  - There may be a loss of income from different sources, such as reduced charity donations coming in to organisations which operate retail shops, reduced fundraising by charities, service users no longer paying for daycare.
  - Some groups noted that they would benefit from extra monies, as future services will require this.
  - Where groups have been commissioned, most were reporting that they were having very positive conversations with commissioners of these services, who recognised that the service model has had to shift to a telephone or digital based support.
- **Returning to previous services:**
  - A number of small groups which have suspended activities are focussed on returning to regular meetings rather that providing a different service offer.
  - This is also dependent on access to buildings, as a number of groups meet in church halls, or other buildings that either have remained closes, or are restricting numbers of people gathering in them.
  - Delays to this may mean that there is a prolonged absence of services. Also, there is some doubt whether or when members will be ready to attend services in person.
  - Some services are considering a model of smaller groups, when feasible, along with continued virtual connectivity and telephone support.
  - There is a lack of guidance over the return to physical meetings. Changes to capacity, layout, or the need for PPE may make groups unable to restart.
- **Maintaining current service:**
  - A number of the voluntary groups considered that they are able to continue to offer the support they are providing at the current time, however have noted that this is dependent on a number of factors, such as capacity of the volunteers, duration this needs to be in place, plus the demand and more complex needs of the people needing their support.
  - Some groups have not fully considered what they can provide or substitute for services in the short-term. There is a lack of awareness of the possibilities.
- **Expanding services (including digital services):**
  - Those providing new digital services have considered ways to expand them. Ideas include providing training or carers assessments remotely. One group reported that

    they have already started adapting their training course so that it could be accessed virtually.
  - The level of digital literacy and equipment is preventing new services from reaching all members. Some schemes have managed to provide equipment (tablets and mobile phones) and guidance to those who could not previously connect digitally; however it was noted that this required a level of intense person centred support to enable these connections to be made, which is not currently widely available.
- **Visits:**
  - Some services have managed to provide individual visits outside the home, such as walking or garden visits. These may be less possible during colder or darker times of the year.
  - These have been provided by services who had not previously undertaken this and therefore the long term sustainability will also be an issue if there is a reliance on volunteers.

Opportunities

Groups have reported examples of **good practice** which represent opportunities moving forward to change or enhance what is currently offered:

- Questionnaires of members to ask about best way to keep in contact
- Virtual buddying up to support someone with access digital resources
- Direct links to doctors for people who live on their own – either by telephone or virtually
- Developing and posting out individualised music playlists
- Working with the council to get carers identified and linked in to priority shopping

DU have utilised the opportunities in undertaking this scoping exercise to **create and strengthen connections and relationships** between groups, services and with the wider GM community.

- DU have linked closely with locality leads as part of this scoping exercise; some have been working closely with DU to send out requests for information on the post diagnostic support in their locality. Where there have been locality specific issues of concern, DU have ensured that these are escalated to Commissioners.
- DU have been collating the issues that PLWD and carers have raised and ensuring that these are shared via DU governance, across GM HSP with connections , as well as in to colleagues as follows; in PCCA and the social prescribing, with the wider lived experience networks, with the Dementia Carers Expert Reference Group and with Ageing Hub colleagues.
- DU have made direct connection with a wide range of VCSE groups; DU will continue to build these relationships in to their wider programme of work. As part of the conversations with groups/services, DU have been building a network of people who are living with dementia, who would welcome being more involved in the wider DU programme of work.
- DU have made connections between groups across localities, linking them in to work that the Alzheimer’s Society is undertaking in the development of a national community hub.
- DU are looking to build on relationships with colleagues in the Ageing Hub into GM work reviewing the focus of the Community Hubs.

Recommendations

There are a number of recommendations that DU consider are important:

- **Support for financial position:** Groups need to be provided with support and guidance to help them identify and bid for money available. Where bidding for public contracts there needs to be flexibility over the differing service provision depending on the presence of absence of pandemic conditions. This needs to be flagged with commissioners so that consideration is given to the reporting and monitoring of these commissioned services.
- **Criteria amendments in order to access post diagnostic support:** Some post diagnostic support is based on having a diagnosis of dementia, but current delays for people to access memory assessment services means that an increasing number of people with dementia will lack a diagnosis. There is a need for flexibility or a review of criteria to enable access for people with memory associated problems even if undiagnosed.
- **Information on what is the post diagnostic support offer:** What is not clear, is how people can access the groups that are offering telephone support. There is a need to have an up to date list of what is on offer during COVID-19, with considerations as to how this can be updated and communicated widely across health, social care and the wider community. This needs to include information on what will be required, if and when services can open e.g. socially distancing, wearing of a face covering.
- **Commissioning where there are gaps in the post diagnostic offer:** To look to future commissioning of services, where there are gaps and consider how these models will look - reflecting the current picture of limited face to face meetings and virtual and telephone support. For example, with volunteers reporting that most telephone calls are with carers, there is a disconnect in terms of that offer of social connection and support to PLWD.
- **To have a platform for groups/services to share resources and experiences:** Being able to connect with groups in their neighbourhood, locality and/or across GM now and in the future.
- **Guidance on face to face meetings:** Most groups asked for guidance on how and when and what would be required of them and support to undertake this. Including~~,~~ the option of garden visits, walking groups and other ways of connecting
- **Access to advice and guidance when faced with issues and challenges from PLWD and carers:** Groups would welcome having information about what is available that they can be signposting people on to, or accessing for them. They wanted clear information on where to get advice, to support PLWD and families, who were reporting increasing distress. This included, having the mechanisms to know where and how to escalate these issues. Some mentioned that they would welcome having access to training resources.
- **Digital access:** Any digital offer would need to take account of the following;
    - Access to equipment and skills base of the volunteers/staff who will be organising it.
    - Access to equipment for the PLWD and/carers, including mobile phones that can access to emails, smart phones, wifi access, computers and other software
    - Ensuring that the range of skills and person-centred resource is available to enable people to connect up and have someone that can talk them through this and provide ongoing support as needed

Next steps

The following are the next steps for DU;

1. To present the findings from this report to both DU's Implementation and Operations and Strategic Board meetings. With an ask for a steer in terms of any further scoping, or next steps that DU may be required to undertake.
2. To establish a remote lived experience network to allow issues to be raised and potential solutions sought.
3. Engage with locality leads on this work and its findings. To produce a more detailed locality picture of the issues and good practice that have emerged from the scoping conversations.

Consider a single shared platform across GM for helping groups share learning and keep up to date on recovery information.

References

Alzheimer's Society briefing (June 2020) Dementia and social contact.

Contacts

Helen Pratt

Project Manager, Dementia United

Helen.pratt5@nhs.net

Emma May Smith

Project Support Officer, Dementia United

Emma.smith96@nhs.net