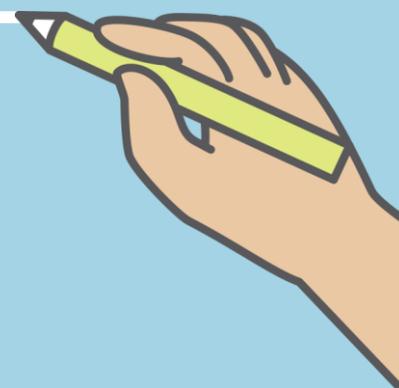


DEMENTIA CARE PATHWAY

Feedback report

APRIL 2021



Background

The creation of a shared Greater Manchester Dementia Care Pathway is one of the key projects for Dementia United. The goal is to create a single statement on the requirements for support which must, should, and could be delivered for people living with dementia and their carers. Although many details of delivery would be specific to individual localities and people's needs and preferences, the Dementia Care Pathway would provide an outline for dementia care in Greater Manchester to which all localities agreed.

Work on the Dementia Care Pathway has been ongoing since 2018, bringing together commissioners, providers, and people with lived experience to focus on what good practice and support should be available across Greater Manchester. The draft Greater Manchester Dementia Care Pathway reflected the NHS England's - The Well Dementia Pathway (see appendix one) 5 key pillars: preventing well, diagnosing well, living well, supporting well and dying well. It contains over 60 requirements and recommendations for support under these key headings. The Dementia United team has also worked to ensure that these recommendations are well-evidenced and based on good practice.

Once the draft Dementia Care Pathway had reached a suitable level of development it was felt that more input from people with lived experience of dementia was required. A wider engagement process was planned to take place in early 2020 to collect evidence from people living with dementia and carers. The goal was to ensure that the Dementia Care Pathway reflected their personal experiences and priorities for dementia support offered in Greater Manchester.

Process

It was acknowledged that the draft Dementia Care Pathway itself is a long document containing some technical language and therefore may be difficult for people living with dementia to engage with. Further, feedback was sought not only on the contents of the draft Dementia Care Pathway but what may be missing. It was felt that engagement based directly on the Dementia Care Pathway would not be the most appropriate method for capturing the desired evidence. However, throughout the engagement process a copy of the draft Dementia Care Pathway was always available to participants and written feedback on it could be submitted.

A set of structured questions were created which would encourage discussion on topics related to the support people had received. This included a question on priorities asking people to rank issues by importance, with the option of including their own. This evidence could then be analysed to understand the comparative importance of different parts of the draft Dementia Care Pathway, but also to discover what aspects were not currently covered. The questions were broken down into four sets according to the Dementia Well Pathway (Diagnosing Well, Supporting Well, Living Well, and Dying Well), and including Caring Well, with each topic being a separate discussion. Dementia United provided a resource pack to support the feedback events.

The packs included (see Appendix two for more detail)

- Poster advertising the events for localities
- Facilitators pack of slides and questions to guide discussion, guidance notes
- Participants information sheet

Events

The main way of collecting lived experience feedback was planned to be a series of events facilitated by VCSE groups and commissioners across all ten Greater Manchester localities. Each of these feedback events would focus on one or more of the four discussion topics. Arrangements for the date, venue, facilitation were then the responsibility of the VCSE group or commissioner.

Dementia United offered a small budget to cover the costs of each event as well as information to publicise the event and information to present at the event. Publicity would be undertaken by both the VCSE group and Dementia United.

A total of 25 Dementia Care Pathway feedback events were planned: two in each of the ten Greater Manchester localities with a further five for specific experience groups – BAME, LGBTQ+ and Mild Cognitive Impairment. The first took place on 13 February and the last was due to take place on 7 April. The total number of attendees was hoped to be between 400 and 500 people, representing a significant level of engagement.

Unfortunately, the arrival of the COVID-19 pandemic brought a halt to the feedback events before most took place. By early March many VCSE groups were reporting that people did not wish to attend due to the risk of infection, and they were considering cancelling. In the week beginning 16 March Dementia United were advising groups not to hold the events, and a week later changes to government rules on social distancing meant that holding the events was not possible anymore.

A total of seven feedback events were held, just under a third of the planned number. These were undertaken by:

- Age UK in Trafford
- Oldham BAME Dementia Advisor – two events
- Making Space Oldham and Oldham's Commissioner
- Stockport Dementia Champions and Stockport's Commissioner
- EDUCATE in Stockport – two events

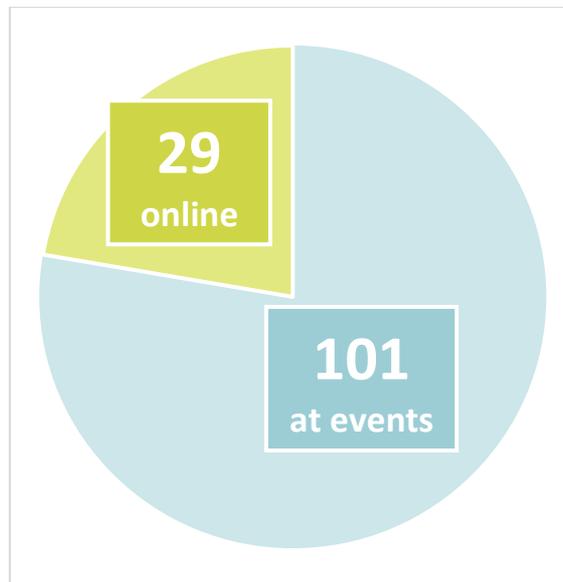
Survey

A set of online surveys were planned to be held alongside the feedback events, with each topic being a separate survey. These were to allow people to provide information about their experiences even if they were unable to attend a feedback event in person. The questions for each survey closely matched the questions used for the feedback events, though with some minor changes to ensure clarity.

After the feedback events needed to be cancelled in March focus for the Dementia Care Pathway feedback shifted to the online surveys. Publicity was created to direct people to the surveys. The surveys remained available over spring and summer closing on the 11 September 2020.

Results

130
respondents
across
12
feedback events
&
online surveys



As the events and surveys were held on individual topics according to the Dementia Well Pathway, the results will be set out likewise: Diagnosing Well, Supporting Well, Living Well, Dying Well. Some topics received more feedback than others, with Supporting Well receiving many times more respondents than Dying Well. The information below is a summary of the evidence collected.

Diagnosing Well

Time to Diagnosis

- Most people said that the time it took to get a diagnosis was acceptable. A number said that their GP delayed referral due to either not listening to their concerns or not dealing with them appropriately.

Information at Diagnosis

- Many respondents felt that the information they received at diagnosis was inadequate. Several complained about being told by letter rather than in-person. A similar concern was found with a large amount of information provided in written form when conversations with real people would have been preferred. There was a broad sense that the process and follow-up could be improved.

Medication

- Awareness of medication was mixed, with some respondents being on medication while others being told that no treatments existed. This likely reflects the fact that different kinds of dementia may or may not have medication available.

Research

- While some people had been offered the opportunity to take part in research, many had not. There seems to be a clear split between those who took part in a feedback event and are more likely to have knowledge of research, and those who responded online and were less likely to be aware.

Carer/Family Experience at Diagnosis

- Some carers and family members felt involved and valued during the diagnosis process. In both cases the respondents felt this was very important. Those who were not involved felt that this was negative to the process and their own wellbeing. Several responded that information about a Carer's Assessment was not offered at this point.

Priorities

- Respondents were encouraged to select their priorities for the most important aspect of receiving a diagnosis. The time taken to diagnosis was almost uniformly considered the highest priority. The next highest was information about support for carers/family members, although some considered information about dementia, medication, and research to be more important.

Supporting Well

Care Plan

- Many respondents stated that they did not have a care plan. Those who did have a care plan typically found it useful in some way. Elements of a care plan that were raised as useful were medication, nutrition, progression of symptoms and "what happens next", as well as having agreed actions to implement.

Delirium

- Many respondents, though not all, were aware of delirium. Of those who were aware of delirium, most understood the impact of delirium on people living with dementia, which they provided through personal experience examples. For those with no experience of delirium knowledge seems to be poor.

Named Support Service

- Those respondents who took part in group events were more likely to have or be aware of a named service. (The VCSE group undertaking the event may have been commissioned as a named service.) They typically found the named service helpful if they used it
- Those who took the online survey gave a more mixed response. A number stated that they had no named service at all. Others who stated that they did have a named service identified a care home or social worker as providing this service at least as often as a memory clinic.

Specific Needs

Respondents raised a number of areas in which they felt more specific help was needed:

- Finances – how to claim money available and how to pay for the care they need, such as care homes, day care, and respite services.
- GP interactions – some poor experiences with GPs who lacked knowledge, also longer appointments to discuss their complex needs.
- Integrated services – services feel disconnected and not communicating or working with one another.
- Lack of responsiveness – services take a long time to respond or offer support, even when the person is in crisis.
- Carer support – the offer of support for carers was either not enough or not accessible.

Priorities

- The highest priority for respondents was information and support on slowing the progression of dementia (where applicable). There was no clear second priority, with respondents choosing between information on community support, financial and legal advice, and advance planning.

Living Well

Accessing Support and Services

- Respondents who took part in group events naturally engaged in many community support and services, which they reported favourably and as a great benefit. Opinions on NHS and local authority services were mixed, with some receiving praise while others were not seen as useful. However, those who responded through online surveys also reported a good level of engagement with community services and positive benefits.

Memory Skills Groups

- Most respondents had not attended or been offered access to memory skills groups. Those who did find them useful. Others expressed a desire for such groups.

Hospital Stays

- Those who had recent experience of a hospital stay generally reported a positive experience and were happy with their overall care, though with some exceptions. Waiting times were a common problem, for ambulance response, to be seen by clinical staff, and admission to hospital. Staff knowledge and ability to care for people living with dementia was sometimes absent and caused issues. Length of stay and discharge were occasionally mentioned as problems.

Communicating Needs and Emotions

- Some people reported feeling frustration when remembering and communicating needs. There were many different sources of help and coping strategies but no overarching theme.

Priorities

- There was no clear top priority for people's needs with regard to living well. The highest was the right to personal choice over how and where they live, but closely followed by support and respite for carers, and help with managing multiple health conditions.

Dying Well

Recognising End of Life

- Carers knew some signs that a person may be nearing the end of their life.
- They were dependent too on GPs, care homes, or other professionals on recognising the situation for them, though they also reported that some professionals lacked appropriate on recognising end of life. More information and learning would be welcome, especially given the differences at the end of life between individuals and those with additional conditions.

Respite Care

- Most carers had some experience of respite care. Often the experience was positive and was very welcome despite limited availability. Carers reported that it was not always easy to place somebody temporarily in a care home and, where it was a positive experience, carers felt listened to and able to do a person-centred handover to the care home staff. This gave some reassurance that the person's needs and values were met.

Bereavement Support

- Many carers had received bereavement support (either from losing a loved one to dementia or another condition) and found it highly positive.

A Good Death

- People living with dementia universally saw a good death as dying at home, with friends and family, knowing that everything is taken care of, being pain free, and being in control. They felt that communicating needs and discussing things early were key to achieve this.

Advanced Care Planning

- People were aware of the importance of advanced care planning but acknowledged that it was a difficult topic for most. While such planning needed to be done in good time for it to be effective, it needed to be at a time when the individual was willing and able to discuss it, and undertaking it as a family was reported to be more effective.

Information on Palliative Care

- Information received about palliative care was very mixed, with some having had no information and those which did received it from various sources.

Priorities

- The two highest priorities for end of life care were support with physical health problems and the prevention of unnecessary hospital admissions. The issue of physical health problems was further refined by some respondents as being specifically around comfort and pain management. Care support was acknowledged as very important but carers voted for the topics related to the person with dementia first – showing that carers often 'forget to look after themselves'.

Analysis

- The results which were received from the feedback events and online surveys may be dependent on a number of factors which should be remembered when using the information. The first is the natural tendency for negative experiences to be more salient and more often shared than positive or neutral experiences.
- People also engage with topics which interest them or on which they have something to contribute, meaning that for some topics the results were based on more data than others. The high number of respondents for certain topics, such as Diagnosing Well, may represent the fact that most involved have been through that stage. Conversely the low number of respondents for Dying Well could either be due to few respondents being at that stage or the aversion to discussing death.
- A similar bias could affect the priorities given by respondents, for example when choosing between receiving information about slowing the progression of dementia or advance care planning. The former may be a greater priority for those in the early stages of dementia and the latter for those in a later stage.
- The way in which the discussion topics were facilitated may have led to differences in the demographics of the respondents themselves. Those events facilitated by VCSE groups engaged people who already perceived the value of such groups, with members who were active in accessing community support, and at a stage where this was appropriate for them.
- The online surveys may have been more accessible to people in earlier stages, younger than average, or had been completed more by carers rather than people living with dementia.

Next Steps

- Despite the unfortunate need to cancel most of the feedback events some useful information has been collected. This information allows us to check that the content and focus of the draft Dementia Care Pathway is correct. It should guide us to make further improvements and provide confidence that people living with dementia and carers will see their experiences reflected in the pathway
- The information in this document will be used in two specific ways over the coming months.

Informing Commissioners

- This report, along with a summary of themes, will be provided to commissioners in the ten Greater Manchester localities to inform them of our findings. Some themes from the discussions have already been shared with commissioners, along with a short analysis which relates them specifically to the current needs around COVID-19.
- It is hoped that this information will add to the knowledge which commissioners use when they consider changes and improvements to dementia-related services. The information may be especially useful as much of it was collected just before the onset of the current health crisis and represents the last snapshot of issues and experiences from that time.

Alterations to the Dementia Care Pathway

- The main use for the information in this document will be to directly inform changes to the draft Dementia Care Pathway. Although some experiences which we heard are already well-covered in the draft pathway, others clearly show where there needs to be more detailed requirements and recommendations.

You Said, We Did

The following are examples of changes to the pathway informed by lived experience feedback:

- **Time to Diagnosis** – the draft Dementia Care Pathway was ambiguous over the referral timeline, with two different deadlines for contacting the person living with dementia after referral. The longer deadline has been removed and the shorter deadline is now the requirement.
- **Medication** – previously the draft Dementia Care Pathway only contained a simple reference that people living with dementia be offered appropriate medication. This has been altered to contain more specific recommendations about individual types of medication so that the information available to non-clinicians in this area is more complete.
- **Carer** – throughout the feedback there was a strong emphasis on the needs of carers and the support they receive. The draft Dementia Care Pathway inadequately handled this aspect. A new structure for the whole pathway has been used which allows the needs of carers to be more easily seen and understood.
- **Care Plan** – the draft Dementia Care Pathway featured the need for care planning quite heavily, but in a way which was potentially confusing. The recommendations for care planning have been simplified significantly to make them clearer.
- **Community Support** – the lived experience feedback was very clear that support from community groups was widely used and highly appreciated. A requirement has been added to the draft Dementia Care Pathway to ensure that they are seen as a key part of the overall offer and commissioners regard them as such even when the groups are independent of commissioned services.
- **Hospital Stays** – although the experience of hospital stays was broadly positive, all requirements and recommendations for hospitals have been identified as such and structured so that they are easier to see and understand as a whole.
- **Staff Knowledge** – the draft Dementia Care Pathway had no specific statements on the need for staff training in dementia. This has been corrected with a specific requirement for all staff who work with people living with dementia, but a recommendation for the type and level of training received.

Further changes to the draft Dementia Care Pathway will doubtless happen with further analysis of the feedback and as the pathway matures into a final product.

Thank you

The Dementia United team would like to express thanks to all the people and groups who offered to hold a feedback event on our behalf. We were very grateful for all the offers and enthusiasm from those groups and are very sorry that many of the events did not happen as expected. We would also like to thank everybody who shared their experience of dementia support and services, both at in-person events and online. We hope that the information provided will improve the Dementia Care Pathway as intended. Lastly, a special thanks for Sarah Fox, who worked with the Dementia United Team, ostensibly on promoting research, but who went outside her role to contribute significantly to the planning and organising of these events, especially the online survey which proved to be more valuable than foreseen at the start.

Appendix one

NHS England - The Well Pathway for Dementia

[dementia-well-pathway.pdf \(england.nhs.uk\)](https://www.england.nhs.uk/dementia-well-pathway.pdf)

NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA				
<p>PREVENTING WELL</p> <p> Risk of people developing dementia is minimised</p> <p>"I was given information about reducing my personal risk of getting dementia"</p> <p>STANDARDS:</p> <p>Prevention⁽¹⁾ Risk Reduction⁽⁵⁾ Health Information⁽⁴⁾ Supporting research⁽⁵⁾</p>	<p>DIAGNOSING WELL</p> <p> Timely accurate diagnosis, care plan, and review within first year</p> <p>"I was diagnosed in a timely way"</p> <p>"I am able to make decisions and know what to do to help myself and who else can help"</p> <p>STANDARDS:</p> <p>Diagnosis⁽¹⁾⁽⁵⁾ Memory Assessment⁽¹⁾⁽²⁾ Concerns Discussed⁽³⁾ Investigation⁽⁴⁾ Provide Information⁽⁴⁾ Integrated & Advanced Care Planning⁽¹⁾⁽²⁾⁽³⁾⁽⁵⁾</p>	<p>SUPPORTING WELL</p> <p> Access to safe high quality health & social care for people with dementia and carers</p> <p>"I am treated with dignity & respect"</p> <p>"I get treatment and support, which are best for my dementia and my life"</p> <p>STANDARDS:</p> <p>Choice⁽²⁾⁽³⁾⁽⁴⁾ BPSD⁽⁶⁾⁽²⁾ Liaison⁽²⁾ Advocates⁽³⁾ Housing⁽³⁾ Hospital Treatments⁽⁴⁾ Technology⁽⁵⁾ Health & Social Services⁽⁵⁾ Hard to Reach Groups⁽³⁾⁽⁵⁾</p>	<p>LIVING WELL</p> <p> People with dementia can live normally in safe and accepting communities</p> <p>"I know that those around me and looking after me are supported"</p> <p>"I feel included as part of society"</p> <p>STANDARDS:</p> <p>Integrated Services⁽¹⁾⁽³⁾⁽⁵⁾ Supporting Carers⁽²⁾⁽⁴⁾⁽⁵⁾ Carers Respite⁽²⁾ Co-ordinated Care⁽¹⁾⁽⁵⁾ Promote independence⁽¹⁾⁽⁴⁾ Relationships⁽³⁾ Leisure⁽³⁾ Safe Communities⁽³⁾⁽⁵⁾</p>	<p>DYING WELL</p> <p> People living with dementia die with dignity in the place of their choosing</p> <p>"I am confident my end of life wishes will be respected"</p> <p>"I can expect a good death"</p> <p>STANDARDS:</p> <p>Palliative care and pain⁽¹⁾⁽²⁾ End of Life⁽⁴⁾ Preferred Place of Death⁽⁵⁾</p>
<p>References: (1) NICE Guideline. (2) NICE Quality Standard 2010. (3) NICE Quality Standard 2013. (4) NICE Pathway. (5) Organisation for Economic Co-operation and Development (OECD) Dementia Pathway. (6) BPSD – Behavioural and Psychological Symptoms of dementia.</p>				

Appendix two

Dementia United's Care Pathway feedback events – resource pack

Poster advertising the feedback events



Greater Manchester
Dementia Care Pathway

Workshop

Add date and time



GMCA GREATER
MANCHESTER
COMBINED
AUTHORITY

NHS
in Greater Manchester

Facilitators presentation slides and guidance



Care Pathway
Feedback Sessions slii



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GM Dementia Care
Pathway Feedback Se:

Participants information



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GET IN TOUCH

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