Wellbeing Plan Pilot Report

Background & Rationale

Receiving a diagnosis of dementia may have a significant and lasting psychological and emotional impact on people with dementia and their families, requiring a period of adjustment and ongoing support. Post-diagnostic support must be tailored to individual needs rather than taking a one-size-fits-all approach.

Personalised care and support planning is an essential prerequisite for helping people living with long term conditions. It transforms their experience from a largely reactive service, which responds when something goes wrong, to a more helpful proactive service, centred on the needs of each individual patient. Personal care and support planning involve addressing all the person's physical, mental and social care needs.

Care for people with long-term conditions forms a significant part of the health and social care system. There are over 15 million people living with a long-term condition in England (NHS England 2016) The NHS Long Term Plan makes personalised care business as usual across health and social Care (NHS England 2019). The Care Act 2014 also sets out requirements for care and support planning for anyone with assessed needs and greater integration across health and social care.

Across Greater Manchester, dementia care plans are currently completed by practitioners with people with dementia and their carers. The practitioners completing the care plans range from General Practitioners and health care workers in primary care, Memory Assessment Service staff, dementia advisors in the voluntary sector, by staff providing social care, Community Mental Health Team staff, Local Care Organisation staff, which includes and is not limited to social workers, nurses, medical staff and allied health professionals, by general hospital staff as well as in care homes, days services and hospices.

From local discussions and feedback, we know that there is great variability in how these care plan reviews are being undertaken. Variability has been noted in what the care plan review covers, how personalised the care plans are, whether a copy is provided for the person with the lived experience, any involvement of carers, and how accessible the plans are to other services.

In Greater Manchester there is a great opportunity to improve the current situation with the implementation of a standardised Greater Manchester Dementia Wellbeing Plan. We are working with our digital partners (Local Health Care Record team in Greater Manchester) to consider how best to digitise the care plans and make them accessible to all services and people with lived experience of dementia and their carers. We are also building on Greater Manchester's Health and Social Care Partnership (2018) framework that supports person centred and community-based approaches.

Note on Terminology

The Dementia United GM Wellbeing Plan was originally referred to as a 'Care Plan'. Feedback from stakeholders suggested that a different name would better describe its contents and focus on the social aspects of living with dementia. In addition, the term 'dementia care plan' is already being used to refer to a more clinically focussed document which is part of the LHCR work. The generic terms are used interchangeably in this report.

Planning

The goals of the pilot were:

1. To understand if the GM Dementia Wellbeing Plan could be implemented across Greater Manchester;
2. To identify what resources are needed to implement the GM Dementia Wellbeing Plan; and
3. To consider whether the GM Dementia Wellbeing Plan is likely to deliver the intended benefits to people living with dementia, their carers, and health and social care staff and organisations.

The overall objective of the pilot was to prepare the Wellbeing Plan for implementation, prepare practitioners for using the Wellbeing Plan, trial in three localities with practitioners who will utilise the care plan, and determine if any changes need to be made to the Wellbeing Plan and training. This can be broken down into the follow key objectives:

- Create and supply a usable care plan and associated suite of documents for use as part of the trial.
- Identify and supply appropriate training to those will be undertaking the care plan reviews for the trial.
- Gather and collate the views of people living with dementia and carers who have their care plan reviewed during the trial.
- Collect feedback and lessons learned from those undertaking the care plan reviews for the trial and their organisations.
- Support participants in the trial to ensure that it remains safe and ethically undertaken throughout.
- Analyse the collected data and report on the overall goals of the pilot, including lessons for the wider implementation of the care plan.

The GM Dementia Wellbeing Plan trial was undertaken in the localities of Salford, Manchester, and Rochdale. The number of localities ensured that different factors in the implementation of the Wellbeing Plan were understood. Specifically, the three localities would trial the care plan with practitioners from different parts of the health and social care system:

- Manchester: Primary Care (GPs, Physician Associates, Advanced Care Practitioners, from different practices) and commissioned VCSE
- Rochdale: Memory Assessment Service, two Clinical Lead GPs, and commissioned VCSE (Alzheimer's Society)
- Salford: Commissioned VCSE (Age UK Salford Dementia Advisors)

Training for the pilot was provided in early January 2020, with participants undertaking planning appointments with the Wellbeing Plan until the end of March 2020.

Training

Before the pilot could take place Dementia United and pilot partners together delivered training to staff who had been identified as practitioners. A half day training session was held by dementia united, facilitated by the pilot partners.

The contents of the training included:

- Introduction to the Wellbeing Plan and supporting documents
- Discussion on Personalisation
- Join Dementia Research
- Care planning roleplay
- Data Collection
- Introduction to Advance Care Planning

The key documents used during the training (and circulated with this report) are as follows:

- GM Dementia Wellbeing Plan
- Leaflet about care planning
- Letter to arrange a meeting for care planning
- Slides used during the training session

It was asked that participants undertake care planning appointments with the Wellbeing Plan in the following way:

Before the Appointment

The practitioner will invite the person living with dementia for a care plan/care plan review appointment. A phone call to arrange and agree the appointment is preferable, with a letter sent afterward as a reminder. The invitation will encourage the attendance of their carer, or family member at the care planning appointment.

The practitioner will also send the care planning leaflet. Within this leaflet are some instructions for the person living with dementia and their carer, for them to prepare for their appointment beforehand by reflecting on their current strengths and needs, making notes where needed on the leaflet. A leaflet will also be sent out explaining about the trial of the Wellbeing Plan in their locality.

During the Appointment

The goal of the care planning appointment is the creation of a person-centred Wellbeing Plan for the person living with dementia. They will be encouraged to talk about what matters to them and agree the contents of the Wellbeing Plan and resulting actions in collaboration with the practitioner. It will be written in a way which is meaningful to the person living with dementia.

The practitioner will use the GM Dementia Wellbeing Plan to help guide the conversation and take notes on the discussion and agreed actions. It will act as a reminder for areas to cover and potential actions for achieving what matters to the patient.

The practitioner will ask the person living with dementia for consent to share the Wellbeing Plan with others involved in their care and support and record details of the consent given. The person living with dementia and carer will be provided with a very short questionnaire to complete about their experience during the care planning appointment that they can drop in a box as they leave.

The total length of the appointment is expected to be 30 to 60 minutes long. It can be undertaken in stages if necessary.

After the Appointment

The care plan will be written up, signed, and dated and a paper copy posted to the person living with dementia and carer within ten working days. The person living with dementia will have the opportunity to amend the care plan if they feel it does not reflect the conversation at the care planning appointment. The care plan will then be shared with relevant services involved in the person's care (such as GP), that the person with dementia has consented to.

The practitioner will take responsibility for actions agreed for the care plan. This includes, but is not limited to:

- Ensuring that the review date is scheduled.
- Referral for Advance Care Planning – or making a separate appointment to undertake this
- Scheduling separate appointment for carer's needs – referring for a carer's assessment
- Referral/signposting for other identified needs.
- Collating unmet need – with the reporting of unmet need as agreed in each locality.

Collecting Feedback

Feedback questions on the Wellbeing Plan asked of people with lived experience of dementia and their family/carers were kept simple and to a bare minimum and focus on their perceptions of the care plan review process.

Questions included:

- Did you feel prepared for the care plan review?
- Do you feel the care plan review was a benefit to you?
- What parts of the care plan conversation were the most valuable to you?
- What parts of the care plan conversation were of little value to you?
- Was there something you would have wanted to talk about and we did not cover as part of the care plan conversation?
- Did you receive a copy of the care plan? (On the follow-up only.)

Data was collected from the practitioners who undertook the care planning appointments during the pilot. This was to understand both whether the GM Dementia Wellbeing Plan as designed is feasible to use and what changes may be needed, but also to judge the benefits which they perceive from the new Wellbeing Plan.

During the pilot practitioners were asked to feed back thoughts on feasibility and ease of use once they had completed a few reviews. This allowed those running the pilot to judge whether any changes were needed during the trial.

The benefits of the new Wellbeing Plan to health and social care staff and organisations was measured at the end of the trial. Practitioners were asked to complete a qualitative questionnaire about their experiences with the new Wellbeing Plan and undertaking the care planning appointments. They were asked to complete a single questionnaire regardless of how many reviews they undertook. Their response is intended to be an overall summary, though specific experiences were welcome as illustration of general points.

Feedback and Outcomes

The number of Wellbeing Plans expected to be completed under the pilot was around 40-50 spread across the three localities. The actual number of plans created being less important than the number of participating practitioners who could feed back on their experience of the new dementia Wellbeing Plan in comparison to any care plans they may have used in the past.

The total number of Wellbeing Plans completed was 21, the majority being completed by Age UK Salford. The shortfall was caused by several issues, but mostly on the impact of COVID-19. The process of identifying people living with dementia and arranging care planning appointments naturally meant that more would fall in the later part of the pilot, in late February and March. By that time the focus of the services delivering care planning was understandably changing and face-to-face appointments may have been less welcome or even impossible.

The localities with Primary Care involvement were worse affected by COVID-19 during the pilot, specifically Manchester and Rochdale. Manchester had an ambition for a practice nurse to be trained to undertake care planning appointments but shortly after starting had to focus on other duties.

Despite the above, enough practitioners completed Wellbeing Plans in all localities to offer feedback on the plan. The feedback was a mixture of positive and critical experiences. In many cases the feedback has already been used to shape the next stage of the implementation of the Wellbeing Plan.

A complete table of feedback and resulting actions is below:

Appointments		
Feedback	**Action**	**Update**
The information sent out beforehand was found to be useful for person living with dementia (PLWD) and carers. Some people completed the wellbeing plan themselves before the appointment.	Need to have this as a resource to send out with digital pilot with Local Health Care Record Exemplar (LHCR) and include it in the training/prep as Master copy	This information is in the master file of resources
Appointments were made by telephone rather than by letter.	To have this as an option and part of training/prep and as a master copy	This is now an option and a letter is included in master file. Training slides have been updated to reflect this
Length of time: at least 30 minutes, probably longer, with time for follow-up. Two hours in Salford, though previously used care plan/assessment document takes the same time. Considered too long for GPs to undertake	Guidance as part of prep/training on different practitioners completing	Training slides updated describing what the appointment might look like.
The wellbeing plan made for a good conversation, made sense, and followed. People felt positive that it was person-centred and were being heard.		

It was difficult to gauge the person's history, as the wellbeing plan focused primarily on current needs/wishes.	Changes needed to content of the wellbeing plan to obtain history and supports the use by different teams	Changes have been made to the plan to reflect this
The person taking the wellbeing plan away with them was positive	This needs to be included as part of the prep and training	To be added into the training.
The ability to change in the future was positive.		
Compares well to existing care plans.		
Need some more focus on carers. Perhaps a separate time for them to speak alone.	This needs to be included as part of the prep and training plan	This is now included in the training.
End of life was difficult to broach during initial appointments.	Dementia United will speak to the Strategic Clinical Network End of Life Care team and consider any additions given COVID. To include resources e.g. Let's talk about death shall we.	This will also be captured in the training.
Most PLWD and carers were only willing to share with GPs, not elsewhere.	To develop a resource to be sent to PLWD and carers in terms of information sharing and to send out in advance with the leaflet; before the appointment.	It will be captured in the training.
Mental Capacity was an issue with PLWD. Related issues on the existence of Power of Attorney and the ability to speak on somebody's behalf were not resolved.	We will include resources that can be accessed by practitioners, including some case study examples.	It will be captured in the training.
Communication with PLWD can extend appointment time, such as with sensory impairment. Made appointments longer.	To be reflected in the training / plan. Examples as to where extra time may be needed.	
Majority of people were not willing to discuss research at the appointment. May be too early in their journey to consider as still dealing with other things. The value of having something to take away on research is important - capture in the training and as part of the master pack of resources	Dementia United to speak to the research team for resources to be provided.	Captured in the training.
A completed wellbeing plan example would be welcomed to highlight how it should look like	Dementia United to complete a care plan example care plan appointment and completion to be available as a remote appointment.	Capture as a questionnaire/audit tool.

Training		
Feedback	**Action**	**Update**
GPs would welcome an e-learning package to fit training into their schedule.	Dementia United to enquire how this can be made possible.	This is being picked up with the virtual training offer, alongside LHCR support and in discussions with GP excellence programme.
May be a need to include/mention COVID-19 into training where relevant, particularly linked to delirium. Perhaps hand out delirium leaflet during the appointment.	To be included in resources and training	Delirium leaflet has been included in the master pack of resources as well as atypical presentations of COVID-19.
Could have provided more discussion with professionals experienced in completing wellbeing plans, and examples of well-completed wellbeing plans.	To action as noted above.	Will be included in the virtual training offer.
Other professionals didn't feel that all people needed care plans.		
Training was seen as good. The personalisation and involvement of PLWD was very important.	If training was to continue face to face / virtually Inc. e-learning a contingency is needed around how lived experience can continue to be involved.	
Stronger link needed to End of Life Care team as well as personalisation colleagues	Dementia Untied to ensure this takes place. Look at amends using video link.	
A section around prepping for your appointment is needed.	This will be added to handouts sent to PLWD and carer (if living apart), making the appointment and what to expect, reviews and appointments completed over the telephone or virtually either with the person and/or carer.	This has been added to the training slides and will need editing over time.

Resources		
Feedback	**Action**	**Update**
Need a clearer statement on the goals and usefulness of the care plan	Dementia United to add this in clearly for professionals and PLWD/Carers.	
Practitioners need more information about the post-diagnostic support available.	Dementia United will link into the Pathway workstream. Dementia United to discuss Dementia Connect with Alzheimer's Society and with Age UK in terms of local resources. To link in with social prescribing teams in localities for this information too.	

Next Steps

Feedback on the Wellbeing Plan and training was broadly positive and it appears that the Dementia wellbeing plan has met most of its design goals. Much of the critical feedback has already resulted in changes to the Wellbeing Plan. One significant issue, the length of the appointment needed for the care planning discussion, will need to be managed in implementation rather than being a flaw in the plan itself.

Dementia United will cascade the most recent GM Dementia Wellbeing plan and training once finalised and colleagues are welcome to continue to use the plan. Amends will take place taking into consideration Table 1 as well as:

- Reviewing against GM Wellbeing plan standards, including linking to social prescribing
- Discussing with project leads for DU Young Onset and Rarer Forms
- GM/LHCR Information Governance standards
- Referral guidance for localities
- COVID-19 – Implications of undertaking remotely, importance of highlighting any Power of Attorney, Advance Directives and carer needs and support and end of life planning
- Manual on how to undertake and what information can be sent out in advance of the care plan appointment
- Seek approval via DU governance, PDS coordination group and care plan steering group
- Update from GM Digital colleagues
- Sustainability and commissioning implications (including a template for reporting unmet need).

Dementia United will take the initial report through the DU governance to obtain advice around the pilot restrictions due to COVID-19. Following these conversations Dementia United will recommend how the care plan is to be implemented at a GM-wide level and next steps. It will set out the benefits and costs, with supporting evidence drawn from the pilot. It will also suggest any required changes to the GM Dementia Care Plan and practical suggestions for implementation.

There is also the need to discuss any requirements for full implementation which were not part of the pilot. Some infrastructure has not been included in the pilot due to either its current unavailability or the inability to implement for short periods. These include digital sharing of the care plan and long-term ownership structures.

Note of Thanks

Dementia United would like to thank those people who volunteered to take part in the Wellbeing Plan pilot, including:

- Dr Jonathan Kaye, GP, and his Primary Care colleagues in Manchester.
- Cath Barningham, Mary Ann Byrne, and their colleagues at Age UK Salford.
- Sarah Kay of Rochdale CCG and her Primary Care colleagues in Rochdale.
- Julie McCaughey of the Alzheimer's Society and members of their lived experience groups who provided roleplay training.