



Dementia United programme Bulletin 18: May 2023

Dementia has been declared a priority for Greater Manchester and Dementia United is the flagship programme for Greater Manchester Integrated Care. Our shared ambition is to improve the experience of being diagnosed and living with dementia and make Greater Manchester the best place to live for all those affected by Dementia.

Dear colleagues,

Welcome to our e-bulletin. If you would like to get in touch with us or have any comments or suggestions, please send them to gmhscp.dementiaunited@nhs.net. Please share this bulletin with anyone who may be interested in our work.

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As part of Dementia Action Week 2023, this bulletin provides an update on Dementia United and our key partners, as we work together to make Greater Manchester the best place to live for all those affected by dementia.

Asking the same question over and over again. over and over again. over and over again.

It's not called getting old, it's called getting ill.

Dementia Action Week
15-21 May 2023



Diagnosis is the focus for Dementia Action Week 2023.

For Dementia Awareness Week the Alzheimer's Society are focusing on increasing diagnosis rates.

Greater Manchester above national average for dementia diagnosis



Greater Manchester has the highest rate for dementia diagnosis in the North West and has done since 2017. The diagnosis rate is currently at 69.4% – nearly 3% higher than the national dementia diagnosis rate target (66.7%) and over 7% higher than the national average (61.8%).

Getting a timely diagnosis of dementia can give you a better understanding of the condition and what to expect. It can also help you make important decisions about treatment, support and care.

We actively work alongside partners including health and social care professionals, and voluntary sector organisations. The programme also puts people living with dementia and their families at the heart of its work, using their insights to improve the quality of care and provide support across Greater Manchester.

You can [read more on our website](#)

Our pledges and commitments

Unique: Commitment that everyone living with dementia has a **UNIQUE** person-centred wellbeing plan

Navigate: Commitment for everyone to have a named dementia care coordinator to **NAVIGATE** the system

Include: Commitment to **INCLUDE** the voices of people with lived experience of dementia in all areas of work

Training: Commitment that mandatory **TRAINING** in dementia awareness takes place for all who work with the public

Educate: Commitment to **EDUCATE** the public about brain health and dementia prevention

Data: Commitment to use **DATA** to measure success and improvement, especially in regard to post-diagnostic support

Help us to **UNITE** Greater Manchester for people affected by dementia



Cartoon by Tony Husband

Meet the team

- Gill Walters, Senior Implementation and Improvement Lead
- Amal Morsi, Project Manager
- Helen Pratt, Project Manager
- Karen Thakuria, Project Manager
- Sarah Kirkland, Project Manager
- Fiona Black, Project Support Officer
- Rachel Spencer, Business Support Officer
- Laura Blake, Communications and Engagement Lead



Partners: Living with Dementia Group

We know people living with dementia are experts by experience and are in the best position to advise Greater Manchester's dementia programme on the needs of people living with dementia. Living with Dementia Group members get involved with and influence our entire programme. Members are equal partners in Dementia United's leadership structure, are represented at our steering and task and finish groups, and on multiple additional projects.

John O'Doherty: Member of our Living with Dementia Group talks about why he would encourage people to get involved



In 2016 I was diagnosed with Vascular Dementia. My journey to diagnosis was lengthy, torrid and impacted greatly upon my family. Had my diagnosis been done in a timely manner, I would not have reached the pit of despair which led me to self-harm. It would have also prevented my family, friends and colleagues being exposed to watching me deteriorating.

My memory was becoming problematic, for example I was forgetting people's names, including my sons and Grandchildren. I could no longer count change, when driving I was getting lost even on familiar journeys to the extent that I started using the bus service. This too became difficult, and I was continuously getting on the wrong bus.

In the workplace I was making mistake after mistake to the extent I was demoted twice. In fact, in my now junior role, I couldn't remember how to use the photocopier. I felt like I was having a nervous breakdown. I was continuously visiting my GP to no avail. It was only when I began to self-harm as I could no longer cope that I was referred to see a psychiatrist.

At my appointment with the psychiatrist, I explained what was happening to me. I was given a memory test which I totally failed. I was then sent for a brain scan which showed abnormalities. I then attended a memory clinic where I was given my diagnosis. It was at this stage my dementia care plan was established.

Prior to the innovations of the dementia care plan, services provided to people living with dementia were often disjointed. The care plan was developed in order that services were streamlined and ensured a level of uniformity across all sectors involved in providing dementia care.

The main aim of the dementia care plan is to create a strategy offering planning and support throughout the dementia journey. That support is given from diagnosis to end of life care.

After my diagnosis I had to take early retirement from work. I found myself alone at home, depressed and in a void doing nothing. I then contacted the Alzheimer's society who in turn linked me with Dementia United.

I have now worked with Dementia United for a number of years and is the greatest level of support I have. I have made friends, colleagues and always feel welcomed. Indeed, due to my work with Dementia United I consider myself as a both a representative and advocate for other people living with dementia.

During my time with Dementia United I have participated in many areas such as:

- Recruitment and appointment of colleagues.
- Served on the board of the Manchester Airport Accessibility Forum.
- Written articles
- Assisted the recruitment of Social Sense who developed the Greater Moments app.
- Addressed conferences.
- Assisted in research such as Housing, Finance, Benefits and Transport.

This is merely a list and is not exhaustive of my work.

In conclusion I would gladly encourage others to become involved in Dementia United's work.

Would you like to get involved with our Living with Dementia Group?

We're currently recruiting for members to join the Living with Dementia Group. If you're living with dementia or know someone who's living with dementia who may wish to get involved. We would love to hear from you.

You can find out more and download our recruitment flyer here: <https://dementia-united.org.uk/living-with-dementia-group/>

Please contact Amal on 07917511678 or email amal.morsi1@nhs.net if you would like to have an informal chat about the group.

Partners – Dementia Carers Expert Reference Group (DCERG)

Members of the Dementia Carers Expert Reference Group are equal partners in Dementia United's governance structure and are represented at each Dementia United task and finish group, and multiple additional projects. They ensure the carers collective voice is represented in the feedback of the development and implementation of all work streams for Dementia United.



Some of the members of the Dementia Carers Expert Reference Group

Jeff Seneviratne, DCERG Member “I believe we really are valued and respected as “Experts by Experience”.



In February 2019 someone suggested that I might be interested in attending a Dementia carers workshop organised by Dementia United and TIDE ([Together in Dementia Everyday](#)). My wife had Alzheimer's, having been diagnosed in 2014, and at this stage I was accepting that I was now her carer.

The purpose of the workshop was to recruit current and former carers of people with dementia to join this new Group which would inform the Dementia United programme. They wanted people with *passion to make a difference and a positive attitude* to consider applying. This was the beginning of the Dementia Carers Expert Reference Group.

From the time of diagnosis, we had largely felt as though we were “on our own”, monitoring the progression of this disease. The diagnostic process had been long drawn out, and I had to chase appointments, and we felt in limbo. Afterwards, there was no regular follow up to assess changing needs. Our lives had changed significantly over the preceding 5 years and many things were becoming more difficult. However, I knew that there was much that needed to be done to improve the diagnosis and continuing care of people with dementia and those who care for them. I felt that this would be an opportunity to influence and use our experience to make improvements. So, with the support of my family and friends, I decided to apply.

The Dementia Carers Expert Reference Group took a while to get up to speed but I really do feel that the last 4 years have been time well spent and that we have made a difference.

- I believe we really are valued and respected as “Experts by Experience”.
- We are represented at the Dementia United Strategic Board and at other Dementia United meetings.
- We are consulted on Dementia United developments and have contributed to the Strategic and Delivery Plan.
- We have been closely involved with the development of the Dementia Care Pathway, a valuable GM Specific web-based resource for people living with dementia, carers and professionals.
- We were associated with the development of the Wellbeing Plan as a *vehicle* to assist navigation post diagnosis. This is now being digitised and I am involved with the project group to demonstrate proof of value.
- Other members of Dementia Carers Expert Reference Group have been closely associated with projects about dealing with delirium and end-of-life care.

In June 2022 Dementia United held an event in Manchester with the aim of identifying how to live well with dementia in Greater Manchester. It was an honour to be invited to be a member of the panel at this event with, among others, Andy Burnham, Mayor of Greater Manchester, and the Chief Executive of the Alzheimer's Society. Following this, in October, I was one of a number of Dementia Carers Expert Reference Group members who contributed to a discussion about improving dementia care at the Greater Manchester Reform Board, chaired by Andy Burnham.

The Dementia Carers Expert Reference Group is an important element of Dementia United and it's clear that it's had a significant impact on its work and continues to do so. The original aim was for there to be two representatives for each of the ten boroughs of Greater Manchester. At the present time this has not been achieved. Recruitment of new members is an important part of any group both to ensure wide representation and to allow for turnover.

Would you like to get involved with DCERG?

We're currently recruiting for members to join the Dementia Carers Expert Reference Group. If you're over 16 and are a current or previous carer for someone living with dementia, or if you know someone who might be interested, we would love you to hear from you.

You can find out more and download our recruitment flyer here: <https://dementia-united.org.uk/dementia-carers-expert-reference-group/>

Please contact Amal on 07917511678 or amal.morsi1@nhs.net if you would like to have an informal chat about the group.

NHS England resources for Dementia Action Week:

- Free e-learning module on improving care for people from ethnic minority communities throughout the dementia care pathway
https://elearninghub.rcpsych.ac.uk/products/NHSE_Dementia
- New guide on intercultural dementia care <https://www.england.nhs.uk/publication/intercultural-dementia-care-guide/>
- New activity booklets <https://www.england.nhs.uk/publication/dementia-care-activity-booklets/>
- New leaflet to raise awareness in ethnic minority communities
<https://www.england.nhs.uk/publication/what-is-dementia-a-leaflet-for-ethnic-minority-communities/>

Greater Manchester's best practice delirium webinar 26th April 2023



“30 years as a GP and one of the best webinars I have attended.” (General Practitioner)

The delirium best practice webinar was a great success, with over 150 attendees representing a broad spectrum of backgrounds and services. We had representation from all 10 localities of Greater Manchester and a wide range of services and organisations attended including from across the UK.

“This has been amazingly educational and very valuable for our work supporting citizens in the community; great to know how much support is available for sufferers of delirium.” (Reablement services)

“Very well presented and it is the BEST webinar I have ever attended.” (Memory Assessment Team)

This webinar hosted by Dementia United had a wide range of speakers covering a wide range of topics.

You can [find out more, download the slides and view the webinar here](#)

Our delivery plan 2023-25

Dementia United have a wide-ranging programme of work, with cross cutting themes of co-production, diversity, and partnership working.



You can find out more about our work here: <https://dementia-united.org.uk/our-work/>

Please note that we are currently updating our website.

Have you heard about the Greater Manchester Dementia Care Pathway?

We’ve been told that finding the right information and support when you’re living with dementia, caring for someone living with dementia or delivering services for people living with dementia can be difficult. That’s why we’ve developed the Greater Manchester Dementia Care Pathway.

You can access the Greater Manchester Dementia Care Pathway via the link here

www.gmdementiaresources.org.uk/. Please note we are in the process of updating the pathway. If you would like to be involved in this project, please contact us. Email: gmhscp.dementiaunited@nhs.net

Whether you're looking for local information for yourself or a loved one, you're a commissioner looking for best practice guidance or you work in health and social care and are looking for the evidence behind different interventions, you'll find it in our dementia care pathway.

Dementia United worked with people living with dementia, their care partners, and professionals in Greater Manchester to **find out what matters to them** and to use this information to **co-produce a set of 75 recommendations** which cover all stages of the dementia journey.

Each recommendation includes **information on how to access support and services across Greater Manchester and nationally**, as well as evidence as to why the recommendation is important and examples of best practice showing how it has been successfully implemented.

"I believe the dementia care pathway is a wonderful initiative which will serve to enhance the lives of people living with dementia. It provides clear guidance on what people can expect when accessing support. The dementia care pathway will also be a great education and training tool for health and social care staff and ensure services are much joined up too". Person Living with Dementia

You can find more information about the pathway and training resources here: [Greater Manchester's Dementia Care Pathway - Dementia United \(dementia-united.org.uk\)](http://Greater Manchester's Dementia Care Pathway - Dementia United (dementia-united.org.uk))

Please join us to support the development of this resource, including a review of the standards and the creation of a pathway oversight group.

We are looking for interested parties to join our project steering group and guide this work over the next two years. This includes people living with dementia, carers, and practitioners who work with people affected by dementia. It is likely the group will meet monthly initially, for one hour via Teams. We are hoping to have representation from each locality of Greater Manchester.

Our first meeting will take place on **Wednesday 31st May 2023 10 – 11am**, via Teams. At this meeting we will provide an overview of proposed project objectives and agree next steps.

Please contact Karen Thakuria (Project Manager - Dementia United) if you would like more information or for a link to join the meeting k.thakuria1@nhs.net.