



Dementia United programme Bulletin 3. July 2020

Dear colleagues,

Welcome to our e-bulletin. We've included updates from across our programme and would welcome your feedback. Do you find this useful? Is there anything else you'd like us to include? If you have any comments or suggestions, please send them to gmhscp.dementiaunited@nhs.net

Delirium

Dementia United's clinical lead, Dr Emma Vardy, chaired the first NHS England and NHS Improvement Live Webinar on Delirium, on the 24th June 2020, with 600 plus delegates attending. Helen Pratt presented on the work that Dementia United have been undertaking on the Community Delirium Toolkit; alongside Alistair Burns who hosted the event and a number of leading clinicians who covered topics such as delirium in the context of COVID-19 (Dr Thomas Jackson), delirium management and follow-up in the context of COVID-19 (Dr Mani Krishnan) as well as delirium in care homes in the context of COVID-19 (Professor Adam Gordon). [You can find the slides from the webinar on our website](#). Thank you to those Greater Manchester multidisciplinary community teams who have already expressed an interest in testing out the working Community Delirium Toolkit. There is still time to do this by [visiting our website](#) and scrolling down to "Delirium" where you will find the Expression of Interest Form to complete (this includes the embedded toolkit for you to view).

Key contacts: helen.pratt5@nhs.net and lyndsey.kavanagh@nhs.net

Dementia Carers Expert Reference group

Regular online meetings are now in place for this group with future work priorities almost finalised. Part of the delivery plan centres on being inclusive and supporting all communities with a specific focus to engage B.A.M.E. carers. A WhatsApp group and supporting leaflets are now available to the South Asian Communities in several languages including Bangla, Kuchi Memon and Urdu (please see tweets below). Work is underway to also have Punjabi and Gujarati versions in the near future.

- Bangla - https://twitter.com/Shahid_MoSardar/status/1277954656577163266?s=20
- Kuchi Memon - https://twitter.com/Shahid_MoSardar/status/1276079698427236355?s=20

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- Urdu - https://twitter.com/Shahid_MoSardar/status/1276069427470127105?s=20
 - English - https://twitter.com/Shahid_MoSardar/status/1275338719583784961?s=20

<https://www.tide.uk.net/>

Dementia research

As we adapt to the new normal, there's still a lot left to learn about the impact COVID-19 has had on our communities. In particular, we understand that these unprecedented circumstances, including lock-down restrictions and shielding for older and more vulnerable individuals, have put significant pressure on our communities' unpaid carers. These carers provide invaluable support not only for those they care for but for their communities and society as a whole. It's therefore paramount that we strive to understand the experiences of carers during lock-down and the impact this has had on their health and wellbeing.

Kings College London have launched a study looking to better understand resilience and stress in unpaid carers during the COVID-19 pandemic. They hope that understanding how some people remain resilient to the stress of COVID-19 and how this differs between carers may help to uncover new ways of supporting people with caring duties in times of crisis such as this.

The study can be completed online so can be accessed from any location in the UK, full details and eligibility criteria can be found on King's College's information page:

https://kclbs.eu.qualtrics.com/jfe/form/SV_eLQEWdDymGK5E5n

The best way to learn about this and many more currently running across the UK is through Join Dementia Research. This service offers access to a number of studies which can be completed online or over the phone. You can find out more by calling the Alzheimer's society and asking about research on: 0333 150 3456 or visiting their website www.joindementiaresearch.nihr.ac.uk

Key contact: Sarah.Fox@gmmh.nhs.uk

Can you support research into COVID-19 isolation?

A group of global collaborators, including the world's leading researchers in the effects of isolation and loneliness are conducting a piece of globe-spanning research on COVID-related isolation. It's easy to participate by phone or computer, open to all over-18s, and completely anonymous. They want to understand how people are coping during the Covid-19 pandemic. They want to learn about the issues people are facing and how they're managing with social distancing and changes to everyday life. There's a sub section capturing the views of people caring for someone who's living with dementia. You can offer invaluable insights into life before and during the Covid-19 pandemic, including key challenges faced and coping strategies used.

The survey's unique in its scope, including the fact that it will sample caregivers' experience from Norway to New Zealand, from Lebanon to Liverpool and therefore represents a real opportunity for us all to participate in a global research initiative in response to COVID-19.

[You can complete the survey here](#)

End of life

Work has resumed on developing Greater Manchester training on end of life care of those with dementia. The syllabus of what this will look like is being finalised with input from people affected by dementia and professional experts. Over half of deaths with a mention of dementia occur in care homes, so training will largely be focussed for care homes and multidisciplinary teams supporting them in the first instance. We believe this also fits in with the NHS Long Term Plan Enhanced Health in Care Homes (EHCH) model to be delivered by Primary Care Networks. This model moves away from traditional reactive methods of care delivery towards proactive care that is centred on the needs of individual residents, their families and care home staff; with a particular focus on high quality end of life, mental health and dementia care. When content is finalised we will be working with educators to ensure they are confident in delivering consistent training across Greater Manchester whilst appreciating individual locality setups and ways of working. It is hoped the training will help increase advance care planning along with increased confidence for professionals in identifying and supporting someone dying with dementia. Watch this space...

Key contact: lyndsey.kavanagh@nhs.net

Post diagnostic support

Dementia United have been undertaking a scoping of post diagnostic support and Memory Services across Greater Manchester (GM), in terms of how they have been affected by COVID-19 pandemic. Thank you to all those groups and services that we've been able to make contact with. The conversations that we've had have highlighted how volunteers and staff have shown such resilience and flexibility in providing support to people affected by dementia. It's been a real pleasure to hear about and bear witness to such wonderful and generous acts of kindness and compassion. It's also vitally important that this is acknowledged, by us in Dementia United and by the wider GMHSP. In terms of next steps, we plan to develop a platform for resources to be shared as well as connecting groups and services up, to enable some shared learning. Some of the groups and services we spoke to, indicated that there may be members that they are in contact with, who would potentially be interested in contributing to and developing our work in Dementia United. We plan to make contact with these groups to follow this up.

Key contact: helen.pratt5@nhs.net

Young onset and rare forms

Many people associate dementia with memory problems and older age. However, there are rarer dementias that affect people and present quite differently, meaning diagnosis can take longer and post diagnostic support on offer may not be appropriate. For example, frontotemporal dementia primarily causes problems with behaviour and language. Pennine Care Stockport, Older People's Mental Health Team identified this gap and have worked with carers and experts to develop the following videos:

- [Part one - An introduction to frontotemporal dementia](#)
- [Part two - Getting help and support with frontotemporal dementia](#)
- [Part three - Living with changes in behaviour in frontotemporal dementia](#)

It's hoped these videos will help raise awareness amongst professionals and the public to better recognise frontotemporal dementia – especially GPs who may be the first port of call when someone is concerned about their symptoms. The videos are also an excellent resource for formal and informal carers to understand what it is like to live with and care for someone with frontotemporal dementia with practical tips and advice. Please share these videos with friends and colleagues you think will find these helpful.

Key contact: gaynah.butler@nhs.net

Other news

Law 4 Dementia Carers

L4DC (Law for Dementia Carers) is a two-year project funded by The Legal Education Foundation to raise awareness of carers legal rights with carers themselves and with front line health and social care staff. The project is based in Greater Manchester and aims to pilot training for carers, and for staff via a social prescribing model which sees access to legal information as improving health outcomes. The project is a partnership between LSN/tide and Making Space working together with the University of Manchester's Dementia Law Clinic. The project started in November 2019 and has completed a UK wide carer survey of legal issues. With Covid-19, the project has pivoted its activities temporarily to focus on carers legal issues as a result of the pandemic including the introduction of the Coronavirus Act. In June, a summary for carers on the health and social care implications of the Coronavirus Act was published on tide and Making Space's websites, and this was followed by a legal webinar held on 23 June where 149 people attended. It included a broad range of legal issues and received very positive feedback from carers. Over the course of the summer there will be a further survey focusing on legal issues during the pandemic across the UK, interviews with carers, and a closer look at what is happening in Greater Manchester both from the perspective of the Greater Manchester Health and Social Care Partnership and how this partnership has helped to coordinate the response across the area and from the experiences of carers of people with dementia. The aim of the pivot in focus is to be able to give voice to the experiences of carers of people with dementia to influence the statutory review of the Coronavirus Act in the autumn. You can [read the statement on tide's website](#). If you would like further details please contact karen@lifestorynetwork.org.uk

Shout crisis service – can you help?

We're thinking of running a communications campaign to promote the Shout crisis service to people caring for someone living with dementia and would appreciate your views regarding:

- Do you think a text service like this would be more accessible than a telephone helpline?

Please can you send your feedback and thoughts about this to laura.blake10@nh.net help and support. People can send a text message any time of the day or night and every conversation is with a trained volunteer who is supported by a clinical supervisor. Its available

across Greater Manchester and we're getting very good feedback from people who have accessed the service. It's easy to use.

- People don't need an app or data
- There's no registration process
- It's silent and won't appear on phone bill
- It's confidential and anonymous.

Just text GM to 85258

After someone sends a text a crisis volunteer will reply. The volunteer will offer support and will also provide sign posting to other services that can offer support and ongoing help in a local area.

Website

We're continuing to add new resources to our COVID-19 resources hub on our website <https://dementia-united.org.uk/home/covid-19-information/>. This provides a wide range of guidance and information for people living with dementia and those that care for them. We're also using this site to signpost people to where they can get the help and support they need, whether it's help with shopping or support with their mental health and wellbeing. All resources have been quality checked and we will continue to add resources as they become available. We would welcome your feedback helen.pratt5@nhs.net or emma.smith96@nhs.net