

Dementia CPG, Friday 10 July 2020; Minutes

In attendance:

Nigel Hullah	living with dementia,
Chris Roberts	living with dementia
Andy Woodhead	living with dementia
Jim Ibell	living with dementia
Jayne Goodrick	carer
Ceri Higgins	carer
David Rowson	carer
Alison Johnstone	Welsh Ambulance NHS Trust
Beth Evans	Carers Wales
Julie Skelton	Marie Curie
Rebecca Cicero	Social Care Wales
Natalie Elliot	Welsh Government AHP Lead
Padraig McNamara	Welsh Government
Helen Cunliffe	NHS
Rhys Jackson	Older People's Commissioner
Dr. Rosslyn Offord	NHS
Louis Mertens	Royal College of Psychiatrists
Stephen Thomas	Care and Repair Cymru
Katie Featherstone	Cardiff University
Sue Phelps	Alzheimers Cymru (Secretariat)
Lynne Neagle	MS and CPG Chair
Eleri Cabbage	Lynne Neagle's Office

Apologies: Michaela Morris

Welcome:

Lynne Neagle welcomed everyone to the meeting and explained the purpose of it was to hear about the experiences of those living with dementia during lockdown. She said she had picked up quite a few concerns from constituents and wanted to hear from CPG members in a bid to identify the issues and learning that could be taken forward and raised with WG ahead of any possible second wave in the autumn.

Nigel Hullah, Chair 3 Nations Working Group on Dementia gave a presentation on a series of webinars that he has been involved with on the impact of Covid-19. The webinars reached some 11,000 people. The views are UK wide but on average 30% of participants were from Wales and included a mixture of professionals, carers and people living with dementia. He said there is going to be a lot of damage to society in general as a result of lockdown, although the rules have been different in the three nations, the impact has been exactly the same. It is a feeling of loss, a feeling of abandonment and people are afraid. People are afraid to go back out there because they are not sure they are safe.

Key messages:

- Participants had taken advice on safety very seriously, stayed in lockdown
- Members felt they wanted to stay in lockdown because of other underlying conditions. Many had shielding letters
- Many felt they had suffered a loss of skills because of isolation: both acquired skills, social and adaptive because of becoming estranged from contacts and friends
- Many felt a loss independence and a need to relearn skills such as travelling on public transport and shopping. On a personal note, Nigel said he had been out the previous day and – although he has lived in Swansea for 15 years – he lost his way.
- The withdrawal of face to face services, although a requirement is hard to understand for someone living with dementia who finds their routine suddenly disrupted
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One webinar was dedicated to carers, issues included:

- The stress of a caring role is a long documented one but it has been exacerbated by lockdown.
- Live in carers/unpaid carers brought up the lack of availability of education.
- The lack of availability of food deliveries and the astonishing decision by supermarkets UK-wide not to treat people with dementia as a vulnerable group.
- People in their care having difficulty understanding why their routine had been changed because of lockdown restrictions.
- A re-occurring point made by carers, if we have to do this again, that some impact assessment needs to be done on the impact it is going to have particularly on unpaid carers who bear the brunt of this.
- It was thought there would be a need for some repair work between carer and person living with dementia. It was felt that carers who hadn't had time to recuperate from caring duties because of lockdown would need to be given special help to redefine the dynamic between them and the person living with dementia. It was felt perhaps that this relationship had been damaged.
- People living with dementia themselves had noted the relationship was breaking down but they couldn't help themselves because of the close proximity.
- A lot of people are going to need more care than they were in receipt of before lockdown.

Nigel said that on a recent call with Young Dementia UK he had been told that when a vaccine is available the UK Government will put people with dementia among the first group to have access to the vaccine. That is the proposal, whether it will happen is another matter.

Conclusions:

- Health and social service workers and third sector organisations continue to play an especially important role in supporting the rights of people with dementia
- Generally, participants trusted the third sector more than statutory services. This was not a criticism, just a preference, They felt the third sector was more likely to take note of their preferences and needs.

- Growing concerns include the lack of technology, the reluctance to admit people into general hospital from care homes, the wide usage of DNR notices and the lack of understanding of the regulations generally between the care homes and the hospitals.
- We believe dementia has been disproportionately impacted by covid-19 and there will need to be some research on the long-term impacts of this and it needs to be done very quickly because as Lynne alluded to, we don't want a second surge but it is a possibility and I think we must learn lessons from the way it has been handled.

Find out more about the webinars and read Nigel's blogs at <https://www.3ndementiawg.org/>

Jayne:

Spoke about her experience of lockdown with her husband Chris who is living with dementia. She said it had been very good. They had enjoyed the 'time off'. She said Chris had received a shielding letter and offers of supermarket delivery slots which they had taken advantage of twice. They were lucky because they had a daughter who was able to bring them fresh provisions back and forth. Social services had been in contact with them. Everything that was meant to be put in place to protect people has worked in their case. They hadn't needed to take advantage of it though.

She said Chris had been very comfortable in his isolated bubble although at the beginning he had suffered from an awful lot of anxiety but he had been able to work through that himself by working in the garden. She said they went into our lockdown the week before the national lockdown because of Chris's emphysema.

She spoke of the difficulty of not being able to see her mum who has dementia and is at the end of life because of cancer. Once outside visits were allowed, they had been to see her mum and her progression was very marked.

She said Chris has had a marked increase in his dementia symptoms his fluency is much reduced, his short-term memory is shot and he is fearful of going outside because he is not confident that people are still aware that he is still shielding. He feels people are becoming very much more complacent about it now that lockdown is virtually lifted. That is his impression. He doesn't go out to gain that impression but that is the way he is feeling because he is with me, I will be able to take him out.

We will be able to work that out together but that isn't going to happen for people living on their own who will be very much more isolated. Chris described it as going even further into his own safe bubble. I can expand that bubble for him that perceived bubble but other people don't have a Jayne to do that for them and that is my biggest worry going forward.

Andy

Andy who is living with dementia said he felt his symptoms had progressed. He felt isolated because his life of going out and meeting friends had been curtailed. He said now if his husband asks him to go shopping, he stays in the car park, he doesn't want to go out anymore.

He said he had been more agitated in lockdown. Tempers had been frayed. He said in 99% of the cases it had been his fault. He said he had difficulty reading because he could not remember what he had read the day before

He said when he was given his diagnosis, it was not like a diagnosis for cancer, because when you get dementia there are very few treatments that are available. You almost feel like you get the diagnosis and then you are on your own.

He spoke highly of the Alz Soc.

Referring to an Alz Soc survey of 880 people he said it had found:

- three quarters said the coronavirus pandemic had made them feel more lonely or isolated than before
- around half said they were struggling to cope in the crisis. Andy said the biggest battle for people with dementia was depression and agitation. He said he had certainly struggled with depression during the four months of lockdown.
- over a quarter were concerned their dementia symptoms were worsening.

Key messages from the survey were:

- The long periods of isolation and the loss of routine and social interaction can be damaging to the person
- The Alz Soc is inundated daily through its support line by people with dementia who have noticed their cognitive ability is declining. They are phoning in to express their concerns.

Andy said his biggest worry now was that when the lockdown is over, he will have lost all his confidence. He said he was having similar thoughts to when he was first diagnosed with dementia, it caused him depression because he did not know how it was going to affect him and how he would be able to live with dementia.

He said, he had learnt to live well with dementia but worried he had now lost that ability. He said he was struggling with depression. He said he had more bad days than good days whereas before the lockdown he had lots of good days and the odd bad day.

He added that the services in the Vale of Glamorgan had been wonderful.

David

David spoke about the difficulties of visiting his wife who has been in a care home in Ammanford for the last four and a half years. He said after the lockdown on March 15 it took up to three months to get a phone into the care home with a sim card. He said the first time he was able to visit physically he found she had gone downhill terribly. She pretty inert and is not connecting with anybody. He said it was very demoralising for carers not to be able to visit her. He said it was all very well for the Welsh Gov to say we can go from the 1st July, but you can't have someone who is 80 years old next month wheeled out in peeing rain for a visit. She almost completely bed ridden. The care home is brilliant they look after her very well but they haven't got time to go round waving phones in front of 40 odd residents.

- Sue Phelps noted she had raised some of David's questions with Adam Price as MS for Carmarthenshire

- Padrig referred to guidance on visiting care homes and outdoor visits, said it also included guidance on indoor visits if people couldn't go outside. Said he would send it over.

Ceri

Ceri, who has until recently been an unpaid carer for her dad, spoke about the death of her father on 3 April from dementia and covid.

She was particularly concerned that the 5 to 6 weeks he spent in hospital that the family had no contact whatsoever with him, even though Ceri had cared for him with covid before he was taken into hospital.

She said she had to ring three or four times a day to help them know how to care for him because the dementia knowledge was so limited. She suggested that might be because of retired staff coming back and younger staff coming off their last year of training etc. She said they didn't know how to get him to eat or that he couldn't walk.

She said his advanced care issues, care planning, end of life care went completely out of the window.

At 9pm the night before he died, she had a phone call to say he was doing well. At 1am that morning she got a phone call from a most fantastic nurse who said she was throwing away the rule book and asked what she could do for him. She went through what was in his end of life care plan and managed to get an element of that done by the nurse. That was 'phenomal' she said.

The issues for Ceri, were people's rights. She said knowledge of dementia seemed quite archaic bearing in mind the country had only been in lockdown for two months. It seemed like dementia – how do we do that?

She felt as if her dad's human rights were completely thrown out the window. She said she would be following up the issue. It was almost as if dementia didn't matter.

She acknowledged things were really bad and the pandemic was unknown to everyone but her concerns were about devaluing humans and what her Dad's rights were and what her family's rights were looking back, with no contact for the five weeks before the end.

She said she felt like they were the experts. It was almost as if the work done in relation to dementia and caring had gone back 10 years. She said she had been 30 years in caring for family and friends with dementia and the treatment that she heard and saw was no different to what she had heard and experienced 30 years ago.

Karen:

Karen, said it was 8 weeks before she got a shielding letter. Before that they had struggled to get food supplies. Personally, she felt she had deteriorated a little bit, she is starting to forget little bits now and again. She said she didn't go out on her own. When she does go out it is with her husband and he often has to force her to go out. She finds it quite scary being out because people do not keep their distance and if you say anything, they have a go at you.

She finds she is snapping more than she used to. Her daughter and baby live with her and her husband and she thinks they have got on top of each other. She said there were strains sometimes, where she ends up biting, where she would normally have been more diplomatic. She said she hadn't noticed but her husband has told her she was doing it.

She had been asked to help at a support group that was hoping to reopen in Sept. She said she would as long as things were put in place to keep people safe.

Jim

Jim from Flintshire, North Wales said he was doing quite well in the lockdown.

He picked up on a point from Ceri on the standard of care. He said he regular speaks about dementia all around North Wales and he is really surprised how many people come up to him at the end and say they have had the same problems as me. He said he had been diagnosed five years ago by a consultant and since then had never ever seen a doctor or a consultant to do with his dementia. He felt it was because there was no cure for dementia. Because they can't cure us, they don't want to know us. I feel as though dementia is not important enough for people to worry about. He paid tribute to the work of the Alz Soc.

Sue Phelps

Sue said the contributions encapsulated what Alz Soc had been hearing through its welfare calls and its companion calls.

She said, like many other agencies the Alz Soc was not having to deliver our services virtually on the telephone or zoom.

They were also trying to gather information about how lockdown has impacted people to take that learning going forward.

She hoped there wouldn't be another pandemic but it was important to take forward the learning from this one.

In particular she suggested three themes:

1. People's experience in hospital: Ceri you articulated that so well of being a remote carer, trying to find out what is happening. Learning at the very least: why wouldn't the ward clerk when somebody is admitted with dementia make direct contact with the carer, the family, the loved one. What do we need to know? Similar sort of thing with care homes keep that contact going with the people who know best
2. Access to routine appointments: What we are hearing out there is because memory clinics haven't been functioning there will be a backlog of people who when services are resumed get their diagnosis. The sudden huge impact that is going to have on services that themselves have only just come out of suspension. Will we be able to cope with that? We are going to be inundated with newly diagnosed people and because of deterioration people in need of services that perhaps they didn't need

before lockdown. How will we cope with that? We need to start planning for that now. That is a big concern.

3. Final thing, is the sorts of services that people really, really benefit from to live their lives as well as they can do with dementia are those services that provide those opportunities to socialise, interact, contribute to society, to be independent. Those services are the ones that have stopped. Those are the ones that have been replaced out of necessity by the digital, telephone type offer. There is a genuine concern that because we have done it so well with the economic effect that is now coming out of the lockdown will those services remain as a virtual telephone offer and will we never get back to those face to face services that are so, so crucial for people living with dementia

Rosslyn:

Rosslyn Offord Clinical Psychology lead for VOG said had heard many of the same things people had described. She said clients were deteriorating and their needs changing though lockdown in the way people had described. She said a lot more people had come to their attention via GPs, police, social services. People who were never under memory assessment services, who didn't have a diagnosis before, but for whom lockdown had been very difficult were now presenting.

She spoke about the problems inviting people in for appointments – the risks versus the benefits. She said many clients wouldn't use online services and didn't have the technology. From the NHS perspectives she said obstacles included a global shortage of headsets, NHS decision not to allow the use of Zoom, concerns that data breaches when using online technology might lead to health boards facing fines of 10% of its budgets.

She agreed with the human rights issue. She felt like people with dementia had come bottom again. She added that they were struggling to get back staff who had been redeployed during the pandemic.

Faisal of Carers Trust

She said she had heard about carers who are really struggling living with people with dementia, some of them are feeling let down. The stress, worry and anxiety they are experiencing had affected their wellbeing and mental health. She highlighted specific issues for BAME people and LGBT people who don't have as much access to digital services and the internet who have been more significantly impacted.

Lynne Neagle thanked everyone for taking part and listed the following issues for follow up:

- Shielding: I think it was a mistake to link shielding to services because that meant people living with dementia and other people who needed support lost out
- Loneliness and isolation: huge issue and the impact that has had on people's personal dementia journey in terms of cognitive decline
- Access to services: which undoubtedly were impacted by the covid bill

- Care homes: importance of ensuring people could still connect with loved ones, equally applies to people in hospital. We have got to do this better, if we are ever in this situation again.
- Staffing and redeployment: really important issue and service recovery issue as well
- Human rights: overall for me it is about people's human rights. I feel they have not been respected as they should have been during this period. Ceri nailed it for me when you said a lot of the gains we had made in recent years around dementia have been lost during this period. The First Minister has talked a lot about the fact there is more than one harm from coronavirus and I agree with this. What this meeting has told me is that my worries about there having been significant harm to people living with dementia is actually what has happened really. And that is a very sobering thing for us to hear.

Actions:

It was agreed Lynne would:

- Write on behalf of the CPG to WG to set out the concerns raised
- Pick up some of the issue in WAQs
- When the letter is written talk to Sue Phelps and others about putting out a press statement about how worried we are
- Sue Phelps suggested holding a second meeting when response to letter had been received