

## Cross Party Group meeting note - 6 November 2020

### Attendees:

Lynne Neagle MS - Chair of the Cross Party Group  
Eleri Cabbage - AM Support Staff  
Huw Owen - Alzheimer's Society Cymru  
Sue Phelps - Alzheimer's Society Cymru  
Bethan Edwards - Marie Curie  
Andy Woodhead - Person living with dementia  
Kevin Jones - Carer for a person living with dementia  
Chris Roberts - Person living with dementia  
Jayne Goodrick - Carer for a person living with dementia  
Ceri Higgins - Carer for a person living with dementia  
Sally Guy - Carer for a person living with dementia  
Amy Kordiak - TIDE  
Nigel Hullah - Person living with dementia  
Rebecca Hanmer - Public Health Wales  
Beth Evans - Carers Wales  
Claire Cunliffe - Equality and Human Rights Commission  
Rebecca Cicero - Social Care Wales  
Kate Cabbage - Carers Trust  
Allison Johnstone - Welsh Ambulance Service Trust  
Helen Cunliffe - Swansea Bay UHB  
Rhys Jackson - Older People's Commissioner  
Catrin Edwards - Hospice UK  
Geraint Rees - Equality and Human Rights Commission  
Ollie John - Royal College of Psychiatrists  
Katie Featherstone - Cardiff University  
Suzanne Duval - Diverse Cymru  
Valerie Billingham - Older People's Commissioner  
Rosslyn Offord - Cardiff and Vale UHB  
Michaela Morris - Public Health Wales  
Eluned Morgan MS - Minister for Health, Wellbeing and Welsh Language  
Julie Morgan MS - Deputy Minister for Health and Social Services  
Joyti Atri - Public Health Wales  
Gill Purse - Carer for a person living with dementia

**LN** opened the discussion and checked if people are happy for the CPG to be recorded. LN summed up the last meeting and outlined the focus of today's meeting on access for visiting care homes.

**SP** summed up Alzheimer Society's campaigning on this issue, and introduced the people giving their experiences in the meeting. SP introduced KJ to tell his story.

**KJ** cares for his partner living with dementia long term. His partner is living with Lewy Body dementia, Parkinsons and epilepsy. She has been resident in a care home for the past 3 years. KJ used to visit every day to help support her and keep their relationship strong, developing

friendly relationships with the care home staff. Whilst visiting in March, the care home manager spoke to KJ and said that KJ had to leave as the home was going into lockdown. KJ tried to explain to his partner that he was unsure of when he could see her next. KJ was then made aware that he had to shield due to existing health problems. KJ noted that he was totally alone during shielding and developed depression, anxiety and stress. He was separated from partner for five months. KJ commented that he tried to speak to the care home, who assured him that there were no issues and they would ring him if any issues developed. KJ had a 'companion call' from Alzheimer's Society Cymru which was his only contact from the outside world during shielding. KJ praised his companion caller as it was the only way he could express his feelings. He had contact from the care home in July informing him that his partner had COVID19. KJ expressed shock as he felt the home should have been in lockdown and a safe place from COVID. He asked how his partner had tested positive and to date has had no reply. KJ had a follow up call to say that his partner was clear of COVID19. When KJ had exited shielding he made an appointment to 'visit' his partner; he was allowed to do this by standing outside her bedroom window. KJ commented that his partner is receiving palliative care and needs hoisting into a chair to allow him to see her. He added that his partner does not recognise KJ and that he has to shout through the window to try and communicate. KJ added that he has asked staff to be allowed to sit next to her and hold her hand. KJ added that he goes every Sunday and finds himself breaking down due to circumstances of the visit and that he feels that it is not a visit at all. KJ added that he goes home to an empty flat. KJ finished by saying that he has been in touch with his GP as KJ has developed further health problems as a result of the stress of the visiting circumstances..

**SP** then introduced **SG** to tell her story.

**SG** is an employee of Alzheimer's Society Cymru, but is sharing her family's story. **SG** began by commenting that her mum was formally diagnosed in 2017 and had lived at home until January 2019 when she moved into supported living. **SG** added that her mum had a fall in May 2019 and was only discharged from hospital in August when she moved into a care home in September. **SG** commented that her mum is only 57, so the family wanted a care home with support for younger onset dementia. **SG** said that her mum was very active in the community, but has now stopped talking. **SG** added that following a lack of access to physiotherapy following her hospital admission, her mum ended up bed bound. **SG** and her family fought for her mum to be admitted into a care home half a mile from the family home to ensure that children and parents could visit mum twice a day. **SG** said that the last visit was on 13 March. **SG** then spoke to the care home manager to find out what was happening with the lockdown, the manager said nothing but a letter arrived the next day to say the family couldn't visit. **SG** and her grandmother called on alternate days to seek assurances over the care provided and to ask the care home about visiting. **SG** commented that the care home asked the family to stop calling and said that they would be in touch if there were any issues. **SG** phoned the care home to see if her grandfather could visit as he had been diagnosed with a terminal illness, the care home allowed this, and **SG's** grandfather went to see **SG's** mum where he found out that **SG's** mum hadn't been eating as a consequence of not seeing the family. **SG** asked for a Zoom call or Skype calls as her mum could listen to and be aware of the conversation without speaking. **SG** said that from March to July the family had six calls as a whole family through WhatsApp, as the home had no tablets or devices with bigger screens. **SG** added that the family had little communication after that. **SG** found out that the home had been feeding her mum through a beaker without having consulted the family first. **SG** said that her mum's move

to a younger people's facility had been put on hold due to COVID and that her mum was left bed bound and going through menopause, SG added that a lack of visits meant this wasn't picked up. SG said that when her mum was moved into a younger people's facility in August that she had to self isolate for two week. Following this SG had a phone call to say that her mum was sick. SG said her mum was given antibiotics but with no change, so an ambulance was called. SG said that her mum sadly passed away before the family could arrive at the hospital to say goodbye. SG believes that regular family visits would have enabled her mum's illness to be picked up a lot sooner and possibly dealt with.

**SP** commented that PLWD need those who know them the best to be part of their care as they can see minute changes in the person. SP then introduced GP to tell her story.

**GP** began by saying that her greatest fear is not being there when her husband passes. GP said that her husband was diagnosed with dementia in December, and, whilst he was in hospital prior to the COVID19 outbreak, that she used to go and collect linen and washing. When COVID19 happened, GP was told to go home and relax until he came home by a nurse. GP said that she received a phone call from a care worker to say that her husband had to self isolate as he couldn't go home. GP fought this and had her husband home, where GP had carers come in four times a day. However, her husband went down hill, being diagnosed with urine infections and being hospitalised with pneumonia. GP said that both her and her husband were diagnosed with COVID, and both recovered, although her husband developed pneumonia again. GP said that she was unable to see her husband during his time in hospital with COVID and during her diagnosis. Following recovery, GP said that she was allowed in to see her husband for one hour a day but her husband's health declined so a move to a care home was suggested, despite her husband being unhappy with the decision. GP said that he has been in a care home since the middle of August, and that she has only seen husband once during a garden visit. GP said it is difficult as her husband thinks he's being taken home when they see each other. She added that he has had five hospitalisations since Mid August, each time her husband has been passed medically fit to go back to the care home, but was left waiting on a social worker. GP's daughter rang the care home and the home said that they wanted to know how her husband's needs had changed, but that the home couldn't get hold of the hospital. GP said that her and her family couldn't find a social worker to sign off the discharge to the care home. She added that the hospital and the care home finally sorted the situation last week. Following discharge GP spoke to the care home, who said that her husband had struggled but was now doing better; GP added that she managed to speak to her husband. GP finished by saying that she believed that no-one has been telling the truth to her and her family and that no-one has been able to help her or her family.

**SP** commented that G's story shows how key communication is to good care for people living with dementia and their families. SP also commented that a total breakdown of channels between the care home, family, hospital and social worker in GP's case seems to have occurred.

**LN** then opened up the floor for discussion and formally thanked the three contributors.

**CH** Commented that she has had a similar experience with the passing of her father. CH said that he was in a care home for three weeks, as he was not a permanent resident. CH said that her father developed COVID passed away three weeks later. CH echoed the earlier point

around lack of communication between care homes and families and commented that care facilities are assuming that it is the family that is bringing the virus into care settings. CH added that the family tried to prepare for end of life care, but failed to do so as everything moved so quickly. CH suggested that people are trying to fit people living with dementia and their carers into 'normal' bereavement boxes, which is not working. CH said that often family members went into settings alive, and with intentions of getting better, not of catching a disease that is unexpected. CH finished by saying 'I understand' is huge and that the ability to talk to people who know is a big help to families.

**EM** thanked contributors and briefly outlined her Ministerial responsibilities

**JM** thanked contributors and said that the current COVID pandemic is unprecedented. JM Commented that striking a balance is incredibly difficult, and is causing issues for the Welsh Government. She added that visits are allowed for end of life care and in exceptional circumstances. JM added that following the 'firebreak' lockdown, the Welsh Government Regulations say that care home visits are permitted. She then commented that the Welsh Government issues guidance, but that Local Authorities are responsible for advising care homes on the guidance. JM said that she wants Local Authorities to issue guidance collaboratively with Public Health Wales and Social Services. JM said that the Welsh Government wants to avoid a restricted blanket approach and that visits should be allowed where possible; JM said that her Ministerial office wants to provide support to Care Homes to enable visits. JM said that decisions on allowing visits lie with the responsible person in the care home and that the Welsh Government wants to encourage an approach to enable everything that can be done to enable visits. JM then said that Care Home managers are nervous, but that she agrees with the lack of communication issue raised earlier in the meeting. JM then said that care homes have made huge efforts to keep residents safe, and that digital tech has, and is, being used, but that is difficult for people living with dementia. JM mentioned there is Welsh Government funding to bring technology into care homes, but that she agrees that technology is no substitute for face to face communication and meetings. JM says that the current regulations do not stop visits, but that it is up to Care Home Managers to implement the guidance as they see fit. She added that the Welsh Government is looking at adaptations such as outdoor hubs to allow visiting and that the Welsh Government is hoping that new instant tests will be available sometime in the new year to help the issue. JM added that the Welsh Government is not aware of any PPE shortages that are stopping visits from happening, but they are aware it could be an issue on a very local level. JM then said that infection rates are rising in parts of Wales, and there are infections in care homes which causes anxiety for care home owners and managers. JM thanked the group again, and said that she is happy to be contacted on any of the issues raised and that the Welsh Government hopes to have more ideas soon.

**EM** then emphasised the importance of hearing first hand stories like those heard today and thanked those who have shared their experiences. EM said that people cannot work in a vacuum and said that this is an issue about people. EM then said that the Welsh Government is keen to involve people in the development of strategies and policies. EM added that she was touched by the preciousness of moments at the end of life, but the struggle to contain infection in places like Merthyr makes getting the balance right difficult. EM added that individuals might be willing to take risk for their loved ones, but it is difficult to contain the

spread and emphasised that the Welsh Government guidance on visits is that they can happen and to push back if you get told 'no'.

**AW** then commented that stories heard today made him angry. AW asked a question around messaging on the guidance as the stories heard highlight that people weren't able to visit loved ones at the end of their life. AW also asked why people from hospitals were discharged to care homes without COVID tests in hospital prior to discharge and suggested that this needs to be looked at very closely. AW then commented on the PPE issue saying that he is aware of care home staff using bin bags and tea towels as PPE to help residents. AW noted that this is an extreme, but that it highlights the issue well. AW also asked why visiting initiatives have taken so long to come through considering the length of the pandemic and that he hopes that the initiatives work and come quickly. AW says that he understands that there are funding issues in Wales, but hopes that these initiatives can work for people.

**JG** then said that people are too risk averse and that staff are tested once a week and are more at risk of taking the virus into care homes than some visitors. JG then commented that the National Dementia Action Plan says that with the team around individual approach, the carer should be the most important person in the team around the individual, but that they are being excluded. JG asked JM if relatives are involved in the decisions being made?

**GP** said that her husband has had a COVID test each time he leaves hospital for his care home, but that he still has to self isolate for a fortnight when he goes back to care home. GP then raised the issue of loneliness around self isolation, and the distress this can cause for people living with dementia.

**KF** then commented that this highlights the systemic issues in dementia care including the lack of communication, the lack of spotting decline, the lack of spotting when a person is moving to the end of life. KF then said that these issues are underlying, and that COVID has underlined and exacerbated these issues and that she believes these are all solvable, and that we cannot blame COVID as the issues were there already. COVID has just brought them to the fore.

**RO** commented that risk assessment and isolation can remove the risk of infection, but that they can contribute to other issues, such as those raised by KJ and that these issues are shortening the lives of people living with dementia and their families and carers due to these issues. RO said that she is hearing that there is an increase in admissions to care homes where there otherwise might not be. She added that the team around the individual approach has been hit so badly that the support isn't there and people are deteriorating faster.

**JM** responded that she understands the anger and the feelings that have been expressed, she added that this might not help people much in the moment. JM said the fact that people don't know the guidance is a failure and stressed that it is only guidance, and decisions have to be made locally. She added that this is difficult and more difficult in areas where COVID is increasing. JM suggested that there will be a UK level inquiry into the handling of the COVID pandemic and that the issue of discharge to care homes raised by AW should be looked at. JM said that research is being done in Wales into determining factors in COVID outbreaks in care homes is the size of the home, adding that the bigger the home, the more likely they are to get an outbreak. JM reiterated that COVID has been a surprise and that all of this is new,

and people are learning more and more as the pandemic progresses. JM said that not enough space is given to the voices of individuals, and is working with the Older People's Commissioner Wales to develop and open up options for people in care homes. JM restated the importance of communication, especially for those in a distressed state and suggested that quicker or instant tests would be a huge help in all areas, but especially in care home visits, and visitors to care homes would be right at the top of the list.

**JA** thanked the contributors and stated that decisions are impossible to make as visits are crucial for the wellbeing of residents and that the impact on residents of not having visits needs to be balanced with the risk of COVID getting into care homes and spreading as care homes are enclosed settings. JA then said that isolation is important during the discharge from hospital process as care home residents are more at risk than those in hospital, due to the 14 day incubation period of the virus, adding that this is the same issue for the professional carer's tests. JA then said that she is expecting the rapid test to be very specific, but that tests are not 100% sensitive.

**AW** commented that the rapid test is available in Liverpool where the whole city is being tested.

**JA** confirmed that Wales is expecting the same.

**JG** said that her mum is living with dementia and cancer and is at the end of her life. JG said that a family member came to visit from Manchester, with everyone wearing masks in a 12 foot by 6 foot room, with the family member testing positive a day or so later, JG added that her mum tested negative for COVID, showing that these visits can be done. JG suggested that family and unpaid carer's don't want to put anyone at risk, and asked for the respect to make that decision as carer's may understand this issue more than professional care home staff. JG finally asked for carers to be given the information to make decisions.

**NH** thanked participants and said that messaging around the difficulties outside of medical impact on people hasn't been good. NH added that people no longer trust the system as a whole, and that will cause difficulties. NH thanked frontline staff working in dangerous conditions and said that this may have been forgotten a little bit. NH added that a large amount of repair work to peoples trust in the system needs to be done. NH finally added that the lived experience of loved ones is vital to dementia care.

**LN** said that she has raised this issue constantly in the Senedd and in private meetings with Ministers. LN added that she is concerned about the wellbeing of families as the stories heard in the meeting show that this is an issue. LN added that decisions cannot be left to Local Authorities as care homes are too risk averse, and that this issue needs some national directive in order to get moving. LN suggested that the Cross Party Group could write a letter to the Welsh Government and issue a press release to call on the Welsh Government to do more. LN then closed the meeting.