

## Dementia Community of Practice Webinar discussion notes

18.05.2020

### Group 1:

- Anita's presentation resonated with everybody.
- Particular interest in resilience and staff support due to the quantity of deaths in a short space of time. Need to ensure people in care homes are taking care of themselves.
- Challenges - routines for patients and carers disrupted. Care home staff are having to manage difficult behaviours, and anti-psychotic medication is becoming a front line defence. They would not usually advocate this.
- Discussed Advance Care Planning during COVID-19. The pandemic is posing unique challenges, there are more people at home with declining support and also people concerned about the spread of the virus.
- There are examples of creativity, a colleague was on the phone with somebody while their mother died. This is creative, but also highlights that this person needs support.
- Dementia Action Alliance are developing a booklet for carers with disrupted routines on how they can manage.
- Liz Bryan - St Christopher's ECHO networks with care homes have revealed a lack of PPE. This is difficult and causes them anxiety. In terms of creativity, the ECHO network has discussed acknowledging the deaths and having memorial services in the care home environment. It acknowledges what a person meant to somebody else.

### Group 2:

- Discussed overcoming challenges in working remotely. Managed to support care homes, and have regular contact with care homes over the phone. This is positive, and provides a platform for care homes to bring up areas of need.
- Another Hospice has put out resources on their website for care homes, and that their helpline is for care home staff to ring up for support also. The idea that someone 'cannot pour from an empty cup'. People need to feel valued in what they do.
- COVID-19 is very uncertain, people in the field of dementia care people are used to uncertainty and ups and downs. They can use this skill to communicate about uncertainty.
- Real sense of partnership has been strengthened in services. The group hopes this continues
- There was discussion regarding using IV therapy in care homes and what this means. It has been done in Huddersfield. This could change treatment and ceilings of treatment.

### Group 3:

- They found the challenges that restricted visiting presents. Families are having to trust care homes to look after loved ones
- Issue of guilt within families, someone put their loved one in a care home as they were worried about the risk of COVID-19 as carers were coming into their home each day. This person ended

up deteriorating and getting COVID-19, had to go to acute hospital. This family has a huge amount of guilt.

- Fear factor. People who wanted to die at the Hospice now want to die at home due to fears of restricted visiting.
- There is now the 'fear factor' of letting a loved one go into a residential home
- Examples of both poor and good communication. The group expressed concern about people isolated in their rooms. One care home said you cannot phone, you have to email, and this is not ideal practice.
- Some homes updating their website where they update with information about loved ones with live streams and pictures. This is all done with permission, and is an example of good practice
- The group further discussed issues around reduced visiting. In some residences, only 2 people can visit and at others it is 1. This is causing conflict amongst families about who can visit. In one hospice, families were lining up in PPE and going in and out. This is stressful for families and staff.
- When someone is actively dying there is leeway to allow more than one person in with the loved one.

#### Group 4:

- The group strongly resonated with Anita's presentation.
- They discussed the speed at which people are adapting and making change. Challenges about different guidance coming out and recommending slightly different things.
- Staff are fearful about lack of PPE access.
- They discussed Advance Care Planning. ACP conversations and ceiling of treatment conversations changed as people no longer wanted to go to the hospital. Another challenge is people no longer wanting to go to care homes for respite care.
- Resonated with the WhatsApp group Anita discussed, it is important to have peer connection.
- Resonated with other topics such as isolation. A colleague asked Anita about people with dementia feeling afraid of staff coming to care for them in PPE. This was not always being seen within the group.
- Theme of managing uncertainty, constant adjustment and managing the innovations that are happening.

#### Other discussion areas:

- There is currently the idea of a social bubble around an elderly person. However, they would need to be extremely careful in care homes
- JC: we are providing online training for the Verification of Expected Death which models the practice to staff who want to become self-competent.
- Challenges for care home workforce: Anita discussed about care home staff having to decide when active treatment is futile. This is a new practice, people need support to make these decisions both in the diagnosis and the emotional labour of making this decision. People in palliative care are more accustomed to this. London Ambulance Service are having to make decisions if it is futile to take someone to Hospital. This is a huge decision to make.
- AA (guest speaker) highlighted they began a Red, Amber, Green COVID-19 Zone in the care home.
  - Green- free
  - Amber- exposed but no symptoms
  - Red- isolating

- This became complex as everyone was at a different stage in their dementia. Having everyone together meant that either people in the latter stage didn't feel as safe, or people with unpredictable behaviour were becoming intolerant of others. Brought home why they have separate areas for people. They returned to the cohorts people are used to living in. This marked a turn to normality, which is what they needed.
- There was discussion of psychological and physical deconditioning. People isolated in their own rooms, but deconditioning began. It was awful watching people lose their ability because they are isolated, and they did not want to do this. This is part of a broader discussion, care homes shouldn't be making these decisions alone.
- It was discussed that it would be useful to have a way that the community could connect in between sessions.

It was agreed the Dementia CoP meetings will be fortnightly as the situation with COVID-19 continues to develop.