

Dementia Community of Practice webinar notes:

04/05/2020

Feedback from first discussion:

Group 1:

- Discussed residents who are living in care homes presenting with unusual behaviour, deeper issues, and accumulation of effects of COVID-19. For example, supporting by phone to a lady who isolated due to COVID-19, no family visiting, staff in masks - all causing distress. Moving onto deterioration due to loss of familiar routine
- Worry about deconditioning in muscle strength and cognitive abilities. Evident impact of social withdrawal
- Real concern about general deterioration due to lack of normal programs, physical, mental & emotional deconditions, social withdrawal and distress at lack of visiting
- Impact of not grasping or retaining the reasons for social distancing, and not being able to access community facilities such as day centres. Causing upset, people with dementia feel as if they have done something wrong
- Technology access would be brilliant. But issues in terms of skill and access

Group 2:

- Isolation for carers & for those with dementia. Primary care, isolated at home & in care homes & isolation in acute trusts, surrounded by people but not who they are used to being with.
- Touching on acute feedback - patient would have the carer or relative come at all times and be with them, interpret, explain give comfort- no longer happening & this causes distress. Happening in other easy such as phone conversations- trying to fill the gap. Causing distress to carer & person
- IT- ability to use it, screens, tablets etc. Some places do not have financial resource for that way of communications. Literacy, cognitive impairment, poverty & culture
- Summary: Isolation, unfamiliarity in acute setting & issues around IT competence & financial implications

Group 3:

- People within group saying how their roles have changed. Lack of PPE, not able to do usual home visits. Causing carers in the community to feel isolated. Also not even services to referred to as they aren't happening & telephone support can be hard
- Relatives are struggling to cope with not being able to visit their loved ones. One family moved their loved one out of the care home as worried about the lack of contact. Some people in group still doing visits but had to rationalise & prioritise who they were visiting

- Issues around training and advice for care homes as they are so stretched. Care homes lack of visitors it is quieter which can help people's behaviour positively
- Difficulties relating to how best to swab people with dementia who may be intimidated.

Group 4:

- Admiral Nurse. Increase in calls about COVID, confusion around guidelines and families struggling to interpret them & what this means to routine. Services also being stopped.
- Cancer services still doing visits, why not dementia
- Reduction in visits isolated and upset & distressed carers
- Hard to self-isolate in care home & behaviour change
- Use of a risk vs benefit analysis
- PPE- confused and someone may not know who you are & environment and how that makes them feel. Guidelines turned on their head from usual
- Communication was huge, & not being able to understand social distancing and what it means

Karren Harrison Denning comments:

- All came with similar issues. Not enough time to discuss all the issues
- One thing very evident is that a lot of the things experienced usually are exacerbated under COVID-19 lenses. Particularly for environment, interesting as they are all adapting to working usually and managing own lives through COVID, re-calibrate what this is like for someone with dementia and their carers. Good practice shining through, care staff are trying to 'soften the blow' in being in full PPE, how to adapt that, similar issues caring for young children with leukaemia when barrier nursing, how to see the person behind the PPE. Some places are personalising their PPE, even a smile on the mask to soften the blow. People laminating a picture of themselves without the PPE to show what they look like
- A lot of issues arisen affect any stage of dementia- loss of services- be even more creative about considering how it feels for someone with dementia. Spoke to someone who was struggling to get her husband to understand he needed to social distance when he went out for a walk. He didn't understand pandemic, COVID-19- just tell him there is a serious outbreak of the flu and it is best to stay indoors. He adapted to this change in language. Have to be creative in dementia with COVID-19. Attempts to use understandable language and adapt behaviour
- Swabbing has come up recently and collectively. If we will go into care homes and offer swabs, what is acceptable in dementia? A lot still comes down to best interest, if a person appears to give consent that is good. If a person with dementia resists a deep throat swab, is it in the best interest to have this forced on them? Wouldn't usually advocate certain interventions if they were distressing- a lot of these issues broached usually, let us think about what is appropriate for that person's situation usually.
- Not just dementia- can relate it back to how we dealt with SARS, MERS, but in general it is an evidence free zone. Try to keep the group abreast of what is being discovered/ Centre for Evidence Based Medicine are doing rapid reviews for Dementia & COVID. There is not much evidence as of yet, but where there is they will give guidance. If there is an appetite for this Community of Practice, they would sift through consensus based evidence and share it in the hope it will help

Liz Bryan comments:

- Rest of world considering leaving lockdown, important to remember these people cannot come out of lockdown. This is going to be long term way of changing working, it is not short term. Definitely worth investment of time & energy as this is a long term thing until there is a vaccine. Group of people they are talking about will need protection and people to work differently. Not temporary, likely to be a year or so if not longer & could learn very important lessons. Do need to share innovation & evaluate them. This is worth it
- Creative with social distance and do need to understand the risks and weigh up the benefits of therapeutic touch- touch people, cuddle & do it safely without putting anyone at risk & ensuring people do not feel isolated and abandoned.
- After this meeting when people reflect, maybe community comes up with priorities and themes to examine during the sessions.

Anita Hayes:

- Access to resources, education & training. Innovative ways to do this and support staff. Focus on different roles people are taking and helpful resources available. Similar discussion around evidence base, a lot of resources produced quickly and what does practical implementation look like. Can discuss feedback and knowledge of what works in practice and will be useful going forwards.

Cat:

- Surprised Advance Care Planning didn't come up as it came up earlier during the pandemic. Have to include this as it is important.

Feedback from Discussion 2

Breakout room 1:

- Remotely working via telephone. Difficulties of not being able to pick up visual cues. Getting collateral history from other health professions, occupation therapists, physios, carers- more than usual. Talking about risk assessments, reduce risk of missed risk assessment.
- Discussing how telephone conversations are done. More detail, asking more open questions about distress and behaviour, tuning it down. Different way of getting more description
- Directing people if they are able to use the internet to gain tips and get tips. Talking through tips in stages with people.
- Summary: Remote working, lack of cues, collateral history through MDT approach, using IT more directly.

Breakout room 2:

- Namaste care program has an individual program developed for people during the time in COVID-19- Maintains connection while infection prevention.
- Remote working has challenged getting good assessments based on abilities to build rapport and pick up on cues, can cause a feeling of disconnection. Challenge of working differently but delivering services

Breakout room 3:

- Increase use of technology and how this can have both positive effects as well as issues.
- One person mentioned within a Trust, the number of people they could see over skype meant they could see 70% more people- a positive outcome of technology
- Issue of red tape- tried to change services for other people to do DNAR respect forms, only since pandemic have these things moved forward. Hoped some of these services will continue beyond the pandemic
- Collaborative working- real upturn in different professions working together and understanding each other's roles and how vital this is.
- Summary: pro's/cons tech, evidence of things that can go well, reduction of red tape & collaborative working

Breakout room 4:

- Namaste community lead mentioned they had suspended home visits, some volunteers wanted to restart but were over 70 years old. Provided weekly sheets with resources for patients and families, with info such as safe use of essential oils. Different ways of delivering the sheets for people without computers for example through the post
- Playlist for Life- online resources.
- Nature on helpline calls has changed, different places to sign post callers
- Teleconferencing/FaceTime/WhatsApp. Usually meet people all over the UK- save time but detriment of in person assessment.
- Likely some changes will remain when it is all over.
- Summary: patient access in a variety of ways, information that needs to get out in different ways, resources in place already we need to use, saving on journey time but to detriment of physical assessment and research

Breakout room 5:

- Encouraging non-paid carers to set up a WhatsApp group to give peer support
- Shared information between services- collaborate going forward
- Hard at the moment as don't know what step down measures will be so hard to plan what care will be going forward.
- Summary: Peer support through WhatsApp, capture information arising from collaborative working & managing uncertainty

Breakout room 6:

- Collaborative working, looking outside the Hospice such as volunteer roles, forced to look more broadly at a whole community approach that has been positive
- Inequality of access to technology. Wherever we are in the world, there is inequality of access to smartphones, tablets etc. This can be seen when attempting ECHO sessions or Zooms.

Additional notes from Chat Box:

- Need to be careful that it is not a DNAR but a DNACPR maybe!
- Didn't get the chance to mention in first discussion group also talked about seeing more people change PPC/PPD to home in order to have more choice and control over visitors at end of life, trying to ease concerns around admission to hospital for potential reversible causes - also conversations around end of life decision making by someone who has capacity, on the subject of quality, vs quantity of life.
- We were also saying a positive was being more involved in IPU teaching on delirium for all staff regularly and also providing carers with education sessions
- In my hospice in Exeter we are offering a Care Home helpline service which is to be extended to a clinical MDT.