

A Practical Guide for Dementia Care During COVID-19

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The nuances of cognitive decline related to dementia require a different approach to care in light of COVID-19. Each individual and their situation is different and the recommendations given here are meant simply as a guide. These approaches can be used in general settings, where dementia is present, as well as in the home environment.

Over **80% of care for people with dementia (PWD) happens in the home** and COVID-19 brings with it the need for specific strategies to assist in home care. The remaining 20% are often in the later stages of dementia and are being cared for in other long-term care settings. Our studies indicate that PWD living in long-term care settings do best when care is administered in a calm, empathic way. Our three-year study of caregivers shows that **providing care that maintains the characteristics of empathic person-centered care results in residents who are more engaged and involved** in their own care helping to stave off additional confusion.

Empathic Person-Centered Care

Empathic person-centered care (EPCC) allows care to be provided with the needs of the person in mind. Caregivers spend time looking at the world from the PWD's perspective and apply it to care. It is the capacity to understand or feel what another person is experiencing from within the other person's frame of reference. EPCC gives the PWD the feeling of being understood especially when the ability to accurately communicate is compromised.

Implementing Empathic Person-Centered Care

Helping caregivers develop an empathic person-centered care (EPCC) approach can be difficult because it is an intangible method. **The Virtual Dementia Tour®** was used as a training tool to elicit changes in staff behavior based on their own experience during the dementia simulation and **The Dementia Aware Competency Evaluation (DACE®)** was used to break down the behavioral dynamics necessary to provide EPCC and make them more tangible. Staff who exhibited EPCC were more likely to:

- Use a soothing tone of voice
- Exhibit non-threatening body language
- Use a friendly greeting
- Touch
- Give choices
- Make eye contact
- Talk during the interaction
- Simplify tasks into smaller steps

During this time, it is important for all of us to hone our skills in the behaviors above. Each one makes a difference in dementia care and during this confusing time they make an even bigger difference.

Social Cues and Environmental Changes and Dementia Care

People with dementia (PWD) are sensitive to agitation, noise, and rapid movements. This is a function of **damage to the Reticular Activating System and Amygdala**. These parts of the brain are designed to alert us to anything different, novel sounds, and rapid movement. In the normal brain we can quickly determine what is relevant and irrelevant and respond accordingly. Because people with dementia have damage in these areas, they tend to respond in a hypervigilant way to change, noise, etc. PWD easily sense when something is wrong and display agitated behaviors as a result.

- Please **avoid prescribing new medications** to ameliorate new behaviors as they are likely transient. They need time to get used to the new normal.
- Go the extra mile to **keep things calm around them**. No loud TV or radio. Calm music or an animal channel work well.
- It's even helpful to keep voices a little lower. Yelling to another staff member or family member can be upsetting, especially since **PWD are frequently unable to process what is being said** and are unable to place a loud voice in context.

In both home and formal care settings, it is tempting to have the television on throughout the day – for background noise, or so family caregivers or staff are aware of what's happening during the current environment. **As tempting as it is, please try to stay away from news channels**. It is difficult for people with dementia to understand the complexity of the virus and the tenor of the news is very fast paced and difficult to absorb. When faced with confusing information people with dementia will draw their own conclusions about what they see and hear. This seemingly psychotic behavior can be ameliorated by ensuring PWD don't have access to it.

- If a PWD asks what is going on, **keep the response short but try to determine what prompted the question**. If possible, direct your response to what you think prompted the question. For instance, if you feel they are worried about the masks or the personal protective equipment, a simple answer such as, "We are wearing all this stuff to keep everyone healthy but everything is OK," followed by a caring touch or kind word. Or, "There is a virus like the flu going around and people are being safe by keeping their distance. That means we have to be safe too, but everything is fine and we are here for you."
- **Try to change the subject and move on to something else**. Diversion works well but if the person continues to ask questions, keep the same response. Going into detail about the virus can create additional anxiety and misinterpretation.

If they become agitated, try to have some homemade or store-bought greeting cards from the family for them to look at or pictures from their past. **A person with dementia has difficulty explaining why they are agitated** but it is important to help calm them by diverting their attention. Ask family members to send cards to their loved one so that you or staff can pull out and share as needed to decrease agitation or provide comfort.

It is true that no matter the level of functioning, **a person with dementia is able to read a caregiver's affect and body language**. We know this because in elder care communities' residents are automatically drawn to those caregivers with a smile on their face and a positive affect.

EPCC During COVID-19

At Second Wind Dreams, we have spent decades learning what the world is like for a person with dementia from **THEIR perspective**. In fact, the Virtual Dementia Tour, our simulation of dementia, does just that. We know from the over three million people who have experienced the tour that one of the most difficult things for participants was the ability to understand what they were supposed to do.

Picture yourself sitting in a chair in a room with people moving around. You aren't sure what's going on and you feel concerned that you are supposed to be doing something, but you don't know what. Everyone else seems to be doing something, they are wearing masks, face shields, strange gowns – they seem anxious. The sounds are confusing too because people are talking in another language, pointing, and gesturing. There may also be people in military uniforms throughout the facility. Then a person with half a face is gesturing to YOU. They are hard to hear and seem to be angry. You don't know what to do and the person starts reaching for you.

In order to understand what is happening **you need to see that person's face, their body language, to better understand** if they are angry or just helping you to stand. All elements of Empathic Person-Centered Care become incredibly important to reassuring the person with dementia, as well as other residents of elder care communities, during this COVID-19 emergency.

If you are in a community that requires all residents wear face masks, **it can be problematic to get people with dementia to wear a mask and to keep it on**. Sometimes it is helpful to solicit the help of the PWD. Statements like, "I need your help to keep you healthy, so I'll help pull that on your face." It will still be removed but keep saying that you need their help. The fact that they will attempt to remove the mask is a hallmark of dementia because of memory loss and inability to understand the need. It's best to keep in mind that it's the disease causing them to behave this way and it's our job to help as we can. Getting upset about this will only add to confusion.

» **Memory problems will make it hard for PWD to understand instruction** about social distancing, hand washing, wearing a mask among other things. Gentle reminders will be helpful and taking the person to the sink to wash their hands with you may help. Telling them to wash their hands will likely be hard to enforce. PWD do best when they are shown what to do.

» PWD have lost their peripheral vision as a function of damage to their occipital lobe. **Approaching them from the side will cause a startle response** and increase agitation. Keep this in mind when administering medications and assisting with meals, approach them from the front so they can engage with you.

Technology During COVID-19

Some PWD have visual agnosia and are unable to recognize themselves in a mirror. This is a function of damage to the brain in the area that interprets visual information. **This will make using Skype, Facetime, or any other video call application very difficult for a PWD to understand.** It is important for the people on the Skype or FaceTime call to understand this and not get frustrated when the PWD doesn't seem to engage. While family members may find it reassuring to see and hear from a loved one, the technology may be unfamiliar to a PWD and may cause agitation or the person may not be engaged at all. A call in-advance to the person who wants a video call may help them understand, **though consider a simple phone call** – which is technology people have been familiar with for generations. If the family insists, take it slow and assist throughout the call.

For the same reason, telehealth is a difficult concept for people with dementia to embrace. They have been in doctors' offices for appointments all their lives and seeing the doctor on a screen can be confusing and the PWD may be difficult to engage. Using the preferred name that the PWD like to be called often during the "visit" can help to orient them to the screen. Still, just as in an actual office visit, try to ask questions slowly and concretely. An open-ended question like, "How are you feeling?" will get "fine," as an answer. **People with dementia can rarely identify if they are in pain.** We have to observe it. It will be important to have an observer on the phone with the patient to report any changes in behavior but it's also important for the observer to be simply an observer. Too frequently people in the medical profession will allow a family member or staff member to be the sole source of information and only orient to them and not the patient.

On the flip side, **telemedicine can be a powerful tool especially for PWD being cared for at home.** The doctor can watch the patient walk, chew food, use utensils, and receive care, providing unprecedented access to daily care.

As horrific as this virus is, **it's forcing us to view our social context from the other person's point of view.** We can hope that this behavior will be imprinted enough after this crisis is over, that it becomes a part of who WE are bringing us closer together and opening the door to a culture of social consciousness and empathy.

Second Wind Dreams® is an internationally-known nonprofit dedicated to changing the perception of aging through the fulfillment of dreams and the offering of educational programs including its flagship, sensitivity training, the Virtual Dementia Tour®. Founded in 1997 by P.K. Beville, M.S., the Atlanta-based organization is recognized as the first in the nation to focus on enhancing the quality of life for elders through the fulfillment of dreams.

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