

SUMMER 2020

# PERSON-CENTERED CARE & COVID-19 RESOURCES

## THE IMPORTANCE OF RESIDENT VOICE

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# PROMOTING RESIDENT VOICE IN THE COVID - 19 ERA



Promoting choice is the most basic and essential principle of person-centered care. The PEAK criteria uses terms like, *“residents direct their own lives, decide how to spend their day, choose where to eat, choose when and where to sleep, when and where to bathe and what to do with their time.”*

How do we as caregivers continue to protect this basic human right while protecting elders from this deadly virus and adhering to the COVID-19 guidelines? How do we keep elders safe while honoring their autonomy?

When the virus first broke out it was something like we have never seen before. Guidance was coming to nursing homes from all directions and changing daily. It was a very stressful time for all involved. In an honorable effort to protect vulnerable residents, friends and loved ones were restricted from visiting nursing homes. Residents were isolated from others and restricted access to things that were important to them. This made sense at the time. The highest priority was protecting them from immediate harm.

As time has gone on, elders have described spending days at a time alone in their room isolated from everyone except their direct caregivers. Going weeks without the company of or contact with loved ones. We are beginning to hear about this experience from their point of view. Many report feelings of isolation, fear and loss of control. Some have even expressed feeling like they are incarcerated and forgotten.

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## INTERVIEW WITH AN 88 YEAR OLD FEMALE RESIDENT

“ I just needed to hug that girl. I could hardly see her through the door and *I knew how much she needed me*. It just broke me. I was just very upset! ”

I didn't do a lot during lock down. At meals, we sat for quite some time with one at a table. The way it was organized, it was supposed to be the north end at 5:30 and the south end at another time. It just didn't work that way. People would sleep too long and show up at the wrong time or things like that and I couldn't find a spot to sit. I chose to eat in my room. I was real comfortable with that. I spent a lot of time in my room. I don't go out to exercise because I have some problems with various things. Bladder issues don't allow me to get up and go like I want, but I'm working on getting that figured out so I can go.

My daughter tried to visit; they could come to my door or window. I could not stand and talk to them there; so they could come to the door and one of the nurses stood in the doorway and I could holler out to them. There is a niece from Kansas City that I had been talking to when the shut down happened. She had a close friend die by suicide and it just devastated her. She told me the whole story but I wasn't sure her whole family knew about it. She called me several times to talk and I would listen and support her. I let her know that I was here day and night if she needed to talk. She came to visit me with her parents and she was right outside my door with her family. I tell you, I just needed to hug that girl. I could hardly see her through the door and I knew how much she needed me. It just broke me. I was just very upset!

You know it is as though they want to make it so they have total control over a person. I tell you what; they are going to have a pretty hard time with me! I just don't like that issue at all. After that, my brother came and they let him come closer to the door. I think they knew how much the first situation broke me and so they had mercy on me. I'm trying to do as they need to have me do.



## WE HEAR YOU

As we realize the threat of COVID-19 will be an on-going situation, it is essential that caregivers begin to think about how we maintain safety and honor autonomy at the same time. We must work to continue to integrate person-centered care into our new norm. Here are some considerations for moving forward.

## KNOWLEDGE IS POWER

It is important that caregivers are intentional in scheduling time with elders to keep them informed of the COVID situation on a regular basis. Engage residents in discussions about current government directives. Make sure they are aware of what is going on in your local community and what you are doing in the home to protect them. Receiving regular information about the situation may alleviate fear.

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## VOICES NEED TO BE HEARD

Work to provide both formal and informal opportunities for elders to express their ideas and concerns. Although we must comply with numerous regulations and precautions, there are decisions to be made related to how we will meet these expectations in our home. Talk with elders about the regulations and listen to their ideas and concerns. This active engagement could alleviate the feeling that rights and decisions are being taken away from them and this new way of life is something being done to them. People tend to be more supportive of decisions they are involved in making. Help residents feel empowered to participate in the precautions being taken in their home. 1x1's, Resident council meetings, learning circles and community meetings are all opportunities to discuss COVID. Be careful to listen and address concerns.

When hosting learning circles or resident council meetings, use your SOCIAL DISTANCING etiquette. Consider doing smaller groups at a time and hosting gatherings in larger spaces where elders can distance. Simple announcements can be made at meal times where social distancing practices are in place or over closed circuit TVs, if in available.



# 07 PEOPLE HAVE RIGHTS & RESPONSIBILITIES

*"None of us has the right to jeopardize the health and safety of someone else when making our choices."*

We often talk about Resident Rights in long-term care. We cannot forget that people also have a responsibility to others around them. This is especially critical in community living. For example, a resident has the right to watch TV late at night. They must also respect the rights of others who are trying to sleep, and should manage the volume appropriately.

It is important to recognize the rights of individuals as they relate to COVID-19 precautions but be prepared to talk about the responsibility we each have to protect others. They may feel that it is their right to have their family and guest come to visit them any time, but at this time, but in the current environment this might introduce a risk for other residents.

None of us has the right to jeopardize the health and safety of someone else when making our choices. It is important to have these conversations with elders regularly. Talk with them about how they are feeling.



- DO THEY HAVE ANY CONCERNS?
- ARE THEY STRUGGLING WITH ANY SPECIFIC PRECAUTION BEING TAKEN TO ADDRESS COVID-19?
- ARE THEIR NEEDS BEING MET? IF NOT, HOW MIGHT YOU WORK WITH THEM TO MAKE THAT HAPPEN?

## 08

**COMFORT AND RISK**

WE ALL HAVE VARYING LEVELS OF COMFORT WITH RISK

*It is so important to remember that all adults will undoubtedly have different reactions to the COVID-19 virus, and people hold different opinions about the precautions that should be taken. One resident may look forward to dinner with a friend each day while others may prefer to eat in their room in an effort to social distance. Pay attention to the expressed desires and work with residents as individuals.*

**SPOTLIGHT:** DAUGHTER WITH A FATHER WITH DEMENTIA IN A NURSING HOME AND MOTHER IN CONGREGATE INDEPENDENT LIVING:

**Q:** WHAT HAS THE PANDEMIC FELT LIKE TO YOU?

**A:** IT HAS BEEN EXTREMELY PAINFUL TO SEE WHAT THE SEPARATION DID TO MY PARENTS. I HAVEN'T BEEN ABLE TO VISIT DAD SINCE THE SECOND WEEK IN MARCH. MOM COULD NOT VISIT AND WENT INTO A DEEP DEPRESSION REQUIRING MENTAL HEALTH INTERVENTION.

**Q:** TELL ME ABOUT HOW THINGS HAVE CHANGED DURING COVID.

**A:** BEFORE COVID, MOM SPENT 4-6 HOURS A DAY WITH DAD AND ASSISTED HIM WITH TWO OF HIS MEALS. SHE WAS TOLD TO STAY HOME AND MY SIBLINGS AND I DID NOT VISIT HER FOR SEVERAL WEEKS. I HAD A PHONE CALL WITH MOM AND BASED ON HER MENTAL STATE I KNEW I (THE DAUGHTER) NEEDED TO GO BE WITH HER IMMEDIATELY. SHE HAD SEVERE DEPRESSION. THIS STARTED SEVERAL FAMILY AND PROFESSIONAL INTERVENTIONS.



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## FAMILY CONVERSATION CONT:

*LAST WEEK, MOM GOT A CALL FROM THE NURSING HOME THAT DAD HAS LOST WEIGHT; HE WAS NOT EATING AND SLEEPING. THEY ALLOWED HER TO COME SEE HIM AND SINCE THEN SPEND ALL THE TIME SHE WANTS IN HIS ROOM. THE FIRST DAY AFTER SHE VISITED, HE STARTED ASKING FOR FOOD, ATE HIS MEALS AND IS SLEEPING AGAIN.*

**Q:** HOW CAN THE NURSING HOME BETTER SUPPORT YOU?

**A:** *BETTER COMMUNICATION WITH MOM ON HOW THE HOME IS HANDLING THE CRISIS AND TO GIVE UPDATES ON HOW DAD WAS DOING. THE ONLY TIME MOM FOUND OUT ANYTHING IS WHEN SHE CALLED.*

*DAD IS HARD OF HEARING SO PHONE COMMUNICATION COULD BE A CHALLENGE. SEEING THROUGH THE WINDOW AND NOT HEARING WAS WORSE FOR MOM SO SHE DID NOT DO THAT OFTEN.*

*I AM A NURSE AT A HOSPITAL SO I UNDERSTAND THE COVID GUIDELINES. I KNOW THEY DID WHAT THEY NEEDED TO DO, BUT IT WAS EXTREMELY HARD ON MY PARENTS AND US KIDS. MY PARENTS HAD THEIR 57TH ANNIVERSARY WITH NO CELEBRATION.*

## LIFE MUST HAVE MEANING

OUR CLINICAL TEAMS HAVE DONE A WONDERFUL JOB ACROSS THE STATE OF ADDRESSING THIS VIRUS. MANY HOURS HAVE GONE INTO PROTECTING OUR ELDERLY DURING THIS TIME. AS WE BEGIN TO GET MORE COMFORTABLE WITH THE NECESSARY PRECAUTIONS, IT IS IMPORTANT THAT TEAM MEMBERS BEGIN TO LOOK BEYOND THE PRECAUTIONS AND DEDICATE EFFORT TO MEETING THE OTHER NEEDS OUR RESIDENTS ARE EXPERIENCING.

SUPPORT OF RESIDENT CHOICE AND PREFERENCES HAS BEEN THREATENED BY THESE PRECAUTIONS. AS WE ALL MOVE FORWARD, IT IS EXTRA IMPORTANT TO WORK WITH RESIDENTS INDIVIDUALLY TO DETERMINE WHAT THEIR NEEDS ARE. WHO DO THEY WANT TO STAY CONNECTED WITH? HOW DO THEY WANT TO MAINTAIN THEIR CONNECTIONS? HOW DO THEY WANT TO SPEND THEIR TIME? ARE THEIR SPIRITUAL AND PSYCHOSOCIAL NEEDS BEING MET? HOW ARE THEY HOLDING UP?



# CREATING MEANING

## STRATEGY TWEAKS AND NEW INITIATIVES

*Below are some ideas you can start with:*



Be aware of the barriers to providing person-centered care created by COVID-19.



Talk with elders about how you can best support them.



Find out if their daily routines and preferences are affected and how that can be addressed.



Adjust care plans to address how you can support elders during this time.



Get creative with support.

### **Consider:**

Are regular in-house opportunities being provided in the absence of visiting clergy? In-house prayers, devotionals, services, on-line services and virtual clergy visits could all be options to consider.

Be sure to ask people about their needs. *Never underestimate the importance of contact with loved ones.*

Dig a little deeper now in talking with elders about their connections and how the team can support them in maintaining these. Could caregivers help write a letter? Send a card? Make a phone call? Zoom or Facetime?

Some homes have facilitated “window” visits with lawn chairs, walkie-talkies and refreshments. Work to get creative. Residents will need assistance to maintain these important contacts.



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**MEANING CONT:**

During this time many funeral services have had restricted attendance. Be sure if elders in your home have experienced loss they have been provided the opportunity to honor their loved one and grieve their loss.

Involve elders in planning leisure activities. Though the calendar may look different right now, we are not excused from providing meaningful leisure activity. This could be an opportunity for elders to help with community needs. Making masks, hand sanitizer or calling home bound neighbors could all be opportunities for people to volunteer.



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## CAPTURE YOUR IDEAS IN PERSON CENTERED CARE PLANS

You all have great ideas! As always, work to create person-centered care plans *rich with information* about what is important to each elder. Care plans should reflect the above discussions. Take credit for all you do to protect and support the people who live in your home.

**We are here for you! You  
got this!**