



National Center on Advancing Person-Centered Practices and Systems

Transcript from a short video titled “We’re Sacrificing the Person to Save the Body” with Diana Blackwelder for NCAPPS’ Pandemic Wisdom series

Diana Blackwelder has been successfully living alone with Younger Onset Alzheimer’s Disease which forced her early retirement in 2017. She performed Information Technology Systems Engineering and was a certified Black Belt in Lean Six Sigma Process Improvement.

She now provides care for her two pet cats, travels internationally and advocates for the betterment of the lives of those living with dementia. Diana serves on the Dementia Action Alliance Advisory Board, represents Dementia Alliance International to the LEAD coalition, is a National Alzheimer’s Association Early Stage Advisor Alumni and consults to the Smithsonian and US Botanical Garden Access Programs for people living with dementia.

Hello, my name is Diana Blackwelder. I'm a former systems-engineer and Lean Six Sigma process improvement Black Belt. And I'm currently living alone with multiple cognitive disabilities caused by young onset Alzheimer's disease.

I'd like to discuss a little bit about Person-centered care in a time of crisis.

I personally, because I live alone, have done a lot of extensive planning and put into place a lot of plans and decisions and failsafe mechanisms for so many possible scenarios to ensure that my care is at the forefront of my power of attorney person. Yet there is no possible way I could conjure up, and plan for, every possible scenario – just like you can't. COVID-19 has brought this reality, right to our faces. None of us could have planned or thought this and how it would impact us living with disabilities, or caregiving for someone with disabilities.

What I've seen is the gamut of responses. I've seen the human, the person, in person-centered care, or how I'd like to call it, person-directed care, removed from the scenario replaced by the “it”, an object, a group of people... a patient, but not a person with personal wishes and desires and preferences, and risk tolerances. Instead, I've seen it range from “it is what it is,” -- again, “it”, no person -- to “we must do whatever is necessary to save these lives.”

These lives. These are people, they're individuals.



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So we need to stop sacrificing the person for the object or the thought, or the number. We count numbers of deaths in nursing homes. These are lives and we need to start looking at them as lives. This is what person-centered care is all about. Whereas I again like I like to call it person-directed care – I should be the one making the decisions. Even if I need to make these decisions in advance and put them in writing so that somebody else understands what my preferences are. I couldn't have made a decision about what do I want to have happen to me living alone with COVID-19. But I could make a decision as to in general, how do I want to live my life? What kind of care do I want to receive? At what point in my life would I prefer to take on additional risk of injury, to include death, if that meant continuing to live the life I want to live? This is an individual that only I can make those decisions. And so only I should be making those decisions. No one else should be making those for me. This is what person-centered or person-directed care is all about. It's just that much more imperative during any time of crisis in an individual crisis, or a global crisis like a global pandemic. It is so critical that we think about the people.

There are people with advanced stages of dementia living in nursing homes and memory care units right now, that are being denied their basic human rights, in order to keep them alive. But while we're trying so desperately to keep these people alive, we are depriving them of their choice, of their autonomy. We are depriving them of those family and loved care partners that come in and provide the extensive necessary care that they do not get from paid staff. That care includes life-saving, feeding, providing fluids and that nurturing warm touch from someone that they know and recognize. They may not know them by name, but they know them as a safe, caring person. And they have been denied this for months and are continuing to be denied this.

People with advanced stages of dementia often do not understand that they're looking at someone as an image on a computer screen, or that they're looking at someone through a glass window. They don't understand those distinctions as to what's happening. And they certainly don't always understand why it's happening, why they're being denied that physical touch that they come to rely



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on as their safety net every single day of their lives. So, we are sacrificing the person in order to keep the body alive, and oftentimes that doesn't even succeed, they're dying of COVID anyway, and they're definitely now dying of malnutrition and other health-related issues because they're not receiving the care that they need. So this is why I really want to take a moment of your time to express the need to keep person-centered, planning, and actions in place, especially in a time of crisis.

Thank you for your time and I hope you take some action on this.