

Dignity and the Caregiving Journey

By Cassandra Van Dyck



“After people learn about dignity, a remarkable thing happens. Everyone recognizes that we all have a deep, human desire to be treated as something of value. I believe that it is our highest common denominator.” – Donna Hicks Ph.D.

When you begin the caregiving journey with your loved one, your level of involvement in their care will depend on their needs. In the early stages, you may be doing simple things for them, such as driving them to appointments or helping out with house chores, like cooking and cleaning. As your loved one’s health conditions change, your role may as well. Depending on your relationship and ability to help, you may find yourself very involved in their care, assisting with tasks such as bathing and dressing. You will also have a role in decision making if you have Power of Attorney or a Representation Agreement, and be faced with tough choices to do with end-of-life care or deciding where your loved one will live. These are challenging roles that will expend your energy and undoubtedly cause stress. Making decisions about what will best support a spouse’s quality of life, or providing physical care for a loved one is a big responsibility, and it is one that can weigh heavily on unpaid family caregivers.

On your caregiving journey, how often do you think about the word “dignity”? You might be aware of it, but struggle to define it. Many associate the word or use it interchangeably with “respect,” but it is not the same. Think of it this way: respect is something that can be earned through one’s actions, and dignity is a right that everyone is born with. To treat someone with dignity is to always take in to account their inherent value as a human being. It means that you remember and make decisions that ensure they are always treated ethically.

No caregiver intends to violate a loved one’s dignity. It may seem incomprehensible to imagine yourself in a position where you could do such a thing to this spouse or family member that you love so dearly – that you have spent so much time caring for. However, despite a family caregiver’s best intentions, sometimes a care partner’s needs are overlooked. Sometimes it is

the caregiver that makes the mistake, and other times it could be the health care professionals. Oversights can occur when family caregivers or health care professionals are stressed and tired. Maybe the client was not given as much privacy as they could have been when they were using the restroom because the care provider was concerned for their safety, or perhaps a caregiver failed to consult their loved one when making a decision about their care. Neither of these errors were meant to harm the individual, but both could have been prevented.

Working to preserve a loved one's dignity is one of the kindest things you can do for someone you care about, and it's likely something you would want for yourself should you ever need a similar kind of care. There are small and big ways that you can do this; some being little things that you can do daily with little effort, and others are big things that might require more planning and preparation.

RESPECT THEIR PRIVACY

This might feel like a no-brainer, but often when someone you care about is not doing well, you might be helping them in more intimate ways than before. For example, you may help them to get out of the bath or shower, or you could be accompanying them to the doctor's office regularly. You have been invited in to these personal spaces, but your loved one will appreciate as much privacy as they're able to get. Remember to knock on the door of the bathroom before entering. Ask their permission to be included in doctor's appointments, and respect their wishes if they'd rather speak to their care provider alone. Get as much consent as possible before doing anything that might invade their privacy. You could ask, "Can I help you take off your shirt?" before helping your loved one change before bed. Assistance will usually be appreciated, but your care partner might feel like they have more ability on certain days to tackle self-care chores on their own. Checking in with them before helping is the best way to assure they're comfortable with the care you're providing.

OBSERVE THEIR BODY LANGUAGE

They say that actions speak louder than words, and perhaps this is especially true when someone is unwell. Your loved one might have asked for help, or you can see that they could use it, but you notice that they pull away or shift their gaze when you try to assist with certain tasks, such as putting on their shoes or making their tea in the morning. If you notice that they're uncomfortable or seem to be able to complete their task on their own, give them some space. If you still think they might need assistance, ask! Again, getting consent is the best way to assure you're giving your loved one what they need. Their needs may differ from one day to the next, so work on honing your observation skills.

MAKE DECISIONS TOGETHER

Whenever possible, make decisions with your loved one. Listen to them and respect their wishes. Plan ahead. If your care partner is able, sit down with them and ask about their wishes for their future. Consult a professional to sign Representation Agreement papers so that you are

both prepared for any changes in their health; or an Enduring Power of Attorney for financial matters. Discussing their wishes ahead of time will take the guess work out of any decisions you'll be faced with down the road, and prevent confusion or uncertainty.

KNOW YOUR PERSON

You know your loved one best. Think about how they like to dress, what they enjoy eating, and the things that they love doing. Ask yourself how you can incorporate those desires in to their life, even when they're struggling physically. Involve them with outfit choices, and cook their favourite meals. Look for ways to engage them in their hobbies, even if it is not in the same way they used to be able to. Maybe that means watching a soccer game on TV with them, or visiting an art museum.

Incorporating these practices in to your caregiving journey is a learning process, and you won't always do things perfectly. There are so many moving parts when it comes to caring for a loved one, and thinking about the moments that you might not have handled things in the best way possible can bring up emotions of sadness or uncertainty. Remember to be gentle with yourself, and recognize the things that you have done well, too.