

Decisions in Palliative Care

What would someone with dementia want if they were able to decide for themselves?

Imagine knowing you have only a few months to live due to a life-limiting illness. What measures would you take to treat an unexpected acute health problem, such as a serious infection?

What if it's not you in this circumstance but a family member with dementia?

"The key to making a decision regarding medical treatment for an acute issue is the same whether the person has dementia or not," explains Beth Helliar, Client Support Coordinator at the Alzheimer Society of Manitoba. "It's about what that person wants or would want if they could make the decision themselves."

Beth, who has experience in palliative care, points out that knowing what someone would want is a lot tougher when the person has dementia – even if you are very familiar with their views.

And if you're not, it's important to find out those views as soon as you can. Having a conversation with the person early after the dementia diagnosis can provide insight into their wishes.

In the best case scenario, the person with dementia has designated a health care proxy: usually a close family member or friend who knows the person well and can make decisions on their behalf.

For example, let's say an acute illness requires that an intravenous be inserted for a week, but this upsets the person with dementia. They don't understand that this is a temporary situation, and they constantly try to pull it out.

The proxy would consider the whole picture. Has their family member's quality of life been deteriorating to the point where the person, if able, would choose



to let nature take its course? In that case, the decision may be to forego treatment because it's causing so much distress. On the other hand, the proxy may have noticed that the person seemed content and happy before the current health episode emerged. Persevering with treatment for the short term may be called for, especially if it is likely that the acute health issue will be resolved and the person can resume a life of reasonable quality.

How Invasive is the Solution?

In the above example, and in many other scenarios, the proxy has to think about the anticipated invasiveness of the treatment and how it will affect the quality of life of the person. This is done in consultation with the health care team, whose members can advise on the expected outcomes.

Situations that may arise include choosing between administering antibiotics orally or by the more invasive intravenous method, which could be painful and disconcerting to a person with dementia.

What if an operation is suggested as treatment? "Surgery is a big decision to make," explains Beth. "Someone with dementia is at high risk for delirium caused by the anesthetic, and delirium is a very serious condition."

It's evident that pieces of the health care puzzle are many and varied for those in palliative care, but a proxy can rest a little easier in the decision-making process knowing they are acting with the values of the person with dementia at the forefront.