

**Patient-Centred Care: “Wishes” are Not Consents**  
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At a recent long-term care conference attended by front line health workers, I was asked to explain the law regarding health decision-making. The organizers wanted to ensure that front line health workers, whether PSWs, nurses, or physicians, understood the definition of “patient-centred care”.

First, the audience needed to understand the basic requirements of the *Health Care Consent Act*. I explained that long-term care home residents have the rights to know about their own health condition, including the possible treatment options, the risks and benefits of these treatments, any alternatives to the treatments being proposed by the health provider, and what might happen if the resident decided to refuse the treatments offered. Communication of this information to the resident by the health provider is required and is part of the responsibility to obtain an informed consent from the resident before treatment is delivered.

Secondly, I had to explain how important it was that health providers understand who would make the decisions about treatment – the resident if capable of consenting to the proposed treatment, or where the resident was not mentally capable, the resident’s substitute decision-maker (SDM). Further, I informed them that it was up to the health practitioner proposing the treatment to determine whether or not the resident was mentally capable of making the decision, meaning that the person had the ability to understand the information relevant to making the decision, and that they had the ability to appreciate the reasonably foreseeable consequences of the decision or lack of decision.

Where the resident was incapable of making the decision, the health care providers needed to know **who** the right SDM for the resident was, as required by the *Health Care Consent Act*. This Act established that that everyone in Ontario found incapable of making a treatment decision has a health decision-maker. This might be someone that the resident had previously appointed as attorney in a Power of Attorney for Personal Care or might be a family member of the resident if he or she has not appointed someone to be his or her attorney. The SDM is the person who is highest ranking on the list of SDMs as set out in the *Health Care Consent Act*, as follows:

1. The incapable person’s guardian of the person;
2. The incapable person’s attorney for personal care;

3. The incapable person's representative appointed by the Consent and Capacity Board under section 33 of the *Health Care Consent Act*, if the representative has authority to give or refuse consent to the treatment;
4. The incapable person's spouse or partner;
5. A child or parent of the incapable person, or a children's aid society or other person who is lawfully entitled to give or refuse consent to the treatment in the place of the parent;
6. A parent of the incapable person who has only a right of access;
7. A brother or sister of the incapable person;
8. Any other relative of the incapable person.
9. Where there is no one else, the Public Guardian and Trustee.

Unfortunately, it quickly became clear to me that many of the attendees at this event did not have an understanding of the basics of informed consent, such as **when** it was necessary to obtain consent from the resident's SDM if the resident was not mentally capable to make treatment decisions.

I was told by one participant that if an incapable resident refused medications to which the SDM had previously given consent, the front-line worker would not take steps to determine if the resident was now capable of giving or refusing consent to the treatment and as such, could now make their own decisions. I was told that even if the resident had been found not capable for making the treatment decision, the front-line worker would not necessarily try to figure out why the incapable person was refusing the treatment, would not come back a bit later to see if the resident would then be agreeable to take the medication, and would not check with other staff to determine whether the medication could be provided in alternative forms or by alternative methods so that the resident would have the benefit of that treatment.

When I suggested that in these situations a health practitioner should be contacting the SDM to discuss both the fact that the treatment had not been delivered as well as possible changes to the treatment plan, I was told that "patient-centred care" meant that the health worker complies with whatever the resident wants to do, whether the resident is capable or incapable of understanding the treatment, notwithstanding the implications of a refusal of the treatment.

I was very surprised. In my opinion, this approach is not patient-centred care. This tactic can cause harm to the resident, as the resident may not receive necessary treatments. Further, no consideration appears to be made as to how better to manage the treatment delivery or to provide alternative treatments.

The law on substitute decision-making was created to be fair to persons who lacked the ability to understand and the ability to appreciate their health condition and treatment options. The law gives the authority to the SDM to "step into the shoes" of the incapable person, providing guidance to the SDM as to how they are to make a decision

about the proposed treatment in the way that the person might have done if still mentally capable.

When the SDM makes decisions for an incapable person, they are required to consider the wishes of the person expressed when capable, about their health care and how they would want to live their life. If those wishes are relevant to the decision to be made, the SDM is required to honour those wishes earlier expressed if it is possible to do so. If the SDM does not know of any such wishes, then the SDM is required to make decisions on behalf of the incapable person that he or she thinks are in the “best interests” of the person.

Although the resident may now be incapable of making treatment decisions, he or she still may be able to communicate about the treatment, which is something that the SDM must also consider. These “incapable wishes” are not required to be followed by the SDM, but they must be carefully considered, as these incapable wishes are indicators that the health providers and the SDM may need to consider other treatments or other forms of care for the resident.

Patient-centred care involves understanding who the patient is and what their care needs may be. Patient-centred care also requires that the health providers determine who the treatment decision-maker is – the resident, if capable, or the resident’s SDM, if the resident is incapable. It must be remembered that the SDM is not only the decision-maker for the incapable resident, but is also their “advocate”. They have the challenging task of bringing the residents’ voices to the table when decisions need to be made for residents who are now unable to make those decisions for themselves.

Ignoring the fact that the resident may be incapable of treatment decision-making, and ignoring the requirement to obtain informed consent from the SDM as health decision-maker are the opposite of patient-centred care. Such actions are not only contrary to the law, they could be considered a form of abuse, as they take away the resident’s rights to have a capable voice at the table for them in determining their care and treatment.