

## Community Alert

**BC has laws governing consent to health care and for planning in the event of incapacity, for end-of-life, and other support needs.**

**These laws are important for any health crisis, including Covid-19**

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**The example of Ariis Knight raises questions about the rule of law and the role of ethics in BC.**

Many of us have read or heard [media reports](#) about Ariis Knight who died recently in Peace Arch Hospital. Ariis is referred to as 'special needs' and was supported by Semiahmoo House Society for Community Living. Semiahmoo staff, familiar with her means of communication, were not allowed to be with Ariis in hospital as was their usual approach.

Nidus has heard from many individuals and families who are concerned, especially during Covid-19, about restrictions on visits by spouses and families to residents in long term care and not allowing personal support staff to accompany people with disabilities in hospital.

It is reported that Ariis did not have Covid-19. She was in hospital for other health care needs. Was the BC law for health care consent followed? What about access to personal supports?

**Did Ariis, and will others in a similar situation, have access to the health care any of us would expect or be entitled to?**

While it is true these are extra-ordinary times, and we all must take extra precautions, we also need to find ways to maintain our ethical standards and human rights.

Most importantly, we can use the legal tools that continue to bring British Columbia international recognition as a leader in support of people living with disabilities.

In fact, everyone, including people with disabilities, is working hard to 'bend and flatten the curve' during the Covid-19 pandemic. We are hearing from BC physicians that hospitals are not overwhelmed or overcrowded. The Provincial Health Officer and Minister of Health shared their plans for ensuring non-Covid-19 patients would receive appropriate treatment by health authorities and recently have taken time in their regular briefings specifically to remind British Columbians that these non-Covid-19 services are available and people should access them as needed.

**BC's legislation for health care consent requires health care providers to get consent for treatment that is offered. In Ariis' situation, the issue of how consent was obtained is confusing – especially for the agency that provided support and for her family.**

Semiahmoo House staff and family members were told that Ariis was receiving the M3 level of care. M3 is an option on a form developed by health authorities called MOST (Medical Orders for Scope of Treatment). If checked, M3 indicates a patient should be provided with treatment except not critical care treatments.

It seems health care providers in hospital determined Ariis was not capable to make health care decisions for herself. Since no Representation Agreement was in place, the medical team asked Ariis' next-of-kin for consent. Her brother took on the temporary role of making health care decisions for Ariis. In this role, he refused critical care treatments (as supported by the medical team) and gave consent to other treatments.

Subsequently, the hospital said Ariis' care was changed to level M1. The next-of-kin was not asked for consent. The M1 option is for comfort care and symptom management only. The next communication was that Ariis was dying. She died without the company of family or her long time staff support.

The hospital communication is confusing because of their reference to levels of care, which are outlined in the MOST (Medical Orders for Scope of Treatment) form. The MOST form is not a legal planning document like a Representation Agreement. It has very limited application under BC law.<sup>1</sup>

We know health authorities, including Fraser Health where Peace Arch Hospital is located, are promoting use of the MOST form. Our concern is that its use is creating confusion and potential conflict with BC's law for health care consent.

The MOST form was adapted from the United States where it is also not in law.

Some years ago, the Ministry of Health called on health authorities to stop using level of care forms and level of care approaches in long term care settings. Currently it seems that health authorities are using the MOST form – a levels of care approach – as an advanced consent in acute and emergency care settings.

### **What if Ariis, or others in a similar situation, had a Representation Agreement?**

If a Representation Agreement is in place and includes health and personal care matters, a representative has authority to help the adult with decisions about health care and personal care – in hospital as well as community settings. Even in an emergency or end-of-life situation, any representative can give consent for treatments to relieve pain and provide comfort. This is especially important to those 'left behind' – knowing the representative was properly involved. It avoids speculation and extra upset.

A Representation Agreement is a legal document and the only way to cover authority for personal care matters, such as arranging for services and supports.

A representative, named in a Representation Agreement, has more authority than a next-of-kin selected by a health care provider for the temporary role of making a specific health care decision. A representative role is not designed to be temporary. A representative has the opportunity to advocate with the adult, and get help from the support staff or others.

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<sup>1</sup> For example, where there is no Representation Agreement, the level of care selections on a MOST form may be considered an expression of a patient's wishes (like a living will) BUT only if the MOST form was signed by the adult/patient when they were capable of informed consent (the patient was informed and understood the meaning and effect of the MOST form at the time of signing it). In addition, a health care provider can only use the MOST form in a health care emergency when the patient is incapable of consent. The health care provider must also be sure there is no possibility the patient might have changed their mind. See section 12.1 of the Health Care Consent and Care Facility Admission Act. The MOST form and goals of care are reasonable for discussion purposes but they are not instructions.

**A representative, under BC’s Representation Agreement Act, is an advocate, with legal authority.**

We have all heard the expression “everyone needs an advocate in hospital.” That is never as true as now. This is not to diminish the amazing efforts of front line workers in hospital. Front line workers have been among the loudest voices in promoting the need for an advocate when dealing with complex systems such as those for health and facility care.

**We are seeing the effects of poor policies and practices in long term care facilities. Are we reinforcing this approach for others in the community?**

We appreciate the Provincial Health Officer, Dr. Bonnie Henry, saying that she has an expectation that health authorities will allow visitors for end-of-life situations. But an expectation is not an order and it is not law. A Representation Agreement is a legal document and it is not only about visiting and personal care, it is about consent to health care.

For people living with disabilities, including dementia, health care consent and personal care support are not just for end-of-life. These concern everyday quality-of-life needs and equity. There is no question about having to adapt and adjust to comply with measures for the Covid-19 pandemic. No one wants to jeopardize the health and safety of front line workers in hospital and in other care settings. There are ways to accommodate needs while maintaining our humanity – we hear it in the voices of BC’s Minister of Health and the Provincial Health Officer who, along with their teams, are leading us through this difficult time.

**What is the law in BC for health care consent?**

See Nidus’ fact sheets at [www.nidus.ca](http://www.nidus.ca) – click Information (top menu bar) > Health Care Consent

Here are links to two of the fact sheets:

[How are health care decisions made if you are incapable?](#)

[Health Care Consent: Your rights and the law](#)

**ACTIONS YOU CAN TAKE:**

**For details, see Nidus’ information sheet on [Actions You can Take Before Hospitalization](#).**

1. Attend a Nidus webinar on Planning for the Future – the legal side.
2. Make a Representation Agreement.
3. Register the completed Representation Agreement with the online Nidus Registry. Print wallet cards for every purse/wallet, glove compartment and backpack.
4. Learn your role – your authority and duties – in the Representation Agreement.
5. Keep arrangements up-to-date. Communication is KEY! Maintain good and regular communication with those named in the Agreement and other supporters.