

# Health Care Decision Making for Individuals with Intellectual Disabilities

Individuals with intellectual disabilities may find themselves in a situation where their treatment provider will not proceed with treatment. This type of situation typically arises when the treatment provider has assessed that the individual does not have the capacity to consent to the proposed treatment and there is no appropriate directive or person present to consent to the individual's care. This document provides answers to common questions in these situations.

## Q1. What is capacity to consent to a health care decision?

Capacity refers to the ability to make a *particular* decision at a *particular* time; it is question and decision specific and should be determined relative to each health care decision being made.

An individual with capacity to consent to a health care decision can:

- Understand information that is relevant to making a health care decision regarding a proposed treatment;
- Understand the consequences (i.e., the benefits and risks) of making or not making a health care decision respecting a proposed treatment; and
- Communicate the health care decision being made.

## Q2. Why is capacity important when consenting to a health care decision?

Medical treatment cannot be provided without consent. In Saskatchewan, assessing an individual's capacity to consent to a particular health care decision is the responsibility of the treatment provider.

For example, The College of Physicians and Surgeons of Saskatchewan has a [policy on Informed Consent and Determining Capacity to Consent](#) that guides doctors in determining whether or not an individual has capacity.

Capacity to consent to health care is not something that can be determined by an individual's supports or family members.

## Q3. What happens if a treatment provider determines that an individual does not have capacity?

If a treatment provider finds that an individual does not have capacity to consent to a particular treatment, the treatment provider must advise the individual of the decision.

The treatment provider must then determine if the individual has a valid directive that gives direction relating to the treatment at issue. If there is a valid directive it will be followed.

Where the individual lacks capacity and does not have a valid directive, the treatment provider must determine who is an appropriate substitute decision maker according to [The Health Care Directives and Substitute Health Care Decision Makers Act, 2015](#) (the "[Act](#)"). This legislation outlines the order of appropriate substitute decision makers when an individual is assessed not to have the capacity to consent.

## Q4. What is a directive?

In Saskatchewan, health care directives, living wills, and Do Not Resuscitate orders are all referred to as "directives".

A directive is a set of written instructions that a person can prepare *while they have capacity* for a time in the future when they may not have capacity. A directive may lay out treatment or care instructions and may appoint a proxy to act as the person's substitute decision maker if they lack capacity in the future.

### Q5. Who can prepare a directive?

Any person over 16 who has capacity to make a health care decision can make a directive. Once a directive is prepared and signed it can be used whenever the person lacks capacity to make health care decisions for themselves.

An individual must have capacity to make a directive. Directives cannot be prepared on behalf of an individual who does not have capacity to consent to the health care decisions. Please see Q1 for more information about capacity to consent.

### Q6. What is a substitute decision maker?

A substitute decision maker is someone who can make treatment decisions for an individual if they cannot make them for themselves.

### Q7. Who is an appropriate substitute decision maker?

If an individual without capacity has named a proxy in a care directive or has had a personal guardian appointed for them, that proxy or personal guardian may make health care decisions for them.

If an individual does not have a proxy or personal guardian in place the nearest relative, as defined in the *Act*, can make decisions.

### Q8. Do day-to-day treatments require consent?

Yes, day-to-day treatments (like basic dental care or visiting the doctor) require an individual to have capacity to consent. If an individual lacks capacity it is possible that they will require a substitute decision maker or directive for these day-to-day treatments.

For day-to-day treatments, where there is no other appropriate substitute decision maker present, the individual's caregiver can make the health care decision.

According to [The Health Care Directives and Substitute Health Care Decision Makers Regulations, 2017](#) (the "Regulations") a "caregiver" is defined as:

- A proprietor of an Approved Private Service Home (APSH) or mental health approved home;
- A foster parent where the individual still lives with the foster parent;
- A personal attorney;
- A person authorized in writing by the proxy;
- A personal guardian; or
- Nearest relative.

### Q9. What qualifies as day-to-day treatments?

According to the *Regulations*, day-to-day treatment includes non-invasive treatments that do not incur an expense for the adult unless the adult's property guardian or attorney has approved the expense.

Day-to-day treatments are outlined in the *Regulations* as follows:

- Physician visits;
- Routine procedures conducted in a physician's office;
- Routine laboratory tests;
- Foot care;
- Basic eye exams;
- Physiotherapy;
- Speech language therapy;
- Basic dental care;
- Wound care;
- Swallowing assessments; and
- Hearing tests.

### Q10. How can we support individuals with intellectual disabilities to still be a part of the decisions concerning their health care?

The [Comprehensive Personal Planning and Support Policy](#) (CPP&SP) provides guidance for the provision of services and supports for individuals with intellectual disabilities in the Province of Saskatchewan. CPP&SP guides CLSD staff and third-party service providers who are contracted, licensed, or certified by the Ministry of Social Services in the provision of effective and ethical support to individuals with intellectual disabilities in Saskatchewan.

Although CPP&SP does not have authority over the legislation that governs how health care decisions are to be made for individuals with intellectual disabilities in Saskatchewan, it can provide useful guidance in how to use a supported decision-making approach to support individuals to participate in decision making that impacts their lives. Policy three of CPP&SP says that individuals have the right to make their own decisions and where assistance is needed, supported decision making should be used to assist. Personal guardians and substitute decision makers may use a supported decision-making process to reach decisions in matters where they are making health care decisions for an individual as well.

More information about CPP&SP can be found at this [link](#).

**Q11. What if there is no appropriate substitute decision maker?**

When the person requiring treatment lacks the capacity to make a health care decision and there is no directive, proxy, personal guardian, or nearest relative, a treatment provider may:

- Provide treatment in a manner and to the extent that is reasonably necessary and in the best interests of a person if:
  - a) the treatment provider believes the proposed treatment is needed; and,
  - b) another treatment provider agrees in writing that the proposed treatment is needed.

**Q12. Can Group Home or Group Living Home staff consent to day-to-day treatments?**

No, they cannot. *The Health Care Directives and Substitute Health Care Decision Makers Regulations, 2017*, does not list Group Home or Group Living Home staff under those they define to be a “caregiver”. As a result, they cannot consent to day-to-day treatment for an individual, unless they have been authorized in writing to do so by the individual’s proxy, personal guardian, or closest relative.

**Q13. Are doctors the only treatment providers that need to determine consent for health care or treatment?**

No, many types of treatment providers must receive consent prior to administering health care or treatment. For example, pharmacists must receive consent before giving flu shots and dentists must receive an individual’s consent before providing dental care.

**Q14. Is a substitute decision maker liable for decisions made under *The Health Care Directives and Substitute Health Care Decision Makers Act*?**

No, a substitute decision maker is not liable for decisions they make, as long as they act in good faith and follow the *Act* and *Regulations*.

A substitute decision maker is not liable for failure to follow a directive, as long as they were acting in good faith when making the health care decision.

**Q15. What can I do if I feel like an individual’s health care is at a standstill due to issues of capacity to consent?**

A good place to start would be getting in touch with the individual’s Community Living Service Delivery (CLSD) Community Services worker (CSW), or an Inclusion Saskatchewan (INSK) representative. The CSW and INSK may be able to help navigate the issue with the individual and connect with the treatment providers involved in the situation. A referral to INSK can be particularly beneficial if an individual has limited representation from family members.

For the contact information for your local CLSD office please see:  
<https://www.saskatchewan.ca/government/directory?ou=40214519-21d3-49cd-866c-6f874e56da21>

For the contact information for an Inclusion Saskatchewan representative in your community please see:  
<https://www.inclusionsk.com/>