



My Health Care Wishes For Supporters

Inclusion Saskatchewan's Supported Decision Making Series





INCLUSION SASKATCHEWAN

supporting individuals with intellectual disabilities

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My Health Care Wishes

My Health Care Wishes is based upon the supported decision making process in which an individual is supported to make choices about their own lives. In order to best support an individual with this resource, we recommend you have a strong understanding of supported decision making. Please refer to our supported decision making resources for more information: www.inclusionsk.com/sdm

In order to make health care decisions, an individual needs to have an understanding of the options so they can make decisions that feel right to them. It is the supporter's role to ensure that the information is presented to the individual in the way that works best for them. Additionally, it is important that the individual is feeling comfortable, safe, and free to express themselves with every member of their support team before they begin.

The History

Historically, people with intellectual disabilities have had their medical care decisions made *for* them, rather than *with* them. There were beliefs that people with intellectual disabilities needed to be protected, that medical decisions would be too difficult to understand, and that they did not have the capacity to make their own medical decisions. Today, we know that people with disabilities want to be involved in making their own decisions, and prefer to be included even if the decisions they are making are challenging to talk about.

Customizing The Process

Some people prefer a formal process and others do not. Who the person is and what their preferences are will help guide what the process of going through *My Health Care Wishes* will look like. It is important that the individual leads the process and that they are able to go at their own pace. If the individual does not want to go over a section or needs time to process, that is okay.

Prior to beginning working through *My Health Care Wishes*, establish:

- Who will be in charge of setting up the meetings?
- If meetings need to be recorded, who will be responsible for this?

- How problems or disagreements will be solved.
- How information will be gathered and presented.
- Who will make the final decision. In most cases, it would be the individual themselves but there may be instances in which the individual would like support. They can then assist in identifying who will make the final decision. A guardianship order may also impact this in which case, the individual should still be actively involved in the decision making process.

My Health Care Wishes can be used as a template and can be customized based on what works best for the individual. If you do customize the process, ensure that the individual is still included in every step in the decision making process.

Taking Responsibility For Your Supportive Role

The health care system can feel overwhelming and challenging to navigate. Supported decision making practices can present information to the individual in the ways that work best for them and with those they are most comfortable with so they can make an informed decision. There may be certain areas in which an individual feels comfortable making a decision and other areas they do not.

Being Proactive

My Health Care Wishes should be filled out when the individual feels safe and comfortable and not when they are already in the hospital. It is important to be proactive so that the individual is not under stress when going through the document. *My Health Care Wishes* should be updated regularly (we recommend annually) so that it continues to reflect who the individual is and what their wishes are.

Regardless of whether you have decision making power for an individual or not, all supporters have a responsibility to uphold an individual's wishes and to amplify their voice.

Who Can Make A Decision On Behalf Of An Individual

It is critical to know who can make a health care decision on behalf of an individual as well as to know an individual's rights so that you can uphold them. A supporter within an agency cannot make health care decisions on behalf of an individual, however, if the individual gives permission, a supporter within an agency can provide information regarding the individual's wishes.

A court appointed **personal guardian** can make decisions on an individual's behalf if the guardianship order includes medical decision making. A personal guardian may have the authority to make the final decision, however, it is still important that the individual is informed and has the opportunity to be a part of the process as much as they would like to be. A court appointed **personal co-decision maker** can make decisions alongside of an individual if the order includes medical decision making.

A **substitute decision maker** can refer to a **proxy** or an individual's **nearest relative** who can make decisions on the individual's behalf in the event that they are not able to. If a substitute decision maker is not involved in the individual's life, it is recommended that they either decline making the decision or, at the very least, consult with others in the individual's life. A proxy is chosen by the individual and must be at least 18 and should know the individual well including their health care wishes and be willing and able to uphold them. A nearest relative is contacted when a medical practitioner needs consent in order to provide care and there is no proxy or decision making order in place. Nearest relatives are contacted in the following order:

1. Spouse
2. Adult son or daughter
3. Parent
4. Adult sibling
5. Grandparent
6. Adult grandchild
7. Adult uncle or aunt
8. Adult nephew or niece

**When there is no designated proxy or appropriate nearest relative, two medical practitioners can sign off for the individual to receive necessary care.*



Capacity, Consent, and Rights

For more information on consent, rights, and resolving complaints, read this research report by Lacey Humenuik: <https://bit.ly/3Of5jsc>

Research

Medical intervention and treatment preferences are just as relevant for people with intellectual disabilities as for the general population, if not more so. It is not uncommon for individuals with intellectual disabilities to have co-morbidities which makes them more vulnerable in terms of health decline or complications with age (Voss et al., 2019a). Supporters should take the initiative to start discussions about medical decisions and preferences as early as possible (McKenzie et al., 2017; Voss et al., 2019a). These conversations should focus on the individual's health literacy, their wishes and preferences about potential medical treatments/life-saving interventions, and cultural considerations. We cannot expect these discussions to only take place within the context of a physician-patient relationship. In order to appropriately support an individual with their health literacy, these discussions must also exist within our supportive relationships which includes preferred relatives and other professionals (Voss et al., 2019a).

Having these conversations before the individual experiences a health decline or cognitive deterioration puts them in better control of their care, ensures decisions do not conflict with their wishes or preferences, and safeguards them from reactive decision making (Voss et al., 2019). In addition to this, research shows that physicians preferred to discuss end-of-life decisions in a calm situation when enough time could be spent on a discussion (Wagemans et al., 2013). Studies show that the best care for end-of-life includes person-centered care, quality of care provided, spiritual/cultural needs attended to, coordination of care across service systems, and a supportive, capable, and peaceful environment (McCarron et al., 2010).

The research also shows improved quality of death and dying when the views of the individual have been incorporated into their end-of-life support (Voss et al., 2019a; Wagemans et al., 2013). In one study, a lack of planning was reported to result in stress and reactive decision-making by supporters and medical staff (McCarron et al., 2010). Another study cited considerable distress experienced by the individual due to not being given information about their illness or intervention options (Bekkema et al.).

Research demonstrates that individuals with intellectual disabilities are largely excluded from decisions regarding their medical care (Voss et al., 2019). There is a stigma that individuals are unable to understand the consequences of medical choices and supporters believe these decisions are too nuanced (Wageman et al., 2013). When we think about decision making, we must focus on the process of involving the individual, despite who may have the ability to make the final decision (Wagemans et al., 2013). It is important to adapt information and discussions to suit the level of understanding and experience of the individual (Voss et al., 2019a).

Opportunities for individuals with intellectual disabilities to express their autonomy and increase their health literacy are often challenged based on incorrect perceptions of competence, issues of who has final decision-making control, and organizational structures (Jenkinson, 1993). Including individuals in discussions about their health and care leads to a more balanced decision-making process (Wagemans et al., 2013). Having the individual's wishes and decisions documented is crucial to ensuring they can be considered and upheld in future decision making (Rogne, 2013).

Appropriately involving an individual in these conversations includes: gathering information about their life history and previous experiences with illness and losses. Individuals with intellectual disabilities tend to base their responses on past and personal experiences (Tuffrey-Winje et al., 2006). A successful technique for discussing abstract concepts, such as end-of-life care, is to show the individual an image of a fictional person in palliative care and ask what they think the fictional person may want or need. Their answers will be based on things they find personally important if they were in that situation, and therefore can be documented as an accurate reflection of their wishes or preferences (Tuffrey-Winje et al., 2006).

In cases of individuals who cannot express themselves verbally, their preferences and understanding can generally be deduced from careful observation of their body language, facial expressions, and behavior (Bekkema et al., 2010; Jenkinson, 1993; Wagemans et al., 2013; Voss et al., 2019). In cases where relatives or supporters have close relationships, these team members can interpret the individual's expressions and supporting their communication to ensure they receive treatment in accordance with their wishes and expectations. It is recognized that this is a heavy responsibility for those closest to the individual (Voss et al., 2019a).

These discussions should take place over a long period of time. This ensures the individual has time to process new information, consider the options, and express their preference confidently (Jenkinson, 1993). Best practices include ensuring that environments are structured for the individual to have maximum control over options, ensuring options are clear, and supporting them in discovering their preferences without our own biases, values, and preferences influencing the individual's final decision. Focusing on the process of supported decision-making and empowerment, we must work through these moments and do our best to uphold autonomy and promote choice (Jenkinson, 1993).

Individuals with intellectual disabilities are capable of sharing their views on end of life care when the information is presented in a way that works best for them (Tuffrey-Winje et al., 2006; Wagemans et al., 2013). Further, this population wants to be informed about their health, and share their preferences (Voss et al., 2019a).

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