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Book 2

Let's Talk...

About the Role of a Substitute Decision Maker (DSM) and Power of Attorney for Personal Care (POA)



Acknowledgements...

This book has been written by members of the London Health Sciences Centre, Renal Program Advance Care Planning Committee.

Content from Fraser Health's Advance Care Planning publications (www.fraserhealth.ca) and St. Joseph's Healthcare Hamilton used with permission.

Additional resources used in the creation of this document include:

Respecting Choices (2008) Gundersen Lutheran Medical Foundation, Inc., 1900 South Ave, ALEX, LaCrosse, WI 54601

A Guide to Advance Care Planning (2006) Government of Ontario, Queens Printer for Ontario

A free copy is available by calling: 1-800-518-7901

Powers of Attorney (2004) Ontario Ministry of the Attorney General, Office of the Public Guardian and Trustee 595 Bay St. Suite 800, Toronto, ON, M5G 2M6. Queens Printer
www.attorneygeneral.jus.gov.ca/english/family/pgt



From time to time the plan should be reviewed to make sure make sure nothing has changed.

Should you keep records?

An Advance Care Plan may also be called an Advance Care Directive or Living Will.

You can record your wishes by stating, recording or writing an Advance Care Plan. The Renal Care Program has a workbook available, “Let’s Talk...About Making an Advance Care Plan for Personal Care”, to help with this process. Included in this booklet is a Power of Attorney for Personal Care form. Speak to any member of the Renal Program team and they will provide you with a copy of this workbook.

It is important to keep a copy of an Advance Care Plan in a safe place. For individual’s currently on dialysis, it is recommended that you share a copy of your advance care plan or verbally share your wishes, so this can be documented on your dialysis medical chart.

Your SDM may encourage you to write an Advance Care Plan, so they can show it to others if needed. This way it is easy to follow and prove to others that this is what you wanted.

What is a Substitute Decision-Maker?

A Substitute Decision-Maker (SDM) is a person who makes decisions on behalf of someone who is unable to make decisions for themselves.

For example, the person may:

- Not understand the information required to make a decision
- Not understand the consequence(s) of making a decision
- Be too sick to make a decision

For example, what if you had a stroke or developed Alzheimer's and you are too sick or unaware of what is happening to be able to make your own decisions?

What is a Power of Attorney for Personal Care (POA)?

A **Power of Attorney for Personal Care** is a written document that states who you have chosen to be your substitute decision maker (SDM) in the event you are not capable of making these decisions yourself. You can name more than one SDM. When there is more than one, they can talk to and support each other.

How do I choose a Substitute Decision Maker for Personal Care?

One of the most important decisions we encourage all adults to make is to think about who they would choose to make decisions for them if something happened and they were no longer able to communicate or capable to make their own decisions.

If you are trying to decide who **you would like to ask to be your** SDM; or if you have picked someone but need to be clear about what is expected of a SDM, think about the following questions:

- “Have I asked this person if he/she is willing?”
- “Have I talked with this person enough so that he/she understands my preferences, values, and goals?”
- “Is this person willing to follow my preferences?”
- “Can this person make decisions under sometimes difficult situations?”

Do I need to consult with a lawyer to complete a Power of Attorney?

No, a lawyer is not required. However, a lawyer can help you complete the Power of Attorney document, if you wish. Otherwise, you can use the SDM form, included in the “Let’s Talk...” workbook number 3, or you can ask your social worker to provide you with a Power of Attorney kit.

You can also use the online resource provided at the following website:

<http://www.attorneygeneral.jus.gov.on.ca/English/family/pgt/poa.pdf>

Or contact the Public Guardian and Trustee office at: 1-800-366-0335

If you want to talk to a lawyer for free contact the Lawyer’s Referral Service run by the Law Society of Upper Canada at: 1-800-268-8326

The Ontario Government’s web site explains the Powers of Attorney and much more at:

www.attorneygeneral.jus.gov.ca/english/family/pgt

The Ontario Government offers a free book called **A Guide to Advance Care Planning**. You can call 1-800-518-7901 and ask for a copy to be sent to your home.

Does the Substitute Decision Maker have to make these decisions alone?

No. Making decisions on behalf of another person can be very emotional. The SDM does not have to be alone at this time.

Many SDM(s) find it helpful to talk to other family members or friends, religious or spiritual groups and members of the health care team such as doctors, nurses, social workers and chaplains. Many can offer support at this time.

However, it is important that the SDM follow what you would have wanted if you could make the decisions for yourself.

As noted earlier, you can also assign more than one SDM. The advantage of having more than one SDM is that they can talk and support each other. They should both be informed about your values, beliefs and expressed wishes. They should be able to agree.

You need to be able to talk with the SDM in advance so they know what your wishes would be. This person needs to be able to make decisions about what you want. The SDM should be someone who can state your wishes when needed.

The SDM should be someone you feel close to and knows you well. The SDM may be a spouse, partner, companion, family member or trusted friend.

When you pick someone you would like to be your SDM, you will need to sign a legal document called the Power of Attorney for Personal Care naming this person as the SDM. If you have not signed this document, the Health Care Consent Act (1996) provides a list of people who can act as a substitute decision maker (SDM).

Judy is adamant that she would never want to be kept alive on a ventilator if there were no hope for recovery. Paul, her husband, loves his wife dearly but does not think he would ever be able to make the difficult decision to turn off the machines keeping her alive. After Judy and Paul discussed this honestly with each other, they agreed that Judy's sister would be better suited to act as POA yet still include Paul in all her care decisions.

When there is no POA, the order of people who can make decisions for you and act as a substitute decision maker is:

1. Spouse, common-law spouse or partner
2. Parents or a child over 16 years of age
3. Brother or sister
4. Other relative by marriage or adoption
5. Office of the Public Guardian and Trustee

If there is more than one person under a particular category (for example, child, sibling), they will have equal say and will have to make decisions together.



What if we have never talked about these issues?

If you have not expressed wishes related to a particular situation, the role of the SDM is to decide what would be in your best interest. The SDM must consider your values and beliefs, and consider how these would bear on the current situation. Also, they would consider the health condition and risk of the proposed treatment e.g. is the treatment going to improve your condition or well-being? They would talk to the doctor about your present medical condition and needs.

Sometimes it helps to think about the past. They might reflect on how they recall you dealing with sickness or death of a close friend or family member. These memories may help them remember what you felt and believed.



How does a Substitute Decision Maker make such hard decisions?

The role of the SDM(s) is to make decisions on your behalf, if you are not able to do so for yourself. Your SDM is required by law to agree to or decline a treatment plan that is offered by the healthcare professional. This is done by giving consent or refusing consent.

Decision must be based on your known expressed wishes from when you were capable. In other words, if you had said exactly what you would have wanted in the situation, the SDM must consent or refuse consent based on this wish.

If you are considering an advance care plan, it is best that you and the person who will be acting as a SDM in the future talk about these decisions in advance. Ideally, it is best if you talk about these issues when you are feeling well enough to think about what is important to you and what your wishes would be. It is important to talk again, from time to time, to see if anything has changed.

When faced with a medical treatment choice, your SDM should ask themselves: 'Has my loved one ever told me what they would want in this type of a situation, or a similar situation? Would they accept this treatment and would they consider the result of it to be a good quality of life?'

Can I have more than one Substitute Decision Maker?

You may choose to have more than one person as your SDM. However, the law requires them to agree on decisions. If you have more than one SDM, it is a good idea to specify how disagreements should be resolved.

You might say that in a case of conflict, one attorney's decision will override the others.

If your SDMs can not agree on decisions, the Office of the Public Guardian and Trustee may be required to make the final decision about your health care treatment.

If you are concerned that the individuals you want to act as SDM are likely to disagree, you may wish to appoint a single decision maker.

If you decide to appoint a single decision maker, you can also appoint a substitute, in case the person you have chosen to be your SDM is not available due to sickness, vacation or for some other reason. It is important to remember that your substitute SDM will have the same authority and powers as the SDM he or she replaces.

What kinds of decisions may a Substitute Decision Maker need to make?

The Substitute Decision Maker should be prepared to make decisions about personal care. These decisions are based on your conversations with them to ensure that they understand what you would want. Personal care includes health care, nutrition, housing, clothing, hygiene and safety.

It is important to know what a SDM is actually required to do.

A SDM is supposed to speak your words or your intentions for you. For example, a SDM cannot ignore your wishes, but this does not mean that they direct care. A SDM can only consent to accept or refuse a treatment plan proposed by a clinician. A healthcare professional must first determine a treatment is appropriate and then offer it. The healthcare team will inform the SDM when decisions are needed. A SDM only makes decisions that are required of them.

For example, if you were in hospital and unable to make decisions, your SDM may need to decide if you can go home, or need to go to a long term care facility. If you go to long term care, your SDM needs to decide how you would be cared for in terms of food, clothing, hygiene and safety.

What about health care decisions?

This is an important part to be prepared for. You need to make sure that your SDM understands what you would want them to do.

Here are some examples about what to discuss...

Do you want...

- To start, continue or stop dialysis?
- To have surgery no matter what?
- To have a blood transfusion or blood product?
- To be started on a feeding tube?
- To live in a retirement home or nursing home if needed?
- To die naturally if you were to stop breathing or your heart stops?
- To go to the Intensive Care Unit and be on a breathing machine?
- To have a breathing machine turned off and have a comfortable natural death?