

A Guide for Being a Substitute Decision- Maker

**Making decisions on
behalf of a loved one...**

Kidney and Urinary Program

What is a Substitute Decision-Maker?

A Substitute Decision-Maker is a person who makes decisions on your behalf if you are not able to make them yourself. The Substitute Decision-Maker can make decisions about personal care. Personal care includes health care, nutrition, shelter, clothing, hygiene and safety. Substitute Decision-Maker is also written as SDM.

Who should be a Substitute Decision-Maker?

The Substitute Decision-Maker needs to be able to make decisions about what a loved one wants.

The SDM should be someone who is close to the loved one and knows him or her well. The SDM should be someone who can state the loved one's wishes when needed. This person needs to be able to talk to the loved one in advance and know what he or she wishes.

The SDM may be a spouse, partner, companion, family member or trusted friend.

When a loved one has picked a Substitute Decision-Maker he or she needs to sign a legal document called the Power of Attorney for Personal Care naming the SDM.

When a loved one has not signed this document, the law provides a list of people who can act as the SDM.

Should the Substitute Decision-Maker keep records?

Your loved one can express wishes by stating, recording or writing an Advance Care Plan. You can ask for the book "A Guide to Making an Advance Care Plan for Personal Care" from a member of the Kidney and Urinary Program team.

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

It is a good idea to keep records of your loved one's health condition and his or her Advance Care Plan in a safe place.

You can encourage your loved one to write an Advance Care Plan so you can show it to others if you need to. This way it is easy to follow and prove to others that this is what your loved one wanted.

From time to time review the plan with your loved one to make sure nothing has changed.

Does a Substitute Decision-Maker have to make these decisions on his or her own?

No. If a time comes when you need to make decisions it can be very emotional. The Substitute Decision-Maker does not have to be alone at this time.

Many SDMs find it helpful to talk to other loved ones, religious or spiritual leaders 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 to follow what your loved one would have wanted if he or she could make decisions.

The law states that your loved one can have more than one Substitute Decision-Maker. When there is more than one you can talk and support each other.

What happens when there is no Substitute Decision-Maker named?

When there is no Power of Attorney Document naming the SDM, the order for decision-making is:

1. spouse, common-law spouse or partner
2. parents or a child over 16 years old
3. brother or sister
4. other relative by marriage or adoption
5. Office of the Public Guardian and Trustee

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 talking to the loved one and knowing what he or she would want.

Personal care includes health care, nutrition, shelter, clothing, hygiene and safety.

For example, when a loved one is in a hospital and not able to make decisions, the SDM may need to decide if the person can go home or needs to be in a long-term care facility. If the person goes to long-term care, the SDM needs to decide how the loved one is cared for in terms of food, clothing, hygiene and safety.

What about health care decisions?

This is an important part to be prepared for. The SDM needs to make sure that he or she understands what the loved one wants for many situations.

Here are some examples about what to talk about.

Does your loved one want...

- to have cardiac resuscitation if he or she stops breathing or has a heart attack?
- to continue or stop dialysis?
- to have surgery no matter what?
- to be started on tube feeding?
- to have a blood transfusion or blood product?
- to go to the Intensive Care Unit and be on a breathing machine?
- to have a breathing machine turned off and have a peaceful death?

How does a Substitute Decision-Maker make such hard decisions?

The role of Substitute Decision-Maker is to make decisions on behalf of another person. Always ask, “What would my loved one want if he or she could make decisions?”

It is best to talk about these decisions in advance when your loved one is able. From time to time, talk again to see if anything has changed.

If your loved one has not expressed any wishes in the past related to this situation, your role as Substitute Decision-Maker is to decide what would be in his or her best interest. Think about what you know about your loved one’s values and beliefs, health condition and risks of the proposed treatment. Then talk to the doctor about your loved one’s present medical condition and needs.

It can also help to think about the past. How did your loved one deal with a sickness or death of a close friend or family member? These memories may help you remember what your loved one felt and believed.