Decision-Making Capacity

A Guide for Families

Everyone has the right to make medical decisions for themselves. However, you may have questions about whether your family member is still able to make some or all medical decisions due to illness or other complications.

What is “Decision-Making Capacity”?

Decision-making capacity is a judgement that a doctor makes about whether someone can make a specific medical decision at a certain point in time. Your family member may lose decisional capacity when ill but regain it once he or she gets better. He or she may be capable of making some decisions but not others; for example, he or she may be able to decide what to eat for lunch but may not have the capacity to make medical decisions about his or her medical care.

Decision-making capacity is different from “competence.” Competence is decided by a judge in a court of law that someone cannot make his or her own medical and/or financial decisions.

How do you determine if your loved one can still make their own medical decisions?

Signs that your family member may not be able to make medical decisions include difficulty paying attention, remembering information, reasoning, or problem solving. If there is a concern that your family member lacks decisional capacity, his or her physician will evaluate your family member. The doctor will try to determine if your family member:

- understands information about the decision;
- shows understanding of how their choices will impact their (short and long-term) health;
- is able to reason and make a decision;
- makes a stable and consistent choice.

When do questions about decisional capacity come up?

Contact your family member’s doctor about a capacity evaluation if you see one or more of the following:

- refuses a medical recommendation or treatment that has low risk and would likely have a good outcome.
- is unaware of safety issues or does not seem to recognize the consequences of their actions.
- recently had an infection or illness, change of condition, or change in mental status.
How does illness, dementia or cognitive impairment affect decision-making ability?

Health problems can affect your family member’s ability to understand information and make decisions temporarily or permanently. Some conditions that may affect your loved one’s decision-making ability include: impairments at birth, confusion from illnesses and infections, side effects of medications, dementias, brain injury from a stroke or accident, or mental illness.

What if my loved one is hard of hearing, blind, or does not speak English?

It is important to help support your family member so that he or she is able to make their own medical decisions. Some ideas to help support them include making sure they have hearing aids and glasses, using written information, drawing pictures, using sign language, showing information on a computer, and using an interpreter if English is not their first language.

What if my loved one disagrees or refuses medical care? Can I override the decision?

The Health Care Representative cannot legally overrule their family member unless the doctor determines he or she lacks decisional capacity. The Health Care Representative still has an obligation to try to make decisions that are consistent with what they know about their family member’s prior preferences.

If your family member lacks decisional capacity, it is still important to treat him or her with dignity and respect. If possible, he or she should be asked to provide assent to treatments. If he or she dissents, this should be honored. Your loved one should not be physically forced to do something just because he or she lacks decisional capacity unless it is critical to their health or safety.

What does it mean for me as a family member?

It can be challenging to care for a family member with limited decision-making ability. Please reach out to your OPTIMISTIC Nurse for support & to learn more.