

Deciding on Goals of Care and Medical Orders for Scope of Treatment (MOST)

Long Term Care

Table of Contents

Our Approach.....	3
Goals of Care.....	4
Medical Orders for Scope of Treatment.....	6
Options for Treatment	6
Option One	7
Option Two	8
Option Three	10
Option Four.....	11
Option Five	12
What is Cardiopulmonary Resuscitation (CPR)?.....	14
We are here to help	16
When you are the Substitute Decision Maker	17
What the words mean	19
It's good to ask.....	back cover

Our Approach

We respect everybody's right to decide about their care. This includes what kind of medical treatment they want or don't want.

These decisions about health care are often based on a person's values and beliefs.

We hope this booklet will help you talk with your care providers about what is most important to you.

Deciding about care

The best person to decide about their care is the person needing care.

If a person cannot express their own wishes or tell us what they prefer, then we speak with someone who knows them very well (the substitute decision maker).

The job of a substitute decision maker is to ask: "If this person could speak for themselves right now, what would they decide?" (See more about this on page 17)

Goals of Care

Many people find it hard to talk about nearing the end of life and end-of-life care.

Talking to your care providers can help you better understand your health and medical condition. Ask about what you might experience in the future as a result of your medical condition. Learn about possible medical treatments (medicines, tests, and other therapies) and what you can expect from these treatments.

Once you understand your medical condition and what could be done to treat your condition, take time to think about what the future might look like as your health changes.

Ask yourself:

- What is important to you? What matters most?
- What does 'quality of life' mean to you?
- What are your goals in the time you have left?
- Do you have any fears about end of life?

Some people might want to live as long as possible and do whatever it takes to make that happen, including tests and treatments that might have little chance of helping. Other people might want to focus on comfort and lessening suffering, only accepting medical care that gives them a certain quality of life.

Talk with us about your wishes. Based on your wishes, current health, and medical condition, your doctor or nurse practitioner will recommend and explain what treatments are available and most likely to help. Together, we agree on the medical approach that best reflects your wishes and medical condition. These become your goals of care.

If there is anyone you would like to include in this conversation, let us know.

We know your wishes and values might change over time or with changes in your health. We will check in with you regularly to make sure we continue to understand your wishes.

Medical Orders for Scope of Treatment (MOST)

After speaking with you, your doctor (or in some places, nurse practitioner) writes down your goals of care as a medical order. We call this ‘Medical Orders for Scope of Treatment’ or MOST. These instructions guide your healthcare team about the general focus of your care, and where you might want care.

We will always try to ask you at the time when a decision is needed about treatment. However, in an emergency or should you not be able to speak for yourself, the goals of care guide us in giving you care the best reflects your health condition, the treatments that will benefit you, and your own wishes and values.

Options for Treatment

We describe here different situations to help you understand the options for treatment. Think about which option best fits with your goals of care.

No matter what your goals of care are, we will always offer you:

- ✓ Medicines and other therapies to help control pain and other symptoms; and
- ✓ Activities to enrich and improve your quality of life.

Option One

Supportive care, symptom management, and comfort measures. Allow natural death.

In this situation, we would:

- Offer medicine and other therapies to control symptoms such as pain and shortness of breath.
- Continue to give medicine to manage chronic illness (Example: If you have diabetes, we would continue with medicine to control high blood sugar.)
- Focus on quality of life and easing symptoms.
- Only use therapies that will improve comfort or quality of life.
- Allow death to happen naturally and not try to resuscitate with CPR.

Example:

Mrs. Chan is 87 and has had dementia for years. She can no longer walk, feed, or dress herself. She does not recognize her relatives when they visit, and can say only a few words.

Lately, it has been hard for her to swallow her food and medicine which is a common problem in end stage dementia. She develops a lung infection (pneumonia) because of the swallowing problems. The doctor says that even with treatment, Mrs. Chan is likely to die from this infection because her dementia is so advanced.

Mrs. Chan’s family understands that treating her will not help her infection, and will be difficult for her. They stay with Mrs. Chan in her room and play her favorite music. The staff makes sure she is comfortable. She lives a few more days receiving comfort care in her room, surrounded by her family.

Option Two

Option One plus therapeutic measures and medications to manage acute conditions within the current setting.

In this situation, we would:

- Continue to offer medicines and other therapies to control symptoms such as pain and shortness of breath, as well as manage chronic illness.
- Give medicines and therapies easily available in the Long Term Care facility to try and fix the health problem.
- Only use therapies that will improve comfort or quality of life.

Example

Mrs. Forsyth is 72 years old with chronic heart disease for many years. She had a stroke 3 years ago.

Since moving into Long Term Care, she has enjoyed socializing with people there. Her friends still take her out to go shopping or for lunch.

Mrs. Forsyth has a son who visits her regularly. She has told him that she does not want to be kept alive if she has another stroke, or an illness that stops her from being able to speak or feed herself.

Mrs. Forsyth gets pneumonia. Her doctor treats her with antibiotics and she recovers after a few weeks.

Three months later, she has another stroke and cannot swallow properly, talk, or lift her arm. Mrs. Forsyth's son wondered about having a feeding tube put into her stomach. In talking with the care team, he finds out that a feeding tube might provide her with more nutrition, but might also cause her discomfort and could lead to infection. Her son knows it is important for her to be able to feed herself. He also knows that she did not want to be

kept alive if she had another stroke. He asks the doctor to do what he can to care for her in the residence.

With the help of rehabilitation therapists, Mrs. Forsyth learns to feed herself with her good hand.

Even though transfer to a hospital for treatment is not part of Option Two, there might be times where you can only be treated in the hospital. For example, if you fell and broke a hip we might feel it could be easily fixed with surgery and so we would offer this to you. If you agreed, we would treat the broken bone, control your pain, and help your recovery. However, if any of your other medical conditions got worse while in the hospital, we would use your goals of care and MOST to guide our treatment of these conditions.

Option Three

Option Two plus admission to an acute care hospital (if not already admitted) for medical/surgical treatment as indicated. No referral to Critical Care.

In this situation, we would:

- Continue to offer medicines and other therapies to control symptoms such as pain and shortness of breath, as well as manage chronic illness.
- Try to fix or control any health problems.
- Transfer to a hospital if the health problem gets worse or basic treatment at the hospital might help.
- Do tests and treatments including surgery.
- If not getting better, allow death to happen naturally and not try to resuscitate with CPR or do any life-sustaining treatments.

Example

Mrs. Jones is 84. She has chronic heart and lung disease. She enjoys caring for the birds at the residence, and going out with family and friends.

She hopes to live long enough to see her first great grandchild, who is expected to be born in 6 months.

Mrs. Jones' heart and lung disease is quite severe and she might not live much longer, but her doctor knows about her wish to see her first great grandchild. Her doctor suggests that if she gets sick with pneumonia or if her heart failure gets worse, she should go to the hospital to get help to control her condition.

Mrs. Jones agrees with this because it will hopefully help her reach her goal of seeing her first grandchild.

Option Four

Maximum therapeutic effort as in Option Three including referral to Critical Care but not including intubation and ventilation.

In this situation, we would:

- Continue to offer medicines and other therapies to control symptoms such as pain and shortness of breath, as well as manage chronic illness.
- Try to fix or control any health problems.
- Transfer to a hospital if the health problem gets worse or special treatment at the hospital is likely to be successful, such as in an Intensive Care Unit.
- Do tests and treatments including surgery.
- Allow death to happen naturally if health worsens or recovery is not likely. We would not try to resuscitate with CPR or do any life-sustaining treatments such as inserting a breathing tube or placing on a breathing machine.

Example

Ms. Porter is a 56 year old with Multiple Sclerosis (MS). Apart from this health condition, she is in good health. She uses her electric wheelchair to go out with friends.

Her doctor tells her that she has a good chance of recovery from illnesses or injuries. However, if she became extremely ill, her MS could worsen. Ms. Porter wants to live as long as possible. However, she does not want to be kept alive if it means she will be bedridden and no longer able to eat, swallow, or communicate.

Option Five

Maximum therapeutic effort as in Option Four including referral to Critical Care and including intubation and ventilation.

In this situation, we would:

- Continue to treat symptoms and try to fix or control any health problems.
- Transfer to a hospital when special treatment is needed, including transfer to the Intensive Care Unit.
- Do whatever tests and treatments are needed to aid in recovery, including life-sustaining treatments such as inserting a breathing tube or placing on a breathing machine.
- We would not try to resuscitate with CPR, and would allow death to happen naturally if your heart stops.

Example

Mr. Black is a 42 year old man living with a head injury who experienced chest pain while working in the residence garden. Mr. Black went to the hospital via ambulance. He needed heart bypass surgery to reverse the cause of his chest pain.

Following the surgery Mr. Black went to the Intensive Care Unit where he needed close monitoring, treatment, as well as a mechanical breathing machine (ventilator) and an airway tube (intubation).

Before experiencing chest pain, Mr. Black had enjoyed a fairly busy and active life at the residence. He is expected to fully recover once his rehabilitation is completed.

Note: Options Four and Five are rare for people in Long Term Care. To learn more, talk to your doctor or nurse practitioner.

Issues to consider

These situations are only examples. Your goals of care and Medical Orders for Scope of Treatment guide your care, particularly if you have a sudden medical problem or your health gets worse. In any situation, there are exceptions. Every person and their health situation are unique.

There are only a few situations where CPR would be helpful. This is why it is not included in most of these options.

If you and your doctor agree that CPR is appropriate to your situation, your doctor will include it on your MOST form.

What is Cardiopulmonary Resuscitation (CPR)?

Cardiopulmonary Resuscitation (CPR) is an attempt to restart the heart when the heart stops beating. If the heart stops beating and is not restarted with CPR, the person will die within a couple of minutes.

CPR can include:

- Pressing on the chest to pump blood through the heart to the body (chest compressions); and
- Forcing air into the lungs, using a mask with a bag attached to it.

Doing CPR can result in broken ribs and possible damage organs such as the heart and lungs. Being without oxygen, even for a short time, can result in damage to the brain.

Does CPR work for everyone?

No. CPR can work for people who are fairly healthy and suffer an event that stops their heart, and someone closeby starts CPR right away. Situations could include a heart attack or a severe electrical shock.

When is CPR not effective?

Unlike what you see on television, CPR is not usually effective. In particular, CPR will rarely restart the heart of people whose medical condition has already caused damage to their heart, lungs, kidneys, or brain. Even if CPR restarts the heart, it will not improve the medical condition that caused the heart to stop. It will likely result in damage to the brain and body functions.

When will we do CPR?

We will only try to revive you with CPR if all of the following occur:

- ✓ Your doctor or nurse practitioner has already concluded CPR might be effective for you; and
- ✓ You decide you want us to try CPR even knowing the risks; and
- ✓ A care provider is with you at the time your heart stops (such as we see you collapse).

We will call '911'. While we are waiting for the ambulance, we will start chest compressions and try to force air into your lungs.

When the ambulance arrives, the paramedics will try to restart your heart with an electrical shock and medications.

When will we not try CPR?

We will not start CPR if a care provider did not see you collapse and you are not breathing and we cannot find a pulse when we find you. In this case, we do not know how long ago the death occurred. The longer the heart has been stopped, the less likely CPR would be successful.

We are here to help

We hope this guide helps you understand the decisions you may face about your health and care.

If at any time you have questions or would like to talk more about this subject, please let us know. A nurse, doctor, social worker, or spiritual care practitioner can speak with you and your family. Our Ethics Committee can also help. Please ask the residence manager, or director of care, for the contact information.

Remember: We can review with you your goals of care and Medical Orders for Scope of Treatment any time you wish. It is a good idea to do this when there is a change in your health.

When you are the Substitute Decision Maker

If a resident is no longer able to make decisions about their own treatment, someone who knows the resident well will be asked to make decisions for the resident. This could be a family member or someone else who is legally appointed as the resident's substitute decision maker.

If you are this person, you would work with the healthcare team to identify what the resident would have preferred if they were still able to decide for themselves. You would not make decisions based on what you would prefer for yourself or what you think is best for the resident.

Most of us find it hard to decide what another person would have preferred. Ask yourself "If this person could speak for themselves right now, what would they decide?"

Other questions that might help guide you:

- Has the resident talked or written about their beliefs and values (such as in an advance care plan)? Have they said anything about how these beliefs or values might affect decisions about the care they would prefer to receive?
- Did the resident spend any time in the hospital? How did they feel about being there?

Comments made by the resident in the past can help guide you to:

- What is important to the resident
- Where and how the resident would wish to spend their time
- What their goals and hopes would be

The substitute decision maker is also often the person who:

- Acts as the main contact for the family.
- Speaks on behalf of the family to the healthcare team.
- Takes information back to the family about the resident.

What the Words Mean

Knowing what the following words mean can help you understand this booklet and words used by your healthcare providers. If you hear a word you don't know, ask us to explain it to you.

Healthcare Team: Includes any person who is licensed, registered, or certified in British Columbia to provide health services (for example: a doctor, nurse, social worker)

Cardiac Arrest: A situation where the heart suddenly stops beating. It results in death if the heart is not restarted within the first few minutes.

Cardiopulmonary Resuscitation (CPR):

A procedure that tries to keep the blood flowing to the organs when a person's heart stops beating.

Intensive Care Unit: An area in a hospital that offers specialized treatment to people who are very sick. Intensive Care benefits people with treatable life-threatening illness or who have had a serious accident.

Symptom Management: Therapies used to control symptoms caused by a health condition. Common symptoms include pain, shortness of breath, swollen legs, nausea, constipation, tiredness (fatigue), poor sleep, poor appetite, anxiety, and depression.

