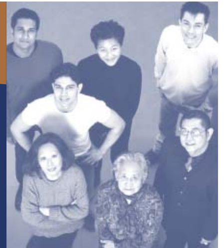
Making Decisions About Life and Care: A Guide for Families*



This booklet is a guide to help you and your family make decisions about your care, including CPR.

www.providencehealthcare.org

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***This booklet is also available in other languages**

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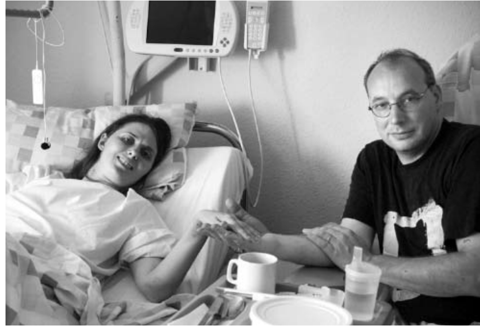
Our Beliefs



This hospital is part of the Providence Health Care organization. We are a Catholic health-care community and we respect the dignity of every person in our care

- We believe that every person is responsible for making decisions about his or her own life, health and care if they can.
- We believe that every person is unique and cannot be replaced. People deserve care that tries to protect every part of their life – physical, emotional, social and spiritual.
- We know that sickness, suffering and dying are an inevitable part of our experience as human beings. We believe that everyone should be given treatment that will give the best quality of life possible.

We hope this guide helps you to make decisions about the care you would wish to receive – or the care you think your loved one would wish to receive. We have also included a glossary in the back to help explain some of the words you may hear or read in this book. If you have more questions, please ask us.

Making Choices about Health Care

Different people, different choices for care.

We all have our own wishes or expectations about the care we want or hope to receive. For example, some of us may want to live as long as possible so we can spend as much time as possible with family - whatever that takes. Others might wish to spend as much time as they can with family only if they stay out of hospital, have as few tests and take as few medications as possible.

Tell us what care you or your loved one wants.

Knowing what you want helps us to provide care that respects what you want. We will keep talking with you about your wishes to make sure we understand them

Remember you are not alone!

These are difficult decisions and no one expects you to make them on your own. Talk to us about your concerns. We will give information and help you in any way possible to make these decisions.

Sometimes you might want to have someone else take part in making decisions with you. It could be a friend or family member who can support and help you. If there is someone you want to include in discussions, please let us know.

Making Choices about Life and Care for Someone Else

If a person is no longer able to make decisions about what treatments they want, someone else will have to make these choices for them. This could be a family member or someone who is their representative. This family member or representative tries to decide what their loved one would choose for himself or herself if they could –they do not choose what they would want for themselves or what they think is best for the resident.

We call this person a 'substitute decision maker'.

Figuring out what someone else would is never easy. Here are some questions that may help:

- Did your loved one spend any time in hospital? How did your loved one feel about being there?
- Has your loved one ever talked about their values and beliefs? Did your loved one say anything about how these values or beliefs might affect their health care decisions?
- Did your loved one have friends or family in a nursing home or residence? What did your loved one say about it?

The comments your loved one made might help guide you in what is important to them, where they wish to spend their time and what kind of care they would like.

You are being asked to make two decisions

1. **Whether to attempt cardiopulmonary resuscitation 'CPR';** and
2. How you want us to treat your disease or illness while you are in hospital. These are called your 'Options for Care'.

Cardiopulmonary Resuscitation 'CPR'

What is CPR?

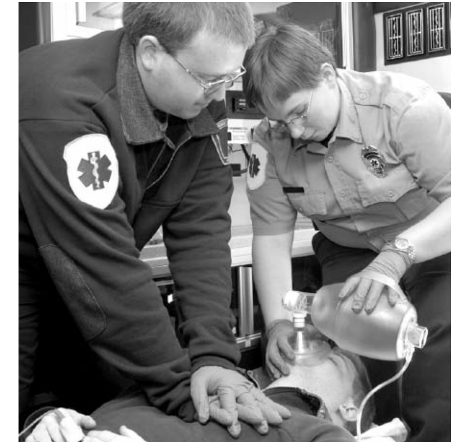
Cardiopulmonary Resuscitation or 'CPR' means trying to restart the heart by pressing on the chest and forcing air into the lungs.

When is CPR effective?

If someone's heart's electrical system is faulty, CPR may restart his or her heart if it stops beating suddenly. This is especially true when the person has few other serious medical conditions.

When is CPR less effective?

If someone has cancer or a disease of the heart, lungs, kidney or brain, CPR will rarely bring them back to life. This is because the disease has damaged the heart or other parts of the body, such as their brain, kidneys, lungs or liver.



What if I don't want CPR?

If someone asks us not to attempt CPR, we will do everything we can to help the person live as well as possible for as long as possible. Deciding not to have CPR does not mean a person will have no medical care. It means when a person dies naturally, we will not try to restart the person's heart.

You will hear the term 'DNAR'. This stands for 'Do Not Attempt Resuscitation.' It means we will not attempt CPR.

What if I want CPR?

If someone asks us to attempt CPR, and their heart stops beating, we will start chest compressions and try to force air into the lungs. We will call a 'Code Blue.'

During a Code Blue, a team of doctors, nurses and respiratory therapists try to restart the heart and possibly take the patient to the Intensive Care Unit for more treatment.

Options for Care

We will always try to ask you about your choices for care. We have found that it is also helpful if we know in advance what your choices would be, that way if you become too sick to make decisions we know what you would have wanted. You can change your mind at any time; and we will continue to discuss options with you as your condition changes.

We invite you to tell us in advance which Option for Care you prefer.

There are four possible options. They are:

Option for Care One

We give medicine and other treatments to control symptoms such as pain, nausea, fever or confusion. We continue to give medicines to control long-term illnesses (for example if you are diabetic we will continue to check your blood sugar and give you medicine to control it). We do not give you tests, medicine or other therapies that attempt to cure the disease. You will continue to receive nursing and medical care.

Here are two examples of people who might choose this option:

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 to get Mrs. Chan to take her regular medicines. Mrs. Chan develops pneumonia "a lung infection", and is admitted to hospital. 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 decides that treating her would not cure her infection and would be hard on her, which is not what she would have wanted. Instead they stay with her and play her favourite music while the staff makes sure that she does not have trouble breathing and is comfortable. After a couple of days she dies comfortably in her room, surrounded by her family.

Mr. Wilde is 34 years old. He was diagnosed with cancer 4 years ago. After many cycles of chemotherapy the cancer is no longer responding to the treatment. He has also had many infections. He often feels tired and weak. He has decided that he does not want to have any more chemotherapy. The doctors and nurses have reassured him that he will still get all the medicine and care he needs to treat his symptoms and control his pain. His family is sad but agree that the treatment is not working and is hard on him. Over the next few weeks he visits family and friends and spends time reading his favourite books. One night he passes away peacefully in his sleep.

Option for Care Two

This option is for those who live in residential care and would benefit from care in the hospital. It gives residents the choice to be transferred to the hospital from their nursing home or residence if they get sick and they could improve with treatment in a hospital. However, this would not involve treatment in the ICU because it is unlikely to be helpful.

Here is an example of someone who might choose this option:

Mr. Kong is 76 years old. He had a stroke on his right side and recently moved into a care home because he is no longer able to live on his own. He is able to say some words and understands everything that is said to him. He is often out with friends and family and enjoys all the activities in his new home. The doctor tells him that apart from the stroke he is in good shape and getting treatment in a hospital would help if he needed it. Mr. Kong agrees that it is worth going to hospital if he gets a new illness that can be treated in the hospital.

Option for Care Three

We give medicine and other treatments to control symptoms such as pain, nausea, fever or confusion. We also give medicine and treatment to try to control or reverse diseases. However, this would not involve treatment in the Intensive Care Unit (ICU) because it is unlikely to be helpful.

Here is an example of someone who might choose this option:

Mr. Singh is a 75 year old man with kidney failure and diabetes. He has gone to the hospital three times a week for dialysis for 6 years. He was active all his life but his health has steadily been declining in the last few years. He has been in and out of the hospital and the Intensive Care Unit numerous times in the last year because of infections and surgeries. Over the last few weeks his breathing has become even harder than usual and he was admitted to hospital again.

In the last year Mr. Singh and his family have found that it is harder and harder for him to recover every time he is given strong treatments. They have many long talks with the doctors and nurses about his illness. They learn that Mr. Singh's illness will continue to get worse over time and he will likely need to be admitted to hospital for other complications of his disease. For now there are still things the doctors can do to help. However it is time to think of what to do in the future.

Mr. Singh and his family decide that his doctors should continue to manage his kidney failure and his symptoms. He will continue to go to dialysis because it is working for now and he is still able to enjoy many of his favourite activities and spend time with his family. However, they decide that when his condition gets worse he will not have treatments in the Intensive Care Unit because it is unlikely to help. For now, the doctors continue to adjust Mr. Singh's medicine and dialysis to control his illness so that he can go home.

Option for Care Four

We give medicine and other treatments to try to control or reverse your illness. If you get very sick, we may offer treatment in an Intensive Care Unit (ICU) if it is likely to help. One example of treatment in the ICU is using a ventilator to breathe for you while the illness is being treated.

Here is an example of someone who might choose this option:

Ms. Porter is 56 years old. She lives in a residential care home and has Multiple Sclerosis. Apart from her Multiple Sclerosis, Ms. Porter is in good health. She often goes out with friends for events and is taking a course at the local community centre.

Ms. Porter's doctor tells her that in general people with Multiple Sclerosis can live as long as people without the disease. If Ms. Porter were to become very ill or have an accident, she could be offered treatment in the Intensive Care Unit if it could help her to recover.

Remember the Options for Care are a Guide

It is important to remember that the Option for Care you choose for yourself is only a guide. For example, if you choose Option One or Two but then fall and break your hip, we may still want to offer you surgery. This would fix the broken bone and control the pain. If your other medical illnesses get worse while you are in hospital, your preferred Option for Care will still be used to help decide how to treat those other illnesses.

Conclusion

We hope that this guide helps you in deciding about CPR and choosing an Option for Care. If you have further questions please let the staff know. A nurse, pastoral care worker, social worker or doctor will talk with you more.

Please also remember that these decisions can be reviewed any time you wish. If there is a change in your medical condition, it may be also be a good idea to review the Options for Care. Even if there are no major changes these options will be reviewed at regular intervals. This helps us keep in touch with you and your choices for life and care.

Terms to Know (Glossary)

Knowing what these terms mean will help you understand this guide and talk to us.

Cardiac Arrest is an emergency situation where the heart stops beating unexpectedly.

Cardiopulmonary Resuscitation (CPR) is a procedure to continue blood flow to the organs when a person's heart stops beating. It involves pushing on the chest and forcing air into the lungs. This is basic CPR. Often medicines and electric shock are needed to restart the heart and the person may need more treatment in the intensive care unit. This is advanced CPR. CPR does not work in all situations.

Chronic Disease Maintenance is a term you may hear. It is treatment used to control long standing diseases. Examples of these treatments include puffers, oxygen, dialysis and medicines like insulin or heart medicines. The goal is to control the symptoms of the disease, not to cure it.

Code Blue is an alarm signal to staff in the area and in the Intensive Care Unit that there is an emergency life-threatening situation. Doctors, respiratory therapists and nurses from the ICU will come to assist the staff on the unit to restart the person's heart. Often medicines and electric shock are needed to restart the heart and the person may need more treatment in the intensive care unit (like a ventilator).

Critical Care areas in a hospital that can give very specialized and advanced care to people who are very ill. These include the Intensive Care Unit (ICU), the Coronary Care Unit (CCU) and the Cardiac Surgery Intensive Care Unit (CSICU).

Disease Management is another term you may hear. It is the plan of treatment given to control or cure an illness or disease. Examples include antibiotics for infections or surgery for a broken hip.

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

Intensive Care Unit This is the area in an acute care hospital that can give specialized treatment to patients who are very ill from a potentially treatable disease.

Options for Care are choices for health care treatments a person may choose with the help of their care provider in the hopes of meeting some goal. Goals could include a peaceful death, rehabilitation or cure. Options for care are chosen with the help of a health care provider.

Symptom Management are treatments are used to control symptoms that are caused by diseases. Examples of symptoms are pain, shortness of breath, nausea, anxiety, fatigue, poor sleep, poor appetite, constipation, low mood, swollen legs and many more.