

Palliative/ End of Life Care

Information Guide for
Patients, Families and
Caregivers

WHAT IS PALLIATIVE CARE?

Palliative Care is special care given to a person whose disease cannot be cured. Palliative Care provides comfort and support to the person, the family, and the caregivers. Palliative Care is aimed at relieving suffering and improving the quality of life of people living with, or dying from, advanced illness or are bereaved. (Canadian Hospice Palliative Care Association).

Palliative Care does not hurry nor delay death. Its goals are to ease pain and other symptoms (such as depression, upset stomach, shortness of breath, etc.), to help the person have a clear mind and to support the person, family and friends, and the entire care team.

For more information about Palliative Care:

[http://www.virtualhospice.ca/en_US/
Main+Site+Navigation/Home/Topics/Topics/
What+Is+Palliative+Care_.aspx](http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/What+Is+Palliative+Care_.aspx)



Central
Health

gml photos

WHERE IS PALLIATIVE CARE RECEIVED?

Palliative Care can be offered in the home, in hospital, in long term care homes, or in other facilities. Being at home helps the person live as normally as possible and remain involved with their families for as long as possible. Some people feel being at home gives them more freedom to make choices about their care.

If you or your loved one do not wish to stay home to receive Palliative Care, you can speak to your healthcare provider about planning where you or your loved one will receive Palliative Care.



SYMPTOM MANAGEMENT AND SORTING OUT HEALTH CONCERNS

A symptom is a physical indication of a disease or illness that you experience. Pain, nausea, and tiredness are all symptoms. There are many different symptoms that you could experience.

Symptoms may not be the same from person to person, they may differ from one person to another regardless of their illness or cause.

Talk to your healthcare professional about any symptoms that you are experiencing, and if any of your symptoms get worse or if they improve. This may affect your medications or other therapies.

Sometimes a symptom diary can be used to record any symptoms you have had. This could include when they occurred and what was done.

Your health care provider can help you record and report your symptoms to health professionals.

SOCIAL, PSYCHOLOGICAL, EMOTIONAL AND SPIRITUAL SUPPORT

People have needs besides pain and symptom management. Palliative Care aims to provide support to the whole person: socially, psychologically, emotionally and spiritually.

Attending Emotional Health Issues

The Canadian Virtual Hospice website hosts a broad range of topics that support emotional health, including grief, guilt, anger, forgiveness, hope, denial and anxiety, as well as many others.

Considering Spiritual Health Issues

A life-threatening illness can raise questions of meaning and purpose, and cause spiritual distress. Even when one holds no religious beliefs, there may be a need to deal with issues of a spiritual nature. During this time people often raise questions about the meaning of life, life in general and the person's life. Spiritual supports can be made available to you through your local clergy members. If you are experiencing Palliative Care in the hospital or long-term care setting, please speak to a member of your care team about accessing spiritual care.

CAREGIVING SUPPORTS

Caregiving can be both a rewarding and challenging experience. When caregiving goes on for a long period of time, or when there are specific challenges in providing care, a caregiver may feel taxed and stressed. Feeling frustrated and upset is normal, but can have serious consequences for both the caregiver, the person they are caring for and other family members. It is an important sign that it is time to seek help. Learning new strategies in caring for the person and caring for yourself is a useful approach to coping with stress. Palliative Care services that help families and caregivers cope include:

- advice and assistance from health care providers who are skilled in providing Palliative Care, such as nurses, physicians and social workers.
- instruction on how to care for the person, such as how to give medication, how to prevent skin problems, how to recognize when the person is close to death, and what to do at that time.
- home support services that provide assistance with household tasks such as self-care and meal preparation.

MAKING YOUR WISHES KNOWN

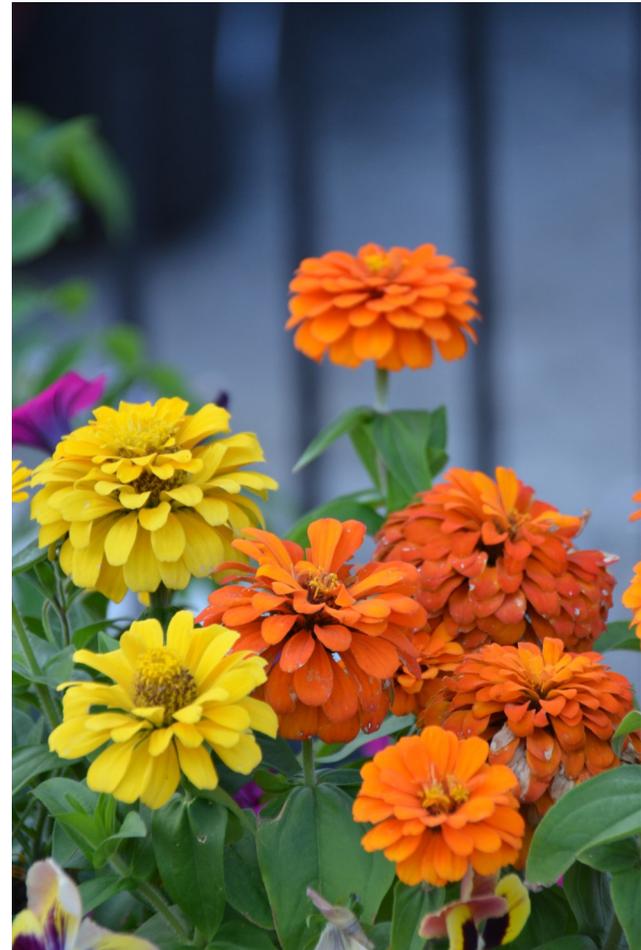
You should talk over your wishes with your family and let them know what you want. You should also put your wishes in writing so when the time comes that you are unable to say what you want, your family and health care providers will know. This is referred to as Advance Health Care Planning.

Advance Health Care Planning is planning for future health care while one is still able to make their own health care decisions. It can be hard to think and talk about the end of one's life but it's best to do these things before a crisis occurs. Talk with loved ones and health professionals about the kinds of health and personal care you would want in the future if you were unable to speak for yourself, including conversations to continue or abandon life-support measures.

Don't assume that family and the healthcare provider know what is wanted. You can seek advice about advance health care planning from your local healthcare provider, which includes your family healthcare provider, community nurse and social worker.

A booklet is available from the Department of Health and Community Service: *'How to make an Advanced Health Care Directive booklet (Newfoundland & Labrador)'*.

More information regarding Advanced Health Care Planning is available online at: <http://www.advancecareplanning.ca/>



BEREAVEMENT SUPPORT

Bereavement support may begin before the death of the loved one. It may begin when the grieving process starts. It is an important part of Palliative Care.

Palliative Care services provide bereavement support for family members to work through their own emotions and grief regarding the life-threatening illness or death of their loved one.

If you or your loved one would like to access grief support, please speak to a member of your health care team. You can also access local mental health counselling services by calling: **1-844-353-3330** or visiting centralhealth.nl.ca/mental-health-and-addictions.



PALLIATIVE CARE SERVICES AVAILABLE IN YOUR COMMUNITY

The following resources may be helpful:

- your family doctor
- your nurse practitioner
- your community health care nurses
- your hospital/community social worker
- your spiritual counselor/clergy
- your provincial Palliative Care association
- your local Cancer Society or other organization concerned with specific diseases such as heart disease, Alzheimer Disease, kidney disease, and MS.



Other resources available to you are:

Canadian Virtual Hospice

<http://www.virtualhospice.ca>

Central Health

www.centralhealth.nl.ca

My Grief

<http://www.mygrief.ca/>

Canadian Hospice and Palliative Care

<http://www.chpca.net/>

Pallium Canada

<https://pallium.ca/>



For more information on the Regional Palliative and End of Life Care services offered in Central Health, contact one of the following:

Regional Palliative Care Consultants

c/o Community Health Building

36 Queensway, Grand Falls-Windsor, NL A2B 1J3

Tel: (709) 489-4703 Fax: (709) 489-8844

OR

c/o James Paton Memorial Regional Health Centre

125 Trans Canada Highway

Gander, NL A1V 1P7

Tel: (709) 571-3149

OR

c/o Lewisporte Community Health Centre

P.O. Box 1209, 394-412 Main Street

Lewisporte, NL A0G 3A0

Tel: (709) 572-9521 Fax: (709) 535-2912

Regional Grief and Bereavement Consultant

James Paton Memorial Regional Health Centre

125 Trans Canada Highway

Gander, NL A1V 1P7

Tel: (709) 235-1412

Regional Palliative Care Physician

Grand Falls-Windsor Community Health Centre

36 Queensway, Grand Falls-Windsor, NL A2B 1J3

(709) 292-3000

