Patient Information Series

Palliative Care for People with Respiratory Disease or Critical Illness

When you have a serious illness, you may suffer from physical discomfort, such as pain, difficulty breathing, nausea (stomach upset) or fatigue. You may also have feelings of psychological distress, such as anxiety or depression, or feelings of spiritual distress. Your health care providers may provide medical therapies to treat or manage your illness, for example, antibiotics to treat pneumonia. In addition, you may receive care that helps you feel more comfortable, but does not treat or cure your illness. This type of care is called palliative (PAL-lee-uh-tiv) care.





What is palliative care?

Palliative care originated in the 1960s as "endof-life care." End-of-life care was provided when there was little chance of curing the disease or restoring an adult (or child) back to "normal." The term palliative care has since evolved to describe the care not only to those who are terminally ill, but anyone with discomfort or distress. The World Health Organization (WHO) defines palliative care as an approach that improves the quality of life of patients and families facing life-threatening illness. Patients with lung problems may suffer from breathlessness and tiredness. Palliative care aims to prevent or relieve these symptoms. Ideally, both medical and palliative care should be offered to patients.

When should I receive palliative care?

You should be considered for palliative care at any time during a serious illness. While traditionally it was considered a treatment approach for only those with a life threatening illness such as lung cancer, it is now known that if you have a sudden, non-life threatening condition like pneumonia or a chronic illness

like chronic obstructive pulmonary disease (COPD), you may benefit from palliative care. You do not have to be hospitalized to receive palliative care. This can be provided in the hospital, clinic, nursing home, hospice, or at home.

Could I benefit from palliative care?

Persons of any age, from children to the elderly may benefit from palliative care. If a serious illness negatively affects your quality of life, you may receive palliative care. You may already be receiving palliative treatments. Some examples are:

Condition	Medical Treatment	Palliative Treatment
Lung cancer	chemotherapy or radiation therapy	Medicines to treat side effects from your medical treatment such as fatigue, nausea (stomach upset), poor appetite, or difficulty breathing.
Chronic Obstructive Lung Disease (COPD)	Oxygen and bronchodilators (inhalers)	Medicines and counseling to help reduce anxiety and shortness of breath. A fan blowing cool air to reduce shortness of breath.
Severe pneumonia	Intensive care and/or antibiotics	Medicines to reduce pain and anxiety or to help you sleep.

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At times, palliative care may be given to prevent discomfort caused by a medical treatment. For example, pain medicine given to children or adults before procedures or tests that are likely to hurt. Also, using both medicines and counseling may help if you are feeling depressed, sad, or anxious about your disease, the side effects of treatment, or the impact your illness is having on your family life. If you have feelings of spiritual distress, palliative care may be of help by addressing your spiritual needs.

How can I get palliative care?

Your health care provider can provide palliative care. If more intensive palliative care is needed, your health care provider may refer you to a Palliative Care Team. Your palliative care team may include your physician, a palliative care physician, a nurse, a social worker, a chaplain, and counselors and therapists (physical, occupational, respiratory, speech). For children, important members of the team may include teachers, the school nurse, and art or music therapists. If you are receiving care at home, a visiting nurse or hospice nurse may be able to make home visits and help coordinate care with others who provide you with support. Hospice care is a special type of support and care for patients who are dying from a condition that cannot be cured.

Palliative care for psychological and spiritual distress

Anxiety and depression are common when you or a member of your family have a chronic or serious illness. Palliative treatment can include not only medicines but also counseling and support. Palliative care can also provide support for spiritual distress and can identify spiritual care providers who may be able to help.

Advance Care Planning

Members of the palliative care team are available to discuss advance care planning with you. Advance care planning enables you to make decisions about and to find answers to important questions, such as: "Who do you want to make decisions on your behalf if you lose your full mental capacity to make them for yourself?" or "What are your most important goals and what aspects

of your quality of life are most important to you?"

The palliative care team can help you to prepare written advance directives, such as a durable power of attorney for medical decisions or a living will.

What is bereavement care?

Bereavement care is the support for your family and loved ones who are suffering before and after your death. Social workers, nurses and bereavement specialists can assist with the grieving process.

Source: ATS End-of-Life Care Task Force, "An Official American Thoracic Society Clinical Policy Statement: Palliative Care for Patients with Respiratory Diseases and Critical Illnesses" Am J Respir Crit Care Med Vol 177. pp 912-927, 2008.

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Additional Lung Health Information

American Thoracic Society

http://patients.thoracic.org/information-series/index.php

Center for Advanced Palliative Care www.capc.org

The National Hospice and Palliative Care Organization

http://www.nhpco.org/templates/1/homepage.cfm

Hospital and Palliative Nurses Association

http://www.hpna.org/DisplayPage. aspx?Title=Patient/Family%20Teaching%20Sheets

R What To Do

- ✔ Palliative care should be offered to anyone who has a severe or life-limiting illness.
- If you have a chronic disease that causes distress and/ or pain, you should ask your health care provider about palliative care to help you have a better quality of life.
- Palliative care can also help your family and loved ones who share in your care.

Doctor's Office Telephone:

The ATS Patient Information Series is a public service of the American Thoracic Society and its journal, the AJRCCM. The information appearing in this series is for educational purposes only and should not be used as a substitute for the medical advice one one's personal health care provider. For further information about this series, contact J.Corn at jcorn@thoracic.org.