

UNDERSTANDING SERIES

LOSS OF MUSCLE & WEIGHT

FROM LUNG CANCER



LUNG CANCER ALLIANCE

1-800-298-2436

LungCancerAlliance.org

A GUIDE FOR THE PATIENT

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WHAT IS CACHEXIA?

If you have lost weight and/or muscle, you may have been told that you are at risk for or have developed cachexia.

Pronunciation: **kə' kek sēə**

Cachexia is uncontrolled and unwanted loss of weight and muscle. It is seen in some serious illnesses, including lung cancer. Over half the people diagnosed with advanced lung cancer also have cachexia.

IMPACTS

- ▶ How well you handle side effects of chemotherapy and other treatments
- ▶ Whether you can complete your cancer treatment or not
- ▶ How you feel, your overall well-being
- ▶ Your ability to stay independent and to do the things that are important to you
- ▶ How long you may live

WEIGHT LOSS

Three things make up your total body weight:

- ▶ *Body Fat*: What people usually lose when they diet
- ▶ *Lean Body Mass*: What the rest of your body (muscle, fluids, organs and other tissues) weighs, except the bones
- ▶ *Bone Mass*: What your bones weigh

In cachexia, lean body mass is lost even if the amount of body fat decreases or stays the same. This means it is possible to be overweight and still have cachexia. The loss of lean body mass causes some symptoms of cachexia like weakness and tiredness not relieved by extra sleep or rest (fatigue). Although good nutrition is very important, the symptoms of cachexia cannot be reversed by just eating more or healthier.

CAUSES

To understand cachexia, it is important to understand how the body works to break down food.

A healthy body uses many signals to break down food into energy to keep working normally. Cancer can disrupt these signals, causing problems that lead to loss of weight and muscle even with normal eating habits. Cancer can make the body unable to use all of the food for energy. It can also make the body burn more energy than normal, even at rest, which breaks down healthy tissue. Inflammation caused by the cancer can speed up this process and lead to cachexia. Cancer can also cause appetite changes, make food taste differently and reduce feelings of hunger even when the body needs food.

You may have cachexia if you are losing weight without trying. Your healthcare team can assess if you have cachexia or are at risk for developing it by asking about your appetite, eating habits and any digestive problems. They may also test your muscle strength.

Symptoms include:

- ▶ Weight loss
- ▶ Loss of muscle mass or strength
- ▶ Feeling tired even after enough sleep or rest (fatigue)
- ▶ Weakness
- ▶ Loss of appetite
- ▶ Changes in taste or smell
- ▶ Feeling full after eating small amounts of food
- ▶ Nausea
- ▶ Bloating

USEFUL TOOLS

Filling out the weight history and questionnaire on pages 10-12 can help you and your healthcare team know if you have or are at risk of developing cachexia.

Even if you have not been diagnosed with cachexia, your healthcare team may be concerned about loss of weight and muscle and work to try to avoid it. The proper treatment or prevention of cachexia will depend on your general health and other factors such as the kind and stage of lung cancer.

WHAT CAN I DO?

Here are some ways that cachexia and its symptoms are treated and may be prevented. One treatment may be used alone or several may be given at the same time (known as multi-modal treatment), which is usually more effective. Continuing your cancer treatment is important because cachexia tends to improve along with tumor response.

- ▶ Nutritional assessment or consultation by a registered dietician. Good nutrition alone may not reverse cachexia but is very important.
- ▶ Stay as physically active as possible. Finding a routine that works for you can help build muscle mass and improve your body's condition.
- ▶ Treat depression. Being depressed can affect the appetite and result in weight loss. Anti-depressants can help and may also ease anxiety and nausea around food.
- ▶ Control lung cancer symptoms and treatment side effects. Easing nausea, pain and constipation can make a big difference to overall health and well-being.

THE GOAL

The goal of preventing or treating cachexia is to reverse or stop the loss of muscle mass and weight if possible. The earlier this is done, the better. Preventing or treating cachexia may help you stay in cancer treatment, improve how you feel and help you to live longer.

CAREGIVERS & LOVED ONES

MEDICATION

No medication is currently approved to treat cachexia but the following may help. **Talk with your healthcare team before trying any medication or supplement on your own.**

- ▶ Appetite stimulants such as corticosteroids or progesterone drugs like megestrol can help you feel more like eating.
- ▶ Drugs that help your stomach empty properly, such as metoclopramide, may prevent you from feeling full too quickly.
- ▶ Omega-3-fatty acids (EPA, DHA) have been shown to help in a variety of ways in different studies.
- ▶ Supplements such as alpha-lipoic acid, N-acetylcysteine, and L-carnitine may have an antioxidant effect and reduce the stress on your body.
- ▶ Some steroids help slow down weight loss and improve your appetite.

NEW TREATMENT

New ways to treat cachexia are also being studied. While not yet approved, promising drugs include:

- ▶ Anamorelin, which targets ghrelin, a natural hormone that can stimulate hunger/appetite and increase body weight (primarily muscle mass and fat).
- ▶ Enobosarm, which mimics the muscle-building properties of steroids and testosterone to help build muscle mass.

It can be very stressful to see a loved one lose their appetite and lose weight when they have lung cancer. Caregivers may blame themselves for not providing the right food or encouraging the patient to eat enough; keep in mind that this is not your fault! Cachexia is complicated and is not fixed by nutrition alone. Remember you are part of a team, so be sure your loved one's healthcare team is aware of his/her symptoms and work with them to find ways to help.

DID YOU KNOW...

Some studies found that patients who aren't pressured to eat actually gain more weight.

YOUR TREATMENT

WHAT SHOULD I ASK?

- ▶ What can I do to improve my appetite?
- ▶ How can I ease nausea, fatigue and other symptoms?
- ▶ Which, if any, medications might help?

BOTTOM LINE

Cachexia can affect how you feel and whether or not you are able to stay in cancer treatment. Weight and muscle loss can be very distressing to people diagnosed with lung cancer and their loved ones.

It is important to recognize and treat cachexia as early as possible to reduce or delay its effects, so bring up any questions or concerns you have with your healthcare team. You can also call the Lung Cancer Alliance HelpLine at 1-800-298-2436 for more information on cachexia or anything having to do with lung cancer.

PREPARE

FOR YOUR NEXT VISIT

Completing this weight history form and questionnaire (pages 11-12) can help you and your treatment team decide what to do next.

YOUR WEIGHT HISTORY

My height is: _____

My current weight is: _____ pounds

One month ago, I weighed: _____ pounds

Six months ago, I weighed: _____ pounds

QUESTIONNAIRE

	<i>Not at all</i>	<i>A little bit</i>	<i>Somewhat</i>	<i>Quite a bit</i>	<i>Very much</i>
▶ I have a good appetite.	0	1	2	3	4
▶ The amount I eat is sufficient to meet my needs.	0	1	2	3	4
▶ I am worried about my weight.	0	1	2	3	4
▶ Most food tastes unpleasant to me.	0	1	2	3	4
▶ I am concerned about how thin I look.	0	1	2	3	4
▶ My interest in food drops as soon as I try to eat.	0	1	2	3	4

	<i>Not at all</i>	<i>A little bit</i>	<i>Somewhat</i>	<i>Quite a bit</i>	<i>Very much</i>
▶ I have difficulty eating rich or "heavy" foods.	0	1	2	3	4
▶ My family or friends are pressuring me to eat.	0	1	2	3	4
▶ I have been vomiting.	0	1	2	3	4
▶ When I eat, I seem to get full quickly.	0	1	2	3	4
▶ I have pain in my stomach area.	0	1	2	3	4
▶ My general health is improving.	0	1	2	3	4

*Part of the Functional Assessment of Anorexia/Cachexia Treatment (FACIT) questionnaire. FACIT and all related works are owned and copyrighted by, and the intellectual property of David Cella, Ph.D. Permission for use of the FACIT questionnaire is obtained by contacting Dr. Cella at information@facit.org.

WHERE CAN I GO FOR MORE INFORMATION?

For more information about lung cancer, treatments and clinical trials, to discuss support options or for referral to other resources, please contact us.

HELPLINE | 1-800-298-2436

**CLINICAL TRIAL
MATCHING SERVICE** | lungcanceralliance.org/clinicaltrials

WEBSITE | lungcanceralliance.org

E-MAIL | support@lungcanceralliance.org

MAIL | 1700 K Street, Suite 660, Washington, DC 20006

WHAT WE DO

- Offer personalized support, information and referral services at no cost through a team of trained, dedicated staff members to help patients, their loved ones and those at risk.
- Advocate for increased lung cancer research funding and equitable access, coverage and reimbursement for screening, treatment, diagnostics and testing.
- Conduct nationwide education campaigns about the disease, risk and early detection.



LUNG CANCER ALLIANCE

SAVING LIVES AND ADVANCING RESEARCH
BY EMPOWERING THOSE LIVING WITH AND
AT RISK FOR LUNG CANCER



LUNG CANCER ALLIANCE

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