



Frankly Speaking About Cancer: Cachexia

A Guide for Talking about Cachexia for Providers and Advocacy Organizations

Patient-Friendly Cachexia Terminology

The Cancer Support Community (CSC) is pleased to share our Cancer Cachexia Lexicon – a set of plain language terms and definitions that help explain cancer cachexia, including its symptoms and resources for support. These terms and their definitions were created to establish a set of patient-friendly terms that healthcare providers and advocacy organizations can use when engaging with patients about cachexia.

The Lexicon includes two primary documents 1) a Cancer Cachexia Engagement Tool for patients and caregivers; and 2) a “How to Talk About Cachexia” Guide that provides instructions for providers and advocacy organizations about how to use the Engagement Tool.

<i>How to use the Cancer Cachexia Engagement Tool:</i>	<i>How to use this guide:</i>
The Cancer Cachexia Engagement Tool is a two-sided document that provides a plain language definition of cachexia, its symptoms and how they differ from cancer and treatment. It also provides support resources. The Engagement Tool is designed for patients and caregivers to facilitate communication around cancer cachexia with healthcare providers. We hope that you will share the Engagement Tool widely and frequently with patients, caregivers, and colleagues. We hope that the Engagement Tool along with this companion resource will empower	This guide was designed for providers and advocacy organizations. The guide provides details about how the Engagement Tool was developed and how to use the Engagement Tool to talk about cachexia with patients and caregivers. This guide will summarize the latest research on cachexia, its symptoms, and challenges in diagnosing and treating cachexia. The guide concludes with a comprehensive glossary of terms defined using accessible and plain language standards.

patients and caregivers to ask necessary questions, encourage patient-provider communication, and lead to early diagnosis, symptom management, and the dissemination of patient-friendly, accessible language about cachexia.	
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Evidence-Based Design

The Cancer Cachexia Engagement Tool was developed through a mixed-methods study with patients and caregivers and reviewed by a multidisciplinary team of healthcare professionals, including endocrinologists, palliative care specialists, oncologists, advocacy partners, and a cancer cachexia caregiver on the Cancer Cachexia Advisory Board and the Cancer Cachexia Coalition. Data were collected through systematic review of scientific literature, testimony from patients, caregivers and professionals, interviews with key-opinion leaders, and two focus groups conducted with both patients and caregivers. The expert insights gleaned from this extensive data analysis informed the content, format, and structure of the Engagement Tool.

For example, the data collected from focus groups with patients and caregivers underscored the importance of using the term “cachexia.” Cachexia legitimized patients’ experiences with debilitating symptoms that were often misdiagnosed and provided them the tools to advocate for their care with providers. One survivor explained the importance of having a legitimate term to describe their experience:

“I think we’re probably...where we need to be...because there’s actually a definition [of cachexia on the Engagement Tool]. There’s a condition. There is a definition. It’s not just in somebody’s head.”

As a result, the Engagement Tool provides a plain language definition of cachexia and its pronunciation, so that patients and caregivers can communicate about the condition.

HAVE YOU HEARD ABOUT **CACHEXIA?**

[kuh-kek-see-uh]

The focus group data was used to inform a prototype of the lexicon that was evaluated via an interactive discussion board with patients and caregivers. Patients appreciated illustrations that demonstrated the symptoms and severity of cachexia. Illustrations also helped distinguish the condition from the side effects of cancer and its treatment.



Illustrations by Erin Lee Walsh

Finally, we evaluated the efficacy of the Engagement Tool in increasing knowledge and intended communication around cancer cachexia via an original survey with nearly 200 patients and caregivers. Survey participants reported significantly greater knowledge about cachexia and greater willingness to talk to their provider, family, and friends about the condition after reviewing the Engagement Tool. Findings underscore the utility and relevance of the Engagement Tool for cancer patients and their caregivers.

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1. Facts about Cancer Cachexia

- **Cachexia** can impact anyone with a chronic illness and is a distinct diagnosis separate from side effects of treatments.
- **Cancer cachexia** is defined as an involuntary loss of 5% or more of body weight over the last 6 months due to cancer that leads to progressive functional impairment and is often accompanied by other symptoms, including fatigue, muscle loss, inflammation, and reduced strength.ⁱ
- Cachexia is estimated to occur **in up to 80% of people with various types of advanced cancer**, depending on the cancer type and how well they respond to treatment. Cachexia directly causes up to 30% of cancer deaths, often due to heart or respiratory failure related to muscle loss.
- Cachexia is most common in people with **advanced gastrointestinal cancers**, such as **pancreatic, liver, and colorectal cancer**. It occurs in about half of people with **lung cancer**. It also frequently occurs in people with other types of cancer, including **head and neck** and **ovarian**.ⁱ
- Healthcare providers sometimes use the term “**wasting syndrome**,” or “**anorexia**,” to describe cachexia, but patients often react negatively to these terms. Providers may also use the terms “malnutrition,” or “sarcopenia” to refer to cachexia. (Terms are defined in the glossary below).
- Many cancer patients and caregivers have never heard of the term cachexia, even those who experience symptoms, such as significant weight loss, severe **muscle loss, severe fatigue**, and **loss of ability to carry out daily functions**.ⁱⁱ

2. Symptoms of Cachexia

(Symptoms are ranked in order based on participants' rating of most to least concerning)ⁱⁱ

1. **Unintentional weight loss**
2. **Muscle loss**
3. **Fatigue**
4. Decrease in **ability to carry out activities of daily life** (e.g., difficulty climbing stairs, opening containers, taking a shower).ⁱⁱⁱ
5. **Loss of appetite** and/or interest in food or eating.
6. An **inability to eat OR inability to gain weight** despite attempted remedies, such as supplemental nutrition.
7. **> 5% weight loss** in the previous 6 months OR **>2% weight loss with a body mass index (BMI) of < 20 kg/m²** or reduced muscle mass.^{iv, v}
8. **Loss of appetite** and/or interest in food or eating.
9. An **inability to eat OR inability to gain weight** despite attempted remedies, such as supplemental nutrition.

3. Challenges diagnosing and treating cachexia

- People diagnosed with cancer often assume they are going to lose weight once they start treatment.
- Many of those living with cancer may attribute muscle loss and weakness to decreased physical activityⁱⁱ or natural aging (sarcopenia) instead of cachexia.^{vi}
- Although the providers typically recommend “dietary counseling,”ⁱⁱ or increasing caloric intake, new research suggests that eating more calories and nutritional supplements may be insufficient.ⁱⁱ
- Cachexia can impose significant mental and emotional burdens on patients and caregivers. This distress is compounded by the uncertainty around treatment and improving symptoms.ⁱⁱ

4. Treatment approaches

- Although there are no known effective treatments for cachexia, researchers are studying new ways to manage the condition.ⁱ

- Patients can manage symptoms through physical rehabilitation or physical therapy. These activities can improve quality of life in people experiencing cachexia.ⁱ
- Research suggests that patients experiencing — or at risk for developing — cachexia should schedule a visit with a registered dietitian and follow their personalized advice. Survivors have identified strategies to increase their nutrient absorption, such as consuming nutrient dense liquids like broths or protein shakes, cutting out caffeine and alcohol, and increasing dietary fiber to support digestion.^{iv}

5. Who should someone experiencing cachexia speak to?

Someone experiencing symptoms of cachexia should speak to their oncology care team. It is important to monitor weight loss and muscle strength throughout treatment.ⁱⁱ Someone experiencing cachexia may be referred to one of the following healthcare professionals:

- **Dietitians** can recommend foods and meal plans and provide nutritional counseling. If people experiencing cachexia are having trouble digesting certain foods or experiencing malabsorption, dietitians can create a personalized list of foods and supplements to maximize nutrient absorption.
- **Endocrinologists** specialize in metabolic disorders and can help address common comorbidities such as low testosterone in men, uncontrolled diabetes, thyroid disease, and adrenal insufficiency.
- **Palliative care specialists** can improve quality of life by treating symptoms of muscle loss and nausea related to cachexia. Palliative care includes a range of support that can be utilized at any time following diagnosis.
- **Physical therapists** can help after surgeries and other treatments to address muscle loss. Although people undergoing cancer treatment often struggle with fatigue and decreased mobility, physical therapy can improve physical activity.^{vii}
- **Occupational therapists** can help people experiencing cachexia maintain and restore their ability to complete activities of daily living, such as hygiene routines and household chores.

6. Glossary

Activities of Daily Living (ADLs): The tasks of everyday life, including eating, dressing, getting out of a bed or chair, and using the toilet^{viii}.

Anemia: insufficient healthy red blood cells to carry oxygen to the body's organs, which results in symptoms of fatigue, weakness, and feeling cold.^{ix}

Anorexia: an abnormal loss of appetite for food. Anorexia can be caused by cancer, HIV/AIDS, mental illness (i.e., anorexia nervosa), or other diseases.^x

Cachexia: a complex syndrome associated with chronic illness marked by unintentional, progressive weight loss and a reduction of skeletal muscle mass with or without depletion of fatty tissue that leads to progressive functional impairment.^{xi}

Cancer Cachexia: an unintentional loss of body weight following a cancer diagnosis totaling >5% OR >2% with a body mass index (BMI) of < 20 kg/m² over the last 6 months that leads to progressive functional impairment. Cancer cachexia is often accompanied by other symptoms, including fatigue, muscle loss and reduced strength.^{xii}

Clinically Significant/Relevant Weight Loss: generally defined as loss of more than 5% of usual body weight over 6-12 months. This is based on specific factors to each person's body and should be discussed with medical professionals prior to action or diagnosis of cachexia.⁸

Dietitian: an individual with training and experience in nutrition who can apply and individualize that information to the dietary needs of the healthy and sick.^{xiii} Registered Dietitians (RDs) are experts on diet and nutrition. RDs who have the letters "CSO" after their names are "Board Certified Specialists in Oncology Nutrition." They have demonstrated experience and skills in developing healthy eating plans for cancer patients.

Eating Disorder: illnesses marked by severe disturbances in one's eating behaviors characterized by fixation or obsession with body weight or shape and control of food intake or exercise.^{xiv}

Endocrinologist: a doctor who specializes in the diagnosis and treatment of hormone-related diseases and metabolic conditions.^{xv}

Extreme fatigue: severe and abnormal tiredness or lack of energy resulting from mental or physical exertion or illness.^{xvi}

Fat tissue: also called “body fat,” includes connective and adipose tissues. It is an interactive organ in the endocrine system which stores energy and communicates through hormone signals to regulate metabolism.^{xvii}

Inflammation: a localized, protective, physical response against potentially harmful stimuli. Inflammation may result in swelling, redness, skin irritation, or other symptoms.^{xviii}

Involuntary progressive weight loss: loss of weight without dieting or increasing physical activity that continues to worsen over time.^{xix}

Malabsorption: marked by a group of symptoms such as gas, bloating, abdominal pain, and diarrhea resulting from the body’s inability to properly absorb nutrients.^{xx}

Metabolism: The process of getting energy from food and converting food into energy. Metabolism also helps get rid of toxic substances and waste.^{xxi}

Muscle atrophy: also known as muscle wasting, is the loss of muscle leading to shrinking, thinning, or weakening of muscles.^{xxii}

Muscle wasting: a weakening, shrinking, thinning, and loss of muscle caused by disease or lack of use. Muscle wasting decreases strength and the ability to move.^{xxiii}

Muscle weakness: loss of muscle strength or tone; inability to perform what you want to do with a muscle^{xxiv}

Palliative Care specialist: a healthcare professional who has special training in providing care to people who have a serious or life-threatening disease, such as cancer. They prevent or treat the symptoms of a disease, side effects caused by treatment, and psychological, social, and spiritual problems related to a disease or its treatment. The purpose of palliative care is to increase the quality of life. Specialists also provide caregiver support and coordinate communication between other members of the healthcare team.^{xxv}

Physical therapists/Physiotherapists: a healthcare provider trained to evaluate and treat people who have conditions or injuries that limit their ability to move and do physical activities.^{xxvi}

Progressive functional impairment: the gradual lessening of ability to carry out daily activities such as climbing stairs, opening a can, and taking a shower.^{xxvii}

Sarcopenia: a condition characterized by loss of muscle mass, strength, and function in older adults due to aging and unassociated with specific conditions or diseases.^{xxviii}

Skeletal muscle mass: makes up about 35-40% of total body mass and includes the muscles that connect to the bones, which allow people to perform a wide range of movements and functions. These are the muscles consciously or voluntarily controlled unlike cardiac (heart) or smooth (digestive) muscles.^{xxix}

Syndrome: a set of symptoms or conditions that occur together and suggest the presence of a certain disease or an increased chance of developing the disease.^{xxx}

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