



# Lack of Appetite and Loss of Weight

By: The Canadian Virtual Hospice Team

# What is loss of appetite and loss of weight?

When someone is living with a serious illness that can't be cured, they will typically experience an ongoing decline in strength and energy. There is almost always a time when their appetite decreases, and they continue to lose weight even if they're encouraged to eat.

### When this happens:

- \* Their body can no longer use the energy and nutrients from the food.
- \* They don't gain weight even when they try hard to eat more.
- \* They don't gain weight even if they receive liquid food through feeding tubes or intravenously.
- \* Providing food doesn't improve their energy, strength, or survival.

This can be seen in illnesses such as cancer, chronic lung or heart disease, and dementia.

### Loss of appetite (anorexia)

The term *anorexia* refers to a lack of appetite. The most common use of this word is in the eating disorder *anorexia nervosa*. This disorder is different from loss of appetite due to advanced illness, which is also called anorexia.

#### Anorexia and anorexia nervosa:

Anorexia and anorexia nervosa are different. Anorexia is a general term for loss of appetite due to illness. Anorexia nervosa is an eating disorder in which a loss of appetite is a key element.

# Involuntary loss of weight

The weight loss seen in advanced illness happens as the body becomes unable to process calories and nutrients. This is the case whether calories are taken in through eating or intravenous. Instead, the body uses its own energy by breaking down muscle and fat. The result is ongoing weight loss.

- \* The term for this loss of weight in advanced illness is cachexia (pronounced ka-KEK-see-ah).
- \* Someone who is ill doesn't lose weight just because they're not eating much.
- \* They can lose weight even if they're still eating.

# The anorexia/cachexia syndrome

This combination of lack of appetite (anorexia) and weight loss (cachexia) in advanced illness isn't well understood. They're often referred to together as the *anorexia/cachexia* syndrome.

# Causes of the anorexia/cachexia syndrome

There are many specific causes of anorexia and cachexia in advanced illness. They're part of the complicated ways serious illness affects the body.

In addition to the anorexia/cachexia syndrome, other things can affect appetite in advanced illness. These include:

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- Pain.
- Constipation or bowel obstruction.
- Anxiety.
- Depression.
- Medications.
- Medical treatments.

# Lack of appetite, weight loss, and emotions

This loss of appetite and weight loss can have an emotional impact on family and friends as well as on the person who is ill.

### Impact on family and friends

Family and friends often worry when someone they care about has no appetite and is losing weight. They may encourage the person to eat and drink more. This is an understandable and natural, instinct.

- Providing food is a basic act of care and nurturing. To do otherwise can feel very wrong and uncaring.
- \* It seems to make sense that the person would become stronger if they ate something.
- Enjoying food together with the people we care about can be an act of friendship and connection.
- It's a helpless feeling to watch someone become increasingly weak and thin, and to be unable to do anything about it.

# Impact on the person who is ill

While it may feel natural and caring to encourage someone to eat and drink, this request can be distressing for the person who is ill. They can feel blamed when they're told, "If you'd just eat, you'd get stronger and better."

Also, people in the advanced stages of illness tend to feel full more quickly than before. They might crave a certain food – then be full after only a bite or two. This response can be difficult for the person who has put time and care into preparing the food – and the person who is ill may feel they've let their caregiver down.

#### Common at end of life

It's important for all concerned to remember that toward the end of a serious illness, it's common for people to eat and drink less.

- They may not feel hungry or thirsty.
- Eating might make them feel uncomfortably full, bloated, or nauseated.

# Other ways to help

Family members can continue to offer care in other ways.

- \* To learn more, go to What you can do in this article.
- \* Your healthcare provider can also provide suggestions.

### Other reasons for loss of appetite

Loss of appetite may also happen if the person who is ill feels depressed, hopeless, or anxious. These issues can often be helped. It's important to talk honestly with the healthcare provider about these feelings. This will help them to know whether loss of appetite is related only to illness or if emotional concerns may be contributing.

To learn more, go to:

- "Decreased food and fluids" in When Death Is Near.
- Asked and Answered
  - How long can someone live without food and water?
  - I feel guilty not being able to get my father to eat. What should I do?
  - Is it painful when a person isn't eating or drinking anymore?
  - \* What can be done to improve someone's appetite?

# Assessing and diagnosing

To learn more about decreased appetite and weight loss, the healthcare provider will probably ask some questions, do a physical exam and may run some tests. This will help them decide how best to help.

#### TIP:

Keep track of your loss of appetite in a <u>daily symptom diary</u>. Sharing this with your healthcare provider will help them to help you.

## Questions

- How is your appetite?
- If you've lost your appetite, how serious is it?
  - Is it mild, moderate, or severe?
  - \* Rate it on a scale from 0 to 10. Zero means you have no loss of appetite and 10 means the worst possible loss of appetite.
- When did you start to lose your appetite?
- \* How long does it last?
  - Is your appetite always poor or does it come and go?
- What makes it better?
  - Certain types of food or drink?
  - \* Eating or drinking in a particular location?
  - \* Anything else?
- What makes it worse?
  - Certain types of food or drink?
  - \* Cooking odours?
  - · Anything else?
- Have you lost weight?
  - \* How much have you lost?
  - \* Over what period of time?
- Do you have nausea or vomiting as well as poor appetite?
- How have your bowels been working?
  - \* Are you constipated? Bloated? Have diarrhea?
- Do you have any pain or discomfort in your abdomen?
- \* Have you noticed a change in the foods you enjoy? Are your food favourites changing?
- \* Do you become full after just one or two bites? Even when you're eating a food you crave?
- How is your energy level?
  - \* Rate it on a scale from 0 to 10. Zero means you have no energy and 10 means very high energy.
- \* How active are you?
  - Active as always? Less active?
- Are you worried about not feeling hungry? (Sometimes family and friends are more concerned than the person who is ill.)

## Physical exam

Your healthcare provider may want to do a general exam, with particular focus on mouth, abdomen, and muscle mass. The exam may:

- Give some ideas about why you have lost your appetite.
- \* Help with decisions about tests and treatment.

#### Tests

Depending on your circumstances, your healthcare provider may discuss or recommend various tests including:

- Blood samples.
- Imaging such as X-rays or CT scans depending on your circumstances.

# Medications and other treatment

#### Considerations

The healthcare provider will consider a number of things when discussing and recommending medications and other treatment. Such as:

- Can the cause of loss of appetite be treated?
- Is loss of appetite and ongoing weight loss due to advanced illness?

**If the cause is a symptom**, such as constipation or nausea, this may be treatable and might improve with treatment specifically for that problem.

**If advanced illness is the cause**, a few medications can improve appetite. However, they provide limited improvement in weight gain, quality of life, or prolonging life.

Before trying such medications, it's important to talk with the healthcare providers about:

- \* The hopes for this medication.
- Whether these hopes seem achievable.
- Possible risks.

#### Medications

Treatment medications include:

- Corticosteroids such as dexamethasone.
  - \* These are used to improve appetite.
- Hormone-related drugs such as megestrol acetate.
  - \* These are used to improve appetite or weight gain.
- Marijuana and cannabis-related medications.
  - Before considering these medications for appetite, talk to your healthcare professional. They can provide information on the laws regarding medical marijuana, safety considerations, adverse effects, and drug interactions.

### Other treatment

#### Artificial nutrition for anorexia and cachexia

This may be considered if calories might still be effective, if the body can still use them, such as early on in illness, if a temporary problem can be fixed or is expected to resolve. For example:

- You might not be able to eat for a while after radiation for a tumour in the mouth or esophagus.
- \* You have a reversible blockage of the throat, esophagus, stomach, or intestines.
- \* You can't swallow safely because you're not alert, due to a temporary problem.
- Your digestive system can't absorb food because of a symptom such as severe diarrhea.

Artificial nutrition might also be considered to make someone stronger before <u>chemotherapy</u> or surgery. This can be done by:

- \* Tube (enteral) feeding.
- Intravenous feeding (through the vein, also called total parenteral nutrition or TPN).

These treatments have risks as well as benefits.

#### Tube (enteral) feeding

When someone isn't able to eat or drink fluids, calories and food nutrients can be given through feeding tubes instead. Tubes are placed into the stomach or intestine through:

- \* The nose, or
- The skin of the abdomen.

With tube feeding, there are several possible complications:

- If the stomach and intestines can't handle the amount, the liquid food may come up the esophagus and into the lungs (called aspiration). This may result in pneumonia.
- \* There may be skin breakdown and infections at the site of the tube insertion.
- \* Some people experience diarrhea.
- \* Someone who is confused and restless may pull the tube out.

# Intravenous (through the vein) feeding (TPN)

Fluids and nutrients may be given this way when the digestive system can't absorb food. However, in advanced illness when weight loss and weakness are due to the body's inability to use calories, TPN doesn't help. In general, TPN doesn't have a role in the palliative treatment of lack of appetite and weight loss caused by advanced illness.

#### Making decisions about tube feeding

### Issues to consider

Many issues must be considered before providing fluids and foods by feeding tube. When deciding whether to use this treatment, talk with the healthcare provider and carefully consider:

- \* The overall goals of treatment, such as:
  - Having more energy.
  - Becoming stronger.
  - · Living longer.
- If the goals are possible with this treatment.
- If the treatment can be given in the location where care is being provided.
- \* The potential risks of treatment.

#### The choice isn't always obvious

For example, the goals may be to:

- · Gain weight.
- Become stronger.
- Have more energy.
- · Live longer.

But the healthcare provider may advise that:

- None of these hoped-for outcomes can happen even with more calories.
- Some of these goals might be possible but the treatment is quite risky, or can't be provided in the place where the care is being provided

These decisions are best approached with as much information as possible and by having ongoing discussions with all involved.

### Complementary therapies

There are many complementary therapies that might help with any emotional distress caused by or causing loss of appetite.

- Acupuncture.
- Biofeedback.
- Breathing and relaxation exercises.
- Distraction.
- \* Energy therapies.
- Hypnosis.
- \* Massage.
- Mindfulness meditation.
- Music therapy.

# Before trying a complementary therapy:

- \* Talk with a healthcare provider first in case they have concerns about a certain therapy and the particular health circumstances. For example:
  - \* Some herbal remedies may affect how well prescribed medications work.
- \* Consider trying different approaches until a helpful one is found.
  - \* A therapy that works for one person might not work for another.

# What you can do

# When you are living with illness

Living with serious illness can be physically, mentally, spiritually and emotionally challenging. In this section, you'll find suggestions that might help you manage these stressful times.

# Talk with your healthcare provider

- \* Tell them what you're experiencing.
- Show them your daily symptom diary.

#### TIP:

Keep track of your symptoms in a <u>daily symptom diary</u>. Sharing this information with your healthcare provider can help them to help you.

#### Try to join your family at mealtimes

- Eating together can be an important time to socialize and connect with people you care
- Even if you have no appetite, you might still sit at the table and enjoy the company of family.

#### Find support

Many people find it helpful to connect with others when they're living with illness. These are some suggestions to consider.

- \* Talk with someone you trust, like a friend or family member. Sometimes just talking with someone can help you to feel better.
- \* Ask your healthcare provider to refer you to a counsellor such as a psychologist or social worker. They can offer:
  - Counselling and emotional support.
  - Education.
  - Practical suggestions to help you manage your symptoms.
- Talk with a spiritual care specialist.
- Find information online.
  - Canadian Virtual Hospice has information on many topics related to serious illness and palliative care.

- Join a support group.
  - If you can manage it, join a support group where you can meet people with the same illness and concerns.
- Join online discussion forums such as:
  - Canadian Virtual Hospice Discussion Forums.
  - Cancer Chat Canada.
- \* Learn more about Programs and Services in your area.

When someone you care about is living with illness

Family and friends often worry about weight loss and a decreased appetite when someone is living with a serious illness. It's natural to encourage them to eat and drink more, hoping this person will feel stronger and live longer. However:

- People with advanced illnesses tend not to feel hungry.
- Someone who doesn't feel hunger and has no desire to eat won't become more uncomfortable by having little or no food intake.
- Forcing a seriously ill person to eat can:
  - Make them nauseous.
  - \* Make them feel uncomfortably full even with small amounts.
  - Upset them if they feel they have to eat, in order to please others.

#### Consider:

The person who is ill is usually the best person to decide what, when, or whether to eat or drink at all.

# Feeding tips for caregivers

A caregiver is anyone caring for someone who is ill. They can be family, friends, neighbours, or coworkers as well as staff at a hospital or care facility.

If you're a caregiver, these are some ways to help someone who doesn't have much appetite.

- Offer several small meals during the day rather than three larger ones.
- Avoid spicy foods if they don't enjoy these anymore.
- \* Avoid cooking odours if these make them feel like throwing up.
  - This may mean cooking with the windows open, using fans to clear odours, or using the barbeque when practical.
- \* Don't be surprised if they crave certain foods one day and doesn't want them the next.
- Try not to get frustrated if they ask for a certain food then don't want it by the time the food arrives.
- Let them decide how much, what, and when they'll eat.
- \* Remember that someone with a serious illness can become full after just a few bites.
- Don't push someone who is ill to eat more. They might become uncomfortably full, feel nauseous, or vomit.
- nauseous, or vomit.

  \* Avoid causing tension at mealtimes because you're worried this person isn't eating enough.

  Just enjoy being together.
- \* Remember that if they reject food, they aren't rejecting you!
- \* Unless a health provider asks for updates, there's no need to keep track of weight.

#### Care for their dry mouth

Someone with no appetite might have an uncomfortably dry mouth. As this person becomes weaker, they may not be able to swallow liquids safely. You can help them with:

- Ice chips and if it's safe, hard candies to suck on.
- Good mouth care.

- Swap the mouth with water or sait water.
- Or spray a mist of water into the mouth.
- \* Over-the-counter mouth moisturizer products ask a pharmacist for suggestions.

Ask a healthcare provider if you're not sure how to safely care for a dry mouth.

To learn more, go to: Care of the Mouth

### Find support

Many people find it helpful to connect with others when they're dealing with illness. These are some suggestions to consider.

- Talk with someone you trust. Sometimes just talking with a friend or family member can help you to feel better.
- Ask the healthcare provider to refer you to a counsellor such as a psychologist or social worker. They can offer:
  - Counselling and emotional support.
  - Education.
  - Practical suggestions to help with stress.
- Talk with a spiritual care specialist.Ask about a support group for caregivers.
- \* Find information online.
  - Canadian Virtual Hospice has information on many topics related to serious illness and palliative care.
- Join online discussion forums such as:
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  - Cancer Chat Canada.
- \* Learn more about Programs and Services in your area.

# Try complementary therapies

\* Various therapies such as relaxation techniques, meditation and yoga can be helpful to manage stress.

#### Take time for yourself

- Choose an activity or something you enjoy. It might be reading, praying, listening to music, watching sports - or something else.
- Regular exercise is important to manage stress. What physical activities do you enjoy? Walking? Biking? Something else?

## Respecting choices

You might disagree with the choices someone makes about treatments and how they live with their illness. Perhaps you feel their choices are unsafe, might cause harm, or risk losing an opportunity to get better. This can be frustrating and upsetting. It's okay to tell this person, respectfully, how you feel about their choices and how they affect you - but remember, everyone has the right to make their own decisions.

If you're concerned this person is no longer able to make good choices, or their choices may be putting others at risk, speak to the healthcare provider.