

WEIGHT LOSS in ADVANCED DEMENTIA

Information for family members

There are many reasons why a person with advanced dementia might lose weight. This booklet discusses those reasons.

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Understanding weight loss in advanced dementia

Studies have shown that once dementia reaches its final stages, one in every two or three affected people will experience severe weight loss. Weight loss may occur despite the person with advanced dementia being given all the food they want. Weight loss may be part of the process of dying from dementia.

Watching someone with advanced dementia lose weight, despite being fed enough food, can be frightening. It is quite normal to feel this way.

Staff in this facility will talk to you about any weight loss issues your family member/friend is facing and support you as you make decisions relating to their care.

How do we monitor weight loss?

Staff monitor weight loss by regularly weighing every person with advanced dementia. If they are losing weight or having problems eating, staff monitor them every week while the problems persist.

Sometimes we stop weighing residents with advanced dementia, even though we know they are losing weight. Weighing will disturb them and our main goal is to keep them as comfortable as possible. We only stop weighing residents after the family members, general practitioner and facility staff have talked it over and all agree that it is no longer appropriate.

What changes in weight do we look out for?

We particularly watch out for anyone who has:

- a 5 per cent weight loss in one month. For example, a person who weighs 50kg and loses 2.5kg in one month will be monitored carefully;
- less appetite than usual. Everyone's appetite can change up or down. Starting a new medication or being ill can change your appetite for a short time. If a poor appetite continues, we need to consider the cause;
- a slow decrease in the amount of body fat, so they are underweight for their height, and
- unexpected weight loss for three consecutive months. Weight, like appetite, can change up and down without there being a problem. Unexpected weight loss that continues for three months needs to be investigated further.

Common reasons for weight loss

Not eating enough food

In this case, staff look at the food given to the person to see whether it needs to be changed. The person might not like the food or it could be the wrong consistency and they are having trouble swallowing it. They might need a larger serve. If necessary, we refer the person to a dietitian or speech pathologist.

The person might not be eating enough because they have got bad teeth, badly fitting dentures or mouth ulcers. They may need to see a dentist or have their daily mouth care changed so they are more comfortable.

We also consider how much help each person needs to eat a meal and, if necessary, give them more help.

Medical problems that cause weight loss

Some conditions can be managed so weight loss slows down or stops, such as:

- depression;
- constipation;
- pain;
- some medications;
- thyroid disease;
- chronic infections;
- special diets such as low cholesterol diets, and
- not drinking enough fluids.

Sometimes blood tests, X-rays or other medical tests are needed to confirm these conditions. Invasive tests, such as taking blood, may disturb a person with advanced dementia.

It is important to consider whether knowing the test result is more important than disturbing the person.

You may decide that you no longer want your loved one to have any more invasive tests, such as blood tests. Staff will support whatever decision you make. For many frail people with advanced dementia, this may be the most appropriate choice.

When weight loss continues

Weight loss may continue even though the common reasons for weight loss have been managed. The weight loss can be inevitable due to advanced disease called *cachexia* (*ka/kek/sia*).

Cachexia is a normal process caused by advanced diseases such as dementia, cancer, heart, liver, kidney and lung failure.

When people have cachexia, they can't absorb the nutrients from food, even when they are eating and drinking enough. They lose weight, have no appetite, and become tired and weak. The person's body slows down and prepares for death.

What can be done about continued weight loss?

When cachexia is present, the best choice is to carefully feed the person using food he/she likes and can swallow. This way the person can still enjoy the social contact that comes from being fed. Tastes and smells from favourite foods can stimulate the appetite. Family members and friends can help feed the person if they want to help.

A person with cachexia should never be forced to eat.

Artificial feeding

Sometimes feeding tubes are considered. These tubes are inserted directly into the stomach to artificially feed a person who has trouble eating or swallowing.

Feeding tubes stop the person from enjoying the social contact of being fed and the taste of foods they like. Feeding tubes are not normally recommended for people with advanced dementia.

Feeding tubes are uncomfortable and may cause infections or bleeding where they are inserted. Research shows that being fed through a feeding tube does not help a person live longer than if they were carefully fed their favourite foods.

If artificial feeding via a tube commences, it may need to be stopped as vomiting or breathlessness from having extra fluid in the body might make dying more uncomfortable.

The decision to stop tube feeding is sometimes harder to make than the decision to start it.

Making decisions is hard

Food is a very important part of our lives. We cook food for others to show our love for them. We eat special food at celebrations such as birthdays and weddings. We enjoy social contact as we share food.

Having to make decisions about feeding and weight loss is hard. When a person has advanced dementia and can't tell us what they want, it's even harder.

Think about what your family member/friend would want and base your decisions on that.

Talk to the nurses and other staff in this facility and the general practitioner, who all know your loved one well. They all want your loved one to be comfortable and honoured.

If you remain very worried, consider speaking to your spiritual advisor or a close friend about the issues to gain extra support.

