Adelaide HIIIs Community Health Service

Diet and nutrition in palliative care



A guide for clients and carers





Contents

| Introduction2 |
|----------------------------------------------------|
| Palliative care nutrition3-4 |
| Key issues in palliative care nutrition5 |
| Optimising nutrition |
| – Protein requirements6 |
| – Good ways to add extra energy to your meals6 |
| – Table 1 - Protein content of foods |
| – Diet quality (vitamins and minerals)9 |
| – Omega 3 fats (fish oils)10 |
| – Vegetarian diets10 |
| Nourishing drinks and nutritional supplements11 |
| Helpful hints |
| – Tips to encourage eating and improve nutrition12 |
| – Steps for planning meals13 |
| Sample meal plans14-15 |
| Dealing with common symptoms16-18 |
| Tube feeding and nutrition support 19 |

Introduction

This booklet provides ideas to help with nutrition and eating, for people with a life limiting illness.

In this booklet you will find practical ideas for coping with some common problems, plus ideas to help with meal planning.

The importance of good nutrition

Good nutrition that is right for your stage of life can help you:

- > Enjoy overall wellbeing and quality of life
- > Maintain a strong immune system and reduce the risk of infection
- > Cope with the demands of illness and treatment
- > Increase wound healing and tissue repair.

Palliative care nutrition

In palliative care, the main focus of nutrition is on reducing worry and improving quality of life.

Due to the huge demands of illness on the body, the recommendations for healthy eating might be different to those for a person who is well.

Healthy eating guidelines that are recommended for the general population are not appropriate when you are tired, not hungry and are eating less than usual.

Firstly, before dealing with nutrition concerns, it is important to:

- > Get help for any pain and other physical symptoms
- > Get help for any mental, social and spiritual problems.

These issues can often make it harder for you to eat well.

Changing needs

Thinking about nutrition should begin as early as possible to have the greatest benefit. You may need to change your plans for nourishing meals, drinks and snacks according to how you feel at different times.

Remember, the benefits of eating and drinking should always outweigh the risks and burdens to a person who is unwell.

An early focus on nutritional problems and needs can help to slow down weight loss and improve quality of life.



Self care for carers and family members

If you are caring for a loved one who is unwell, you also need to look after your own needs. How can you look after someone if you become unwell yourself? Take time to plan for your own needs so that problems are not just shifted from one person to another.

Long term roles may have changed and you may be doing caring tasks that make you feel uncomfortable or overwhelmed. If you are struggling with changed roles and routines speak to someone from your local palliative care service.

Other people may want to help but may be unsure how they can best help you. Accept any offers of help and make suggestions about what would be most useful.



Key issues in palliative care nutrition

Loss of appetite (Anorexia)

It is normal when you are unwell to not feel hungry, and it is very common towards the end of life. While providing good food can be an important way for others to show love and care, it is important that you do not feel that you must eat more to protect the feelings of those caring for you, especially if it makes you feel worse.

A loss of appetite can be caused by many things

For some people, loss of appetite is caused by anxiety or depression because of feelings about the illness. Taking medication for depression or anxiety may help improve appetite.

If you are anxious, then learning to relax may help. Try doing something that makes you feel good. You could get a massage, listen to music or try meditation.

Some medications used for pain can stop you feeling hungry. If you believe this is happening to you, speak to your doctor or someone from the palliative care service.

Appetite stimulants

If not feeling hungry worries you, talk to your doctor. There are some medications that can help you feel hungry, but they can cause other problems. Your doctor is the best person to talk to about whether they would be okay for you.

Sometimes it's hardest on a carer watching a loved one not eating enough. Try to remember, if you are caring for an unwell person, to put their needs first, even if they are different from your own.

Weight loss

Not feeling hungry and not eating very much isn't the only cause of weight loss. The body uses more energy than normal to deal with the disease as it gets worse and weight loss happens to most people as a disease progresses.

Stopping weight loss or gaining weight doesn't stop the disease from getting worse, but it can help with weakness and tiredness. Eating better can make you feel better and help you enjoy life more.

Managing symptoms

Whether you are caring for yourself or being cared for by others, getting help if you are in pain or have other problems can improve your nutritional intake. It is most often these problems that can decrease your quality of life.

If you have difficulty eating despite a good appetite, perhaps due to tiredness, a dry mouth or nausea, see pages 16-18 of this booklet. Here you will find some suggestions for dealing with some of these common issues.

Optimising nutrition

If you are struggling to eat and drink enough to maintain your weight, or if you are losing weight, it is important to make everything you eat and drink 'count'.

Try to have foods and drinks that are high in protein and calories (energy). Eat less foods and drinks that are low in protein and energy like fruits, vegetables, watery drinks like tea, coffee and clear soups.

Protein

Include foods high in protein at every meal and snack

Protein provides the building blocks for repairing damaged tissues, maintaining muscle and maintaining a healthy immune system.

Due to the increased demands of illness, protein needs are often increased. People who have lost weight or have lost muscle may need twice the amount needed for a person who is not sick.

The usual need for protein for a healthy adult is about 0.8 grams of protein per kilogram of body weight per day. This can increase to as much as 1.4 to 2.0 grams per kilogram for those suffering from advanced disease.

You can check the protein content of the foods you eat by using the protein lists on pages 7-8. Try to eat more of the foods higher in protein.

People with kidney disease should not increase their protein intake without consulting their doctor and seeing a dietitian.

Good ways to add energy (calories) to your meals

Add high fat ingredients to meals, drinks, desserts and snacks to boost energy without increasing the volume you have to eat.

Good things to add to savoury meals are cheese, oil, butter, margarine, cream, sour cream, avocado, ground seeds, toasted nuts or nut spreads, coconut cream/milk, evaporated milk, mayonnaise, full fat yoghurt and creamy dips.

Good things to add to sweet snacks and desserts are cream, sour cream, ice cream, condensed milk, full fat yoghurt, milk powder, butter, margarine, sugar, honey, caramel, icecream toppings and chocolate.



Table 1: Good food sources of protein

| Food | Quantity | Protein | |
|-----------------------------------------------------------|---------------|---------|--|
| Meat / Fish / Poultry | | | |
| Beef (lean, cooked) | 100g | 31g | |
| Beef mince cooked | 100g | 27g | |
| Chicken | 100g | 29g | |
| Fish | 100g | 25g | |
| Pork | 100g | 30g | |
| Lamb | 100g | 28g | |
| Tinned sardines in oil | ½ 95g tin | 10g | |
| Ham | 100g | 16g | |
| Egg | 1x 60g | 7.2g | |
| Tuna in oil | 85g | 15g | |
| Dairy product | S | | |
| Full cream milk | 250ml | 8g | |
| Skim milk | 250ml | 9g | |
| Soy milk full fat calcium fortified | 250ml | 10g | |
| Custard full fat | 200ml | 7g | |
| Full fat yoghurt – natural | 200g | 12g | |
| Cheddar cheese | 20g (1 slice) | 5g | |
| Ricotta cheese | 50g | 5g | |
| Cottage cheese | 50g | 7.5g | |
| Cream cheese | 1 tablespoon | 1.6g | |
| Icecream | 1 small scoop | 2g | |
| Whey powder (chemists / health food stores / supermarket) | 1 tablespoon | 6.5 | |
| Skim milk powder | 1 tablespoon | 2.3g | |
| Beans / Legumes and products | | | |
| Chickpeas, lentils | ½ cup | 8 – 9g | |
| Kidney beans, cannellini beans | ½ cup | 7.5g | |
| Baked beans | 200g | 10g | |
| Green peas | ½ cup | 4.3g | |

| Food | Quantity | Protein |
|--------------------------------------|---------------------------|----------|
| Nuts and | Seeds | |
| Almonds | 30g | 6g |
| Tahini | 1 tablespoon | 4g |
| Ground chia seeds | 1 tablespoon | 3g |
| Ground flax seeds | 1 tablespoon | 1.5g |
| Almond butter | 1 tablespoon | 2g |
| Peanut butter | 1 tablespoon | 4.6g |
| Grai | ns | |
| Weetbix | 2 | 4.8g |
| Porridge (oats) | ½ cup cooked | 4g |
| Wheat bread – white / wholemeal | 2 slices | 7g |
| Wheat pasta | 1 cup – cooked | 10g |
| Quinoa | 1 cup cooked | 8g |
| Couscous | ½ cup (cooked) | 5g |
| Otho | er | |
| Spirulina powder (health food store) | 1 tablespoon | 4g |
| Chocolate | 50g | 5.5g |
| Rice pudding | 200g (1 cup) | 7g |
| Nutritional supplement drinks – su | upermarket / chemist*, ch | nemist** |
| Sustagen Regular and Hospital* | 60g | 13 |
| Ensure powder** | 250ml | 9 |
| Proform powder** | 60g | 15 |

Diet quality and other health considerations

While making sure you include plenty of protein and high energy foods, try to also eat a variety of all food types. This will reduce the risk of vitamin and mineral deficiencies. This is particularly important for nerves and muscles which require key nutrients to work well.

Try to include foods from the 5 food groups every day:

- > Meat, chicken, fish, nuts and legumes
- Dairy foods like milk, yoghurt, cheese and custard, and alternatives such as soy products
- > Breads, cereals, whole grains, rice and pasta

> Vegetables

> Fruit

If you struggle to eat enough, it is okay to relax your diet and include more of those foods that you do enjoy. They may have been 'forbidden foods' while you were in good health, like creamy foods, fried foods and favourites from the bakery. Healthy eating when you are very ill means eating highly nourishing foods that are rich in energy.

If you have heart disease or diabetes, strict control of blood sugar and cholesterol levels may no longer be as important as maintaining your body weight. Speak to your doctor or a dietitian if you are unsure what dietary changes are important for you.



Omega 3 fats

Inflammation in the body is common in cancer and chronic diseases. The omega 3 fatty acids found in fish oils have been shown to slow down loss of muscle tissue, and the tiredness that goes with it.

Taking 1.4 to 2.0 grams per day of marine omega 3's (fish oils) can help. This is equivalent to:

- > 8 to 11 fish oil capsules
- > 2 teaspoons of liquid fish oil
- > Around 150 to 200 grams of oily fish such as sardines or salmon.
- Taking more than the recommended dose of fish oils does not have a greater effect and may be harmful. Consult your doctor before taking any new supplements.
- > Fish oils are not a significant source of mercury. Large predatory fish such as shark and swordfish are, so limit these to one serve a week maximum
- > Fish oil is safer than cod liver oil, because cod liver oil contains vitamin A, which is harmful in large amounts.

Vegetarian diets

For a number of different reasons many people choose to not eat animal foods. This may be something they have done for a long time or something that they choose to do once they become ill.

While there are many good things about a plant based diet, plant foods are often lower in protein and energy than animal foods. They may not provide the extra nourishment you need during illness, unless you are careful to ensure your needs are met.





Nourishing drinks and nutritional supplements

Many people can't eat enough to get the nutrition they need. Nourishing drinks can help ensure good nutrition.

Ideas for nourishing drinks

- Fortified milk. Add one cup of skim milk powder to 1 litre of full cream milk, or 1 cup of evaporated milk to 2 cups of regular milk for extra energy and protein. Store in the fridge and use in place of regular milk on cereal, and in place of water in coffee and chocolate drinks.
- Make milkshakes and smoothies with full cream milk and your choice of egg powder, skim milk powder, drinking chocolate powder, topping flavours, vanilla, icecream, yoghurt, fruit or coffee.
- > Fruit and vegetable juice. This provides energy but is low in protein, unless you add a few tablespoons of protein powder or spirulina powder (available from health food stores).

Nutritional Supplements

These are commercial drinks or powders that contain protein, energy and added vitamins and minerals. Your dietitian can advise you on suitable supplements, and how to get them.

Examples of common supplements include:

- > Powdered formulas such as Sustagen Hospital, Ensure Hospital or Proform. Try to make these up in milk, but use water if this makes you feel uncomfortable
- Ready to use tetra paks / bottles in fruity or milky flavours such as Sustagen, Resource, Fortisip, Fortijuce and Ensure Plus
- Energy or protein powders such as Polyjoule, Protifar and whey protein powder.



Helpful hints

Throughout the rest of this booklet you will find some useful and practical ideas for increasing appetite, adding energy and protein to your diet, planning meals and dealing with common problems and symptoms that impact on eating.

If you still don't feel confident about what you are doing, ask to be referred to a dietitian who can help you to find solutions. Ask your doctor or nurse to refer you to Meals on Wheels if you cannot manage meal preparation at all.

Tips to encourage eating and improve nutrition

- Have 6 to 8 small meals and snacks per day instead of a few main meals. Make sure that meals and snacks are easy to eat and drink.
- 'Make every mouthful count' by choosing high energy, high protein foods and drinks instead of low energy foods and fluids. See table 1 'Good food sources of protein' on page 6 and 'strategies for adding energy to foods and drinks' on page 11).



- Include nourishing fluids if food intake is poor. Drinks can be just as nutritious as food and are often easier for a tired person (see page 11 'Nourishing drinks').
- > Ask for help with eating and drinking if needed
- Eat when you are hungry, rather than waiting for normal meal times.
 However, if you have no appetite, schedule meals and snacks at set times.
- Take your medications on time so that symptoms such as pain or feeling sick are treated and don't stop you from eating.
- Eat meals somewhere that is comfortable. If possible, this should be away from the bedroom. Flowers, light, candles, nice dinnerware and a view onto a garden can make meals more pleasant.
- > Avoid cooking smells and serve foods cool or at room temperature if smells make you feel sick.
- Have a small glass of wine or sherry before a meal. This can stimulate appetite and raise mood. Check with your doctor first, in case there is a reason why you should avoid alcohol
- Serve soft, blended, pureed, mashed and moist foods such as soups, dips, fruit, creamy desserts and mashed vegetables with gravy or sauce for easy eating.

- > Try some of the wide range of frozen or fridge single serve meals and desserts in the supermarket.
- > Stock up on favourite high energy and high protein snack foods like yoghurt, custard, rice pudding, ice-cream, tinned soup, dips, cheese and biscuits, chocolate.

Steps for planning meals

- Plan meals to include a protein food, for example: eggs or baked beans at breakfast, tinned fish or cheese at lunch and meat or chicken at dinner time. Make sure they are soft enough for you to eat easily.
- 2. Add some carbohydrate food like pasta, bread, potato, sweet potato or rice.
- Add some brightly coloured vegetables or fruits (either cooked or raw and easy to eat).



Sample meal plans

| Sample Menu | Protein (g) | | |
|-------------------------------------------------------------------------------------|-------------|--|--|
| Breakfast | | | |
| ½ cup (75g) rolled oats made into porridge with honey | 9 | | |
| 250ml milk (full cream) | 8 | | |
| 1 banana | 1 | | |
| Mid morning | | | |
| 200g full fat yoghurt with honey | 9 | | |
| Lunch | | | |
| 250ml bowl of meat and vegetable soup or stew containing 50g of cooked beef or lamb | 19 | | |
| Slice of wholemeal bread or roll with margarine | 3 | | |
| Afternoon | | | |
| 40g cheese and biscuits and glass of lemonade | 10 | | |
| Dinner | | | |
| 100g fish pan fried in oil or butter (cooked weight) | 25 | | |
| Mashed potato ½ cup with 1 tablespoon sour cream | 2.5 | | |
| ½ cup cooked vegetables | 2 | | |
| Supper | | | |
| 250ml milk and Milo | 10 | | |
| Total Protein | 98.5 | | |

| Sample Menu – Vegetarian | Protein (g) | | |
|----------------------------------------------------------------------------------------|-------------|--|--|
| Breakfast | | | |
| ½ cup oats made into porridge with honey | 9 | | |
| 250ml full fat calcium fortified soya milk | 8 | | |
| 1 banana | 1 | | |
| Mid morning | | | |
| 250ml soya milk berry smoothie made with full fat soy, blueberries, soy icecream | 10 | | |
| Lunch | | | |
| Pureed vegetable and bean soup containing 1/2 cup cannellini beans | 10 | | |
| 2 slices of wholemeal bread with thick tahini, margarine, avocado or smooth nut butter | 10 | | |
| Mid afternoon | | | |
| 1/4 cup hummus with crackers or rice pudding made with soya milk or coconut milk | 8 | | |
| Dinner | | | |
| 150g firm marinated tofu stir fried cooked with 2 tablespoons olive oil | 25 | | |
| 1 cup cooked vegetables | 4 | | |
| 1 cup noodles | 8 | | |
| Total Protein | 93 grams | | |

Dealing with common symptoms

| Symptom | Helpful strategies |
|-------------------------------|-----------------------------------------------------------------------------------------------------|
| Dry mouth | Frequent mouth rinsing and / or water spray. |
| | Suck on ice chips or frozen lemon slices. |
| | Use a humidifier at night. |
| | Apply lip balms. |
| | Suck on sugarless gums and sweets (this can cause loose bowel motions in some people). |
| | Use artificial saliva (see pharmacist). |
| | Drink plenty of appropriate fluids (nourishing fluids, thickened fluids) and sip fluids with meals. |
| | Moisten foods with sauces and gravies. |
| | Maintain good oral hygiene and brush with a soft toothbrush several times a day. |
| | Limit or avoid alcohol, caffeine and cigarette smoke. |
| Thick saliva | Moisten foods with sauces and gravies. |
| | Sip fluids throughout the day such as lemon juice in water or soda water. |
| | Use regular mouth rinses (alcohol free). |
| | Rinse / brush teeth regularly through the day. |
| Mouth / throat pain | Discuss any pain with your doctor. |
| | Use prescription anaesthetic mouth wash. |
| | Choose soft bland foods, pureed moist foods. |
| | Avoid rough foods, acidic foods, spicy foods, very salty foods, spirits, fizzy drinks. |
| | Avoid really hot or really cold food or drink. |
| | Try to have foods at room temperature. |
| Taste change or loss of taste | Don't eat food or drink that doesn't taste nice to you until taste returns. |
| | Sugar free gums or mints can help the bad taste in the mouth. |
| | Marinate meats with sauces, try adding flavourful herbs and spices. |
| | Serve foods at different temperatures and textures within a meal. |

| Symptom | Helpful strategies |
|-------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Taste change or loss of taste (continued) | Tart foods like lemon and orange may improve taste. |
| | Stronger tasting food may be necessary eg. use garlic, onions, spices, parmesan, anchovies, pickles, mustards. |
| | Use plastic utensils if food tastes metallic. |
| | Foods may taste better cold or at room temperature. |
| | Retry foods after a couple of weeks. |
| Swallowing problems | If you have trouble swallowing, you need to be assessed by a speech pathologist. They will advise about you what foods and drinks are safe, to avoid aspiration (food entering the lungs which can cause pneumonia). |
| | The Speech Pathologist may suggest a modified texture diet eg. thickened drinks. |
| | A dietitian can help you to plan a modified consistency diet that meets your nutritional requirements. |
| Nausea and Vomiting | Nausea can stop you feeling hungry. It can be caused by anxiety, medication or treatment. If you have anti-nausea medications, make sure you take them as your doctor suggests. |
| | Avoid strong food / cooking smells. |
| | Cold or room temperature foods are usually preferred. |
| | Eat small, frequent meals and snacks over the day. An empty stomach can make you feel worse. |
| | Sip nourishing fluids such as milk drinks, fruit juices, avoid fatty foods, highly seasoned foods. |
| | Eat and drink slowly. |
| | Some people find ginger helpful to reduce nausea. |
| Constipation | Discuss with doctor as this can be caused by medications. |
| (difficulty passing stools) | Make sure you are drinking enough. Liquids can include water, soups, juice, milk, nutritional supplement drinks and teas. |
| | Limit coffee and alcohol as they cause water loss; include high fibre foods and natural laxatives such as prunes, prune juice, figs. |
| | Get some light exercise if possible after meals. |

Dealing with common symptoms (cont.)

| Symptom | Helpful strategies |
|------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Diarrhoea | Avoid high 'roughage'/fibre foods such as wholegrain breads and cereals, skins and pips of fruits, dried fruit, raw vegetables, vegetable skins and stalks, liquorice, jam containing peel. |
| | Can be a short term lactose (milk) intolerance caused by antibiotics/treatments. If you think this could be the case, try limiting or avoiding lactose -rich foods such as milk, icecream, and custard. (Yoghurt and cheese may be okay). Use an alternative such as soy milk or a lactose-free milk such as Zymil. |
| Loss of appetite | Discuss this with your doctor as this can be caused by pain medications. |
| | Make everything you eat and drink count. This means having up to six small meals and snacks which are high in energy and protein. |
| | Have meals and snacks often instead of waiting for hunger signals. Choose your favourite foods. A small glass of wine or beer may stimulate the appetite. |
| | Use a small plate and make food look nice. |
| | Try to eat together and make meal times as normal and pleasurable as possible. |
| | Drink nourishing drinks throughout the day if food intake is minimal. |
| | Limit low energy foods and fluids such as vegetables, tea, coffee, clear soups and diet drinks. |
| | Avoid drinking with meals. |
| Fatigue / | Have regular small meals and snacks. |
| breathlessness | Choose foods that appeal to you and are easy to eat. |
| | Make everything you eat and drink count. Focus on energy and protein rich foods rather than low energy foods and drinks. |
| | Sit down and rest for a little while before eating. |

Tube feeding and nutrition support

It is always best to eat and drink to get nutrition. However, in some cases the disease or medical treatments cause swallowing problems or block off parts of the gut, so it's difficult to get enough nourishment.

In these situations tube feeding may be suggested. This means the doctors put in a tube through the nose (short term) or through the stomach wall (long term). Special nutrition formula feeds are then given through the tubes.

This will provide nutrition to help slow down weight loss and give fluid to make sure the body has enough water. However, it may not increase the length of life, and in some cases can be uncomfortable.

It can be difficult deciding when to start feeding with a tube and when to stop. It is important that you and your carer/s discuss this with your medical team before any treatment plan is started. Your views can be considered as part of an advanced health care plan.

Notes

Further reading

Care Search
www.caresearch.com.au

Palliative Care Australia www.palliativecare.org.au

Cancer Council of South Australia www.cancersa.org.au

Peter MacCallum Cancer Centre, Victoria www.petermac.org

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