

Nutrition in palliative care

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Introduction

This booklet has been compiled with advice from Dietitians, Specialist nurses, and a Speech and Language therapist.

Nutrition is a complex science but of course it is also all about food! Something that we are all concerned with every day of our lives and is hugely important to us all. When our children are young, we associate it with their ability to thrive, and as we become ill, and so often lose weight, this becomes a worry.

Poor appetite can be a common feature of illness and so although we may be losing weight – not fancying food inhibits our ability to redress this balance. Just trying to force food down or your loved ones forcing you to eat will only cause distress. This booklet acknowledges these difficulties and others and seeks to give advice for different problems that may occur. Trying to still enjoy what you eat even though the portions may be smaller, is an important aim.

There will be a section on general nutrition, looking at a balanced diet. When a balanced diet is not possible because of the eating difficulties you may be experiencing, there are other chapters to consider. They identify main eating difficulties which can be associated with the disease itself, medication and /or certain treatments. It is important to remember that side effects of treatment vary from person to person in the nature and degree of the reaction to a specific intervention.

There are many symptoms encountered with any illness, which can affect an individual's nutritional intake. It is important that underlying factors contributing to malnutrition have been corrected where possible, or explained, examples may include:

- Poor oral health e.g. oral thrush
- Nausea and / or vomiting
- Psychosocial e.g. depression, anxiety
- Dietary requirements / considerations
- Ability to obtain and prepare food
- Swallowing difficulties
- Malabsorption e.g. due to bowel obstruction
- Dental problems or poorly fitted dentures, often due to weight loss

We wouldn't suggest you read every chapter— just go to the section that meets your need at the time.

The information in this booklet is not intended to replace the advice given to you by your doctor or dietitian. If you have complex needs or simply require more information please ask your Nurse, Doctor or Clinical Nurse Specialist to refer you to a Dietitian.

General nutrition and the 'Eat well guide'

All our food that we eat can be split into 5 food groups. These 5 food groups provide us with all the nutrients, vitamins, protein etc. that we require. The Eatwell Guide shows how much of what we eat overall should come from each food group to achieve a healthy, balanced diet.

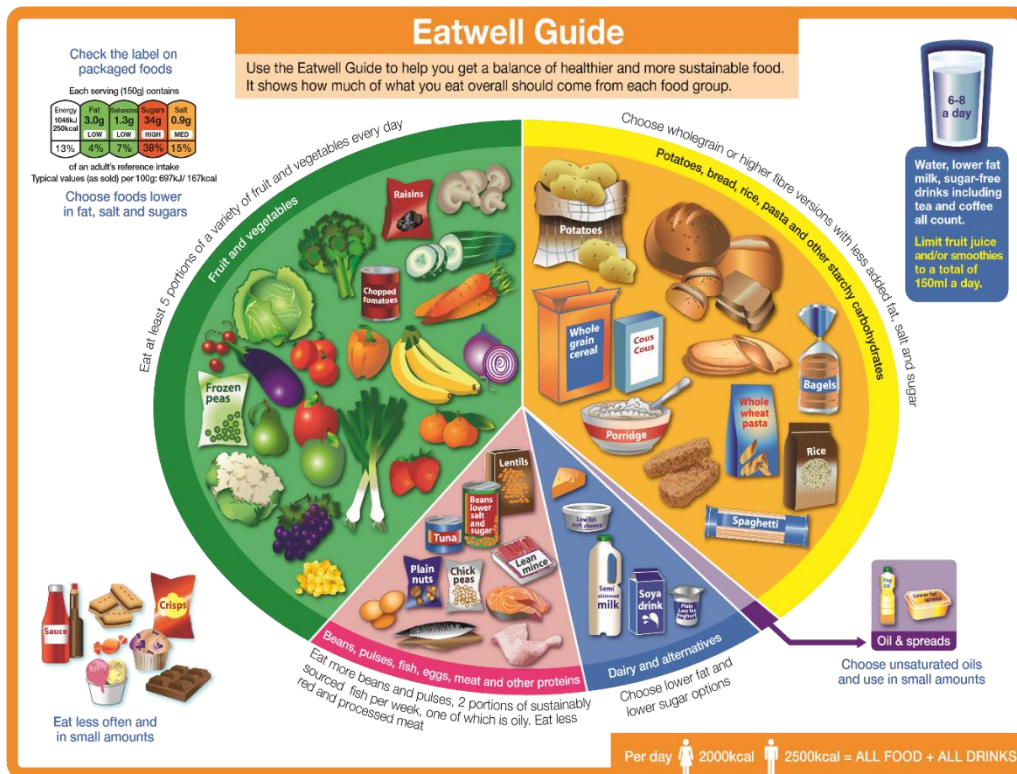
The "eatwell plate" shows the proportions of the 5 food groups that should be consumed to maintain good health. Please note anyone with special dietary requirements or medical needs might want to check with a registered dietitian on how to adapt the Eatwell Guide to meet their individual needs.

Fruit and vegetables should make up over a third of the food we eat each day. Aim to eat at least 5 portions of a variety of fruit and veg each day. Choose from fresh, frozen, tinned, dried, or juiced. Fruit and vegetables are a good source of vitamins, minerals, and fibre.

Starchy food should make up just over a third of the food we eat. Choose higher fibre wholegrain varieties, such as whole wheat pasta and brown rice, or simply leave skins on potatoes. There are also higher fibre versions of white bread and pasta. Starchy foods are a good source of energy and the main source of a range of nutrients in our diet.

Milk, cheese, yoghurt and fromage frais are good sources of protein and some vitamins, and they're also an important source of calcium, which helps [keep our bones strong](#).

Beans, pulses, fish, eggs, and meat are good sources of protein, vitamins, and minerals.



Unsaturated fats are healthier fats and include vegetable, rapeseed, olive, and sunflower oils. Remember all types of fat are high in energy and should be eaten sparingly.

Saturated fats include foods such as chocolate, cakes, biscuits, sugary soft drinks, butter, ghee, and ice cream.

Drink plenty of fluids – the government recommends 6 to 8 cups or glasses a day. Water, lower fat milks and lower sugar or sugar-free drinks, including tea and coffee, all count. Fruit juice and smoothies also count towards your fluid consumption, but they contain free sugars.

Poor appetite and feeling full quickly

Loss of appetite is often part of the disease process itself and in many instances may lead to weight loss. Other factors such as isolation, depression, bowel problems, nausea and the effects of treatment can cause a poor appetite.

There are many reasons for feeling full, which could include previous surgery such as a gastrectomy, breathlessness, bloating and constipation.

Try to increase the number of calories consumed by eating small and frequent meals and snacks e.g. every two hours. Here are some snack ideas:

- Biscuits and cakes, sandwiches, small pieces of pizza, flan, sausage rolls
- Fruit (fresh and dried,) cheese and crackers, cheese straws & cubes
- Fun sized chocolate bars
- Ready-made desserts e.g. yoghurt, crème caramel
- Crisps, nuts, and savoury biscuits
- Crumpets, scones, muffins, croissants

TIPS:

- Try not to get out of the habit of eating. You need to eat to stimulate your appetite
- Your appetite may come and go, so it is important to make the most of the times when you feel like eating.
- Don't worry if it isn't 'normal' foods at 'normal' times – if you fancy cereal at midnight, enjoy it!
- Try to relax and enjoy what you eat. Eat slowly and chew your food well, trying to rest before and afterwards.
- A short walk before a meal or some fresh air may help give you an appetite.
- A small glass of wine, beer, sherry, or your favourite drink taken half an hour before a meal may boost your appetite. Check with your doctor first.

- Experiment with different foods. You may find that you like things you don't usually eat.
- Try to make your food and drinks as nourishing as possible by fortifying food- see below for suggestions.
- Don't worry if you don't feel like cooking. Cold meals can be as nutritious as hot meals.
- Accept offers from friends and relatives to help with cooking and shopping.
- Convenience foods are a useful standby and can be just as nourishing.
- If you have a freezer, try to prepare food in advance when you feel like cooking and store it for when you are not feeling so well.
- Avoid filling yourself up with large servings of vegetables, salads, water, and fizzy drinks. They provide bulk but little nourishment.
- Tempt your appetite by making food look attractive –use small portions on a small plate and try adding garnishes such as lemon or parsley.
- Sometimes the smell of food will be appetising, while at other times it may put you off. If this happens, try to keep away from the kitchen while food is being prepared, or eat cold foods, which often have less smell.
- Avoid drinking with meals as this may fill you up and spoil your appetite.

How to fortify food:

If your appetite is poor and you are not eating as well as you would normally, the following tips may help you to get more calories without necessarily having to eat more food.

You can fortify your food i.e. add extra calories in the following ways:

- Milk: Add 2oz (4 tablespoons) of skimmed milk powder such as Marvel or '5 Pints' to 1 pint of full cream milk. This can be used in the usual way in drinks, on cereals, in sauces and puddings.

To savoury foods add cheese, fortified milk, gravy, skimmed milk powder, pulses, meat, cream, crème fraiche, or butter/margarine (rather than low fat spread). For example:

- Add beans and pulses to soups and casseroles
- Cheese on mashed potato with extra milk and butter/margarine
- Butter, cheese, or white sauce on vegetables
- Add one tablespoon of skimmed milk powder to one portion of white sauce
- Add grated cheese/cream/milk to soup
- Add cream/sour cream or crème fraiche to casseroles
- Add mayonnaise or salad cream to sandwiches or have two fillings, e.g. egg mayonnaise and bacon, cheese, and ham

To sweet foods add fortified milk, sugar, cream, honey, syrup, ice cream or evaporated milk. For example:

- Cream/custard/ice cream/evaporated milk with pies, sponge or
- Fruit
- Add extra sugar, honey or syrup to desserts and cereals
- Jelly made with milk
- Add 1 tablespoon of skimmed milk powder to 1 portion of porridge, milk puddings, and custard
- Add cream, yoghurt, sugar, honey, evaporated milk, dried fruit to breakfast cereals

Nutritional supplements and recipes

If you are struggling to meet your nutritional needs through adjusting your diet or you are losing weight, it may be necessary to consider nutritional supplements. If you have a milk allergy / intolerance or renal impairment you will require a referral to a dietician. If you have diabetes, advice around recommended supplements will differ. If you have a diagnosis of dysphagia (impaired swallow) please discuss with your speech and language therapist whether you require any thickener added to your supplements. Pre-thickened supplements are also available; these are required on prescription with the advice of a dietician.

Nutritional drink supplements available to purchase at your local pharmacy or supermarket include Complian and Meritene. Please do not use these if you have Milk & / or lactose allergy / intolerance, Diabetes, or Phosphate and potassium restricted diet due to renal impairment. Prescription only nutritional

supplements include products such as Fortisip, Ensure, Fortijuice, Fresubin Jucy, Aymes, and Fresubin Energy. First-line nutritional renal impairment. Prescription only nutritional supplements include products such as Fortisip, supplements for patients with Diabetes include Aymes Complete and Fresubin Energy (prescription only).

Drinks, Smoothies & Snacks	Ingredients	Method
Milkshake	<ul style="list-style-type: none"> • 1 sachet of Complian or Meritene (any flavour) • ½ pint of milk • 1 scoop vanilla ice cream 	Mix sachet with the milk and ice cream and serve. You can also add fresh fruit, but you will need a blender to liquidize the fruit
Strawberry Froth	<ul style="list-style-type: none"> • 1 bottle of strawberry flavoured prescription supplement (e.g. Fresubin) • 1 scoop vanilla ice cream • 6 strawberries 	Blend the milky supplement, ice cream and strawberries together and serve.
Juicy Fizz	<ul style="list-style-type: none"> • 1 bottle, any flavour, of juice-based prescription supplement (e.g. Fortijuice) • 100ml of sparkling water, tonic, soda, or lemonade 	Mix all ingredients together and serve (ideally chilled).
Hot Chocolate	<ul style="list-style-type: none"> • 1 bottle of chocolate flavoured prescription supplement (e.g. Fresubin) • 2 teaspoons of hot chocolate powder • 100ml of milk 	Warm the chocolate supplement in a saucepan but do not boil. Mix the hot chocolate and milk together and add to the pan, then heat and serve. Serve with some cream on top.
Porridge	<ul style="list-style-type: none"> • 1 handful porridge oats • 1 sachet of Complian or Meritene (vanilla flavour), or 1 bottle of vanilla flavoured prescription supplement (e.g. Fresubin) • ½ pint milk 	Make up the Complian or Meritene using instructions on the packet. Add drink to small saucepan, add porridge oats and simmer for 10 minutes.
Strawberry Milk Jelly	<ul style="list-style-type: none"> • 1 packet strawberry jelly • 1 sachet of Complian or Meritene (strawberry flavour) 	Dissolve jelly in ½ pint boiling water. Make up Complian or Meritene using instructions on the packet. Once made, add / mix together with the jelly and place in fridge until set.

Juicy Sorbet	1 bottle, any flavour, of juice-based prescription supplement (e.g. Fortijuice)	Place the supplement in the freezer until frozen. Remove from the freezer and leave to soften slightly, take out of bottle, and chop up to serve with fruit if desired.
Butterscotch Whip	<ul style="list-style-type: none"> • 1 packet butterscotch Angel Delight • 1 bottle of toffee flavoured prescription supplement (e.g. Fresubin) <p>Note- use any matching flavours e.g. strawberry angel delight with strawberry flavoured supplement</p>	Whisk Angel Delight and supplement together until smooth. Place it in the fridge and allow to set.
Flavoured High Calorie Ice Cubes	<ul style="list-style-type: none"> • 2 bottles of neutral flavoured prescription supplements (e.g. Fresubin) • 1 sachet of Complian or Meritene (any flavour) 	Mix supplement and sachet together in a jug then pour into an ice cube bag and freeze.
Juicy Jelly	<ul style="list-style-type: none"> • 1 bottle, any flavour, of juice-based prescription supplement (e.g. Fortijuice) • 1 pack jelly (flavour to match above) 	Dissolve jelly in ½ pint boiling water, add juice supplement, pour into small bowls and place in fridge to set.
Homemade vegetable soup	<ul style="list-style-type: none"> • 1 bottle of neutral flavoured prescription supplement (e.g. Fresubin) • 1 onion (chopped) • 2 carrots (chopped) • 2 parsnips (chopped) • 2 sticks celery (chopped) • 1 head of broccoli (chopped) • ½ swede (chopped) • 2 vegetable stock cubes • 1 pint boiling water • 2 bay leaves • 1 bunch parsley (chopped) Pinch of salt & pepper 	Heat 2 tablespoons of olive oil in a large saucepan, add onion and celery and gently cook for 5 minutes. Add all other vegetables and cook for a further 5 minutes. Dissolve stock cube in the boiling water then add to the pan. Add the bay leaves and simmer for 30-40 minutes. Add the parsley and season with salt and pepper. Remove from the heat and liquidize. Add 1 bottle of neutral flavoured supplement.

Probiotics

“Probiotics are live bacteria and yeasts promoted as having various health benefits. They're usually added to yoghurts or taken as food supplements and are often described as "good" or "friendly" bacteria.

Probiotics are thought to help restore the natural balance of bacteria in your gut (including your stomach and intestines) when it's been disrupted by an illness or treatment.

If you're considering trying probiotics, there are a few issues you need to be aware of. Probiotics are generally classed as food rather than medicine, which means they don't go through the rigorous testing medicines do. Because of the way probiotics are regulated, we can't always be sure that:

- the product contains the bacteria stated on the food label
- the product contains enough bacteria to have an effect
- the bacteria can survive long enough to reach your gut

There are many different types of probiotics that may have different effects on the body, and little is known about which types are best.

You may find a probiotic helps with one problem. But this doesn't mean it'll help other problems, or that other types of probiotics will work just as well. There is likely to be a huge difference between the pharmaceutical-grade probiotics that show promise in clinical trials and the yoghurts and supplements sold in shops.”

(<https://www.nhs.uk/conditions/probiotics/>)

Constipation

This can be caused by:

- Decreased fluid and food (particularly fibre) intake
- Lack of exercise
- Depression
- Side effects of some medication and treatments

Below are some suggestions to help you increase your fibre and fluid intake, however

these suggestions will not be suitable for everyone, especially if you have a sore mouth or have difficulty swallowing. If this is the case, ask to be referred to a dietitian for more individualised advice.

Note: *If constipation is caused by opioid (pain relief) based medication, speak to your doctor about appropriate laxatives as sometimes fibre will not resolve constipation caused by opioids and in some instances can make you feel worse.*

Increasing fibre in the diet

Sometimes called 'roughage', dietary fibre is the structural part of the plant that humans cannot digest properly. Dietary fibre is found in plant foods such as cereals, pulses, fruits, and vegetables.

How to increase the fibre in your diet:

- choose wholegrain, granary and brown bread instead of white bread
- choose more wholegrain breakfast cereals e.g. Weetabix, bran flakes, unsweetened muesli, Shreddies and porridge oats
- use wholegrain pasta and brown rice instead of white pasta and rice, new potatoes in their skins and jacket potatoes with skins
- fresh and dried fruits – particularly if you eat the skins
- replace half of the white flour in recipes with wholemeal flour (plain or self-raising are available). Use for scones, crumble topping, cakes, and pastry
- choose wholegrain biscuits and crackers. Try oat biscuits or digestives, crisp breads, and whole-wheat crackers
- pulses, such as peas, baked beans, broad beans, kidney beans, butter beans, sweetcorn, chickpeas, and lentils are all good sources of fibre. Add tinned versions to soups, casseroles, and rice and pasta dishes.
- include some nuts and seeds in your diet. You can eat them as a snack, add to breakfast cereals, or sprinkle onto salads
- eat plenty of vegetables, salad, and fruit. Fresh, frozen, and tinned fruit and vegetables are all suitable.

Drinking enough fluids on a high fibre diet

Fibre soaks up fluid or water in the digestive system, swelling and forming a large, soft bulk. It is important to drink plenty of fluid if you are increasing the amount of fibre you eat. Drink at

least 6-8 large cups or glasses of fluid each day, such as water, tea, coffee, squash, or fizzy drinks. Choose sugar-free varieties if you are on a weight reducing diet or have diabetes.

Diarrhoea and/or wind

Please note that diarrhoea that is primarily caused by a side effect of treatment, medication, the disease process itself, or an infection, will need to be managed with appropriate medication and medical intervention. In this instance, diet has a very small role to play. It is important that the cause of your diarrhoea is established. It is not advisable to restrict any types of foods for long periods of time without seeking advice from a dietitian.

The advice given below is only for those people that have established a link between their symptom and the food they eat. It is very important that if you have diarrhoea you speak to your doctor about suitable medication and drink plenty of fluid: 6-8 cups a day of water, juice, milk, nutritional drinks, tea, and coffee (if tolerated). It may also be useful to follow the tips on "Poor appetite and feeling full quickly" if you have a reduced appetite.

Try the following adjustments to your diet if you have diarrhoea:

- Try reducing your portion sizes of fresh fruit, dried fruit, salad, and raw vegetables (if you are in the habit of eating these foods regularly). Do not eliminate fruit and vegetables from your diet completely. *Note:* If you are not in the habit of eating fruit or vegetables regularly, you may benefit from introducing fruit in small amounts into your diet – try tinned fruit e.g. tinned peaches/ apricots/ pears).
- Cook vegetables thoroughly.
- Peel fruit and vegetables and avoid pips.
- Softly cooked carrots, parsnips, butternut squash, pumpkin, potatoes, and broccoli-and-cauliflower florets are usually well tolerated by most people.
- Eat pasta, rice and white bread but avoid whole-wheat varieties if you have severe diarrhoea.
- Change from bran cereals and muesli to Cornflakes, Rice Crispies or porridge.
- If you find that milk increases your symptoms, change to soya milk or low lactose milk. Most

people may still be able to tolerate yoghurt and hard cheese.

- Avoid bowel irritants such as caffeinated drinks and spicy foods.
- If you find that fatty foods increase diarrhoea, choose lean meats, and opt for fat free cooking methods such as grilling, roasting, boiling, or steaming rather than frying. Do not remove all fat from your diet as this could lead to weight loss.

If you have wind:

Avoid gas forming foods and drinks that could increase flatulence such as garlic, onion, cabbage, brussels sprouts, broccoli stalks, cauliflower stalks, sweet corn, peas, beans, mushrooms, fizzy drinks, beer, lettuce, pips, hard skins, and bran.

Swallowing problems

You may experience problems with swallowing. Perhaps you cough after drinking or find certain foods such as bread pieces of meat or dry crumbly foods difficult to manage. If you are concerned about your swallowing, make an appointment to talk to your GP. They may refer you to a speech and Language Therapist, who will be able to assess your swallow and give support and advice on how to manage any difficulties.

Sometimes swallowing difficulty may be due to an obstruction in the gullet or due to past surgery. If you are only able to manage a very soft diet and liquids or liquids alone, it is very important that you speak to your consultant or dietitian as they might be able to help you manage the problem better.

Eating and breathlessness

Conditions such as heart failure, COPD, lung cancer, and pulmonary fibrosis, may affect the ability to eat very much due to symptoms of breathlessness. It may be difficult and tiring to eat and regulate your breathing at the same time. Trying to eat large meals may aggravate your breathlessness as an overfilled stomach may put pressure on your diaphragm, making it more difficult to breathe. Below are some tips you may find useful, to help you cope with eating and breathlessness.

Tips

- If you struggle to chew and breathe when you eat, go for softer, moist foods that are easier to chew and swallow.
- Try having more nourishing liquids such as milk, smoothies, juice, and soups.
- Don't overeat. Give your lungs and diaphragm more room to do their job by not filling your stomach too much. Avoid gas forming foods and drinks as they can cause bloating.
- Try eating smaller meals and snacks more often. You may find it helpful to look at the 'Poor appetite and feeling full quickly' section.
- If possible, try to ensure a balanced diet. You may find it helpful to look at the 'General nutrition and the eat well guide' section. *Please note* this recommendation may not be appropriate for everyone.
- Take time when you eat. Try to swallow every mouthful before going on to the next. Eat and chew slowly. Take your time with your meal to take deep breaths to fill your body with the oxygen it needs. Take smaller bites and rest in between. If you feel out of breath, slow down and take a break.
- Try to clear your chest an hour before eating. This may include breathing techniques and controlled coughing or using some of your prescribed medications such as bronchodilators. You may find it useful to look up the Active cycle breathing technique (ACBT).
- Adequate hydration keeps mucus thin, making it easier to cough up. *Please note* this recommendation may not be suitable for everyone as some individuals may be on fluid restriction.
- Eat sitting up to make space for your lungs and diaphragm to expand for easier breathing.
- If you are on oxygen therapy, you may be advised to administer this via a nasal cannula during meals to ensure your body receives the oxygen it needs for healthy digestion.
- If you find eating tiring due to breathlessness, you may find it helpful to rest before meals to save energy.

- If you're losing weight without planning to, you may need a nutritional supplement. Talk to your doctor who may prescribe a supplement or refer you to a dietitian.

Nausea

Ask your doctor or nurse about anti-sickness tablets. There are several different anti-sickness tablets available. If the first one you are prescribed is not effective, it may need to be changed or increased or you may also require an additional tablet.

- Try to stay calm and relaxed at mealtimes.
- Don't force yourself to eat when you feel sick. Drink plenty to prevent dehydration.
- Eat in a well-ventilated room away from cooking smells.
- Avoid strong smelling foods.
- If the smell of hot food puts you off, choose cold meals or snacks.
- You may like to ask for your food to be cooled to room temperature **before** it is brought to you.
- Try dry foods such as toast or crackers if you can manage these.
- Try to have regular snacks as nausea can be made worse when your stomach is empty.
- Try having drinks between meals rather than with your food. Wait 30 minutes after a meal and then sip fluids slowly.
- Avoid greasy, fatty, or fried foods.
- Foods or drinks containing ginger can help to reduce feelings of sickness.
- Sipping a fizzy drink slowly may help.
- Try not to lie down flat immediately after eating.

Altered taste

Some people find that during treatment their taste changes. Most changes are only temporary. You may find that foods you previously enjoyed now taste unpleasant. Foods such as red meat or coffee can taste bitter, some people complain of a metallic taste, others find everything tastes the same "like

cardboard". If you experience these problems, here are some tips to help make your food more palatable:

- Eat the foods that you do like the taste of and avoid those that you don't. Re-try any 'problem' foods after a few weeks as your taste may have returned to normal.
- If sweet foods taste too sweet - try a selection of savoury foods instead. Using stronger seasonings may help or try adding lemon juice.
- Sharp tasting foods e.g. grapefruit, lemon, and drinks such as bitter lemon may help stimulate your taste buds, increase the flow of saliva, and get rid of any unpleasant taste in your mouth.
- If meat tastes bitter or metallic try marinating it before cooking e.g. in fruit juice, wine, barbecue, or sweet and sour sauce.
- Avoid cooking in metallic containers and use plastic or wooden utensils.
- Cold meats may taste better served with pickle or chutney.
- If meat tastes unpleasant, don't worry, fish, milk, cheese, eggs, and pulses e.g. lentils, beans can all provide the same nourishment as meat.
- Some people find cold or warm foods easier to manage and more palatable than hot.
- If foods taste bland, try adding strong tasting herbs, spices e.g. oregano, rosemary, or sauces e.g. soy, Worcester, barbecue.
- If tea and coffee taste strange, try milky drinks, fruit juices or fizzy drinks (avoid drinks containing artificial sweeteners as these sometimes leave a metallic taste in the mouth)
- Try to drink plenty of fluids and keep your mouth and tongue clean. Brush your teeth regularly and use a soft toothbrush to clean your tongue if necessary.
- If your mouth is sore, ask your doctor to advise on an appropriate mouthwash/medication to help.

Dry mouth

Saliva is very important for dental and oral hygiene. It has several functions including the lubrication and commencement of digestion of food. It also reduces the risk of oral infection.

- If you find that you need to breathe through your mouth due to breathlessness you may find that you become very dry. Other causes of a dry mouth include some treatments such as radiotherapy, drugs including morphine, water tablets, inhalers, and other factors such as dehydration and anxiety. The use of oxygen can also cause a dry mouth. Try using a nasal cannula instead of a mask. If using oxygen for prolonged periods of time, ensure that it is humidified.
- Try to sip drinks frequently. Keep drinks cool by adding ice cubes and chilling. Carbonated mineral water can be mixed with plain in equal parts in order to reduce the gas content.
- Suck ice cubes. These can be flavoured according to taste with fruit cordials, juice, or high calorie drinks.
- Fruit drops, chewing gum, boiled sweets, or pineapple chunks (preferably fresh) help to stimulate saliva production.
- Pasta, casseroles, porridge, Readybrek, omelette, scrambled eggs, minced meat or soft mashed potatoes, milk jellies and puddings are often more easily tolerated than dry foods such as toast, particularly if your mouth is sore. Avoid sticky, chewy, and dry foods as they can stick to the roof of the mouth e.g. chocolate, pastry, bread, and cold meats.
- Add gravies, sauces, or custards to meals in order to make them moist.
- Keep lips moist with balm, please check with a healthcare professional which is safe if you are on oxygen therapy.
- If dryness becomes a source of discomfort, then your G.P. can prescribe artificial saliva in the form of a spray or gel.

Sore mouth

A sore mouth can have various causes including loose fitting dentures, infection such as thrush, antibiotics, and anaemia or vitamin deficiencies. Oral thrush can be identified by thin white plaques on the lining of the cavity or tongue. The tongue may be sore and very red. If you have a sore mouth the cause needs to be identified and treated by the G.P. or dentist as appropriate.

- Avoid dry, rough, or hard foods such as toast, biscuits, and crisps.
- Avoid highly spiced foods e.g. chilli, very salty foods e.g. crisps, and sharp acidic foods e.g. vinegar.
- Alcohol (especially spirits) may irritate a sore mouth.
- If you are finding it difficult to chew soft foods add extra gravy, sauces, butter, custard, or cream etc.
- Drink plenty of nourishing fluids e.g. full cream milk, milky drinks, and milkshakes.
- Eat little and often and have plenty to drink. Try small sips throughout the day if you can't tolerate a lot at one time.
- Try drinking through a straw-it may be less painful than from a cup.
- Very hot drinks may irritate your mouth; warm or cold drinks may be more soothing.
- Avoid very hot food and drinks and allow to cool first.
- Try adding ice or ice cream to drinks.
- Try to sip drinks frequently. Keep drinks cool by adding ice cubes and chilling.
- Suck ice cubes or ice-lollies. If you are using nourishing supplement drinks these can also be frozen.
- Mouth hygiene is important, especially if you are taking sugary drinks and snacks. Brushing your teeth regularly with a soft toothbrush and using fluoride toothpaste is advisable. Mouthwashes can be helpful, whether you have your own teeth or wear dentures.
- Take any painkillers or mouthwashes your doctor suggests **before** you eat or drink.

Support from family and friends

Food provides more than just nutrients. It has cultural, emotional, and social meaning in all societies. There are many symptoms encountered with any illness, which can affect an individual's nutritional intake.

Family members often consider the quantities of food and liquid consumed to be an indicator of one's overall condition. Patients however may have other issues, which they consider to be of more importance, and this can cause conflict. If possible, try to communicate your feelings by sitting down together and having an honest discussion. It is important that you are comfortable and that you do not feel hungry. Fundamentally you need to enjoy what you eat!

Why won't they eat?

This aims to answer frequently asked questions about appetite and weight loss when the person you are caring for is very ill. It accompanies 'Fluids & drips' and is aimed mainly at carers. However, some patients may also find this information helpful.

Why have they stopped eating? I keep cooking tempting dishes and they just push them away.

Many people with serious illnesses lose their appetite as they become less well. Sometimes there is an obvious cause like feeling sick or having a sore mouth which medication can help. However, very often the illness itself causes the loss of appetite. It can feel very hurtful when the person you are caring for pushes food away, especially when you have taken trouble to make something they like, but it is important to remember that it is not meant to upset you. They just don't feel like eating, and often feel bad about that themselves. It may help to talk to the nurse or doctor about how it makes you both feel.

Why does this happen?

Many cancers and other advanced illnesses make the body produce chemicals which break down muscle and fat faster than it should. These chemicals also 'trick' the part of the brain that controls appetite into thinking that the person is full after only a few mouthfuls or even after no food at all. These chemical changes will only go away if the underlying illness is successfully treated.

But won't they starve to death if they don't eat?

The answer is no. Changes that occur in the human body during severe illnesses such as advanced cancer or heart failure are completely different from those that happen in healthy people who have been forced to go short of food. In advanced illness, people can start to lose weight even when their appetite is still fairly normal because the body is no longer able to use the food it is given to build itself up. This is why the appetite gets smaller – the body seems to recognise that it can no longer cope with food. Surprisingly, people with advanced illness often live for some time after they have stopped eating completely, although it is often one of the signs that the person is becoming less well.

Are there alternative feeding methods?

What about 'drip' or 'tube' feeding?

We know from research that neither drip nor tube feeding will make most people with advanced cancer put on weight or live any longer. Feeding via a tube through the nose into the stomach (nasogastric tube) or directly through a hole into the stomach (gastrostomy) is provided for some people who have an appetite but are not able to eat properly, but this is only done in certain specific circumstances.

Drip-feeding (given into a vein, called TPN or total parenteral nutrition) is done very rarely and usually for just a short time, for example after some types of bowel surgery. It is not helpful to people with advanced illnesses.

What will happen to someone who is already being fed through a tube? Will their food be stopped?

At any time, a patient has the right to say that they want to stop being artificially fed. If they get less well, their appetite may also get smaller, and decisions may then have to be made about whether artificial feeding should be stopped. If they become too ill to make that decision, the doctors and nurses will make a careful assessment and discuss fully with the patient's family the right thing to do. The ultimate responsibility for decisions about starting and stopping artificial feeding rests with the senior doctor caring for the patient. Sometimes it can do more harm than good to carry on feeding. The sort of harmful effects that could happen when someone is in the last few days of their life and very weak include regurgitation, sickness, and food spilling over into the lungs ('aspiration').

Things that may help:

- Offer small meals or snacks spread out over the day rather than large meals
- Don't worry too much about balanced meals, 'a little of what you fancy does you good'.
- You might find it helpful to talk to a dietician about different sorts of meals and foods. Ask the nurse or doctor if this would help.
- Food supplements can be obtained on prescription. These can help if the person you are caring for likes them.
- Alcohol can sometimes help to stimulate appetite and will not usually interfere with medication (but please check first with the doctor or nurse).
- Gentle exercise can help slow up muscle loss; a physiotherapist may be able to advise you further, ask your nurse.
- As the ill person becomes weaker, you may notice that food begins to go down the 'wrong way' causing them to cough and splutter. This may be a problem that can be

solved by changing the texture of the food and by ensuring as upright a position as possible while eating. It could also be a sign that they are becoming less well.

Are there any medications that can help with appetite or weight gain?

Some medications, such as steroids and progestogens, can help boost appetite. Often the effect is only temporary. However, any weight gained in this way is only fat or fluid and not muscle (which is the most useful).

Fluids and drips in advanced illnesses

Below are answers to some frequently asked questions about fluids and the use of artificial hydration (fluid intake given by a drip) in advanced illness. It is aimed mainly at carers, but some patients may also find this information helpful.

If someone doesn't drink, won't they die of dehydration? Isn't fluid even more important than food?

It is normal for people who are dying from advanced cancer and other illnesses to eventually stop drinking and to stop feeling thirsty. As the body weakens and the systems start to work less well, there is less and less need for fluid.

It is important to remember that it is the illness that is making the body's systems fail, not a lack of fluid. If someone is very weak and is given fluid by mouth it may go down the 'wrong way' and make them cough and splutter.

What can I do if they complain that they have a dry mouth?

A dry mouth can be a very common problem at any stage of the illness. Ask the medical or nursing staff about it. This feeling is quite different from feeling thirsty. Medicines such as special saliva sprays, gels and chewing gum may be helpful.

What can I do to help?

If staff feel it is safe to do so, you can carry on offering drinks (as the staff will do when you are not there) but don't be surprised if your loved one only wants a few sips at a time. The staff will help you to make sure that the drinks are not causing coughing or spluttering.

Some people like to have their favourite drink frozen as an ice-lolly or ice chips - this can be easier to suck on than trying to drink.

Do you ever use drips?

Yes. A drip is the name for fluid, which is usually sterile salt water, given to the patient through a tube that goes in either under the skin or through a vein. Sometimes the doctors and nurses may feel that giving a drip might help. If a drip is started, it will be reviewed by staff over the next 24 to 48 hours to see if it is helping and also to make sure there are no side effects from it.

However, for most people with only hours or days to live, their body's systems are shutting down and thirst is not a problem. Drips often do not help, and good mouth care is the most important comfort measure.

Can you give drips at home if they might help?

For most people, this is not necessary. It is not usually safe to do so at home.

Are there any disadvantages to drips?

Yes. In the last few hours or days of life the body cannot handle fluid as efficiently as before - giving drips can sometimes make things worse by overloading the delicate fluid balancing mechanisms of the body. If this happens the person may experience 'chestiness' or noisy breathing, and swelling of the arms or legs, as their body cannot process the fluid from the drip.

Once a decision about a drip has been made is it final?

No. The doctors and nurses will always monitor the situation and discuss it on a regular basis. The patient always has the right to say that they want to have a drip removed. If the patient is too ill to make that decision, the doctors and nurses will make a careful assessment and have a discussion with the patient's family about the right thing to do. The ultimate responsibility for decisions about starting and stopping a drip rest with the senior doctor caring for the patient. Any decision that is made can always be reviewed.

Useful Resources

Macmillan Cancer Support - www.macmillan.org.uk

British lung foundation – www.blf.org.uk

National Health Service - www.NHS.uk

Cancer research - www.cancerresearchuk.org

Nutricia ONS - www.nutritionincancer.co.uk

Useful Contacts

If you require any further advice, please contact:

St Helena

Single Point

Barncroft Close

Highwoods

Colchester

Essex CO4 9JU

Telephone: 01206890360

East Suffolk and North Essex NHS Foundation Trust

Nutrition and Dietetics Department, Colchester,

Tel: 01206 742668

Anglian Community Enterprise

Dietetics Department,

Main Gateway Tel: 03000032144