



Huntington's
Disease
Association



Huntington's disease: Eating well guide

Contents



The importance of eating well 2



The impact of Huntington's on diet and nutritional needs 3



Swallowing problems 8



A healthy and balanced diet 11



Weight loss and the nutrition gap 13



Dental care 18



Resource library 21



Notes 23



The importance of eating well

Good nutrition is essential for health and well-being. Certain health conditions can put a strain on the body, and people living with Huntington's will often be more at risk of not getting enough good nutrition compared to someone without the condition.


Huntington's disease affects everyone differently, not everyone will face the same challenges and this includes challenges with eating and drinking.

As Huntington's progresses, issues with nutrition may become more prevalent as cognitive and physical changes, and changes in mood, may make eating and drinking more difficult. This can lead to weight loss or malnutrition.

Malnutrition and reduced dietary intake can further decrease energy levels and can result in increased muscle wastage, reduced physical strength, a weakened immune system and an increased risk of infections. In the event of malnutrition, it is important to act quickly to reduce the risk of adverse effects and to promote positive physical outcomes.

Practical nutritional advice may help people with Huntington's disease and their carers cope with challenges relating to nutrition.

Our Specialist Huntington's Disease Advisers are able to provide advice, guidance and signpost to other organisations that can help on all matters relating to diet, nutrition and dental care. To get in touch with your local adviser, contact us at:

 0151 331 5444

 info@hda.org.uk



The impact of Huntington's on diet and nutritional needs

Huntington's is a hereditary condition which usually occurs in adulthood and affects the central nervous system. There is a rare form of the disease that affects children and young people under the age of 20 years known as Juvenile Huntington's disease. Symptoms vary from person to person and some may be evident before diagnosis.

How does Huntington's affect diet and nutrition?

Chorea movements

Chorea movements are jerky, uncontrollable muscular movements. These movements tend to use more energy, thereby contributing to weight loss if enough calories are not being consumed to counter-balance the increased energy needs.

Stumbling or clumsiness

Stumbling and clumsiness can make eating and drinking difficult and can cause embarrassment, which may result in eating less.

Poor concentration and short term memory lapses

Poor concentration and short-term memory lapses can lead to difficulty in planning when and what to eat. In some cases, people can often completely forget to eat as they do not recognise hunger in the same way that they used to.

Depression and mood changes

Depression and mood changes can affect the desire and motivation to eat.

Communication issues

Issues with communication can also have an impact on reducing nutritional intake as it may be difficult to effectively articulate needs.

Muscular changes

Muscular changes can lead to practical issues around eating, drinking and posture. These can include reduced hand to mouth co-ordination and jerky chorea movements limiting food getting into the mouth.

Swallowing problems

Swallowing problems, also known as dysphagia, can lead to difficulties whilst eating and drinking due to increased risk of choking.

Why does Huntington's affect diet and nutrition?

Increased energy expenditure

A person with Huntington's who is having chorea movements will be using up more energy than they would be without the movements. This means more protein and calories will be required to maintain weight. As the condition progresses, requirements are significantly more compared to standard intake.

Changes in appetite

Changes in appetite can occur at various stages of Huntington's and can be for a variety of reasons. They can be due to physical changes, like difficulty with swallowing, or mental changes, like low mood or depression. Fear of spilling foods or choking can also contribute to someone not eating.

Dry mouth

Medication and/or dehydration can result in a dry mouth. If a person has dry mouth it may help to take small sips of water frequently,

suck on sweets with sharp citrus tastes to increase saliva or suck on ice cubes made from fruit juice. If the problem persists a GP may also be able to give advice on artificial saliva preparations which are available on prescription.

Communication and cognition

Communication, cognition (the process of planning what to say) and speech production (the process in which thoughts become speech) can all be affected by Huntington's disease. It is therefore essential to maintain as much communication as possible from the beginning.

Huntington's can make it difficult for people to put thoughts into words. Due to short term memory loss it is common for people to lose their train of thought and become harder to understand. This can have an impact on many day-to-day activities including eating habits, meal planning and ensuring food preferences are met.



Tips on improving communication

For those living with Huntington's

- It may help to make a list of food preferences early on, highlighting specific likes and dislikes. This can be helpful when other people are preparing food or assisting with eating, especially when communication becomes more difficult.
- It can be difficult when multiple things are happening at once. Reducing noise and distraction at meal times can help with focus and concentration.



Tips on improving communication

For carers

- A person with Huntington's may need more time to make a decision, express their thoughts and make themselves understood, so it is important to be patient and not rush them.
- Communication aids can be helpful and it is advised that they are introduced early enough when the person can still learn a new skill. Picture boards can be particularly useful when making meal plans and choosing from menus.
- A person with Huntington's may not be able to communicate with speech, but may still be able to understand a lot of what is going on around them. A speech and language therapist can evaluate and maximise communication skills and where possible provide management techniques which can be used throughout the progression of the condition.

Muscular changes

A reduction in both muscle strength and range of muscle movement makes the action of eating, drinking and swallowing more difficult. In addition to the jerky movements, a person's strength and coordination can impact on how efficiently they eat, drink and swallow. Upper arm and hand muscles can be affected, making hand to mouth co-ordination more difficult and the ability to prepare food and eat it more challenging.

An Occupational therapist can help with practical tips to assist with eating and drinking. For example, they can advise using beakers or cups fitted with straws and valves if drinking from a glass has become a struggle. A GP is able to make a referral to an Occupational therapist.



Swallowing problems

As Huntington's progresses muscles in the face and throat become weaker. This can lead to problems with swallowing as muscles in the face and throat are used to chew food, hold food and drink in the mouth, pass food and drink to the back of the throat, and then down the throat to swallow.

Many people with Huntington's can experience the following:

- Difficulty placing liquid food in the mouth, closing lips together to keep food in the mouth, chewing food or holding the drink in the mouth in preparation to transfer the food or drink to the back of the throat.
- Difficulty with co-ordination, timing and speed of getting food to the back of the throat. Sometimes food or drink may transfer too quickly or too slowly.
- Difficulty with food or drink being efficiently and effectively swallowed and entering the oesophagus and not 'going down the wrong way' into the airways to the lungs.

It is important to be aware of early changes affecting swallowing and concerns should be raised with a GP or one of our Specialist Huntington's Disease Advisers (SHDAs), who can make a referral to a speech and language therapist (SALT). This can be a particularly distressing and alarming time, so seeking advice from a speech and language therapist will provide reassurance. A speech and language therapist will assess the strength of the muscles in the throat and mouth and will measure ability to swallow. They may recommend foods and drinks which are easier to swallow.

Signs to look out for that may indicate early problems with eating or swallowing



Coughing and choking when swallowing food or after meal times.



A gurgling or wet sounding voice.



Food left in the mouth.



Feeling chesty.

What to expect from a speech and language therapist

A speech and language therapist will generally start by assessing the level at which someone is struggling with eating, drinking and swallowing.

An assessment may involve a discussion around any difficulties experienced when swallowing, a meal time observation and a swallow assessment.

A swallow assessment is a non-evasive clinical assessment of 'swallow function', which measures how food and drink is being chewed and swallowed. If the speech and language therapist identifies swallowing difficulties, they will recommend foods with appropriate consistencies which are considered safe to swallow.

As thickened foods and drinks are easier to control in the mouth and to swallow, they may suggest adding a thickening product to meals to thicken food. This is classified into various degrees of texture modification. Thickening products can be prescribed by a GP.

Foods that may be particularly hard to swallow

- Stringy and fibrous foods, like pineapple, celery and lettuce.
- Foods that have a skin, like peas, grapes and baked beans.
- Mixed consistency foods, like soup with lumps, stewed fruit, mince with thin gravy and muesli.
- Crunchy foods, like toast, crisps and flaky pastry.
- Hard foods, like nuts, seeds and chewy sweets and toffees.
- Husks, like sweet corns and grains.



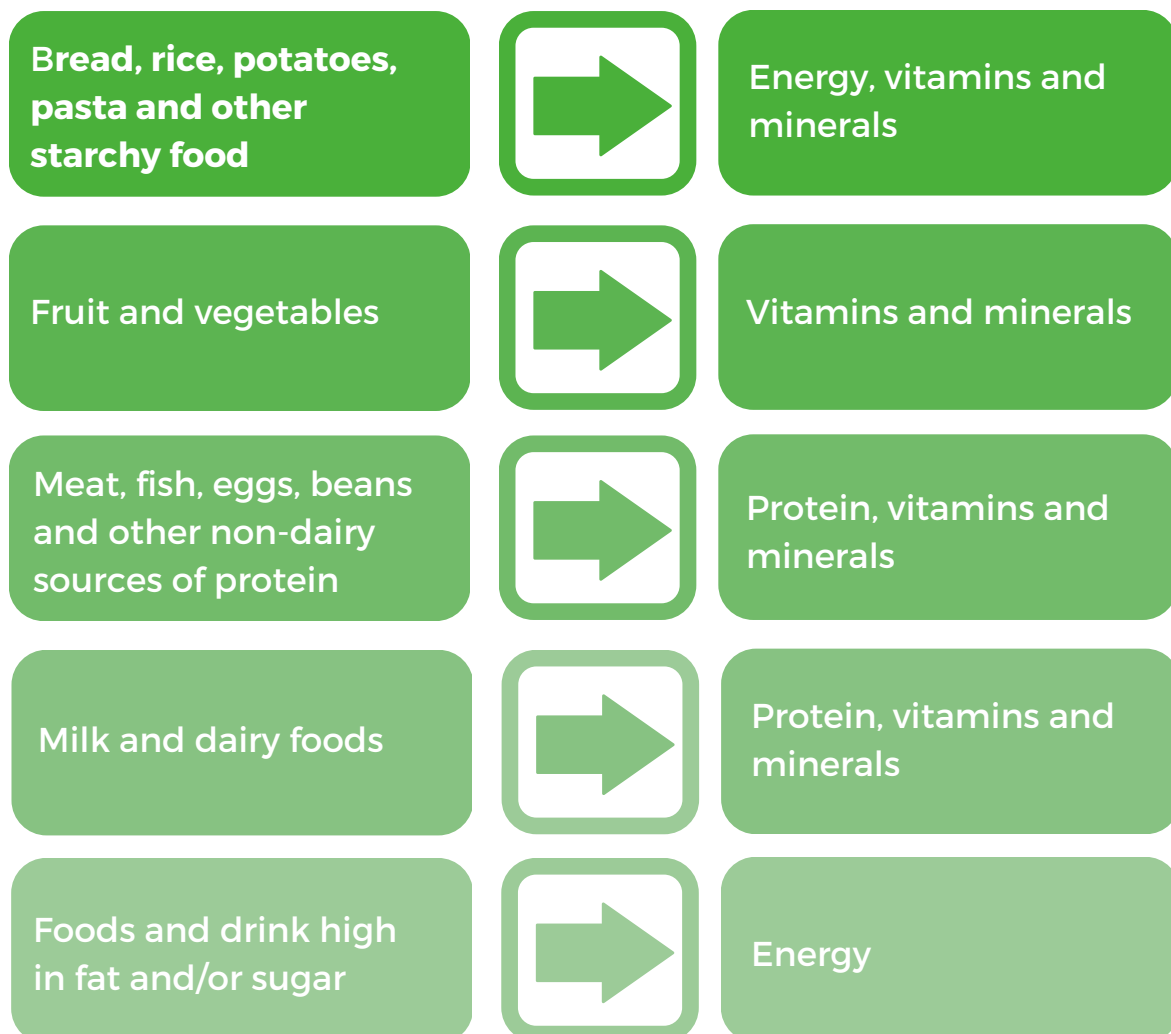
Tips on preparing food

- Chopping, mashing or mincing food, where possible.
- Removing lumps of fruit, vegetables and potato with a fork, masher or stick blender.
- Using a blender or food processor to mince meat and chicken into smaller, more manageable sizes.
- Varying flavours by adding soy sauce, Worcester sauce, tomato ketchup, curry powder, or herbs and spices to savoury dishes, and jam to sweet dishes.



A healthy balanced diet

Eating a healthy, balanced diet is essential to maintain a good level of health. This includes eating a variety of foods from all the different food groups on a regular basis, to provide the body with all the energy and nutrients that are needed.



Breads, cereals, potatoes, pasta and rice

Breads, cereals, potatoes, pasta and rice provide energy. It is important to consume a selection of these foods throughout the day in order to keep energy levels up. As the day progresses, tiredness can increase, so basing meals on starchy carbohydrates will help to increase energy. Where possible it is best to choose wholegrain versions, as they are a good source of fibre.

Meat and protein

Meat and protein is essential for maintaining muscle mass and for growth and repair of tissues, including those that support the immune system. A portion of protein should feature in at least two meals a day, as well as with snacks. Good sources of protein include meat, fish, dairy products, tofu, beans and lentils. A wholegrain cracker with cheese or pâté can be a more nutritional snack than a sweet biscuit.

Fruits and vegetables

Fruits and vegetables provide a good source of vitamins and minerals, which help to support the immune system. It is best to aim for five portions of fruit and vegetables a day and this can include tinned and frozen products, as well as fresh. A glass of fresh fruit juice at breakfast, a banana on toast as a snack and tinned mandarins served with custard or rice pudding as a dessert are all good ways to ensure inclusion of fruit and vegetables within a diet.

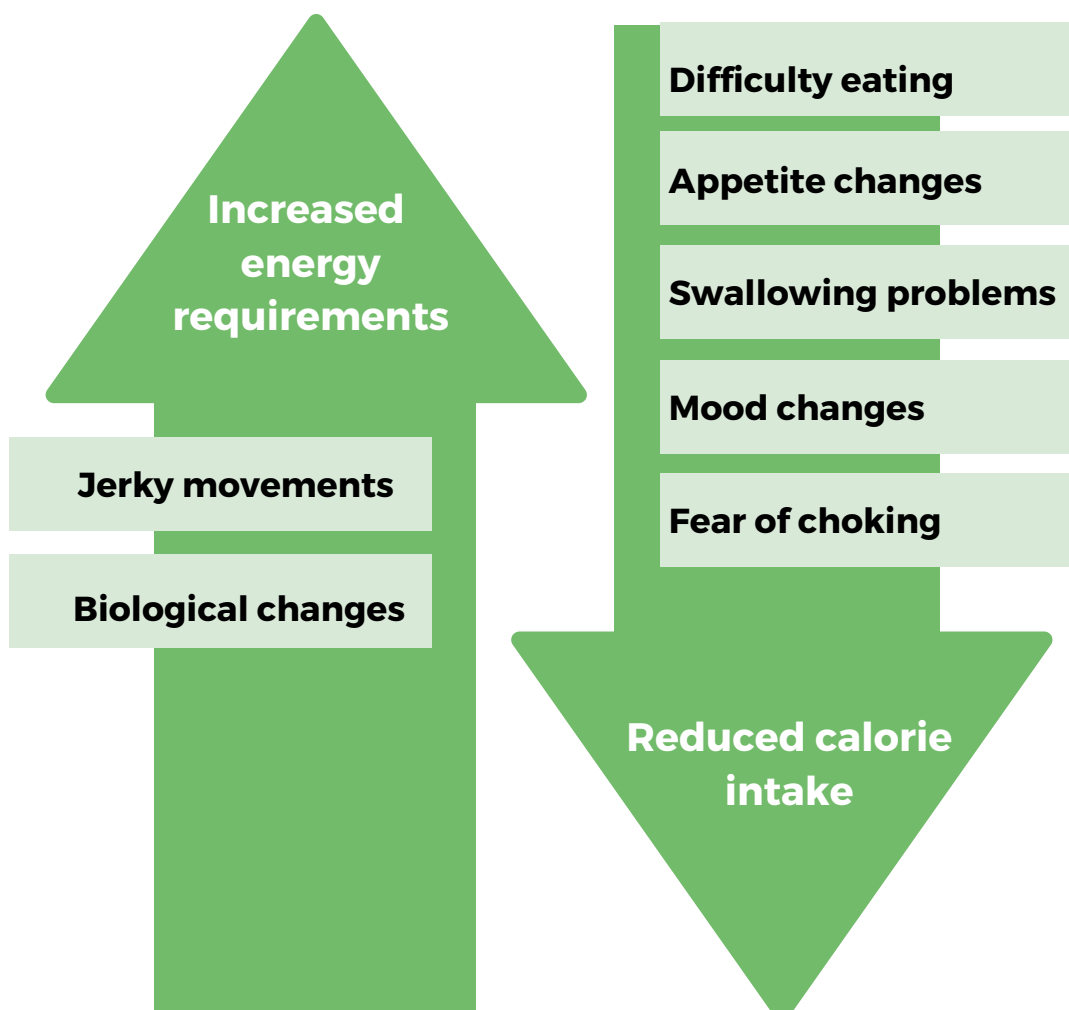
Milk and dairy foods

Dairy products are rich sources of protein and calcium, and are required for bone strength. Examples include milk, cheese, cream, yoghurt, fromage frais and custard.



Weight loss and the nutrition gap

Weight loss may slowly occur during the early stages of Huntington's disease and may go unnoticed for a while. As Huntington's progresses and more symptoms appear, people often find it more difficult to maintain their weight and to prevent significant unintentional weight loss. People with Huntington's usually need to eat a diet which is higher in calories than normal in order to minimise weight loss. However, it is more common to see somebody using up more energy, whilst also decreasing food intake. This is known as the nutrition gap.





Tips on how to increase nutritional intake and avoid weight loss

- Instead of three main meals a day it may be easier to try smaller meals and snacks every two to three hours.
- Prioritising food which is high in calories and protein means that even if a small amount of food is managed, vital nutrients can still be absorbed.
- Similarly, using full fat milk or cream as an accompaniment to cereals, puddings and drinks is an easy way to increase protein and calcium intake.
- Adding extra butter, cheese or mayonnaise to savoury meals, and syrup, sugar, jam or honey to sweet snacks, is a good way to add calories to a meal.
- Drinking with a meal can decrease appetite, so should be monitored or avoided altogether.
- Regular snacks like biscuits, chocolate and crackers should help keep weight up.
- Fortified drinks based on full fat milk, such as Complan, are commercially available and can be added to meals to increase energy and protein intake.
- Keeping a food diary can help a health professional identify where there may be areas that need attention. Details like portion size and the way that a meal is cooked can be incredibly helpful.

What to do if food is not enough

Food may not be enough and if weight loss continues regardless of what is being eaten, speak to a GP to discuss the unintentional weight loss. Bringing along a five day food diary and indication of the total weight lost over the last three to six months may help the conversation. If the GP identifies there is a risk of malnutrition, they may make a referral to a dietitian.

What to expect from a dietitian

A dietitian will carry out a nutritional assessment which focuses on how Huntington's disease is impacting nutritional status. A nutritional care plan will then be created and carefully monitored to ensure nutritional requirements are met. If someone is at risk of malnutrition or are malnourished, the dietitian may advise on the use of prescribed medical nutrition for the dietary management of disease-related malnutrition and/or dysphagia.

Medical nutrition

Medical nutrition products are specialised foods designed to meet the needs of those living with a medical condition, recovering from an illness or operation, of those who have become weak over time. They are often referred to as Oral Nutritional Supplements (ONS) or Food for Special Medical Purposes (FSMP).

Medical nutrition products are usually prescribed by a healthcare professional and must be used under medical supervision.

Oral nutritional supplements

Oral nutritional supplements are available in a variety of formats and styles, including shakes, juices, yoghurts, and desserts, as well as a variety of flavours to suit different taste preferences.

Making the decision to start tube feeding

Despite best efforts, sometimes it becomes no longer safe or possible to meet nutritional needs by mouth. When a person can no longer eat safely, it may be that a healthcare professional suggests tube feeding. This can be difficult to deal with especially if someone is also struggling with thinking and speaking challenges. It is important to discuss preferences about what will happen in the future earlier on in the disease.

Tube feeding is a way of getting a body the nutrition it needs. It provides a liquid form of nourishment that delivered into the body through a flexible tube. The nutrients are similar to those someone would get from normal food, and are also digested in the same way. It contains all the nutrients someone would need on a daily basis, including carbohydrates, protein, fats, vitamins, minerals and water.

Tube feeding

Everyone has different nutritional requirements. The product a person requires will be tailored to their needs and will depend on weight, height, activity level, and if they can still eat and drink small amounts. A dietitian will be able to discuss and advise on the most appropriate product.

Types of feeding tubes

There are two main types of feeding tubes which can be used. Nasogastric tubes (NG) are inserted through the nose and into the stomach. They are easier to fit as they do not require surgery, but they are generally used for shorter term feeding. Gastrostomy tubes are inserted via a procedure called an endoscopy, which requires anaesthetic. If someone is going to need a feeding tube for a long time, a gastrostomy is likely to be the preferred option.

A healthcare professional will recommend what type of feeding tube is needed.

Feeling overwhelmed is natural when faced with the decision to start tube feeding. Advice and support surrounding this topic can be found at:

 www.tube-feeding.com

This is a website dedicated to supporting individuals and their families throughout their tube feeding journey.



Dental care

The importance of dental care in Huntington's*

The teeth of someone with Huntington's disease are no different from those of someone without, but people with Huntington's do present clinically with more dental problems. This is primarily due to difficulty in cleaning the teeth properly and clearing the mouth of food after eating.

For a dentist, the treatment of someone with advanced Huntington's can be difficult. They may be faced with a person who, needing a number of fillings, cannot open their mouth widely or sit still. Aspects like financial difficulties, transport problems, limited access to dental surgeries and apathy or resentment can all add to the fact that people don't always access the treatment they need.

It is possible that a person with bad tooth decay would be advised to have the affected teeth removed and full dentures constructed, but this can be the beginning of more problems. Initially, a full denture stays in by suction, but they are also held by the pull of the facial muscles forcing the dentures into place. This muscle activity is automatic, but for someone with Huntington's low-level muscular activity is often overridden by uncontrolled involuntary movements that could frequently and spontaneously push a denture from the mouth. If a person has no teeth and no dentures they may suffer from low self-esteem.

Specific dental problems and their causes

Using a toothbrush can become difficult and sometimes impossible. Consuming a diet that is high in sugar in order to increase energy intake can contribute to tooth decay.

This is caused by sugar being processed by bacteria in the plaque into acid, which goes onto dissolve the tooth.

A tooth is considered to have a threshold, which varies from person to person and this is the number of times a day that it can withstand acid attack without decaying. A tooth can recover by remineralization between attacks, but if the threshold is exceeded regularly then the surface of the tooth will be disrupted and an irreversible lesion will have occurred. Bacteria in the plaque on the teeth can also irritate and destroy the gums and the ligament which attaches the teeth to the bone. This is called gum disease and as it progresses the teeth can become loose, sensitive to pressure and gum boils may occur.

Prevention of dental issues

It is important for everyone to care for their teeth, regardless of whether they have any health conditions. Someone with good dental hygiene prior to diagnosis, will be at an advantage. As the disease progresses the ability to manage personal dental care can decrease, therefore it is very important that someone becomes responsible for this.

Prevention of gum disease

Prevention of gum disease is ensured by keeping the teeth free from plaque and irritation by bacteria. This is done with a toothbrush and dental floss. Early in the course of Huntington's it may be possible for someone to floss their own teeth, but as the disease progresses they may require help from a family member or carer. It is advisable to use a good quality electric toothbrush as early as possible and to practice good dental hygiene, which should remain an automatic behaviour during the course of the disease. The massaging action of the electric toothbrush helps to remove plaque.

Prevention of tooth decay

Diet

Almost all foods contain enough sugar to cause decay, but some foods such as milk, contain protective factors.

Mouth care

The correct and regular use of dental floss and an electric toothbrush help prevent tooth decay. Toothpaste that contains fluoride can also help. Specialist equipment is available and community dentists may be able to make a home visit.

Before bed

As saliva flow is much less during sleep, food clearance is slowed. It is therefore advised not to eat within half an hour of going to bed.

Fluoride treatment

Toothpastes and mouthwashes with more than the normal concentration of fluoride can help in fighting tooth decay. It is also advisable to have a dentist apply fluoride to the teeth in a stronger solution, or as a slowly dissolving varnish, during regular check-ups.

Care by a dentist

A dentist can de-scale the teeth to prevent gum disease, apply fluoride to improve the resistance of the teeth (raising the frequency of intake threshold) and detect early cavities. If they know that a patient is at risk of Huntington's disease, they can choose specific filling materials (such as glass ionomers) that, although being a little more brittle than silver amalgam, do tend to increase resistance to decay. Normal cavity design can sometimes be modified with a view to preventing decay. Design of partial dentures should take Huntington's into account and should therefore have extra retention to counteract excessive dislocating forces. As extraction of other teeth is more likely, denture design can allow for easy addition of extra teeth.



Resource library

The following charities, organisations and information sites may be able to provide further information and guidance on the topics covered in this guide:

| Organisation | Contact details | Support |
|--|--|---|
| Huntington's Disease Association | 0151 331 5444 info@hda.org.uk www.hda.org.uk | <ul style="list-style-type: none">AdviceSupport resourcesOnline forum |
| Nutricia Advanced Medical Nutrition | www.nutricia.co.uk | <ul style="list-style-type: none">AdviceMedical nutritionLocal services |
| British Association of Parental and Enteral Nutrition (BAPEN) | www.bapen.org.uk | <ul style="list-style-type: none">AdviceSupport resourcesScreening tool |
| Carers UK | 0808 808 7777 info@carersuk.org www.carersuk.org | <ul style="list-style-type: none">AdviceSupport resourcesOnline forum |
| Living with tube feeding | www.tube-feeding.com | <ul style="list-style-type: none">AdviceSupport resources |
| Patients on Intravenous & Nasogastric Nutrition therapy (PINNT) | www.pinnt.com | <ul style="list-style-type: none">AdviceSupport resourcesPeer support |

NHS UK

Local telephone list
www.nhs.uk

- Advice
- Medical services
- Referrals

Emergency services

999

- Medical
- Crime
- Fire

NHS 111

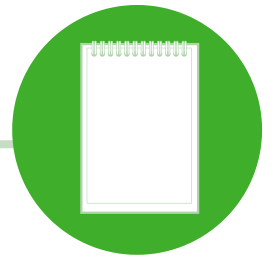
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- Non emergency medical advice

* The chapter containing information about dental care (pages 18 - 20) has been produced solely by the Huntington's Disease Association

**NUTRICIA**
LIFE-TRANSFORMING NUTRITION

The information contained within this guide has been produced in partnership with Nutricia Advanced Medical Nutrition.



Notes

Get in touch

For advice and support
or to speak to a
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