



Nutrition & Huntington's Disease

Who can help?

The main source of support regarding nutrition will be a dietitian and you should ask for a referral from your GP or HD Specialist Nurse. Ideally you, and your family, should be aware of the potential issues surrounding diet and weight management from early on in the disease. This will allow you to foresee and hopefully avoid some common problems. You should also seek a referral to a Speech and Language Therapist whose job is also to look at swallow, which might affect food intake.

If you need help or support please contact HDANI info@hdani.org.uk and one of our Family Support Workers will be in touch.

Common Problems

- Depression may cause a reduced interest in food
- Cravings for certain types of food
- Difficulty swallowing
- Choking
- Increased calorie needs
- Jerky movements and poor co-ordination making eating slow and messy
- Distraction or agitation during mealtimes
- Medication might affect diet

Your questions answered

The following Q&A is taken from a session held in October 2020 with Jude Munn, a Specialist Dietitian, working with the West Midlands Regional HD Service. Please note that the answers given are general and you should seek advice from your GP or a referral to a Dietitian and/or Speech and Language therapist for specific advice.

How soon after you are diagnosed with HD should you change your diet?

Everyone benefits from a well-balanced nutritious diet and people with a predictive diagnosis of HD are no different. Unless specific dietary issues have been diagnosed you should continue to eat a good mix of healthy food with plenty of fruit and vegetables and ensure you stay well hydrated.

I find it very hard to get my wife to take any interest in food. Can you get me any advice?

Sorry to hear your wife has lost interest in food and has a small or reduced appetite, 'healthy eating' may not be appropriate for her at this time. When you are unable to eat as much as usual there are some things you can try to make the diet as nutritious as possible.

Try not to worry too much if she can't face 'normal' meals. Try to encourage her to eat or drink something nourishing every couple of hours, even if it's small. It is important that the food and drinks she has contains as much calories and protein as possible.

The following tips can help to get the most out of food:

Tips to help improve appetite:

- Eating little and often can help improve a reduced appetite. Try to include three small meals and 2-3 nourishing snacks per day.
- Avoid low-fat or reduced-sugar foods or drinks, for example, use full-fat (whole) milk instead of skimmed or semi-skimmed milk and normal butter/margarine/olive oil or sunflower spread rather than low-fat spread.
- Try to encourage her to eat in a relaxed, quiet and comfortable environment.
- Serve a smaller portion of the meal to prevent her feeling overwhelmed, she can always go back for more.
- Aim for her to drink at least 6-8 cups of fluid daily, ideally 568ml (1 pint) of which is full-fat (whole) milk or fortified.
- Encourage your wife not to rush her meals – encourage her to take time to relax and enjoy them.
- I'm not sure if your wife smokes but if she does it can suppress appetite. If she does smoke, encourage her not to smoke in the half-hour before the meal.
- Try not to let her fill up on drinks shortly before or during meals, have drinks after meals.
- A small glass of alcohol 30 minutes before a meal may help to stimulate appetite; however, check with your doctor/pharmacist first to make sure this is suitable with any medications she might be taking.
- Fresh air can often stimulate appetite too. If possible, go for a brief stroll or encourage her to go outside for a while before eating. Eating in a well-ventilated room can also help
- Eating in the company of others might help too.
- Encourage her to try to sit up at a table or have meals on a tray.
- On the days when your wife's appetite is better, make the most of these good days and encourage her to eat well. Try to include her favourite foods.
- Choose a variety of foods. Alternating what she eats can help keep things interesting, however she might be happy to have the same foods and that is okay, the main thing is she is eating- there is no good and bad food- they all contain energy and some nutrients.
- Extra protein and calories can be added to normal foods to increase the nutritional content without increasing the portion size. This is known as food fortification. This means that each mouthful eaten is more nourishing.

Tips for fortifying foods:

- Fortified milk can be made by adding 4 heaped tablespoons (about 50g) dried skimmed milk powder to 1 pint full-fat milk, this can be used, for example, in drinks, on cereal, in custard and rice pudding and in cheese sauce
- Spread butter/margarine thickly on bread and use liberally as follows:
 - Melt onto vegetables, boiled potatoes or jacket potatoes
 - Stir into hot pasta or rice
 - Stir into baked beans or scrambled eggs
- Add grated cheese to soups, omelettes, scrambled eggs, baked beans or tinned spaghetti
- Add cream, ice-cream or custard to puddings or fruit (fresh or tinned)
- Add salad cream/mayonnaise to sandwich fillings or serve as an accompaniment with suitable foods.
- Add sugar, honey or syrup to puddings, sauces, drinks and cereals.
- Add full fat yoghurt to breakfast cereal and puddings.
- Add ice-cream to fruit (fresh, tinned, frozen) and puddings.
- Have a pudding once or twice a day. It may help to have it as a snack in between meals rather than straight after the meal if your wife is likely to be full
- You may find that fruit and veg is bulky and filling try a glass of fruit juice or soft tinned fruit as an alternative

Nourishing Snacks and Drinks

- Milky drinks such as coffee, malted drinks or hot chocolate
- Milkshake - try adding ice-cream
- Small bowl breakfast cereals with full-fat or fortified milk
- Small piece of cheese
- Examples of toppings for toast, croissants, crumpets include: butter, jam, marmalade, honey, peanut butter, chocolate spread, tinned tuna, tinned salmon, chicken, corned beef, ham, egg and cheese.
- small bag of crisps- skips and wotsits are softer options
- sausage rolls, Scotch eggs, spring rolls, pakora, onion bhajis, samosas

Sweet snacks

- 2-3 biscuits, e.g. shortbread, digestive, ginger, cream/jam filled biscuits, chocolate covered if they are not too hard, she could dunk in tea if they need to be softer
- Cake, e.g. sponge cake, Danish pastry, doughnuts, jam tarts, iced buns
- Small packet of sweets, e.g. soft sweets, jelly, or marshmallows
- A few squares of chocolate or chocolate buttons- melt in the mouth
- Scone with clotted cream and jam, Scotch pancake with butter and sugar, Hot cross bun and butter
- Full fat yoghurt, mousse, crème caramel, cheesecake, trifle, custard, rice pudding
- Full fat ice cream

Nourishing drink ideas:

- Nourishing drinks can be a good way of supporting nutritional intake in addition to the foods eaten. Try to encourage her not to fill up on tea, coffee, Oxo, Bovril, fizzy drinks, water and clear soup as these have little nutritional value and tend to fill you up. (milky drinks, smoothies and fruit juice have more calories than tea and water).
- Make homemade milkshakes adding double cream or ice cream to make the drinks more nourishing
- Ready-made milkshake such as Yazoo, Frijj, Mars, Galaxy or supermarket own brands are an option too.
- Over the counter nutritional supplements such as Complian and Meritene can be purchased in most major supermarkets and chemists.

Recipe ideas for nourishing drinks:

Fruit Smoothie

1 ripe banana or handful of frozen berries
1 scoop of ice cream
1 teaspoon of sugar
200ml fortified full fat milk
Blend until smooth.

Malt honey milkshake

1 teaspoon malted milk powder
1 tablespoon of honey
1 scoop of ice cream
200ml fortified full fat milk
Blend until smooth.

Super Shake

2 teaspoons of milkshake flavouring e.g. Nesquik or Crusha
3 tablespoons of double cream
1 scoop of ice cream
200ml fortified full fat milk
Blend until smooth.

Super Soup

1 packet of cup-a-soup/ powdered soup
2 tablespoons of double cream or grated cheese
200ml warmed fortified full fat milk
Mix together and serve warm.

What food is given in the PEG?

Special liquid feeds are given through a PEG, they are nutritionally complete and contain all the vitamins & minerals, protein, energy & fibre (if required) for someone. The feed regime is worked out by a dietitian to meet someone's specific needs, they might need more protein, more calories, or more fibre. These feeds are either in bags if pump feeding or 200ml bottles if bolus feeding (fed with a syringe at regular times). They are prescribed by the GP.

Are there any superfoods for HD? I read on Facebook a person that recommended brushing your gums every day with coconut oil and eating blueberries daily.

Blueberries are high in antioxidants which are beneficial to health – heart disease, certain cancers, brain health & aging; some research studies have found they are of benefit with brain health specifically in Huntington's disease.

Coconut oil is high in MCT short for (Medium Chain Triglycerides) which have been found to improve brain function and has been shown in research to help brain health in HD. Coconut oil certainly wouldn't damage your teeth but I'm not sure it would taste very nice. Coconut oil can be used in cooking but introduce it slowly as too much can upset your stomach. In addition coconut oil wouldn't be recommended if someone has a high cholesterol as it is a saturated fat (please note: it is relatively uncommon for patients with Huntington's Disease to have a raised cholesterol).

My mum sometimes chokes a bit on her food. Should I puree everything just in case? She was a great cook and used to love her food- I don't think purees look very appetizing.

Dietitians work very closely with Speech & Language Therapists and they assess patients swallow and give recommendations on the correct consistency of food someone with swallowing problems should have in their diet. Pureed diets are often advised for people with swallowing problems. It can take practice to make pureed meals look attractive – it helps to puree the foods separately so the colours of the foods don't mix – if the foods mix they can look grey/brown and not so appealing. Special moulds of the foods being pureed can be bought on the internet too and these can be used to keep the foods separate and their colours so the meal looks a lot more attractive which can help. There's a company called Wiltshire Farm Foods (they have a base in Dublin) who produce a range of pureed meals in line with new IDDSI (The International Dysphagia Diet Standardisation Initiative) descriptors – level 4 pureed meals, level 5 minced, level 6 soft & bite sized- it might be worth a look on their website you could request a brochure to look at for meal ideas and maybe buy some, they are nutritionally balanced and provide the nutritional information they are quite good for calories too– often 500kcal per meal. They have small portions too.

In there anything you can do form a dietary perspective to help those who have a fear of choking/aspiration when eating and drinking?

The Speech & Language Therapist, who we work closely with would recommend the safest IDDSI level (The International Dysphagia Diet Standardisation Initiative) descriptors – level 4 pureed meals, level 5 minced, level 6 soft & bite sized- for a patient who has a fear of choking/aspiration when eating and drinking. This would reduce their risk of choking; using the most appropriate texture for someone would hopefully increase their confidence with eating.

Dietitians would support patients with suitable meal choices and ideas with the recommended modified texture (IDDSI level). Ensuring the diet meets the patients need as best they can by fortifying meals where possible to make them energy dense with butter, oil, cream, full cream milk and milk powder and advise on nutritional supplements if they someone is not meeting their nutritional needs with food alone.

Do you have any food suggestions for good fats?

It is important to have fat in your diet especially if someone is trying to either avoid losing weight and if they need to gain weight as fats are such a good source of energy. I would advise anyone to use fat in their diet from the foods they like and enjoy – butter, oil for frying food- olive, sunflower, coconut, cream, mayonnaise, smooth nut butters, pate, cheese, soft cheese. Fortunately very few patients have raised cholesterol so we don't often need to be concerned about saturated fats (hard fats that can raise cholesterol), but if anyone did have a raised cholesterol I would suggest they do not have too much hard fats like butter and coconut oil but to use more olive, sunflower, rapeseed, vegetable oil or olive oil or sunflower based margarines.

What are the most useful aids to support meal times?

- Adapted cutlery that is easier to hold e.g. <https://tinyurl.com/yyk235fq> and adapted plates that are slightly heavier than normal and designed so food is less likely to spill off the plate might be an option e.g. <https://tinyurl.com/y6zlyu2q>
- Beakers or mugs with lids might be easier to use and reduce spills.
- Non-spill, 360-degree flask mugs are available for purchase from HDANI
- Spouted beakers could help e.g. <https://tinyurl.com/yyecybxxy>
- Sports bottles are sometimes a good alternative to mugs and cups e.g. <https://tinyurl.com/y47jj2g5>
- Plate warmers can be a good option if it's taking someone a long time to eat a meal e.g. <https://tinyurl.com/y4tna64s>
- If too tired to cook, use ready-made oven/microwave foods or freeze extra portions of meals when cooking and use another day. Slow cookers are a great way to make bulk meals for freezing with limited cleaning e.g. <https://tinyurl.com/y3bdy5at>
- There are a variety of ways that you can purchase meals such as ready meal delivery services. Consider what would be convenient for you.

Online resources

There are some excellent, specialist HD resources available online which provide an explanation of how HD affects a person's metabolism, tips on nutrition and even recipes to try including the following;

Huntington's Disease Association of America
<https://hdsa.org/find-help/living-well-with-hd/nutrition/>

Huntington's Disease Association, *Huntington's Disease: Eating Well Guide*
<https://www.hda.org.uk/media/2108/huntingtons-disease-eating-well-guide.pdf>

HDBuzz- *Do Dairy Foods Accelerate HD?*
<https://en.hdbuzz.net/150>

Nutrition and HD by Anna Gaba
<http://endoflifecare.tripod.com/hunt-disease-faqs/id103.html>

Recipes for People with HD by Renette Davis
<http://endoflifecare.tripod.com/hunt-disease-faqs/id103.html>

The view our video training session on nutrition please visit
<https://www.youtube.com/watch?v=rxWHPU2t7BQ>