



Huntington's Disease Association

Huntington's disease

HD and Diet

Fact Sheet

Huntington's Disease and Diet

Why do I need to eat well?

People with Huntington's disease can find it difficult to maintain their body weight, or they can be underweight. People who are very underweight are prone to infection, have slower wound healing and progressive muscle wasting and lethargy. People with Huntington's disease usually need a much higher calorie intake than normal.

I am hungry but find eating difficult

You do not have to eat large meals. Small frequent snacks, high in calories (little and often) can be just as helpful.

Do not drink large amounts of fluids with meals as these will make you feel full quickly but do try to drink plenty of fluids in between meals. Take your time over meals. Sit comfortably.

Add extra calories

MILK is a good source of protein. Try to drink at least one pint of full cream milk a day. You can add calories easily to milk by adding 2oz skimmed milk powder to 1 pint of full fat milk.

YOGHURT or similar desserts can be used on fruit and puddings. Those with added cream or the thick 'n' creamy ones are ideal. Avoid low fat or diet yoghurts.

DOUBLE CREAM added to cereals, fruits, puddings, soups and mashed potato etc will increase calories.

CHEESE is a good source of both protein and calories. Full fat cheeses such as cheddar and Lancashire are the best. It can be sprinkled on creamed potatoes, soft vegetables, soups, fish in sauce, minced meats and baked beans. Add cheese to omelettes and scrambled eggs. Cheese in a sandwich, on biscuits or on toast is an excellent snack.

MEAT AND FISH in any form is useful. Cook well and serve with plenty of gravy or sauce. Tinned fish in oil or mayonnaise rather than brine or tomato sauce has more calories.

LENTILS AND BEANS are also a good protein source. They can be added to soups, casseroles, and stews, or used just as a vegetable. Baked beans on toast is a useful snack.

Foods you may find difficult to swallow

Raw or hard cooked vegetables, salads, peas, sweetcorn, broad beans, tomato skins; hard fruits such as apples, pears, grapes, pineapples, fruit skins or fruit peel; crusty bread, pre-sliced bread, granary bread, high fibre white bread, bread crusts, toast, crackers and crisp breads; sponge cakes; crisps; hard chips; flaky and puff pastry; hard pastry crusts; nuts and food containing nuts; dried fruit and foods containing dried fruit; shredded wheat.

Put more energy in it!!

SUGAR - use lots. Put it in hot and cold drinks, on softened cereals and in desserts.

HONEY, JAM, MARMALADE, GOLDEN SYRUP, TREACLE can be spread generously onto bread, biscuits and scones, if you can swallow these. Stir them into milk puddings and softened breakfast cereals. Add honey to Greek yoghurt for an excellent snack.

CHOCOLATE - can be melted in the microwave and added to custard, puddings or milky drinks.

TROUBLE SHOOTING

Dry mouth

If you find you have a dry mouth you may find the following suggestions helpful:

- small sips of drinks frequently - a small flask with a lid and straw like a cycling flask can be carried around easily.
- fruit drops may help to get the saliva flowing - some people have commented that acid drops help.
- sucking ice cubes is useful unless you are likely to swallow or choke on them. You can make these with lemonade or fruit juice as well as plain water.
- Sorbet

Ask your Doctor about the possibility of prescribing one of the artificial saliva preparations available.

Care of the mouth

To keep your mouth in a healthy condition:

- use mouthwashes regularly. Ask your nurse or Doctor about the best one for you to use
- if your lips are dry, apply a lipsalve eg. Vaseline.
- clean your teeth frequently. Use dental floss.
- visit your dentist for regular check-ups.
- a cube of cheese after each meal will neutralise the acid that causes tooth decay.
- if you wear dentures, keep them clean and make sure they fit correctly. Ask your dentist for advice. Dentures are one of the first things to become loose when people lose weight.

sometimes foods may not taste the same or seem to have no taste - good mouth care can minimise this.

Keeping food down

- sit upright to eat your meals. Try not to lie flat immediately after a meal.
- eat your meals in a well ventilated room and wear comfortable clothing.

- try to ensure there is a calm, relaxed environment.
- minimise what is going on around you so you can concentrate on eating.
- discuss with your doctor or a dietician any problems regarding eating you may be having.

Changing your diet to suit your need

At times it may be necessary to avoid foods that you know cause you problems, actually identifying these can sometimes resolve the problem.

Sometimes you may need to change the consistency of the food i.e. eat softer or puréed food.

If you find you are having difficulty swallowing thin liquids, try thickening them slightly, this often helps and prevents coughing.

There are many thickening agents on the market; your GP can prescribe one for you.

How to get the texture right if you need soft or puréed food

There are three different ways to try:

Using a liquidizer

A liquidizer is the quickest and most efficient way giving the best results.

The following tips may help you:

Try not to liquidize all of the meal together, liquidize the meat and vegetables separately. You can add sauces to give flavour.

Meat and Fish

Remove all skin, bone and gristle from cooked meat and fish, cut into small pieces add stock or gravy or sauce to get the right consistency.

Vegetables

Cook them to soften before liquidizing again add stock, gravy or sauce to get the right consistency. Cooking them by steaming will maintain their nutrients.

Fruit

It is easier to blend fruit that is soft, or thawed if frozen. Tinned fruit in syrup is a good choice. Stewed fruit can also be liquidized.

Using a Hand Blender

These are cheaper than liquidisers but take longer and some foods may not liquidise.

Using a sieve and spoon

After cooking some food can be forced through a sieve this may need to be done more than once.

Whichever method you use it is important to remember:

- meals need to look attractive
- all utensils should be kept clean
- meals may need warming during serving if feeding takes time.
- remember a calm relaxed environment will help!
- nutritional supplements which can help to add calories to your diet are available from your GP.
- a dietician can advise you on your individual needs. Referral can be arranged by your GP.
- a referral by your GP to a speech therapist can be helpful in resolving some of your swallowing problems.

Some ideas for soft and puréed diet

DRINKS

FORTIFIED MILK

1 pint of milk (full fat)
glucose powder

Put the powder into a jug. Add the milk gradually, stirring all the time until all the powder has dissolved. Store in the fridge.

HONEY CUP

1/2 pint fortified milk
2 tsp honey

Warm the milk. Put the honey into a cup. Pour the warm milk into the cup, stirring well.

MILK SHAKE

1/2 pint fortified milk
1 scoop ice cream

Milk Shake flavouring

Stir all the ingredients together in a tall glass

YOGHURT FLIP

1/2 pint fortified milk
1 carton of ordinary fruit yoghurt
sugar to taste

Whisk all the ingredients together in a tall glass, serve chilled.

MINT CHOCOLATE COOLER

1/2 pint fortified milk
2-4 heaped tsp drinking chocolate
peppermint flavouring
grated chocolate

Mix the drinking chocolate and the peppermint flavouring with a little milk. Add the remainder of the milk, stirring well. Pour into a glass and decorate with grated chocolate.

CITRUS SURPRISE

1/2 pint fortified milk
lime cordial
orange and lemon slices for decoration

Add milk to the lime cordial according to taste. Serve chilled in a tall glass decorated with orange and lemon slices.

WHISKY AND HONEY WARMER

3/4 cup of warm milk
2 level teaspoons clear honey
1 tablespoon whisky or brandy

Warm the milk, stir in honey, and pour into a cup.

HOT MILK MOCHA

1/2 pint of milk
2 tablespoons drinking chocolate
1 level teaspoon instant coffee
1 tablespoon double cream.

Boil milk and pour into mugs, add chocolate and coffee, stir well, swirl in fresh cream and serve.

There are a wide range of high calorie, high protein drinks in many sweet and savoury flavours available from your GP or contact your Dietician.

Meal ideas for those who have difficulty swallowing

Breakfast

Porridge
Instant hot oat cereal
e.g. Readybrek
Weetabix
Fruit juice
Puréed fruit
Plain or flavoured yoghurts
Rice Pudding
Custard

Main Meals

soup
casseroles, hotpots etc,
fish with sauces
pasta dishes
cauliflower cheese
cheesy potato bake
lentil bake

Puddings

puréed fruit
milk puddings eg rice puddings,
semolina, custard, blancmange
jelly, including milk jelly
smooth yoghurts and fromage frais
ice cream and sorbet
instant desserts e.g. Angel Delight,
Birds Instant Whip
egg custards and crème caramel

NB: TRY TO HAVE A GLASS OF FRESH ORANGE OR GRAPEFRUIT JUICE OR BLACKCURRANT CORDIAL EVERY DAY TO PROVIDE YOU WITH SOME VITAMIN C.

A Dietician can give you detailed individual advice about your needs. A referral can be made via your GP.

The Huntington's Disease Association has a team of Specialist HD Advisers who can offer help on a wide range of problems. For details of the Specialist HD Adviser in your area please contact Head Office on 0151 331 5444.

Fact sheets available from the Huntington's Disease Association:

- General information about Huntington's Disease and the Huntington's Disease Association
- Predictive Testing for Huntington's Disease
- Talking to Children about Huntington's Disease
- Information for Teenagers
- Eating and Swallowing Difficulties
- Huntington's Disease and Diet
- The Importance of Dental Care
- Communication Skills
- Behavioural Problems
- Sexual Problems
- Huntington's Disease and the Law
- Huntington's Disease and Driving
- Advice on Life Assurance, Pensions, Mortgages etc.
- Seating Equipment and Adaptations
- Checklist for Choosing a Care Home
- Advance Decision to Refuse Treatment (ADRT)
- A Carers Guide
- A Young Adults Guide
- Challenging Behaviour in Juvenile Huntington's Disease
- A Brief Guide to Juvenile Huntington's Disease for Children's Hospices and Palliative Care Service
- A Young Person with Juvenile Huntington's Disease at School

All fact sheets can be downloaded free of charge from our website www.hda.org.uk or ordered from Head Office.

For a publication price list/order form, membership form, details of our Specialist HD Advisers and local Branches and Groups, please call Head Office on:
Tel: 0151 331 5444 or Email: info@hda.org.uk

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