scottish huntington's association

Keeping well

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Key points from this fact sheet

- Good diet and exercise and looking after yourself can slow the onset of symptoms for some people, or make them easier to manage
- You can look out for your mental health and wellbeing too and that will also make a difference
- Keeping well now can also make a difference later on

General advice on keeping well

The best advice at the moment is that anyone with the HD gene should aim to keep themselves as well as possible. This may slow the onset of symptoms. Also, when you do begin to have symptoms it may be easier to deal with them if you are generally well.

Keep fit and active

We know – it's mostly the advice that everyone gets. But it has special significance for people with HD because there is good evidence that it can have an impact on the speed that symptoms develop.

- Try to have at least 30 minutes exercise at least 5 times a week
- It can be anything that keeps you active – walking, cycling, gardening, playing golf.
- If you want to do something that is more active, like going to the gym, running, mountaineering, playing football etc. – keep that up too.

Tips and hints for the early stages of HD

- If you are already doing this sort of thing, keep it up.
- If you aren't doing it, try to build it into your life now.
- Get a friend or your partner to do it with you. It's better fun doing this sort of thing with a pal and they'll already be there if you need a bit of help later on.

Tips and hints for people who have more symptoms

- Get a friend to help you keep an eye on symptoms that might be a problem with your chosen activity, such as poorer balance.
- Think of ways to keep active in a gentler form – such as walking instead of running or jogging, or not going so far.
- What for when you get tired. Do more active things earlier in the day, or do activities that are not too risky if your concentration and co-ordination are less good after a few hours.
- Look for other things that you can do which are more flexible and you'll be able to keep on enjoying them for longer.
- There are now arrangements for GPs to refer people to a local sports centre for coached exercise that is right for each individual person. Some places also have what is called 'green prescribing', where you get a prescription for outdoor activities. Ask your GP what is available in your area.

Sources of further information

The British Heart Foundation has some nice publications on starting to take exercise if you don't already do it. There is a copy on the SHA website.

Paths for All is an organisation in Scotland that supports local health walks – these are supported walking projects, with Walk Leader, for people who are not very active. There is a list of the local walking projects they fund on their website and they may be able to tell you about other walks in your area: www.pathsforall.org.uk

Most local authorities will have information on easy accessible paths in their area and about other outdoor activities. They will also have information about access to sports facilities and swimming pools.

Good food and nutrition

This time, our advice is a bit different from what you usually hear. People with HD can have problems with losing weight and not getting all the nutritional benefit of the food that they do eat.

- Try to have a healthy diet – mix of foods, your 5 fruit and vegetables a day.
- But also make sure that you are eating enough. Think about nourishing yourself – food to give you strength, energy and comfort.

Tips and hints for the early stages

There are some adverts around for food supplements that are claimed to slow or prevent the onset of HD symptoms. So far, there is no scientific proof that any of these work. Some people feel they are useful and help them.

Most people with symptoms of HD will consider taking some of the food supplements that have been suggested and whether you do or not is a very individual decision.

- Make sure that you get as much information as you can about them – the HD Lighthouse is a good source: www.hdbuzz.net
- So far there is no scientific proof that any supplement can help

- You could try them and see if you think there is one what you feel works for you. But be aware of the placebo effect – which is when somebody's symptoms improve when they take an otherwise ineffective treatment, mostly because they expect or believe the treatment will work.
- Watch the cost – these supplements can get very expensive if you take them for a long time.
- Look at the balance of vitamins and so in the supplements. You may be able to get this in other ways that are part of a good everyday diet.
- The best evidence, to date, is still that a healthy diet and exercise will do more to delay the onset of HD than any supplements.

Tips and hints for later on

- Watch for having a poorer sense of taste, so just not being as interested in food and starting to lose weight.
- Remember that people with HD may need more calories than the average person as the condition progresses so keep an eye out if you start to lose weight or ask someone to help you do that.
- The environment we eat in makes a big difference for everyone – and especially when you have HD. Think about things like eating at the table, being with someone, taking time to enjoy your meals rather than just grabbing something quick and watching TV.
- Find ways of getting food that is easy to prepare – like extra portions in the freezer to pop in the microwave, or fillings for sandwiches or baked potatoes that are ready to use.
- There are lots of ways of getting extra calories into food that still give you a balanced diet. There are some good suggestions from dieticians and on websites if you want some ideas.
- There is a good cookery book available through SHA with lots of recipes and more suggestions.

Looking after yourself

Tips and hints for the early stages

Keep looking after your general health.

- Remember to still do all the preventative health checks.
- Ask about preventative health care such as the flu jab.
- Watch for problems that are at least partly about lifestyle.
- Watch for other inherited problems, like a family history of heart disease or diabetes. The HD gene doesn't protect you from any of these (sorry!).
- Get enough rest as well as taking exercise and keeping active.
- Drink alcohol within a sensible level.
- If you smoke, try to give it up or at least cut down. Smoking can make HD symptoms worse, as well as adding to other health problems you may have.

Tips and hints for later on

- You might need a bit of help – for example, if you find it is harder to keep your balance, or you are getting tired. Talk to the doctor about getting advice from staff such as physiotherapists.

Looking after your mental health and wellbeing

One in 4 people have a mental health problem – that means at least a quarter of us can expect to have mental health problems at some point even if we didn't have the HD gene.

Mental health problems are more common in people who have HD. It can sometimes be caused by changes in your brain rather than as a result of your circumstances. And having a condition like HD will bring added pressures for some people – it's part of the normal reaction to the more difficult situations we find ourselves in.

So it's important to take extra care of your mental health.

Reducing stress is one way that is proven to slow the onset of HD symptoms. And if you can look after your own mental health and wellbeing it will help you to cope with whatever happens.

Good mental health means:

- Feeling able to cope with life.
- Feeling optimistic about the future.
- Feeling good about yourself – self esteem.
- Being able to cope when circumstances change – being resilient.

Tips and hints for any stage

There are things you can do to keep yourself well. In each case, they help to reduce the causes of mental health problems or reduce the symptoms for someone who has a mental health problem.

- Have a good, balanced diet.
- Take exercise. Physical exercise releases chemicals in your brain that give you the right balance and reduces symptoms of depression, for example.
- Take time to relax. Think of places and things that make relaxation easier for you.
- Keep in touch with people who help you feel happy and who look out for you, such as friends and family.
- Have a routine to your day.
- Do things that are good fun and make you laugh. These are often things you do with friends, which is another reason for keeping in touch with people.
- Remember that we all change as we go through life and get older. And that includes living with HD. So you may find that you are not able to do things as quickly as before, or that you have aches and pains. It might be part of the HD, or just not being as sharp as you were 20 years earlier. Check out anything that is worrying you or giving you pain with your doctor. But also relax, give yourself a bit longer to do things.
- Learning about your mental health and wellbeing, and then building in the things that keep you well as part of your day. It might be 15 minutes time to yourself each day, or listening to music.

Tips and hints for everyone

Try keeping a diary of how you feel. Many people find this helps them understand what happens on good days and the not-so-good ones.

- It can help you spot when symptoms are beginning.
- It can help you realise that some things are down to other factors – like having a bad cold or your menstrual cycle.
- It is also useful to take this along to the doctor or other people who are helping you, to help you explain how you are feeling. This will help the doctor work out what treatment can work best for you.

Managing medication

Some people find that they get a bit forgetful when they are in the early stages of HD. It's often more to do with stress and trying to keep on top of all the things that are happening to you and what you are beginning to deal with than with symptoms of HD.

But one consequence is that people sometimes forget to take medication – for aspects of HD, or coping with it, or for an existing condition such as your blood pressure. And then you feel really unwell on top of everything else that is happening.

Tips and hints

- Ask the pharmacist for any wee gadgets they have to help people keep track of medication, such as weekly medication boxes.
- Use a small wall planner or even a notice pad in the bathroom or kitchen or wherever, and mark off when you take each dose. Or you can get a medication timer and reminder.
- Check with the doctor whether you should look out for particular symptoms if you do miss some of your medication, or take a double dose by accident.

Keeping well: Tips and Hints for family and friends

- Encourage the person with HD in keeping well.
- Look out for changes that they may not have noticed and talk over the symptoms and changes they may have noticed.
- Work with them to think of new ways you can do the activities you enjoy together.
- Look after yourself well.