

Relationships

What is in this fact sheet

- Tips and hints for everyone
- Tips and hints for relationships within families
- Tips and hints for relationships with friends
- Tips and hints on your relationship with your partner
- Sources for further information

Key points from this fact sheet

- Support from family and friends is a big help to many people with HD
- Recognise that your relationships may change over time anyway as well as by adjusting to the HD
- Keep on with the things you enjoy doing together

Tips and hints for everyone

Most people with HD find their friends and family are a big part of living well and keeping well.

But for some people this is a difficult aspect of having HD.

Our general advice is to involve your family and friends from the outset – or do it as much as soon as you feel you can. There may be some difficult conversations, but stick with it as it helps in the long-term. Having more people around you – family, close friends and people like neighbours and folk you say hello to – makes a big difference in anyone's health and wellbeing and can be especially significant for people with HD and their families later on.

It helps to remember that other things may be going on in your life and in the lives of your family and friends. HD may not be the biggest or the most urgent problem at the moment, so don't let it distract you from other matters that need to be tackled.

Also don't let HD take away from the good things that are happening.

Give yourself and your family and friends some slack. Recognise that having a diagnosis of HD or confirmation that you have the gene is a big step. You need time to come to terms with it. Your family and friends will need time as well.

Remember that we all take in information and process the facts and our feelings in different ways and at different paces. So don't get into a tizz if it seems that one person is not taking it in, or is ignoring what you've told them. Give them some time and space to process it at their own pace.

Look after yourself when you are telling people who are important to you about your HD, and when you are having a big conversation about the future or what it all means for them. It is stressful. Plan for a gentle day when you aren't in a rush. Give yourself some wind down time, or try to take the next day off. Pamper yourself.

Remember that all relationships change over time. If things become strained, or you find you are less close to someone than before – maybe this would have happened anyway. And other relationships may grow closer as you work together to deal with a big change in your life.

Talk to your GP about speaking to a psychologist or counsellor if you are finding relationships more difficult. Remember the SHA's HD Specialists can also help.

Tips and hints for relationships with families

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Tell both sides of the family, not just the side that has the HD gene. The side that doesn't have the gene might be able to help more.

Keep having conversations within the immediate family. It's about how everyone feels about HD and how it affects them, not just about how you are affected. Our advice is to try keep the focus on how you deal with it as a family.

Think about where and when you have the big discussion. Ideally, it is at a time and place that works for everyone. And with everyone getting on with their lives, that can be hard to organise. So if it ends up as a big discussion that is made up of a series of smaller discussions, that's fine – much better than not having it at all or getting everyone so anxious about the arrangements that they can't have a productive conversation.

Talk about the genetic side of things as well as the living with HD and symptoms bit. We know of people who have lived for years with wrong assumptions about HD – like it only affects girls, or if one person in a family has it then his brother is safe, or if one person doesn't have it the other must have the gene. The truth is that each child who has a parent with the faulty gene that causes HD has a 50% chance of having the faulty gene themselves, and what has happened for their brothers and sisters does not make any difference to whether or not each person has the gene. There is more information in Living with genetic risk which is in the Information and Resources part of the SHA website.

Tips and hints for relationships with friends

Aim to get friends to support you over the long-term. If you can keep in touch with friends and wider family who understand about HD, it will be easier when the symptoms develop.

Remember that it is friends for the whole family. If your partner's friends are there for her/him, that helps that person and also helps you.

Try to get a couple of people in your children's lives who they can use – an auntie or someone in the traditional godparent sort of role. It might help if they are not all actual family members. It's to give your children someone to talk to, get some extra help for later on, and to help them think ahead.

Try not to get prickly when friends offer to help when you feel you don't need help. It's good to keep your independence and do as much as you can. But it's also good to have people there when you need them. Think about things that friends can help with, that will work well for you both.

Hobbies and sports and activities like that are a good way to meet new friends. You may find that you get to know people after you've had the news about HD, who know you and like you as a person with HD.

Tips and hints on your relationship with your partner

Accept that getting news of a life-changing condition such as HD can put a strain on any relationship. Try to give yourselves some space as a couple to work at the relationship – caring about each other and being in love as well as physical intimacy.

Try to get some time away from work, family and HD for just the two of you. Even a weekend or mid-week break once a year is good. Check out out-of-season deals at hotels or see if you can use the points on your supermarket rewards card to help with the cost.

If you need to have a conversation that only one of you finds difficult, try to make sure you are not tired, or is isn't after a situation when you are getting stressed.

Keep a focus on you as a couple. You might find that health care staff and staff in other services refer to your partner as your carer – even at the beginning when you don't have many symptoms. They mean to be helpful and recognise the additional role, but some people find it undermines the existing relationship. You can make use of all the support that is available to your partner through carers' network and welfare benefits for carers and so on, but still refer to each other and think of each other as you did before.

One of the symptoms of HD that some people experience is behaviour changes. It may feel just like before for you, but your partner is learning to live with someone who reacts and behaves differently – and that can be harder than dealing with the more obvious symptoms. Try to find a way of talking about this or describing it which works for you as a couple.

If the physical side of the relation isn't so good, think about making time to be together when you are both less tired and stressed, even if it is for a cuddle.

Sources of further information

The SHA Youth Project provides support for children and young adults affected by HD. There are good resources on the project's website. hdscotland.org/shayp-home

The HD Association has produced a fact sheet on HD and Sexual Problems. These are available on their web site. www.hda.org.uk

The Princess Royal Trust for Carers has information on many issues that affect people who care for a relative or friend. www.carers.org