

Daily living

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Key points from this fact sheet

- There are lots of practical things you can do now to help you have a good life when the symptoms of HD begin to increase
- There are things you can do now that make life easier later on – and also help now
- When you come across a problem, it is often useful to try the small, practical solutions that anyone would use before you think about bigger, more specialist and more expensive answers

Keeping in touch with people – phone, internet and so on

Tips and hints for the earlier stage

If you haven't got into the internet yet – do it now. It is great when you want to keep in touch with friends and for things like ordering your shopping and getting it delivered.

Check out all the free and low cost courses to get people started with computers and for people who did that before but haven't done much with their computer and feel they need to start again. The courses are often for everyone in your area who feels that way, not just for people with HD or other health problems.

Many local libraries have computers where you can get free or cheap access to the internet, typically for an hour at a time. There is usually a nice helpful person around to help if you are stuck – so it can be useful going here sometimes when you are getting started even if you do have a computer at home.

Tips and hints for the later stages

Use a phone with bigger keys. It is easier when your co-ordination isn't as good or if your eyesight changes as you get older.

You can get some good equipment for computers, such as bigger key boards. These make it easier if you find it harder to type.

Having a computer may make life easier for things like shopping and paying bills..

There are lots of gadgets that are designed to make life easier for lots of people. Try these out first whenever there is something that you begin to find difficult. You can get advice about this from a community Occupational Therapist (contact your local social work department) or HD Specialist, if there is one in your area.

Driving and getting about

Getting out and about is important – it lets you keep on doing the other things you enjoy. For some people it is about using public transport. For others, it is about being able to drive.

Tips and hints for everyone

Think about transport in the wider sense – public transport as well as your car. Aim to have choices and options, so you can get about whatever your circumstances.

Most people want to keep being able to drive as long as it is safe – it's part of being independent. This section has tips to help you do that.

The law says that you need to tell DVLA about your condition once you develop any conditions or symptoms that could impair your driving. This is to protect you, your passengers and other road users. HD is one of the conditions that you must tell DVLA about once you have a diagnosis and symptoms begin.

You do not need to tell DVLA if you have confirmation that you have the HD gene, but have no symptoms yet.

Check your insurance policy – you may have to tell the insurance company about factors that increase your risks when driving.

Find out about community transport schemes in your area and about extra help for anyone who is finding it more difficult to get about – such as taxicards. It's useful to know about them even if you may not want to use them yet.

Tips and hints – mostly for the later stages once symptoms begin

Plan your journeys so that you are not under stress – leave enough time, try to avoid busy roads that are unfamiliar, check the arrangements for getting onto the train if it is a station that you are not familiar with.

Try to avoid distractions – so don't have conversations with passengers or listen to the radio while you are driving.

Watch the times you travel. Try to avoid peak times when the roads or public transport are very busy if you can.

Allow for more breaks on the journey if you are travelling a long distance.

Apply for a disabled sticker (blue badge) for your car – or for the car of someone who regularly drives you places – as soon as you think you qualify. It is good for times when you get tired and there is a long walk if you are in the ordinary car park. Your local social work department can tell you how to apply.

There will be staff at railway stations and airports to help any passenger who needs extra help because of a disability. Check out what they can offer you. You usually have to arrange it a day or two, before you travel. You tell them what sort of help you need – they don't need to know details of your condition.

Think about using a wheelchair if you get tired on long journeys. It makes getting about car parks and airports easier. It also usually lets you go to the head of the queue for checking in etc. – so less stress and hassle as well as being less physically draining. Ask about help with transport for people in your area who have a health problem or a disability, such as taxicards and dial-a-bus. The arrangements vary from place to place, but you should be able to get information from the local authority.

Sources of further information

There is more information about driving on the SHA website.

Alzheimer's Scotland has an information sheet that covers driving and other forms of transport. There is a copy on the website.

- http://www.alzscot.org/information_and_resources/information_sheet/1771_driving_and_dementia

The contact number at DVLA for the Medical Support Team for enquiries about reporting any health conditions is 0300 790 6806.

There is information for disabled travellers on the websites of railways, train providers and for airports.

Looking after the house

Tips and hints for the early stages

In the early stages there aren't any more problems for people with HD than for anyone else.

But you might want to get some routines in place that will make life easier now as well as later on, such as getting help round the house and using the message board as a general family communication system.

Start to declutter. Later on, it may be easier if you have more space in your house – less furniture and fewer ornaments etc.

Tips and hints for the later stages

Have a message board somewhere really obvious, where everyone in the family can see it. Write up the things you have to buy or do – like when something needs repaired.

Try to avoid furniture and ornaments that can easily get broken if anyone trips.

Check out the new types of kitchen and bathroom fittings. Some of them are really easy to use if your hands are not as steady as before or you don't have as strong a grip, and they look good to everyone.

Arrange to get some help around the house. It could be cleaning, or gardening or someone to do the ironing. As a first step, think of what makes you tired and what you like doing least, and aim to get someone else to do that.

Ask your HD specialist for advice on ways to make looking after the house easier now and for over the next few years.

Ask for an Occupational Therapist to come out and give you advice. There may be equipment or adaptations that will make your life much easier and safer.

Get an occupational therapy assessment again as your symptoms change, as there may be more things she can suggest or new bits of equipment that have been developed recently.

Talk to the Social Work Development and see what help they can give to enable you to stay at home – such as someone coming in to help with tasks that are getting difficult for you.

Holidays

Tips and hints for early on

Keep on enjoying the sorts of holidays you enjoy.

Also think about doing other things too. If there is something you want to do, do it. Later on this may be more difficult.

Try different holidays so you have more options later on. It's also about having more choices, about finding out about new things that you like.

Tips and hints for later on

Take friends and family with you if that helps. Just organise another car if you need to take equipment with you.

Use all the tips for travelling and getting about – such as help at stations and airports, using a wheelchair if you get tired, using your taxicard to get you to the station at the start of a journey, and breaking up a long journey.

If it is a holiday in the UK and you need extra stuff like special food, the company that supplies you will often deliver to the holiday address. That way you've got less to carry. They might not, but it's worth asking.

If you are in Europe, you can generally get health care from the place you are visiting. Ask in advance about access to equipment that you only need occasionally, and about staff who can help if you need them. That way, it is all in place so you don't need to worry.

There are lots of companies that specialise in holidays for people with disabilities. Check out what they can offer you. They may not know much about HD but they do know about giving people a good holiday when there are some things they find difficult or where they need extra support. These companies also often have links with insurance companies and can organise that side of things for you too.

There is a good website www.euansguide.com which gives lots of information about places you can go and that is written by people living with a disability.

Hobbies and having fun

Tips and hints for everyone

Remember that your interests change over the years anyway. It's always good to try new things, even if you don't have HD.

Hobbies and interests include being a sports fan, such as going to football games and the like. Keep that up too.

Often we make friends through our interests. Some people find that this is how their network of friends grows as their circumstances change.

The HD Specialist and the Occupational Therapist will be able to suggest things that can help you go on enjoying hobbies as well as for improving things around the house.

Tips for family and friends on all aspects of daily living

Encourage people with HD to keep up activities that they enjoy.

Think of things you can do to help someone learn new activities, or find new ways to get about.

Keep the focus on 'we are doing things in ways that are easier for both of us' rather than 'you are not able to do so much'.