



Huntington's Disease and Everyday Activity

Who can help?

The main source of support regarding what are called activities of daily life (washing, dressing, household chores, shopping etc.) will be an occupational therapist 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 movement and cognition from early on in the disease. This will allow you to foresee and hopefully avoid some common problems and maintain your independence for as long as possible. You should also seek a referral to a physiotherapist whose job it is to help you with movement, preventing falls and recovering from ill health or accident.

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 or apathy may impact motivation to undertake daily tasks
- Reduced mobility and/or function of limbs
- Problems with balance and gait
- Difficulty planning and prioritising tasks
- Issues with memory and concentration
- Jerky movements and poor co-ordination making tasks difficult
- Medication might affect movement and/or ability to plan

Your questions answered

The following Q&A is taken from a session held in October 2020 with Alexander Fisher, a Specialist Occupational Therapist, 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 an Occupational Therapist and/or Physiotherapist for specific advice.

Am I allowed to drive with HD?

This will depend on the stage of your illness and how it is affecting you. So speak to your Consultant (or GP) and let them negotiate with you the best course of action. Driving, even though you may have been doing it for many years, is a complex activity made up of many different skills – all of which can be potentially affected by HD. Whatever point you are at – you should let your licensing authority and your insurers know. If they have any questions they will ask your Consultant. If there are any doubts, your Consultant in conjunction with your licensing authority may recommend you undergo a driving assessment to determine the outcome. For information on driving assessments visit <https://www.disabilityaction.org/driving-assessment>

What exercise is best for HD?

Evidence does not specify any particular exercise but does state at any stage of your illness, keeping active and mobile is key for your whole wellbeing providing it is safe and if you are prone

to HD weight loss that you are taking your calorie intake into account. So exercise will help your mood/cognition and behaviour. Just as with anyone – the exercise/activity should be enjoyable as you or your loved one may struggle with motivation.

You will find some HD specific workout tips to help strength and balance here;

https://www.youtube.com/playlist?list=PLLQmMRDsNEY1cLor6pzk_f4prjomEznp0

I've been cycling for years but have started to show signs of chorea- does that mean I have to stop?

No not necessarily but here's the big BUT. Check out if you are safe. Folk with a HD brain often have a different perception of their movement than others without so you might be aware of more or less movement. Also if you have chorea, you may well have problems with cognition such as attention and multitasking. Cycling is a complex activity even if you have done it for years. I recommend checking it out with a trusted other/or professional and be aware that you might not agree with them and plan for that i.e. such as getting them to video you. If it is problematic but you love it – how can you alter the activity so it's safer? Like static cycling. Make the changes now so your brain has a chance to adapt as you may be struggling with the impact of your illness but also changing itself can become more difficult with HD as time goes on.

I'm 19 and have received a positive predicted test. Should I do anything now with my routine or wait for symptoms to start?

The thing about waiting for obvious symptoms such as movement to start is that your brain has already made a lot of HD changes so if you feel you can, do what you can but here's where I'd suggest you start;

- If you are struggling with this news, seek out psychological support
- If you are not active, get and keep active but as I said earlier be aware of your HD nutrition
- Get a good structure and routine to your life so that you give your brain the optimal conditions to function / make sure you keep a diary (on the phone with prompts or a calendar in the same place) to help you organise yourself. This is a skill that becomes difficult early in the illness.
- If you are working/college – think about telling them so that they are aware and can make the adjustments, you might need.
- Start to plan for the future and talk to trusted others about the plans so that they know what your wishes are and then write them down and make sure professionals such as your GP know them – this sounds scary but many of our patients say that once these things are done, it makes them feel more in control

My husband sits in his armchair all day every day and rarely leaves the house. Is there anything I can do to help his exercise? Is it making him worse sitting about?

I am sorry he's doing this and yes it will not be helping his HD as he will be becoming deconditioned. Yes, exercise will help but firstly (if it's not already done) – he needs checking out by a professional for problems with his mood/and whether he's in pain/or if there's something else going on as people with HD aren't just all about their HD.

If all of these things have been ruled out, then it may be that as your husband has become more poorly then his neurological apathy which is a neurological lack of motivation has increased. You need professional advice on how to deal with this which can be really difficult as there are currently no good pharmacological treatments. This is more about understanding how if possible to support and direct the individual.

If it's safe for you to motivate him, try concrete communication rather than abstract choice which is often difficult for the HD brain – so let's do x (concrete), rather than shall we do x or x (abstract) or you are not doing x (abstract/may cause tension). Use this method in conjunction with meaningful activity (see below).

Setting up a structure and routine with meaningful activity (i.e. something that you don't call exercise) will help so that he knows what to expect and when to expect it will help with planning and anxiety. Start small and do not change it once it's in place (as he probably is unable to tolerate change) – if you must change it, make sure he knows days in advance. This will reduce frustrated behaviour which results from rigid thinking.

Sometimes people respond differently to others, so get a trusted other involved or if you can, a carer or professional. There is also less of a chance of blaming you for something that he may not wish to do as he is struggling with it. Make sure you are looking after yourself and talking to others about this as it's really common and can cause huge tensions for both of you. Speak with HDANI about ways to link in with other carers which can be a great support.

What can I do to help my mum maintain her independence in her own home? she is starting to show signs of dementia and has had a couple of falls?

Please get your GP to make a referral to both a physio and OT for your Mum but in the meantime, look at her home through the lens of it being a hazard - shoes, clothing, carpets, stairs, wires, lighting, clutter, hearing and vision all need to be addressed and make a huge difference. Falls in HD increase with dehydration and problems with nutrition so also get a referral to a Dietitian. Lastly think about technology and check out falls sensors and pendants and hopefully by this time, the referrals will be done.

My dad is in a nursing home. He is always very slumped in the chairs in the dayroom and has literally slid out of them a few times. The nursing home says they can't strap him in for human rights but I'm more worried about him hurting himself. Can I make them get him a special chair? I found one for HD that's £4,500 and no way I can afford it.

This is sadly really common and it's a complicated answer. The key issue here is that the home are there to protect your Dad and this must not be forgotten. Firstly, let's deal with the provision of a chair. The home will have a contract with local health or social care and this will probably state that the home only have to provide standard equipment to their residents. This includes regular armchairs but not equipment that caters for people who lost the ability to sit like folk with HD. My opinion is that homes should consider the long term needs of their residents and plan for this but it is not always the case that they do. I do not believe that the person or the family should have to pay for what is a clinical need.

So we have to look at how this can be funded. If your Dad's needs have changed, then this needs to be recognised and you/the home should request a review of his care through social services and at the same time his seating through occupational therapy. A social care review and OT assessment will formalise the need. As social care may not pay for the chair, they may suggest that your Dad is reviewed through Continuing Health Care. As your Dad's health needs are influencing his seating needs, it may be that other aspects of his health will enable him to reach the level required for full health or part health/part social care funding. If this is the case, then the Occupational Therapist can make a case to health care for the funding for the chair. If your Dad does not meet health funding, but still has a need for the chair a referral can be made to the health authority as an individual funding request but all of the other processes must happen first. If all of these avenues have been exhausted contact HDANI and we may be able to help you access a grant from a charity to help towards the purchase of special equipment.

In reference to the homes comments about his human rights, the home is right in that some of the chairs and some people with HD require straps or tilting to keep them in a good position and stop them injuring themselves. This could be viewed as restraint. The home should be asking does your Dad have the ability to understand the risks he places himself under by sliding out of the chair? Chances are he does not. This means he lacks capacity into the risks. Therefore, the home need to make a decision as to how to protect him. They should hold a meeting with you and professionals and discuss the solution. It may be that to keep him well, they can restrict his movement because he does not understand that he is injuring himself and this could be through the use of a specialist chair. Restriction is time bound and proportionate to the risk that your Dad presents. If the meeting does not think this is appropriate, they must look at alternate ways to protect your Dad. This meeting gives more weight to the application and need for an appropriate chair.

My sister is in a nursing home. She is 41. All the other people are much older and many are senile. The home is nice and the only place within 50miles but I think her condition has gotten worse since she's been there. She doesn't seem to do anything. Can you recommend any activities?

Your feelings about your sister being inactive and it having an impact on the deterioration may well be right but I don't know your sister and the stage of her illness when she went into care or her CAG repeat from her diagnosis which will also have an impact on getting worse. I also wonder if she is low in mood too and this needs to be checked out. However, with regards to inactivity, we know that this will have an impact – particularly if she had structure and routine prior to her admission as structure and routine optimises function in HD. The other thing is that if she is deteriorating, regardless of the reason, that she will be experiencing neurological apathy and cognitive changes which if the home does not know about – will appear as though she does not want to take part, when in fact it will be these aspects of the illness which will be stopping her.

The home need guidance on both neurological apathy/cognition in HD and mood and activity provision particularly for someone who is cognitively impaired. It's important that the activity is meaningful to your sister but also tailored to her level of impairment. The home also need to be aware that means that this might mean she may not fit into their activity schedule and need more 1:1 activity. This doesn't have to be leisure activity which is sometimes what we think as activity and can be things such as brushing hair and being read to which create the opportunity for connection.

NICE have produced Guidelines and quality standards on these issues with signposting to resources via the Royal College of Occupational Therapists and they do apply to Northern Ireland. Please do not think just because they have older people in the title, they do not apply to your sister as they are just as relevant. A really great and low cost tool for care homes to use is the Pool Activity Level to work out some of these issues. <https://www.rompa.com/blog/explaining-the-pool-activity-level-instrument>

My wife has HD and moves about a lot in bed. Sometimes I get no sleep. Can you advise anything? I'd really rather not have to leave her on her own.

Have you spoken to your Consultant about medication? I suggest you do. If you have and it's still problematic then the options are very pragmatic if you still wish to sleep together – so consider the space/width of the bed, swapping to a twin with separate bedding can help so your wife is not pulling the sheets off you. Movement can be made worse by heat which is problematic for people with HD so having separate bedding which has a different tog for you both may help. Falling out of bed can be a worry for her and this may cause increased movement due to anxiety so address this by where the bed is and looking at items such as bed levers.

Ultimately there's a balance to be had here and that's between you being exhausted and looking after and loving a person with HD or being refreshed and looking after and loving a person with HD. Can you sleep in another room for 1 night out of 3 and negotiate this with your wife and telling her why? I appreciate this is a very personal issue and represents something more than just getting a good nights sleep.

What are the most useful aids to support meal times?

First and foremost – is positioning and seating. This is overlooked and must be addressed. From this comes much better control of the limbs but also it lessens problems with swallowing even when a person is artificially fed. Additional time is important as is environment – so as to maximise concentration and minimize anxiety.

Meal times may not be traditional meal times as people may have altered body clocks or be hungry outside of set times and changes should be made to accommodate this. Be aware that a meal is a social event and work out ways that this can still work in a dignified manner (if the person still wishes to do this) but also be aware that people may not want to do this anymore and that's hard for everyone particularly if it was part of your identify.

Thereafter look to height of table / type of flooring around table as well as the persons' dignity with items such as aprons or bibs to protect clothing. If they do not want to wish to sit at a table or be in a good functional position – how can it be facilitated as much as possible? Small changes can be made to the table such as no slip place mats, crockery such as deeper bowls and plumbers piping on utensils to increase feeling and grip on the handles. Looking at specialised utensils can help but these are expensive and the weighted ones don't often have enough weight to minimize chorea or dystonic jerks. The money here is best spent on items such as altered drinks cups or utensils which are smaller to prevent cramming of food or breaking in the mouth due to spasms. Hand over hand may be required to help guide the food or to slow down the rate of which the person is eating but also sometimes to co-ordinate all of the latter.

Are there any specific aids to help with or prevent memory loss?

Memory loss is often not the thing with HD, its more about attention and organisation and so earlier on I referred to the importance of structure and routine in helping the HD brain and this will help at any stage. The earlier that these things are put in place the better either by the individual or their loved ones. Keep it consistent and simple and avoid change as that can become harder as the illness progresses. Keeping active / keeping hydrated and nutritionally sound also help. Make sure you are aware of the impact on the environment and too much going on for you and your loved one.

There is often a connection between impaired cognition and impaired communication so it's important to make sure this is addressed with a speech and language therapist. There are some (but not all) occupational therapists/psychologists who are trained in cognitive rehabilitation but at present the leaning with HD is rather than specific brain training, the key to brain health is more about activity and environment. The Dementia Centre have great online resources with practical examples of how small changes in your home can make a big difference <https://dementia.stir.ac.uk/design/virtual-environments/virtual-care-home>

Aides such as calendars, diaries and timetables as well as signage with key messages help. Keep it in the same place and prompt the individual to them as often as you can so that the person knows where to check for information.

Is there anything to help manage chronic pain and associated fatigue?

Pain is in and of itself tiring so please make sure you have checked out the source of the pain as not all pain is HD type pain. So if you are getting older you are just as likely to have arthritic or other pain. Make sure this is being optimally managed. Alongside of this is understanding how to pace with your pain and of course you can again seek advice here so that you can try and avoid boom/bust which aggravates it.

Fatigue also causes pain so the two are interconnected. Fatigue is also common in HD as you are literally running several marathons at a time. Have a structure and routine that prioritises what you need to do as a first point of call and then go from there, grading your activity as you go.

HD pain is something that the boffins are looking into. This is thought to be the precursor to the muscles contracting and dystonia usually in the bigger groups of muscles around the hips and legs. There are medications which will help which relax the muscles so do seek the help of your Consultant but also your physiotherapist and occupational therapist as exercise as well as activity and positioning will make a difference.

Can you recommend anything that can be used to help keep the head upright during the day?

This depends on the problem causing the head to droop and how fixed the problem is. I would advise an occupational therapy assessment in the first instance to look at whether positioning or something such as a collar may work. If the problem is fixed, it's important to know that as the head is heavy that a collar would need to be very robust and not cause additional skin problems. The same is true of items such as head straps. Sometimes medication may need to be used alongside of these measures. As with all of these solutions – a risk versus benefit analysis needs to be made and of course the cost and how this will be met will also need to be considered.

Online resources

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

Professional resources

Development of guidelines for occupational therapy in Huntington's disease

<https://www.futuremedicine.com/doi/pdf/10.2217/nmt.11.81>

Care Home guidance

<https://www.rcot.co.uk/about-occupational-therapy/living-well-care-homes-2019/care-home-managers>

Dementia Care Pathway

<https://pathways.nice.org.uk/pathways/dementia>

Meaningful Activity

<https://www.nice.org.uk/guidance/ph16>

Pool Activity Level

<https://journals.rcni.com/mental-health-practice/the-pool-activity-level-pal-instrument-for-occupational-profiling-mhp.11.9.23.s23>

Physiotherapy clinical guidelines for Huntington's disease

<https://www.futuremedicine.com/doi/pdf/10.2217/nmt.11.86>

Physical activity self-management and coaching compared to social interaction in Huntington's disease: Results from the ENGAGE-HD randomized, controlled, pilot feasibility trial
<http://orca.cf.ac.uk/98529/>

Family resources

Caregivers Guide

<http://hdsa.org/wp-content/uploads/2015/05/HDSA-LET-Caregivers-Guide1.pdf>

A standard of care for Huntington's disease: a patient and family perspective

<https://www.futuremedicine.com/doi/pdf/10.2217/nmt.12.1>

HD Roadmap

<https://hdscotland.org/wp-content/uploads/2016/10/HDRoadMap.pdf>

To view our video training sessions please visit

https://www.youtube.com/watch?v=ovTLX5T_ZR8

