

**Huntington's New South Wales**



**Lifestyle and  
Huntington Disease**

**Supported by NSW Health**

## **Fact Sheets**

- Huntington's Disease in the Family – A Booklet for Young Children
- Huntington's Disease – A Fact Sheet for Teenagers
- Talking to Children about Huntington's Disease
- Presymptomatic Testing – The Consumer Experience
- Understanding Challenging Behaviour in Huntington's Disease
- Living with Someone who has Huntington Disease
- Making a Decision About Residential Care
- Guidelines for Meeting the Nutritional Needs of People with Huntington's Disease
- Eating and Swallowing Difficulties in Huntington Disease
- The Importance of Dental Care in Huntington Disease
- Communication and Huntington Disease

*These Fact Sheets are available from  
Huntington's NSW  
Please see the back page for contact details.*

# **Active and Able: supporting people with Huntington Disease to engage in everyday life**

## **About this fact sheet**

People diagnosed with Huntington Disease (HD) can help to reduce the impact of their symptoms by staying socially, physically and mentally active. This fact sheet suggests strategies to assist people with HD to engage in leisure and domestic activities that will help to maintain their skills and enhance their quality of life. Families and carers supporting someone at home or staff supporting people in a residential care facility can use it.

## **The impact of Huntington Disease on everyday life**

The behaviour of people with HD can change as a direct result of the changes occurring in the brain as the disease progresses. For example, family members, friends, carers or support staff may notice that the person affected by HD has:

- a decreased ability to plan and organise;
- decreased attention and concentration;
- co-ordination difficulties;
- and increased fatigue.

Apathy and decreased motivation are two of the most disabling symptoms of HD and are often wrongly labelled as 'laziness' or 'lack of interest'. Symptoms like these can appear at any stage of the illness and are probably the most difficult for carers and family members to deal with because of the way they impact on everyday life.



The strategies outlined below will help you to develop and/or adapt activities so that people with HD can stay active and motivated for longer and get more out of life.

## **Structure and routine**

People with HD can become anxious and frustrated by change so daily structure and routine are very important. Routines for personal care, domestic tasks and leisure activities will help people to start and finish these tasks more easily and planning tools like diaries and calendars are very useful for people with HD to create their own structure and routine. Encourage them to select and use a diary or calendar that suits them.



## **Encourage participation or suggest a project**

Boost a person's motivation by encouraging them to participate in a specific project or task. In some cases it may be useful to actually start the task with the person so that it is clear how the task is to be completed. Working along side the person with HD may also sustain their energy and attention levels.

## **Offer choices**

Offering choices is essential but if you don't set people with HD some guidelines for decision-making they may become overwhelmed and not want to participate in any activities at all. Rather than giving an open-ended choice, which may be confusing, for example, "What would you like to do now?" it is better to provide two choices at a time such as "Would you prefer to go to the bank or the supermarket first?"

## **Reinforce the person's identity**

People with HD, and particularly those living in residential care facilities, often "lose" their identities when carers and support staff become too intensely focused on their medical care and support needs. Immediate physical needs have to be balanced with opportunities for individuals to be recognised as more than "just a disease".

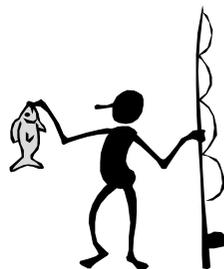
Creating a personal print or video diary, a scrap book or a photo album is one enjoyable way for people to record their interests and personal histories. It can also be used as a tool to stimulate discussion and reinforce the person's identity as the disease progresses. If people are moving into a residential care facility, it is a good idea to start a diary, scrap book or album shortly after they arrive and continue to update and discuss it as staff change.

### **Use a visitor's book or diary**

Another useful communication tool for people with HD living in residential care facilities is a visitor's book or diary. When family and friends visit, encourage them to write down details of their visit and any information or news that may have been discussed. This will act as a "conversation starter" and is very useful for people who may have cognitive impairment as a result of HD.

### **Consider the person's interests and roles**

We all know that new activities can be more daunting than familiar ones. People with HD (and without) will probably react more positively if they are encouraged to take on a task or role that they have done many times before. A person's interests and/or previous job roles provide clues about the tasks they can do, the tasks that are meaningful to them and the tasks that they enjoy doing the most. What were their previous and current roles and how can activities incorporate these things?



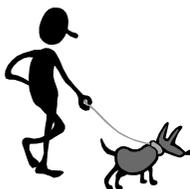
### **Allow extra time to complete tasks**

Giving a person with HD extra time to complete tasks and to discuss any difficulties they may be having with the task are essential. People who are hurried through their daily tasks will become anxious, frustrated and will be less likely to complete them successfully. Enabling tasks to be finished in plenty of time motivates people to want to do the task again.

## Alone or in a group?

It is true that not all people like to do activities in groups. Some people will prefer to do activities by themselves while others may simply enjoy watching what is happening. If someone with HD is invited to do a group activity but is reluctant to participate be aware that it could be due to some of the symptoms of HD discussed above.

### Physical activity is crucial



It can be as simple as a walk around the block or up to the local milk bar to buy the morning paper, but incorporating exercise and movement in the daily routine is particularly important for people with HD. If walking doesn't appeal perhaps a structured exercise program, as part of an activity group would be more suitable. All activities need to be continually reviewed and monitored and particularly as physical HD symptoms progress; and risk of falls and fatigue increases.

### Choose activities that require gross motor skills

Fine motor skills are impaired by HD which means that activities, which require precise co-ordination such as writing, sewing or craft, become very difficult. Instead, ask people with HD to help with activities that rely mainly on gross motor skills like sweeping, raking leaves, bringing the clothes in off the line, folding the washing etc.

If components of an activity do require fine motor skills ensure that these can be done by someone else or that the person with HD can get assistance with them.

It is also essential for people living at home to take an active and meaningful part in the daily routine. This helps to encourage and maintain independence and to reinforce the person's role within the household.



## **Make tasks achievable**

Select activities and tasks that can be completed with a successful end product or outcome, which then enhances self-esteem and self-confidence. These activities do not have to be complicated. The essential element is that they are achievable and meaningful for the person with HD.

## **Break tasks down**

As HD progresses, it may be necessary to breakdown tasks into small, simple steps. This will assist the person with HD who may have difficulty with organisation and planning to undertake and complete tasks successfully. It will also reduce any anxiety, which may impact on task performance.



## **Reduce distractions**

Busy environments are overwhelming and make completing tasks more difficult, if not impossible, for people with HD. Distractions such as excessive noise, light and movement will increase anxiety, frustration and distress while reducing concentration. Seeking out places that are calm and relatively quiet will enable people to complete tasks at their optimum level.

## **Be aware of fatigue**

People with HD fatigue easily, so it is important for them to take several short breaks throughout the day and particularly during busy periods.

It is also useful to work out times of the day that the person functions best and target activity for these periods. For example, is he or she a “morning person” or a “night person”?

Finding out as much as you can about techniques and aids that help to conserve energy would also be very helpful in easing fatigue.

## **Helpful Contacts**

### **Huntington's NSW**

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### **NSW Huntington Disease Service**

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For further information on Huntington Disease, a membership form, or details of HD services in NSW, please contact Huntington's NSW

Acknowledgements: Huntington's Victoria