

---

# Minding your Mental Well-being

while living with Huntingtons Disease



# Background Information

Huntington's Disease (HD) is a hereditary neurodegenerative disorder that can cause different symptoms in an individual's physical and mental health. Every individual will experience a unique set of symptoms.

The average onset of symptoms is usually between the ages of 30-50 years but some individuals may present under the age of 20 (Juvenile HD) or after the age of 65 years.

Physical symptoms can include difficulties with motor muscle movements and can lead to impairments in walking, speaking or swallowing.

Mental Health issues can include problems with anxiety, mood and difficulties with concentration and thinking processes.

HD is a rare genetic disorder and each child of an affected individual has a 50% chance of inheriting the gene. A small number of individuals have no known family history of HD. It has been estimated that approximately 700 individuals in the Republic of Ireland may have HD and about 2,500 individuals are at risk (Morrison et al, 2010).

Being aware of and attending to one's own Mental Health needs for an individual with HD is vital.



We need to plan services that offer Mental Health assistance, from the moment of considering genetic testing onwards as things may change and difficulties may arise. A combination of therapeutic approaches may be helpful and access to an experienced Mental Health Multidisciplinary Team for those with HD is considered best practice.

The Multidisciplinary Team will assess an individual's mental health, physical condition, and general health issues such as nutrition and speech and language function. Neuropsychiatrists, Neuropsychologists, Nurses, Occupational Therapists, Pharmacists, Physiotherapists, Speech and Language Therapists and Social Workers can all contribute to the care of those with HD. Research has shown that a combination of physical and cognitive activities can help delay the development of symptoms. Early interventions can significantly impact the quality of life for those with HD and their families and caregivers.



**IT HAS BEEN ESTIMATED THAT APPROXIMATELY 700 INDIVIDUALS IN THE REPUBLIC OF IRELAND MAY HAVE HD AND ABOUT 2,500 INDIVIDUALS ARE AT RISK.**



# Looking after your Mental Health

## HD and Stress

A diagnosis of Huntington's Disease (HD) is a stressful experience for the individual and their family. The stresses can change, as symptoms arise and doing certain tasks are no longer as easy as before.

## The changes of HD

Changes are part of the picture of HD. These changes can occur in the person's thinking skills, physical abilities, emotions and behaviours and this often means an increased need for help and support. As time passes, the person may need more help in certain activities; they may need help to compensate for what is more difficult for a time. An example of this is being reminded to take their medication, if their memory is not as good as it once was.

Many of the changes that can happen with HD can be unwelcome, and all are uninvited. Despite this, some changes may challenge you to tap into inner strengths you may never have known you had. People with HD and their families are managing to juggle so much in terms of the changes they encounter and all with the general demands of life added on top. Give yourself credit for all that you are doing.

When a family is faced with a diagnosis of HD, they can often feel a sense of uncertainty about the future. Managing this uncertainty can be stressful. Stress can have many effects on us; it can make us feel tired and worn out; it can be harder to think straight and dampen our mental sharpness. Stress can make us feel sick and can make us act out in ways in which we usually would not, e.g. becoming irritable and angry at those around us.

## “Self-care”

“Self-care”, the importance of looking after yourself, is essential when you have HD or are caring for someone who has HD. Looking after yourself means you will be the best you can be, even if that is different from before.

What helps you to feel good in yourself and about yourself? For everyone it's different..... Having coffee with a friend; playing a game of tennis; sitting down and reading a book or watching your favourite box-set; having a long bath; whatever you enjoy.



## Advice from “CBT”

Cognitive-behavioural therapy (CBT) is a psychological therapy which helps people who feel low or anxious and who may have other difficulties. Part of the message of CBT is reframing how we think about things; another part focuses on what we do. CBT says that we all need to do things every day that we enjoy and things that we feel we're good at. This is what helps us to feel good in ourselves.

Making time for the things that you enjoy and that you feel you are good at, is very important when you are managing the changes and challenges that HD can bring, whether you have a diagnosis of HD or are caring for a family member with HD. In order to meet these challenges you need to be feeling as good as possible both mentally and physically, so as you can keep up with the life changes that HD can bring.

**If life is feeling very tough or if you, or those around you are concerned about how you are doing, contact your GP or local Hospital. Seek help. You are not alone.**

## How stress effects on our Functioning

### Emotional

- Anxiety
- Low mood
- Hopelessness
- Apathy
- Feeling overwhelmed
- Reduced confidence

### Thinking Skills

- Poor Attention and
- Concentration
- Memory difficulties

### Behavioural

- Withdrawal
- Agitation & Irritability
- Poor sleep
- Reduced desire to socialise or take part in everyday tasks



## It is important to know, things that can be done to help:

- Talk about it – with someone close to you or perhaps a professional – we are here to listen and help – Talk to your GP who can help arrange a referral to specialist services.
- Looking after yourself is important – make time for it!
- Try to have balance in your life
- Make sure that you are linked in with your GP and healthcare team, so you can understand the changes that are happening and how best to manage them.
- Do whatever gives you a sense of wellbeing.
- Use your supports – friends, family and professionals.
- If you or others around you are concerned, seek help from your GP.
- Find out who may be able to help you now and in the future.
- Link in with the Huntington’s Association of Ireland.
- Come to the Bloomfield Hospital HD Café, meet others managing the same circumstances and find out information that will help you.
- Seek help as soon as you need it – things don’t need to be as difficult as they might be
- Have realistic goals for yourself
- Pace yourself
- Value and appreciate what you’re doing
- Take a break or plan to do something for yourself such as relaxation
- Take some physical activity or exercise and eat a healthy, balanced diet
- Don’t be too critical of yourself or be a perfectionist
- Set limits – you have rights and feelings too
- Ask for assistance, identify resources for yourself
- Accept offers of help
- Do the things that you enjoy – It is important to experience PLEASURE
- Do the things that you feel you are good at – develop a sense of MASTERY



# Make time for yourself – You are important

## General Advice

### Sleep

Individuals with HD can have difficulties with getting enough sleep. Sometimes a person can be exhausted from choreiform movements if these are burdensome. Regular rest periods may need to be scheduled. Anxiety and depression can also present with insomnia and again should be discussed with your mental health care provider. Specialist mattresses or bedding materials may help those with significant chorea.

### Expressing Sexuality

The intimate relationship between a couple, is unique and personal. Difficulties can arise for individuals with HD due to choreiform movements.

Impulsivity can be evident in sexual behaviour as well as with other behaviours.

Intimacy can change over time in every relationship. It is important to be able to discuss any difficulties you might be experiencing with your health provider. A loss of libido may be a symptom of depression or a side effect of various medications and should also be discussed with your mental health provider.

### Work and Play

Occupational Therapy can help people overcome barriers that prevent a person from doing the activities (occupations) that matter to them. This in turn, helps to increase a person's independence and satisfaction in all aspects of life. The "Occupation" in the title, refers to practical and purposeful activities that allow people to live independently and have a sense of identity. This could be essential day-to-day tasks such as self-care, work or leisure.

Occupational therapists (OTs) will often use assessments or questionnaires to understand how a person performs activities or occupations. OTs explore and assess how the physical, social and cultural environment affects a person's occupational performance.



### **Occupational Therapy Interventions:**

Can be carried out individually or in group setting and usually focus on engaging in an activity.

Occupational Therapists are often part of a Multi-disciplinary team that can assess a person's wheelchair or specialist seating needs.

### **Social Work Services**

Social Workers can offer a wide range of services to both individuals with HD and their families. The potential changes of role within the family unit, the potential loss of gainful employment and the resulting financial implications can have a negative impact on the mental health and wellbeing of both the patient and their families.

Social Work services can provide

- Comprehensive social assessment
- Individual work with patients
- Carer support and family work
- Advice for patients and family on financial matters
- Liaison with other agencies and community services

### **Legal and Financial Affairs**

It is important for all of us, no matter who we are, to be organized with regard to our future health and financial planning.





Advance Directive or “Living Will” is a statement where you can state in advance what your wishes are regarding medical treatment.

A person may become unable to make decisions for themselves. It is therefore important to have considered an Enduring Power of Attorney to document a person’s wishes in order that a next of kin can support their wishes.

A person with HD should feel comfortable having their wishes known and clearly documented. Of course these can be edited in the future if a person changes their mind about a certain intervention e.g. peg feeding. Additional more in depth information on these processes can be found as described in the Think Ahead program from the Irish Hospice Foundation.

As a person’s Physical Health can have a significant impact on their mental health, it is important that it is given recognition and attention.

### **Physiotherapy and exercise for persons living with HD**

It is widely recognized that physical activity and exercise is important to maintain a healthy lifestyle. People with Huntington’s Disease are often less inclined to take part in regular physical activity through age, embarrassment of their movements, shaking or stiffness, awkwardness, reduced gait or through mood difficulties. Physiotherapy can support and enable people with Huntington’s Disease to remain active and maintain function.

Physiotherapy can be by prescribing specially adapted exercise programmes

- Enhance fitness and strength
- Stabilize gait and balance
- Maintain respiratory capacity
- Prescribe and fit assistive devices or walking aids
- Educate and support caregivers

As well as supporting physical health and function, exercise and activity can also have an important role in improving mental health. Depression and anxiety can occur more commonly for people with Huntington’s Disease. Research suggests that exercise is an effective adjunct treatment for depression and anxiety for people in the early to middle stages of Huntington’s Disease. Therefore, remaining as active as possible is extremely important to help maintain a person’s physical and mental wellbeing.



## **Nutrition**

It is very important for individuals with HD to pay attention to their nutrition and weight, making sure to eat a healthy diet.

- Weight should be maintained at the top end of healthy range with a Body Mass Index (BMI) of between 24-26. If BMI is below this it is essential to promote weight gain and prevent further weight loss.
- WEEKLY WEIGHTS: It is very helpful to track your weight so you can inform your healthcare provider

### **Being underweight can cause**

- Loss in muscle mass which can lead to an individual feeling weaker
- The likelihood to catch infections which in a person living with HD may take longer to recover from
- Apathy and depression
- The development of pressure sores if a person's mobility is reduced.

### **Difficulty maintaining or regaining body weight can be helped by:**

- Taking foods of higher calorific intake
- Eating small frequent snacks, that are high in calories
- Not drinking large amounts of fluid with meals as it can make you feel too full
- Taking time over meals
- Sitting comfortably
- Adding extra calories
- Increasing energy through sugar intake jams/sugar or butter/cream
- Making sure you are taking food of the correct texture

### **Maintaining Normal body temperature**

The temperature regulation centre may be impaired. Therefore it is important to be aware of the possibility of developing hypothermia during the cooler winter weather or hyperthermia during the warmer summer weather. Individuals with HD may not feel the heat or cold as sensitively as others. If a person's nutrition is compromised it may be difficult to generate enough body heat. Certain medications can cause photosensitivity and this should be discussed with an individual's health care provider.



## Speech and language Services (SALT)

Speech and language services provide assessment of the oral management of food and tongue co-ordination that is essential to both speaking, eating and drinking. A Speech and Language Therapist can advise on the recommended texture and temperature of food to and on techniques to assist with communication. It is important to continue to maximize a person's functional abilities.

## Dental Care

- An individual with HD may have difficulty or dexterity using a toothbrush
- Diet (high in sugar) can cause tooth decay

## The aim is to

- To prevent tooth decay
- Prevent Gum disease
- Use a specialist tooth brush as required

## In Summary

All persons living with Huntington's Disease and their family need support and hope.

The cause of this disease is known and targets for intervention have been identified. There is intense scientific activity across the globe and new potential therapeutic interventions are in development.

Most of all there is an active organized receptive HD community ready to advocate and support all individuals with HD and their families. Individuals with HD need to remain as active and healthy for as long as possible. Attention to minding their mental health is huge part of this work.

We hope you have found this booklet to be of some help. If you require any further information about our services at Bloomfield Hospital please call or visit our website:

[www.bloomfield.ie](http://www.bloomfield.ie)

or the website of the Huntington's disease Association of Ireland:

[www.huntingtons.ie](http://www.huntingtons.ie)

