



Huntington's Disease  
Association of Ireland

## **Address to Joint Oireachtas Committee on Social Protection, Community and Rural Development, and the Islands**

### **The impact of means testing on Disability Allowance, Disablement Pension and other social welfare schemes 29 May 2024**

**Sandra Porter, Financial Wellbeing Officer, Huntington's Disease Association of Ireland**

I work as the Financial Wellbeing Officer for the Huntington's Disease Association of Ireland. Huntington's disease (HD) is a rare, inherited, and highly complex neuro-degenerative disease that brings a huge burden to families affected. My work involves supporting individuals and their families as they try to secure their families finances in their changing circumstances. I see first-hand how challenging, difficult and stressful this is for families. It is particularly challenging if they have dependent children.

Huntington's families experience a financial burden ranging from extreme financial stress to poverty due to the degenerative nature of the disease. This is directly linked to both a person's inability to maintain employment and their lack of access to financial supports due to means testing.

Means testing is a very arduous process for a person experiencing cognitive or mental health difficulties. A claim refusal is devastating for a person in need of support; the Disability Allowance application process is already very stressful, confusing and difficult, and the idea of making an appeal is exhausting and daunting.

The removal of means testing would make supports more accessible and remove this burden both for people living with Huntington's disease and their caregivers, who often struggle with their altered family circumstances.

The current means test system requires a deep level of household income poverty to be eligible for Disability Allowance, with household income calculated at gross instead of net - with no consideration of mortgage, rent or any other financial obligation.

Our social protection system needs to understand that people living with a neurodegenerative disease will not be able to sustain paid employment; therefore, it is imperative that welfare payments are sufficient and accessible to cover the extra costs of disability to protect people from poverty.

The stark reality is that while people living with Huntington's struggle to keep up with prior financial commitments, they also worry about a bleak financial future.

Families with a parent living with Huntington's disease may fall into poverty during the period when the person is not able to maintain their employment. Due to cognitive and mental health changes, a person may be unaware of or in denial about their condition and so refuse to seek disability or social welfare support. This leaves the household subject to extreme financial stress or poverty,

depending on each family's situation- whether they have savings or investments, with mortgage and rent obligations being an immediate area of concern.

A person living with Huntington's in the majority of cases will leave work due to their undiagnosed symptoms and often fall through the cracks of social welfare payments. A number of years may pass before a person receives a confirmed diagnosis. At this stage, the person and their family believe they are not eligible for Invalidity Pension as they are outside the "prescribed time". A person living with Huntington's and other neurodegenerative conditions may have worked for all their adult life, for decades, up until the point their symptoms manifest.

I would like to offer some recommendations and suggestions around gaps and anomalies in the system that I have seen in my work supporting people and their families impacted by Huntington's:

- Remove all means testing of disability payments for people living with life-long and degenerative life limiting conditions or at a minimum, remove means testing for a household income of less than €100,000.
- Provide an increased universal non-means tested non-taxable payment with an automatic entitlement for people with *life-long conditions / degenerative life limiting diseases* based on a medical professional's report or diagnosis.
- Recognise the cost of caring/living in the allowable deductions in any remaining means assessment and have income assessed on net value.
- Consider the Cost of Disability and the risk of future disability in the case of hereditary diseases – and the resultant need for families to save carefully.
- An enhanced support system should be provided for people with disabilities - an independent holistic advice service that helps people with their claim, to replace the current system of "signposting", providing direct referrals and warm handovers for applicants with greater support requirements.

In relation to savings and the impact on means testing, for families impacted by HD savings set aside may be required to meet the cost of living with HD. This may include accessible alterations to housing, an adapted car, specialist seating or other equipment, counselling and other supports to family members at risk, the cost of private home support care or nursing home care, setting aside a fund for funeral expenses or other emergencies. Savings may also go towards assisting other family members who may develop HD in the future.

There needs to be more consideration of how inheritance and Disability Allowance can coexist. A person-focused approach is required to understand the long-term needs and costs of a person and their family living with a disability.

A person living with HD, like so many other conditions, will need any savings they have accumulated over their working life to meet the cost of their illness or disability. People living with HD can avail of multi-disciplinary care through primary care services where available but where a post is unfilled or waiting lists are very long families may have to seek a private service. Psychological or counselling supports is not automatically available to people at risk

Means testing also forces people living with a disability to be financially reliant on their partners or family. They will have lost so much already, and the removal of their financial independence can cause huge stress and distress, depending on their family situation. This increases financial strain on

the family household. In certain extreme situations, a person may become homeless, malnourished, or vulnerable to exploitation if they do not have people to support them and advocate on their behalf.

**Notes:**

The Cost of Disability in Ireland Report 2021 estimates the annual costs of disability in Ireland range from €9,482 per annum to €11,734 per annum. It estimated a cost of €16,284 for people with severely limiting disabilities such as HD.

Page 90 [www.gov.ie/pdf/?file=https://assets.gov.ie/206636/f8e1b2af-af48-442b-9ca0-aff9efd35bd7.pdf#page=null](https://www.gov.ie/pdf/?file=https://assets.gov.ie/206636/f8e1b2af-af48-442b-9ca0-aff9efd35bd7.pdf#page=null)

From the Statistical Information on Social Welfare Services Annual Report 2022 and Appeals Office Annual Report 2022, approximately 56% of disability allowance applications were refused on first application. Approximately 58% of disability allowance applications were granted in whole, in part or revised on appeal.

Ireland adopted the Intersectoral global action plan on epilepsy and other neurological disorders 2022-2031, making a commitment to improve access to treatment and quality of life of people with neurological disorders. In line with this commitment HDAI request that the any changes implemented offers scope to improve support and access to financial welfare benefits by families living with a neurological disorder.

Ireland has ratified the International Covenant on Economic, Social and Cultural Rights, which recognises the right of everyone to an adequate standard of living, including people with a disability and their families.

Social welfare supports and retirement provision are often the only options available to people with a HD diagnosis in their family. People with a family history of HD face genetic discrimination when accessing life insurance, salary protection and serious illness protection.

**GAPS:**

- The Homemaker Credit Scheme should be considered as reckonable for invalidity pension.
- An automatic transfer from the non-means tested non-taxable support payment to the non-contributory state pension – removing the burden on families of the pension means test process.
- Provide a separate Invalidity Pension Late Claim with Good Cause application form and make this known to the wider community.
- The supports should be adequate to cover both the cost of living and the Cost of Disability – consideration should be given to the extremely high costs of certain disabilities and the need to provide whole of life supports.

- Remove tax on invalidity pension
- Self- employed people do not have access to illness benefit – and in turn no access to disability allowance due to the means test. Options limited
- **Universal payment** made to individuals rather than households - A guaranteed income for everyone in society living with a disability to cover basic needs acknowledging the cost of disability to create a minimum income floor. The goal must be to insulate people who cannot work due to an illness from poverty and deprivation.
- **Safety net** – if a person is not meeting their jobseekers allowance conditions for example due to cognitive and are at a risk of being knocked off the payment - a person centred approach is required

### **Huntington's Disease**

Huntington's disease is widely misunderstood in society, the workplace and general health and social care services, causing HD families to face daily barriers in all areas of life.

Rehabilitative therapies such as physiotherapy, occupational therapy, speech and language therapy and diet and nutrition expertise can help manage HD symptoms. Support and information, neuropsychological and psychiatric services can help with cognitive and neuropsychiatric changes. A healthy diet, which maintains regular weight, is also important.

Approximately 750 people with symptoms and an estimated 400 with the Gene with approximately 3000 people with a genetic risk of HD.