

Professionals involved in your care

You are likely to come across a range of professionals over the years. How their roles differ can be confusing, so this is an overview of the types of practitioner you might meet and what it is that they do.

1. HD Specialists

[HD Specialists](#) are employed by Scottish Huntington's Association to support families. They have expertise in working with individuals and families impacted by Huntington's disease and have a background in health and social care. They help with a range of issues such as symptom management and future planning. They also provide information and advice to people at risk of Huntington's disease and to carers.

2. Doctors

Your GP will know a bit about most medical conditions which is why they are usually the first port of call if you feel unwell. If your problem requires in-depth knowledge of particular body part or issue, your GP might refer you to a specialist. Specialists you may encounter include psychiatrists (mental health doctors) and neurologists (doctors who diagnose and treat disorders of the brain, spinal cord and nerves). Your specialist HD consultant (or HD Clinical Lead) is usually a psychiatrist or a neurologist but, depending on where you live, may also be a geneticist or a neuropsychologist.

3. Genetic Counsellors

Genetic Counsellors are professionals who are qualified to advise those at risk of a genetic condition and help them to make decisions about their healthcare. For example, if you wish to be tested for Huntington's disease, then you will have a number of sessions with a Genetic Counsellor beforehand to ensure you understand how the test result could impact your life.

4. Social Workers

Social workers provide advice, support and resources to individuals and families to help them solve their problems. Many social workers specialise in a particular field, such as working with children or older adults. You may encounter a social worker for a variety of reasons, such as:

- Concerns about your safety at home or if you feel the services you receive are inadequate. You might meet with a social worker who can assess what additional support would be helpful.
- If your current accommodation no longer meets your needs, a social worker might help determine what kind of place you could move to, for example a supported living facility.

5. Speech and Language Therapists

Speech and Language Therapists are trained to help people who have issues with communication and/or swallowing. Your therapist might recommend a specific type of diet or help you to develop strategies to make it easier for you to communicate with others.

6. Occupational Therapists

Occupational Therapists (OTs) work with individuals to find practical ways to overcome barriers that they encounter in their day-to-day lives. Their aim is to help you to continue living life to the full. Your OT might suggest aids and appliances that make your daily activities easier (such as a shower chair or special cutlery), or changes to your living environment (such as the installation of hand rails or changes to the layout of your room). They can also advise employers about adaptations to help you at work.

7. Physiotherapists

Physiotherapists are experts in movement. They are interested in maximising your physical potential. You might see a physiotherapist if you are having issues getting about or if you are having falls. They may suggest specific strategies to manage these issues, offer you aids that could be helpful (like a walking frame) or recommend exercises to improve your balance and coordination.

8. Dieticians

Dieticians are experts on diet and nutrition. Huntington's disease can cause weight loss and dieticians can help you to minimise this with advice about what to eat. They may also prescribe supplements like high-calorie drinks. Some people with Huntington's disease choose to be tube-fed (via a PEG tube) if swallowing becomes too difficult. A dietician can recommend an appropriate feeding regime and assist with the management of your PEG tube.

9. Financial Wellbeing Officers

Scottish Huntington's Association employs Financial Wellbeing Officers who provide advice on money issues including benefits, debts and your energy bills. [Find out more about our Financial Wellbeing service.](#)

10. Specialist Youth Workers

Huntington's disease affects the whole family. [The Scottish Huntington's Association Youth Service](#) provides advice and assistance to young people aged 8-25. The Specialist Youth Advisors also advise parents about how to speak to young people about Huntington's disease and provide age-appropriate resources.

11. Clinical Psychologists

Clinical Psychologists help people with a range of psychological issues. You might see a psychologist if you are having particular issues with your thinking or behaviour. Their assessment can be used to recommend what strategies or interventions might be beneficial to you. Psychologists often work closely with other professionals such as doctors and OTs.

12. Home Care Workers

Home Care Workers attend your house to help with basic day-to-day tasks such as personal care or meal preparation. They will visit more or less often depending on how much help you need.

This list is not exhaustive and there may be additional people who will be involved in your care over the years. It can be helpful to keep a list of these people along with their contact details and what job they do. You will find

more information about services available in the [National and Regional Care Frameworks for Huntington's Disease](#).

Useful links

[Contact a Scottish Huntington's Association HD Specialist](#)

[Scottish Huntington's Association Financial Wellbeing Service](#)

[National and Regional Care Frameworks for Huntington's Disease](#)

[Scottish Huntington's Association Youth Service](#)

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Updated January 2022