Every one of us carries the Huntingtin gene which assists nerve cells in functioning effectively. For some of us, the gene is faulty, leading to Huntington’s disease (HD) – a fatal genetic condition. This disease does not discriminate between race, gender, ethnicity and age. While this devastating disease might not be well known within the wider community, it is not rare. It could affect someone you know.

What is HD?
Huntington’s Disease (HD) results in brain cell death and affects the basal ganglia and frontal lobe regions of the brain. These regions are responsible for motor movement control and coordination, cognition, personality and emotions. Deterioration in these regions of the brain results in significant impairments in one’s ability to think, feel and move.

Symptoms of HD:

**Physical**
- Involuntary movements
- Impaired balance & coordination
- Swallowing difficulties
- Slurred speech
- Impaired communication

**Cognitive**
- Memory difficulties
- Impaired thinking, planning & organising tasks
- Rigidity in thought patterns
- Impulsive & disinhibited behaviours
- Perseveration

**Emotional/Psychological**
- Depression & anxiety
- Obsessive compulsive behaviour
- Psychosis
- Personality changes

Symptoms vary between individuals and between family members. There is no cure for HD, however, there are limited medical interventions available to minimise and assist in the management of these symptoms.
Basics of Huntington’s Disease

Who is affected by HD?

HD onset predominantly occurs in young to middle adulthood (20–60 years). There is a juvenile form of Huntington’s disease that presents before the age of 20 and is more rapidly progressive. Being a genetic disease, each child of an affected parent has a 50% chance of inheriting the defective Huntingtin gene. HD both directly and indirectly affects the following:

- **Diagnosed** with Huntington’s disease – this is someone who is showing symptoms (symptomatic)
- Tested **gene positive** after predictive testing – this is someone who is not symptomatic but will eventually develop symptoms of HD
- **At-risk** of developing Huntington’s disease – this is someone with a parent with HD but has not been tested or diagnosed.
- Family members found to be **gene negative**
- **Carers** of persons identified above

How do I find out if I or someone I know has HD?

A gene test is available which allows a person at risk to find out if they carry the faulty HD gene and will someday develop the disease. The test cannot determine when the symptoms of the disease will begin or how severe the symptoms will be.

Please refer to **Predictive Testing & Diagnosis** (information sheet 2) for more information.