“Case History”

Living with Huntington’s disease

ERROL WALSH
Support Worker
Tel: 028 2177 1812
Email: errol@hdani.org.uk
Website: www.hdani.org.uk

Huntington’s disease in brief

- Huntington's Disease (HD) is a highly complex neuro-degenerative disorder, with a fluctuating progression, affecting both mind and body.

- It is caused by a faulty gene which progressively destroys the central area of the brain affecting many aspects of an individual’s health including general physical capacity, involuntary movement, moods, and thinking processes.

- Because the damage caused by HD is only inside the brain, the person with HD may look relatively able bodied until the later stages of the disease.

- Children who have one parent with HD have a 50% risk of inheriting the faulty gene.

HD is a ‘Family disease’

Meet the Smiths:

They live in a two storey house
in the Northern Trust Area

Q: Why is this important?

A: Location determines access to the Specialist HD Nursing team or heavy reliance on GP

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Dad is 45 and worked as a community bus driver for Health & Social Services until he was diagnosed with HD because of issues with his balance; cognition and poor concentration.

- Mum is 40 and a school teacher
  (The Smiths have two children:)

- Ben is 15 and Ann is 9
- Dad is an only child, his mother is alive but his father died in a car accident 20 years ago:
- There was no indication of any history of HD in the family.

Issues affecting individual family members:

- Trauma of diagnosis *(no warning, no history)*
- Shame & Stigma *(misunderstood and often socially embarrassing symptoms)*
- Guilt *(children's genetic risk)*
- Realisation of what this means in real terms both emotionally and practically for himself and the entire family *(stress, depression, loss of independence, constant worry and fear about every single aspect of the future)*

- Other major issues that will inevitably confront Dad are things like loss of income, future care, access to accurate information and support services, transport and family relationships
- Other issues, that are as yet unrealised, will include the reality of the development of potential behavioural issues... which can impact enormously on relationships within some families & may result in major dysfunction and even family breakdown.

- Trauma of diagnosis (realisation that life will change utterly for the whole family)
- Fear of the genetic implications for the children and grandchildren
- How to tell the children?
- Potential transition to full time carer and the attendant financial implications of that.
- Access to the full range of support that will be required for dad and children.. and self!
- Fear, stress, fatigue, depression, isolation.

The challenges facing Ben and Ann are many.. and frightening.. and will require a lot of support and understanding

- Genetic testing
- Family breakdown
- Secrecy and Stigma
- Increased stress, anxiety and emotional pressure
- Young caregivers
- How to explain to peer groups
- Worries about family relationships
- Watching the future unfold
- Accurate information
- Family planning
- Isolation
- Fear, denial, guilt
- Disadvantage and lack of opportunity
- Serial loss and bereavement

Risks to the development of young people living with HD

- Genetic risk
- Mental health
- Confidence and self-esteem
- Self harm and suicide
- Physical/Emotional harm at home

- Mum and dad, as adults, will share most of the issues that have been attributed to them as individuals in this presentation.
- The children too will be impacted by the changes in their lives and a potential fate which is not uncommon in HD families... that of family breakdown often caused by inability, or sometimes sadly, unwillingness, to cope.
- Another contributory factor to family breakdown for all families faced with loss of income & full time carer responsibilities is poverty... or relative poverty and debt.

In Conclusion:

I hope this presentation has demonstrated how the entire family is enormously impacted in both similar and different ways.

"Huntington's disease is a family disease, and only an approach which recognises and embraces the needs of whole families, can succeed in adequately enabling them to meet the extraordinary challenges that confront them"

It is also vitally important to realise that, with the extraordinary acceleration in scientific research in recent years, there is now real HOPE for the future