

Breaking Down Barriers



Poppy Hill - Specialist HD Adviser covering West Midlands Region



Project Overview

Huntington's disease

- A complex neuro psychiatric degenerative disorder. Ave Age of onset 30-50. Prognosis 15-20 years
Inheritance: autosomal and dominant

Barriers identified through our research with S.A families with HD

- Rarely access predictive testing only diagnostic – Stigma shame/ affect marriage/ denial HD is palliative
- Families not always accessing services and specialisms available: Lack of education? language barriers ?
Poor info available/?Our lack of understanding as HDA? GP ltd knowledge?

Project Year 1 :

- 1 leaflet in basic English covering what you need to know e.g. what it is/ help out there, family planning options
- Also GP flow chart to advise best practise

Year 2: (in progress)

- Short video animation to provide more in depth info re services to access. Set up :HD adviser talking with a daughter who's Mum and Grandad have HD. Very rep of how we work. In English



Challenges

- Stigma and denial – closed doors
- Time constraints– our unpredictable workloads v time needed to work on project – remote working not as effective
- Language: to translate or not/ simplicity of vocab / Communicating tricky areas like death and termination
- Images and copyright
- Branding of HDA v our vision
- Now video – getting enough info across with human story but not too long/ Keeping objective/animation where to start- the unknown....



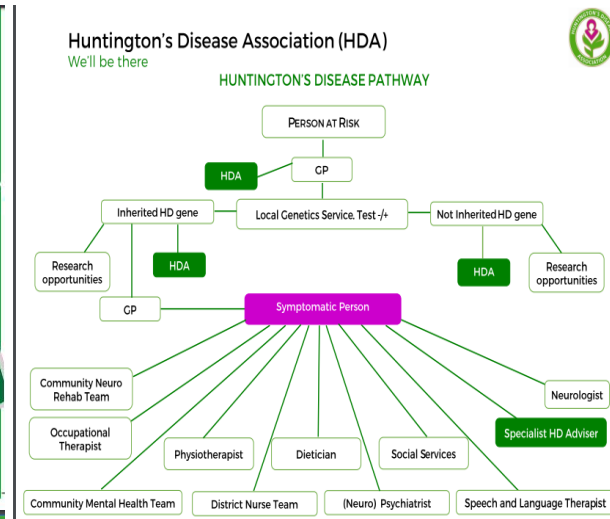
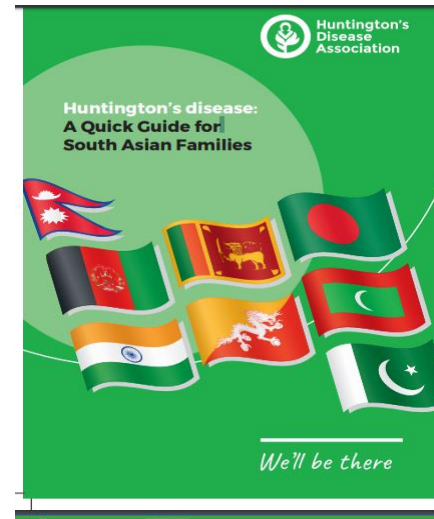
Areas of Success

We have one basic leaflet to give to families now as needed instead of the poor overly complex and poorly translated ones we had before.

Flow chart for GP's to ensure families are accessing best levels of care – Can be adapted to cover other regions to ensure everyone is accessing right care and best long term journey.

Our journey as organisation and individuals - Less naïve and more confident around cultural differences and sensitivities. Realistic expectations of how can break down barriers as such - small steps....

Through research process families worked with have said they have learnt new things about HD HD and positive feedback re leaflet and objectives



Questions



Thank You



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