Huntington's Disease Association

HDPassport

Your space for personalised support

Huntington's
Disease
Association

How to use the HD passport

The Huntington's disease passport is a document that shares information about your family life and how Huntington's disease effects you. It provides a space to share important information with others who support you at school, college, university and work. The document will help those around you to develop a basic understanding of how to support you. It is up to you how much or how little you share in this document.

How to fill out your HD passport:

- Each text box has some ideas and instructions, just change this text to your text and you're good to go.
- Once you're finished, delete this first page and download it ready to print.

Remember:

- It's up to you what you share in this document. Only add information you feel comfortable with sharing.
- Each section can be filled in using words or drawings.
- Don't worry about spelling or grammar.
- This is your document, so you can come back to it and change it as much as you would like or as things in your life change. Make sure to share your updated copy.
- This document could be shared with a class teacher, a work supervisor, a boss or any other person who supports you.

Helpful links and resources

- Young adults guide
- Teenagers guide
- Teachers guide
- Huntington's Disease Association website

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[name's] Huntington's Disease Passport

Huntington's disease is a rare neurodegenerative condition, with no cure It affects a person's mind, movement and mood and progressively gets worse over time. The condition can affect everyone differently which means someone can experience more or less of certain symptoms compared to others. Huntington's is genetic. This means anyone with the gene has a 50% chance of passing it on to their children. Huntington's has a massive impact on family life, as the person with the condition needs lots of care and support. This can mean that young people take on caring responsibilities at a young age. As Huntington's disease is rare, it is common that young people affected by the condition can feel quite isolated.

This passport helps to explain my family life and the support I need. It also contains private and personal information about my life. Please do not share it with anyone else without consent.

Who is the person affected by Huntington's disease and what is their relationship to you

How am I impacted by Huntington's

How I support my affected family member

How you can support me

What does family look like to you?

Who is important to me?

My likes

My dislikes

Anything additional I would like you to know about me ...

If you want further information about Huntington's Disease and how to support this young person, please contact hdyes@hda.org.uk