



## **What is 'A guide to talking to young people about Huntington's disease'?**

Thank you for requesting 'A guide to talking to young people about Huntington's disease'. The guide book has been created to inform young people about Huntington's, also known as HD, and to help them explore their feelings and ask questions.

Our intention is for the guide book to be used by an adult to introduce Huntington's to a child when they feel they need to understand more about Huntington's.

There is no rule about how to deliver information about Huntington's but we do recommend that you are sensitive to the child's age and level of understanding or maturity. Be honest and avoid trying to hide information. People are able to access information very easily through the internet and it is not always factually correct. It can be very upsetting for a child to find out this way rather than speaking with a trusted adult or family member about the subject.

The guide book is not intended to be handed to a child as an information booklet or for something that they should

complete by themselves. You may want to work through the guide with the child, covering the sections you feel are relevant to them at a particular time or you may just want to use it as a prompt for conversations. It contains all the pertinent information about Huntington's, including how someone gets the disease and mortality.

You may deem some of the information inappropriate for your child due to age or their emotional wellbeing at that time. These subjects are particularly sensitive and we recommend that they are discussed openly, honestly and sensitively. You might want to wait until these questions are asked before giving this information or you may feel that it is better to tell them and pre-empt the questions.

We would recommend that you never close the subject of Huntington's and allow a child time to digest information and ask questions at a later date. It's a challenging time and subject for everybody so be prepared for the child to keep coming back with questions over long periods of time.

## Useful organisations for families with Huntington's disease:

### The Huntington's Disease Association - [www.hda.org.uk](http://www.hda.org.uk)

Specialist youth workers' contact details

North of England and Wales

James O'Connor:

Mobile - **07718 424 905**

Email [james.o'connor@hda.org.uk](mailto:james.o'connor@hda.org.uk)

South of England and Wales

Lilly D'Cruz:

Mobile - **07711 004 146**

Email - [lilly.d'cruz@hda.org.uk](mailto:lilly.d'cruz@hda.org.uk)

### Huntington's Disease Youth Organisation - [www.hdyo.org](http://www.hdyo.org)

HDYO is a fantastic online space where adults and young people of all ages can explore and further their knowledge about Huntington's disease. There are a number of interviews in which people talk about their experiences with Huntington's and offer an insight into their lives so people can have a better idea of what to expect.

### Carers Trust - [www.carers.org](http://www.carers.org)

Carers Trust believes in a world where the role of unpaid carers is recognised and they have access to the quality support and services they need to live their own lives.

### Young carer information:

#### The Children's Society -

[www.childrenssociety.org.uk/youngcarer/home](http://www.childrenssociety.org.uk/youngcarer/home)

The Children's Society campaign for change, promote best practice with central and local government, and work in partnership with key workers to support young carers.

Telephone - **0300 303 7000**

Email - [supportercare@childrenssociety.org.uk](mailto:supportercare@childrenssociety.org.uk)

Live chat - on their website from **10am-4pm, Monday-Friday**

#### Young Carer Info - [www.youngcarer.info](http://www.youngcarer.info)

An online guide for young people to get support, know their rights and get advice.

### Bereavement support:

#### Cruse -

[www.cruse.org.uk](http://www.cruse.org.uk)

Phone - **0844 477 9400**

Email - [helpline@cruse.org.uk](mailto:helpline@cruse.org.uk)

#### Winstons Wish -

[www.winstonswish.org](http://www.winstonswish.org)

Freephone - **08088 020 021**

Enquiries - **01242 515157**

Email - [info@winstonswish.org](mailto:info@winstonswish.org)

#### NHS directory -

[www.nhs.uk/livewell/bereavement/Pages/bereavement.aspx](http://www.nhs.uk/livewell/bereavement/Pages/bereavement.aspx)

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## Huntington's Disease Association

Further information can be  
found at

[www.hda.org.uk](http://www.hda.org.uk)

email [info@hda.org.uk](mailto:info@hda.org.uk)

phone **0151 331 5444**



@hda\_tweeting



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## Huntington's Disease Association

Suite 24,

Liverpool Science Park IC1

131 Mount Pleasant,

Liverpool L3 5TF

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*We'll be there*