How do we keep your information safe?

Security measures

- Appropriately trained volunteers and staff
- Locked cabinets and drawers
- Information is kept secure, accurate and up to date
- Information is held only for as long as is necessary and for purposes which it was collected
- Information is securely destroyed within the relevant timescales in accordance with our data protection policies

What are your rights?

Access, amend, erase

- You have the right to know what we know about you, make changes or ask us to stop holding your information.

Further information

Privacy policy and notice

Further information about the use of your data is available on our website

W www.hda.org.uk/privacy-policy

ICO

You can also contact the Information Commissioner's Office

T 0303 123 1113

W www.ico.org.uk

Contact us

If you have any concerns about the use of your information you can write, email or phone us using the contact details below:

W www.hda.org.uk

T 0151 331 5444

E info@hda.org.uk

A Huntington's Disease Association
Liverpool Science Park IC1
131 Mount Pleasant
Liverpool, L3 5TF

Registered charity no. 296453

Huntington's Disease Association

How we use your information

This leaflet explains why we collect information about you and how we use it if you are members of our Branches and Support Groups.

The Huntington's Disease Association is committed to protecting your personal information and making sure it is processed in a fair, open and transparent way. All Huntington’s Disease Association Branches and Support Groups and staff are bound by the Huntington’s Disease Association data protection policies.

How do we collect information about you?

Directly from you

When you give it to us directly when you contact the organisation for all Branch and Support Group matters.

Other organisations and third parties

Other organisations and third parties may contact us to refer you into our service and work with them jointly to support you.

What information do we collect and how do we use it?

Supporting you and your family

We may collect personal information to keep in touch with you (for example your phone number and email address.) You may give us personal information about your health so we can provide peer support.

Service development

We may use the information you provide to us to help inform how we should deliver and develop our services in the future.

Statistics

We may use some information for statistical purposes to measure the impact of our services, inform national projects and create a picture of the reach of Huntington’s. We take strict measures to make sure you cannot be identified.

What information do we share?

What we will do

- ✓ Share your information with other health related agencies if you give us specific permission to do so
- ✓ Disclose your information if required to do so by law
- ✓ Share your information if we have concerns about your safety and wellbeing of you or another person
- ✓ Disclose your information if we have special permission because it is in the public interest
- ✓ We may share information with the Huntington’s Disease Association Advisory service or other members of Huntington’s Disease Association staff if we feel that a greater level of support is needed.

What we won't do

- ✗ Sell or share your personal information with organisations who may use it for marketing
- ✗ Share your information with people who don't need access to it