# Branches and Support Groups privacy statement

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| Issue date: | February 2024 |
| Version number: | 1 |
| Review date: | February 2026 |
| Status: | Approved |

# Branches and Support Groups privacy statement

## Introduction

The Huntington's Disease Association takes the privacy of our beneficiaries very seriously. We are committed to protecting and keeping any personal data you share with us, or we get from other organisations, safe.

The Huntington's Disease Association is subject to the UK General Data Protection Regulation and the Data Protection Act 2018. We are registered with the Information Commissioners Office as a Data Controller (registration number: ZA233740).

This branches and support groups privacy statement explains what personal information our branches and support groups will hold about you, how they collect it, how they will store it, how they will use it and how they may share information about you to provide the most appropriate support and help. Most importantly, this statement outlines your rights regarding the use of your personal information and what to do if you no longer wish to be contacted by the Huntington's Disease Association, either directly and/or through our branches and support groups.

Our branch and support group network is volunteer-led and provides peer support on a local level, giving attendees opportunity to meet others affected by Huntington's, share stories and advice, meet socially and get involved in fundraising.

Please ensure that you read this privacy notice and any other similar notice we may provide to you and contact us if you have any questions about the data we collect and hold about you on info@hda.org.uk or 0151 331 5444.

## Data protection principles

The Huntington's Disease Association and our branches and support groups comply fully with the data protection principles when gathering and using personal information, these principles are set out within our Data Protection Policy.

## Legal basis for processing your information

In accordance with UK General Data Protection Regulation, the lawful reasons we use to process your information if you are engaged with our branches and support groups are 'legitimate interest' and 'consent'.

### Legitimate Interest

We process your personal information because there is a legitimate interest to do so to provide peer support.

### Consent

We process your personal information for future communications from the Huntington's Disease Association branch or support group that you are engaged with where you have given us your communication preferences and permission to do so, for example to keep you up to date with local events and meetings, provide you with information about the charity and about fundraising opportunities.

## How we collect information

We will only collect information from or about you that is necessary to provide you with relevant support, information and advice, and for future monitoring and evaluation purposes. Where information is stored for monitoring and evaluation purposes we will ensure that it is anonymised at the earliest possible stage in accordance with our data protection policies.

If in the future, we would like to use your information for another purpose, or the reason for using your personal information has changed we will ask your permission before doing so.

### Directly from you

We obtain personal information when you give it to us directly, for example when you attend a branch or support group meeting or otherwise provide us with your personal information.

### Other organisations and third parties

The Huntington's Disease Association is committed to helping and supporting you and all those affected by Huntington's and an important element of caring and supporting you is working with other professionals. Where relevant to your support, you may be encouraged to speak with your local Specialist Huntington's Disease Adviser or Youth Worker, who may refer you into the wider charity advisory service, where specialist knowledge around Huntington's is required.  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.

If referred to the advisory service by branch or support group volunteers, advisory service staff may, with your permission, refer you into other services and work with them jointly to support you.

## What information do we collect and hold

### Support for those affected by Huntington's disease

Our branches and support groups provide peer support at a local level to people affected by Huntington's disease and those involved in their care and support. Our support extends to children living in Huntington's families and to those that have the juvenile form of the disease themselves (JHD).

During the course of branch and support group meetings, attendees may choose to share sensitive personal information about themselves and their circumstances for the purposes of peer support. Any such information is shared in strict confidence and is not recorded in writing or by any other means.

Some branches offer welfare grants for people in their local area affected by Huntington's who require financial support. Applicants for this support may be required or may choose to share sensitive personal and financial information as a part of the application process.

Branches and support groups may engage in fundraising activities (either for the branch or for the wider charity). If a person donates to one of these activities, we may collect the following:

- Name
- Date of birth
- Email address
- Postal address
- Telephone number
- Credit/debit card details (When you make a donation or purchase, your card information is not held by us, it is collected by our third-party payment processors, to ensure the secure online capture and processing of transactions.)
- Information about whether you are a UK taxpayer for gift aid claim purposes
- Photographs of fundraising activities (where you have given us written consent to use them)

We will use this information to do the following as relevant:

- Process your donation
- Provide you with information about branch and support group activities and events
- Support your fundraising and encourage others to fundraise
- Administer gift aid
- Ensure we know your contact and mailing preferences
- Tell you about the progress the Huntington's Disease Association is making or tell you about ways you can support us and or get involved where you have given us consent to communicate with you in this way. If you want to opt out of communications you can do so at any time by contacting your local branch or support group.
- Send you communications by post about upcoming events, opportunities and fundraising that we think you may be interested in, unless you have told us that you don't want to hear from us by post.
- Learn more about how we can improve our services for you.

## How we keep your personal information safe

Your information is accessed only by branch and support group leads, and in certain circumstances by charity staff (for example when branches and support groups send information for archiving). We ensure that any external contractors and third parties we use (for example fundraising platforms or payment processing platforms) are comprehensively checked and adhere to a formal agreement in which our expectations and requirements regarding the way in which they manage, collect and access any personal data, are met.

It is required that branches and support groups have relevant controls and permissions in place on any websites and social media channels that they administer.

Data protection training is provided for all branches and support groups, and is mandatory for branch and support group leads.

Branches and support groups take appropriate measures to ensure that any personal information you disclose is kept secure, accurate and up to date. Appropriate security measures are in place to prevent personal information from being accidentally lost, used or accessed in an unauthorised way. Access to your personal information is limited to those who have a genuine business need to know it. Those processing your information will do so only in an authorised manner and are subject to a duty of confidentiality.

Branch and support group leads will only disclose your personal information where they have your permission or when they are obliged to disclose personal data by law, or the disclosure is 'necessary' for purposes of national security, safeguarding, where there is a risk of harm to self or others, taxation and criminal investigation.

## How long do we keep your information

Branches and support groups ensure that your personal information is kept only for so long as is necessary and for the purposes for which it was collected.

## Accessing your information

You have the right to find out what information branches, support groups and the Huntington’s Disease Association hold about you, how this information is used and how long your data is kept. You also have a right to request a copy of the information that is held about you. If you would like further information or you would like a copy of the information we hold, please contact us via telephone on 0151 331 5444, by email info@hda.org.uk, or write to us at Huntington’s Disease Association, Liverpool Science Park, IC1, 131 Mount Pleasant, Liverpool, L3 5TF.

We want to make sure your information is up to date, so please contact us to ask us to correct it if it needs updating.

If you are unhappy about how we handle your personal information you can contact the Information Commissioner’s Office. For further information please visit the Information Commissioner’s website www.ico.org.uk or call 0303 123 1113.