Huntington's
Disease
Association

Privacy policy

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Introduction

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

The information we collect allows us to learn more about who uses and supports our charity, taking your needs and interests into account to make more informed decisions and ultimately help make life better for those affected by Huntington's disease.

The Huntington's Disease Association is subject to 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 policy outlines exactly how we collect personal information, exactly what we collect, how we use it and how we store it. It also makes clear your right to know what we know about you and your right to control this data.

Scope

This policy applies to anyone whose personal data is processed by the Huntington's Disease Association.

How we collect information

Directly from you

We obtain personal information when you give it to us directly, for example when you enquire about our activities, use our services, sign up to our mailing list, send or receive an email, make a donation to us, ask a question or otherwise provide us with personal information.

Third parties

Your information may be shared with us by third parties, for example where there is a contract in place between the Huntington's Disease Association and a third party or where you have agreed for the third party to do so. These might include fundraising sites like Just Giving and Enthuse, independent event organisers like the London Marathon.

Referrals can also be made to us from other organisations or individuals, such as your GP, if they think you would benefit from the Huntington's Disease Association's support services.

Information available publicly

On occasion, we might obtain information from open websites such Companies House, from annual reviews, from company websites and from publicly available articles in newspapers and online news sites.

When you use our website

Our website uses ‘cookies’ to remember you so that the next time you visit, your experience is more streamlined. For example, if you are returning to buy another product in our shop your name and address might automatically appear in the text fields or we might be able to tailor the information you see based on your previous visit to the site and the information that interested you.

To help make improvements to our website and ensure we provide the best service for users, we will often gather general information about usage via Google Analytics. Google Analytics collect and report information on how our website's used, such as which pages people visit most often and which services, events or facilities are of most interest, helping us improve your experience. We may also determine which pages users visit when they click on links in Huntington's Disease Association emails. Wherever possible we use aggregated or anonymous information which does not identify individual visitors to our website. You can opt out of analytics cookies if you would prefer.

Cookies are a common feature used by over 90% of websites. They aim to make your interaction with the website faster and easier. If you would prefer to, you can disable cookies altogether. Guidance on how to do this can be found here. Turning cookies off may cause a loss of functionality when using our website.

When you use social media

When you follow and interact with us on social media channels, such as Facebook, Twitter and Instagram, we may obtain information about you, for example when you tag us in photos, donate to us or comment on our posts. The information we receive is dependent on the privacy settings and preferences you have in place for the relevant platforms. If you follow us and interact with us on social media, we encourage you to read the privacy policy of the relevant social media platform.

In the same way as on our website, we collect and use your personal information using cookies, including social media / third party cookies. This helps us to improve your user experience and provide you with personalised content.

What information we collect and how we use it

The personal information we collect and how we will use it is dependent on why you gave it to us in the first instance.

Support for those affected by Huntington’s disease

To help us deliver our advisory service, we collect sensitive personal data when you speak to us or email us. Our advisers use this to provide support, advice and guidance to you. This information is managed separately from other data provided to the charity and is accessed only by those who need to as part of their role at the charity. involved in your care.

To better support you, our advisers, on occasion will discuss what they know about you with other health and care professionals. They will only discuss matters concerning your health and care needs and will only share information if you have provided permission for them to do so. They will respect your privacy and only share information as needed and will not act against your wishes unless they are required to do so by law or there are safety concerns for yourself or others.

We have an online message board, accessible from our website, for peer support, sharing best practice and seeking guidance from others who understand your situation. You will be asked for an email address when registering and our moderators may contact you for administrative purposes or where relevant. Users of this forum are given the option to use a pseudonym to allow them to post sensitive information anonymously.

We provide welfare grants to people affected by Huntington’s who apply for financial support through this scheme. We collect information about the person and their financial position for the purposes of processing grant applications.

Our, volunteer led, Branches and Support groups collect information about their members in order to keep them informed about Huntington’s Disease Association activities. Our branches also collect information when an individual applies for a welfare grant from the branch funds. All Huntington’s Disease Association Branches and Support Groups are bound by the Huntington’s Disease Association Data Protection Policy.

We also ask people to evaluate our services and use anonymised comments for our continuous improvement of services and to demonstrate our impact in charity communications.

If you work or volunteer for us, or apply to do so, we collect some personal details from you such as name, address, qualifications and employment/ volunteer history as part of the recruitment process to determine your suitability for the role. We also verify your I.D and your driving status where this is relevant to the position. National insurance number and bank details are also collected where a salary is paid. Where relevant, we collect information from the Disclosure and Barring Service (DBS) and details of training undertaken as needed to ensure the safety of those we support.

Supporters

If you support us, for example, give us a donation, volunteer, register to fundraise, sign up for an event, sign up to our mailing list or buy something from our shop, 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

We may also collect sensitive personal information such as information about your health if this is required for the purpose you have contacted us e.g. if you take on a fundraising challenge event.

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

- Process your donation or shop order
- Provide you with information on our services and products
- Support your fundraising
- Communicate with you and support you in your volunteer role
- Send you communications which you have requested such as regular eNewsletters
- Administer gift aid
- Ensure we know your contact preferences
- Learn more about how we can improve our services and products for you
- Monitor website traffic and learn more about who uses our site and it is used

Data about children

Our support extends to children living in Huntington's families and to those that have the juvenile form of the disease themselves (JHD). We are also often supported by children who take part in fundraising activities for us.

For those children engaged in support we collect the same sensitive information about their health and support needs as we would for any adults we support. We will obtain the consent of parents or guardians before collecting and sharing personal information about a child and work to the same stringent information sharing guidelines for both adults and children.

For our young supporters, we collect the same basic personal data including name, date of birth, address, a parent or guardian's email address and a parent or guardian's credit / debit details.

Sharing your story or knowledge

A number of families, volunteers and supporters choose to share their experience of Huntington's with us to help us in our work. These stories and / or photographs are often featured in case studies in our charity print and online communications. This could include sensitive information relating to their health and family. We will only share this information if we have received full written consent from the family or individual involved.

We rely on experiences and knowledge of Huntington's disease families to ensure the Huntington's community has an input into the work of our charity and to the wider work and research relating to the disease. We have a patient public involvement group, called HD Voice, who contribute from a family perspective to help inform research and the direction of various charity initiatives.

Communications

Fundraising and marketing

Email, phone and SMS - If you have given us your consent, we will use these communication methods to tell you about the progress our charity is making and from time to time we may ask you for donations or tell you about other ways you can support us.

We make it clear and easy for you to tell us how you want us to communicate with you. We include information about how to opt out or change your preferences. If you don't want to hear from us, we ask you to let us know either by phoning us on 0151 331 5444 or emailing us at info@hda.org.uk. We do not sell or share personal details to any third parties.

Post - We may send you communications by post about marketing and fundraising that we think you may be interested in based on your previous interaction with us, unless you have told us that you don't want to hear from us by post. The legal basis for doing this according to GDPR is legitimate interest. As with email, phone and SMS communications, you have the right to opt out or change your preferences at any time by phoning us on 0151 331 5444, emailing us at info@hda.org.uk or writing to us at Huntington's Disease Association, Suite 24, Liverpool Science Park, 131 Mount Pleasant, Liverpool, L3 5TF

Using our services

We may send you communications without your consent where this relates to an administrative process to acknowledge an event booking, purchase, donation or membership application and provide you with relevant updates and reminders.

Online advertising

We use online advertising through google and social media sites like Facebook and Instagram to promote the work of the charity, our fundraising opportunities and the services we provide. This could be through advertising directly on particular websites or to people on social media sites based on what the respective platforms already know about them and their interests. This may involve the use of custom, saved and / or matched audiences and tracking interactions using cookies.

Understanding our supporters

We may analyse the personal information you give us to create a profile of your interests and preferences so that we only contact you in the most appropriate way and with the most relevant information. This allows us to understand more about you and helps us tailor our requests to you.

We may, if appropriate, ask supporters who may be able and willing to give more to us than they already do to help advance our service.

We may need to share your information with our service providers, associated organisations and agents for the purposes described above.

How we keep your data safe

We make sure that your information is accessed only by appropriately trained staff and approved contractors. We ensure that any external contractors we use are comprehensively checked and adhere to a formal contract in which our expectations and requirements regarding the way in which they manage, collect and access any personal data, are met. All staff and volunteers at the Huntington's Disease Association are bound by policies, procedures and agreements relating to Data Protection and Confidentiality.

We make sure that there are relevant controls in place on our website and on our data networks to safeguard your personal details. All of our online forms are protected by encryption. We also use a secure server so that when you make a donation or payment via our website, your details are protected. The Huntington's Disease Association's webpages are secure, evidenced by the lock icon that appears in the web browser next to the website address.

We take appropriate measures to ensure that any personal information you disclose to us is kept secure, accurate and up to date. We ensure that your personal information is kept only for so long as is necessary and for the purposes for which it was collected. Information is securely destroyed within the relevant timescales in accordance with our information governance policy.

We want to assure you that we do not sell or share donor details with charities or other third parties.

We will only disclose data when obliged to disclose personal data by law, or the disclosure is 'necessary' for purposes of national security, taxation and criminal investigation, or if we have your consent.

GDPR lawful basis of processing

There are six lawful basis for processing information according to General Data Protection regulation. The following five are most relevant to the Huntington's Disease Association:

1) That we have **direct consent** from you, such as when you sign up to our mailing list

2) That there is a **contract** in place with you, such as when you become a member or you sign up to our lottery
3) That we have a **legal obligation** to do so, such as when we are ordered by the Police, the Charity Commission, the Fundraising Regulator or other relevant authorities.
4) That there is a **vital interest** to protect someone's life, such as a medical emergency or a serious safeguarding issue.
5) That there is a **legitimate interest** to do so that is fair and does not impact your rights, such as sending you information about events, services, products and activities that may be of interest to you by post or monitoring interaction with and opinion of the charity to better improve our services.

We have a series of privacy notices, in addition to this policy, for the following areas to explain further the different basis for processing personal information and how this is carried out safely:

- Specialist Huntington's Disease Advisory Service
- Supporters (fundraising, donations, shop purchases)
- Membership
- Recruitment
- Staff
- Volunteers

Keeping your information up to date

We need you to let us know when your details change. We may on occasion, use information available publicly, such as the Post Office's National change of address database.

How long do we keep your information

We keep your information for only as long as is necessary to enable us to carry out relevant activity and comply with regulation. Retention periods for all data we hold are detailed in our data retention and destruction schedule which is reviewed annually and information destruction processes implemented where relevant. Please contact us if you would like to find out how long your data is kept.

Your rights

It is your information so you have the right to find out what information we hold about you (right of access), correct any errors or omissions (right to rectification), object to us using your data in a particular way (right of objection), or request deletion of your data (right of erasure). We will always comply with these requests as far as we can, subject relevant exceptions.

If you would like to make any of the above changes or access your information, please contact is on 0151 331 5444, info@hda.org.uk or Huntington's Disease Association, Suite 24, Liverpool Science Park, IC1 131 Mount Pleasant, Liverpool L3 5TF.