

## Our Privacy Policy

Cure Parkinson's ("we") promises to respect any personal data you share with us, or that we get from other organisations and keep it safe. We aim to be clear when we collect your data and not use your data in a way you wouldn't expect.

Developing a better understanding of our supporters through their personal data allows us to make better research decisions, fundraise more efficiently and ultimately, help us to reach our goal of finding a cure for Parkinson's.

We only send marketing communications to those who have already given consent or through legitimate interest and we communicate via their preferred channel(s) (email or post). In all direct marketing and postal communication we offer 'opt out' preferences and 'opt in' for email communication.

Our marketing communications include information about our latest research and fundraising to fulfil our aim to slow, stop or reverse Parkinson's. If you would like to receive such communications but have not let us know, please contact us on 0207 487 3892 or [preferences@cureparkinsons.org.uk](mailto:preferences@cureparkinsons.org.uk).

- **Where we collect information about you from**

We collect information in the following ways:

When you engage or give to us **directly**

You may give us your information in order to sign up for one of our events, tell us your story, make a donation, make a purchase on our online shop, fundraise for us (directly), sign up on our website, communicate or meet with us. We are responsible for your data at all times.

When you give to us **indirectly**

Your information may be shared with us by independent event organisers, for example the London Marathon or fundraising sites like JustGiving or Virgin Money Giving. These independent third parties will only do so when you have indicated that you wish to support Cure Parkinson's and with your consent. You should check their Privacy Policy when you provide your information to understand fully how they will process your data.

Your information may also be shared with us through introductions for example through a Cure Parkinson's supporter or Trustee.

### When you give permission to **other organisations** to share or it is available publicly

We may combine information you provide to us with information available from external sources in order to gain a better understanding of our supporters to improve our fundraising methods, products and services.

The information we get from other organisations may depend on your privacy settings or the responses you give, so you should regularly check them. This information comes from the following sources:

- Third party organisations

You may have provided permission for a company or other organisation to share your data with third parties, including charities. This could be when you buy a product or service including but not limited to Farewill, ebay or [christmascards.org](http://christmascards.org).

- Social Media

Depending on your settings or the privacy policies for social media and messaging services like Facebook, WhatsApp, Twitter or LinkedIn, you might give us permission to access information from those accounts or services.

- Information available publicly

This may include information found in places such as Companies House, the Charity Commission and information that has been published in articles/newspapers.

### When we collect it as you use our WEBSITES OR APPS

Like most websites, we use "cookies" to help us make our site – and the way you use it – better. Cookies mean that a website will remember you. They are small text files that sites transfer to your computer (or phone or tablet). They make interacting with a website faster and easier – for example by automatically filling your name and address in text fields. There are more details in our [Cookie Policy](#).

In addition, the type of device you're using to access our website or apps and the settings on that device may provide us with information about your device, including what type of device it is, what specific device you have, what operating system you're using, what your device settings are, and why a crash has happened. Your device manufacturer or operating system provider will have more details about what information your device makes available to us.

### • **What personal data we collect and how we use it**

Personal information is any information that can be used to identify you. For example, it can include information such as your name, date of birth, email address, postal address, telephone number and credit/debit card details, as well as information relating to your health or personal circumstances.

Data protection law recognises that certain categories of personal information are more sensitive. This is known as special categories and covers the processing of personal data revealing racial or ethnic origin, political opinions, religious or

philosophical beliefs, or trade union membership, and the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health or data concerning a natural person's sex life or sexual orientation. We would only collect sensitive personal information where there is a clear need to do so such as participation in a challenge event, to ascertain what services are relevant to you (for example by understanding your Parkinson's diagnosis) or to cater other support to you. Before collecting any sensitive personal information from you we will always make it clear to you what sensitive personal data we are collecting and why. We will also ask for your consent to store and retain this data.

Where it is appropriate we may also ask why you have decided to donate to us. We will never make this question mandatory, and only want to know the answer if you are comfortable telling us.

We will mainly use your data to:

Provide you with the services, products or information you asked for

Administer your donation or support your fundraising, including processing gift aid

Keep a record of your relationship with us

Ensure we know how you prefer to be contacted

Understand how we can improve our services and information

If you enter your details onto one of our online forms, online shop, or donate online and you don't 'send' or 'submit' the form, we may contact you to see if we can help with any problems you may be experiencing with the form or our websites.

We are entitled to use your data in these ways because:

- the use of your data is necessary for the performance of a contract to which you are subject or in order to take steps at your request prior to entering into a contract
- you have consented to us processing your data for a specific purpose;
- we have legal and regulatory obligations that we have to discharge;
- we may need to in order to establish, exercise or defend our legal rights or for the purpose of legal proceedings; or
- the use of your data as described is necessary for our legitimate business interests.

Understanding supporters and targeting fundraising and communications

We use research and screening techniques to ensure communications are relevant and timely, and to provide an improved experience for our supporters. We conduct research as it enables us to understand more about the people who support us and help us to make appropriate requests to supporters who may be able and willing to give more than they already do. Importantly, it enables us to raise more funds, sooner, and more cost-effectively, than we otherwise would.

In conducting our research, we may analyse geographic, demographic and other information relating to you so we better understand your interests and preferences in order to contact you with the most relevant communications.

### Direct Marketing

With your consent from time to time we will contact you to let you know about the progress we are making and to ask for donations or other support. Occasionally, we may include information from partner organisations or organisations that support us in these communications. We make it easy for you to tell us how you want us to communicate, in a way that suits you and we will only contact you by email, phone or SMS with your consent. Our forms have clear marketing preference questions and we include information on how to 'opt out' when we send you marketing. If you don't want to hear from us, that's fine. Just let us know when you provide your data or contact us on 0207 487 3892 or [preferences@cureparkinsons.org.uk](mailto:preferences@cureparkinsons.org.uk).

We do not sell or share personal details to third parties for the purposes of marketing. If we run an event in partnership with another named organisation your contact details will not be shared but names may be provided for administrative purposes e.g. registration/security. We will be very clear what will happen to your data when you register.

### Sharing your story

Some people choose to tell us about their experiences with Parkinson's to help further our work. They may take on a role as an Ambassador or Volunteer, attend our patient focused events or sit on our committees. This may include them sharing sensitive information related to their health and family life in addition to their biographical and contact information.

We monitor the types of people who are involved to ensure that the views we hear are representative of all people affected by Parkinson's. If we have the explicit involvement and informed consent of the individuals, this information may be made public by us at events, in materials promoting our campaigning and fundraising work, or in documents such as our annual report.

If we have the explicit and informed consent of the individuals, or their parent or guardian if they are under 18, this information may be made public by us at events, in materials promoting our campaigning and fundraising work, or in documents such as our bi annual postal publications (annual review and newsletter) or our monthly e-news.

### Children's data

Information is usually collected when children attend our events or fundraise for us.

Our fundraising events request specific information about the age of participants. If you are under 18 and would like to get involved, please ensure that you have consent from a parent or guardian before giving us your personal information. When we collect information about a child or young person aged under 18 we will make it very clear as to the reasons for collecting this information and how it will be used.

Where possible and appropriate we will seek consent from a parent or guardian before collecting information about children.

- **How we keep your data safe and who has access to it**

We ensure that there are appropriate technical controls in place to protect your personal details. For example our online forms are always encrypted and our network is protected and routinely monitored.

We undertake regular reviews of who has access to information that we hold to ensure that your information is only accessible by appropriately trained staff, volunteers and contractors.

We sometimes use external companies to collect or process personal data on our behalf. We do comprehensive checks on these companies before we work with them, and put a contract in place that sets out our expectations and requirements; especially regarding how they manage the personal data they have collected or have access to.

We may need to disclose your details if required to the police, regulatory bodies or legal advisors.

We will only ever share your data in other circumstances if we have your explicit and informed consent.

The personal data that we collect from you may be transferred to, and stored at, a destination outside the United Kingdom ("UK"). It may also be processed by staff operating outside of the UK who work for our affiliates or for one of our suppliers.

Where we transfer your personal data outside the UK, we will ensure that it is protected in a manner that is consistent with how your personal data will be protected by us in the UK. This can be done in a number of ways, for instance:

- the country that we send the data to might be approved by the UK Information Commissioner's Office; or
- the recipient might have signed up to a contract based on "model contractual clauses" approved by the UK Information Commissioner's Office, obliging them to protect your personal data.

In other circumstances the law may permit us to otherwise transfer your personal data outside the UK. In all cases, however, we will ensure that any transfer of your personal data is compliant with data protection law.

You can obtain more details of the protection given to your personal data when it is transferred outside the UK (including a copy of the standard data protection clauses which we have entered into with recipients of your personal data) by contacting us in accordance with the "Contacting us" section below."

- **Keeping your information up to date**

Where possible we use publicly available sources to keep your records up to date; for example, the Post Office's National Change of Address database and information provided to us by other organisations as described above.

We really appreciate it if you let us know if your contact details change.

How long we hold your personal data for will vary. The retention period will be

determined by various criteria including:

- the purpose for which we are using it – we will need to keep the data for as long as is necessary for that purpose; and
- legal obligations – laws or regulation may set a minimum period for which we have to keep your personal data.

Where your information is no longer required, we will ensure it is disposed of in a secure manner.

- **Your right to know what we know about you, make changes or ask us to stop using your data**

You have a number of legal rights in relation to the personal data that we hold about you. These rights include:

- the right to obtain information regarding the processing of your personal data and access to the personal data which we hold about you;
- the right to withdraw your consent to our processing of your personal data at any time. Please note, however, that we may still be entitled to process your personal data if we have another legitimate reason (other than consent) for doing so;
- in some circumstances, the right to receive some personal data in a structured, commonly used and machine-readable format and/or request that we transmit those data to a third party where this is technically feasible. Please note that this right only applies to personal data which you have provided to us;
- the right to request that we rectify your personal data if it is inaccurate or incomplete;
- the right to request that we erase your personal data in certain circumstances. Please note that there may be circumstances where you ask us to erase your personal data, but we are legally entitled to retain it;
- the right to object to, and the right to request that we restrict, our processing of your personal data in certain circumstances. Again, there may be circumstances where you object to, or ask us to restrict, our processing of your personal data but we are legally entitled to continue processing your personal data and / or to refuse that request; and
- the right to lodge a complaint with the data protection regulator (details of which are provided below) if you think that any of your rights have been infringed by us.

You can exercise your rights by contacting us using the details set out in the "Contacting us" section below. You can find out more information about your rights by contacting the Information Commissioner's Office, or by searching their website at <https://ico.org.uk/>.

- **Changes to this policy**

We may change this Privacy Policy from time to time. If we make any significant changes in the way we treat your personal information we will make this clear on our website [cureparkinsons.org.uk](http://cureparkinsons.org.uk) or by contacting you directly.

- **Contacting us**

If you have any questions, comments or suggestions, please let us know by post – Cure Parkinson's, 120 New Cavendish Street Street, London, W1W 6XX or email [preferences@cureparkinsons.org.uk](mailto:preferences@cureparkinsons.org.uk).

For more information please email [preferences@cureparkinsons.org.uk](mailto:preferences@cureparkinsons.org.uk) or call 0207 487 3892.

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Cure Parkinson's is the operating name of The Cure Parkinson's Trust. The Cure Parkinson's Trust is a registered charity in England and Wales (1111816) and Scotland (SCO44368) and is a company limited by guarantee – company number 5539974 (England and Wales).