

Parkinson's Connect privacy policy

This privacy policy explains how and why we use your personal information as part of Parkinson's Connect Alpha. This means you stay informed and allows us to use your data fairly and lawfully.

We'll update this privacy policy page to show you all the things we do with your personal data.

This privacy policy applies if you use Parkinson's Connect Alpha, the Information & Support service, visit our website, email, call or write to us.

Direct referral form consent statement

"Parkinson's UK can provide you with information and support. Are you happy to provide your name and contact details for Parkinson's UK to send you invites via text or email to access their information and support?"

Who we are

Whenever you see the words 'we', 'us', 'our', 'the charity' or 'Parkinson's UK', it refers to the Parkinson's Disease Society of the United Kingdom and its subsidiary.

Parkinson's Disease Society of the United Kingdom is a registered charity in England and Wales (258197) and in Scotland (SC037554). A company limited by guarantee. Registered no. 948776 (England and Wales). Registered office: 215 Vauxhall Bridge Road, London, SW1V 1EJ.

The Parkinson's Research Ventures Limited, a company limited by guarantee and registered at Companies House (registered in England and Wales as 11228595). The company's activities includes the granting of licences of intellectual property rights licensed to it by Parkinson's UK and the commissioning of research and development services in the Parkinson's indication. If you have any questions in relation to this privacy policy or how we use your personal data they should be sent to:

- Email: dataprotection@parkinsons.org.uk
- Written inquiries: Data Protection Officer, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ

While it may be helpful to contact us in the first instance, you can also lodge a complaint with the Information Commissioner's Office, which is the supervisory authority for data protection matters in the UK. Contact details are available on the Information Commissioner's Office

website.

You can also view a full copy of our compliance framework.

Parkinson's Connect Alpha

We are developing a new Information and Support service for people with Parkinson's, and family, friends and carer's of people with Parkinson's, called 'Parkinson's 'Connect'.

Parkinson's Connect is in the 'Alpha' phase of it's development which means we are designing and testing elements of the service with real people. You will have reached this page if you have agreed to be referred to us by a healthcare professional.

The Alpha phase of Parkinson's Connect will run until the end of April 2020. During this time you will have access to Parkinson's Connect Alpha content on the website and you will have the opportunity to opt in to hearing more from our Information and Support service.

When you visit our website we will collect data on how you interact with the pages using Google Analytics. See our section on 'Cookies and links to third party sites' for more information. If you choose to opt in to hearing from our Information and Support service we will request additional, optional information about you to deliver the service.

If at any time you do not wish for us to continue processing your personal information as part of Parkinson's Connect Alpha please contact

- Email: dataprotection@parkinsons.org.uk
- Written inquiries: Data Protection Officer, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ

Your rights

Here is a list of the rights that all individuals have under the General Data Protection Regulation (GDPR). They don't apply in all circumstances. If you wish to use any of them, we'll help you as much as possible.

You have a right to:

- access your information. This is called a Subject Access Request. Whether you are requesting information about yourself or on behalf of someone else, find out more about how to complete a Subject Access Request.
- correct any information that we hold about you
- erase any of your information that we no longer have a right to hold about you

- access a machine readable version of your data, although there are some conditions
- ask us to stop us doing anything with your data unless we must by law or a contract
- stop any automated decision making. This is where a computer makes a decision about you. It should be noted that we do not do this

To exercise any of these rights please contact our data protection officer:

- Email: dataprotection@parkinsons.org.uk
- Written inquiries: Data Protection Officer, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ

What personal data do we collect?

Personal data you give us may include name, title, address, date of birth, age, gender, email address and telephone numbers. We'll only collect the personal data that we need to deliver Parkinson's Connect Alpha and the Information and Support service.

Parkinson's Connect Alpha processes personal information to enable us to:

- provide an information and support service
- develop our information and support user experience and content

You can give us your personal data by completing an online referral form with a healthcare professional.

Special categories of personal data includes health information, race, religious beliefs, genetic and biometric data and political opinions.

Sometimes we will ask to collect special categories of personal data – for example whether you are living with the condition yourself, or perhaps you have a relative with the condition. You do not have to provide this information if you do not wish to do so.

We hold this information on our database so that we can tailor our communications to you for information and support. We only collect this information with your explicit consent.

When you consent to receive a call from the helpline we collect - with your consent - only the data that you are happy to give us, in order to provide advice, guidance, or to receive feedback and comments. We do record all calls for training purposes. Some of this information will be health information, which is special category data.

If you would like us to provide any services to you, we will ask for some information about your circumstances to help us to support you. We will only collect this with your consent. You should

only provide that information that you would like to. You will be given more information at the point at which we collect the information.

Where you have said that you want to receive more information from us to give you ongoing support, we may merge information from the helpline, local advisers, referral forms and other places where you have given us your information with your consent. This helps us to build a picture of your needs and to provide you with the best support. We do not use this information for anything else.

How we make sure it is legal to process data?

Parkinson's Connect Alpha relies on the following legal bases to use your personal data.

With your consent or explicit consent

1. For some direct communications including those by email and SMS.
2. For some of our profiling and other automated decision making.
3. For some of our processing of special categories of personal data such as about your health

Where it is in our legitimate interests to do so

1. To continue processing personal data on an individual who has exercised their right to erasure/to be forgotten. We will need to keep basic data to identify that individual and retain it solely for suppression purposes to prevent further unwanted processing.
2. To follow guidance and recommended best practice of government and regulatory bodies.
3. For management and audit of our business operations including accounting.
4. To carry out monitoring and to keep records of our communications with you and our staff (see below).
5. To administer our good governance requirements, such as internal reporting and compliance obligations or administration required for AGM processes.

Cookies and links to third party sites

Cookies are small text files stored on your computer when you visit certain websites.

We use first party cookies (cookies that we have set, that can only be read by our website) to personalise your online experience.

We also use third party cookies (cookies that are set by an organisation other than the owner of the website) for the purposes of website measurement and targeted advertising. Please find

more information regarding our cookies in our terms and conditions.

If you browse our website without filling in any forms we use Google Analytics to understand how you use the website. Google Analytics collects information including IP address, geographic location of the device, browser type, browser language, date and time of your request, time(s) of your visit(s), page views and page elements (ie links) that you click. Find out more about our use of Google Analytics.

Links to other websites

Our website may, from time to time, contain links to and from the websites of other relevant stakeholders. If you follow a link to any of these websites, please note that these websites have their own privacy policies and that we don't accept any responsibility or liability for these policies. Please check these policies before you submit any personal data to these websites.

This privacy policy applies solely to the personal data collected by Parkinson's UK for Parkinson's Connect Alpha.

How we secure your data

We operate a process for assessing, managing and protecting new and existing systems which ensures that they are up to date and secure against the cyber security threats.

Our Data Protection Impact Assessments consider security in detail.

Our staff complete mandatory data protection training upon employment and annually thereafter to reinforce responsibilities and requirements set out in our data protection policies, such as those on handling data securely and setting secure passwords.

Disclosure and sharing your information

When we allow third parties acting on behalf of Parkinson's UK to access your information, we will always have complete control of what they see, how long they see it for and what they are allowed to do with it. We do not sell or share your personal information for other organisations to use.

Personal data collected and processed by us may be shared with the following groups where necessary:

- third party cloud hosting and IT infrastructure providers who host the website and provide IT support in respect of the website
- third party processors.

Also, under strictly controlled conditions:

- contractors
- Advisors

We may also disclose your personal information to third parties if we are under a duty to disclose or share your personal data in order to comply with any legal obligation, or in order to enforce or apply our terms of use or cookie policy and other agreements, or to protect the rights, property, or safety of Parkinson's UK, our members and supporters. This includes exchanging information with other companies and organisations for the purposes of fraud protection.

How long we keep your personal information

Unless we explain otherwise to you, we'll hold your personal information based on the following criteria:

- for as long as we have reasonable business needs, such as managing our relationship with you and managing our operations
- for as long as we provide services to you
- retention periods in line with legal and regulatory requirements or guidance