



Parkinson's Ireland Data Privacy Policy

December 2025

Version	Purpose/ Change Summary	Approved by Board	Effective Date	Next Revision
1.0	Original Policy	2022	2022	2025
2.0	Updated policy - after periodic legal review by charity's solicitors	December 2025	December 2025	2028

Introduction

Parkinson's Ireland is a charity, registered in Ireland as CHY 10816, with its head office at **Carmichael House, North Brunswick Street, Dublin 7, Ireland**. The Data Protection Officer is Shane O'Brien and any queries can be sent by [email to: nationaloffice@parkinsons.ie](mailto:nationaloffice@parkinsons.ie).

The General Data Protection Regulation (GDPR) (2016/679) aims to safeguard the rights of individuals in regard to how information about them is collected, processed, transferred, and stored. It does this by placing obligations on people and organisations that control and process personal data. This privacy policy reflects Parkinson's Ireland's processing of personal data as part of its functions.

The objectives for which Parkinson's Ireland exists are:

- to facilitate people with Parkinson's Disease ("PD") to control their lives and environment, to live with dignity and participate in the community,
- to provide support for the families and carers of people with PD,
- to co-operate with the medical, scientific, social and caring professions to promote scientific research into the cause of, cure for and management of PD, and the alleviation of medical and social symptoms of PD,
- to exchange and disseminate information relating to PD, and
- to provide an identifiable focal point by developing an efficient, effective and caring organization to serve the needs of people with PD.

PARKINSON'S IRELAND is committed to protecting the privacy of people who use our services, employment candidates and current employees, contacts, fundraisers, business partners, and other third parties we deal with, such as family members of people living with PD.

This Privacy Policy details how PARKINSON'S IRELAND collects, processes transfers and stores your personal data . It applies to personal data about you that we collect, use and otherwise process in connection with your relationship with PARKINSON'S IRELAND.

PARKINSON'S IRELAND as Controller of your Personal Data

PARKINSON'S IRELAND is a nationwide charity that operates from its headquarters in **Carmichael House, North Brunswick Street, Dublin 7, Ireland**. PARKINSON'S IRELAND also has a network of Voluntary Branches, each of which processes personal data submitted to it directly and/or through a client's consent when he or she has ticked the "*I would like my details sent to the nearest Voluntary Branch*" on PARKINSONS IRELAND's Yearly Membership Form. Any personal data processed by PARKINSON'S IRELAND in connection with this Privacy Policy is ultimately controlled by PARKINSON'S IRELAND as the "data controller" as provided for under the GDPR, the Irish Data Protection Acts, 1988 to 2018, and the Data Protection Commission (DPC) Guideline for the Charity and Voluntary Sector, each as may be amended, supplemented or replaced from time to time.

The elected Secretary of each Voluntary Branch is the controller of the personal data processed in that branch.

You may request information about the personal data that PARKINSON'S IRELAND holds about you by emailing us at nationaloffice@parkinsons.ie or writing to us at **Carmichael House, North Brunswick Street, Dublin 7, Ireland**.

Please note that throughout this Privacy Notice the word "website" refers to <https://www.parkinsons.ie>.

1. Collection and Processing of your Personal Data

INFORMATION COLLECTED BY USING PARKINSON'S IRELAND WEBSITE

1. You are not required to provide any personal data to access public areas of PARKINSONS IRELAND's website, beyond strictly necessary cookies (for more information on how we collect cookies, see our Cookie Policy below).
2. However, when you visit the PARKINSONS IRELAND website we record your IP address and details of your visit, including the date and time. An IP address is an assigned number, similar to a telephone number, which allows your computer to communicate over the internet. In addition to your IP address the following technical information will also be collected: your login information, browser type and version, time zone setting, browser plug-in types and versions, operating system and platform, information about your visit including the full Uniform Resource Locators (URL), clickstream to, through and from the website (including date and time), pages viewed, download errors, page interaction information (such as scrolling clicks) and methods used to browse away from the website.

3. PARKINSONS IRELAND uses this IP information for its legitimate interests to compile statistical data on the use of our website and to track how users navigate through our website in order to enable us to evaluate and improve.
4. Personal information such as names, addresses, email addresses, telephone numbers, and other personal data relating to services that we are providing to you will only be collected from users of the website who voluntarily input such information, for example through our membership forms.
5. ilikecake Limited website designer acts as a data processor for Parkinson's Ireland in relation to the PARKINSON'S IRELAND website. In this capacity, ilikecake processes data under our instructions, including: donations, staff data, the personal information of clients / service users (including names, addresses, email addresses), enquiries and membership data.

CONTACT DATABASE

We may retain information you have provided us with in PARKINSON'S IRELAND's contact database. Examples of information that we hold in our database includes:

1. your contact information, including your name; job title; organization's name; address; phone number(s), email address(es) and other identification information;
2. the area(s) that you have an interest in
3. historical fundraising activity for PARKINSON'S IRELAND.

Once your details are included in PARKINSON'S IRELAND's contact database we may also record details of any

- a. PARKINSON'S IRELAND's mailing lists you have subscribed to or unsubscribed from;
- b. mailings (including services updates and event invitations) we have sent you;
- c. hyperlinks you have clicked in any mailing that we have sent you;
- d. meetings we have held with you;
- e. event invitations you have replied to; and
- f. events you have attended.
- g. your care records.

From time to time we may ask you by email to review your contact details and preferences, and update them as necessary. This not only helps us to keep the contact information we hold about you up-to-date, it also ensures that we only send you information that you have requested and/or is relevant to you.

INTERACTIONS WITH PARKINSON'S IRELAND

We retain personal data relating to interactions between PARKINSON'S IRELAND and people who use our services, clients, job applicants and current employees, contacts and business partners. This includes information relating to the services that we provide. We only retain information that is necessary for the purposes set out in this Privacy Policy .

HOW WE PROCESS YOUR PERSONAL DATA

PARKINSON'S IRELAND, in the head office, and throughout its network of Volunteer Branches, will only collect and process personal data where it has a legal basis for doing so.

PARKINSON'S IRELAND processes personal data which we have collected from you in order to:

1. provide our core care and research functions as a charity revolving around PD, from assisting our clients / service users with their needs to engaging with a range of actors and stakeholders in this space in furtherance of our charitable objectives.
2. provide you with a more tailored and effective service and/or care;
3. perform analysis aimed at improving our products, services and technologies for people with PD
4. communicate with you through certain mandatory service communications, such as welcome letters.
5. ensure compliance with regulatory requirements and applicable law;
6. provide updates and newsletters, including our PARKINSON'S News magazine by mail and our electronic newsletter, and invitations to events and meetings;
7. carry out administrative purposes (including within the PARKINSON'S IRELAND regional offices and the network of Voluntary Branches) including our functions as an employer. This administration, may include, for example, accounting and billing, auditing and identification checking;
8. undertake system testing, maintenance and development in order to ensure network and information security;
9. let you know ways you can get involved in our fundraising and campaigns; when you are making a donation, registering for a campaign or event, as appropriate, you may be asked to provide personal details such as name, email address, postal address, phone number or payment information as needed
10. prevent fraud; and
11. market our services and products to you where PARKINSON'S IRELAND has a legitimate interest or you have consented to us doing so and in accordance with your preferences.

In processing your personal data for the purposes outlined above, we rely principally on the following legal bases under Article 6 of the GDPR:

- With your consent, such as where you have opted in to receiving marketing communications.
- Where necessary to perform a contract we have with you, for example where you have entered into a service contract with us.
- Where necessary to comply with a legal obligation that Parkinson's Ireland is subject to, for example to comply with certain legal reporting requirements in the charity space.
- Where necessary for our or others' legitimate interests associated with our work, including the legitimate interests of our clients and service users in availing of an optimal service provided by us, and the interests of broader communities and society more generally in the work that we do.

PARKINSON'S IRELAND will only collect, use and otherwise process information revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, trade union membership, genetic data, biometric data, or data relating to your health, sexual orientation or sex life or otherwise which is treated by applicable data protection laws as a "sensitive" or "special" category of personal information under Article 9 GDPR where you provide your explicit consent or where another derogation under Article 9 applies, for example where the processing falls under the employment law derogation or legitimate activities of not-for-profit bodies derogation under Article 9.

Any data collection that is optional will be made clear to you. However, PARKINSON'S IRELAND may need to collect and process personal data for certain legal compliance purposes or in order to perform certain services for you, including compliance with legal requirements relating to our anti-fraud, anti-money laundering, or 'know your customer' obligations. If you choose not to give us this personal data then it may delay or prevent PARKINSON'S IRELAND from meeting PARKINSON'S IRELAND's obligations or it may mean that PARKINSON'S IRELAND cannot perform certain services for you. PARKINSON'S IRELAND will advise you if this is the case.

MARKETING and INFORMATION COMMUNICATIONS by PARKINSON'S IRELAND

We may use the personal data that we collect about you to provide you with relevant marketing communications. This may include sending tailored direct marketing and information e-mails and other communications relating to our services or those of our PARKINSON'S IRELAND head office or Voluntary Branches, and sending you invitations to seminars and other events related to the care of yourself or your family member.

We shall only send such marketing communications to you to the extent that doing so is in the legitimate business interests of PARKINSON'S IRELAND or where you have consented to us doing so. As set out in the Data Subjects Rights table below, you may withdraw that consent at any time by contacting us at nationaloffice@parkinsons.ie. In addition, each electronic communication that you receive shall have a very clear "unsubscribe" option, which will allow you to stop receiving similar communications in the future.

HOW AND WHY WE SHARE YOUR INFORMATION

- a) PARKINSON'S IRELAND shares data between our head office and our Voluntary Branches, where necessary, for the purposes outlined in this Privacy Policy.
- b) PARKINSON'S IRELAND ensures that your personal data is shared in accordance with applicable data protection laws, at all times providing adequate protection to your personal data.
- c) PARKINSON'S IRELAND works with third party service providers in order to provide services for people with PD , such as medical professionals. In some instances, we may disclose your personal data to third parties where this is necessary to perform the services for which you have engaged PARKINSON'S IRELAND or otherwise in furtherance of an outsourcing or other data processing arrangement. In those circumstances PARKINSON'S IRELAND will ensure that the third party is contractually bound to only process personal data in accordance with applicable data protection laws and with PARKINSON'S IRELAND's specific instructions and requirements, and at all times in a manner that protects your rights under applicable data protection laws. Our suppliers and service providers will be contractually required to meet our standards on processing information and security. The information we provide them, including your personal data , will only be provided in connection with the performance of their function. They will not be permitted to use your information for any purposes other than those outlined in this Privacy Policy .
- d) In relation to any other third parties, for example public bodies or other organisations in the charities space, PARKINSON'S IRELAND will only disclose or transfer your data where you have given your consent or where we are required to do so by law or other regulatory code or practice.

3. TRANSFER OF INFORMATION ABROAD

Parkinson's Ireland will never transfer your data outside of the European Union.

4. DATA RETENTION

PARKINSON'S IRELAND will only retain your personal data as needed in order to provide our services and for the purposes set out in this Privacy Policy. Typically, the retention of your data will correspond with your ongoing use of and engagement with our services, but we have cyclical deletion practices in place to routinely delete data that we determine is no longer necessary for processing purposes. Our retention procedure is to only keep data while you are engaging with our services/are a member and to delete it

following the end of this engagement, except where information is required to be held for legal purposes, for example the retention of financial information for a 6 year period following the end of this engagement, in accordance with our legal obligations. We also delete personal data when you request deletion of your data, or if required under applicable law, when you withdraw consent to us using your data, subject to any exemptions that may apply. Please see the Data Subject Rights section below for more information on how to exercise your data subject rights.

5. PROTECTION OF YOUR PERSONAL DATA

PARKINSON’S IRELAND is committed to protecting the security of your personal data . We use a variety of security technologies and procedures to help protect your personal data from unauthorized access, use, or disclosure, across all of our computer systems, Parkinson’s networks, website, mobile phones, regional offices and Voluntary Branches.

6. Data Subject Rights

You have rights in respect of the personal data that we collect and process about you, subject to certain exemptions under the GDPR and the Data Protection Act 2018.

Access	You may request that we provide you with a copy of your personal data held by us, and information on our processing of your data.
Rectification	You are entitled to have any incomplete and inaccurate personal information held by us rectified or updated on request.
Right to erasure (right to be Forgotten)	In some cases, you may request to have your personal data erased, for example where the data is no longer necessary for the purposes for which it was collected and/or processed or you withdraw consent to our use of it.

Restrict Processing	You can ask us to restrict the processing of data PARKINSON’S IRELAND holds about you, for example if you dispute the accuracy of the data we process about you or if you have objected to our processing of your personal data.
Portability	In certain circumstances you are entitled to receive a copy of your personal data information in a structured, commonly used and machine readable format and for that data to be transmitted to another data controller, where technically possible.

Object	You may object to PARKINSON’S IRELAND’s processing of your personal data based on legitimate interests or for direct marketing purposes. In such circumstances we shall cease processing your personal data unless there are compelling legitimate grounds or legal claim grounds for continuing to process the personal data, or we are otherwise permitted to continue to process such data under applicable data protection laws.
Withdraw Consent	Where you have given us consent to process your personal data for any of the purposes outlined in this Privacy Policy and we have no other legal basis for the processing, you shall be entitled to withdraw that consent. The lawfulness of our processing before you withdraw your consent will not be affected by such withdrawal.
Right to Complain	If you have concerns or complaints regarding this Privacy Policy or the manner in which PARKINSON’S IRELAND collects, uses and otherwise processes your personal data you can contact us at nationaloffice@parkinsons.ie with your query addressed to Shane O’Brien (Data Protection Officer). You are also entitled to lodge a complaint about the processing of your personal data to the Data Protection Commission whose contact details can be found on their website contact us page .

This Privacy Policy may be updated from time to time. We post any changes we make to our Privacy Policy on this page and, where appropriate, we will provide you with reasonable notice of any material changes before they take effect or as otherwise required by law.

The current version of this Privacy Policy can be found on the PARKINSON’S IRELAND website or may otherwise be requested at nationaloffice@parkinsons.ie

COOKIE POLICY

1. Policy Statement

This policy covers the use of cookies on the Parkinson’s Ireland website.

2. Aim(s) of Policy

This policy aims to inform Parkinson’s Ireland website users that cookies and similar technologies are used on the website and how to go about opting out of non-strictly necessary cookie usage.

3. Scope of Policy

This policy applies to all visitors to the Parkinson's Ireland website

4. Background and Opting out Procedure for Cookies

Cookies and other similar technologies (collectively called “Cookies” in this Cookies Policy) are small text files that are stored on your computer or device by the websites that you visit. Cookies are useful for website providers and are used by most websites to let users navigate between pages efficiently, ensure security of the webpage or application, understand how their websites are used, remember user preferences and generally improve the user experience. This can help improve content created and how navigation of the site is handled. It can also be used to tailor your experience and ensure that the most relevant information is presented to you based on your preferences. Some cookies are used to enable essential functionality of the website.

The length of time a cookie will stay on your computer or device depends on whether they are ‘session’ or ‘persistent’ cookies. Session cookies are only stored for the duration of usage of the site and are deleted once the browser is closed. Persistent cookies can remain on your computer for longer specified periods.

There are two types of cookies: First-party cookies that are set by the site you are visiting and Third-party cookies which are set by other sites that have features embedded on the site you are visiting – such as third party advertisements or YouTube videos. More information on cookies and their use can be found at www.aboutcookies.org or www.allaboutcookies.org.

Cookie Details

Parkinsons Ireland uses both session and persistent cookies on our website. By using this website you are agreeing to the use of cookies as described in this Policy.

We use the following local cookies:

- Google Analytics to track users as they navigate the website – these cookies are named: _utma, _utmt, _utmb, _utmc, _utmz
- AddThis – provides access to social sharing buttons for Facebook, Twitter, etc
- Cookies to allow use of the shopping cart and to process payments

We also use Third-party cookies:

- YouTube to embed video content into our site
- DoubleClick and Google Analytics to allow us to advertise and monitor performance on Google

We use cookies for the following purposes:

Strictly Necessary purposes

Strictly Necessary Cookies are essential for our website to function and therefore cannot be switched off. They are usually only set in response to actions made by you which amount to a request for services, such as setting your privacy preferences, logging in, or filling in forms. These also include cookies we may rely on for security purposes.

Performance purposes

We use these Cookies to track users as they navigate the Parkinson's website.

Functional purposes

We use these Cookies to remember the choices you make. For example, cookies to process payments.

Managing Cookies

You can choose not to allow cookies to be used on your machine / device or delete cookies that are already there, except for strictly necessary cookies which are necessary for the functioning of our website. Please note, if you set your browser to disable cookies, this may have a negative effect on your browsing experiences as a lot of website functionality requires the use of cookies, with the effect that you may not be able to access parts of our website and other parts of our website may not function properly.

Contact Information

If you have any questions in relation to this Privacy Policy or Cookies Policy please contact us at nationaloffice@parkinsons.ie