

# Privacy Notice – Community of Practice

## Our contact details:

The Lewy Body Society

Unity House, Westwood Park, Wigan, WN3 4HE

T: 01942 914 000 | E: [info@lewybody.org](mailto:info@lewybody.org) | W: [www.lewybody.org](http://www.lewybody.org)

**Date of Privacy Notice: April 2025 | Review Date: April 2026**

## Introduction

The Community of Practice (CoP) is a platform for professionals to connect, share knowledge and resources and raise awareness of Lewy body dementia (LBD). When you join our CoP, we need to collect and process some personal data (information about you) to help you get the most from your membership.

This privacy notice outlines what personal data we process as part of your CoP membership, why we need it and how it is used; you will also find some useful information about your rights.

## Who we are?

The Lewy Body Society is a charity registered in England, Wales and Scotland dedicated to raising awareness and funding research into LBD. We operate the CoP in conjunction with ‘Dementia UK’ a specialist dementia nursing charity that supports individuals and families living with dementia.

We are the Data Controller for your personal data, this means that we are responsible for the personal information that we collect and process about you. If you have any questions about how and why we use your personal data, please contact us.

## Legislation

When processing your personal data, we will comply with the following legislation:

- UK General Data Protection Regulation (UK-GDPR)
- Data Protection Act (DPA, 2018)
- Privacy and Electronic Communications Regulations (PECR, 2003)

## What personal data we process?

### CoP Registration

When you register as a member of the CoP, we ask that you provide us with the following information:

Data Category	Why we need it?
Full Name*	To identify you.
Email Address*	To contact you and provide you with access to the member area.
Password*	Your password will link with your email address (username) to provide you with access to the member area.

Profession*	The CoP is designed for professionals only and not members of the general public; we therefore need your profession to verify your membership and ensure the CoP is appropriate for you and your role. Your profession also helps us to analyse who our members are so that we can improve the member area and ensure the content is relevant to you and your role.
Professional Postcode	This helps us to analyse and report on the location of our members for development purposes.

\*Mandatory categories of data

Under the UK-GDPR, we must meet a lawful basis (condition) to process your personal data. When processing your personal data as part of your registration, we rely upon the following lawful basis:

- Contract: we need to process your personal data to deliver our CoP services to you; we cannot provide you with access to the resources within our member area without processing your name, login details and verifying your profession to ensure the area is suitable for you and your role.
- Legitimate Interests: where the processing of your personal data helps us to analyse and improve our services and offerings to you, namely the use of your professional postcode.

### Webinars & Events

Once you become a member of the CoP, we will use your name and email address to inform you of events and webinars that may be of interest to you and beneficial to your role. The use of your email address for this purpose is completely optional and you can update your preferences at any time by contacting us.

If you register for one of our events, we will use your email address to notify you of the key details such as dates, joining information and links etc; we have a contractual obligation to use your data in this way; we cannot provide you with access to such services without processing your data in this way.

**Important Note:** our live webinars are recorded and published on our website and YouTube channel to ensure that those unable to attend on the day can still access the content. Whilst attempts are made to ensure that personally identifiable information are not visible on the recording, this cannot be 100% guaranteed. We therefore ask that your camera is switched off and your screen name anonymised where necessary.

Following each of our online webinars, we will extract an attendee list which includes your name, email address and factual information including the date and times that you spent on the webinar. This information helps us to analyse and improve our webinars; we have a legitimate interest to process your personal data in this way.

### Cookies & Usage Data

We use 'cookies' and other analytical tools to improve the performance of our website and enhance your user experience. Please visit the 'cookies' policy on our website to find out more:

<https://www.lewybody.org/cookies-policy/>

### **Where we get your information?**

Most of the personal data that we process is provided directly by you when you register for the CoP or attend one of our webinars. On occasion, your employer or professional contacts may provide us with your name and email address if they feel your attendance at one of our webinars or events would be useful for your role.

Any further personal data is collated by ourselves as our professional relationship with you develops. For example, logs of your attendance at webinars, correspondence etc.

### **Who we share your personal data with?**

The CoP is managed by ourselves with support from a small steering group of LBD professionals from 'Dementia UK' and other organisations who volunteer their time, knowledge and expertise to deliver the best resources and services to our members. You can find more information on the steering group in the CoP member area.

Access to your personal data is strictly limited and will not be shared outside of this small group unless it is necessary for legal or operational purposes; we do not share your personal data outside of the United Kingdom. If a situation arises whereby we must share your personal data internationally, we will do so in compliance with the UK-GDPR.

### **How we store your personal data?**

All personal data that we hold about you is kept securely on our electronic system which is operated and maintained by Microsoft and Google Workspace. Access to your records is strictly limited on a 'need to know' basis and is protected by high levels of encryption. As a charity, we have achieved 'Cyber Essentials' accreditation as an extra safeguard to secure your data.

### **How long we keep your personal data?**

We will typically retain your personal data for the duration of your membership. In the event that you close your membership account, we will securely dispose of your records within 3 months of closure unless it is required to fulfil a legal obligation.

### **Your data protection rights**

Under data protection law, you have a number of rights with regards to your own personal data that you can enact under certain circumstances:

- The Right of Access: you can ask us about how and why we process your personal data and ask that we provide you with copies of your personal data that we hold.
- The Right to Rectification: you can ask us to rectify any personal data that you feel is incomplete or inaccurate.
- The Right to Erasure: you can ask that we securely dispose of your personal data unless there is a legal obligation or compelling grounds for us to keep it.

- The Right to Restrict Processing: you can ask that we temporarily restrict the processing of your personal data if you are unhappy with how we are processing it. In such scenarios, we will continue to store your personal data but refrain from any further processing until we have investigated your concerns and provided you with a full response.
- The Right to Object to Processing: under certain circumstances you can object to our use of your personal data. Typically this will include our use of your information in relation to direct marketing and personal data processed under the grounds of 'legitimate interests'.

You also have rights in relation to 'data portability' and 'automated decision making & profiling'. It is not anticipated that such rights will apply to our data processing activities, we will however deal with and respond to any requests accordingly.

We ask that any requests relating to your rights are addressed to our CEO Jacqueline Cannon using the contact details provided in this privacy notice. We have one calendar month to provide a response to you; we reserve the right to extend more complex requests by a further two calendar months, we will however inform you of any intention to extend within the first month. In most scenarios, we will not charge a fee for dealing with your request.

### **Complaints**

If you have any concerns about our use of your personal information, it would be very much appreciated if you could contact us in the first instance to allow us an opportunity to resolve your complaint.

You can also complain to the Information Commissioners Office (ICO) if you are unhappy with how we have used your data:

Information Commissioner's Office  
Wycliffe House  
Water Lane  
Wilmslow  
Cheshire  
SK9 5AF

Helpline number: 0303 123 1113

ICO website: <https://www.ico.org.uk>