



Data and Privacy Policy



Guidelines and code of practice for all team members and public statement

This Policy was devised and distributed to all OCD-UK staff in December 2024

This policy will next be reviewed in January 2026

OCD-UK is a non-profit making charity and is not associated with any other organisation.

Charity Registration Number: 1103210

Charity Postal Address: OCD-UK, 8 Chapel Street, Belper, Derbyshire DE56 1AR



Introduction

This data and privacy notice explains when and why we collect personal information about people who use our website and services, how we use it, conditions under which we may disclose it to others and how we keep it secure.

OCD-UK is committed to ensuring and respecting that your privacy is protected. Should we ask you to provide certain information by which you can be identified when using this website, you contact us about products and services, to make a donation, to purchase products/services, to work in partnership with us in any capacity, to volunteer or work with us, to fundraise, or if you registered to receive one of our newsletters then you can be assured that it will only be used in accordance with this privacy notice.

OCD-UK may change this privacy notice from time to time by updating this page, as we keep this policy under regular review. This notice was last updated in December 2024. Where we have made any changes to this notice then we will make this clear on our website. You should check this page from time to time to ensure that you are happy with any changes.

It is important that you read this privacy notice when we are collecting or processing personal data about you so that you are fully aware of how and why we are using your data.

Any questions or concerns regarding this data and privacy notice or OCD-UK's privacy practices should be sent by email to: office@ocduk.org or in writing to:

OCD-UK,
8 Chapel Street,
Belper
Derbyshire
DE56 1AR

Should you not be satisfied with our response/s, you have the right to make a complaint at any time to the Information Commissioner's Office (ICO), the UK supervisory authority for data protection issues (<https://www.ico.org.uk>).

Who we are:

We are a registered charity (1103210). OCD-UK has been working for children and adults affected by Obsessive-Compulsive Disorder since 2004.

We provide advice, information, and support services for those affected by OCD, and campaign to end the trivialisation and stigma of OCD.

Uniquely, the charity is completely service-user led which means that everyone involved in the organisation has personal experience of OCD, either directly or through a loved one.

OCD-UK are also a “data controller” for the purposes of the EU General Data Protection Regulation 2016/679 (“GDPR”). This means that we are responsible for, and control the processing of, your personal data.

We obtain information about you when you use our services or website, when you:

- contact us about products and services;
- contact us to make a donation;
- become a member of OCD-UK;
- purchase products/services;
- work in partnership with us in any capacity;
- volunteer or work with us;
- fundraise;
- sign up to join our support groups or conferences;
- sign up to attend one of our educational workshops or webinars;
- register to receive one of our regular e-newsletters.

What type of information is collected from you?

The personal information we collect might include your name, postal address, email address, IP address and information regarding what pages are accessed on our websites and when and which browser and device size you may be using.

If you make a donation online or purchase a product/service from us, your card information is **not** held by us, it is collected by our third-party payment processors/banks, who specialise in the secure online capture and processing of credit/debit card transactions and direct debit processing, as explained below.

Functional Data

Certain categories of the data that we collect are absolutely necessary for you to receive the benefits of membership of OCD-UK (e.g. email or postal address to receive *our OCD Magazine*, email address to access the members area of our website) and as such you will not be able to opt out from this data collection, sharing and/or processing (“Functional Data”) unless you no longer wish to access our services.

Personal Information

For those using the OCD-UK website for any of the following purposes:

- membership subscriptions;
- volunteering enquiries;
- e-newsletter sign-ups;
- training;
- research requests;
- fundraiser requests;
- support (including via forum and advocacy);
- sponsorship enquiries;
- self-help group listings;
- purchase of products.

We will collect all or some of the following information:

- Name;
- Gender;
- Contact information including email address and/or postal address;
- Date of birth;
- Demographic information such as postcode, ethnic background, sexual orientation, religion;
- Gift aid status;
- Details of fundraising activity/event;
- Details of research project including contact details of researcher and supervisor;
- Whether you wish to participate in volunteering opportunities (including media work);
- Where you heard about OCD-UK;
- Details of amount paid /donation given to OCD-UK;
- Contact details of self-help group facilitators and details of self-help groups;
- For those using the OCD-UK helpline service, email support/forums support/social media support: We collect information as follows:
 - email address;
 - IP address (where available);
 - Username;
 - Contact phone number (where available).
- For those using the OCD-UK website to make any online purchase. We collect information as follows:
 - name of purchaser;
 - billing and shipping addresses (and other contact information provided);
 - details of products purchased;
 - amount paid;
 - payment method (but not card payment information). For those paying through Paypal your email address is recorded.

We do not obtain data about you from any third party without your knowledge or express written consent. The above information is collected by OCD-UK to ensure that the services provided are accessible and for monitoring and evaluation purposes. We collect all or some of the above information depending on the product or service that you wish to access and/or your reason for making contact with us.

Sensitive Data

If you share your personal experience of OCD or any data about your health and well-being we will treat this information with the utmost confidence and always in accordance with this notice.

In the event you provide us with any sensitive data we will only use this information:

- For the purposes of dealing with your enquiry, providing products or services, training, and quality monitoring or reviewing the services we provide; and
- Where you have given us your express consent or otherwise clearly indicated to us that you consent for your sensitive data to be passed on to a specific third party or to be used in a certain way (i.e. to help you access treatment services).

We will never pass on your details to anyone else without your express permission except in exceptional circumstances. Examples of this might include anyone reporting serious self-harm or posing a threat to themselves or others.

If you share your personal experience with us for the purpose of it being shared on the OCD-UK's websites or in our magazine, then you can decide if you want to remain anonymous publicly or not, although we will retain your details to identify the anonymous author. If you are happy to share your personal details with staff members or if you would like us to share your story with the media or other parties then we will, subject always to you having provided your consent to such sharing.

Call Recording

We record our support calls to:

- Help improve the quality of our helpline service and to ensure the information we provide is consistent and accurate;
- To have an accurate record of all calls relating to support any client interaction or transactions that take place over the phone (card payment details are not recorded, the operator pauses the recording for that); and
- Establish the facts in the event of a complaint by a client/service-user accessing the helpline service.

OCD-UK's helpline service is a confidential service. However, there are certain situations where information will need to be shared even if this is against the wishes of the service user. These reasons can be found in the 'when we may have to disclose Information' section.

Is my call information being held securely?

Personal data (telephone number, unless withheld and call recordings) is stored in a secure database by our telecoms provider *RingCentral*. They provide the technology platform from which our helpline services are delivered. All data is stored in the UK. Data is never transported or stored outside the UK for any reason. All call recordings are automatically deleted after six months, telephone data is stored for up to one year as per our retention policy shown in the table below.

Who will be able to access call recordings?

Call recordings can only be accessed by senior members of the OCD-UK staff, currently Chief Executive and Support Coordinator for the purposes of volunteer training. All staff are trained in GDPR and have read and understood this data and privacy policy.

The legal basis for collecting your data

OCD-UK will only use your personal data when the law allows us to. Most commonly, we will use your personal data in the following circumstances:

- Where we need to perform the contract we are about to enter into or have entered into with you (for example, because you've placed an order on our website or signed up as an OCD-UK member);
- Where it is necessary for our legitimate interests and your interests and fundamental rights do not override those interests; and
- Where we need to comply with a legal obligation.

You have the right to withdraw consent to marketing from OCD-UK at any time by email to: office@ocduk.org or in writing to:

OCD-UK,
8 Chapel Street,
Belper
Derbyshire
DE56 1AR

There are also other lawful reasons that allow us to process your personal data and one of those is legitimate interests. This means that the reason that OCD-UK are processing your personal data is because there is a legitimate interest for us to process your information to help us to achieve our mission to work to relieve and support those living with OCD by providing information, support and understanding via an extensive range of services.

We do not use your personal data for activities where our interests are overridden by the impact on you (unless we have your consent or are otherwise required or permitted to by law). You can obtain further information about how we assess our legitimate interests against any potential impact on you in respect of specific activities by contacting us.

Some examples of where we have a legitimate interest to process your personal data are

- conduct research to improve our services;
- for our legal purposes (for example, dealing with complaints)
- for complying with guidance from the Charity Commission.

How is your information used?

We will mainly use this information to:

- Ensure that members of OCD-UK are able to access the range of membership benefits they are entitled to during the course of their membership term including receipt of our *OCD Magazine*;
- To be able to respond to incoming training, partnership, consultancy, informal partnership, volunteering, fundraising, donor and research enquiries effectively;
- To process and thank donors and/or fundraisers and to claim Gift Aid on donations where consent has been given;
- To respond to those using our email, groups, forum and helpline services requesting help and support. Additionally, to provide follow-up information (via email /phone/text/) for those accessing such services;
- For website newsletter sign-ups, to ensure that signees receive an e-newsletter and other communications which you have requested and that may be of interest to you;
- To fulfil and process online orders made via the OCD-UK website;
- To keep a record of your relationship with us;
- Where you volunteer with us, to administer the volunteering arrangement; and
- To communicate with you about our activities and ways that you can support us, e.g. fundraising, volunteering, purchasing products and services, accessing new and existing services.

Unfortunately, if you do not provide this information, then we will not be able to process your donation, sign you up as a volunteer or deliver the products or services you have requested.

We review our retention periods for personal information on a regular basis. We are legally required to hold some types of information to fulfil our statutory obligations (for example, the collection of Gift Aid). Details of our retention policy can be found on the table further down this document. We will hold your personal information on our systems for as long as is necessary for the relevant activity, or as long as is set out in any relevant contract that you hold with us.

We may from time to time create statistical and aggregated data derived from your personal data to enable OCD-UK to share aggregated outcome data for the purpose of evaluation, promotion, marketing and research of OCD-UK's services. Any aggregated data will be in anonymous form and will not identify you as an individual in any way.

Who we share information with/who has access to your information:

We recognise the importance of your data and confidentiality.

OCD-UK will never sell or rent your personal information to third parties and we promise to keep your details safe and secure. We will not and will **never** share your personal information with third parties for marketing purposes.

Third Party Service Providers working on our behalf (i.e. fundraising platforms):

We may pass your information to third party service providers and other associated organisations for the purposes of completing tasks and providing services to you on our behalf (for example to our bank to process donations and direct debits). However, when we use third party service providers, we disclose only the personal information that is necessary to deliver the service and we have a contract in place that requires them to keep your information secure.

Please be reassured that we will not release your information to third parties beyond the OCD-UK network for them to use for their own direct marketing purposes.

When you are using our secure online payment system, your payment is processed by a third party payment processor, who specialises in the secure online capture and processing of credit/debit card transactions.

When we may have to disclose information

OCD-UK's support services are confidential services. However, there are certain situations where information will need to be shared even if this is against the wishes of the service user. This includes situations where:

- a client's life is at risk;
- other individuals' lives are at risk;
- it is the requirement of a court order; or
- it is the requirement of law
- it is a safeguarding issue

There may also be occasions where there is a public interest justification for the disclosure of information including:

- public accountability and monitoring purposes (i.e. protecting the public, equality of opportunity or treatment);
- where there is a serious risk to public health;
- the prevention, detection or prosecution of serious crime.

Your choice

You have a choice about whether or not you wish to receive information from us. If you do not want to receive direct marketing communications from us about the vital work that we do supporting those with OCD and our range of products and services, then you can select your choices by ticking the relevant boxes on the form on which we collect your information.

We will not contact you for marketing purposes by email, phone or text message unless you have given your prior consent. We will not contact you for marketing purposes by post if you have indicated that you do not wish to be contacted. You can change your marketing preferences at any time by contacting us by email: office@ocduk.org

How you can access and update your information

The accuracy of your information is important to us. We're working on ways to make it easier for you to review and correct the information that we hold about you. In the meantime, if you change email address, or any of the other information we hold is inaccurate or out of date, please email us at: office@ocduk.org or in writing to:

OCD-UK,
8 Chapel Street,
Belper
Derbyshire
DE56 1AR

You have the right to ask for a copy of the information OCD-UK hold about you. Please direct all requests to either of the above contact addresses.

Data Retention Policy

OCD-UK requires that different types of records be retained for a specific period of time to comply with UK legislation and good practice. OCD-UK requires that records be treated consistently. All records whether physical or digital are covered by this policy.

This policy is intended to ensure that OCD-UK meets its obligations under the Data Protection Act 1998 and keep records and documents only for as long as necessary. Data is cleansed each year according to this schedule.

Personal Data

| Type of Record | Retention Period | Storage Media Location | Reason for Retention |
|---|--|------------------------|---|
| Staff Emails | Up to 2 years | Electronic | Essential business continuity |
| Support Emails | Up to 2 years | Electronic | To deliver continuity of service |
| Support Call Recordings | Up to 1 year | Electronic | To deliver continuity of service / volunteer training |
| Zoom online support group and conference registration emails | Up to 1 year | Electronic | To deliver continuity of service |
| Zoom online support group and conference chat transcripts | Up to 1 year | Electronic | To deliver continuity of service |
| Project participation data (i.e. Young Ambassador, Parents Workshops) | Up to 3 years | Electronic | To deliver continuity of service |
| Forum registration email | After 5 years of inactivity (logging on) | Electronic | To deliver continuity of service |

| | | | |
|--|--|---------------------|--|
| Tax including Gift Aid | 7 years | Electronic | To comply with HMRC regulations |
| Training Records (externally delivered) | 7 years | Electronic/Physical | Essential business continuity |
| Volunteer Records & Data | Up to 18 months post cessation of volunteering | Electronic/Physical | For supply of references |
| Employee/Personnel Records | Up to 2 years after employment ceases | Electronic/Physical | For references and business continuity |
| Incidents, Complaints Data (including accident data) | 7 years | Electronic/Physical | To comply with Charity Commission guidance |
| Membership information and application forms | Up to 7 years | Electronic | Essential business continuity |
| Recruitment data | Up to 2 years | Electronic | For monitoring purposes & HR compliance |
| Fundraisers and donors | Up to 7 years | Electronic/Physical | To comply with Charity Commission guidance |
| Shop Purchase sales data | Up to 7 years | Electronic | To comply with HMRC regulations |

Security precautions in place to protect the loss, misuse or alteration of your data and information

We are committed to ensuring that your information is secure. In order to prevent unauthorised access or disclosure we have put in place suitable physical, electronic and managerial procedures to safeguard and secure the information we collect online.

When you give us personal information, we take steps to ensure that it's treated securely. Any sensitive information submitted via our website (such as credit or debit card details) is encrypted and protected with the following software 256 bit encryption on SSL. When you are on a secure page, a lock icon will appear on the address bar of web browsers such as Microsoft Internet Edge or Google Chrome.

Non-sensitive details (your email address etc.) are transmitted normally over the Internet, and this can never be guaranteed to be 100% secure. As a result, while we strive to protect your personal information, we cannot guarantee the security of any information you transmit to us, and you do so at your own risk. Once we receive your information, we make our best effort to ensure its security on our systems. Where we have given (or where you have chosen) a password which enables you to access certain parts of our website (forums or members area of our main website), you are responsible for keeping this password confidential. We ask you not to share your password with anyone. We cannot see your password.

OCD-UK ensures the compliance of its staff and volunteers through training and supervision and has systems and policies in place with regard to data protection and confidentiality and relevant associated legislation.

Use of cookies

A cookie is a small file which asks permission to be placed on your computer's hard drive. The cookie helps analyse web traffic or lets you know when you visit a particular site. Cookies allow web applications to respond to you as an individual. The web application can tailor its operations to your needs, likes and dislikes by gathering and remembering information about your preferences.

We use traffic log cookies to identify which pages are being used. This helps us analyse data about web page traffic and improve our website in order to tailor it to customer needs. We only use this information for statistical analysis purposes and then the data is removed from the system.

Overall, cookies help us provide you with a better website, by enabling us to monitor which pages you find useful and which you do not. A cookie in no way gives us access to your computer or any information about you, other than the data you choose to share with us. You can choose to accept or decline cookies. Most web browsers automatically accept cookies, but you can usually modify your browser setting to decline cookies if you prefer. This may prevent you from taking full advantage of the website.

We use the following cookies on our websites:

| Cookie Name | Cookie Category | Description | Expires after |
|--------------------------------------|-------------------|---|-------------------|
| _ga | Forum and Website | Used by Google Analytics to register a unique ID that is used to generate statistical data on how the visitor uses the website. | 2 years, 2 months |
| _gat | Forum and Website | Used by Google Analytics to register a unique ID that is used to generate statistical data on how the visitor uses the website. | 2 years, 2 months |
| _gid | Forum and Website | Used by Google Analytics to register a unique ID that is used to generate statistical data on how the visitor uses the website. | 3 days |
| __stripe_mid | Website | Used by website payment processed to provide fraud prevention. | |
| __stripe_sid | Website | Used by website payment processed to provide fraud prevention. | |
| 1P_JAR | Website | Google | 1 month |
| ANID | Website | Google | 1 year |
| consent | Website | Google and You Tube | 17 years, 4 month |
| cmplz_banner-Status | Website | to store if the cookie banner has been dismissed. | 1 year |
| cmplz_marketing | Website | to store cookie consent preferences. | 1 year |
| cmplz_policy_id | Website | to store accepted cookie policy ID. | 1 year |
| cookieLawInfo-checkbox-necessary | Website | Determines whether the user has accepted the cookie consent box. | 1 year |
| cookieLawInfo-checkbox-non-necessary | Website | Determines whether the user has accepted the cookie consent box. | 1 year |
| fr | Website | Facebook used by WP Quiz plugin | 3 month |
| IDE | Website | Used by Google Doubleclick within YouTube video embedded on our webpage to register and report the website user's actions after viewing or clicking one of the advertiser's ads with the purpose of measuring | 1 year, 1 month |

| | | | |
|---------------------------|---------|--|-------------------|
| | | the efficacy of an ad and to present targeted ads to the user. | |
| ips4_IPSessionFront | Forum | | When session ends |
| ips4_forum_view | Forum | | 24 hours |
| ips4_guestTime | Forum | | When session ends |
| ips4_hasJS | Forum | | 24 hours |
| ips4_ipsTimezone | Forum | | When session ends |
| mp | Website | | 1 year |
| nid | Website | Google | 6 month |
| Rc::a | | This is the recaptcha plugin on our website. Powered by Google, this cookie is used to distinguish between humans and bots. | When session ends |
| Rc::c | | This is the recaptcha plugin on our website. Powered by Google, this cookie is used to distinguish between humans and bots. | When session ends |
| tk_ai | Website | Woo commerce | When session ends |
| viewed_cookie_policy | Website | Registers whether or not the user has viewed the website's privacy policy when accepting cookies. | 24 hours |
| VISITOR_INFO1_LIVE | | This cookie is created by YouTube videos embedded on our website. It tries to estimate the users bandwidth on pages with integrated YouTube video. | 6 month |
| wf_loginalerted | Website | Website firewall protection | 24 hours |
| wfawf-authcookie | Website | | 12 hours |
| woocommerce_cart_hash | | Website shop | When session ends |
| woocommerce_items_in_cart | | Website shop | When session ends |
| wp_woocommerce_session | | Website shop | 2 days |
| wpgmza-api-consent-given | Website | Used by Google Maps app to store cookie consent preferences. | 1 year |
| wordpress_logged_in_ | | WordPress cookie for a logged in user | 15 days |
| wordpress_sec | | | 15 days |
| wp-settings-1 | | | 1 year |
| wp-settings-time-1 | | | 1 year |
| YSC | | This cookie is created by YouTube videos embedded on our website. It registers a unique ID to keep statistics of what videos from YouTube the user has seen. | When session ends |

Links to other websites

Our website may contain links to enable you to visit other websites of interest easily. However, once you have used these links to leave our site, you should note that we do not have any control over that other website. Therefore, we cannot be responsible for the protection and privacy of any information which you provide whilst visiting such sites and such sites are not governed by this privacy statement. You should exercise caution and look at the privacy notice applicable to the website in question.

Transferring your information outside of Europe

As part of the services offered to you through this website (including membership), the information which you provide to us may be transferred to countries outside the European Union (“EU”). By way of example, this may happen if any of our servers are from time to time located in a country outside of the EU, (i.e. some Microsoft servers may be located in the US).

These countries may not have similar data protection laws to the UK. By submitting your personal data, you’re agreeing to this transfer, storing or processing. If we transfer your information outside of the EU in this way, we will take steps to ensure that appropriate security measures are taken with the aim of ensuring that your privacy rights continue to be protected as outlined in this Policy.

If you use our services while you are outside the EU, your information may be transferred outside the EU in order to provide you with those services.

Storing of your data

In order to allow us to deliver some of our services we may integrate third party services (i.e. Zoom to host online support groups). When collating your data, we may also store your data on third party secured databases in order that our entire team spread geographically can access (i.e. Excel and Word documents stored within Microsoft Office 365 cloud). We take great efforts to ensure data is stored securely and encrypted where possible. OCD-UK uses the following third-party services to deliver our services. Your data is not used by these third parties and is only stored for the purposes of allowing OCD-UK to deliver its services.

- **RingCentral** – Technology and platform used for the OCD-UK helpline
- **eTapestry** – Owned by US based Blackbaud, database used to store the charity’s members, volunteer and fundraising database.
- **Microsoft Teams** – To store charity project documents for internal team access only.
- **Zoom** – Used to power online support groups and conferences. Data is stored when somebody registers for one of our meetings. Data is transferred by OCD-UK to Microsoft Teams.

Your Rights

You have the right to:

- **Request access to your personal data** (commonly known as a “data subject access request”). This enables you to receive a copy of the personal data we hold about you and to check that we are lawfully processing it.
- **Request correction of the personal data** that we hold about you. This enables you to have any incomplete or inaccurate data we hold about you corrected, though we may need to verify the accuracy of the new data you provide to us.
- **Request erasure of your personal data.** This enables you to ask us to delete or remove personal data where there is no good reason for us continuing to process it. You also have the right to ask us to delete or remove your personal data where you have successfully exercised your right to object to processing where we may have processed your information unlawfully or where we are required to erase your personal data to comply with local law. Note, however, that we may not always be able to comply with your request of erasure for specific legal reasons which will be notified to you, if applicable, at the time of your request.
- **Object to processing of your personal data** where we are relying on a legitimate interest and there is something about your particular situation which makes you want to object to processing on this ground as you feel it impacts on your fundamental rights and freedoms. You also have the right to object where we are processing your personal data for direct marketing purposes. In some cases, we may demonstrate that we have compelling legitimate grounds to process your information which override your rights and freedoms.
- **Request restriction of processing of your personal data.** This enables you to ask us to suspend the processing of your personal data in the following scenarios:
 - If you want us to establish the data’s accuracy.
 - Where our use of the data is unlawful but you do not want us to erase it.
 - Where you need us to hold the data even if we no longer require it as you need it to establish, exercise or defend legal claims.
 - You have objected to our use of your data but we need to verify whether we have overriding legitimate grounds to use it.
- **Request the transfer of your personal data to you or to a third party.** We will provide to you, or a third party you have chosen, your personal data in a plain text format. Note that this right only applies to automated information which you initially provided consent for us to use or where we used the information to perform a contract with you.
- **Withdraw consent at any time where we are relying on consent to process your personal data.** However, this will not affect the lawfulness of any processing carried out before you withdraw your consent. If you withdraw your consent, we may not be able to provide certain products or services to you. We will advise you if this is the case at the time you withdraw your consent.



Some of these rights only apply in certain circumstances and we may not be able to fulfil every request and there may be some circumstances where OCD-UK is allowed to withhold information from you.

There are some very specific situations where OCD-UK may be allowed to withhold personal information from you and these include:

- if your request is 'unfounded or excessive';
- if it includes personal information about someone else (third party information); or
- if sharing it would be likely to cause serious harm to you or another person ;

If OCD-UK feel that it genuinely needs to withhold the information from you then we will tell you why (except where an appropriate health professional has confirmed to us that sharing it would be likely to cause serious harm to you or another person).

- **ENDS**