

Privacy Notice

Carers of East Lothian's approach to Data Protection, Record Keeping and Confidentiality – May 2025

Who we are

Carers of East Lothian (CoEL) is a registered Scottish Charity (Charity Number SC027000) and a Company Limited by Guarantee (Company Number SC366908)

The information and records that we keep

In order to provide our services we keep records about the people that we support and the nature of the support that we provide. For the purposes of the data protection law, we are the data controller of the personal data that we collect about you. This will include information about you (if you are a carer we are supporting) and it may also include some details of the person (or people) that you care for. The kinds of information we keep includes:

- Your contact details (name, address, telephone number(s) and e-mail address).
- Some statistical information (for example your gender, date of birth, the health categorisation of the person you care for).
- A summary of the conversations we have had with you and of the advice and/or support that we have provided (which we take notes of to ensure that we are providing you with high quality support and so we can do so on a consistent basis).

When we assist you (or the person you care for) with benefits claims we may also collect national insurance numbers to allow us to speak to the Department for Work and Pensions (DWP) on your behalf if you give us your consent to do so. We also retain records about the outcomes of any benefit claims that we have helped with.

Some of the information we keep is defined as *special category data* under data protection law (for example information about health problems or ethnicity). However, we know that ALL of the records we keep are sensitive and we are committed to keeping them confidential.

Where we get information from

Most of the time we will ask you for the relevant information that we need and you can of course decide not to share some information with us although that may make it harder for us to support you effectively. Sometimes we are given information about you (or the person you care for) by another person, local authority, organisation or another voluntary sector organisation. Most commonly this will be by a professional (such as a doctor or social worker) when they are referring a carer to CoEL for support or when we are following up on issues on your behalf.

Why we keep this information and these records

For the carers we support and, in some cases, the person they care for, we keep records relating to their name, address, telephone number, email address, gender, conversation summaries, support record and date of birth (as well as national insurance number, if applicable) so that we can provide you with support including:

- Enabling us to contact you to provide you with support. We may contact you by telephone, email or text message with information that you have asked for (e.g. we may text you to remind you of a carer support group meeting that you would like to attend).
- Keeping a record of the advice and support we have provided to enable us to do so consistently and effectively and to help ensure that we provide a high standard of support.
- Informing you of other support organisations and notifying you of events, workshops and/or support groups that you may find useful.
- Sending you a regular newsletter, and occasional details of fundraising activities we may be taking part in, by post
- Allowing us to investigate and respond should you have any questions or concerns about our service.
- Gathering statistical information to enable us to analyse the work that we do, the groups of carers we support and the kinds of issues that carers are supported with. This analysis enables us to report to the organisations that fund our work, to contribute to research and to advocate for improved services for carers and the people they care for.
- For auditing purposes.

Under data protection law these are known as CoEL's *legitimate interests* in providing you with the support you have asked for.

We may also need to collect information from you about your health, the health of the person that you care for and your ethnicity in order to provide our services and for the purpose outlined above. For this *special category data* that we collect about carers and the people they care for we are relying on the following legal basis:

- Health information – consent (when we collect information about your or the cared-for person's health in order to provide our services) or statistical purposes (when we categorise the health condition(s) of the cared-for person to provide statistical information to the local authority and/or the Government).
- Ethnicity – statistical purposes (we only collect this information in order to provide statistical information to the government for statistical research purposes).

Please contact us as soon as possible when there is any change to your personal details, including your contact details.

Sharing your personal data

We will treat ALL your personal data, including the information you give us, with great care. The only circumstances where we will share your personal data with anyone outside of CoEL are:

- If you agree or ask us to do so – for example, if you ask us to make a referral for you to another support service. We will only pass on your details in this way where we have obtained your prior consent.
- If we are required by law to do so - for example, if we were to become significantly concerned about you or someone else's wellbeing we would need to notify the statutory services (Police, Social Work and/or the NHS) so that they could assess if action was needed to keep you (or someone else) safe- this is on the basis of protecting your vital interests.
- To facilitate research by the NHS, Government or Carers Trust into the needs of carers and the effectiveness of policies to support them – for example, we provide statistical information which includes details of carers' postcodes and dates of birth (but not their names or contact details) to allow the Government to ensure that the information provided has not been duplicated as well as

other anonymised information about your needs and the support we have provided (including the adult carer support plan you may have) to the Scottish Government as part of their Carers Census project – this is on the basis of statistical research. All such research projects are governed by strict rules and any reports published by them will be totally anonymous so that no individual could be identified from them.

We also need to use third party external service providers and suppliers in order to run our organisation and provide our support services. In the course of using these external services the following third parties may have access to your personal information for the purposes noted below:

- Microsoft hosts our email on Office 365;
- our database and CRM provider, who is currently CharityLog;
- our cloud storage provider, who is currently Microsoft;
- our website hosting provider, who is currently WP Maintain;
- our IT support provider, who is currently Scottish Council of Voluntary Organisations (SCVO);
- our waste management providers, who are currently GTFM and NHS Lothian.

We also use the following third party external service providers for the purposes noted. If you have signed up to these, they store your personal information on our behalf:

- our email mailing list provider, currently MailChimp;
- our online fundraising provider, who is currently JustGiving; and
- Facebook who we use for social media

The data that we collect from you will be stored inside the UK or the European Economic Area (EEA). However, MailChimp, JustGiving and Facebook are based in the United States so the data they process will be stored there. We only use third party external service providers who provide an adequate level of protection for your data in keeping with our obligations to you.

Access to a copy of your records and your rights

You have certain rights under data protection law, which can be exercised by contacting us using the details below, including:

- The right to access the personal data we hold about you by making a subject access request. We are happy to provide you with a copy of the information we have about you in our records if you wish. We can provide this in either a paper form or electronically to facilitate data portability.
- The right to have your personal data rectified if it is inaccurate or incomplete.
- The right to request to have your personal data deleted in certain specific circumstances.
- The right to request to restrict the processing of your personal data in certain specific circumstances.
- The right to ask us not to process your personal data for marketing purposes or for purposes based on our legitimate interests.
- The right to ask us to not undergo automated decision making. However, for the avoidance of doubt, we do NOT conduct any profiling and/or automated decision-making in providing our services.
- Where you have provided consent, the right to request to withdraw that consent at any time.

If you choose to exercise your rights to have your personal data restricted or deleted, we may not be able to continue to support you through our service.

Retaining Records

We will not hold your personal information for any longer than is necessary for our purposes of supporting you and providing our services. We keep your records for 7 years after we last supported you. If the records are not needed after that time, we will anonymise your personal details on our systems so there will no longer be anyway that you can be identified.

Receiving newsletters, information about events, fundraising materials etc. by post

When we sent out information to you about upcoming events and/or fundraising materials via postal mail, we are doing so on the basis of our legitimate interests. If you do not wish to receive this kind of information please let us know by contacting our office and we will stop sending them to you.

Receiving newsletters, information about events, fundraising materials etc. electronically

We will only ever send you this kind of information via e-mail if we have your consent to do so (because there are additional rules about electronic marketing). You can change your mind about giving us consent at any time by letting us know that you no longer wish to receive such communications via e-mail.

We will send you information about our events, fundraising materials and newsletters by post and/or by e-mail for 7 years after we last supported you. You can ask us to stop doing so at any time by contacting us using the details below.

Using our website

We use cookies on our website to provide you with a more personalised web service. Cookies are small text files that are placed on your computer by websites that you visit. For more information on how we use cookies please visit: www.coel.org.uk/privacy.

Questions or Concerns?

If you have any questions or concerns about the way that we use your data or anything in this Privacy Notice you can contact us at:

Carers of East Lothian, East Lothian Community Hospital, Alderston Road,
Haddington, EH41 3PF
0131 665 0135
centre@coel.org.uk

You can also contact the Chief Executive of CoEL who is our nominated Data Protection Manager. You can contact him/her at chiefexecutive@coel.org.uk or via the ways listed above.

Right to Complain

We are committed to working to very high standards and we hope that we can resolve any concerns you may have quickly and directly. However, if you remain dissatisfied with the way we have responded to your concerns, you can complain to the Information Commissioner's Office (ICO). You can do so via:

www.ico.org.uk
0303 123 1113