

We care about you



We care about your **personal information**

I 05. Privacy Policy for Carers & Members

Welcome

We appreciate that when you contact Carers Link, you trust us with not only your contact details but also with a lot of personal and sensitive information. We use this information to provide you with suitable support but we want you to understand what data we collect, why we collect it and what we do with it.

This Privacy Policy might seem a long document but there is a lot that we need to tell you! Hopefully it will give you a good understanding and answer all your questions, but if it doesn't just call us on 0800 975 2131 and ask for Clair Hegarty or Jennifer Roe. Or you can e-mail us at enquiry@carerslink.org.uk

Scope

This Privacy Policy only applies to adult carers (the people that use our services) and our Members. We have a separate policy relating to the Privacy of Information of Young Carers.

There are also separate policies relating to personal information of Volunteers and Staff. These latter policies are not posted on the website but made available directly. However the policies are also available on request.

Background

Most people will have heard of Data Protection and there has been a Data Protection Act (DPA) since 1998. This Act put a range of obligations on organisations that held data or information and also gave you the right to see any information held, although usually for a small fee. Carers Link was previously registered under this Act.

In May 2018, the Data Protection Act will be replaced by new EU General Data Protection Regulations (GDPR). This puts stricter controls on organisations, requires greater transparency and gives individuals more rights (this time without cost). As before, GDPR applies to both computer and paper (manual) files.

This Privacy Policy has been written to reflect the new regulations, however you can read more about your individual rights at:

<https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/individual-rights/>

Our Promise

Carers Link supports the Personal Information Promise and promises that we will:

- Value the personal information entrusted to us and make sure we respect that trust;
- Go further than just the letter of the law when it comes to handling Personal Information, and adopt good practice standards;
- Consider and address the privacy risks first when we are planning to use or hold personal information in new ways, such as when introducing new systems;
- Be open with individuals about how we use their information and who we give it to;
- Make it easy for individuals to access and correct their personal information;
- Keep personal information to the minimum necessary and delete it when we no longer need it;
- Have effective safeguards in place to make sure personal information is kept securely and does not fall into the wrong hands;
- Provide training to Staff, Students and Volunteers who handle personal information and treat it as a disciplinary matter if they misuse or don't look after personal information properly;
- Put appropriate financial and human resources into looking after Personal Information to make sure we can live up to our promises; and
- Regularly check that we are living up to our promises and report on how we are doing.

In addition, Carers Link subscribes to the GDPR principles, namely that data or information must be:

- Fairly and lawfully processed in a transparent manner
- Collected for a specific and limited purpose(s)
- Adequate, relevant and limited to what is necessary
- Accurate and up-to-date, and if incorrect rectified or erased without delay
- Not kept longer than necessary
- Processed in a manner that is secure

Definitions

We will often use the word '**data**' in this policy. Essentially, data are the facts, statistics and general information that we keep about people or our services.

Personal data means:

- Any data which relate to a living individual who can be identified as a result of that information
- It includes any expression of opinion about the individual and any indication of the intentions of the data controller (see below) or any other person in respect of the individual.

Sensitive data are special categories of personal data and relate to:

- A person's racial or ethnic origin, political opinions, religious beliefs, trade union membership, sexual life, genetic and biometric data and a person's physical or mental health or condition.

A **Data Controller** is the person who determines the purposes and means of processing personal data. Within Carers Link, the Data Controllers are:

- Jennifer Roe, CEO
- Clair Hegarty, Office Manager

Data Processors are those responsible for processing personal data i.e. all the staff and some volunteers within Carers Link. By **processing**, we mean the act of obtaining, recording or holding the information as well as organising, using, sharing and ultimately destroying the data.

Why We Collect Information

There are many reasons why we collect information. Your personal information (including some sensitive data) is used to:

- Respond to your enquiries or requests for help and/or support
- Ensure that we understand your caring situation and that you receive the service or services best suited to your needs
- Save you having to repeat your situation over and over again to different staff or volunteers
- Provide a record of what we have done to support you and/or keep track of support within a caring role that may continue over many years
- Advocate on your behalf – and with your permission - to evidence the need for statutory support services (e.g. respite, homecare)
- Let you know about activities, events and groups, and to keep you up-to-date with what is happening generally at Carers Link
- Monitor the quality of a service or services provided
- Evidence permissions given
- Administrate our membership records

Although your personal details are **never** shared with anyone without your consent, we do use **anonymous** statistical information that is extracted from the above. This is used to:

- Demonstrate the need for a particular service and/or for more funding
- Evidence to funders and the public how we have used any funding or donations provided to us
- Look for trends in service delivery that may help us plan better
- Monitor the quality of a service or services provided
- Report statistics as required to the Scottish Government for their Carer Census so that they can track the impact of the Carers (Scotland) Act (see section on Carer Census)

What Information is Collected

The Appendix shows what information we collect. Whilst some information is generic to the organisation, other details are collected and used only within certain services.

We will ask for your consent before storing any information about you and you can change your consent at any time.

How is this Information Stored & Safeguarded

It is important to us that we reassure you that all information is held securely.

We restrict access to personal information to Carers Link employees. Some volunteers also have limited access to information if they are involved in delivering a service to you.

Staff and volunteers are trained to respect your privacy; not to misuse confidential information or to carelessly care for confidential information.

Since 2018, Carers Link has used a cloud-based database as a central location for all information stored. It requires the unique database name plus 2 additional passwords to access the encrypted information. There are different levels of access between staff and volunteers.

Prior to 2018, Carers Link used a password-protected database stored on our own servers, also with different levels of access. You also required a password to access the server. We also maintained computer 'support records' which summarised our communications with you. Access to these records has always been limited but as of April 2018, only the Data Controllers and Operational Manager (Paul Peter) will have access.

Information collected from paper forms is either scanned and saved onto our secure server or transcribed into the database. We endeavour not to keep paper copies. Examples of physical safeguards when we do keep paper files include locks on doors, cupboards and filing cabinets.

Please read below about how we destroy your information.

Sharing and Not Sharing Information

Carers Link will **NOT** share information about you to any third party unless we have your permission. This will usually be required if we are advocating on your behalf about an issue or for example about a need for statutory services (e.g. respite or homecare).

Any other shared information will always be anonymous statistical data with the exception of information required for the Carers Census (see below).

Nevertheless there are times when we may have to share your information when we are required by law to do so. Such reasons would be:

- The prevention or detection of crime
- Regarding actual or suspected abuse of a child or any other such concerns about a child's welfare.
- If there are significant or immediate concerns about a risk of harm or injury either to a Carer by themselves, by the person they care for or another individual, or risk of harm or abuse to the person being cared for.

Carers Census

In April 2018, The Carers (Scotland) Act came into force. This Act confers a number of rights for Carers but it also obligates local Carer Centres such as Carers Link to complete a Carers Census.

The annual Carers Census collects information which will be used by the Scottish Government, COSLA, Health and Social Care Partnerships, Local Authorities and other stakeholders such as Carer Centres to

monitor the implementation of the Carers Act. It will help the Scottish Parliament, the Scottish Government, carers' organisations and other stakeholders to understand how the new Act is making a difference to the lives of carers across Scotland.

A Baseline Census was submitted covering data relating to carers who used a service from Carers Link between April 2017-March 2018. This information was completely anonymous and comprised on the number of males/females within 3 age-bands that used a particular types of services or had a Carers Assessment (now called Support Plans or Young Carer Statements).

Future Carer Census submissions will also explore the range of services used and Adult Support Plans/Young Carer Statements. However it also requires us to submit items of personal data – namely your postcode and date of birth. As Local Authorities also submit information for the Carer Census, this information is required to check for duplicates where a carer is known to both Carers Link and East Dunbartonshire Council.

The Scottish Government have informed that:

- There is an exemption in the **UK data protection legislation for collecting data for research and statistical purposes (Article 89(1) of the GDPR)**. Under this exemption it is not necessary to ask consent for collecting data for research and statistical purposes. The sole use the Scottish Government intends to make of carer census data is research and statistical.
- **Only anonymous data** from the carer census will be published by the Scottish Government (Statistics & Registration Service Act 2007).
- The Scottish Government will, as always, be bound by the **statistician's code of conduct**, which stipulates that only those who need to see personal data have access and measures are taken to ensure nobody can be identified from published data (Statistics & Registration Service Act 2007).

If any carer wishes further information or details on the Carers Census, please contact the CEO on jennifer@carerslink.org.uk

Your Right of Access

You have the right to access the information held about you by Carers Link at any time. Carers Link will not charge you to access this information, but does have the right to charge an administrative fee (based on the time and costs involved) if the request is “manifestly unfounded or excessive”, repetitive or for further copies of information already provided.

When requesting your personal information please contact the CEO preferably in writing or by e-mail (jennifer@carerslink.org.uk) including the following information:

- your full name, address and contact telephone number
- any information to identify or distinguish you from others of the same name (e.g. date of birth and postcode);
- details of the specific information you require and any relevant dates

Carers Link will normally respond to any requests within a month but if your request is complex, we will advise if we require further time.

Archiving, Disposal & Your Right to be Forgotten

Under the new GDPR legislation, you have the right to be ‘forgotten’. This right is to enable an individual to request the deletion or removal of personal data where there is no compelling reason for its continued processing, however please be aware that it is not an ‘absolute’ right as there may be legal reasons why your information cannot be scrubbed.

If you would like to invoke your right to be ‘forgotten’, please also contact the CEO preferably in writing or by e-mail (jennifer@carerslink.org.uk) including the following information:

- your full name, address and contact telephone number
- any information to identify or distinguish you from others of the same name (e.g. date of birth and postcode);
- whether all of your information or just specific information (for example in relation to a particular service) requires deletion and any relevant dates

Our database features an ‘Anonymisation’ function accessible that allows the deletion of identifiable data, while leaving statistical details. This would be used in any such requests; however it will also be used as part of our archiving processes.

We are required to up-date our consents every 2 years. Any carer who does not update their consent will be automatically archived. A list of names and ID numbers will however be kept in a secure location – accessed only by the 2 Data Controllers. We are required to keep this record for 5 years. We are required by law to keep a record of our membership, past and present, for as long as the life of the company. However this information contains no more than your name, address and dates of membership. (See Appendix)

Any paper records – or indeed any paperwork that contains a name or any other identifiable information – that require disposal are stored in secure and locked cabinets within the main office. These are then professionally shredded by an external agency on a regular basis.

Your Photographs & Quotes

People like stories and pictures, and they help to tell people what we do, the quality of the service we provide, and the difference that it makes to people. Carers Link therefore endeavour to use words from and images of carers to promote our work.

We will always seek consent before taking any photographs and we will always seek separate written consent before using any photograph or quote in our printed or online publications. These separate consent forms will provide full details of the intended use.

Direct Marketing

Carers Link does not regularly engage in direct marketing. Our contact is usually limited to our What's On Communications, by post or e-mail.

When you first contact Carers Link, we seek your consent to send our What's On Newsletter by either post or by e-mail.

Our What's On newsletter is sent out quarterly and always contains the opportunity to inform us that you no longer wish to receive mailings by either using the Freepost envelope and reply slip provided or by simply telephoning us.

If you have requested the What's On – or other e-bulletin – online, there is the option to update your preferences or to unsubscribe from the list at the bottom of each e-mail sent.

All other updates about events or activities concerning carers or Carers Link are contained within these newsletters or e-bulletins. On the rare occasion that we contact you regarding events or news outwith our standard communications, we will only do so if you have given consent for us to contact you in that way.

***We will only contact you by post, telephone, e-mail or text
if you have given permission for us to do so.***

Online

From April 2018, our websites will use cookies to provide easier navigation around the Site and to gather anonymous analytics information. Cookies are text files placed on your computer to track visitor use of websites, to compile statistical reports on website activity and to enhance the user's experience by customising webpages. They do not contain any user specific information.

You have the right to choose whether or not to accept cookies and to set your own cookie preferences on your computer. All web browsers are different and to learn how to change your cookie preferences, check the "Help" menu of your browser. However if you do so, please note that some parts of the Site may not function properly and you may not be able to use this Site to its fullest.

Policy Review

This Policy will be reviewed annually or as appropriate and in accordance with legislation.

Date	Activity	Date	Activity
April 2004	Policy Created		Choose an item.
December 2008	Reviewed & Updated		Choose an item.
February 2013	Reviewed Only		Choose an item.
March 2014	Reviewed & Updated		Choose an item.
January 2015	Reviewed Only		Choose an item.
June 2015	Reviewed & Updated		Choose an item.
March 2017	Reviewed & Updated		Choose an item.
February 2018	Reviewed & Updated		Choose an item.
August 2018	Reviewed & Updated		Choose an item.
	Choose an item.		Choose an item.

Appendix

- Most carers will fall under areas 1 and 2 below. Any additional activity is dependent on the carer choosing to engage with that service.
- The 2 Data Controllers (see page 2) have access to all information if or as and when required

Service Area	Data Held (where known)	How long is it stored for	Legal Basis	Who has access
1. All Carers	Name & Contact Details Location, Publicity source Communication preferences, Date of first contact, Gender Age Range/Date of Birth Relationship to cared-for Care condition	For length of involvement as a carer and for a maximum of 2 years beyond by which time carers are archived if no further contact, leaving only statistical information	Your consent including verbal consent (GDPR 6(1)a)	Service related staff Assigned Carers Call volunteer if applicable Data Controllers
2. Support & Advocacy	Summary of caring situation. Other agencies involved. Reasons for Care. Nature of caring responsibilities. Impact on Carer's physical and emotional health. Summary of conversations	As above	Your explicit consent by e-mail or by form (GDPR 9(2)a)	Service related staff
3. Carers Call	Summary of conversations	As above	Your explicit consent by e-mail or by form (GDPR 9(2)a)	Assigned Carers Call volunteer Service related staff
4. Groups	Attendance at groups	As above	Your consent & engagement	Service related staff
5. Wellbeing Reviews	Carer's health, lifestyle & wellbeing information and goals/achievements	As above	Your explicit consent by e-mail or by form (GDPR 9(2)a)	Service related staff
6. Training	What's On Reply Slips Pre- Course questionnaires Course Evaluations Course attendances	As above Paper/digital copies are kept for 3-4 months & then shredded or deleted.	Your consent & engagement	Service related staff Admin Volunteer

Service Area	Data Held (where known)	How long is it stored for	Legal Basis	Who has access
7. Emergency Plans	In depth information on both carer and cared-for on a scanned copy of the completed form. The scan is password protected and stored in a limited access folder.	The Emergency Plans are updated at a minimum level on annual basis or more frequently as required. They will be kept for the life of the Care-Aware-Prepare project or as agreed with the carer and reviewed thereafter.	Your explicit consent by e-mail or by form (GDPR 9(2)a)	Service related staff Assigned Volunteer may help complete the form but does not have access thereafter
8. OPAL Helpline	No personal information is stored, only broad nature of enquiry, gender and location	No personal information is stored	Not applicable	Not applicable
9. Membership	Name, address, phone numbers & e-mail (if known), location, communication preferences, dates joined, date of ceased membership	Company registers should be kept for the entire life of the company	Your explicit consent by e-mail or by form (GDPR 6(1)c, 9(2)a and 9(2)d)	Finance Administrator, Events Co-ordinator
10. Carer Census	Gender, Date of Birth, Postcode. Whether an Adult Support Plan or Young Carers Statement has been completed, type of supports.	Within Carers Link as per Service Area 1. above. Within the Scottish Government the pseudonymised Carers Census data will be kept indefinitely because the data is only for statistical and research purposes.	Under exemption for statistical or research purpose in accordance with Article 89(1)	Not applicable