



**Fibromyalgia Action UK**  
Fighting for Freedom from Fibromyalgia

## **PRIVACY POLICY**



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## PRIVACY POLICY

This policy describes how and why Fibromyalgia Action UK uses your personal information, how we protect your privacy when doing so, and your rights and choices regarding this information. We promise to respect any personal data which is under our control and to keep it safe. We aim to be clear when we collect your information about what we will do with it.

We have relationships with fundraisers, volunteers, supporters, groups, and clinicians we may use your personal information. Our use of personal information allows us to make better decisions and fundraise more efficiently. We aim to be clear when we collect your data and not do anything you would not reasonably expect. Here we tell you what we will and will not do with your information. This policy is effective from 25 May 2018.

### Who we are

In this Privacy policy “Fibromyalgia Action UK”, “FMAUK”, “we” or “our” means

1. Fibromyalgia Action UK (registered Charity 1042582) (Company Registration Number SC4920450)

### .This policy includes:

- What personal data we collect and how we use it
- Where we collect information about you from
- How we keep your data safe and who has access
- Keeping your information up to date
- Changes to this Policy



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## How we collect information about you

We collection information in the following ways:

### Information you provide to use directly

You may give us your information in order to sign up for one of our fundraising events, make a donation, purchase our products, register as a volunteer, local support group join our social media networks or otherwise communicate with us.

When you use our website, we collection your personal information using “cookies” (and other tracking methods. There are more details on the cookies and tracking methods we use in our *Cookie Policy*

### Information you provide to use indirectly

Your information may be shared with us by third parties:

- Professional fundraising agencies
- Independent event organisers i.e. Just Giving or Virgin Money Giving
- Volunteering through an agency i.e. Job Centre

We may also receive data about your from companies acting on our behalf who provide us with a payment or delivery service.

You should check any privacy policy provided to you where you give your data to a third party.

### Social Media

Depending on your settings or the privacy policies for social media and messaging services like Twitter, Facebook or Health Unlocked you might give us permission to access information from those services, i.e. Use us in a tag or event photo.

## What personal information we collect and how

We collect, store and use the following kinds of personal information:

- Name
- Contact details – this includes full postal address, telephone number, email address and social media identity
- Date of Birth
- Gender
- Send you correspondence and communicate with you
- We will contact you if you enter your details onto one of our online forms, and you don't 'send' or 'submit' the form, to see if we can help with any problems you may be experiencing with the form or our website.
- We will process your application for a volunteering position or job vacancy
- We will audit or administer our accounts

The quantity and type of information we collect and how we use it depends on why you are providing it.

## Supporting Us

If you are supporting us through fundraising, donation, volunteering, buying something from our online shop, requesting information from us we will usually collect:

Where it is appropriate we may ask for:



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- Information relating to your health (for example, if you are taking part in a high-risk event)
- Your motivation for giving, including whether this relates to your personal experience of fibromyalgia. We will never make this question mandatory, and only want to know the answer if you are comfortable telling us.

We will mainly use your data to:

- Provide you with the services, products or information you asked for
- Administer your donation or support your fundraising, including processing gift aid
- Manage your marketing preferences
- Understand how we can improve our services, products or information.
- Keep a record of your relationship with us.

### Online shop

If you buy a product from our shop, we will use the information you provide to complete your order. We will also use your details to ask you to complete a feedback survey via a survey agent about the products you've bought. We need to share your information with our suppliers to do this, but we'll keep your data safe while we're doing this.

### Your rights

- Under UK data protection law, you have rights over personal information that we hold on you
- lawful basis for processing the information is consent or for the performances of a contract
- Carrying out the process of automated means
- Right not to be subject to automated decision-making including profiling

### Direct Marketing

With your consent, we will contact you to let you know about the progress we are making and to ask for financial and non-financial support. We make it easy for you to tell us how you want us to communicate, in a way that suits you. We operate an 'opt-in only' Our forms have clear marketing preference questions and we include information on how to opt out when we send you marketing. If you do not want to hear from us, that's fine. Just tell us so when you provide your data or contact us on **0141 255 1570** or [head.office@fmauk.org](mailto:head.office@fmauk.org)

We do not sell or share personal details to third parties for the purposes of marketing. But, if we run an event in partnership with another named organisation your details may need to be shared. We will be very clear what will happen to your data when you register

We will always give you the option of 'opt-out' of our mailing list activities postal or email.

### Events and Fundraising

When you have asked for details of

When you have signed up for an event with a 3<sup>rd</sup> party (i.e. Great Run) and told the event organisers that you wish to fundraise for us, we may contact you with information and support for your fundraising for that event.



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## Case studies

Some people agree to share their fibromyalgia story with us to help us in our work and to help other people who may have similar experiences. This may involve you providing us with more detailed information about your health, background, ethnicity and fibromyalgia story. We're always really grateful when people agree to get involved in our work in this way and we'll always ask you for your consent to use this information so that you stay in control of how this information is used.

## Sharing your Story

Some people choose to tell us about their experiences with fibromyalgia to help further our work. They may take on a role as a volunteer or case study. This may include them sharing sensitive information relating to their health and family life in addition to their biographical and contact information.

If we have the explicit and informed consent of the individuals, or their parent or guardian if they are under 18, this information may be made public by us at events, in materials promoting our campaigning and fundraising work, or in documents such as our reports.

With your consent, we may share your story for example fundraising event, personal story on our website or through social media.

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## Where we Collect Information About You

We collect information about you when you give it to us directly or indirectly

You may give us your information to sign up for one of our events, tell us your story, make a donation, purchase our product or communicate with us.

We may also receive information about you from 3<sup>rd</sup> parties that we work with for example Just Giving where you have consented to them sending us information. These 3<sup>rd</sup> parties will only share your information with us when you have indicated that you wish to support Fibromyalgia Action UK and with your consent. You should check their Privacy Policy when you provide your information to understand fully how they will process your data.

## How We Keep Your Data Safe and Who Has Access

We ensure that there are appropriate technical controls in place to protect your personal details; example where transaction are places through ourselves or 3<sup>rd</sup> party websites we ensure that they are always encrypted and our network is protected and routinely monitored.

We undertake regular reviews of who has access to information that we hold to ensure that your information is only accessible by appropriately trained staff and volunteers.

We may need to disclose your details if required to the police, regulatory bodies or legal advisors. We will only ever share your data in other circumstances if we have your explicit and informed consent.

## How long will we keep your information for?

Fibromyalgia Action UK we determine how long we will retain your information for, retention periods are governed by law, in other cases it is best practice. i.e. we are required to keep some



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personal information for tax purposes i.e. Gift aid as well as keeping a record of your interactions with us:

	Years held
Fundraising and events information	2 years for change of address 6 years for best practices consent to direct marketing
Fundraising sponsor forms	6 years from end of fiscal year – compliance with Finance Act 1988
Compliance with data protection law and privacy law correspondence about donations	6 years from the end of the fiscal year
Gift Aid claims	6 years from end of fiscal year 6 years - HMRC inspections/Limitations Act 1980 Gift Aid
Gift Aid Declaration	
Donations	6 years from end of fiscal year in which the last payment under the declaration was made. Compliance with Finance Act 1988
Application forms and interview notes (for unsuccessful candidates)	Six months to 1 year – Equality Act 2010 – (one year limitation for defamation actions under Limitations Act)
Personnel files and training record	Maximum 6 years after the employment ceased
Records relating to working time	2 years after creation demonstration compliance with Work Time Regulations
Complaints	Hold for 6 years
Organisational Chart	Permanently
Expense records	Six years plus the current fiscal year – Taxes Management Act
Insurance Policies	Three years after lapse – Data Protection Act 2018
Health and Safety Records	Three years
Accident Reports and relevant correspondence	Three years from settlement – Data Protection Act 2018
Contract with customers, suppliers or agents, licensing agreement, rental/hire purchase agreements, indemnities and guarantees and other agreements or contracts	Six years after expiry or termination of the contract. If the contract is executed as a deed, the limitation period is twelve years. – Limitation Act 1980

### When we Collect, It Using Our Website

Like most websites, we use “cookies”, to help us make our site, and the way you use it better. Cookies mean that a website will remember you and your preferences. They’re small text files that sites transfer to your computer (or phone or tablet). They make interacting with a website faster and easier – for example by automatically filling your name and address in text fields.

### Keeping Your Information Up to Date

We use our best endeavours to keep your details up to date and accurate. We appreciate it if you let us know if your contact details change.





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## Legal basis for processing

Data protection law means that ... The relevant legal bases are set out in the General Data Protection – EU Regulation 2016/679 and in current UK data protection legislation.

**Specific Consent** is where you have given us information in a certain way, and you agree to this i.e. promotional/fundraising information sent by post, text or email. Where we use your information for a purpose based on consent, you have the right to withdraw consent for any future use of your information for this purpose at any time.

## Legal Obligation

We may need to collect, process and disclose personal information to comply with a legal obligation. i.e. Charity Commission, Fundraising Regulator, HMRC we are legally required to hold donor transaction details for Gift Aid or accounting/tax purposes or to use information we collect about you for due diligence or ethical screening purposes.

## Vital Interests

We have a basis to use your personal information where it is necessary for us to protect life or health. For instance, if there were to be an emergency impacting individuals at one of our events, or a safeguarding issue which required us to contact people unexpectedly or share their information with emergency services.

## Performance of a contract

If you purchase something from our online shop, work or volunteer for us, we need to be able to process your information for the purpose of meeting our contractual obligation.

## Legitimate Interest

In certain circumstances, we collect and use your personal information by relying on the legitimate interest legal basis. Our “legitimate interests” means our interest in being able to run “Fibromyalgia Action UK” as a charitable entity effectively in pursuit of our aims. This includes;

- Marketing material to supporters by post for fundraising purposes
- Conducting research to better understand who our supporters are and better target our fundraising activity.
- Processing donations
- Use of personal information to administer, review and keep an internal record of the people we work with, including supporters, volunteers and researchers
- Staff recruitment and taking applications for volunteers and contacting volunteers about their role
- Where you have signed up with us on charity place for a third party event i.e. sponsored event not organised by Fibromyalgia Action UK. Sharing personal information with the third party event organiser so they can administer the event
- We only rely on legitimate interests where we consider that any potential impact on you positive or negative, how intrusive it is from a privacy perspective and your rights under data protection laws do not over-ride our or others interests in us using your information in this way.



## Your rights

**Rights to be informed** – you have the right to be informed about the collection and use of your personal data. This is a key transparency requirement under GDPR

### Rights to access your personal information

You have a right to ask us to confirm whether we are processing information about you, and to request access to this information. If you wish to access your information, send a description of the information you want to see by post to address or email. (contact details at end of document)

### Right to rectification

You have the right to require us to rectify information about you this is inaccurate, and you may also ask us to remove information which is inaccurate or complete information which is incomplete. If you inform us that your personal data is inaccurate, we will inform relevant third parties with whom we have shared your data so they may update their own records.

We want to ensure that your personal information is accurate and up to date. If any of the information that you have provided us changes, i.e. Changes of address, name, phone number etc. let us know by email or telephone us. We will update your details as soon as possible and within one month. We may refuse a request for rectification in certain circumstances such as where we need to keep an audit trail.

### Right to erasure

You may ask us to delete some or all of your personal information and in certain cases, and subject to certain exceptions, you have the right for this to be done. We will respond to a right to be forgotten request within 1 month.

### Right to restrict processing

You have a right to ask us to restrict our processing of your information ('right to restriction') if:

- You contest to the accuracy of your personal data, we will restrict the processing until you have verified the accuracy of the personal data;
- Processing is unlawful and you ask us to restrict use of it instead of erasing it
- No longer need the information for processing, but you need it to establish or defend legal claims
- You have objected to the processing of your information being necessary for the performance of a public interest task or purpose of legitimate interests. The restriction would apply while we carry out a balancing act between your rights and our legitimate interests.

This is an alternative right to the right to be forgotten and it is not absolute right. If we refuse a request for restriction, we will explain why. We will respond to requests for restriction within one calendar month.

### Right to object

- You have the right to object to processing based on legitimate interest or performance of a task in the public interest/exercise of official authority (including profiling)
- Direct marketing (including profiling)



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- Processing for purposes of scientific, statistical or historical research.
- We must comply with any request to stop processing for the purposes of direct marketing. The right to object is not absolute in relation to processing for legitimate interests and research purposes.

### Right of data portability

You have the right to obtain and reuse your personal information for your own purpose, without hindering the usability of the data. This includes the right to require us to pass on the information we obtained from you to another data controller. The right applies when we process your data with consent, pursuant to a contract and we are carrying out processing by automated means.

### Rights related to automated decision making including profiling

You have the right not to be subject to a decision based solely on automated processing, including profiling, where this has a legal or similar effect on you. If we carry out profiling that does not meet this definition, we can continue to carry out profiling if we comply with General Data Protection Regulation.

## Complaints

If you are unhappy with any aspect of how we are using your personal information we would like to hear from you. [www.fmauk.org/complaints](http://www.fmauk.org/complaints) policy. We appreciate this feedback and we can learn and improve.

## Changes to Policy

We may change Privacy Policy from time to time. If may make any significant changes in the way we treat your personal information we will make this clear on Fibromyalgia Action UK or by contacting, you directly.

### Contact us

If you have any questions, queries or comments, please contact us on:

Telephone No: 0141-255-1570

Email: [head.office@fmauk.org](mailto:head.office@fmauk.org)

Post: Fibromyalgia Action UK  
Suite 3007  
Mile End Mill  
Abbeymill Business Centre  
12 Seedhill Road  
PAISLEY  
Renfrewshire  
SCOTLAND  
PA1 1JS