



Fibro Active

CONSTITUTION

1. NAME

The name of the organisation is **Fibro Active**.

2. AIMS

The aims of the Group shall be to:

- Provide support for sufferers of Fibromyalgia (FM) and Chronic Fatigue Syndrome (CFS) and their carers; and
- Remain a positive and inclusive group that focuses on healthy lifestyles, light exercise, support and sharing information as well as educating members about their condition and helping them move forward with the acceptance and management of illness.

3. POWERS

To further these aims the committee shall have power to:

- Obtain, collect and receive money or funds by way of contributions, donations, grants and any other lawful method towards the aims of the Group;
- Associate local authorities, voluntary organisations and the residents of Erewash in a common effort to carry out the aims of the Group; and
- Do all such lawful things as will further the aims of the Group.

4. MEMBERSHIP

- a. Membership of the group shall be open to any person aged 18 years or over, living or located in the Erewash area, who is willing to abide by the constitution and is interested in helping the group to achieve its aims, and willing to pay any subscription agreed by the Management Committee. Members from outside the Erewash area are also welcome however they will not be able to access further facilities and health classes offered by Erewash Borough Council.

- b. Membership shall be available to anyone without regard to age, gender, race, nationality, disability, sexual preference, religion or belief.
- c. Every individual full member shall have the right to attend the Annual General Meetings, at which they shall be entitled to one vote.
- d. The Management Committee shall have the power to approve or reject applications for membership or to terminate the membership of any member provided that the member shall have the right to be heard by the committee before a final decision is made.
- e. Members attending weekly group meetings will pay £2.00 each week to cover the costs of the group. Members will be expected to pay an additional fee to be determined by the Management Committee for trips, craft supplies and other activities incurring additional cost to the Group.
- f. In line with lockdown limitations pre-payment method will be instated to ensure places are booked when able to meet face to face. A charge of £10 a month by standing order or one-off payment of £90 to access weekly programme meetings or £25 one off payment for 11 monthly programme meetings.
- g. Meetings will also be live streamed on Zoom. A charge of £10 a month by standing order to access weekly programme meetings or £25 a year one off payment for 11 monthly programme meetings.
- h. Membership will begin as soon as a consent form has been submitted. Membership is life time or until the member wishes to leave the group, except where clause d above is applicable.
- i. A list of all members will be kept by the membership secretary, taking account of the principles of the EU General Data Protection Regulation (GDPR).

5. MANAGEMENT & COMMITTEE MEETINGS

- a. A Management Committee elected annually at the Annual General meeting shall manage the group.
- b. The committee shall consist of a chair, secretary, treasurer, and at least one other voting member.
- c. The committee may co-opt up to a further 4 voting members who shall stand down at the next Annual General Meeting.
- d. The committee shall meet monthly. Committee members will receive dates for the year ahead at each AGM. Venues, dates and times for each meeting will be confirmed at least 1 week prior to each meeting.

- e. At least 3 committee members must be present at a committee meeting to be able to make decisions.
- f. Voting at Management Committee meetings shall be by a show of hands. If there is a tied vote, then the Chair shall have a second vote.
- g. The Management Committee may, for a good and proper reason, remove any Committee member, provided the member has the right to be heard prior to a final decision being made.
- h. Any Committee member not attending a meeting for three months without apology will be contacted by the Committee Chair to ascertain their circumstances with a view to determining whether they must resign.
- i. A proper record of all transactions and meetings shall be kept.

6. DUTIES OF THE OFFICERS

The duties of the Chair are to:

- Chair meetings of the Committee and the Group;
- Represent the Group at functions/events/meetings that the Group has been invited to; and
- Act as a spokesperson of the group when necessary.

The duties of the Secretary are to:

- Take and keep minutes of meetings;
- Prepare the agenda for meetings of the Committee and the Group in consultation with the Chair;
- Maintain the membership list;
- Deal with correspondence; and
- Collect and circulate any relevant information within the Group.

The duties of the Treasurer are to:

- Supervise the financial affairs of the Group;
- Keep proper accounts that show all monies collected and paid out by the Group; and
- Make regular reports to the Committee on the financial status of the organisation.

7. MEETINGS

- a. An **Annual General Meeting** (AGM) shall be held within 15 months of the date of the adoption of this constitution and each year thereafter.

- b. Notices of the AGM shall be published two weeks beforehand and a report on the Group's financial position for the previous year will be made available at the same time. The quorum for the AGM shall be 6 members.
- c. The business of the AGM will include:
 - Receipt of a report from the Chair on the group's activities over the preceding year;
 - Receipt of a report from the Treasurer on the finances of the group;
 - Election of the Management Committee; and
 - Consideration of any other matters as may be decided to be appropriate.
- d. A **Special General Meeting** may be called at any time at the request of the Committee, or not less than one quarter of the membership by written request to the Chair or Secretary stating the reason for their request. The meeting will take place within 21 days of the request and the Secretary shall give all members 14 days' notice of the meeting date, time, venue and the business to be discussed. All members shall be entitled to attend and vote. The quorum for the meeting shall be 10% of the membership or 10 members, whichever is the greater number.

8. AMENDMENTS TO THE CONSTITUTION

Proposals to change the constitution must be given in writing to the Secretary at least 28 days before a general meeting and approved by a two thirds majority of those present and voting.

9. ACCOUNTS

- a. The funds of the group including all donations, contributions and bequests, shall be paid into an account operated by the management committee. All cheques drawn on the account must be signed by at least two unrelated members of the Management Committee.
- b. The funds belonging to the group shall be applied only to further the aims of the group.
- c. A current record of all income, funding and expenditure will be kept.

10. DISSOLUTION

- a. The Group may be dissolved by a resolution passed by a simple two-thirds majority of those present and voting at a Special General Meeting.
- b. If confirmed, the committee shall distribute any assets remaining after the payment of all bills to other local (Erewash) charitable group(s) or organisation(s) having aims similar to Fibro Active.

Signed by Chair: *J Barker*

Date: 15/01/2019

Signed by Secretary: *J Barker & LJ Gordon*

Date: 15/01/2019

Signed by Treasurer: *LJ Gordon*

Date: 15/01/2019



Fibro Active Group Policies

- 1. Equal Opportunities**
- 2. Health and Safety Policy**
- 3. Safeguarding Adults Policy and Procedure**
- 4. Social Media Policy**
- 5. GDPR**

FIBRO ACTIVE: EQUAL OPPORTUNITIES POLICY

1. STATEMENT OF INTENT

Fibro Active has as its central value a belief in equal opportunities. We recognise that many groups and individuals within society have been and continue to be discriminated against, both directly and indirectly, on the grounds of, for example, their race, nationality, ethnic or cultural origins, gender, age, disability, sexual orientation, gender reassignment, religion, political belief, social class, employment status, low income, mental health, marital/civil partnership status, HIV/AIDS status, appearance, refugee status, caring responsibilities and unrelated criminal conviction. (This list is not in any order of priority.)

We also recognise that passive policies are inadequate as a means of combating discrimination. We are therefore committed to taking positive action to address barriers experienced by people who are discriminated against in the above ways.

We will demonstrate this commitment to equal opportunities by:

- working in an anti-discriminatory manner;
- requiring committee members and volunteers to promote and act on this policy;
- requiring our members, service users, hirers and any other users to respect this policy;
- recognising our responsibilities under all relevant anti-discriminatory legislation, including the Human Rights Act (2001);
- following the requirements and guidance of the Equality Act (2010):
- listening to the voices of users and consumers who are experiencing discrimination;
- encouraging co-operation, networking, consultation, participation and negotiation between voluntary and statutory agencies in a way which promotes equal opportunities.

2. SERVICES

Our services are available to all members of the community who suffer with Fibromyalgia and Chronic Fatigue Syndrome. We are also committed to prioritising our services and targeting our resources and being responsive to communities and groups in greatest need and/or facing discrimination. Services are designed and publicised to reflect these commitments and are monitored

accordingly. As far as possible and reasonable given its resources, *Fibro Active* will endeavour to provide its services in ways and in premises which are accessible to the communities it seeks to serve.

3. MONITORING SERVICE PROVISION

Services and groups worked with will be periodically monitored.

4. PUBLICITY

In publicity and information materials, we will try to:

- avoid jargon and use clear, direct language;
- use positive images of a wide range of groups;
- reach all sections of the community by advertising in a wide range of appropriate publications and locations.

Date Policy Adopted: 27th September 2016

Policy Review Date: 27th September 2018

Next Policy Review Date: 15th January 2022

Fibro Active: Health and Safety Policy

1. STATEMENT OF INTENT

The policy of Fibro Active is to provide and maintain safe and healthy working conditions and environment for all our volunteers and users, plus any other people who are directly affected by our activities, such as members of the public at our events.

2. RESPONSIBILITY

Overall and final responsibility for health and safety at all events and activities organised by Fibro Active lies with the management committee. This responsibility will be delegated to a named volunteer for each event or activity. This volunteer will be responsible for ensuring that this policy is upheld.

For our monthly management committee meetings, the responsible person is: **Julie Barker**

For all other events the responsible person will be named in advance and their name will be noted on all relevant risk assessments. All volunteers involved will be made aware of who is responsible for health and safety.

3. GENERAL ARRANGEMENTS

- The main activity of Fibro Active is to organise social activities and support for the members. A risk assessment will be carried out before every one-off event. This will include assessing risk as it relates to all aspects of the event including: equipment; venue; volunteers; attendees. Appropriate precautions will be taken to minimise hazards at all events and activities.
- Fibro Active may also run regular events at the same venue or using the same equipment, such as our monthly committee meetings. In this case we will carry out a general risk assessment for the event/activity/equipment/venue. All general risk assessments will be reviewed at least once a year.
- We will have a trained first aider present at all events which are open to the public.
- We will make sure all volunteers and staff at events and activities are aware of the location of fire exits.
- All volunteers and staff will be made aware of the precautions they need to take as noted on the relevant risk assessment.
- No volunteer or employee will run an event or activity on their own, and at least two volunteers or employees should stay at an event until it is finished and the last attendees have left.
- Fibro Active will hold Public Liability Insurance

Review

This policy will be reviewed every year

Date: 15/01/2019

Signature (Chair) *J Barker*

Signature (Secretary) *J Barker & LJ Gordon*

ADULT SAFEGUARDING POLICY AND PROCEDURE

INTRODUCTION

Fibro Active aims to create an atmosphere where all adults feel valued and safe and a place where their welfare is promoted.

This policy sets out the procedures for safeguarding adults working with Fibro Active staff, board members or volunteers.

This Policy replaces the previous **Fibro Active** policy “Protection of Vulnerable Adults” and is compliant with the Care Act 2014. Fibro Active staff, board and volunteers are expected to be aware of Derbyshire and Derby Safeguarding Adults Policy and Procedures May 2015 which can be found at the following link:

http://www.saferderbyshire.gov.uk/images/Safeguarding%20Adults%20%20Policy%20and%20Procedures%202015%20Final%20Version_tcm46-206136.pdf

SIX KEY PRINCIPLES UNDERPIN ALL ADULT SAFEGUARDING WORK:

- **Empowerment**
People being supported and encouraged to make their own decisions and have informed consent
- **Prevention**
It is better to take action before harm occurs
- **Proportionality**
The least intrusive response appropriate to the risk presented
- **Protection**
Support and representation for those in greatest need
- **Partnership**
Local solutions through services working with their communities.
Communities have a part to play in preventing, detecting and reporting neglect and abuse
- **Accountability**
Accountability and transparency in delivering safeguarding

SAFEGUARDING ADULT'S CRITERIA

The safeguarding duties apply to an adult who:

- Has needs for care and support (whether or not Fibro Active is meeting any of those needs)
- Is experiencing, or at risk of, abuse or neglect
- As a result of those care and support needs is unable to protect themselves from either the risk of, or the experience of abuse or neglect.

Although Fibro Active is not a member of the Derbyshire & Derby Safeguarding Adults Boards (SAB) it agrees to comply with the Derbyshire & Derby Safeguarding Adults Policy, Procedures, Statutory Guidance and local Practice Guidance and be clear on their roles and Adults Safeguarding responsibilities

Any concerns will be taken seriously and acted upon appropriately and the organisation will pay attention to what adults feel.

Fibro Active will be rigorous and vigilant in protecting everyone using our services from abuse, bullying and intimidation. Fibro Active will do this through a careful recruitment and selection process, ongoing supervision and monitoring arrangements and guidance on appropriate behaviour.

Everyone involved in Fibro Active is obliged to make sure that anyone using the services is safe.

They must report concerns to the Chair Person without delay.

All those involved in the organisation will be made aware of this policy and of what to do if they have any concerns. There is guidance for those responsible for responding to concerns so that they are properly dealt with.

EQUALITY & DIVERSITY

These Policy & Procedures recognises the diversity of our society. Individuals and organisations need to be responsive to needs of different groups and individuals and have due regard to issues relating to:

- Gender
- Religion
- Sexual orientation (Gay, Lesbian, Bisexual & Transgender)
- Racial origin, culture and linguistic background
- Disability
- Age

Within safeguarding procedures actual or potential effects of decisions should be considered in relation to the equality issues above and any subsequent outcomes for the adults at risk. Further information on the Equality Act 2010 can be found here: <https://www.gov.uk/equality-act-2010-guidance>

DEFINITION OF ABUSE

Abuse is a violation of an individual's human or civil rights, by any other person or persons. Professionals should not limit their view of what constitutes abuse or neglect, as they can take many forms and the circumstances of the individual case should always be considered. The following types of abuse and neglect are identified within the Care Act 2014, but should not be considered exhaustive;

Physical abuse – including assault, hitting, slapping, pushing, kicking, misuse of medication, restraint or inappropriate physical sanctions.

Domestic abuse – An incident or pattern of incidents of controlling, coercive or threatening behaviour, violence or abuse by someone who is or has been an intimate partner or family member regardless of gender or sexuality. Includes psychological, physical, sexual, financial, emotional abuse, so called 'honour' based violence, Female Genital Mutilation and Forced Marriage.

Sexual abuse – including rape, indecent exposure, sexual harassment, inappropriate looking or touching, sexual teasing or innuendo, sexual photography, subjection to pornography or witnessing sexual acts, indecent exposure and sexual assault or sexual acts to which the adult has not consented or was pressured into consenting. **Sexual exploitation**- involves exploitative situations and relationships where people receive 'something' (e.g. accommodation, alcohol, affection, money) as a result of performing, or others performing on them, sexual activities.

Psychological abuse – including emotional abuse, threats of harm or abandonment, deprivation of contact, humiliation, blaming, controlling, intimidation, coercion, harassment, verbal abuse, cyber bullying, isolation or unreasonable and unjustified withdrawal of services or supportive networks.

Financial or material abuse – including theft, fraud, internet scamming, coercion in relation to an adult's financial affairs or arrangements, including in connection with wills, property, inheritance or financial transactions, or the misuse or misappropriation of property, possessions or benefits.

Modern slavery – encompasses slavery, human trafficking, forced labour and domestic servitude. Traffickers and slave masters use whatever means they have at their disposal to coerce, deceive and force individuals into a life of abuse, servitude and inhumane treatment.

Discriminatory abuse – including forms of harassment, slurs or similar treatment; because of race, gender and gender identity, age, disability, sexual orientation or religion.

Organisational abuse– including neglect and poor care practice within an institution or specific care setting such as a hospital or care home, for example, or in relation to care provided in one's own home. This may range from one off incidents to on-going ill-treatment. It can be through neglect or poor professional practice as a result of the structure, policies, processes and practices within an organisation.

Neglect and acts of omission – including ignoring medical, emotional or physical care needs, failure to provide access to appropriate health, care and support or educational services, the withholding of the necessities of life, such as medication, adequate nutrition and heating

Self-neglect – this covers a wide range of behaviour neglecting to care for one's personal hygiene, health or surroundings and includes behaviour such as hoarding.

CRIMINAL OFFENCES

Some instances of abuse will constitute a criminal offence. In these cases, reference to the police should be made as a matter of urgency. The responsibility for initiating action rests with the police and the Crown Prosecution Service.

- Criminal investigation by the police takes priority over all other lines of enquiry.

Who are the Abusers?

Adults may be abused by a wide range of people including:

- Relatives and family members
- Professional staff
- Paid care workers
- Volunteers
- Other service users
- Neighbours, friends and associates
- People who deliberately target vulnerable people
- Strangers

PROCEDURES FOR DEALING WITH BREACHES OF THE POLICY

In the case of paid staff, a serious breach of this policy may be grounds for disciplinary action.

In the case of members (including trustees), a serious breach of this policy may result in termination of membership and removal from the Board, in line with the procedures contained within the Memorandum of Agreement and Articles of Association (which includes calling a Special General Meeting).

In the case of honorary officers, a serious breach of this policy may result in the other Board members voting to remove them from office, but they cannot be removed from the Board other than by calling a Special General Meeting, as above.

SAFE WORKING ARRANGEMENTS

The **Senior Officer** will be the lead officer for adult protection responsible for making sure that the Safeguarding Adults Policy is working. She/he will be trained to know how to respond when safeguarding adult concerns are raised to him/her.

All relevant staff will receive training in recognising the signs of abuse. Fibro Active will ensure that users of the service, their families and carers are aware of the Safeguarding Adults Policy and who to speak to if they have any concerns and the procedures to follow.

Fibro Active will develop appropriate guidance for staff working with adults, which outline codes of behaviour. These will be developed on a group-by-group basis taking into account the needs of the particular group.

Responsibility for implementing and monitoring the policy rests with the Board.

All work with adults will be monitored in accordance with the organisation's monitoring and evaluation procedures which are:

- the Board receiving regular reports from its recruitment panels, sub-groups and staff.
- all staff receiving line management which includes monitoring the equal opportunities aspects of their work;
- specific surveys are carried out from time to time in communities experiencing deprivation;
- the results of any monitoring and evaluation exercises are fed into priorities for work and future funding.

GUIDELINES FOR THE LEAD OFFICER

The Lead Officer should:

- know about signs and symptoms of abuse;
- know about how abusers (perpetrators) behave; Ask about training if you don't know these things
- know about Derbyshire & Derby Safeguarding Adults Boards' guidelines on dealing with concerns about abuse;
- know who to contact at the Derbyshire Safeguarding Adult Board so that he/she can either ask for advice when they are not sure what to do or, refer a case without delay where there are adult safeguarding concerns; Referrals to Derbyshire County Council will be made by telephone in the first instance, via Call Derbyshire on 01629 533190 (08456 058 058) or minicom on 01629 585400 during the hours of 08.00 and 20.00 Monday to

Friday. Outside of these hours calls should be made to the Out of Hours Team on 01629 532600. The safeguarding adults referral form is available at [http://www.saferderbyshire.gov.uk/what we do/safeguarding adults/default.asp](http://www.saferderbyshire.gov.uk/what_we_do/safeguarding_adults/default.asp)

- Make sure that adults using Fibro Active know;
 - about the Safeguarding Adults policy and procedures,
 - that you are the person to speak to if they have any concerns,
 - who to speak to if you are not there,
 - make sure staff and volunteers know how to respond if an adult talk to them about abuse,
 - make sure they have access to guidelines;
- provide information about help lines and other sources of help for adults.

GUIDANCE FOR WORKERS ON ACTION TO BE TAKEN

If you suspect an adult is being abused:

- immediately discuss with the lead officer
- record the facts as you know them

If an adult discloses abuse by someone else:

- allow them to speak without interruption, accepting what is said
- advise that you will offer support where possible, but you must pass the information on
- discuss with the lead officer

If you receive an allegation about any adult or about yourself:

- immediately discuss with the lead officer
- record the facts as you know them
- try to ensure no-one is placed in a position which could cause further compromise

GUIDELINES FOR PROJECT WORKERS/VOLUNTEER: RESPONDING TO A REPORT OF ABUSE FROM AN ADULT

Do's and Don'ts

DO

- Do treat any allegations extremely seriously and act at all times towards the adult as if you believe what they are saying.
- Do tell the adult they are right to tell you.
- Do reassure them that they are not to blame.
- Do be honest about your own position, who you have to tell and why

- Do tell the adult what you are doing and when and keep them up to date with what is happening.
- Do take further action – you may be the only person in a position to prevent future abuse – tell your lead officer immediately.
- Do write down everything said and what was done (see notes on recording).

DON'T

- Don't make promises you can't keep.
- Don't interrogate the adult – it is not your job to carry out an investigation – this will be up to the police and Derbyshire Safeguarding Adults Board, who have experience in this.
- Don't cast doubt on what the adult has told you, don't interrupt or change the subject.
- Don't say anything that makes the adult feel responsible for the abuse.
- Don't do nothing – make sure you tell your lead officer immediately – they will know how to follow this up and where to go for further advice

Fear puts a lot of people off telling others about wrongdoing.

Remember, you always have a duty to make sure concerns are reported. Then appropriate action can be taken.

Tell the Lead Officer in Fibro Active. S/he will be able to get further advice and/or refer the situation to Derbyshire Safeguarding Adults Board.

If for any reason you cannot tell the Lead Officer, then you should tell the most senior person on duty.

KEEPING A RECORD OF CONCERNS

When a safeguarding adult concern arises, it is essential you record what is said or seen and what action was taken.

This record or any other written record should be kept in a locked cabinet or drawer. Access should be limited to only:

- the person who has completed the form;
- the Lead Officer;
- the Chair of Fibro Active if the person complained about is the Lead Officer

The adult concerned can be shown this document, but discretion should be used. Their permission should be obtained before showing to the family/carer.

REVIEWED: 27th September 2018
Next review by: 15th January 2022

SOCIAL MEDIA POLICY

The purpose of the Facebook group is for people with Fibromyalgia and/or ME/CFS (and/or their carers) to interact and support each other while living with these chronic illnesses.

The Facebook group is the centre hub of communication of Fibro Active. It provides a positive place where people can share helpful tips, ask questions and learn from each other's experiences, band together and support each other to create better lives for ourselves and others.

The membership of the group is predominantly local to Erewash, Derbyshire/ Nottinghamshire England, however we do have one or two members globally. Should you wish to join our group, you will be asked to answer three relevant questions regarding your request. Once these questions have been answered we can consider your application; any applications made without answering the questions will be removed after 7 days.

ADMINISTRATORS

The site is monitored by Administrators who will ensure the group stays positive and inclusive. However, from time to time there may be a member who may need further support. Do not be offended if we delete posts that may be linked with messages of support. We follow our Safeguarding Policy as above.

If you have a question and no one has answered it, do not be offended. It just may be that no one knows the answer. If this is the case, you may want to search google. Admin need their rest too. Please do not instant message admin between 9pm and 9am unless it is an emergency.

RULES AND GUIDELINES

1. Each member is expected to know and follow all group rules whether that member has clicked 'Like' or not. The site is monitored by Administrators. Failure to comply with these group rules can and will result in the removal by the Administrators of violating posts and potentially the removal of offending member/s from the Fibro Active Support Group. If a member is found to be a hindrance to the group, then they will be banned from the group. This is to ensure a safe and comfortable environment for all members.

2. Please be respectful at all times. If you comment please do so kindly, and in a constructive way, especially if you do not agree with another member. No swearing or use of foul language.

3. This is a local group to Erewash Derbyshire UK. However, we welcome any sufferer or carer who is in search of support and advice.

4. This is a friendship and support group NOT an advocacy group. We all want to raise awareness of these illnesses, but this will not be achieved by arguing among ourselves about the name, the proper definition, or the true symptoms. Until such time as there is a definitive scientifically-proven method of distinguishing between CFS and ME the two terms are to be considered as covering one disease. Themes, posts or comments seeking to separate ME from CFS will be removed. Themes, posts or comments which claim that ME/CFS originates from or is a form of another disease must be supported by definitive independently-verified scientific evidence.

5. Political discussions are strongly discouraged. Publishing information about government policies that affect sufferers is of course acceptable but political debating is not. Similarly, religion is a personal matter. We are a diverse group, which means our beliefs systems are also diverse. It is important that we respect each other's beliefs, and that we do not try to force our belief systems on to others. We must ensure this group is a safe and comfortable place for all its members.

6. Bullying, personal attacks or inflammatory antagonistic behaviour will not be tolerated. This will be taken especially seriously in the case of bullying for reasons of religious, racial, or sexual orientation, and will result in a permanent ban from the group. The Administrators may report your conduct to Facebook, who may delete your account. They can also report your actions to the police if the incident is considered serious enough. The person being bullied does not have to be the person reporting it.

7. If a post, comment or member is under investigation by the Admin Team then interim action may be taken while discussions take place. Such discretionary action could include: commenting on the relevant post may be turned off; the comment may be hidden; any members involved may be muted for up to 3 days.

8. This is a CLOSED group. Personal data is a sought-after commodity so please apply the usual internet safety rules. A member must receive permission from the admins before posting any polls, surveys, or links to external polls or surveys, as we have a duty of care to our members. Whilst we will not refuse a reasonable request, we do want to ensure these things are done properly and are suitable and relevant to our members' needs. Occasionally, the Admins may run surveys for fun, or to generate discussion.

9. NO SALES, ADVERTISING and ASKING FOR MONEY.

We take this very seriously and apply the following rules for the protection of all our members. The basic rule is: no selling without Admin approval. Offending posts will be removed; further action may be taken.

9a. No posts inviting members to undertake financial transactions may be posted on the Fibro Active site without prior approval from the Admin

Team. Such posts include SELLING, FUNDRAISING, or SOLICITING FOR MONEY (begging), either directly on the Fibro Active site or by a link to an external source. The advertising or promoting of products, treatments or processes is prohibited unless approval has been obtained from the Admin Team.

9b. We encourage members to ask questions, and it is perfectly acceptable for other members to tell of their personal experience with a particular product, treatment or process but should avoid including in their posts (or replies) links to external sales advertising or promotion sites. Except for personal experience no member shall make claims for products, treatments or processes for which they have no independently-verified scientific evidence.

9c. Any member who repeatedly makes posts about or posts links to a particular organisation or site may be considered to be engaged in advertising or promotion and therefore in breach of rule 9a.

9d. Direct messaging of members or asking people to contact you for more information about products, treatments or processes is not allowed. Information should be either openly shared on site or not shared at all.

10. Any unwanted or inappropriate personal messages received from another member must immediately be reported to the Admin Team (a list of Admins appears at the end of this post). Please notify the admins immediately if you are contacted by a member trying to sell to you or trying to solicit your involvement in an activity outside the group. Do not reply to the message.

11. This is a CLOSED group, and the privacy of the members is vital. No-one is permitted to share anything discussed in the group, OUTSIDE of the group without the permission of the original poster. If you wish to share a link, meme or picture, provided it is not the property of the original poster, and does not identify any member or the group, please save it to your own device first, then repost afresh.

12. Undermining, arguing or disrespecting any Admin may result in an instant ban. Admins' decisions are final and binding on all members. Blocking an Admin is cause for immediate removal from the group as we have to be able to see everyone's posts and message members privately if necessary.

13. IF YOU ARE IN CRISIS! There are support documents in the 'FILES' section under constitution. If you are in a bad way mentally, emotionally or physically, please go to your nearest A&E or a place of safety such as a Police or Fire Station. Members and Admins are not qualified to deal with these situations.

14. We here at the Fibro Active 'Support Group' are not physicians, nor do we claim to be any replacement for your usual physician or care plan. Should you

have questions regarding any medical issues relating to any of the information contained in this 'Support Group', you should obtain medical advice from your own licensed, trained and competent medical provider/s.

15. It is not acceptable that members should advise or ask other members on medication/s dosage to use. This includes supplements.

16. Admin cannot guarantee the authenticity of articles posted by members of the group. While there are many legitimate and informative sites that exist, there are also those that are click-bait, plagiarize authors work and target those with chronic illness to increase readership and advertising revenue. Some may also exist that have malware. These may get shared by accident from time to time by group members. If a member should encounter one of these sites that they know are clickbait please contact admin directly rather than debating it in the group.

Implemented on 31st January 2018

Review date January 15th 2022

Data Protection Policy 2018 (GDPR)

| Contents | Page |
|---|-------------|
| Introduction | 23 |
| Policy Statement | 23 |
| Appendix A - General information Rights of the data subject | 25 |
| Rights of the data subject | 25 |
| The Public Interest Disclosure Act 1998 | 25 |
| The Freedom of Information Act 2000 | 25 |
| The Human Rights Act 1998 | 26 |
| Appendix B – Sensitive Data | 26 |
| Appendix C – Registration | 27 |
| Appendix D – Data Protection Notice | 28 |
| Appendix E – Use of mailing lists | 30 |

Introduction

The General Data Protection Regulation (GDPR) came into effect on 25 May 2018 supersedes the **Data Protection Act 1998** and other **Data protection Regulations**. It sets out basic principles that any data controller must adhere to, that is a person or organisation controlling the use of personal data.

Any person who processes personal data must comply with the eight enforceable principles of good practice; that personal data must be:

- ✦ fairly and lawfully processed;
- ✦ processed for limited purposes;
- ✦ adequate, relevant and not excessive;
- ✦ accurate;
- ✦ not kept longer than necessary;
- ✦ processed in accordance with the Data Subject's rights;
- ✦ kept secure;
- ✦ not transferred abroad without adequate protection.

Personal data covers both facts and opinions about a living individual and can be any type of material including text, photographs, video or audio.

This policy is intended to assist staff in complying with the requirements of General Data Protection Regulation 2018 and its related legislation:

- ✦ the Freedom of Information Act 2000 (FOIA)
- ✦ the Human Rights Act 1998 (HRA)
- ✦ the Public Interest Disclosure Act 1998 (PIDA)

Policy statement

It is the policy of **Fibro Active** that it will hold all personal and sensitive data in accordance with the principles and requirements of GDPR 2018 and other relevant legislation. We will comply with both the law and good practice, respect individuals' rights, be open and honest with individuals whose data is held, provide training and support for staff who handle personal data, so that they can act confidently and consistently and notify the Information Commissioner if the need arises.

All staff are committed to maintaining procedures that will ensure the unbiased processing of data relating to individuals (data subjects) and to raising awareness within the organisation of data protection issues.

Every member of staff and every volunteer is responsible for taking precautions to ensure the security of personal information and to prevent unlawful disclosure. This applies:

- when it is in their possession
- when they are allowing access to it by another person or organisation
- when they are transferring it to another person or organisation.

Information covered by this policy

Personal data means data which relates to a **living individual** who **can be identified**.

Sensitive data is a subset of personal data and is defined as information or opinions about an individual i.e., ethnicity, religion, health information, criminal record etc.

It may take any of the following forms:

- ✦ Computer documents;
- ✦ Data processed by computer or other equipment, for example text, images, video or audio;
- ✦ Information in some forms of structured manual records including photographs.
- ✦ Social Media

Policy detail

- The Data Controller or Resource Coordinator will review this policy for its effectiveness, minimum one year and maximum of three years.
- The Data Controller or Resource Coordinator will advise and consult on all aspects of personal data protection, including disclosure and security.
- This member of staff will regularly perform internal audits of **Fibro Active** information systems to maintain compliance with GDPR. The senior management team will determine the frequency of auditing.
- **Fibro Active** will issue and maintain guidelines on:
 - a) the secure storage of data;
 - b) permissible disclosure of personal data: if **Fibro Active** will disclose, how it will disclose it and how it will make the data subjects aware of this;
 - c) how long the various data records will be retained (Data Retention document); and
 - d) how personal data will be destroyed after the retention period.
- Any person who is engaged in processing personal data will have training in awareness of data protection requirements.
- **Fibro Active** will maintain a separate procedure for handling subject access requests.
- **Fibro Active** will maintain a separate procedure to deal with data subject requests to correct or erase inaccurate data.
- **Fibro Active** will maintain a separate procedure for dealing with employment references, according to the eight data protection principles, specifically that references are adequate, relevant, not excessive and that they are accurate.
- There will be a condition in all **Fibro Active** employment contracts, agreements and job and role descriptions to the effect that individuals must abide by the statements made in this policy.
- Failure by an individual to follow this policy will be dealt with in accordance with internal disciplinary measures.

Fibro Active will issue a standard notice to allow data subjects to opt out of **Fibro Active** using their data.

Appendix A- General information Rights of the data subject

The data subject has the following rights to:

- ✦ access the information that they are the subject of;
- ✦ prevent processing likely to cause damage or distress;
- ✦ take action for compensation if they suffer damage as a result of any breach of the act;
- ✦ take action to rectify or destroy inaccurate data;
- ✦ consent or to withhold consent;
- ✦ opt out of direct marketing;
- ✦ restrict automated decision making;
- ✦ make a request to the Information Commissioner for an assessment to be made as to whether any provision of the Act has been contravened.

On written request from the data subject the data controller is obliged to supply and give the data subject a copy of the data:

- a description of the data;
- the purpose for which it is being held;
- the source of the data;
- details of the person(s) they will or may disclose the data.

The data controller must supply everything held at the time of the application within one month.

The Public Interest Disclosure Act 1998

The Public Interest Disclosure Act 1998 is an act which protects workers who blow the whistle about wrongdoing in the workplace. It mainly takes the form of amendments to the Employment Rights Act 1996, and makes provision about the kinds of disclosures which may be protected, the circumstances in which such disclosures are protected and the persons who may be protected.

Confidences must be respected so far as is possible, with due regard to the individual's rights to privacy under data protection and human rights legislation. However, a person who is under inquiry is entitled to know the nature of the allegations being made and any person criticised as a result of an inquiry has a right to be told the nature of the evidence upon which the criticism has been based.

The Freedom of Information Act 2000

The Freedom of Information Act 2000 is designed to change the default position from the need to know to the right to know. The Act is intended to promote a culture of openness and accountability amongst public authorities by providing people with rights of access to the information held by them. It is expected that these rights will facilitate better public understanding of how public authorities carry out their duties, why they make the decisions they do and how they spend public money.

Section 40 of the Act sets out an exemption from the right to know where the information requested consists of personal data. It can be summarised as follows:

- If the personal data is about the person requesting the information, then there is no right to know under the Freedom of Information Act. However, any such requests automatically become subject access requests under the Data Protection Act and must be treated as such. This means that despite the exemption under the Freedom of Information Act, the applicant has a right to his or her information under the Data Protection Act.
- If the personal data is about someone other than the applicant, there is an exemption if disclosure would breach any of the Data Protection Principles.

The Human Rights Act 1998

The Human Rights Act came into force on 2 October 2000 and incorporates into UK law certain rights and freedoms set out in the European Convention on Human Rights. Article 8 states: "Everyone has the right to respect for his private and family life, his home and his correspondence." The right to privacy also includes the right to have information about individuals, such as official records, photographs, letters, diaries and medical information, kept private and confidential. Unless there is a very good reason, public bodies should not collect or use such information.

Consequently, the principles of Article 8 are reflected in the legislation concerning data protection and the interception of communications.

Appendix B - Sensitive data (Special Category Data)

There is now increased protection for what is termed sensitive data or special category data.

This is information on:

- racial or ethnic origin
- political opinions or membership of a political organisation
- religious and affiliations
- philosophical beliefs
- membership of a professional association or trade union
- physical or mental health condition
- sexual preferences and orientation
- criminal record
- genetic or biometric information

Sensitive data can be processed provided that

- the data subject has given their explicit consent
- it is a legal requirement of the subject's employment
- it is necessary to protect the vital interests of the subject
- is carried out by certain non-profit bodies established for political, philosophical, religious or trade union purposes
- it is necessary for legal proceedings
- it is necessary for medical purposes
- it is necessary for monitoring equal opportunities

- The Secretary of State has given consent
- it is necessary for the prevention or detection of any unlawful act
- it is necessary for the provision of services such as confidential counselling or advice
- it is necessary for insurance or occupational pension scheme contracts

The list is not exhaustive and new categories can be added by way of statutory instrument.

Appendix C – Registration

Registering to process personal information is a statutory requirement and organisations must register with the ICO, unless they are exempt. Failure to register is a criminal offence. Further information on exemption can be found <https://www.gov.uk/notification-to-process-personal-data>

The process of registration will be carried out by the Data Controller and will contain details of:

- name and address;
- similar details for a nominated representative;
- details of the personal data to be processed;
- the relevant categories which are applicable;
- details of the purposes for which the data is being processed;
- description of possible recipients of the data;
- details of the possible transmission of data outside the EEA.

Appendix D – Example Data Protection Notices

The following forms are an example data protection notices, which must be part of any data collection form.

They can be tailored to meet the needs of the data collection form; for example, the signature at the bottom of the form may not be necessary.

Example 1:

Organisation's Name

Logo



Data Protection Notice

Organisation's Name is the data controller for the purposes of processing personal data and complies with the General Data Protection Regulation 2018.

Organisation's Name will hold personal data for the purpose of:

➤ (for example, providing you with requested products or services)

and will keep personal data only for as long as is necessary.

We **will not** provide information about you to other organisations, agencies or groups for marketing purposes. We disclose information about you only with your consent, or if we are required to do so by law.

Organisation's Name will make every effort to ensure that your personal data is kept secure against:

- loss;
- unauthorised access; • disclosure; and
- destruction.

You can request a copy of the details that we hold about you. We may charge a fee of £10.00 if the administration workload is significant. Please use the contact details below.

I confirm that I have read the above Data Protection notice.

Full Name: _____

Signature: _____ Date: _____

For more information on how we collect, use and look after your details please read our updated Privacy Policy - you will need to refer to your organisation's Privacy Policy

Example 2:

Organisation's Name

Logo

Information Sharing Consent Form

Organisation's Name is the data controller for the purposes of processing personal data and complies with the General Data Protection Regulation 2018.

Organisation's Name will hold personal data for the purpose of:
and will keep personal data only for as long as is necessary.

We **will not** provide information about you to other organisations, agencies or groups for marketing purposes. We disclose information about you only with your consent, or if we are required to do so by law.

Organisation's Name will make every effort to ensure that your personal data is kept secure against loss, unauthorised access, disclosure; and destruction.

You can request a copy of the details that we hold about you. We may charge a fee of £10.00 if the administration workload is significant. Please use the contact details below.

•
•

• I hereby give my permission for *Organisation's Name* to share personal information with other i.e. *partner agencies* in connection with I agree to a referral being made to *partner agencies*, in order to *support my needs*. I understand that the partner agencies may hold information about me from *Organisation's Name* and as such my rights under the Data Protection Act 2018 will not be affected.

Statement of Consent:

- I understand that personal information is held about me.
- I have had an opportunity to discuss the implications of sharing/not sharing information about me.
- **I agree that personal information about me may be shared with other partner agencies.**

Are there any specific agencies you do not want us to share or gather additional information with?
Please list them here:

☐

I agree to my information being shared and gathered between agencies.

Your consent to share personal information is entirely voluntary and you may withdraw your consent at any time. Should you have any questions about this process, or wish to withdraw your consent, please contact:

Name:

Address:

..... Post code

Signature Date

For more information on how we collect, use and look after your details please read our updated Privacy Policy - you will need to refer to your organisation's Privacy Policy.

Appendix E - Use of mailing lists

Any data which *Organisation's Name* collects in order to create and maintain a mailing list must comply with the eight data protection principles (see Section 1 - Introduction).

In particular, the data subjects whose personal data will be stored in the mailing list must:

- be made aware that their personal data is held in the mailing list;
- be made aware who is collecting their data
- be made aware for what purpose(s) the mailing data will be used; and
- be given an option to opt in. Once the opt-in has been selected further emails must have an opt out script.

As an example, the following could be used:

You can opt out of having your personal data held by us by ticking this box: ☐

For example, you can provide us with a job title instead of your name, but please consider the implications. It might not be possible to contact you for the above purposes if your name is part of your email address and we have to remove it.

Examples:

Privacy Statement for existing mailing lists where people have already opted in:

- You are receiving this email because you are part of the Network. *Organisation's Name* will never pass your data to a third party and promise to keep it safe and secure. You can change your mind at any time so if you decide you no longer wish to receive emails regarding the Network, please contact For more information on how we collect, use and look after your details please read our updated Privacy Policy.

Privacy Statement for new mailing lists where people have not already opted in:

- Please tick the 'opt in' box ☐ to continue to receive emails. *Organisation's Name* will never pass your data to a third party and promise to keep it safe and secure. You can change your mind at any time so if you decide you no longer wish to receive emails contact us.

Attendance Lists

Where attendance lists are used for meetings or training sessions asking attendees to sign in with their personal details, an additional column should be added asking whether they are willing to be contacted in relation to the meeting or training which they have just attended.

Where possible include the statement below:

**For more information on how we collect, use and look after your details
please read our updated Privacy Policy.**