Complete Guide to Running a Pulmonary Fibrosis Support Group

Contents

An overview

How we can help

At Action for Pulmonary Fibrosis (APF), we're keen to increase the number of support groups, making them accessible to as many people as possible. We actively encourage and help to set up support groups across the UK, although we don't run the groups ourselves.

Come to us for:

- Advice and support from your Regional Support Coordinator
- Policy templates
- APF resources and leaflets
- A grant to get your group up and running
- Regular online meetings with other support group leaders
- Your group to be advertised on our website

This guide will walk you through each step of setting up a support group to help you make important decisions. It's based on the experience of people involved in establishing and operating some of the country's longest-running and still very successful groups. If you're unsure if starting a support group is for you, read more about why people start support groups and the aims and objectives.

How to start a support group

Connect with healthcare professionals

- It's not essential but can help find members and speakers.

- Read more about connecting with healthcare professionals.

Find your members

- Decide who your group is for.
- Advertise your group online, in local shops, GP surgeries, and community venues.
- Read more about finding members.

When and where

- Will your group be online or in-person? If it's in-person, ensure your venue is accessible and has suitable facilities.
- Choose a meeting frequency and time of day that most people can attend.
- Read more about the time and location of your meeting.

Your first meeting

- During this meeting, decide how the group will be run. Will certain people have specific responsibilities? How will you communicate with group members?
- Record this information so new members know how the group runs. This record is often called a constitution.
- Read more about writing a constitution and your first meeting.
- Find constitution templates on the Parks Community website or download one from the Voluntary Services Centre.

Speakers and topics

- Many groups invite speakers to talk about a relevant topic. You can ask your group what speakers and topics they would like.
- Read more about speakers and topics.

Managing bereavement and emotional topics

- Unfortunately, many groups experience loss and bereavement at some point. It can be helpful to prepare for emotional discussions around these topics.
- Read more about managing bereavement and emotional topics.

Finances

- There are some costs associated with running a support group, which could include venue hire, Zoom subscription or printing costs.
- Someone will need to manage the money, which is often easily done by opening a charity or community bank account.
- Read more about finances.

Creating a safe and positive culture

- Everyone who attends your group should feel safe and welcome.

- Some groups have an equality, diversity and inclusion (EDI) policy to ensure all group members know what is and isn't acceptable.
- Read more about creating a safe and positive culture and find an EDI policy template on the Resource Centre website.

Managing information

- You will need to collect information about group members, such as their names and email addresses, to tell them when the next meeting is.
- You must comply with the General Data Protection Regulations (GDPR) to ensure the information you collect is used in the right way.
- This is relatively straightforward once you have set up a system within your group. It often involves storing members' contact details in a password-protected file and ensuring no one leaves personal information visible on an open laptop or paper.
- Read more about managing information and find a template privacy policy on the Resource Centre website.
- The Information Commissioner's Office has advice on managing data for small groups.

Health, safety and insurance

- The group has a responsibility to keep members safe whilst attending. If there is an injury or damage to property, the group could be held responsible.
- Many venues have public liability policies that cover costs associated with an injury or damage. If they don't, you might want to buy your own policy.
- Read more about health, safety and insurance.

Safeguarding

- You should know what to do if you think a group member might be affected by abuse or neglect within or outside the group. Many groups have a policy that says what to do in this situation.
- Read more about safeguarding and find a template safeguarding policy on the Resource Centre website.

Types of groups

- Support groups are not-for-profit organisations, but there are different not-for-profit organisation structures depending on how the group is run.
- Most support groups are unincorporated associations which are simple to set up and run.
- A very small number of groups register as charities once they are well established.
- The Resource Centre website has more information on types of groups.

Help and support for you

Your Support Network Coordinators are here to help with any questions. Please see below for their contact details. If you aren't sure which region you are in, the team can direct you to the right person.

Name	Role	Area	Email/Phone
Alison Stewart	Support Network Coordinator	Scotland and Northern Ireland	alison@actionpf.org 07508 857192
Cathy Jackson-Read	Support Network Coordinator	Southwest England, West Midlands and South Wales	cathy@actionpf.org 07931 745886
Julia Stoward	Support Network Coordinator	London and Southeast England	julia@actionpf.org 07494 479241
Nicola Griffiths	Support Networks Manager	Cambridgeshire, Norfolk and Suffolk	nicola@actionpf.org 07931 745885
Wendy Jones	Support Network Coordinator	North England, Yorkshire, East Midlands and North Wales	wendyj@actionpf.org 07508 857190

The information in this toolkit is based on the experiences and ideas of APF and other support group leaders and is not intended to be comprehensive advice. We've done our best to include information you will find helpful and to cover many different topics. However, there may be things we haven't mentioned that your group needs to consider. Please ensure your group complies with legal requirements and seek advice if needed.

Section 1: Why start a support group?

Starting a support group can be hugely rewarding as you're helping to improve the lives of people affected by pulmonary fibrosis. There can be many different things to think about, but we're here to support you with this. For most groups, once you have made the main decisions about the format and structure of the group, overseeing the ongoing meetings should be straightforward.

What's the aim of a support group

Most groups have similar aims and objectives, but your group might want to dedicate the meeting to a more specific activity or outcome. Some groups like to create a space for mostly informal discussion between members, whereas others want to focus on spreading education and information from speakers and professionals.

The best way to decide on your group's aims and objectives is to discuss this with your members at the first meeting. This will help you to determine what will happen at future meetings.

Here are some broad aims and objectives relevant to most support groups. You can use these to help you think about your group's aims and objectives.

Overall aim (what you plan to achieve)

To provide a support group for people diagnosed with pulmonary fibrosis in an environment where people can:

- Learn about their condition,
- Share ideas with other people in a similar situation and
- Gain mutual support to facilitate a better quality of life.

Objectives (how you will achieve the aim)

- Provide **accurate, up-to-date information** about pulmonary fibrosis, diagnosis, treatment and research.
- Provide an awareness of the various **social and community help** available for people affected by pulmonary fibrosis, i.e. disability allowances, employment assistance, and carers allowance.
- Provide an opportunity to **make new friends** and feel confident to **share and hear personal experiences** respectfully and confidentially.
- Encourage **emotional support** through sharing experiences and receiving reassurance from others.
- **Alleviate feelings of social isolation** often experienced due to disability or a change in circumstances.
- Provide an environment to **discuss anxieties and concerns,** which some may find difficult to discuss with family and friends.

It is important to ensure that members fully appreciate that, whilst attendance at a support group should help them to understand the disease better, it's not a medical clinic. Members should speak separately to their consultant or nurse about their medical issues.

If support group members express concerns about access to key medications for pulmonary fibrosis, such as anti-fibrotics, they should be advised to discuss their individual case with their health care professional team. If these concerns should lead to suggestions of sharing medication with others in the group, it is important to be aware that sharing or supplying prescription medication is both **unsafe and illegal**, even between people who believe they are on the same treatment. Although such offers may be made with good intentions, doing so can carry serious health risks and may result in legal consequences, including fines or imprisonment.

If concerns about medication supply are raised in your group, we encourage you to:

- Advise the individuals to discuss their case with their health care professional team.
- Discourage any suggestion of sharing medication and the potential implications of doing so.

- Remind the group that prescription medicines should only be taken as directed by a healthcare professional.
- Let APF know if the issue is causing concern locally. We may be able to help by making enquiries, offering reassurance, or raising the issue with the appropriate authorities.

Section 2: Connect with local healthcare staff

Most groups are set up either by healthcare staff or with their support. There are several benefits to this as staff can often:

- Advertise support groups in hospitals and surgeries.
- Signpost patients to the groups during their appointments.
- Provide credibility to the group.
- Help to find people from a medical background to speak at the group.
- Be a familiar face if seen both in clinics and at support group meetings. This can build a sense of community.

If you are a healthcare professional

The first step is to let your team know that you want to set up a support group. Tell them what you want to do and how this will benefit people affected by pulmonary fibrosis. There is work involved in setting up and running a group, so sharing responsibilities within a team will help to make it manageable.

Someone in your place of work might already have experience setting up a patient group, or your employer might have guidelines that can help you with the process.

If you aren’t a healthcare professional

You don’t have to make links with healthcare professionals, but it will likely make setting up and running a group much easier.

You might already know healthcare professionals involved in pulmonary fibrosis who work within the hospitals or clinics you go to.

This might include:

- Specialist interstitial lung disease (ILD) centres
- Respiratory departments in local hospitals
- GP surgeries

If not, you can find a list of ILD centres on the APF website or contact your local GP surgery or hospital. When discussing the support group with a healthcare team or professional, you might want to decide:

- Will the group be part of the hospital or clinic, or separate?

- Will the healthcare professional be the support group leader, or will they be involved in a different way? How will they be involved? e.g. advertising in clinics, visiting the group to answer questions.
- Does the hospital or clinic have any charity funds that could be used towards the costs of running the group?
- How will tasks be divided between everyone involved?

Many healthcare staff have limited time for non-clinical work. The group members can make it easier for staff to be involved by taking over the day-to-day running of the group. The staff may then have more capacity to be involved with finding and arranging speakers or visiting the group to answer questions.

Section summary

- *Most support groups are set up alongside respiratory healthcare staff, who can refer patients to the group and help to find clinical speakers.*
- *You can also develop connections with healthcare staff after starting a group.*

Section 3: Finding members

Step 1: Decide who the group is for

You'll need to decide who will attend your meetings. Most groups welcome a broad range of people, including carers, family members and those who are bereaved. Including people with any interstitial lung disease (ILD) is also common, as people with different conditions might still benefit from the support and information.

There may be times when you request that only certain people attend. For example, if the group is for carers, patients may attend for an informative talk, but it might be asked that it is carers only for the informal discussion afterwards. This is so that carers can speak freely without worrying about upsetting people with a diagnosis of pulmonary fibrosis.

Step 2: Advertise the group

It's worthwhile putting some time and effort into advertising your group so that as many people as possible can benefit from the group's support.

You'll first need print or digital posters to put up online and in different venues.

Creating a poster and more

Contact your APF Regional Support Coordinator for free printed or digital posters. You can also use free software such as Canva to create them yourself. You can even use Canva to create your own logo to use on different promotional materials.

There are several free platforms (for example, Wix or Squarespace) that you can use to make a website for your group if you'd like to. A website isn't necessary to successfully run a group, but some people want a place to house additional information and updates.

Places to advertise

- APF website – let us know about your group, and we will list the details on our website.
- Local hospital websites
- Create your own website
- Social media – Facebook, Twitter, LinkedIn or Instagram
- Local noticeboards in supermarkets or community venues
- Local press
- Local radio
- Local ILD centres, respiratory departments or GP surgeries – ask to display posters and for clinicians to refer their patients to the group
- Other local voluntary groups

Section summary

- *Decide who your group is for and make your group known to them using several different channels.*

Section 4: Where and when to hold a meeting

Some groups are solely in-person or online, whereas others prefer a combination. Consider what will work best for your group and what you can organise.

In-person meetings

When finding a venue for your meeting, you will need to consider:

- Venue hire fee.
- Car parking and charges.
- Distance to walk to the venue.
- Toilets.
- Accessibility to the building, the meeting room and toilets.

- If the venue has appropriate insurance. You might want to take out your own policy if it doesn't. Read more about insurance for your group.
- Comfortable seating and a warm, welcoming building. Many groups prefer round tables of about 6-8 people, which allows members to chat and mingle.
- Refreshment facilities, which are usually at least a table with tea/coffee. Alternatively, you could ask that members purchase refreshments at the venue or bring their own.
- Consider speakers attending the meeting who may be working. Is it a convenient place within a short distance of the hospital that staff can get to during their working day? Clinical staff will need to fit the meeting into their clinical rotas, so ensure the venue is convenient to reach.

For your first meeting, it might be suitable to meet in a public space such as a coffee shop or café. This could work if you only have a few people attending and are not discussing confidential information. Read more about protecting people’s privacy.

Venue Ideas

- Local community centres/halls
- Leisure centres
- Hospices
- Charity buildings
- Libraries – some have meeting rooms
- Hospitals and health centres - some have lecture halls or education rooms
- Council buildings
- Golf clubs
- Tennis/bowling clubs
- Village hall

Online meetings

Since the pandemic, many groups adapted to online meetings. This has some advantages, including reducing travel and the infection risk of being around other people.

If you choose to hold meetings online, you can do this via Zoom or Microsoft Teams. A basic Zoom account is free, but you will be very limited by how many people can join your meeting and for how long. Most groups will need a paid account, which you can pay monthly or annually. You can then create a meeting and send the link to anyone who wants to join.

Running a meeting online does carry risks, read about the possible risks and some useful tips on how to mitigate them here Reducing the risks in running an online meeting

Digital support

You can contact your local library if you are struggling with setting up a digital meeting. Most run weekly sessions under the ‘Get online at your library’ scheme, where you can go along with your laptop, and they can help you.

You can also find support at:

- Citizens Online. They have a free digital support helpline: 0808 196 5883.
- Abilitynet
- Action for Pulmonary Fibrosis

Time of meeting

The time of a meeting is important as it can affect whether people can attend.

The most popular meeting times are the afternoon and late morning. However, people at work during the day may be unable to attend these times. So that people who work can attend, some groups meet on a Saturday or in the evening. Some groups vary the days and times each month so more people can attend.

Times that are often difficult for people to attend include:

- Early in the morning
- Rush hour
- Late evening
- Meal times

It's a good idea to have consistency when deciding when to meet, for example, on the second Tuesday of every month. This helps people keep track of when the next meeting will be. Most groups meet every 1-3 months. If you want to make your meetings educational and informative, meeting less often might give you more time to source a speaker.

Meetings often last about two hours to allow time for a speaker to present and for members to chat more informally. Longer than two hours may be too tiring for some people to attend and get the most out of the meeting. Online meetings can be shorter, around 1-1.5 hours. The length of a meeting varies depending on the group's needs. You can speak to your group members to see what works for them.

Section summary

- *Meetings can be held online or in person. You will need to find a suitable venue for in-person meetings.*
- *Carefully choose the time of your meeting so that most people can attend, including speakers.*

Section 5: What happens during your first meeting

Make sure to greet your new members with a warm welcome and help them to feel comfortable, especially as some people might be nervous about attending their first meeting. Introduce yourself to the group, and you might want to talk about your link to pulmonary fibrosis, and why you wanted to start the group.

There will be a small amount of housekeeping at the start of the meeting. This might include:

- Letting people know where the fire exits and toilets are.
- Taking a register and explaining what will happen with people's information.
- Explaining how confidentiality will work. Some groups say: 'What is said in the group stays in the group unless you have permission from that person'.
- Reminding the group to be respectful and treat people fairly.
- Telling the group to report any issues or concerns to the group leader.

Some groups write this information on the sign-up sheet so members can read it as they register.

During your first meeting, it might be helpful to discuss how the group will be run and what will happen during future meetings. This could include:

- What the group wants to achieve and how will you do this. Read more about the aims and objectives of a group.
- Agreeing a venue, date and time for future meetings. Read more about when and where to hold meetings.
- How to communicate with the group (see below).
- Who will take on what responsibilities within the group (see below).

It's helpful to record this information so that all members have the same up-to-date information about how the group is run. Recording this information is often called a constitution, which is a document that explains how a group will be run. Read more about writing a constitution.

Communicating with the group

- Most groups communicate through email, but remember that not everyone has access to the internet. Always try to offer an alternative method of communication, such as sending the details of the next meeting in the post.
- Some groups have a website or a Facebook page where they post updates for group members to see. You will probably still need to send emails reminding people of upcoming meetings.

Sharing responsibilities within the group

- As there are different aspects to running a group, such as booking a venue, managing finances and leading the meeting, some groups share these roles among members.
- Sometimes, this is referred to as a 'committee'. As the tasks are shared, each person has fewer responsibilities, and it's easier to cover for someone if they are unwell.

Section summary

- *Use your first meeting to decide how future meetings will run.*

Section 6: Speakers

Some groups use the whole time for an informal chat between members, but most have a speaker as part of the meeting. A speaker talks about relevant topics such as oxygen therapy, research or mental health. Make sure to allow at least half of the meeting for group discussions or informal chats between members.

Here are some ideas for speakers and topics. You can also ask your group what they want to hear about and if they have any contacts for potential speakers.

Ideas for speakers/topics

- Diagnosing and treating pulmonary fibrosis.
- Current research and clinical trials.
- Pulmonary rehabilitation and maintenance exercise programmes.
- Other types of exercise, e.g. Yoga, Tai Chi.
- Oxygen therapy and equipment.
- Relaxation and breathing techniques.
- How to conserve your energy and manage breathlessness.
- Managing anxiety and depression.
- Diet and nutrition.
- Travelling with pulmonary fibrosis – including oxygen and insurance.
- Lung function tests for pulmonary fibrosis.
- ‘Question time’/panel discussions - invite a panel of consultants, nurses, people affected by pulmonary fibrosis, and other specialists for a questions and answers session.
- Local carers’ groups, services and support available.
- Lung transplants.
- Supportive and palliative care (which is not just for end-of-life) - invite hospice staff, GPs or district nurses.
- Social care services and resources.
- National and international patient advocacy groups.
- Disability, work and legal issues, e.g. power of attorney.
- Singing for health.
- Ask group members to speak about their interests (singing in a band, bonsai gardening, bird watching, fundraising, or discussing their personal experiences as a patient with the condition).
- Local fire service (safety in the home, oxygen in and out of the house).
- Ask other charities to come and talk about what they offer and what they can do to help and support.

Section summary

- *Most groups have a speaker for half of their meeting. There are many potential topics, and the whole group can get involved with finding speakers.*

Section 7: Managing bereavement and emotional topics

This section of the toolkit talks about bereavement, grief and death.

As pulmonary fibrosis is life-limiting, many groups will experience loss and grief. Whilst support groups aim to have a positive and hopeful atmosphere, they also want to remain realistic and be a space where people can share difficult feelings. It might take some practice to balance both these aspects during the meetings.

The APF-led support group leader meeting is a space for leaders to discuss how their groups are run and give advice to other leaders. It's an excellent opportunity to hear how other groups manage difficult emotions and topics.

Cruse UK is a charity that offers advice and support for people dealing with bereavement and those supporting people who are grieving. It may be helpful as a group leader to understand more about coping with grief and to be able to signpost people to Cruse UK if needed.

You can talk to a professional counsellor for free at Grief Chat.

At a Loss is a UK bereavement signposting website.

We've also included guidance on how to manage bereavement and emotional topics. These might not be suitable for all groups, as every situation is unique.

If someone in the group is bereaved:

It's important to ask the person what they need from you and the group now. They can tell you if they want:

- To talk about their loved one who has died.
- The other group members to know.
- Other group members to approach them or not.
- Physical space (not everyone likes to be hugged).

You could ask the person before the meeting how you can support them.

Many groups welcome bereaved relatives, carers, and friends to stay with the group for ongoing support.

You can signpost them to Cruse UK or the APF support line if they are looking for more direct support. They might want to attend the APF-run carer's support group, which welcomes bereaved carers, family and friends.

If someone in the group has died:

This is a very emotional time for a group, and everyone will approach this in their own way.

- You might not always know someone has died due to patient confidentiality. In some cases, a family member or friend of the person who has died will tell the group.
- If you know a group member has died, many groups advise contacting the friends and family before telling the group. The family or friends of the person who has died might want to tell the group themselves.
- You might want to ask the group what they'd like to do to remember the person who has died.
- Some groups will contact the bereaved family and friends to offer support.

Talking about life expectancy and death in the group

There might be times when a group discussion involves life expectancy and death. This topic is important, but not everyone will be ready to discuss it.

- Remember that some group members may not want to discuss this. Some groups don't talk about life expectancy and death with the whole group. Instead, they will have individual or small group discussions if someone wants to talk about this.
- Remind group members that they can take a break from the meeting whenever they need to. That might be stepping outside the room or muting a Zoom meeting.
- Watch out for anyone who might need additional support. This isn't always easy to recognise, but if someone is quieter than usual or more emotional, check in with them. This might be more difficult during online meetings if someone has their camera and microphone switched off. You could remind the group that they can reach out for support.
- It might be helpful to ensure the meeting contains lighter topics, particularly at the end.
- At the end of the meeting, let people know where they can go for further support.

Section summary

- *At times, there might be difficult discussions involving loss and bereavement in support groups.*
- *There isn't a simple solution to these discussions, as each situation is unique. Use your best judgment and get support. The APF team is here to help.*

Section 8: Finances

There are some costs involved in running a support group. These could include:

- Venue hire
- Paying for a Zoom account
- Refreshments
- Printing costs

Initial costs

There are several ways of raising a small lump sum to start a group.

- Fundraising activities such as raffles.
- Ask for donations from potential members.
- Grants may be available from your local Community Voluntary Service.
- Small lottery grants can be applied for annually.
- Action for Pulmonary Fibrosis can assist you with a small financial grant to start your group.

Long-term costs

In the long term, groups should be self-sufficient.

Most groups find that members are happy to give a small donation. You could also arrange:

- A raffle with donated small prizes.
- A collection for tea and coffee to cover the meeting costs.

Managing money

Many groups open their own bank account. That way, you can clearly show the financial transactions that have taken place on behalf of your group, and it's a safe place to put any donations you will hopefully receive. You would also need a bank account to apply for any funding or to register to become a charity.

A charity or community bank account is ideal (sometimes known as a treasurer's account). These are similar to current accounts but offer some additional benefits, such as multiple people can sign off on transactions. You will probably need two people to open the account, but this does not mean two people need to authorise every transaction.

Some accounts come with a fee, so look at different options. Read more about bank accounts for support groups.

Section summary

- *You will need some funds to run a group, which can be raised by donations, fundraising or grants.*
- *It's usually easiest to open a bank account for the group so that your funds and spending are easy to track.*

Section 9: Policy templates

You'll find these templates throughout the other documents in the support group toolkit. We've listed them all in this document for your convenience.

Constitution

- Parks Community website
- Voluntary Services Centre document

Equality, diversity and inclusion

- Resource Centre website

Privacy policy

- Resource Centre website

Safeguarding policy

- Resource Centre website