



## SEPSIS SUPPORT GROUP TOOLKIT

### WHAT ARE PEER SUPPORT GROUPS?

Support groups - also often referred to as self-help groups - are groups of people who gather to share common issues and experiences associated with a particular situation, condition, illness, or personal circumstance. In a support group, people are able to talk with other folks who may have found themselves in a similar situation - people who may understand what they're going through and can share the type of practical insights that come from first-hand experience.

Here are some of the common characteristics of support groups:

- They are made up of *peers* - people who are all directly affected by a particular issue, illness, or circumstance
- They usually have a professional or volunteer discussion leader or facilitator
- They tend to be fairly small in size, to better allow everyone a chance to talk
- Attendance is usually voluntary.

### WHY HAVE A SEPSIS SUPPORT GROUP?

There are many benefits to peer support groups:

- If you don't know many - or any - other people who have been affected by sepsis experiencing and coping with sepsis can be difficult; you can feel isolated and stigmatised. Support groups help people with an issue or illness feel less alone and more understood.
- Support groups provide the opportunity to ask questions and find out if what you're going through is normal.
- Support groups can empower people to work towards resolving their own issues.
- Members can share information, keeping one another up to date on news of interest to them.
- Among people who are experiencing similar issues, there is a unique emotional identification that can be different from the kind of support that can be offered from professionals.
- Members can act as role models for each other. Seeing others who are experiencing the same difficulty and making progress in their lives is inspiring and encouraging.
- A support group can offer a safe space for someone who needs to talk about intensely personal issues, experiences, struggles, and thoughts.
- Talking to others in support groups may help reduce anxiety, improve self-esteem, and may increase a sense of overall wellbeing.

## HOW TO SET UP A SEPSIS SUPPORT GROUP

### The group will require a lead volunteer

- This is usually someone with first-hand experience of sepsis, be it a survivor or a close relative of a survivor.
- The lead volunteer will be supported by the Sepsis Trust support team. One of the UKST support team will attend the first two groups if required. They will also provide remote support with reassurance that people can be signposted to the UKST support team.
- The role of the volunteer is to
  - Find a suitable location for the group to meet
  - Book the venue and agree dates. Inform UKST support team of the dates
  - Promote the group locally
  - Engage with local healthcare professionals
  - Co-lead group with a healthcare professional

### A healthcare professional should attend the group

- This should be someone with a knowledge of sepsis and some of the problems that are experienced afterwards. Knowledge of critical care is desirable but not essential.
- The healthcare professional can be from a variety of backgrounds, commonly a critical care nurse, outreach nurse, acute medical nurse or infection control nurse.
- The healthcare professional will be supported by the Sepsis Trust support team. One of the UKST support team will attend the first two groups if required. They will also provide remote support with reassurance that people can be signposted to the UKST support team at any time.
- The key role of the healthcare professional is
  - To co-lead the group with the lead volunteer
  - To offer advice and help make sense of what happened while in hospital
  - To signpost to other sources of support where appropriate

### Establish a time and venue for the group to meet

A suitable venue will be required and consideration should be given to

- A sensitive/ neutral location, ideally not a hospital or healthcare facility. People who have been affected by sepsis may have been traumatised by their experience and may have anxieties about visiting such places
- Accessibility with good transport links
- Ample parking and easy access to the building
- Disabled facilities

Suggested venues that meet these requirements

- Supermarkets. Most national supermarkets have a community rooms that are often available free of charge, these will usually meet all of the essential requirements. If

you contact your local store community champion or co-ordinator, they should be able to let you know what is available.

- Retail parks. These sometimes have community rooms and will have the same benefits as the supermarket chains.
- Church halls, these sometimes require a small donation.
- Libraries and other local authority buildings.
- Schools, university and other public buildings

### **When is the best time to hold the meeting?**

The groups usually meet on a weekday evening. 6:30pm is a good time to start, allowing people who work or have young children time to get to the meeting.

An ideal time to allocate for the meeting is 1.5 hours bearing in mind that many people find it difficult to sit for longer than 2 hours. Group members often chat at the end of the meeting and exchange contact details etc. This can often add another half hour.

### **How often should the group meet and how long should the meeting last?**

The group meet every 2-3 months depending on the availability of the lead volunteer, healthcare professional and meeting room. If the lead volunteer and healthcare professional are in agreement they may meet more frequently.

### **What's the best way to advertise and promote the group?**

#### **The Sepsis Trust will promote the group by:**

- Posting the details of the groups on our website support page.
- Posting on social media, Facebook, Twitter etc.
- Signposting callers to the Sepsis Helpline to groups that are being held in their area.

In addition to this, flyers can be printed and displayed in places where survivors are likely to see them such as GP surgeries, hospitals, libraries and community bulletin boards.

## **HOW DO YOU FACILITATE A SEPSIS SUPPORT GROUP?**

### **Prepare yourself for the meeting**

Spend a few minutes before the meeting thinking about how you are going to lead the meeting. Prepare your opening comments, ground rules of the group and any updates you may want to give the group members.

### **Prepare the room**

Arrive 20 -30 minutes early to arrange the room, check heating is working and prepare area for refreshments. A small display can be set up with sepsis information books and other promotional materials.

## Start the meeting

Greet people as they arrive, welcome them and introduce yourself. Bear in mind that many people will have had to pluck up a lot of courage to attend and are often apprehensive and emotional as they enter the room.

Aim to start the meeting on time with a simple 'let's get started' or 'we will start in 5 minutes'. Try to avoid late starts as group members may need to get away on time for commitments such as child care.

## Open the meeting

Introduce yourself to the group.

Give details of relevant housekeeping info such as fire escapes and toilets

Explain the importance of the ground rules of the group.

- Confidentiality
- Respect for other members' experience
- Listening to other group members and not interrupting

## Key skills when leading a support group

### **Encourage members to listen to each other**

Being a good listener - and acting as an example to group members in this regard - means being an active listener, one who is obviously listening and understanding what is being said.

How do you let people know that you're listening?

- Body language (leaning slightly towards the speaker, not fidgeting)
- Eye contact (looking in the speaker's eyes, not looking around the room)
- Brief encouraging statements, also sometimes called nonverbal encouragers ("Uh-huh" or "Mmm-hmm")
- Nodding

### **Encourage members to offer each other support**

While being supportive yourself, you must also help others in the group learn how to be supportive as well. Demonstrate the active listening skills listed above while the member is speaking. Wait 10 seconds or so and then, if no other members have done so, offer support. Group members will usually pick up on this and start offering support themselves. If they don't you may have to ask them questions about how they are affected by the discloser's experience.

### **Encourage members to talk about themselves.**

One advantage of support groups is that they can create an atmosphere in which members feel comfortable talking about and working through very personal issues and experiences. Disclosure - the act of revealing personal information - gives other members a chance to offer support, ideas, and assistance. It also encourages other members to share their own experiences and fosters an atmosphere of trust in the group. To maintain that trust, facilitators may find that they also need to disclose information from time to time.

When a member discloses information, the facilitator may have to guide the discussion to make the member comfortable or encourage others to join the discussion. Asking open-ended questions - those which cannot be answered with a simple "yes" or "no" - is very useful at this point.

### **Offer support**

This is the main aim of your group! Fortunately, offering support is one of the simplest things to do in the course of running a support group. Giving members support can help them realise that reaching their goals is possible, give them hope, or just let them know that you understand and empathise with what they're going through.

Support consists of making statements that show your understanding, sympathy, and concern. Listen to the feelings expressed by the member, and address those feelings. Support can also be expressed through body language (such as making eye contact or smiling). Care should be taken in using touch as a form of support, such as patting an arm or hugging - in some circumstances, such as a support group for survivors, touch may be threatening and uncomfortable instead of comforting and should only be used when you are confident it is appropriate.

Usually, members will offer support to each other on their own, or they will quickly pick up on how to do so by following your example. However, you may have to ask questions to coax them into offering support by asking questions.

### **Help members solve problems**

While solving issues shouldn't be the only goal of a support group, it is something that many members hope for. All members can take part in the problem-solving process so that no single person is seen as the solution to their difficulties. It's the facilitator's job to help members learn how to help each other with problem solving.

Here are the steps to problem solving:

- *Clarifying the problem:* Make sure everyone fully understands the problem. If you aren't sure what the problem is, ask questions to get more information.
- *Talking about the alternatives:* Bring up possible solutions to the problem, but be very careful to word them in a way that doesn't give advice. For example, instead of "You should do this," a better wording could be "I wonder what it would be like for you to try this" or "Maybe you could do this." **Telling people what to do is not the purpose or responsibility of a support group.** It takes away a person's sense that they can handle their own problems and can make people feel attacked and uncomfortable. Try asking members to say what's worked well for them in similar situations. You can also ask the person with the problem what they think might work.

- *Choosing which option(s) to take:* Have the group discuss the pros and cons of each suggestion. You can then let the person with the problem come to a decision, or they may want to take some time on their own to consider the possibilities. Let them know that the group cares and wants to know how things turn out.
- *Offering help:* Sometimes members may offer to assist each other. For example, if the issue being discussed is a member's problem with transportation to the meetings, other members might offer to give that person a ride. Or a group member may have expertise in a specific field such as benefits advice or employment law.

### **Closing the meeting**

Most support group meetings last between an hour and two hours. If the group is caught up in a particularly intense discussion or in helping a member solve a problem, you might go a few extra minutes, but generally it's best to stop before everyone is tired and eager to leave. When the discussion is winding down or when a previously agreed-upon ending time has arrived, wrap things up. Here are some ways you can close the meeting:

- *Make a summary statement:* Summarise the topics that were discussed and alternatives that were chosen. Highlight any positive observations or solutions that came up
- *Ask for additional comments or questions:* Check to see if anyone in the group has anything to add
- *Remind members about the next meeting:* Let everyone know the time and place for next time
- *Give a final greeting:* Thank everyone for coming, say goodbye, and encourage them to come again
- *Make final notes:* Shortly after the meeting, make some brief notes about what was discussed while it's fresh in your mind. This information can be used to jump-start the next meeting. Keep any notes on the group in a safe place to ensure confidentiality and do not record names or anything else that may reveal identity.

### MANAGING GROUP MEMBERS WITH DIFFERING NEEDS

The majority of people that attend sepsis support groups are survivors who want to meet others that have been affected in similar ways and are looking for ways to deal with their recovery. Most groups will also have one or more members attend that have been bereaved as a result of sepsis. This can present some potential problems.

- The bereaved person may find it difficult to be with individuals who have survived sepsis and are unhappy and complaining about their outcome.
- The group is not a bereavement support group and, although it may be the place to learn more about what happened to their loved, they may be better suited to group or one-to-one bereavement counselling services such as those offered by Cruse.
- Those that have survived sepsis may experience survivor's guilt and may feel uncomfortable and unable to open up and share how they are feeling in the presence of someone bereaved.

In practice this is rare and both groups tend to benefit from offering support to each other and being in a group when everyone knows about sepsis and they can talk openly about their experience. At the start of the meeting you should explain that there are people who have been affected in a variety of ways and if anyone doesn't feel comfortable with this they can leave the group at any point and we can talk one to one with them.

## TIPS ON HANDLING DIFFICULT GROUP MEMBERS

In dealing with difficult group members, support group facilitators must learn a delicate combination of assertiveness and control mixed with kindness. This sort of assertive caring directly addresses problems with the group without insulting or offending members. You may use assertive caring during a meeting to get the discussion back on track, or you may wish to speak to the member in private after the meeting.

### WHEN TO USE ASSERTIVE CARING:

- When a member talks too much, monopolising the discussion
- When a member rejects every suggestion made by others - the "yes, but" phenomenon
- When a member appears to have issues that are more than the group can handle - such as someone who's had a change in health and should seek medical attention, or someone who may have psychological problems needing professional attention
- When a member interrupts others or brings up inappropriate or irrelevant subjects
- When a member's issues aren't strictly relevant to the aims of the support group.

### THE STEPS TO ASSERTIVE CARING:

- *Show that you understand the member's position or dilemma:* State that you understand the reason(s) behind the member's negative behaviour. Use "I" or "we" statements, which show how his behaviour affects you and the group. For example, "I know things are difficult for you, but right now we're trying to figure out how Liam can make his complaint."
- *Set limits:* Gently but firmly correct the behaviour. Explain your reasons, letting the member know why you need to change the situation will make him more likely to cooperate. For example, "I know things are difficult for you, but right now we're trying to figure out what Liam can do about his complaint, and it's hard to do when you keep interrupting."
- *Suggest an alternative:* Explain what you'd like to see the member do instead of the negative behaviour. For example, "I know things are difficult for you, but right now we're trying to figure out what Liam can do about his complaint, and it's hard to do when you keep interrupting. I wonder if we could wait to talk about your problem until after we've come to some conclusions about what Liam can do."
- *Get the member's agreement on the alternative:* Make sure the member understands what is being asked of him and agrees to do it. For example, "I know things are difficult for you right now, but we're trying to figure out what Liam can do about his complaint right now, and it's hard to do when you keep interrupting. I wonder if we could wait to talk about your problem until after we've come to some conclusions about what Liam can do. Is that okay with you?"

## IN SUMMARY

Support groups are a great way to provide support to the people who have been affected by sepsis, without a huge investment of time or money. Moreover, running a support group is a good way to reach out and get people interested in the other things the UK Sepsis Trust does such as awareness and fund raising. It's also a way to give back to the community - improving or supporting a good public image for UK Sepsis Trust. Finally, it's just a good thing to do. With relatively little effort and cost, a support group can make a significant impact in the lives of people dealing with the aftermath of Sepsis. What better reason can there be?

## FURTHER READING

Community Tool Box, Section 2. Creating and Facilitating Peer Support Groups. Ctb.ku.edu

Handbook for Self Help and Support Groups, Macmillan Cancer Support.

Q Lab Peer Support Project <https://q.health.org.uk/q-improvement-lab/lab-1-peer-support-available/>