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Starting a Support Group

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Living with HIV can be challenging. For some, it can be helpful to find the support of others living with HIV through support groups, peer counseling, or places like our [A Girl Like Me](#) blog, which is an online community of support. Others prefer to be more private, confiding only in a few close friends. Either approach is fine, as long as it helps you.

What Is a Support Group?

A support group is any group of people whose purpose is to support one another in dealing with an issue. A support group may be small (an informal gathering at someone's kitchen table) or large (a group at an HIV service organization (ASO) or in the meeting room of a religious organization). The participants can be from a specific part of the HIV community (e.g., cis and/or trans women living with

HIV, caregivers of those living with HIV, members of a faith community), or they can be open to anyone who wants to come and talk about HIV.

There is no "right" or "wrong" way to organize a group, as long as it is safe, supportive, and respectful of all participants.

Some support groups are informal and led by the members themselves, while others are more formal and led by a trained facilitator. Some are general and provide opportunities for people to talk about anything on their minds, while others have a topic on which they focus, such as HIV medications or how to deal with [substance abuse](#) issues. Some are "open" (members can join at any time or "drop in" as needed), while others are "closed" (require some sort of joining process and a commitment to attend regularly).

Some groups get together just to share information and encouragement, while others grow into longer-term mutual support communities where members help each other with carpools, childcare, or caregiving when a member gets sick. Still others grow into educational programs with outside speakers coming in to teach about various issues.

There is no "right" or "wrong" way to organize a group, as long as it is safe, supportive, and respectful of all participants. People living with HIV who participate in support groups often take better care of themselves and are less likely to feel isolated or [depressed](#). As a result, people living with HIV who have support — either through a group or through family and friends — live longer, healthier lives. If there are no support groups available in your community, you may want to start one yourself.

Setting up a Support Group

Partnering

If you partner with an organization in your area that provides services to women living with HIV, that organization may be willing to tell its members about your group so that those who are interested can join. If you are not familiar with organizations in your area, you can search for them in the [Health Services Directory](#). You can ask whether organizations in your area already have a support group; if they do not, you can ask them for suggestions and for ways they might help you start a group in your community.

Purpose and Participants

As you begin planning your group, consider the following:

- What is the purpose of the group? Possible purposes include providing social support, educational support, and/or mental health support.
- Who can participate in the group? Is this a women-only group or are men allowed to join? Is the group open to both cis and trans participants or is it only for transgender people? (*Note: The guidance below assumes that you are coordinating a women-only group but it is also relevant to other kinds of groups.*)

Facilitator

Next, decide who will facilitate (lead) the group. Facilitators may be responsible for one or more of the following: lead discussions, create a safe and respectful environment for all participants, monitor ground rules, serve as timekeeper.

If you want to participate in the group, it is easier to do if someone else is leading. Often, feelings that people have hidden inside will come out in a safe, supportive environment. Therefore, it is important to

find a qualified person in the community (e.g., a mental health professional or someone experienced in leading support groups) who can assist with facilitating the group.

Structure of Meetings

Next, you can think about the structure of the meetings – will they be free flowing or have a set agenda? Ask the women who participate in the group to help make this decision. Having them choose the way the meetings are carried out can help them feel some ownership of the group. The more ownership women have, the more likely they are to participate in the group.

Some successful support groups for women have participants come to the first session of each year with their ideas for topics they would like to learn more about. The group then decides together which topics will be covered and which social events will be planned. Once these decisions have been made, a calendar is created, and various participants volunteer to help arrange the events on the calendar. When new participants attend the group, they are provided with that calendar. This process has helped the core participants take ownership of the group and allows new participants to become familiar with the purpose, agenda, and structure of the group.

Location and Organization

Other questions to consider include:

- How often will the group meet?
- Where will the group meet? You can meet in person, or use the Internet to connect via chatrooms, meeting platforms such as Zoom or Google Meet, and other online spaces. If you choose an online platform, consider its security features to ensure privacy.
- What time will the group meet, and for how long?
- Will the group be closed or open to new members? If closed, how often will it open to new members?
- Will the group run for a certain number of weeks or be ongoing?
- Will the group adopt rules and delegate responsibilities?
- Will there be a cost for participating in the activities?
- Will there be meals or snacks? If so, how are they paid for?
- Will incentives such as childcare, transportation assistance, grocery coupons, or gift cards be offered? If so, how are these financed?

Getting the Group Started

Creating the Right Atmosphere

It is important to ensure that your support group provides a space that is safe, confidential, and welcoming. Try to create a non-judgmental atmosphere where participants, both old and new, feel comfortable sharing their feelings. It can help to explain what confidentiality means to all members so that all participants have the same understanding and expectations for privacy. This is especially important for people living with HIV, since [disclosing](#) one's status can have negative effects and is often an emotionally challenging thing for people to do. In fact, one of the roles of a support group is to provide a safe space in which people can talk about living with HIV without having to be concerned about possible negative consequences.

Sharing experiences allows members to give each other support, and to exchange practical information and ways of coping. It also allows participants to understand themselves better through the insights of others.

Outreach

When a group is new, participation may be small. It is important not to be discouraged and to continue to meet as scheduled. The women in the community need to see that the group continues to meet. Besides, the 'success' of a group is not based on how many people attend, but on the relationships that develop and the support that is provided.

If the group is open to new members, increase awareness by posting flyers at local organizations. Group name, meeting place, and meeting time are important facts to include. If a group is closed to keep it more confidential, then the name and contact information of the organizer and/or facilitator can be made available to local organizations for referrals. You may also want to talk to area case managers, attend local meetings, and keep in contact with other organizations in your area that serve women living with HIV.

Developing Ground Rules

As the number of participants grows, it will be important to create some ground rules. These can also be framed as "group agreements," and it is often helpful if participants create for themselves the rules or agreements by which the group will be run. Ground rules are a way of establishing boundaries and keeping order in the group. If the rules are broken, it is important to remind the group of the agreements that the group established, so as to provide a level of continuity and safety.

Some common ground rules include:

- Expectations around confidentiality: "what you say in the room, stays in the room"; anything said or noticed in the room will not be repeated or discussed at another time or place
- Openness and respect: group members are expected to listen to each other without interrupting, take turns speaking, and speak without judgment or giving advice; by the same token, choosing not to speak is also respected
- Language: group members are expected to avoid [language](#) that would offend
- Promptness: meetings will begin and end on time

As the Group Grows

Deal with Issues Immediately

Since being part of a support group is intended to help you live more healthfully with HIV, it is fine to leave a group if it no longer serves its purpose for you.

As the group grows, the different personalities of participants and facilitator(s) may cause some tension or division. As the group organizer, it will be important to deal with issues as they arise. Try to stick to the rules and consequences the group created.

There may be times when the group process becomes difficult, and you want to quit. If that happens, try to reconnect with the reason you started the group and work out the difficulties so the group can continue. This may mean passing the organization or 'ownership' of the group to someone else. Since being part of a support group is intended to help you live more healthfully with HIV, it is fine to leave a group if it no longer serves its purpose for you. If you are the group's leader or organizer, it is also okay to rotate out of your role and become a regular member of the group. This not only gives others an opportunity to step forward and assume a leadership role, but also gives you the chance to benefit from membership in a group you helped to create.

The Power of the Support Group

There is power in a group. Through support groups, women have the opportunity to learn about HIV, provide support for other women, develop leadership skills, set boundaries, gain respect, and grow their

self-esteem and confidence. Through your group, women can learn that they are not alone – they have a family they chose to support them as they live with HIV.

Additional Resources

Select the links below for additional material related to starting a support group.

- [The Well Project's Connect With Us page](#)
- [Support Groups: Make Connections, Get Help \(Mayo Clinic\)](#)
- [Guide to Starting Your Own Support Group \(Anxiety and Depression Association of...\)](#)
- [Emotional Wellness Groups \(Iris House\)](#)
- [Starting a New Online Support Group \(PsychCentral\)](#)
- [Creating and Facilitating Peer Support Groups \(Community Tool Box at the Univer...\)](#)
- [Program Development and Management: Four Phases \(Peers for Progress\)](#)
- [What Do You Need to Start Your Own Support Group? \(Phoenix Society\)](#)
- [Preventing Eavesdropping and Protecting Privacy on Virtual Meetings \(US Nationa...\)](#)
- [15 Steps to Starting an HIV Support Group \(Guide for a Peer Advocate\) \(Center f...\)](#)
- [Support Group Facilitation Guide \(Mental Health America's Center for Peer Suppo...\)](#)



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