

How to support and care for a person with HIV

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How to support Angela



Angela's story

Angela is a young woman who lives in Rio de Janeiro, Brazil. She works at an office downtown and lives with her boyfriend. She and her boyfriend are close to her family, which also lives in the city. Angela is two months pregnant and has felt more tired than usual. She has also had some diarrhea. She came to your clinic for some medicine and had some laboratory tests done, including one for HIV. The HIV test was positive. She does not have the courage to tell her boyfriend about the test. She says to you, "I do not want to live now that I have HIV."

Facing challenges together

Having HIV is isolating. Most people do not know very much about it and are afraid of the virus. Some people think that living near someone with HIV will give them the disease. Friends and family members may abandon someone who has HIV. Coworkers may not want to work with a person who has HIV. Even though HIV cannot be spread in these ways, many people do not know this and avoid contact with anyone who has it.

Supporting people with HIV can be a rewarding experience for a health worker, family member, or friend. The work can also be very demanding. People with HIV need emotional support and physical comfort. People are afraid when they find out they have HIV or AIDS—they fear being left alone, feeling pain, and dying. Having a chronic and fatal disease can be overwhelming. The reaction of the community can make it worse. If you have HIV yourself, you can be a special source of support for others who have the virus. Through your support, you can make a difference in a person's life.



People with HIV must deal not only with medical problems, but also with social and emotional problems. People with AIDS worry about what will happen to their spouses and children when they become ill or after they die. They worry about how they will pay for medical expenses. They feel sad, fearful, angry, and anxious. They may lose hope in the future. These are normal feelings for anyone with a serious illness. These feelings may become so strong that the person cannot carry on with day-to-day activities. When this happens, you can help people find ways to cope with their feelings.

On the other hand, knowing that they have a fatal illness may give people the courage to focus on what is important to them. A serious illness can give people the opportunity to change or walk away from situations that are unpleasant or unhealthy. Many health workers find it rewarding to work with people who are seriously ill because the health worker shares their new sense of purpose. Some people see being infected with HIV as a challenge; they want

to be in charge of their household, their finances, and their health. Others may feel less able and need more help. Remind people with HIV that needing and asking for help is normal. Help people with HIV and their families find a balance between dependence and independence.

There are many ways to live with HIV. Some people with HIV do not let others know that they have the virus. Some people become active in fighting the epidemic when they find out they have HIV. Helping someone else avoid the virus provides a sense of purpose. Helping others can give people with HIV a sense of community and self-worth even when their own lives are difficult. Just as people with alcoholism or cancer help others who have the same problems, people with HIV can reach out to others. Many people with HIV talk about AIDS in schools and at community meetings. Some become HIV counselors. Others work as activists for improving services for people with HIV. Some volunteer to be friends or “buddies” for other people with HIV. Each chooses to live with HIV in her own way.



Project First Hand

Some people do not believe that HIV is a threat to them. Others think that since they do not belong to a risk group (such as drug users) they will not get the virus. People with HIV have a special ability to reach other people and help them understand how they might be at risk.

In the city of Santa Cruz, California, in the United States, people with HIV help educate other people about AIDS. Six HIV-infected men who were willing to share their personal stories with the community organized Project First Hand. At community meetings, they shared their "firsthand" experiences of living with HIV. By telling their own stories they were able to help people relate to HIV on a personal level. The men were role models for other people with HIV in the community.

Over time, more people with HIV volunteered for the program. They went through short training classes about HIV and public speaking. Then, together they held a small meeting where they practiced talking about their experiences with HIV.

Project First Hand then set up meetings in the community. Health workers were there to help with technical questions and any hostile people in the audience. Friends asked questions if the crowd was too shy or timid. People who have heard the talks have been so moved that they have written letters of support to the speakers. You may want to start such a program in your own community.

Denial and other emotions

Some people do not believe that they have HIV even when a health worker tells them they do. They are not able to face the truth. They do not want to believe that they will die. They do not want to know that a person they love may have given them HIV, or they do not want to think that they may have given the virus to someone they love. Denial can be dangerous for a person with HIV and for others. People who are "in denial" do not take care of themselves because they do not believe that they are sick. If they refuse to take precautions, they can give the virus to others. Sometimes people turn to alcohol or drugs in order to forget that they have the virus.



Sometimes people are in denial after hearing that they have had a negative test. They find it hard to believe that they have not been infected, or they do not want to recognize that fact. For example, a woman whose husband has HIV may not want to believe that she had a negative test, because it means she will have to change how she has sex with her husband or leave him.

Yet denial is not all bad. Some denial helps people deal with the day-to-day challenges of life and plan for the future. Denial may help people live without thinking about the seriousness of their illness all of the time.

People with HIV often must cope with many strong emotions. They may have recently lost a loved one to AIDS. Some may feel guilty about the behavior that led to their infection. Most fear rejection from people around them. They may feel that they do not want to continue living, and they may even make plans to kill themselves. You should ask about these feelings and explain that it is normal to have them. You can work with people on ways to cope with these feelings. Anyone who is thinking of killing himself should be taken seriously. Ask him to promise to contact you or someone he trusts before he attempts suicide. Although this may seem silly, it works; just talking with someone often prevents people from harming themselves.

Family counseling

People with HIV have family, friends, and coworkers who will all be affected by their illness. In most communities the family is the basic unit of social organization. Families are able to survive many types of stress. Most families have dealt with death, separation, and economic hardship. HIV and AIDS place new strains on a family. Usually it can adapt, but occasionally a family breaks up when one of its members has HIV. When you sense that this is a possibility, try to help family members get the support they need to stay together. It can be useful to meet with the entire family. Family members may have questions about how to deal with HIV. You can help them talk about problems, solve conflicts, learn how to support each other, and find other sources of help from the community or government.

If a parent has HIV or AIDS, encourage her to talk about it with her children. Children often can tell that something is wrong. They may already have had one parent die of AIDS. It is important for parents to talk with their children about what to expect in the future, even if this might include becoming an orphan.

Help parents plan for their children's future

When adults with HIV die, they often leave behind children. Many parents with HIV worry about this and try to arrange for their children to be cared for by others, but in areas where HIV is widespread this can be difficult. Millions of children have been orphaned by HIV.

Parents often need support to appoint a guardian or make a will that leaves family assets to wives or children and gives other instructions about the children's future. A counselor can help parents see this planning as security for the family rather than just preparing for death. Caregivers of orphans also need support, especially in places where HIV is very common. This support



can be through counseling, parenting training, burial and lending funds, community food programs, shared childcare, or help in paying school fees. Orphans should also be provided HIV counseling and testing so that they can receive care and treatment if needed.

Children not yet orphaned but living with ill and dying parents also need support, to make sure their needs for food, attention, education, and health care are being met.

If a woman has HIV, the chances are that one out of every three babies she gives birth to will have HIV. People with HIV will need help making decisions about family planning. Encourage people with HIV to talk with their partners about family planning. This is a time when giving accurate information and supporting someone with HIV will most help her.

Supporting children with HIV

Children with HIV, even young ones, need to know that they are sick. Younger children may only need to know a little bit about HIV. Give them short, simple answers to their questions. Older children understand more and need correct information and honest answers. If they do not get this information from you or their family, they may get the wrong information from someone else. A child with HIV may suffer silently because of shame or fear. She may have problems sleeping or trouble at school. She may avoid family and friends. Warn families about these signs and help them to talk openly with children who have HIV.

Support groups

It is often useful for a group of people with the same problem to get together and talk about their lives. “Support groups” of people with HIV give people a chance to talk about their problems and successes. People with HIV can learn how to deal with common problems from other people in the group. Support groups help members feel less lonely. People gain strength from their group because they know that they are not alone in struggling with HIV.



There are different types of support groups. “Drop in” groups meet regularly but people go to meetings only when they want help with a particular problem or when an emergency arises. In other groups, the same people meet weekly for a few months; everyone goes to the meetings, whether or not they have a particular problem to talk about that day. There are also long-term groups that last for years. Long-term groups may be especially useful because they allow people to get to know each other well. These groups also experience the sadness of having members of the group become sick and die.

It is helpful when groups are made up of people with similar lifestyles. The members understand each other’s situation and language. You can start support groups that are made up of people with similar backgrounds, such as people of the same social or ethnic background, or people who share a certain risk or condition, such as sex workers, drug users, or pregnant women.

Support groups are also useful for the families and friends of people who have HIV. Even though these people do not have HIV, they may fear losing a friend, becoming infected, or being shunned by their communities and families. A support group can help them with many of the problems they face in having a loved one with HIV.

Care for people with HIV

A person with HIV can live a longer, healthier life with some simple and low cost interventions. Medicines to treat HIV are important (see the appendix at the end of this book), but there are many other measures that can also make a difference in a person’s health. See the next page for a sample list of interventions for helping people with HIV.

Basic care for people with HIV

Cotrimoxazole (trimethoprim/sulfamethoxazole) is a low cost antibiotic that prolongs the lives of children and adults with HIV and prevents malaria and diarrhea, and avoid hospitalization. See the appendix at the end of this book for information on giving this medicine.

Safe drinking water is important for everyone. It is essential for people with HIV because diarrhea caused by unclean water is more common and severe for them. Simple methods for cleaning drinking water are boiling for 3–5 minutes, or adding 5 drops of 5% bleach solution to every liter of water. Also, try pouring water into cups or pots, instead of dipping them back into a full bucket of water, which spreads germs to the water that everyone shares.

Medicine to prevent TB (isoniazid). Tuberculosis (TB) is a common and dangerous lung infection. It is especially common and deadly in people with HIV. Some HIV treatment programs are now giving medicine called isoniazid for 6 to 9 months to prevent TB. Note: it is important *not* to treat people who *already* have TB with isoniazid because people who already have TB need more than one drug. If possible, everyone should be tested for TB before receiving isoniazid, and no one with symptoms of TB (coughing, fever, weight loss, night sweats) should be treated with isoniazid without being tested first. See the section on TB in the appendix for more information about diagnosing and treating TB.

Bed nets treated with insecticides can prevent malaria, a common infection passed by mosquitoes. Problems from malaria are more common and dangerous in people with HIV.

Good nutrition and multivitamins improve the health and prolong the lives of people with HIV, and lower the chances of a mother passing HIV on to her baby. The best way to get vitamins is by eating a variety of nutritious foods like fruits, vegetables, grains, beans, eggs, milk, and meats every day. Taking multivitamin pills every day may offer additional protection.

Offering counseling, testing, and treatment for HIV to family members can help people with HIV talk openly about their status with their partners and family. It can help people with HIV get more support and help from their families, including the support they need to take medicines. It is also useful because many family members of people with HIV are also infected with HIV, but do not know it because they have not been tested. Providing testing, treatment, and a regular supply of condoms to people with HIV and their partners prevents transmission in a couple where one person has HIV and the other does not, and can help prevent transmission from mother to child. Providing testing to family members allows those who have HIV to seek care and treatment.

Social support

All people with HIV will at some time need help. In some countries this will come from their families. In other countries this will come from the community or the government. For example, counseling, home care, needle-exchange programs, and assistance with food, shelter, or transportation may all be available. Find out what services are available and direct people to them when needed. If there are no services available, start some. This may mean starting a support group for people with HIV, making a list of health workers and counselors who work with people with HIV, or setting up a “buddy system” where people with HIV volunteer to be friends to others who are infected. Be creative and talk with people who have HIV about their needs and how they can be met.

Home care

Most families take care of sick members at home. It is often the best way to care for people with HIV. But some people are afraid to care for loved ones with HIV at home. You can help people get over this fear and give practical advice on how to best give home care. With a few precautions, it is possible to care for people with HIV safely at home. You should remind people who are thinking of home care that HIV has never been spread by sharing food, cookware, towels, or other household items.

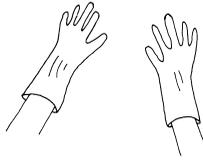
The real risk with home care is for people with HIV. They catch diseases from other people in the household, not the other way around. Even colds or the flu can be serious for someone with AIDS. Some simple things will help people live more happily at home. Living areas



Supplies for home care



Plastic for bed



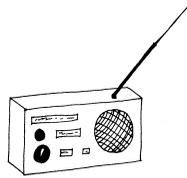
Gloves



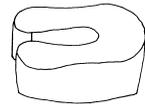
Walker



Plastic urinal made
from an old container



Radio



Bedpan or bedside
commode

should be clean. Rooms should have plenty of light and air. People with HIV can cook for others without any risk of passing the infection. If they have open sores they should avoid cooking until the sores are better. Anyone who cooks should wash his hands with soap and clean water before preparing food. Dishes should be washed in hot, soapy water. Foods that have dirt on them should be well washed. This is especially true for vegetables grown with animal or human stool as fertilizer. All people should wash their hands with soap after going to the bathroom to prevent the spread of disease.

There are many simple things that can be used to make life at home easier for people with HIV and their families. Some of them may already be in a person's home, such as a radio, a bedpan, gloves, or a walker.

People with HIV have many needs and there are never enough services to help. Money and other resources are often lacking and people with HIV and their families often feel alone in their personal struggle against the disease. You can be a source of hope and help for people and their families.

Home care in Zambia

The AIDS Care and Prevention Programme at the Chikankata Hospital in southern Zambia is a good example of home-based care and prevention efforts in Africa. The program's three-stage effort includes providing medical and nursing care, offering free counseling, and teaching other communities about HIV.

In the home care part of the plan, health care workers make home visits. These visits are made not only for people with HIV and AIDS but for people with serious conditions like epilepsy and cancer. This approach helps avoid discrimination against the people being visited. The home care team teach families about HIV and about practical matters in home care, like how to make a solution (oral rehydration solution) to replace fluids lost by diarrhea. They also draw blood samples and ask families how the team can best help them. Hospitals are often overcrowded and better care can be given at home. These home visits help both the family and the hospital work more effectively.



Support for health workers

People who counsel or care for very ill people sometimes become sad and tired. This “burnout” may happen if health workers do not have sufficient time to rest and talk about their own sense of frustration and loss.

Burnout can be emotional, intellectual, physical, or all three. It affects how people do their job. People start to feel tired, helpless, or hopeless. Even workers who usually have a lot of energy and hope may find themselves struggling with burnout. It is important for you to realize that this may occur and to take steps to avoid it.



Burnout

Here are some things that can help prevent burnout among health workers.

1. Keep a sense of humor; it helps in stressful situations.
2. Take on a variety of jobs so that you are not doing one stressful job all of the time. This will keep you interested in your work.
3. Make sure you work a reasonable number of hours. Most people who work too much do not work well after a while.
4. Encourage volunteers and reward them with parties or small gifts to let them know their work is appreciated. Make yourself available to answer questions, and acknowledge their efforts in front of others.
5. Recognize work that is well done. People need to know they are doing a good job. Each person needs something different, so give personal compliments.
6. Keep your eyes on the big picture—all the good things in life—so that you do not get lost in the day-to-day struggle.
7. Recruit people who are dedicated and are from the community with which they will be working. They are often more committed and comfortable with the job.
8. Give people days off from their jobs so that they can rest and recover from stress and the strong emotions they may experience at work.
9. Everyone can burn out, even a director or group leader. Be aware of signs of burnout in yourself and others, and work together to avoid it.

How to support Angela

“I do not want to live now that I have AIDS.”

Angela is clearly feeling sad and overwhelmed by the news of having HIV. This is understandable, but she has other reasons to be hopeful. She has HIV infection but does not have AIDS. She has a boyfriend who loves her and can help her cope with her illness. She has a family that cares for her. She will live to see the birth of her child. There are medicines that can treat some of the illnesses she will get in the future, and people with HIV are now living longer than they did in the past.

You can talk with Angela about telling her boyfriend about her HIV test. This will bring up many issues, including whether he or she has had sexual partners outside their relationship. It may help for you and Angela to practice how she will tell him that she has HIV. You can offer to talk with her and her boyfriend together about how to live with HIV. There will be many issues you will want to talk about with them, including whether Angela’s boyfriend might want to get tested and the fact that the virus can spread from mothers to their babies. Angela may want to talk with other people, especially pregnant women, who have HIV. If there are no support groups in her area, you can help Angela start one. Angela spoke about not wanting to live. Talk about suicide should always be taken seriously. Try to meet with Angela regularly so that she does not feel alone. Encourage her to think positively.