



Connectors Kit Community Action for Advanced HIV Disease

2nd Edition 2026 – IMPAACT4HIV



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Introduction

This guide is for anyone in the community who wants to help others living with HIV, especially those who are very sick or getting weaker.

It's built from community feedback of the needs of caregivers, young people, traditional healers, health workers, and community leaders across countries, not just more information, but more understanding, more connection, and more support.

Too many people are still getting very sick or dying because of HIV-related illnesses like TB or a syndrome like AIDS. This stage, called Advanced HIV Disease (AHD), is often invisible until it's too late. But it doesn't have to be.

Remember that when someone is living with HIV they are part of a bigger story. Their health is linked to the people around them: the caregiver who reminds them to take their pills, the nurse who listens without judgment, the friend who walks with them to the clinic, the teacher who notices when they're struggling, and the traditional healer who offers comfort in familiar ways. When one person's immune system is under attack, the whole community has a role to play in support, healing, and hope. HIV is not just a medical issue, it's a community journey. And when we walk it together, no one has to face it alone.

This guide helps you:

- Spot the signs early (before it's too late)
- Support people with care, not shame
- Talk about HIV using local language
- Understand how disclosure is a journey, not a one-time conversation
- Use peer support and storytelling to build trust
- Work together as a team. Caregivers, parents, health workers, youth, elders, and healers.

Keep an eye open for our "Say It Out Loud" sections: these sections will give you ideas for discussion groups or activities!

We know now that prevention and treatment of advanced HIV disease is not just a medical problem, it's a human one.

If you're someone who helps others — at home, in a clinic, in your church, school, or a traditional healer — this guide is for you. Let's make sure no one slips through the cracks. Let's help people stay strong, live longer, and know they are not alone.

HIV and

Advanced HIV Disease



Remind Me About HIV

HIV (Human Immunodeficiency Virus) is a virus that attacks the body’s immune system – the “soldiers” called CD4 Cells that protect us from getting sick. Over time, if HIV is not treated, it weakens the body so much that even small infections can become severe.

HIV spreads when the virus moves from one person’s body into another’s, usually through certain body fluids like blood, semen, vaginal fluids, and breast milk.

The most common ways this happens are

- ! during unprotected sex,
- ! by sharing needles or sharp objects,
- ! or from a parent to a baby during pregnancy, birth, or breastfeeding (but that can be prevented with treatment).
- ! In rare cases, HIV can also spread through unsafe blood transfusions.

Ways of stopping HIV from spreading

			
Using condoms	Taking antiretroviral drugs	Getting circumcised	Keeping communication open

You can’t get HIV from

			
Hugging	Sharing food	Using the same toilet	From mosquito bites. That’s just a myth.

Knowing the real facts helps you stay safe and helps stop stigma too. The good news is HIV can be managed. With the right medicine (called ARVs), people with HIV can live long, healthy lives, have children, and stay strong.

Why Are People Still Getting Very Sick From HIV Then?

Even with free medicine and improved services, too many people are still getting very sick or dying from HIV-related illnesses. Your immune system has cells in your blood called CD4s. These CD4 cells are like the body's soldiers, they help protect us from getting sick. These special cells fight off germs and infections. When someone has HIV, the virus attacks and destroys these CD4 cells. The fewer CD4 cells you have, the weaker your body's defence becomes.

The CD4 count is used to see how strong the immune system is



A high CD4 count
means your body is
still strong.



**A low CD4
(especially under 200)**
means your body is in
danger and needs
urgent support.

Sometimes people living with HIV feel completely fine for years so they don't test, or they stop taking their ARVs because they don't feel sick. But even when someone feels well, the virus can still grow quietly in the body and spread to others through sex, pregnancy, or breastfeeding – without them even knowing. That's why it's so important for everyone to know their status.

"The fewer CD4 soldiers you have, the harder it is to fight back when sickness comes."



If you test negative, take steps to stay negative and get retested when needed.

And if you're living with HIV, the best thing you can do is start treatment early and take your meds every day. That's how you stay healthy and protect the people you care about.

Advanced HIV Disease (AHD)

is a advanced HIV sickness that can happen when HIV has weakened the body's immune system so much that it can't fight off infections anymore. Sometimes when there is more than one type of infection all at the same time, or the body becomes ill in other ways, we call it AIDS.

Without treatment, a person with HIV is more likely to get very sick from illnesses like:



Tuberculosis
(TB)



Meningitis
(brain infection)



Pneumonia or
other lung
infections



Cancers



Diarrhoea, fever,
and extreme
weight loss

This means that ARVs are very important!
They don't cure HIV, but they stop the virus from growing and they protect your immune system.

Getting tested for HIV is something to be proud of too. It shows courage, it means you're taking charge of your health and looking out for others too. People who test are showing leadership, not weakness.

And those living with HIV who take their treatment every day? They are strong. If you stay on treatment, then the virus load gets so low that it can't even be detected! And that means you can't pass on the virus to someone else. You become HIV SAFE if you stay on treatment, which means you can't pass on the virus to someone else. It takes commitment to stay on ARVs, to stay healthy, and to protect your loved ones. These are the people holding our communities up with honesty, care, and strength.

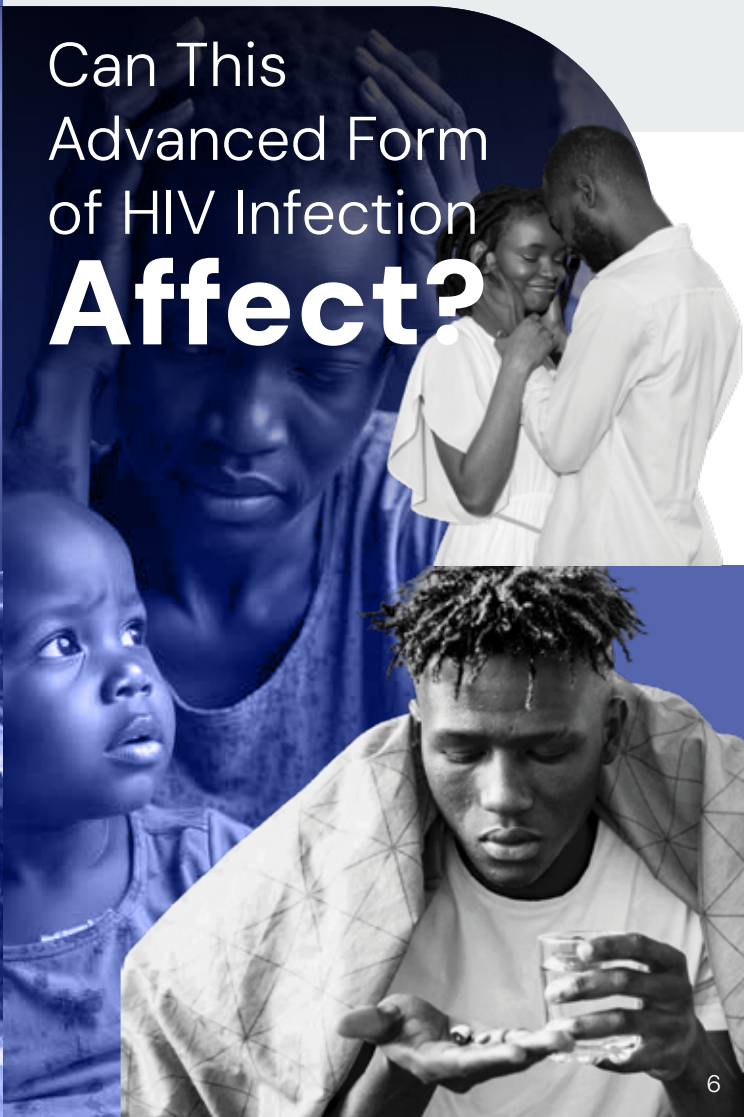
"My brother stopped taking his pills. He said he felt fine. But three months later, he had TB. The clinic said his CD4 was very low. We didn't even know what that meant."



2

So, Who

Can This
Advanced Form
of HIV Infection
Affect?



This Advanced Form of HIV Infection Affects...



People who stop taking their ARV treatment:

Like we saw above, ARVs only work if you take them every day, and at the right time.. When someone stops, even for a few weeks, the virus wakes up, starts to multiply and starts attacking the body again, especially the immune system.

Sometimes people stop taking treatment because

- they feel fine, or
- because of side effects,
- stigma, or
- life stress,

not because they don't care.



People who don't know they have HIV:

Some people live with HIV for years without knowing it. They don't feel sick until suddenly, they do. By the time symptoms show, the virus may have already done serious damage to the immune system or other parts of the body – including the brain, the kidneys and the heart.

These people often arrive at the clinic very sick and may already have Advanced HIV Disease (AHD) without realizing what is happening in their bodies.



People who are living in poverty or alone:

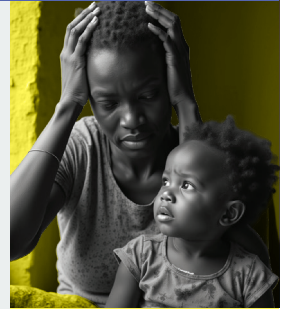
When someone is struggling just to survive with no transport, food, or support then going to the clinic may not feel possible.

People who move around a lot may find it difficult to stay at the same clinic or stick to appointments but with no phone number or fixed address it makes it difficult for clinics to find them. They might miss appointments, stop taking medicine, or not get tested at all.

Without care, HIV can get worse quietly until it becomes AHD.

Orphans or children whose caregivers are overwhelmed:

Children depend on adults to help them get tested, take their medication, and understand their health. But some caregivers like grandmothers, aunts, or older siblings are doing their best with very little. They may be grieving, confused, or simply too stretched. This makes it easy for a child's health to slip through the cracks. Sometimes children move between households, or different caregivers, and no one explains that the child is supposed to be on HIV treatment. Because the child still looks healthy, the new caregiver might not even know they need medication. Teenagers face their own challenges. As they grow more independent and start questioning rules, they may stop taking treatment, especially if they haven't been told why it matters or are still struggling to accept their diagnosis. That's why clear communication, support, and honest conversations are so important – so no child or teen falls through the cracks.



That's why clear communication, support, and honest conversations are so important – so no child or teen falls through the cracks.

People who feel ashamed or afraid:

HIV still comes with a lot of fear and silence. Some people hide their status, skip pills, or avoid going to their clinics because they're scared of being judged. If they stop treatment or never start, HIV can weaken their body over time, — until they become very sick. It's also key to remember that not everyone who gets very sick with HIV has done something wrong. Sometimes, even people who take their treatment every day can still develop AHD Advanced HIV Disease (AHD). This might happen if one develops drug resistance, or if their immune system struggles to recover, which can be caused by things like age (very young or older adults), and other health conditions (like diabetes, high blood pressure, TB, or cancer), or even what they eat their diet.



Sometimes people take a break from their treatment or are unable to continue for a while, and then feel scared to go back. They worry that they'll be shouted at, blamed, or treated badly at the clinic, so they keep delaying. Others are afraid someone at home might find their pills or clinic card, or spot them at the facility. Fear, shame, and stigma can push people to hide even when they want help. That's why it's so important to welcome people back with kindness and no judgment. What matters most is that they've come back and they're trying. That's when they need our support the most.

People who have other medical conditions:

- Sometimes people’s immune systems don’t recover because they have other medical conditions like diabetes, hypertension or cancer that can affect their bodies.
- Immune system recovery can also be affected by drinking alcohol and smoking, as well as age (the really old and really young are more vulnerable).

Some people with advanced HIV sickness might:



Lose a lot of weight quickly



Feel weak or tired all the time



Have repeated episodes of diarrhoea



Feel confused or dizzy



Have no appetite



Get sores in the mouth or on the skin



Get a painful, itchy rash



Get repeated fevers, coughs, or headaches

In children, it might look like:

- Not growing properly
- Not wanting to eat
- Falling behind at school
- Constant flu, diarrhoea, or tiredness
- They might also just seem “not the same” as they used to be.

Also, because children under 5 years old (and babies) who are living with HIV are more likely to get very sick very fast, we treat them like they already have advanced HIV!



We’ll look at these signs again in the next section.

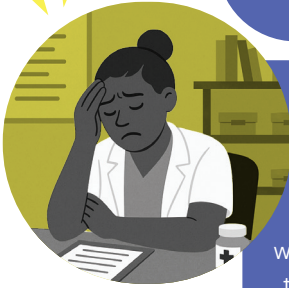
Remember that when someone is living with HIV, their story is deeply connected to others.



A child's health often depends on the strength and understanding of their caregiver,

like the older aunt who feels guilty for not disclosing earlier,

or the grandmother who forgets pill times because she's caring for many children alone or wasn't given instructions in a language she is comfortable with.



In the clinic, the frustrated nurse may be doing her best with no emotional support or time to explain,

while the community healer or teacher, though trusted, often feels shut out of formal care systems. This disconnect is what we must strive to close.



Meanwhile, young people who know their status may feel silenced, even though they're ready to lead and support others — like the teen who just needs a space to speak.



And some children quietly struggle, confused about their bodies, scared to ask questions, and often misunderstood coupled with pubertal changes..



All of these people are part of the same ecosystem and when just one link is weak, it affects everyone. Supporting someone with HIV means supporting a whole circle of care. And when we do it with empathy, honesty, and shared responsibility, we create a net that can catch people before they fall into advanced HIV disease crisis.

Say It Out Loud

Here are some things to talk about in a group:

?

Have you ever known someone who got really sick because of HIV? What happened?

?

Why do you think some people wait until they're really sick before they go to the clinic?

?

Is there something specific about your community that might influence people to hide symptoms or delay getting help?

?

If someone asked you, "What is advanced or severe HIV disease?" — how would you explain it to a friend?

?

Have you ever been sick yourself or helped someone who was? What was that like?

?

What slang do people use around here for HIV or AIDS?

?

If you were just diagnosed with HIV, who would you tell?

?

Are there any sayings, nicknames or metaphors people use when someone is sick or weak?

?

Why is it still hard to talk openly about HIV, especially with friends or family?

?

How can we make HIV conversations feel more real, safe, and respectful — without shame?

How Do I Know

3

If I Or Someone I'm Helping
Has Advanced HIV Disease?



How Do I Know If I Or Someone I'm Helping Has Advanced HIV Disease?

People should test for HIV regularly and if they are living with HIV they should stay on their medication but if they are unable to, then HIV can spread in the body until they have an advanced HIV infection.

Some warning signs are:

- Weight loss
- Constant tiredness
- Long-lasting fever
- Persistent cough
- Confusion or dizziness
- Mouth sores or skin rashes
- Have repeated episodes of diarrhoea

In children these signs may be a little different, so parents or carers need to keep an eye open for:

- Poor growth or weight loss
- Not playing or learning like others their age
- Getting sick often (e.g. flu, diarrhea)



- ✓ There might be other reasons for these symptoms but if you are caring for someone with HIV then it's a good idea for them to visit a clinic, even if the symptoms are small.
- ✓ Sometimes, spotting the signs early and stepping in to help can really change someone's life for the better.
- ✓ If you notice any of these symptoms, or if you're just feeling unsure, it's always a good idea to talk to a health worker—they're there to support you.
- ✓ Regular check-ups, open chats about how you're feeling, and reaching out to your community can all help keep people with HIV healthy and safe.
- ✓ Also, not everyone with these symptoms is living with HIV, but testing is always a good idea if you're unsure.
- ✓ Even better to get tested every time you have a new partner or pregnancy – even if you feel completely well!

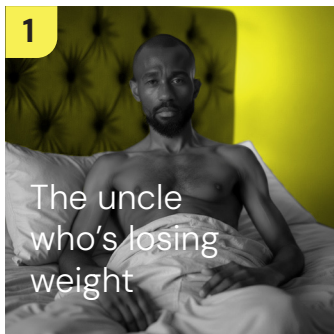
When families, friends, and community helpers work together, everyone stands a better chance.

Say It Out Loud

Sometimes role playing can help people remember important information. Here's a role play activity you can use in a group:

What's Really Going On? Sometimes people living with HIV get very sick — often because they didn't know they had HIV or stopped taking their treatment. These roleplays will help us spot the signs and talk about what to do early.

1



The uncle who's losing weight

Characters:

- 👤 **Uncle Sipho** (coughing, tired, losing weight)
- 👤 **Niece** (notices he's been in bed a lot)
- 👤 **Neighbour** (says, "He just needs herbs")

Prompts:

- ❓ What signs do you notice?
- ❓ What should the niece do?
- ❓ Why might Uncle Sipho not want to go to the clinic?

2



The teen who stopped taking arvs

Characters:

- 👤 **Teenager**
- 👤 **Best friend**
- 👤 **Caregiver**

Prompts:

- ❓ Why did the teen stop taking medicine?
- ❓ What might the friend notice?
- ❓ How can someone talk to them without judgment?
- ❓ What signs of advanced HIV are we seeing?

3



The child who's always sick

Characters:

- 👤 **Young child**
- 👤 **Grandmother caregiver**
- 👤 **Clinic nurse** (visited weeks ago, no follow-up)

Prompts:

- ❓ What is the child showing (tired, not growing, missing school)?
- ❓ Why might the grandmother be unsure what to do?
- ❓ What would a friend or neighbour say to help?
- ❓ What other signs of advanced HIV might we see?

Make up some of your own, this is a very good brain training exercise.

A black and white photograph of a young Black couple sitting on a couch, looking at each other. The woman is on the left, wearing a patterned tank top, and the man is on the right, wearing a t-shirt. The background is a solid lime green color. There are decorative diagonal stripes in the top left and bottom right corners.

*"If we can talk
about it, we can
deal with it."*

How Can We

**Support
Each Other?**

4

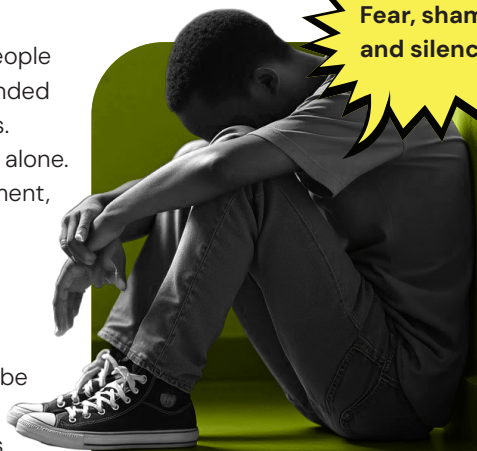
Even though HIV treatment has improved and people can now live long, healthy lives, HIV is still surrounded by fear, shame, and silence in many communities. This silence can be harmful. It makes people feel alone. It stops them from getting tested, starting treatment, or asking for help when they feel sick.

Remember that HIV isn't a moral failing and no-one set out to get HIV on purpose.

Some people would rather suffer in silence than be judged. This can lead to Advanced or Severe HIV Disease! But when we talk openly, we help others feel less afraid and more supported. Whether you're a caregiver, a young person, a friend, or a health worker your words can make a big difference.

When we share stories, speak kindly, and create safe spaces, we remind people that HIV doesn't define them, but it does need to be treated.

**Fear, shame,
and silence**



Remember

"No one went to the market purposefully to buy HIV!"

We must always remember that HIV doesn't have a "look" and it doesn't have a type. There are so many ways a person might be living with HIV, and none of them deserve blame or shame. It's not just about what people assume.

- There's the woman who has only ever been with her husband — but he had other partners she didn't know about.
- There's the young man or woman who was born with HIV and only found out in his/her twenties.
- There's the nurse who got HIV after a needlestick injury on the job.
- There's the teenage girl, in her first relationship, who didn't know her older boyfriend was living with HIV.
- There's the woman who was raped while pregnant — and still trying to heal.
- There's the married man whose wife stopped her treatment without telling him.
- There is the married man who takes his medication at work and has never told his wife about his status. There is a pregnant woman who tested positive, and her husband also does not know his status.
- There is a woman born with HIV, living with her in-laws, her husband is negative and has accepted her status but has not told his family yet.

Every story is different. What people need is support, not judgment. When we drop the stigma, we make space for healing.

Talking Openly to Reduce Fear and Stigma

HIV is still surrounded by shame and silence. This can stop people from getting help. We must change this by:

- Sharing stories of people living well with HIV
- Saying: 'HIV is not a death sentence' and showing support
- Creating support groups where people feel safe to speak
- Changing our own beliefs and knowing HIV is not a death sentence but another condition that one can live a long healthy life with.

Telling Children in Age-Appropriate Ways

Children living with HIV need support to understand their condition.

See the “Let’s Chat – Talking to Kids” section below.

Peer Support and Youth Leadership

Teens trust other teens. Support youth clubs, peer mentors, and Whatsapp chat groups can provide:

- Basic HIV knowledge
- Mentorship and psychosocial support
- Support dreams and aspirations, these are the engines that drive young people
- Training on communication and self-care
- Stop negativity about those living with HIV around them, and have helpful conversations.
- Answer questions as honestly as possible without being judgemental

Things like chat groups may still need to be monitored by a trusted young adult to ensure the correct info is shared and myths or gossip doesn't spread.

Caregivers (like grandparents, aunts, or older siblings) often feel lost. Help them by:

- Giving clear information and counselling
- Connecting them with other caregivers
- Recognizing their role and thanking them publicly



Understanding the People in the Advanced HIV Disease Journey

Every person living with or caring for someone with HIV walks a different path. Here are some characters that represent common experiences, emotions, and challenges. We can step into other people's shoes and ask:

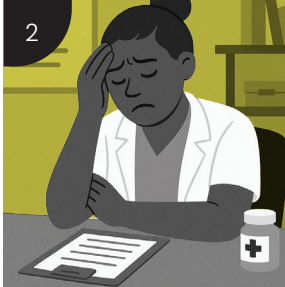
"What do they need?", "What support would help them feel stronger, not judged?", "How can I help", "How can I be there for them?", "Who else in their inner circle can work with me to support them?"



The Older Caregiver

She's a grandmother or auntie raising a child whose parents are deceased, away or otherwise unable to care for them.. She tries her best but often forgets instructions, struggles with guilt, or avoids care because of trauma or fear.

"I don't always understand the medicine. I just hope I'm doing the right thing. It is not my duty to tell the child of this condition the parents should have told the child."



The Frustrated Health Care Worker

She wants to help, but she's overwhelmed. There's too much work, not enough support, and no space to deal with emotional pressure.

"I want to care, but I'm tired. The system and patient attitudes make it hard."



The Protective but Overwhelmed Mother

She's trying to shield her child from stigma, pain, or the truth. But she feels alone, unsure how to navigate the clinic or talk about HIV.

"I don't know what to say... I'm scared my child will hate me or her father." Or "I feel that my child is too young and will not be able to keep a secret." Or "I don't know how to tell my child this story without exposing my anger towards the person who gave HIV to me"



The Community Healer or Connector

They're trusted by the community — a “mover & shaker”, teacher, or church leader — but feel left out of formal health systems. They want to help but lack training or tools.

“People come to me first. But I’m not part of the clinic system.” “I do not think I have enough information yet to share with people who trust me to know about this”



The Silenced Adolescent Leader

They live with HIV and want to support others, but no one listens. They're ready to lead — if only someone would give them a voice.

“I know what this feels like. I just want to help others like me.”



The Quietly Struggling Child

This child may not speak up, but they're feeling the weight of HIV. They may miss doses, get sick often, or feel alone and confused.

“They say I’m fine. But I don’t understand what’s happening to me.” Or “They say I take this medication for headache or Asthma but I feel fine, when will it end?”

Remember that HIV doesn't happen in isolation. Everyone has a story — and when we understand that, we respond with compassion, not judgment.

Say It Out Loud

Talking to Kids About HIV One Step at a Time

Telling a child they're living with HIV can feel scary — but it doesn't have to happen all at once, and you don't have to do it alone.

We follow a simple idea:

- tell them slowly,
- in a way they can understand,
- at the right age and time.

This is called age-appropriate disclosure, and it means giving children little pieces of the puzzle until they're ready for the full picture.

For little ones (around 4–6 years old)



You don't need to say "HIV" yet. Just help them understand they have a sickness that needs medicine every day.

"This is your strong medicine and these pills give the soldiers of your body the strength to fight against bad germs. They become bigger and stronger than the germs!"

For kids (around 7–9 years old)



They start asking more questions like "Why do I take medicine?" "Why do I go to the clinic?"

You can explain that there's a virus in their body that the medicine keeps under control.

"You've got a tiny germ in your body, but your pills keep it asleep so you can grow strong."

For older kids (around 10–12 years old)



Now's the time for full disclosure, tell them the name of the virus: HIV. But don't just drop the word and walk away. Talk gently. Give them time. Be ready for feelings.

"You have something called HIV and it's why you take medicine. But lots of people live full, happy lives with it."

"HIV is not something you can catch from everyday things. You cannot get HIV from hugging, sharing food, using the same toilet, playing together, or touching someone. It does not spread through coughing, sneezing, or kissing on the cheek."

For older kids (around 10–12 years old) continued



"HIV can only be passed in very specific ways, usually through blood, or from a parent to a baby before or at birth. That's how you got it—it's not your fault."

Let them know they are safe and not dangerous to others:

"You are not a danger to anyone. You can go to school, play sports, have friends, and do all the things other kids do."

For teenagers (13 and up)



Teens might already know or suspect. They need honesty, space to ask questions, and support to deal with real things like school, sex, dating, and future plans. They also need to know they're not dirty, broken, or to blame.

*"Knowing your status is power. You've got this.
And we've got your back."*

"You can come to me if you need to understand something"

Some more tips for Caregivers and Supporters:

- Take your time. This is a journey, not a one-time chat – and the sooner you start the easier it gets to add information over time.
- Ask for help. Nurses, counsellors, and teen mentors can guide you.
- Use stories, drawings, dolls, or metaphors.
- Keep checking in. Kids might not say much now, but they're thinking, and they'll come back with questions.
- Find age appropriate support groups for kids to participate in.
- Remind them often: ***"You are loved. You are not alone. And this does not define who you are and this is not the end of the world. You can be whoever you want to be if you just believe it."***

It's important for children to have a good understanding of HIV in order for them to make the right choices when they're older to prevent severe HIV or Advanced HIV Disease.



What Can We
As Communities

Do to Help?



HIV care doesn't only happen in clinics, it also happens in homes, schools, churches, taxis, tuck-shops, and WhatsApp groups. That means the community as a whole has a role to play. You don't need to be a doctor or nurse to make a difference. Whether you're a neighbour, youth leader, caregiver, shop owner, or traditional healer you can help someone get support before it's too late.

Chances are that you got this guide from someone who works with a local organisation or knows what type of activities are happening in the area. Ask them for more info or jump in to help.

The most important thing you can do is share information! Share what you learned in the previous sections of this guide, it will save lives.

Use What People Know and Love in Your Area

- Street theatre and storytelling to spark conversations
- WhatsApp voice notes or local radio to share messages in home languages
- Church announcements or roadside shop chats to spread information in everyday spaces

Provide Safe Spaces for Sharing

- Support groups for caregivers or youth
- Quiet corners at the clinic or community hall for check-ins
- Snack & chat circles — casual meetups where people can talk freely

Train Local Champions

- Train peer educators, caregivers, and community leaders
- Teach people how to talk about HIV without shame or fear
- Show them how to recognise AHD symptoms and act early

Support One Another with Action

- Walk with someone to the clinic
- Help with childcare or chores if a caregiver is sick
- Check in kindly on children missing school or always sick

When communities feel informed, connected, and confident — people are more likely to get help early, take their treatment, and feel cared for. Everyone has a part to play in stopping advanced HIV before it takes hold.



Talking It Out: More About Community Dialogues

Good health care doesn't start with pills – it starts with trust. And trust starts with talking. Community dialogue is about bringing together caregivers, clinic staff, local leaders, and young people to have real conversations. These conversations help us understand each other better, break down fear, and find ways to work together. For children and adults with AHD, these conversations are life-saving.

Here's why dialogue matters:

- It builds trust.
- It uncovers real issues.
- It sparks solutions.
- It makes leaders accountable.
- It helps everyone understand the system.
- It includes everyone.

If you're living with HIV and doing well on treatment, your story matters. In fact, it might be the most powerful tool we have. When you choose to share your journey – how you got tested, how you started ART, how you've kept going – you help others see what's possible.

You don't need to be a doctor or a nurse to change someone's life. Just by being open, you show others they're not alone. Even if they're too scared to ask questions or speak up, they're listening. And just hearing your story might give them the courage to keep going. It also tells them: "This is someone I can trust. This is someone who understands." You are living proof that thriving with HIV is possible and that makes you a powerful voice of hope.



There's no exercise for this!
This is what it all boils down to in communities:
make connections, share information, get out there and make a difference.

Contact local organisations for support or guidance – see the list at the end of the guide.
[country and region specific appendix]

6

What About **Clinics, Medicines and the Government?**



Sometimes people want help but the clinic is too far, the line is too long, or the medicine isn't there. That's not the community's fault. For people to stay on treatment and get support early, clinics must feel safe and welcoming, medicine must be available, and decisions made by departments of health should include the voices of ordinary people. This can be difficult in countries and areas that might be struggling with resources or other constraints. That doesn't mean that we as a community can't nudge things in a better direction.

There are Civil Society Organisations and groups for People Living With HIV that work in communities and engage with clinics, the Health Department and the Government.

- Your first step is to connect with them and see what's happening in your area.
- If you work for one of them already, see what others are doing.
- And sometimes the best way to improve health services is to listen to the people who use them.

That's what Community-Led Monitoring (CLM) is all about.

With CLM, community members and civil society groups track what's really going on like whether medicines are available, if staff are kind, or if services are working for children. They collect this info by

- talking to caregivers,
- observing clinics,
- using tools like scorecards or surveys.

This helps spotlight what's working and what's not. It gives communities the power to speak up backed by evidence. And it opens space for real conversations with clinic managers, government, and donors to push for change that matters.

But remember that we are working to support health facility staff as well. When communities and clinics work hand-in-hand, children and adults with Advanced HIV Disease (AHD) get the care they need faster.

One helpful way to build this partnership is through something called **C3: Clinic – Community Collaboration**. Instead of working alone, the C3 model

- helps everyone share knowledge,
- spot gaps in services, and
- create solutions that work in real life.

For children and adults living with advanced HIV illness, this kind of partnership can be the difference between falling through the cracks or getting back to health.



It starts with
planning

(spotting problems,
sharing resources),

moves into
action

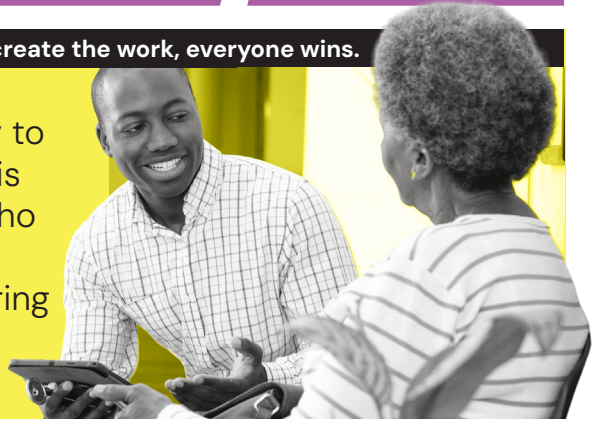
(joint activities
and follow-up),

and leads
to change

(advocacy and
better policies).

When clinics and communities co-create the work, everyone wins.

Sometimes the best way to improve health services is to listen to the people who use them. That's what Community-Led Monitoring (CLM) is all about.



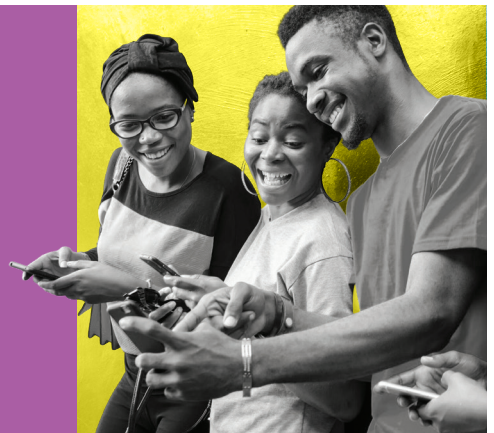
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This data helps spotlight what's working and what's not. It gives communities the power to speak up — backed by evidence. And it opens space for real conversations with clinic managers, government, and donors to push for change that matters. When used well, CLM doesn't just collect stories — it drives action, especially for children with AHD.

Get busy!

- Call, Whatsapp or email each other
- Attend local meetings
- Raise awareness for each other
- Celebrate wins, like when someone with advanced HIV gets treatment and gets healthy again or when a clinic manages to make a child friendly space

Join the dots!



Say It Out Loud

Remember it's not about complaining but rather about working together.

Local communities can do a lot when everyone works together. Remember to make those connections!

If you have the opportunity to speak to clinic managers or local government officials, here are some suggestions or questions for you to share:

Make the Clinic Feel More Friendly

- *"Please ask staff to greet people nicely and explain things clearly to everyone? Especially to older people or teens."*
- *"Is there a private space to talk about HIV or serious HIV illness?"*
- *"Could someone from the community help welcome people or answer questions when they arrive?"*

Keep the Medicines and Tests Ready

- *"People are scared to come back when the medicine isn't there. Can you help make sure it's in stock?"*
- *"Please make sure very sick patients get started on treatment right away."*

Use Us, the Community

- *"Could we help with a suggestion box or small check-ins so you hear from the community?"*
- *"We've got stories of people who got better let's share those too."*
- *"Can we sit in on some of your meetings about or give feedback? We might be able to help."*
- *"Could we have a community day at the clinic, something relaxed where we can talk and learn?"*
- *"Don't forget the local teachers, pastors, or traditional healers, they can help spread the message."*
- *"Support groups for teens and caregivers really help, can we get more of that linked to the clinic space?"*

Connecting With

Care 7



We all know that good communication in communities is important to make them successful. The way we speak to people, especially when it comes to HIV, can make all the difference.

A kind word, a calm tone, or just really listening can help someone feel safe, seen, and supported. But when we speak with judgement, impatience, or pressure, people can shut down or stay silent. This section offers simple tips to help you talk in a way that builds trust whether you're chatting with a caregiver, supporting a teen, or helping someone who's scared to get tested or take treatment. It's not about having all the answers immediately, it's about showing up with empathy, respect, and care.

A Body Language (What You Don't Say Still Matters)

- 1 Posture:** Sit or stand up straight and face the person you're talking to. Lean in a little, it shows you're paying attention.
- 2 Facial expression:** A relaxed, friendly face helps others feel more at ease. Even a small smile can make a big difference.
- 3 Eye contact:** Look at the person when they're talking, not at your phone, or side glances as if you are expecting someone, or your watch. This shows respect and builds trust.
- 4 Notice their emotions:** If someone looks upset, nervous, or scared, pause and check in. Body language often says what words don't.



B Speaking and Listening With Respect

- 1 Tone of voice:** Speak calmly and clearly. A gentle tone helps people feel safe.
- 2 Ask open questions:** Instead of *"Are you okay?"*, try *"What's been on your mind lately?"* or *"How have you been feeling?"*
- 3 Give people space to speak:** Don't rush or interrupt. Some people need time to find their words.
- 4 Show empathy:** Say things like, *"That sounds really tough"* or *"I can see this is upsetting you, let's talk about it."*

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5 Use the word "we": Make it a team effort. Say,

"Let's figure this out together," or *"How can we make this work for you?"*

6 Recognise their effort: A little encouragement goes a long way. Amplify their strengths. Say;

"It's great that you came today," or *"I know it's not easy, but you're doing well."*

7 Never give a solution to the problem. Instead give imaginary scenarios that will lead to a solution they can handle. It helps them to rethink and realise they are doing well. Let them know they are not alone.

"Suppose or in a perfect world where everything was alright, what do you think you will be doing"

then
from
there
mention

"To get there, now that you have this issue how can we still achieve your goal in this case"

C Helping People Understand and Learn

1 Ask what they know first: Before explaining, ask,

"What do you think is going on?" or *"What have you heard about this?"*

2 Use simple words: Skip medical jargon. Say "virus" instead of "pathogen," "strong germs" instead of "opportunistic infections."

3 Check for understanding: Use short sentences. Pause often.

"Does that make sense?" or *"Would you like me to say it another way?"*

4 Repeat the important bits: People don't always remember everything — especially when they're stressed. Say the key messages more than once.

5 End on a positive note: Smile, thank them for their time, and leave them with hope. Say, "You're not alone — we're here for you."

"You're not alone — we're here for you."

or

"You are not alone- You have support around you"

Kindness, patience, and honesty go a long way.

Working with Different People Respectfully

When working with people in the community — whether women, men, youth, or other vulnerable groups — it's important to remember that everyone comes with their own fears, challenges, and lived experiences.

- Some women may feel shy or judged when talking about sexual health, especially if the health worker is a man.
- Men might feel uncomfortable in clinics, or avoid care because they're scared of what an HIV diagnosis could mean for their future.
- Others like adolescents, people with disabilities, sex workers, or men who have sex with men often face even more barriers due to stigma, discrimination, or lack of support.

That's why it's so important to create a safe, welcoming space in your activity where people are treated with kindness, respect, and privacy. Use simple, honest language, don't rush, and never judge. Whether someone walks in with questions, fear, or frustration just listen, respect their dignity, and meet them where they are. That's how we build trust.



8

Tell Me Again Why This Isn't Like 'Normal' HIV?

Advanced HIV Disease or severe HIV illness isn't just "normal HIV" — it's what happens when someone's immune system is already badly damaged, and they're at serious risk of dying.

These are the people who fall through the cracks:

- they might not know their status,
- might have stopped treatment, or
- might be too sick, too scared, or too late to act alone

People need

- extra support,
- quick treatment, and
- care that's not full of shame or blame.

Advanced HIV needs its own community actions because it's urgent, it's different, and it's preventable.

This Connector Kit helps you spot the warning signs early and shows how friends, families, and youth leaders can step in before things get worse.

"Getting very sick from HIV doesn't mean the end, it just means it's time to show up for ourselves or others. With the right support and the right medicine, we can bounce back. Our story doesn't stop here, it gets stronger!"

Your Story Matters

Some things can only truly be understood by someone who's been there. That's why your lived experience is one of the most powerful tools we have.

- Maybe you're a mother who stuck with your ART and helped your baby stay HIV-negative with PEP.
- Maybe you're someone who struggled with denial but found your way forward.
- Maybe you're a caregiver who was afraid to disclose to your child and it actually went better than you expected.
- Maybe you're a teenager learning to take charge of your own care.
- Maybe you're an adult who had "the conversation" with a new partner.

We need YOU. Your courage, your journey, your voice — they can help someone else feel less alone and more hopeful. Your story could be the reason someone takes their treatment seriously, finds the strength to disclose, or shows up at the clinic tomorrow.

Please contact your local organisation if you would like to help!



Acknowledgements

This toolkit would not have been possible without the strength, insight, and lived experience of the communities it is designed to serve. We extend our deepest gratitude to the individuals, caregivers, peer supporters, healthcare workers, and community partners who contributed their voices, stories, and time to shape this resource.

On behalf of the IMPAACT4HIV Project, we would like to thank all project and community collaborators who played a role in the successful development of the Community Connectors Kit. We particularly acknowledge Paediatric-Adolescent Treatment Africa (PATA) for overseeing the development process, and extend special thanks to UNITAID, our primary funder, and the Aurum Institute, the project lead.

Special thanks to the following community-based organisations for their grassroots commitment to supporting people living with HIV:

- Côte d'Ivoire: RIP+
- Democratic Republic of Congo: UCOP+ (<https://ucopplus.org>)
- Mozambique: MATRAM (<https://matram.org.mz>)
- Nigeria: ANAYD (<https://anayd.org>)
- Sierra Leone: NETHIPS (<https://nethips.org>)
- South Africa: Lefika La Ka (<https://lefikalaka.org.za>)

We further thank AFROCAB and human centered design partner Matchboxology for their technical support throughout the development process.

To all the networks, activists, and changemakers working to reduce stigma and support those with Advanced HIV Disease: we see you, and we thank you.

