The Advanced HIV Disease Community Engagement and Advocacy Toolkit

A PRACTICAL GUIDE FOR COMMUNITIES

Developed by community leaders and civil society partners
under the IMPAACT4HIV and THRIVE consortiums

Unitaid SAVE LIVES FASTER
THE AURUM INSTITUTE
PATA
Solthis Committed expertise in health
cihp
DNDi
MARKET ACCESS AFRICA
IMPAACT4HIV IMPROVED ACCESS TO AHD CARE & TREATMENT 4 HIV
THRIVE Empower Locally, Catalyze Impact Globally
AFROCAB Treatment Access Partnership
match boxology

About IMPAACT4HIV

IMPAACT4HIV is a consortium funded by UNITAID and led by The Aurum Institute.
The consortium includes:

- Paediatric-Adolescent Treatment Africa (PATA)
- Market Access Africa (MAA)
- Drugs for Neglected Diseases initiative (DNDi)
- Centre for Integrated Health Programs (CIHP)
- Solidarité Thérapeutique et Initiatives pour la Santé (Solthis)

Aligned with UNITAID's Advanced HIV Disease portfolio approach, IMPAACT4HIV pilots innovative models for managing Advanced HIV Disease (AHD) among people living with HIV in six countries: Côte d'Ivoire, Sierra Leone, the Democratic Republic of Congo, Nigeria, Mozambique, and South Africa.

More information: https://www.auruminstitute.org/areas-of-expertise/hiv/impaact-4-hiv

About AFROCAB

The Afrocab Treatment Access Partnership (AFROCAB) is an African network of HIV community leaders and advocates working to accelerate access to optimal HIV and co-morbidity treatments and prevention products.
Founded in 2011, AFROCAB facilitates dialogue between communities, policymakers, pharmaceutical manufacturers, UN agencies, civil society organisations, and other stakeholders involved in HIV treatment access and clinical research.
AFROCAB operates across sub-Saharan Africa, with headquarters in Zambia and a network spanning 19 countries. AFROCAB is a member of the THRIVE Consortium.

More information: https://www.afrocab.org/

About the Fight AIDS Coalition (FAC)

The Fight AIDS Coalition is a global network of more than 100 activists and organisations working across national, regional, and global platforms to achieve zero AIDS-related deaths.
Established during the AIDS 2017 Conference, the Coalition coordinates civil society advocacy to improve prevention, diagnosis, treatment, and care for Advanced HIV Disease.
Through evidence-based advocacy and collective action, the Coalition works to secure the resources and policy commitments necessary to protect the most vulnerable communities.

Facebook: FightAidsCoalition

About THRIVE

THRIVE (Transforming Advanced HIV Disease CaRe in LMICs through ComprehensiVe and Equitable Access) is a consortium led by the Clinton Health Access Initiative (CHAI), in collaboration with AFROCAB and Penta.
THRIVE aims to reduce mortality among adults and children living with HIV by expanding access to prevention, screening, and treatment commodities, while centering local leadership and community-driven solutions.

More information: https://www.thriveinfo.org/

About UNITAID

Unitaid is a global health initiative working with partners to introduce innovations that prevent, diagnose, and treat major diseases in low- and middle-income countries.
With a strong focus on HIV, tuberculosis, malaria, and co-infections, Unitaid identifies game-changing solutions and works to scale them quickly and affordably.
Established in 2006 by Brazil, Chile, France, Norway, and the United Kingdom, Unitaid plays a central role in accelerating progress toward ending HIV, TB, and malaria.

More information: https://www.unitaid.org/

Executive Summary

Advanced HIV Disease (AHD) remains a major cause of preventable illness and death among people living with HIV, despite the availability of effective diagnostics, medicines, and clear global guidance.

Advanced HIV Disease is defined as a CD4 count below 200 cells/mm³ or World Health Organisation (WHO) clinical stage 3 or 4. For all children under five years who are not clinically stable receiving antiretroviral therapy (ART), Advanced HIV Disease is diagnosed regardless of cell count or clinical status (WHO, 2024). People hospitalised with Advanced HIV Disease face high mortality risk, and many experience severe illness or death after discharge due to weak follow-up and incomplete care.

People develop Advanced HIV Disease not because solutions do not exist, but because health systems may fail to deliver the full package of care. Missed CD4 testing, incomplete opportunistic infection screening, stock-outs of essential medicines, delayed referrals, weak discharge planning, and poor continuity of care all contribute to avoidable deterioration.

This toolkit was developed by and for communities affected by HIV, including activists, civil society organisations, community health workers, peer supporters, and people living with HIV. It recognises that communities see service gaps first and are central to preventing avoidable deaths.

The guide provides:

- Clear explanations of Advanced HIV Disease
- A practical breakdown of the WHO-recommended Advanced HIV Disease care package
- A monitoring checklist of essential Advanced HIV Disease commodities and services
- A 5-step action flow for identifying and responding to service gaps
- Guidance for responding to emergency situations
- Tools for documenting challenges and community impact
- A systems-level framework for strengthening Advanced HIV Disease responses from community to national level

This toolkit supports community-led monitoring and accountability at facility, district, national, and global levels, including engagement in national HIV strategic planning, Global Fund processes, and broader HIV policy and financing discussions.

Advanced HIV Disease is preventable. When people die from Advanced HIV Disease, it reflects gaps in implementation, and sometimes individual failure. Communities do not just observe the HIV response, they strengthen it, shape it, and hold it accountable.

How to Use This Guide

This guide is designed to be practical, flexible, and action-oriented. You do not need to read it from beginning to end. Each section can be used independently, depending on your role and purpose. This is both a learning resource and a tool for action.

The Guide Can Be Used For:

- Community health worker and peer supporter training
- Facility service review meetings
- District-level performance discussions
- Community-led monitoring activities
- Documentation of service gaps
- Advocacy engagements with policymakers
- Participation in national HIV strategic planning processes
- Engagement in Global Fund (including GC8) and other HIV financing discussions

Structure of the Guide

The guide is organised into nine sections:

Sections 1–3:	Understanding Advanced HIV Disease and why it still happens
Section 4:	The WHO-recommended Advanced HIV Disease care package
Section 5:	Essential Advanced HIV Disease commodities and services (community monitoring checklist)
Section 6:	The role of communities and CHWs in preventing Advanced HIV Disease
Section 7:	Using evidence for accountability and change
Section 8:	Strengthening the Advanced HIV Disease response across community, facility, district, and national levels
Section 9:	A collective call to action

Some sections, particularly Sections 5 and 7, can be printed as pull-outs or adapted into pocket tools for field use.

How to Approach This Guide

You can use this guide to:

1. Recognise early warning signs of Advanced HIV Disease
2. Check whether the full WHO-recommended package is being delivered
3. Identify patterns of missed services or stock-outs
4. Document challenges and community impact
5. Engage facilities constructively
6. Escalate systemic gaps where necessary
7. Advocate for stronger implementation and financing of Advanced HIV Disease services

This guide supports community leadership at every level of the HIV response: from household visits to national policy dialogue. Advanced HIV Disease is preventable when systems function properly. Communities play a central role in ensuring they do.

Contents

1

Why This Guide Exists

Advanced HIV Disease still occurs, not because medicine has failed, but because gaps remain in how care is delivered and accessed.

The Advanced HIV Disease (AHD) Toolkit Guide exists to help healthcare providers, programs, and community organizations to early prevent, identify, manage, and reduce deaths among people with advanced HIV infection.

Why Are People Still Getting So Sick from HIV?

Despite major advances in HIV treatment and diagnostics, people still become seriously ill from HIV largely due to gaps in care and social challenges. Many individuals are diagnosed late, interrupt treatment, or struggle with stigma. Poverty, food insecurity, migration, and weak health systems also disrupt care. As a result, the full package of Advanced HIV Disease prevention, diagnosis, and treatment does not always reach people in time.

1.1. What Is Advanced HIV Disease?

Advanced HIV Disease is a new term to describe what used to be called AIDS.

According to WHO, Advanced HIV Disease is defined as:

- CD4 count below 200 cells/mm³ (adults and adolescents), OR
- WHO stage 3 or 4 condition

All children under 5 years living with HIV, unless stable on ART, are considered at high risk of Advanced HIV Disease.

Advanced HIV Disease means that the immune system is severely weakened. When this happens, the body becomes vulnerable to serious infections such as tuberculosis, cryptococcal meningitis, and severe bacterial disease. But it is important to say this clearly:

Advanced HIV Disease is preventable and treatable, and in many cases, it is predictable.

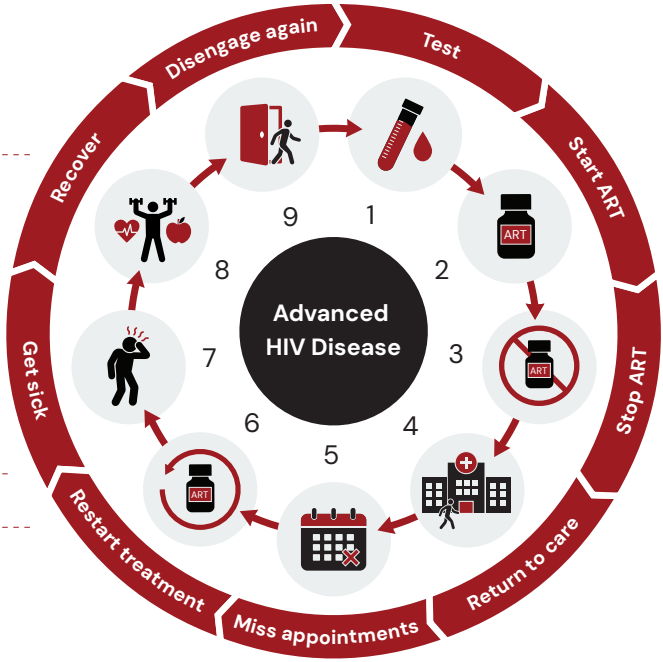
1.2. The HIV Journey Is Not a Straight Line

Health programs sometimes assume that once a person tests HIV-positive:

Test → Start ART → Stay on ART → Achieve viral suppression → Stay well

But for many people, the journey looks very different. It may include:

1. testing,
2. starting treatment,
3. stopping treatment,
4. returning to care,
5. missing appointments,
6. restarting medication,
7. getting sick,
8. recovering,
9. and sometimes disengaging again.



1.3. When Programs Are Not Designed with Communities

Many HIV programs are often driven by reporting requirements, funding timelines, and clinic efficiency goals, which can limit meaningful community participation. People with lived experience are sometimes included only superficially rather than as genuine partners in program design. As a result, differentiated care models and follow-up systems may not fully address real community needs. This gap can lead to treatment interruptions, loss to follow-up, and advanced illness.

Community perspectives are essential for designing effective programs, as persistent barriers not individual failure continue to drive Advanced HIV Disease.

Key Message

Advanced HIV Disease does not continue because people have failed. It continues because barriers persist.

People living with HIV often face real-life obstacles that make testing, treatment, and follow-up difficult. Health systems do not always respond flexibly to changing needs. Follow-up during critical moments can be inconsistent. Community insight is often underused in programme design.

Preventing Advanced HIV Disease requires more than medicine alone. It requires meaningful community engagement, early identification of immune suppression, consistent delivery of the full Advanced HIV Disease package of care, and shared accountability at every level of the health system.

"Preventing Advanced HIV Disease is everyone's responsibility."

Questions for Reflection and Advocacy

Before moving forward, it is important to ask:

- ? Are people being tested early enough?
- ? Is CD4 testing consistently available?
- ? Are stock-outs contributing to treatment interruption?
- ? Is follow-up happening after hospital discharge?
- ? Are community organisations involved in programme design in meaningful ways?

The answers to these questions shape whether Advanced HIV Disease declines or continues.

2

Understanding What Is Happening In The Body

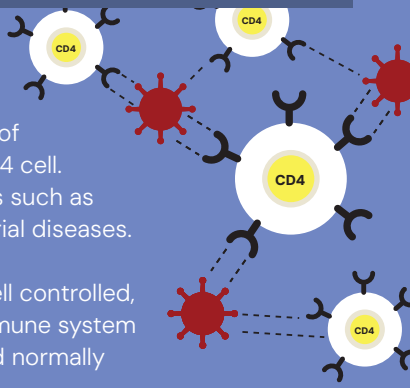
Why This Section Matters

In Section 1, we explored why Advanced HIV Disease still occurs, not because medicine has failed, but because gaps remain in how care is delivered and accessed. This section takes a closer look at what is happening inside the body when someone develops Advanced HIV Disease.

Understanding the biology is not only for clinicians. When community health workers, peer supporters, caregivers, and nurses understand how immune suppression develops, they can:

- Recognise risk earlier
- Explain danger signs clearly
- Encourage testing and referral
- Prevent deterioration before crisis

Advanced HIV Disease is not mysterious.
It follows a pattern and that pattern can be recognised.



2.1. How HIV Affects the Immune System

The immune system protects the body from infection. One of its key defenders is a type of white blood cell called the CD4 cell. CD4 cells help coordinate the body's response to infections such as tuberculosis, fungal infections, pneumonia, and other bacterial diseases.

HIV specifically attacks CD4 cells. Over time, if HIV is not well controlled, the number of CD4 cells falls. As CD4 levels decline, the immune system becomes weaker and less able to fight infections that would normally be controlled.

This weakening does not always happen quickly. It can develop gradually over months or years, especially if someone is not on treatment, interrupts treatment, or starts treatment late. When CD4 levels fall below certain thresholds, the risk of severe illness rises sharply. This is when we begin to see Advanced HIV Disease.

2.2. What Is a CD4 Count?

A CD4 count measures how strong the immune system is. In most healthy adults, CD4 levels are between 500 and 1500 cells/mm³. When CD4 drops:

Below 200

High risk of serious infections and mortality

Below 100

Very high risk of cryptococcal meningitis

Below 50

The immune system is extremely compromised and life-threatening infections are common.

A CD4 count below 200 is one of the definitions of Advanced HIV Disease.

In recent years, many programmes have focused heavily on viral load monitoring, which is important. Viral load tells us how much HIV is circulating in the blood and whether treatment is working to suppress the virus. But viral load does not tell us how strong the immune system is.

Some people may achieve viral suppression but still have low CD4 counts, especially if treatment was started late. Others may experience incomplete immune recovery due to factors such as malnutrition, co-infections, chronic illness, or prolonged untreated HIV.

This is why CD4 testing remains critical for identifying people at risk of Advanced HIV Disease.

2.3. What Are Opportunistic Infections?

Opportunistic infections (OIs) are infections that take advantage of a weakened immune system. When CD4 levels are low, infections that are normally controlled can become severe or life-threatening. Some of the most common opportunistic infections in people with Advanced HIV Disease include:

Tuberculosis (TB)

TB is the most common cause of illness and death in people living with HIV. It usually affects the lungs but can also affect other parts of the body. Symptoms may include persistent cough, fever, night sweats, weight loss, or severe weakness.

Cryptococcal meningitis

This is a serious fungal infection that affects the brain and spinal cord. It often begins with headaches, fever, neck stiffness, confusion, or sensitivity to light. Without early treatment it can quickly become fatal.

Severe bacterial pneumonia

This is a serious lung infection caused by bacteria. People may experience chest pain, difficulty breathing, fever, and a severe cough.

Persistent diarrhoeal disease

Long-lasting diarrhoea can lead to dehydration, weakness, and severe weight loss. In people with advanced HIV, this may be caused by infections that the body can no longer fight effectively.

Pneumocystis pneumonia (PCP)

PCP is also referred to as Pneumocystis jirovecii pneumonia (PJP), and primarily affects the lungs, it causes these air sacs to fill with fluid and debris, making it increasingly difficult to breathe. The most common signs include a persistent dry cough, shortness of breath that worsens with even mild activity, and a lingering fever.

Oral thrush (candidiasis)

A fungal infection that causes white patches in the mouth or throat. It may make eating or swallowing painful and is often a sign that the immune system is weakening.

Toxoplasmosis

An infection that can affect the brain in people with very low CD4 counts. Symptoms may include headaches, confusion, seizures, or difficulty speaking or moving.

CMV-related eye disease

Cytomegalovirus (CMV) can damage the eyes in people with advanced HIV. Symptoms may include blurred vision, dark spots, or loss of vision if not treated early.
These infections are preventable and treatable but only if identified early.

Histoplasmosis

Histoplasmosis is a serious fungal infection that can affect people with very low CD4 counts. It usually begins in the lungs but can spread to other parts of the body, especially when the immune system is weak. Symptoms may include fever, cough, weight loss, tiredness, night sweats, swollen glands, or an enlarged liver or spleen. It can look similar to TB, so early testing and treatment are important.

Mpox

Mpox is a viral infection that can cause more severe illness in people with advanced HIV, especially when CD4 counts are very low or HIV is not well controlled. Symptoms may include fever, swollen glands, body aches, tiredness, and a painful or itchy rash, blisters, or sores. In people with weakened immune systems, mpox can last longer, spread more widely on the body, and may require urgent medical care.

2.4. Viral Load vs CD4: Why Both Matter

Viral load	tells us how much HIV is in the blood.	CD4	tells us how strong the immune system is.
!	If a person has a **high viral load** – high risk	!	If a person has a **low viral load but still low CD4** – still at risk

Some people achieve viral suppression but do not fully rebuild their immune system. These individuals remain vulnerable and require careful monitoring. Good HIV care considers both viral load and immune recovery.

Good HIV care considers both:

?	Is the virus suppressed?	?	Has the immune system recovered?

If immune recovery is incomplete, additional screening and preventive measures may be required.

Ignoring CD4 testing can mean missing the opportunity to intervene before severe illness develops.

2.5. Warning Signs That Must Never Be Ignored

Advanced HIV Disease often gives early signals before becoming life-threatening.
In adults and adolescents, urgent referral is required if someone living with HIV develops:

Do not wait for symptoms to worsen.

Warning Signs in Children

Children can deteriorate quickly. Urgent referral is required if a child has:

Chest indrawing

Severe weight loss

Poor feeding

Fast or difficult breathing

Repeated infections

Lethargy

Convulsions

Unstable Children under 5 living with HIV should always be considered high risk and monitored carefully. Waiting for symptoms to "settle" can be dangerous. Early referral saves lives.

2.6. What Community Health Workers Can Do

Community health workers are often the first to notice changes. During home visits or community sessions, simple questions and observations can make a difference:

- Are you taking your ART every day?
- When was your last clinic or hospital visit?
- Did you have a CD4 test?
- Have you recently felt much weaker or lost weight?
- Have you had severe headaches or persistent fever?

If the warning signs are present, urgent referral is essential. Follow-up after referral is equally important. Small, consistent actions can prevent severe outcomes.

Key Messages From This Section

- CD4 shows immune strength
- Low CD4 means higher risk
- Opportunistic infections are preventable when immune suppression is severe.
- Viral suppression alone is not always enough
- Early identification and referral save lives

See Section 3 to identify who requires prioritisation.
See Section 4 for the full package care for Advanced HIV Disease.

3

Who Is Most At Risk Of Advanced HIV Disease?

Why This Section Matters

In Section 2, we looked at what happens inside the body when the immune system weakens. This section turns that understanding outward. It helps identify the people who are most likely to experience immune decline, often before severe illness becomes visible.

Early identification is not about lab results alone. It is about recognising patterns in people's lives, care journeys, and social environments. This section supports:

- Proactive follow-up
- Prioritisation of high-risk individuals
- Community planning
- Early referral

It can be used independently as a quick risk-identification guide.

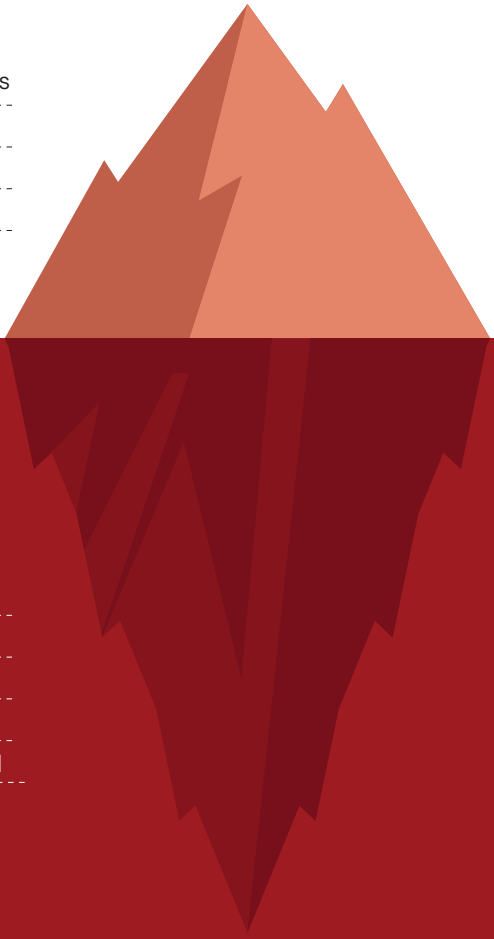
3.1. The Community Lens: The Advanced HIV Iceberg

Advanced HIV Disease is often the visible result of deeper, hidden challenges. The iceberg analogy helps explain this.

Above the surface, we see:

- People hospitalised with severe infections
- Diagnosed Advanced HIV Disease
- Severe weight loss
- TB with very low CD4 counts
- Cryptococcal meningitis

These are the visible cases, the emergencies.



But below the surface

are many others who are at risk, even if they are not severely ill, who are often missed. Just below the surface:

- People who stopped ART
- People lost to follow-up
- People returning to care
- People with low CD4 but no symptoms
- People recently discharged from hospital
- Adolescents struggling with adherence

Deeper still

are the structural forces that shape these risks:

- HIV-related stigma and discrimination
- Poverty and food insecurity
- Long distances to health facilities
- ART stock-outs
- Weak follow-up systems
- Poor discharge planning
- Limited CD4 access
- Inadequate provider training

Advanced HIV Disease often reflects these hidden layers. It is frequently a system signal, not a personal failure. Prevention begins below the surface.

3.2. High-Risk Groups That Require Proactive Follow-Up

The following people should be prioritised for screening and follow-up because their risk of immune decline is higher.

1. People Newly Diagnosed with HIV

Anyone newly diagnosed should be assessed carefully, especially if:

- CD4 testing has not yet been done
- They present with symptoms
- They appear clinically unwell

Starting ART quickly is essential but understanding immune status is equally important. A person may already have significant immune suppression at the time of diagnosis.

2. People Who Interrupted Treatment

Treatment interruption significantly increases the risk of immune decline. This includes individuals who:

- Missed appointments
- Stopped ART for weeks or months
- Restarted treatment after a gap

Even if they look well, their immune system may have weakened during the interruption.

3. People Lost to Follow-Up

Individuals who:

- Have not collected medication
- Have not attended clinic visits
- Cannot be reached

They may not appear sick, but they are at risk. Community tracing and supportive re-engagement are critical. The longer someone remains out of care, the greater the risk of Advanced HIV Disease.

4. People Recently Discharged from Hospital

The period after hospital discharge is one of the highest-risk moments. People treated for:

- Tuberculosis
- Severe bacterial infections
- Cryptococcal meningitis
- Severe weight loss

The period after discharge is high risk. Without structured follow-up, relapse and mortality risk increase. Community follow-up during this period can prevent avoidable deterioration.

5. Adolescents and Young Adults

Adolescence is a period of transition and vulnerability. Young people may experience:

- Treatment fatigue
- Disclosure challenges
- Mental health stress
- Transition gaps between paediatric and adult care

They require supportive and non-judgmental follow-up.

6. Children Under 5 Living with HIV

All children under 5 are considered high risk for Advanced HIV.

Children can deteriorate quickly. Extra vigilance is needed for children who:

- Have poor growth
- Have repeated infections
- Were recently hospitalised
- Miss appointments
- Have caregivers facing hardship

Protecting children requires proactive monitoring and early referral. (See Section 4 for full childcare guidance.)

3.3. Late Diagnosis and Missed Opportunities

Advanced HIV Disease often results from missed opportunities.

These may include:

late presentation for testing,

delays in CD4 testing,

failure to switch treatment when needed,

weak follow-up after hospital discharge

poor retention systems.

In some cases, individuals may achieve viral suppression but experience incomplete immune recovery. Immune rebuilding depends on multiple factors, including timing of ART initiation, nutrition, co-existing infections, and overall health status. Recognising these risk moments early allows intervention before severe illness develops.

Practical Actions for Community Health Workers

When reviewing your caseload or planning outreach, consider:

- Who has missed appointments?
- Who recently restarted ART?
- Who was discharged from hospital?
- Who has unknown or low CD4 count?
- Which children under 5 require closer follow-up?

Do not wait for visible illness. Prevention begins below the surface.

Red Flag Moments

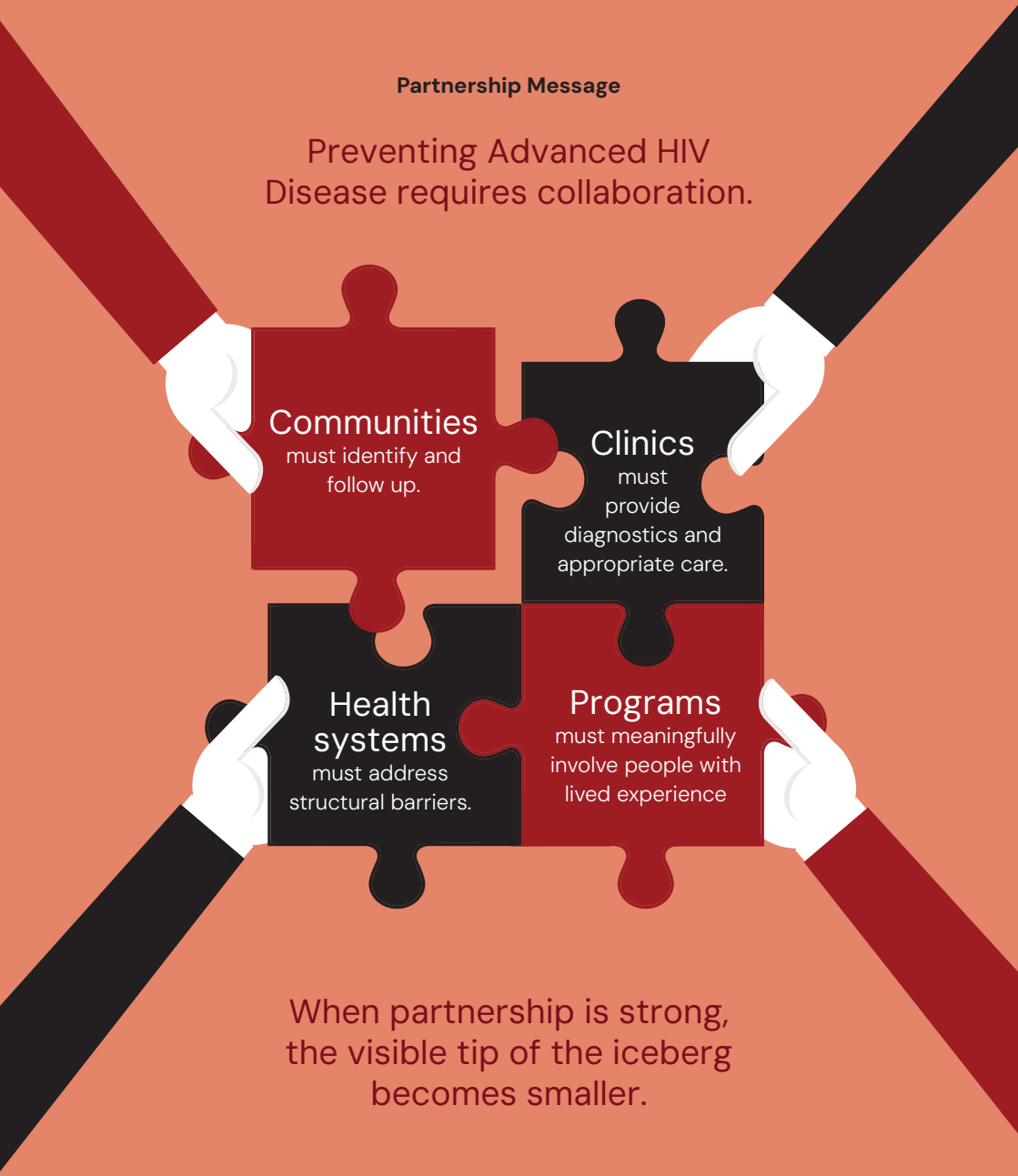
Certain situations require urgent screening and follow-up:

- When someone has health concerns after stopping ART.
- When a person with tuberculosis has an unknown CD4 count.
- When a recently discharged patient misses follow-up.
- When an adolescent repeatedly misses visits.
- When a child living with HIV shows growth concerns.

These are critical intervention points, and acting early can prevent Advanced HIV Disease.

Partnership Message

Preventing Advanced HIV Disease requires collaboration.



When partnership is strong, the visible tip of the iceberg becomes smaller.

Quick Decision Support Tool for Advanced HIV Disease (AHD)

This quick guide helps community health workers recognise warning signs of Advanced HIV Disease and support timely referral to health facilities.

If a person living with HIV has…	Recommended Action
 Severe headache or confusion	Urgent referral to health facility (possible meningitis or severe infection)
 Persistent fever (more than a few days)	Refer for medical evaluation and infection screening
 Severe weight loss or extreme weakness	Encourage immediate clinic visit and CD4 testing
 Persistent cough or difficulty breathing	Refer for TB screening and clinical assessment
 Night sweats or ongoing fatigue	Encourage clinic visit for infection screening
 Severe diarrhoea lasting several days	Refer to clinic to prevent dehydration and complications
 Stopped taking ART or missed treatment for weeks/months	Encourage immediate return to care and clinic follow-up
 Recently discharged from hospital after HIV-related illness	Ensure follow-up clinic visit and community support

4

What Care People With Advanced Hiv Disease Must Receive

Why This Section Matters

Section 3 identified who is most at risk of Advanced HIV Disease and why deterioration often occurs below the surface. The next question is critical:

What must happen once someone is identified as having, or being at risk of, Advanced HIV Disease?

This section outlines the minimum standard of care based on WHO recommendations. It can be used by nurses and clinicians, community health workers, facility managers, community organisations, and advocates monitoring services. If any part of this package is missing, people are placed at unnecessary risk.

4.1. Advanced HIV Disease Requires More Than ART Alone

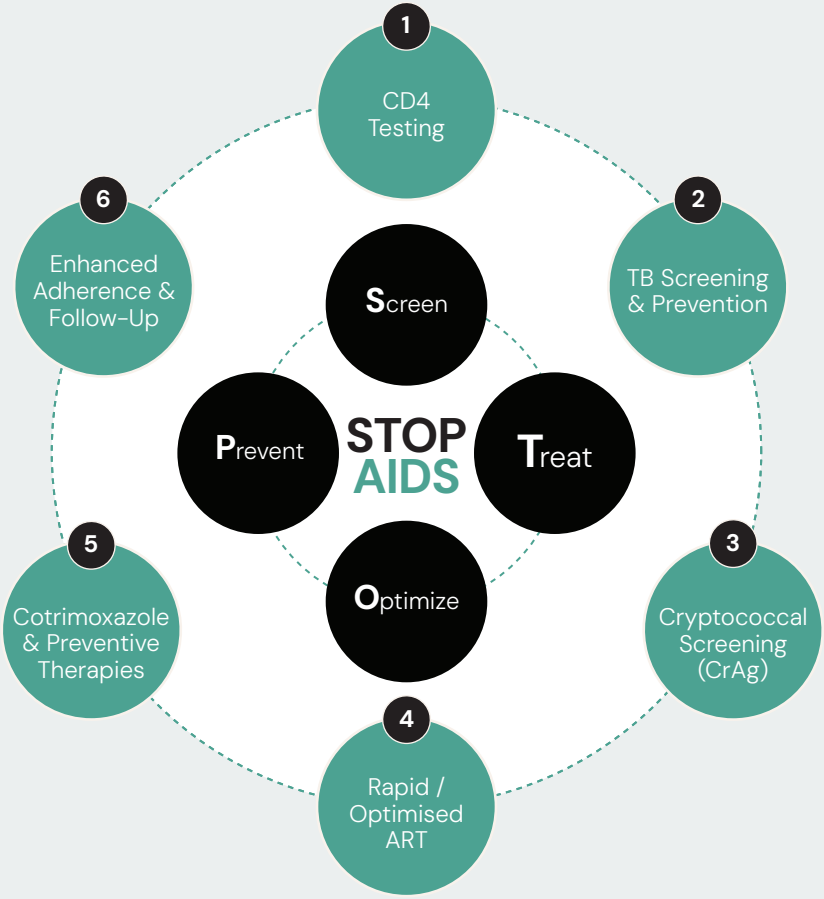
It is a common misunderstanding that starting ART is enough. ART is essential. But for someone with Advanced HIV Disease, it is not sufficient on its own.

When the immune system is severely weakened, the body is vulnerable to infections that may already be present, even if symptoms are not yet obvious. For this reason, WHO recommends a specific package of interventions for people with Advanced HIV Disease.

This package includes:

- Screening for opportunistic infections
- Rapid initiation or optimisation of ART
- Preventive therapies
- Management of diagnosed infections
- Structured and sustained follow-up

The package works best when delivered together. Partial implementation leaves dangerous gaps.



What the WHO Package Means in Practice

1 CD4 Testing	CD4 testing identifies who is at highest risk. A CD4 count below 200 signals Advanced HIV Disease. A CD4 count below 100 signals very high risk for severe infections such as cryptococcal meningitis. Even in the era of viral load monitoring, CD4 testing remains essential for identifying vulnerability.
2 TB Screening & Prevention	Tuberculosis remains one of the leading causes of death among people living with HIV. Every person with suspected Advanced HIV Disease should be screened for TB using appropriate diagnostics according to national guidelines. TB preventive therapy should be provided when active TB has been excluded and eligibility criteria are met. Early identification prevents severe illness and death.
3 Cryptococcal Screening (CrAg)	For individuals with CD4 counts below 100 cells/mm³, cryptococcal antigen (CrAg) testing is recommended. CrAg screening detects cryptococcal infection before meningitis develops. If detected early, pre-emptive antifungal treatment can prevent a life-threatening condition. Waiting for symptoms such as severe headache or confusion may be too late.
4 Rapid / Optimised ART	Rapid initiation of ART is essential for people newly diagnosed with Advanced HIV Disease, unless a short delay is clinically required (for example, in cryptococcal meningitis). If a person presents with Advanced HIV Disease while already on ART, clinicians must assess: • Adherence challenges • Possible drug resistance • Need for regimen switch • Gaps in follow-up Continuing an ineffective regimen can allow further immune decline.
5 Cotrimoxazole & Preventive Therapies	Preventive medicines reduce mortality significantly when implemented consistently. These may include: • Cotrimoxazole prophylaxis • TB preventive therapy • Pre-emptive fluconazole for CrAg-positive individuals Prevention is as important as treatment.

6 Enhanced Adherence & Follow-Up	Advanced HIV Disease requires closer follow-up than routine HIV care. This includes: • Clear discharge planning after hospitalisation • Scheduled early follow-up visits • Community health worker engagement • Monitoring of symptoms • Reinforcement of adherence support The period after hospital discharge is especially high risk and requires structured follow-up.

4.2. Early Screening Saves Lives

When someone is identified with low CD4 or suspected Advanced HIV Disease, screening for serious infections should not be delayed.

Tuberculosis remains one of the leading causes of death among people living with HIV. Every person with suspected Advanced HIV Disease should be assessed for TB using appropriate diagnostics based on national guidance.
For individuals with CD4 counts below 100 cells/mm³, screening for cryptococcal infection using cryptococcal antigen (CrAg) testing is recommended. Detecting cryptococcal infection early, before meningitis develops, can prevent fatal outcomes.

Severe bacterial infections, pneumonia, and other opportunistic infections must also be assessed promptly. Waiting for severe symptoms can mean missing the opportunity to intervene early.

4.3. ART Must Be Initiated or Optimised Without Delay

Rapid initiation of ART is essential for people with Advanced HIV Disease, unless temporary delay is clinically indicated due to specific infections such as cryptococcal meningitis.

At the same time, careful assessment is needed to determine whether the individual may be experiencing treatment failure. If a person has been on ART but presents with Advanced HIV Disease, clinicians must consider:

Adherence challenges	Possible drug resistance	Whether a need for regimen switch is needed	Gaps in follow-up

Continuing an ineffective regimen can be dangerous.
Switching promptly to a fully active regimen may be life-saving.

4.4. Viral Suppression Does Not Always Mean Immune Recovery

Viral load monitoring is critical, but it does not tell the full picture. Some individuals achieve viral suppression but continue to have low CD4 counts. These individuals are sometimes referred to as immunologically non-responsive.

Immune rebuilding can be influenced by:

How late ART was started

Severe baseline immune suppression

Malnutrition

Ongoing infections

Alcohol or substance use

Other chronic health conditions

These individuals remain vulnerable and may require closer monitoring and supportive interventions. Recognising this prevents false reassurance based only on viral load results.

4.5. Advanced HIV Disease in Children Requires Special Attention

Children are not small adults. All children under 5 years living with HIV are considered at high risk of Advanced HIV Disease because their immune systems are still developing.

Children with Advanced HIV Disease may present differently.

Early warning signs may be;

Growth failure

Recurrent infections

Malnutrition

Symptoms may be subtle, and caregivers' observations are critical. In many settings, provider skills in identifying Advanced HIV Disease in young children remain limited. Paediatric formulations may be inconsistent. Follow-up after hospital discharge may be weak.

Children with Advanced HIV Disease require:

- Immediate clinical assessment
- Age-appropriate ART
- Preventive therapies
- Nutritional support
- Caregiver counselling
- Structured follow-up

Delays in recognising Advanced HIV Disease in children can have rapid and severe consequences.

Prevention Matters as Much as Treatment

The Advanced HIV Disease package does not only focus on treating infections, it also emphasises prevention. Preventive therapies may include:

- TB preventive therapy when appropriate
- Fluconazole for pre-emptive treatment of cryptococcal antigen positivity
- Cotrimoxazole prophylaxis

Preventive strategies reduce mortality significantly when implemented consistently.

Nutrition and Mental Health Matter

Immune recovery depends on more than medication. Nutrition plays a significant role in immune rebuilding. Malnutrition increases the risk of mortality in both adults and children with Advanced HIV Disease.

Mental health challenges, stigma, and social isolation also affect adherence and health outcomes. Comprehensive Advanced HIV Disease care should therefore include nutritional assessment and referral where needed, psychosocial support and linkage to community-based services. Clinical care and social support must work together.

The Period After Hospital Discharge Is High Risk

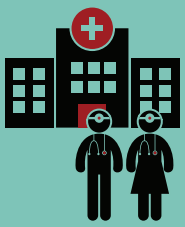
One of the most critical gaps identified in many programs is weak follow-up after hospital discharge. People treated for tuberculosis, meningitis, severe bacterial infections, or other opportunistic infections remain vulnerable for months after discharge.
Without clear referral pathways and community follow-up:

- Appointments are missed
- Medication adherence declines
- Relapse occurs
- Mortality risk increases

This is where partnership between facilities and community health workers becomes essential. Follow-up after discharge should not be optional — it is part of the Advanced HIV Disease care package.

What Communities and Facilities Must Work Together To Ensure

Preventing death from Advanced HIV Disease requires coordination.



Facilities must:

- Provide CD4 testing
- Screen for opportunistic infections
- Initiate and optimise ART
- Ensure medication availability
- Provide clear discharge plans

Communities must:

- Identify and follow up high-risk individuals
- Support adherence
- Monitor service gaps
- Advocate when services are incomplete

When any element of this package is missing, risk increases. When the package is delivered fully and consistently, Advanced HIV Disease becomes preventable.

Key Message

Advanced HIV Disease care requires more than ART. It requires:

- Early immune assessment
- Immediate infection screening
- Rapid and effective treatment
- Preventive therapies
- Nutritional and psychosocial support
- Structured follow-up

This is the minimum standard of care, not an optional extra.

In the next section, we translate this WHO package into a practical checklist of essential diagnostics, medicines, and services that must be available to make this standard of care possible.

5

Advanced HIV Disease Commodities & Services

Community Monitoring & Accountability Tool

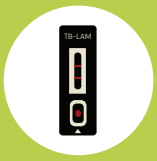
Why This Section Matters

Section 4 outlined the WHO-recommended package of care for Advanced HIV Disease. This section translates that package into practical terms. It identifies the essential diagnostics, medicines, and services that must be available in order for the Advanced HIV Disease package to function properly. When these commodities and services are missing, mortality risk increases.
This tool can be used for:

- Community-led monitoring
- Facility engagement meetings
- District-level advocacy
- CHW supervision
- Training sessions

You do not need to read the full guide to use this table. It can function independently as a monitoring reference.

Essential Advanced HIV Disease Commodities & Services

DIAGNOSTICS & TESTS				
	Commodity / Service	**Who Needs It**	**Why It Matters**	**What Communities Should Check**
	CD4 Test	Newly diagnosed; returning to care; symptomatic patients	Identifies immune suppression (Advanced HIV Disease if CD4 <200)	Is CD4 testing available? Are eligible patients tested? Are results returned quickly?
	TB Symptom Screening	All people living with HIV	TB is a leading cause of death in PLHIV	Is TB screening done at every visit?
	TB-LAM (where indicated)	Severely immunosuppres-sed individuals	Rapid TB detection in very sick patients	Is TB-LAM available and used according to guidance?
	Cryptococcal Antigen (CrAg) Test	Individuals with CD4 <100 cells/mm³	Detects cryptococcal infection before meningitis develops	Is CrAg testing available for eligible patients?
	Viral Load Test	People on ART	Measures treatment effectiveness	Are viral loads done on time? Are results reviewed?
	Timely Return of Test Results	All tested patients	Delays can result in missed treatment	Are results returned quickly? Are patients informed and linked to care?

PREVENTIVE MEDICINES				
	Medicine	**Who Needs It**	**Why It Matters**	**What Communities Should Check**
	Cotrimoxazole	Individuals with Advanced HIV Disease; children	Prevents severe bacterial infections and certain OIs	Is cotrimoxazole provided consistently?
	TB Preventive Treatment (TPT)	Eligible individuals without active TB	Prevents development of TB disease	Are eligible patients offered TPT? Any stock-outs?
	Pre-emptive Fluconazole	CrAg-positive individuals without meningitis	Prevents progression to cryptococcal meningitis	Is fluconazole available for pre-emptive use?

TREATMENT FOR OPPORTUNISTIC INFECTIONS				
	Medicine / Service	**Who Needs It**	**Why It Matters**	**What Communities Should Check**
	First-line TB Treatment	Patients diagnosed with TB	Treats TB and prevents death	Are TB medicines consistently in stock?
	Amphotericin B + Flucytosine (or national recommended regimen)	Cryptococcal meningitis patients	Life-saving antifungal treatment	Are recommended medicines available and initiated promptly?
	Fluconazole (treatment dose)	Treatment of cryptococcal infection	Essential antifungal therapy	Is correct dosing available?

TREATMENT FOR OPPORTUNISTIC INFECTIONS CONTINUED				
	Medicine / Service	**Who Needs It**	**Why It Matters**	**What Communities Should Check**
	Antibiotics for Severe Bacterial Infections	Pneumonia, sepsis patients	Prevents complications and death	Are appropriate antibiotics available?

ART & HIV MANAGEMENT				
	Commodity / Service	**Who Needs It**	**Why It Matters**	**What Communities Should Check**
	Effective ART Regimens	All people living with HIV	Suppresses HIV and supports immune recovery	Any ART stock-outs? Are failing patients switched promptly?
	Paediatric ART Formulations	Children living with HIV	Children require age-appropriate dosing	Are paediatric formulations consistently available?
	Regimen Switching When Indicated	Individuals with treatment failure	Prevents immune decline and progression to Advanced HIV Disease	Are patients assessed and switched in time?

SUPPORTIVE & SYSTEM SERVICES				
	Service	**Who Needs It**	**Why It Matters**	**What Communities Should Check**
	Nutritional Assessment & Support	Malnourished adults & children	Nutrition supports immune rebuilding	Are patients screened for malnutrition? Are referrals available?
	Psychosocial Support	Individuals facing stigma, stress, mental health challenges	Supports adherence and recovery	Are counselling services available?
	Post-Hospital Discharge Follow-Up	Recently hospitalised patients	High-risk period for mortality	Is structured follow-up arranged after discharge?
	Clear Referral Pathways	Severe cases requiring higher-level care	Ensures timely and appropriate management	Is referral clear? Is transport supported when needed?

Community Monitoring Checklist

Communities can document findings during facility visits:

Service / Commodity	Available (Yes/No)	Stock-Outs in Last 3 Months?	Patients Receiving It?
CD4 Testing	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗
CrAg Testing	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗
TB-LAM	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗
Cotrimoxazole	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗
TB Preventive Therapy	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗
OI Treatment Medicines	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗
Paediatric ART	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗
Post-Discharge Follow-Up	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗

When to Escalate

Escalation is needed when:

CD4 or CrAg testing is unavailable

TB diagnostics not functioning

OI preventive medicines are missing

Children lack paediatric formulations

ART stock-outs occur

Post-discharge feedback is absent

Escalation should be documented and constructive, with clear communication to facility or district leadership.
(See Section 7 for guidance on documenting and escalating service gaps.)

6

The Role Of Communities And CHWS In Preventing Advanced HIV Disease

From Commodities to Care

In Section 5, we outlined the medicines, diagnostics, and services that must be available to prevent and manage Advanced HIV Disease, but commodities alone do not save lives.

A CD4 test in a laboratory does not help unless it is done.

CrAg kits do not prevent meningitis unless eligible patients are screened.
Paediatric ART in a storeroom does not protect a child unless it reaches them consistently.
A discharge plan does not prevent relapse unless someone follows up.

This is where communities and community health workers play a central role. Communities are the bridge between what should happen in theory and what happens in reality.

6.1. Why Communities Matter in Advanced HIV Disease

Advanced HIV Disease does not begin in a hospital ward.
It begins much earlier, often quietly in homes and communities:

- When someone misses an appointment.
- When someone stops treatment.
- When a child's weight gain slows.
- When a person feels too ashamed to return to care.
- When transport money runs out.
- When a health system does not respond flexibly.

As discussed earlier in this guide, Advanced HIV Disease is not simply a clinical condition. It is often the outcome of accumulated barriers and communities see those barriers first.

Community health workers, peer supporters, PLHIV networks and caregivers often recognise risk long before a facility does. They notice weight loss before a CD4 result is done. They hear fear in someone's voice before a viral load is elevated. They see food insecurity, migration patterns, stigma, and treatment fatigue. Communities are not an "extension" of the health system. They are a foundation of prevention.

What Happens Before Crisis

Advanced HIV Disease rarely appears suddenly. In many cases, there were earlier signs:

- ! A person who stopped collecting medication
- ! A child missing clinic visits
- ! A patient discharged without clear follow-up
- ! A person never offered CD4 testing
- ! An adolescent disengaging from care

Community health workers often see these warning signs first. Preventing Advanced HIV Disease begins with noticing and responding early. Sometimes prevention looks simple when you ask:

- ? Have you been able to go back to the clinic?
- ? Are you still taking your medication?"
- ? Is anything making it difficult to continue?

These conversations, when done respectfully and without blame, prevent immune decline from becoming severe illness.

6.2. Supporting a Non-Linear HIV Journey

Earlier in this guide, we emphasised that the HIV journey is not a straight line. People move in and out of care. They interrupt treatment. They restart. They struggle. They recover. They disengage again. Community workers understand this lived reality deeply.

When someone has interrupted treatment, the goal is not to ask **"Why did you stop?"** in a blaming way.

The goal is to ask:

- What made it difficult?
- Was it transport?
- Stigma?
- Side effects?
- Food insecurity?
- Negative experiences at the clinic?

Supportive re-engagement protects immune recovery and prevents progression to Advanced HIV Disease.

6.3. After Hospital Discharge: The Invisible Risk Period

One of the most dangerous moments in the Advanced HIV Disease journey is after someone leaves hospital. A person may have been treated for:

- Tuberculosis
- Cryptococcal meningitis
- Severe bacterial infection
- Severe weight loss

They return home weak, overwhelmed, sometimes confused about medications, sometimes fearful. Without structured follow-up, this is when relapse and mortality occur.

Community follow-up can include:

- Visiting shortly after discharge
- Confirming understanding of medicines
- Checking appointment dates
- Watching for new or worsening symptoms
- Communicating concerns back to the facility

This is not an optional add-on. It is part of preventing avoidable deaths.

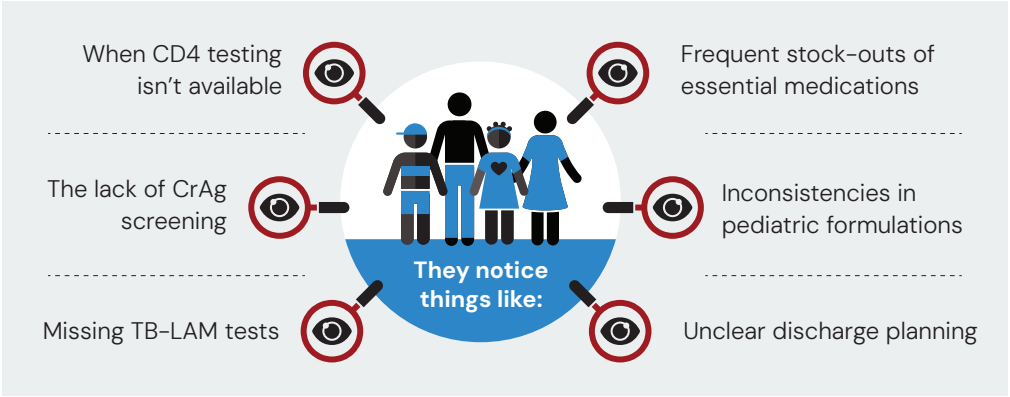
6.4. Protecting Children Requires Extra Vigilance

Children living with HIV, especially those under five, are automatically high risk for Advanced HIV Disease. Children do not always present clearly. Early signs may include

Community workers often serve as trusted bridges between caregivers and health facilities. They support correct dosing, monitor weight, encourage follow-up, and act quickly when symptoms appear. Protecting children from advanced HIV disease requires attentiveness, consistency, and rapid referral.

6.5. Bridging Households and Health Systems

Communities function on two important levels. On the household level, they provide essential support by helping individuals stay connected to their healthcare, follow their treatment plans, and recognise symptoms early on. Meanwhile, at the system level, they play a crucial role in observing broader patterns.



This dual role is incredibly powerful. Communities are not just caregivers; they also serve as keen observers of how the healthcare system performs.

6.6. Partnership, Not Policing

In the world of healthcare, many providers face immense pressure and work within tight resource constraints. However, the goal of engaging with the community isn't to create conflict; it's to foster improvement and collaboration.

Community-led monitoring shouldn't be about assigning blame; it's about building partnerships. It embodies a mindset of inquiry and cooperation: "We're noticing a pattern here. How can we work together to find a solution?"

Trust flourishes when we embrace the following principles:	
Share findings constructively:	Approach discussions with positivity and a shared desire for progress.
Document patterns clearly:	Ensure that everyone understands the issues at hand by presenting data transparently.
Discuss solutions collaboratively:	Engage all stakeholders in the problem-solving process to generate ideas and buy-in.
Acknowledge improvements:	Celebrate successes, no matter how small, to strengthen our partnership and motivate continued efforts.

This collaborative approach reflects the very spirit in which this guide was crafted. Let's work together to improve health outcomes in our communities, building trust and partnerships that lead to lasting change.

6.7. The Power of Community Voice

Addressing Advanced HIV Disease isn't solely a matter of scientific advancements; it is about ensuring that our systems work effectively for everyone. Communities play a crucial role in this fight, and here's how you can contribute:

Spot Early Warning Signs:

- Be vigilant and educate those around you.
- Recognizing the early signs of health issues can lead to timely interventions.

Support Re-engagement:

- Help individuals who have disengaged from care find their way back.

Your encouragement can make a world of difference in their journey.

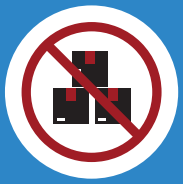
Protect Children:

- Safeguarding the health of children is vital.
- Engage in initiatives that focus on their wellbeing and education about HIV.

Strengthen Post-Discharge Follow-Up:

- When individuals leave care facilities, ensure that there's a plan in place for follow-up.

Your involvement can help bridge the gap and ensure they receive the support they need.



Monitor Commodities:

Stay informed about the availability of essential medical supplies and medicines in your community.

Your observations can help highlight shortages and prompt action.

Raise System Gaps Respectfully:

- Speak up about the challenges you see in the healthcare system.
- Approach discussions with facility leadership openly and respectfully to facilitate meaningful change.

Each time you visit a household, complete a monitoring form, or meet with health facility leaders, you're taking an important step. These actions may seem small, but they collectively combat the larger issues we face.

Remember, communities are not just bystanders in the fight against Advanced HIV Disease. You are vital players in this effort, making a significant impact every day. Together, we can build a stronger response and create a healthier future for all.

Despite best efforts, there will be times when gaps persist. When that happens, observations must move beyond conversation. They must be documented clearly and escalated appropriately. The next section explains how to do that.

7

Using Evidence For Accountability & Change

Why Evidence Matters in Advanced HIV Disease

In the earlier sections, we explored how Advanced HIV Disease often develops quietly, what is below the surface and through missed opportunities, stock-outs, delayed referrals, stigma, or weak follow-up. Communities see these issues first.
But seeing a problem is not always enough to change it. Change happens when experience becomes evidence.

- When a missed CD4 test is documented.
- When repeated stock-outs are recorded.
- When discharge gaps are tracked.
- When caregivers report the same barriers again and again.

One story can raise concerns, and patterns matter. When communities organize those patterns into evidence, they become powerful.

This is the foundation of community-led monitoring: strengthening health systems through respectful, evidence-based partnership.

7.1. The 5-Step Community Action Flow (This can work as a Pocket Tool)

When you see something that puts recipients of care at risk, it is crucial to take action immediately and effectively. The 5-Step Community Action Flow provides a structured approach to address these situations. Here's a breakdown:

STEP 1

NOTICE IT

Take a moment to really observe what's going on around you. Here are some specific situations to think about:

1. Is there a test that hasn't been conducted?
2. Are we running low on stock or supplies?
3. Is there a gap in patient referrals that needs attention?
4. Is a child not gaining weight as expected?
5. Has a patient missed their screening?

Be specific in your observations and focus on the facts. Jot down what you see to help understand the situation better.

STEP 2

CHECK IF IT IS REPEATED

Take a moment to really observe what's going on around you. Here are some specific situations to think about:

- Has this happened before?
- Are multiple patients affected?
- Is it happening?

If yes, It may be a system issue.

STEP 3

LOG IT

Make a short note:

- Date
- What happened
- Who was affected

Small notes prevent bigger crises.

STEP 4

DISCUSS LOCALLY FIRST

Raise the issue with:

- Nurse in charge
- Facility manager
- Supervisor

Use facts, not blame.

Example:
"In the last three weeks, three patients with CD4 below 100 were not screened for CrAg. Can we review the protocol?" Many issues can be resolved at this level.

STEP 5

ESCALATE IF NECESSARY

Escalate if:

- The issue continues after discussion
- High-risk services are affected (CD4, CrAg, TB-LAM, ART, children)
- Multiple patients are at risk
- A child's safety is compromised
- Preventable Advanced HIV Disease cases are recurring

Escalation should always be:

- Evidence-based
- Respectful
- Focused on patient safety
- Solution-oriented

The goal is improvement, not confrontation.

7.2. Advanced HIV Disease Service Gap Log

Use this log to identify patterns over time.

Date	What Happened?	Who Was Affected?	Repeated? (Y/N)	Who Was Informed?	Facility Response Received?	Follow-Up Date

If the same issue appears repeatedly, it requires system-level attention.
This tool captures short incidents. It helps identify patterns.

7.3. When to Escalate Beyond the Facility

Some issues cannot be resolved locally. Escalation may be required when:

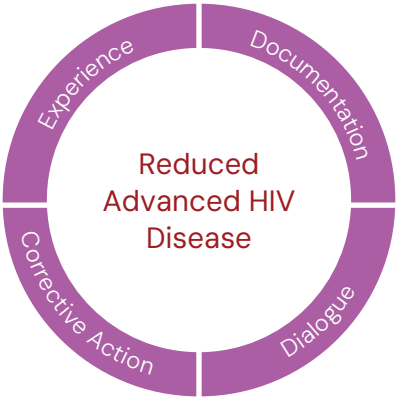
- CD4 testing is unavailable for extended periods
- CrAg screening is not performed for eligible patients
- TB diagnostics are not functioning
- ART or paediatric formulations are repeatedly out of stock
- Post-discharge follow-up systems are absent
- The same preventable Advanced HIV Disease cases keep returning

Escalation pathways may include:

- District review meetings
- Community monitoring reports
- Civil society forums
- National programme engagement

Escalation restores system function. It does not assign blame.
Paediatric gaps require particular urgency, as children deteriorate more quickly.

7.4. From Evidence to System Improvement



When community evidence informs:

- Facility improvements
- District planning
- National programming
- Global learning

The Advanced HD response becomes strongeHIV Disease

"Communities do not just observe the HIV response. They shape it."

7.5. Documenting Challenges and Impact

In this guide, we have emphasised the importance of recognising issues early and respectfully voicing concerns. But communities do more than identify problems; they actively work to solve them.
They prevent decline, re-engage individuals, strengthen follow-up, protect children, and help restore services. These moments are significant and deserve to be documented.

Many cases of Advanced HIV Disease begin with small, yet critical gaps in the system, such as:

- ! Lack of CD4 testing
- ! Missed CrAg screenings
- ! TB-LAM stock shortages
- ! Inaccessible pediatric ART
- ! Discharged patients lacking follow-up

Sometimes, these issues persist, but community action can lead to change. A stock-out gets resolved after being highlighted, clinics screen all eligible patients for CrAg, follow-up systems are implemented for discharged patients, and children receive correct dosages thanks to community health workers. These actions are pivotal as they represent real improvements in the system.

The Community Impact Story template assists in documenting:

- The challenge faced
- Actions taken in response
- The changes that occurred
- Who benefited from these changes
- The lessons learned

It turns local efforts into measurable impact.

When Should You Write a Community Impact Story?

Use the template when:

- A serious gap was identified and addressed
- A recurring problem was resolved
- A life may have been protected because action was taken
- A service improved due to community engagement
- There is learning that could help other communities

Not every issue becomes an impact story. The Service Gap Log captures routine patterns. It captures meaningful change and lessons learned.

Why Document Impact?

Documenting impact helps:

- Show what community-led monitoring achieves
- Strengthen engagement with facilities
- Inform district and national planning
- Protect essential Advanced HIV Disease services
- Share learning across regions
- Demonstrate value under funding mechanisms such as GC8

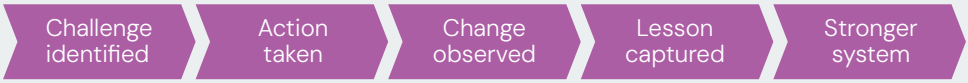
They ensure community work is visible, credible, and recognised.

What the Community Impact Story Template Includes

1. What was the challenge?
2. Who was affected?
3. What actions were taken?
4. What changed?
5. Who benefited?
6. What did we learn?
7. What should happen next?

The full template is provided in Annex X.

A Simple Way to Think About It



Community Impact Stories turn experience into documented progress.

Understanding Community-Led Monitoring

Community-led monitoring (CLM) is much more than just checking in on clinics—it's about building authentic partnerships rooted in the experiences of the people we serve. At its core, CLM involves several key components:

1. Gathering straightforward and consistent data
2. Listening closely to the experiences of patients
3. Identifying gaps in service delivery
4. Sharing our findings in a respectful and constructive manner
5. Following up on agreed-upon actions to ensure accountability

The ultimate goal of CLM is to improve health systems. When implemented effectively, it enhances the way our health systems operate rather than undermining them. By working together, we can create a stronger, more responsive healthcare environment that truly meets the needs of the community.

7.6. Transforming Data into Meaningful Conversations

Data alone doesn't drive change; it's only the beginning. To truly make an impact, we must share this information in ways that resonate with our communities. Here are some effective strategies to engage with facilities:

Present Findings Clearly:	Share your documented results in a straightforward, accessible manner.
Show Trends Over Time:	Illustrate how data evolves, emphasizing patterns that matter.
Highlight Practical Solutions:	Focus on actionable steps that can be taken to improve situations.
Agree on Follow-Up Timelines:	Establish a plan for revisiting discussions and tracking progress.

For instance, consider these questions to spark dialogue:

"If CD4 testing hasn't been available for two months, what kind of support can help restore the supply?"

"If children aren't consistently receiving their pediatric formulations, what steps can we take to address this issue?"

When we approach conversations with structure and respect, we create an environment where accountability is a shared responsibility, fostering collaboration and positive change.

7.7. From Evidence to Impact: Understanding the Role of Community Health Workers

Imagine a dedicated CHW visiting a family in their home, checking in on health needs and providing support.

Picture them completing a monitoring form after a visit to a healthcare facility, noting crucial details about the available resources.

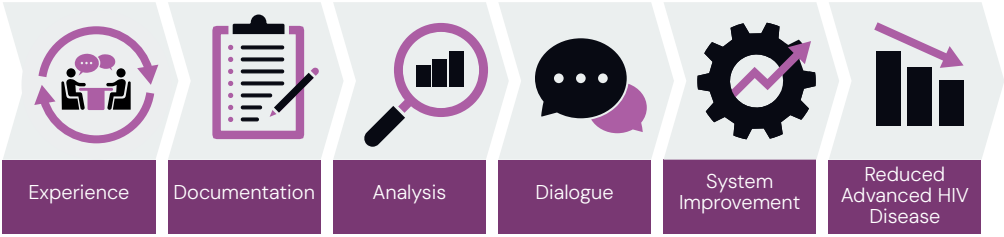
Think about the serious challenge of a stock-out, where essential medications are unavailable,

and the urgency of meeting with a clinic manager to discuss solutions.

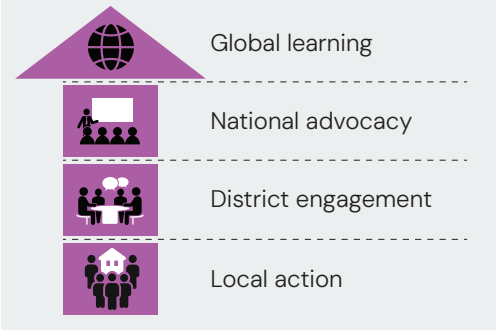
While these actions might seem small on the surface, they are part of a larger, powerful narrative. Together, they play a vital role in:

- Enhancing service delivery to those who need it most
- Preventing avoidable infections that can have devastating effects
- Reducing hospital admissions by addressing health issues before they escalate
- Protecting children and ensuring their well-being
- Saving lives by making healthcare more accessible and effective

Advanced HIV Disease is often a hidden crisis, exacerbated when health systems fail to address the needs of the community. Through the diligent efforts of CHWs and the collection of community evidence, these failures come to light, prompting necessary action and fostering a healthcare system that truly serves its people.



"Communities do not just observe the HIV response. They shape it."



Advanced HIV Disease is not inevitable. It emerges when warning signs are missed and systems do not respond. Communities help to:

- Identify those warning signs
- Support individuals directly
- Document systemic gaps
- Advocate for complete care

By turning our experiences and insights into actionable steps, we can save lives. Every step we take to raise awareness and improve care can significantly reduce mortality rates. Together, we can make a difference.

8

Strengthening The Advanced HIV Disease Response

How This Section Builds on Section 7

Section 7 focused on what to do when we identify a specific service gap and how to document it, raise it, and strengthen accountability. But when the same gaps appear repeatedly, a deeper question must be asked: Is the system strong enough to prevent Advanced HIV Disease?

Advanced HIV Disease does not persist due to a lack of clear guidelines. The WHO has provided recommendations, and national policies are in place. We have the necessary tools, yet Advanced HIV Disease continues to be a problem because implementation is inconsistent. It persists when diagnostics are not consistently available, when follow-up systems are weak, when paediatric services are neglected, when funding does not match policy commitments, and when accountability mechanisms fail to respond.
Section 8 steps back from individual cases and looks at the broader system.

Section 8 steps back from individual cases and looks at the broader system. It helps you ask:

- ? Are the right structures in place at every level?
- ? Where are the weak points?
- ? Are responsibilities clearly defined?
- ? Are funding and policies aligned with prevention of Advanced HIV Disease?
- ? Do national plans and donor investments reflect what communities are seeing?

If Section 5 helps you identify what should be available, and Section 7 helps you respond when something is not working, Section 8 helps you assess whether the overall system is designed to prevent those problems from recurring.

This section is not about blame. It is about strengthening what already exists, from community to national level.

Why Policy and Financing Matter

As healthcare and community workers, it's important to recognise that service gaps in our system rarely happen by chance. Often, repeated issues like stock-outs of essential supplies, missing diagnostic tools, ineffective post-discharge support, and delays in referrals point to deeper systemic problems. Understanding these underlying issues can help you advocate for change more effectively.

These service gaps are often linked to several critical factors, such as:

- The priorities established in the National Strategic Plan
- How budgets are allocated
- Procurement decisions
- Global Fund funding cycles
- Performance monitoring frameworks
- District-level oversight systems

You don't need to be a policy expert, but being aware of how national commitments and funding decisions impact what happens in facilities and communities is crucial.

For example, if there isn't enough budget earmarked for CD4 testing, this crucial service might diminish over time. Similarly, if paediatric Advanced HIV Disease indicators aren't included in national monitoring frameworks, they may not get the regular attention they need. And if Advanced HIV Disease components aren't prioritised during Global Fund grant cycles, the gaps in services might continue without any structured plans for improvement.

When you, as a community or healthcare worker, understand how national strategies and funding processes work, including the cycles of the Global Fund, you are in a stronger position to ensure that Advanced HIV Disease remains a priority in your discussions and planning efforts.

This knowledge not only helps you advocate for better services in your community but also strengthens accountability across the healthcare system, ensuring that we can effectively meet the needs of those we serve.

Integrated 4-Level Advanced HIV Disease Strengthening Framework

Strengthening the Advanced HIV Disease Response: What Must Be in Place to Prevent Avoidable Deaths

LEVEL 1: COMMUNITY

What Must Be in Place:	
1	Active and supported CHWs
2	Routine follow-up after hospital discharge
3	Treatment adherence support
4	Linkage to care mechanisms
5	Monitoring of children and adolescents
6	Clear communication channels with facilities
7	Community documentation of recurring service gaps

Warning Signs	
!	Patients returning very sick
!	Children missing doses
!	Repeated treatment interruption
!	No feedback loop with facilities
!	Community concerns not reaching district review platforms

LEVEL 2: FACILITY

What Must Be in Place:	
1	Functional CD4 testing
2	CrAg screening for CD4 <100
3	Routine TB screening and diagnostics
4	Paediatric ART formulations consistently in stock
5	Clear discharge plans and follow-up instructions
6	Advanced HIV Disease indicators reviewed regularly
7	Engagement with community-led monitoring findings

Warning Signs	
!	CD4 testing deprioritised
!	CrAg not implemented
!	Repeated stock-outs
!	No structured post-discharge coordination
!	Advanced HIV Disease cases discussed only during crises

Facilities are where policy meets practice. If services are inconsistent, it may reflect gaps at district or national level.

LEVEL 3: DISTRICT

What Must Be in Place:	
1	Active supply chain monitoring
2	Laboratory turnaround time oversight
3	Review of Advanced HIV Disease indicators and mortality trends
4	Functional referral pathways
5	Inclusion of paediatric Advanced HIV Disease in district review meetings
6	Structured discussion of community monitoring findings
7	Clear response mechanisms when facilities report recurring gaps

Warning Signs	
!	Repeated stock-outs across facilities
!	No response to facility reports
!	Delays in equipment repair
!	No review of AHD-related deaths
!	Community monitoring findings not discussed

District level is where coordination happens. If district oversight is weak, facility-level gaps become systemic.

LEVEL 4: NATIONAL

What Must Be in Place:	
1	Full WHO Advanced HIV Disease package included in national guidelines
2	Dedicated budget allocation for CD4, CrAg, TB diagnostics, and paediatric ART
3	Inclusion of Advanced HIV Disease indicators in national performance frameworks
4	Community-led monitoring integrated into national review processes
5	Advanced HIV Disease prioritised in HIV strategic plans
6	Alignment of Global Fund (including GC8) grant implementation with Advanced HIV Disease service delivery
7	Review of Advanced HIV Disease-related mortality and implementation gaps during national programme evaluations

Warning Signs	
!	CD4 testing removed from policy without alternative risk screening
!	CrAg testing not funded or procured
!	No national Advanced HIV Disease reporting indicators
!	Paediatric Advanced HIV Disease not prioritised
!	Community evidence not reflected in grant performance reviews
!	Implementation gaps not addressed during Global Fund grant cycles

National decisions determine whether lower levels are supported or constrained. If Advanced HIV Diseaseis not visible in strategic plans, budgets, and funding requests, service gaps will continue.

Strengthening Through Planning and Investment Awareness

To prevent Advanced HIV Disease, national planning and financing must align with service delivery realities. Programme managers and community leaders should periodically ask:

- Does the National Strategic Plan explicitly address Advanced HIV Disease?
- Are Advanced HIV Disease targets measurable?
- Were previous Advanced HIV Disease commitments achieved?
- Are Advanced HIV Disease commodities sufficiently budgeted?
- Are community-led monitoring findings discussed during grant performance reviews?
- Are Advanced HIV Disease priorities reflected during Global Fund funding requests and grant implementation cycles?

Engagement should begin early, before plans are finalised and budgets are locked. When communities prepare evidence summaries in advance of NSP revisions or Global Fund cycles, they move from reactive advocacy to strategic influence. Prepared engagement leads to stronger systems.

Question		Yes/No	Action Needed
?	Is CD4 testing consistently available?	☐✓ ☐✗	
?	Are CrAg tests done for CD4 <100?	☐✓ ☐✗	
?	Are paediatric ART formulations in stock?	☐✓ ☐✗	
?	Is post-discharge follow-up routine?	☐✓ ☐✗	
?	Are Advanced HIV Disease indicators reviewed quarterly?	☐✓ ☐✗	
?	Are community monitoring findings discussed at district level?	☐✓ ☐✗	
?	Is Advanced HIV Disease reflected in national grant implementation (e.g., GC8)?	☐✓ ☐✗	
?	Are Advanced HIV Disease priorities included in national strategic plans?	☐✓ ☐✗	

When systems function effectively at every level, community, facility, district, and national, avoidable health-related deaths become a reality we can prevent. When we align our planning, financing, monitoring, and service delivery, we can significantly reduce unnecessary losses. Addressing avoidable health deaths is not just about a single initiative; it requires a collective and coordinated effort across all levels. When communities grasp how these different layers connect, they can become powerful agents for positive change and system improvement.

The Global Environment Matters

National HIV systems do not operate in isolation. They are shaped by global guidance, financing cycles, and international commitments.

WHO defines the Advanced HIV Disease package.
Global Fund cycles influence how resources are allocated and monitored.
Global funding reductions can directly affect commodity procurement and service delivery.

When engaging nationally, communities should understand how global processes influence:

National Strategic Plans

Grant implementation cycles

Budget ceilings

Indicator selection

Performance reviews

Strong national engagement is often the most effective pathway to influencing global priorities.

9

A Collective Call To Action

Preventing Advanced HIV Disease is Possible.

We have the science, guidelines, medications, and diagnostics necessary to tackle Advanced HIV Disease (AHD). What truly matters is our commitment to delivering these resources consistently, equitably, and completely. Preventing unnecessary deaths requires a united effort at every level of society; it is a responsibility we all share.

9.1. Communities: The Heart of Prevention

Communities play a vital role as the first line of defence against Advanced HIV Disease. Together, we must:

- Know our HIV status early on and adhering to ART.
- Identify early warning signs of advanced disease.
- Support individuals in maintaining their treatment.
- Check in on patients after their hospital discharge.
- Safeguard the health of children and adolescents.
- Document service gaps to better understand our needs.
- Constructively share evidence to drive improvement.

Community-led monitoring is not merely an addition to our response; it is essential in our fight against Advanced HIV Disease.

9.2. Health Workers & Facilities: Turning Knowledge into Practice

Health facilities are where the promise of prevention and treatment becomes reality. Health workers and facility leaders should:

- Implement the complete WHO STOP AIDS Package of care.
- Ensure all eligible patients receive CD4 and CrAg testing.
- Give particular focus to paediatric care.
- Develop and communicate clear discharge plans for patients.
- Review Advanced HIV Disease cases and mortality patterns to identify trends.
- Engage with findings from the community proactively.

Preventing Advanced HIV Disease requires more than just starting ART; it requires holistic, coordinated care.

9.3. District & Subnational Leadership: Bridging Policy and Practice

District structures serve as the crucial link between policy and on-the-ground practice. Therefore, district leaders should:

- Regularly monitor supply chains and laboratory systems.
- Keep track of Advanced HIV Disease indicators and mortality rates.
- Address recurring stock-outs in a timely manner.
- Integrate community monitoring insights into regular meetings.
- Ensure robust and functional referral systems are in place.

Effective district oversight can stop small gaps in care from escalating into tragic outcomes.

9.4. National Programs & Policymakers: Catalysing Change

The priorities set by national leadership can make or break our efforts to prevent Advanced HIV Disease. National programs must:

- Incorporate the complete WHO Advanced HIV Disease package into official guidelines.
- Allocate budgets for necessary CD4, CrAg, TB diagnostics, and Optimal Pediatric ART.
- Integrate Advanced HIV Disease indicators into performance evaluation frameworks.
- Protect and promote community-led monitoring efforts.
- Align grant implementation, including Global Fund funding, with Advanced HIV Disease service delivery.

It is essential that our policies translate into actionable practices on the ground.

9.5. Donors & Global Partners: Supporting Implementation

Global partners can significantly influence successful implementation. Donors and technical agencies should:

- Ensure ongoing access to crucial Advanced HIV Disease diagnostics & medications.
- Prioritize services tailored for paediatric patients.
- Fund grassroots efforts in community monitoring & engagement.
- Make certain that grant evaluations focus on identifying implementation gaps, not just on coverage statistics.
- Foster cross-country learning to share best practices.

To truly reduce mortality associated with Advanced HIV Disease, we must align our funding with the realities of implementation.

Conclusion

Advanced HIV Disease continues to affect many lives, where:

- ! Warning signs go unnoticed.
- ! Services are fragmented.
- ! Children's needs are overlooked.
- ! Health systems struggle silently.

But when:

- Communities are empowered to act.
- Health facilities deliver comprehensive care.
- Districts respond swiftly to identified gaps.
- National policies match funding with needs.
- Global partners rally behind implementation efforts.

We can make Advanced HIV Disease preventable.

This guide serves not only to highlight risks but to emphasise our shared mission to prevent unnecessary deaths. We have the tools, the evidence, and most importantly, the collective responsibility to act. The time to strengthen our response to Advanced HIV Disease is now.

Glossary and List of Abbreviations

AHD	Advanced HIV Disease. A stage of HIV infection defined by a CD4 count below 200 cells/mm³ or the presence of a WHO stage 3 or 4 condition. ALL children under 5 living with HIV not stable on ARTs.
AIDS	Acquired Immunodeficiency Syndrome. The most advanced stage of HIV infection defined by life-threatening opportunistic infections.
ART	Antiretroviral Therapy. Medicines used to treat HIV and suppress the virus.
ARVs	Antiretroviral medicines used in HIV treatment.
CD4 Cells	White blood cells that help the immune system fight infections.
CD4 Count	A test measuring the strength of the immune system by counting CD4 cells.
CHW	Community Health Worker who provides health education, referrals, and support in communities.
CrAg Test	Cryptococcal Antigen Test used to detect cryptococcal infection.
HIV	Human Immunodeficiency Virus that attacks the immune system.
OI	Opportunistic Infection that occurs when the immune system is weak.
PLHIV	People Living with HIV.
TB	Tuberculosis, a bacterial infection common in people with HIV.
TB-LAM	A rapid urine test used to diagnose TB in people with advanced HIV.
Viral Load	A test measuring the amount of HIV in the blood.
WHO	World Health Organization.

Key HIV Terms Every Community Activist Should Know

HIV	A virus that attacks the immune system.
Immune System	The body's defense system that fights infections.
CD4 Cells	Important immune cells that HIV damages.
Viral Load	The amount of HIV in the blood.
Undetectable	When HIV levels are so low that tests cannot detect them.
ART	Daily medicines that control HIV.
Treatment Adherence	Taking HIV medicines every day as prescribed.
Opportunistic Infections	Serious infections that occur when the immune system is weak.
Advanced HIV Disease	Severe immune suppression often with CD4 below 200.
Community Health Worker	A trained person who supports health services in communities.

APPENDIX A

Community Impact Story

Community Impact Story Template Advanced HIV Disease (AHD)

Documenting how community action improves services, referrals, follow-up, advocacy, and patient outcomes.

Who Can Use This Template?

This template can be used by:

- Community health workers (CHWs)
- Peer supporters and peer navigators
- Community monitors
- Civil society organisations (CSOs)
- Community-led monitoring (CLM) teams
- Treatment literacy and advocacy groups
- Programme staff and supervisors
- Community-based organisations supporting people living with HIV

When Should It Be Used?

Use this template when community action contributes to a meaningful change, improvement, solution, lesson learned, or positive outcome related to Advanced HIV Disease.

Examples include:

- A patient successfully linked back to care
- A referral system that improved access to services
- A stock-out that was resolved through community action
- Improved follow-up for children living with HIV
- Advocacy that resulted in service improvements
- A community intervention that improved patient outcomes

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APPENDIX B

ADVANCED HIV DISEASE

Community Pocket Reference

This Is a reference book for all communities, community health workers, and partners involved in the HIV response. It provides practical guide to support a holistic response to Advanced HIV disease in children and adults. Recommendations are guided by the WHO and informed by emerging lessons on community engagement on the IMPAACT4HIV project. This guide helps you recognise Advanced HIV Disease early, act quickly, and ensure people receive the care they need.

Informed communities strengthen the advanced HIV disease response.

Unitaid SAVE LIVES FASTER · THE AURUM INSTITUTE · PATA · Solthis Committed expertise in health · cihp · DNDi

MARKET ACCESS AFRICA · IMPAACT4HIV IMPROVED ACCESS TO AHD CARE & TREATMENT 4 HIV · THRIVE Empower Locally, Catalyze Impact Globally · AFROCAB Treatment Access Partnership · match boxology

Contents

1. What Is Advanced HIV Disease (AHD)?

Definition

- CD4 count below 200 cells/mm³ in adults and children older than 5.
- OR they have a serious HIV-related illness (WHO Stage 3 or 4)
- **ALL children under 5 living with HIV not stable on ARTs**

Below 200

The lower the CD4 count, the higher the risk of life-threatening infections.

Below 100

Very high risk of cryptococcal meningitis

Below 50

Extremely compromised. Act urgently.

2. Warning Signs — Do Not Wait

If you see any of these signs, REFER URGENTLY to the nearest health facility. Do not wait.

A Adults & Adolescents

- ! Persistent fever
- ! Night sweats
- ! Severe weight loss
- ! Extreme tiredness
- ! Persistent cough
- ! Severe headache
- ! Confusion or vision changes
- ! Persistent diarrhoea
- ! Oral thrush
- ! Difficulty breathing

B Children

- ! Fast or difficult breathing
- ! Chest indrawing
- ! Severe weight loss
- ! Poor feeding
- ! Repeated infections
- ! Lethargy
- ! Convulsions
- ! Growth faltering
- ! Caregiver concern
- ! Missed clinic visits

Who Is Most At Risk?

Prioritise follow-up for:

- Newly diagnosed — assess immune status with CD4 cell count immediately
- People who interrupted ART
- Children under 5
- Lost to follow-up — trace and re-engage
- Recently discharged from hospital
- Adolescents / young adults (transition risk)

Red Flag Moments

act immediately when you see this:

- People with a new HIV diagnosis
- Baseline ART initiation
- Returns after stopping ART
- TB diagnosis + unknown CD4
- Discharged patient misses follow-up
- Discharged patient falls sick
- Adolescent repeatedly misses visits
- Child with growth concerns
- Children under 5 not stable on ARTs for up to 1 year
- ARTs are taken but don't seem to work
- Reoccuring illness or infections

3. WHO Recommended Advanced HIV Disease Care Package

This is what every person with Advanced HIV Disease should receive at the health facility.

Starting ART alone is not enough. The full package must be delivered together.

1 CD4 Testing

Identifies immune suppression. Essential even with viral load .

2 TB Screening

- TB is the leading cause of death in PLHIV.
- Clinical TB screening should be done at every clinical consultation.
- Lab testing TB screening (urine LAM-TB or PCR Xpert/Truenat) is done based on clinical indication and/or when CD4 cell count is <200 cells/mm3.

3 Serum CrAg Screening

For CD4 <100. Detects cryptococcal infection before meningitis develops.

4 Rapid / Optimised ART

Start or switch without delay. Assess for treatment failure if already on ART.

5 Preventive Therapies

Cotrimoxazole, TB preventive therapy, fluconazole for serum CrAg+.

6 Enhanced Follow-Up

- Clear hospital discharge plan.
- Community follow-up.
- Structured return visits.

Special Considerations

Children with Advanced HIV Disease need:

- Immediate clinical assessment
- Age-appropriate ART formulations and dosing
- Preventive therapies
- Nutritional support
- Pediatric routine vaccination schedule
- Caregiver counselling
- Structured follow-up

Even if viral load is controlled, a person can still be very weak and at risk. Some people achieve undetectable viral load but still have low CD4. They remain vulnerable. Always check both. Starting ART alone is not enough. The full Advanced HIV Disease care package must be provided.

Post-hospital discharge period carries high mortality risk:

Follow up within days of discharge (physically, phone call…).

Confirm medications

Check symptoms

Reinforce adherence

4. The 5-Step Community Action Flow

Use this process whenever a patient is at risk or a service gap is identified

When you see something that puts patients at risk, follow these steps.

1 NOTICE IT

1. Is there a missing test?
2. A stock-out?
3. A referral gap?
4. A child not gaining weight?
5. A missed screening?

Be specific. Write down what you see.

2 CHECK IF IT IS REPEATED

- ? Has this happened before?
- ? Are multiple patients affected?
- ? Is it happening to more than one patient?

If yes, it may be a system issue.

3 LOG IT

Record:

- Date
- What happened
- Who was affected.

Small notes prevent bigger crises. Use the Service Gap Log.

4 DISCUSS LOCALLY FIRST

Raise with the nurse in charge, facility manager, or supervisor.
Use facts, not blame.
Example: "In the last three weeks, three patients with CD4 below 100 were not screened for CrAg. Can we review the protocol?"

Many issues are resolved here.

5 ESCALATE IF

Escalate if:

- issue persists after discussion
- high-risk services affected
- multiple patients at risk
- child safety compromised
- preventable Advanced HIV Disease cases recurring.

Escalation Pathways:

- District review meetings
- Community monitoring reports
- Civil society forums
- National programme engagement

Escalation must always be:

- Evidence-based
- Respectful
- Focused on patient safety
- Solution-oriented

The goal is improvement, not confrontation.

Service Gap Log (Example of a Field Tool)

This tool can be used to track issues and follow up until they are resolved.

Date	What Happened?	Who Affected?	Repeated?	Who Informed?	Follow-Up Date
Example: 12 Feb	No CD4 testing available	3 patients	☑ ☐	Reported to nurse	
			☐ ☐		
			☐ ☐		
			☐ ☐		
			☐ ☐		
			☐ ☐		
			☐ ☐		
			☐ ☐		
			☐ ☐		
			☐ ☐		

5. Advanced HIV Disease Commodities & Services — Monitoring Checklist

This checklist is mainly for community monitors, supervisors, and facility visits

Use this checklist during facility visits. Document findings and escalate gaps. Focus on identifying missing tests, medicines, or delays that put patients at risk.

Diagnostics & Tests

Service / Commodity	Available?	Stock-outs?	Action Needed
CD4 Test	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Cryptococcal Antigen (CrAg) Test	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
TB Symptom Screening	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
TB-LAM (used for very weak patients who cannot produce sputum)	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Viral Load Test	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Timely Return of Test Results	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	

Preventive Medicines

Service / Commodity	Available?	Stock-outs?	Action Needed
Cotrimoxazole	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
TB Preventive Treatment (TPT)	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Pre-emptive Fluconazole (for CrAg+)	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	

Treatment for Opportunistic Infections

Service / Commodity	Available?	Stock-outs?	Action Needed
First-line TB Treatment	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Amphotericin B	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Flucytosine	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Fluconazole (treatment dose)	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Antibiotics for Severe Bacterial Infections	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Itraconazole	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	

ART & Supportive Services			
Service / Commodity	Available?	Stock-outs?	Action Needed
Effective ART Regimens (TLD)	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Paediatric ART Formulations (pALD)	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Regimen Switching When Indicated	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Nutritional Assessment & Support	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Psychosocial Support	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Post-Hospital Discharge Follow-Up	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	
Clear Referral Pathways	☐ ✓ ☐ ✗	☐ ✓ ☐ ✗	

Escalate immediately when:

CD4 or CrAg testing is unavailable

TB diagnostics not functioning

OI preventive medicines are not available

OI treatment medicines missing

ART stock-outs

Post-discharge feedback is absent

Nutrition gaps are affecting recovery

Treatment modalities such as regimens are not accurate

Advocate for:

Medicine formulations that are child-friendly

Better availability of diagnostic tools

6. Integrated 4-Level Advanced HIV Disease Strengthening Framework

This section helps you understand how different levels of the system should function

Preventing unwanted deaths from Advanced HIV Disease requires every level to function. These indicators help identify whether Advanced HIV Disease is sufficiently captured or poorly prioritized

L1 Community

Must be in place:

- Active, supported CHWs
- Routine follow-up after discharge
- Treatment adherence support
- Monitoring of children & adolescents
- Community documentation of gaps (community observatories)

Warning signs:

- Patients returning very sick
- Children missing doses
- No feedback loop with facilities

L2 Facility

Must be in place:

- Functional CD4 testing
- Serum CrAg being done for people with CD4<100
- SBI testing
- Routine TB screening
- Paediatric ART in stock
- Treatment for CrAG, TB, histoplasmosis, SBIs
- Clear discharge plans

Warning signs:

- CD4 deprioritized
- CrAg not done
- Repeated stock-outs
- Advanced HIV Disease is only addressed when patients are very sick

Histoplasmosis test will be made available if prevalent in country, don't hesitate to ask for histoplasmosis testing

L3 District

Must be in place:

- Active commodity availability and supply monitoring
- Lab turnaround time oversight
- Review of Advanced HIV Disease indicators & mortality
- Paediatric Advanced HIV Disease and outcomes in district reviews
- Adolecsent Advanced HIV Disease in district reviews
- Response when facilities report gaps

Warning signs:

- No response to facility reports
- Delays in equipment repair
- Community findings not discussed

L4 National

Must be in place:

- Full WHO Advanced HIV Disease package in guidelines for primary and hospital care
- Dedicated budget for all commodities: CD4, CrAg (testing and treatment), TB (testing, treatment and TPT), paediatric ART, Histo LAM (if available) SBI testing
- Advanced HIV Disease indicators in performance frameworks
- Advanced HIV Disease prioritised in HIV strategic plans
- Advanced HIV Disease for children and adolescents explicitly prioritized
- Funding allocation alignment with Advanced HIV Disease delivery needs

Warning signs:

- CD4 removed without alternative risk screening
- CrAg not funded or procured
- TBLAM not funded or secured
- SBI testing not prioritized in children
- Prevention not prioritized – e.g cotrimoxazole for children
- Advanced HIV Disease reporting indicators are not tracked in national reporting systems
- Paediatric Advanced HIV Disease is not prioritized in funding or procurement provisions

7. Collective Call To Action

Use this to guide who to engage when issues are not resolved at facility level.

Knowing each person's role helps you target your communication and advocacy. It takes collaboration for these efforts to achieve our collective aim.

Communities:

- Identify early warning signs
- Support individuals to stay in care
- Follow up post-discharge
- Protect children & adolescents
- Document and report service gaps

Donors & Global Partners:

- Ensure access and availability of Advanced HIV Disease diagnostics & medicines
- Prioritise paediatric services
- Fund community monitoring efforts
- Focus evaluations on implementation gaps
- Foster cross-country learning

District & National:

- Monitor supply chains & lab systems
- Review of Advanced HIV Disease indicators performance and outcome tracking
- Use data from the field to inform priorities and allocation
- Include Advanced HIV Disease in national strategic plans
- Define Advanced HIV Disease packages both for primary health care and for hospital level
- Align Funding allocations (global and national grants with Advanced HIV Disease delivery
- Protect community-led monitoring

Health Workers & Facilities:

- Implement the full WHO Advanced HIV Diseasecare package
- Ensure CD4 & CrAg for all eligible patients
- Prioritise paediatric care
- Develop clear discharge plans
- Link feedback to communities
- Review Advanced HIV Disease cases and mortality

Advanced HIV Disease is preventable when it is recognised early and managed correctly.

IMPAACT4HIV
auruminstitute.org

THRIVE
thriveinfo.org

UNITAID
unitaid.org

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