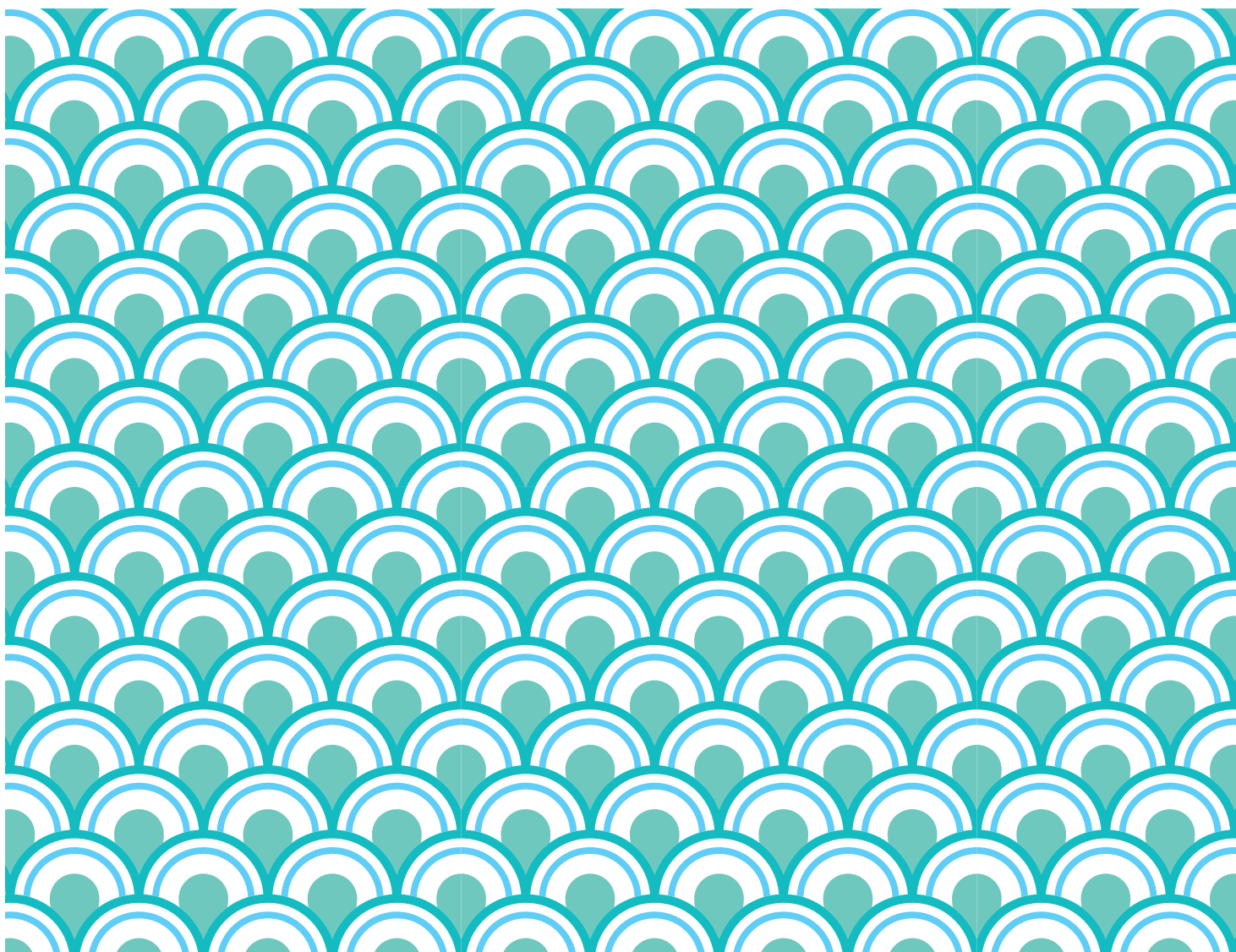


# HIV care and support

HIV care and support taking into account  
the 2016 WHO consolidated guidelines





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# Purpose

*“Care and support is a comprehensive set of services, including medical, psychosocial, physical, socioeconomic, nutritional and legal support. These services are crucial to the well-being and survival of people living with HIV and their caregivers and orphans and other vulnerable children. **Care and support services are needed from the point of diagnosis throughout the course of HIV-related illness, regardless of ability to access antiretroviral therapy.**”*

The purpose of this document is to:

- Describe what HIV care and support is.
- Describe the purpose of care and support in the context of the 2016 World Health Organization (WHO) *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection* (1).
- Illustrate how care and support is essential, alongside HIV treatment, to reduce the numbers of HIV-related illnesses and deaths and increase the well-being of people living with HIV, including orphans and other vulnerable children, adolescents, key populations and people aged 50 years and over.

Care and support is a comprehensive set of services, including medical, psychosocial, physical, socioeconomic, nutritional and legal support. These services are crucial to the well-being and survival of people living with HIV and their caregivers and orphans and other vulnerable children. Care and support services are needed from the point of diagnosis throughout the course of HIV-related illness, regardless of ability to access antiretroviral therapy.

This document builds on the 2016 WHO *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection* (1) and the United States President’s Emergency Plan for AIDS Relief (PEPFAR) care and support technical considerations (2). It emphasizes the essential role of care and support in meeting the 90–90–90 targets, whereby 90% of people living with HIV know their HIV status, 90% of people who know

their HIV-positive status are accessing treatment and 90% of people on treatment have suppressed viral loads.

The document is intended to support actors seeking to maximize non-antiretroviral therapy care and support services to enhance the effectiveness of antiretroviral therapy by increasing access to

HIV testing and counselling and linkage to and retention in HIV treatment of people living with HIV, and improving the quality of life of people living with HIV.

The audience of this document is people living with, at risk of or affected by HIV, national HIV programme managers, service providers and policy-makers.

# Introduction

*“The knowledge and tools now exist to end the AIDS epidemic by 2030 (3, 4) and may be augmented with additional tools, including a cure and a vaccine. Political commitment and sustainable financing of the AIDS response are critically required to use the existing tools effectively.”*

The global AIDS response has changed to match an evolving HIV epidemic. The HIV epidemic remains one of the world’s most significant public health challenges. Millions of lives are being saved due to major scientific breakthroughs and accumulated knowledge over three decades of the AIDS response. The knowledge and tools now exist to end the AIDS epidemic by 2030 (3, 4) and may be augmented with additional tools, including a cure and a vaccine. Political commitment and sustainable financing of the AIDS response are critically required to use the existing tools effectively.

When antiretroviral therapy first became available, people living with HIV had to take many pills. Delivery of antiretroviral therapy was specialized and centralized, mainly in big hospitals in urban areas. The number of people dying from AIDS-related illnesses was high—and remained high (5).

Since then, antiretroviral therapy has improved tremendously, especially for adults. Newer antiretroviral medicines are more potent, are more durable, have fewer side-effects, and come in fixed-dose combinations that are easier to take and adhere to than older medicines. Costs of antiretroviral medicines and related diagnostics have reduced significantly, facilitating widespread access to antiretroviral therapy (6, 7).

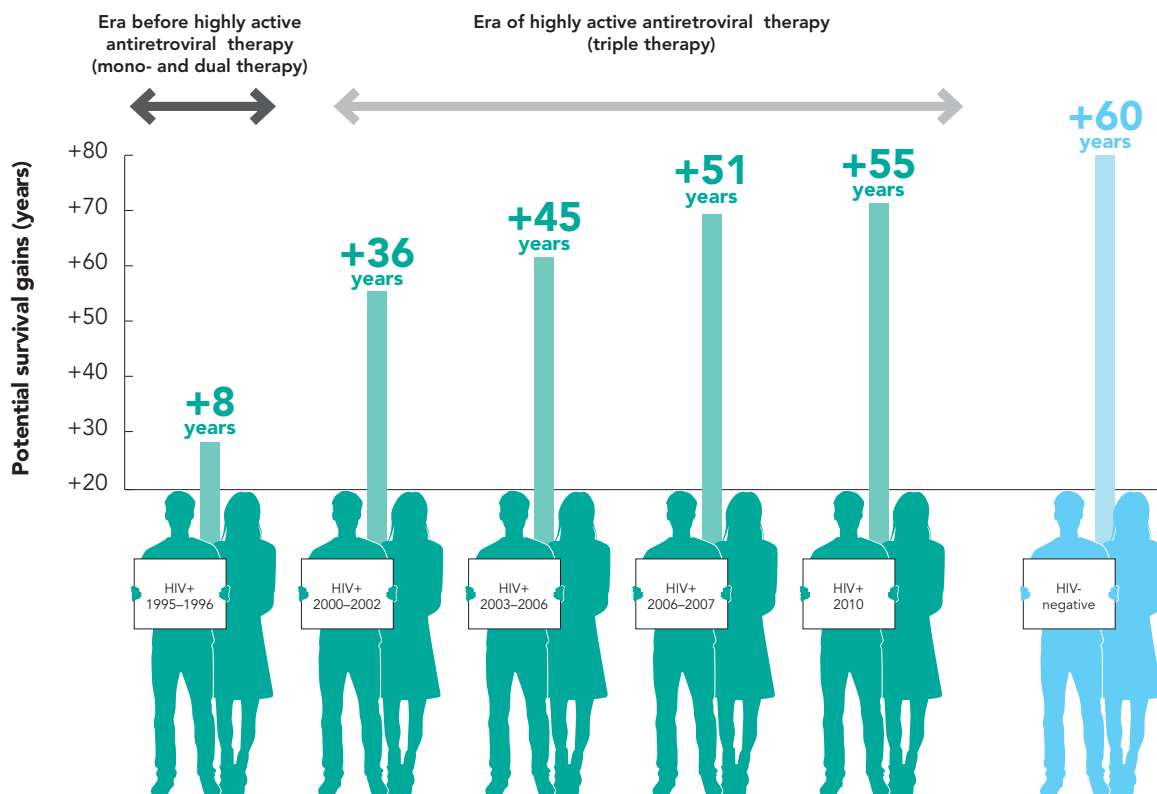
The numbers of AIDS-related illnesses and deaths have reduced dramatically. People are living with HIV for longer: their life expectancy is now measured in decades (5), close to the normal life expectancy of the general population. Life expectancy at age 20 years for a person living with HIV and newly initiated on antiretroviral therapy

increased from 36 years in 2000–2002 to 51 years in 2006–2007. A 20-year-old person living with HIV in a high-income country such as Canada or the United States of America who is initiated on antiretroviral therapy is now expected to live into their early 70s, a life expectancy close to that of the general

population (Figure 1). Differences by race, sex, age, HIV transmission risk group and CD4 count remain, however: life expectancy is lower among people with a history of injecting drug use, people who are non-white and people who begin antiretroviral therapy at a lower CD4 count (8).

**Figure 1**

Expected survival of a 20-year-old person living with HIV in a high-income country across different time periods



Source: *The gap report*. UNAIDS, 2014.

The near-normal life expectancy of people living with HIV on antiretroviral therapy in high-income countries has also been reported in low- and middle-income countries. In Uganda, a person living with HIV initiating antiretroviral therapy at age 20 years is expected to have an additional 26 years of life (9). In rural South Africa, life expectancy for people living with HIV newly initiating antiretroviral therapy increased to 60.5 years in 2011 from 49.2 years in 2003, when antiretroviral therapy was not available in the public health system (10). In Rwanda, life expectancy for people living with HIV on antiretroviral therapy at age 20 years in the period 1997–2007 was 20.4 additional years; this increased to 25.6 additional years for the period 2008–2011. Across the countries, life expectancy varied by sex, with women having greater gains; improved life expectancy was greatest among people with a CD4 count at initiation of treatment above 200 cells/mm<sup>3</sup> (11).

Millions of people living with HIV do not have access to HIV treatment and care, and support is still needed for people who are on HIV treatment. Although access to antiretroviral therapy has led to a dramatic reduction in AIDS-related deaths and has clear health benefits, antiretroviral therapy does not fully restore health. Other non-AIDS-related deaths have increased, and a wider range of complications is being seen than in the past. Importantly, people living with HIV need to take antiretroviral therapy for the rest of their life, a daunting task for which they will need support (5).

Figures 2 and 3 show the most common causes of death among people living with HIV in Europe,

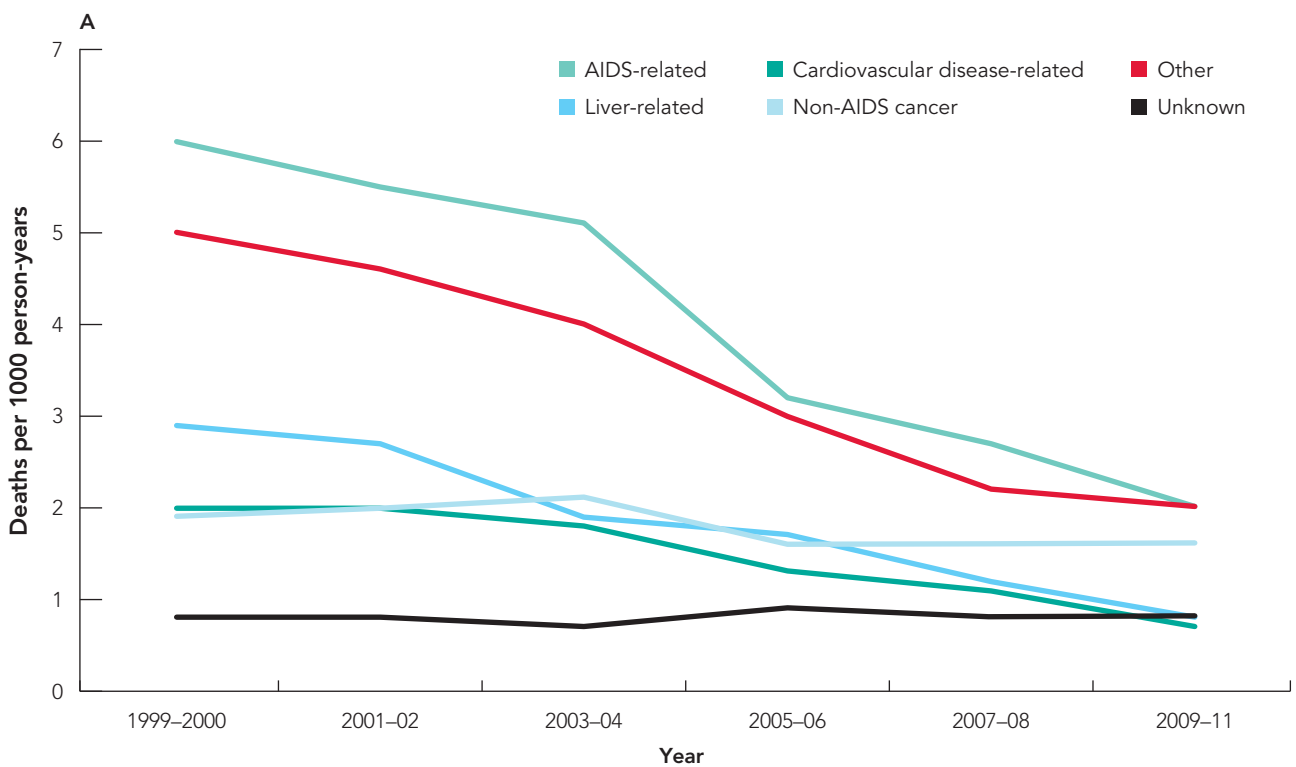
Australia and the United States, and Uganda. A study of trends over time in all-cause mortality and by specific causes of death among people living with HIV participating in cohort studies of people receiving care in Europe, the United States and Australia found that the number of deaths among people on HIV treatment decreased from 1999–2000 to 2009–2011; the most common causes of death were AIDS-related causes, followed by other causes. Invasive bacteria, suicide and drug overdose were the most common causes of death listed as “other causes”. AIDS-related causes and “other causes” of death had the most reductions. Non-AIDS-related cancers increased in comparison with liver and cardiovascular diseases (12).

In one of the very few studies conducted in a low-income setting that included causes of death among people living with HIV from 2002 to 2012, the rate of death among people living with HIV decreased over time (Figure 3). The estimated rate of death reduced from 21.86 deaths/100 person-years of follow-up in 2002 to 1.75 deaths/100 person-years of follow-up in 2012. The proportion of deaths due to communicable conditions and AIDS-defining malignancies decreased from 84% [74–90%] to 64% [53–74%]; the proportion of deaths due to chronic noncommunicable conditions, other noncommunicable conditions, and a combination of communicable and noncommunicable conditions increased. Nevertheless, communicable conditions and AIDS-defining malignancies remained major causes of the majority of deaths (13).



**Figure 2**

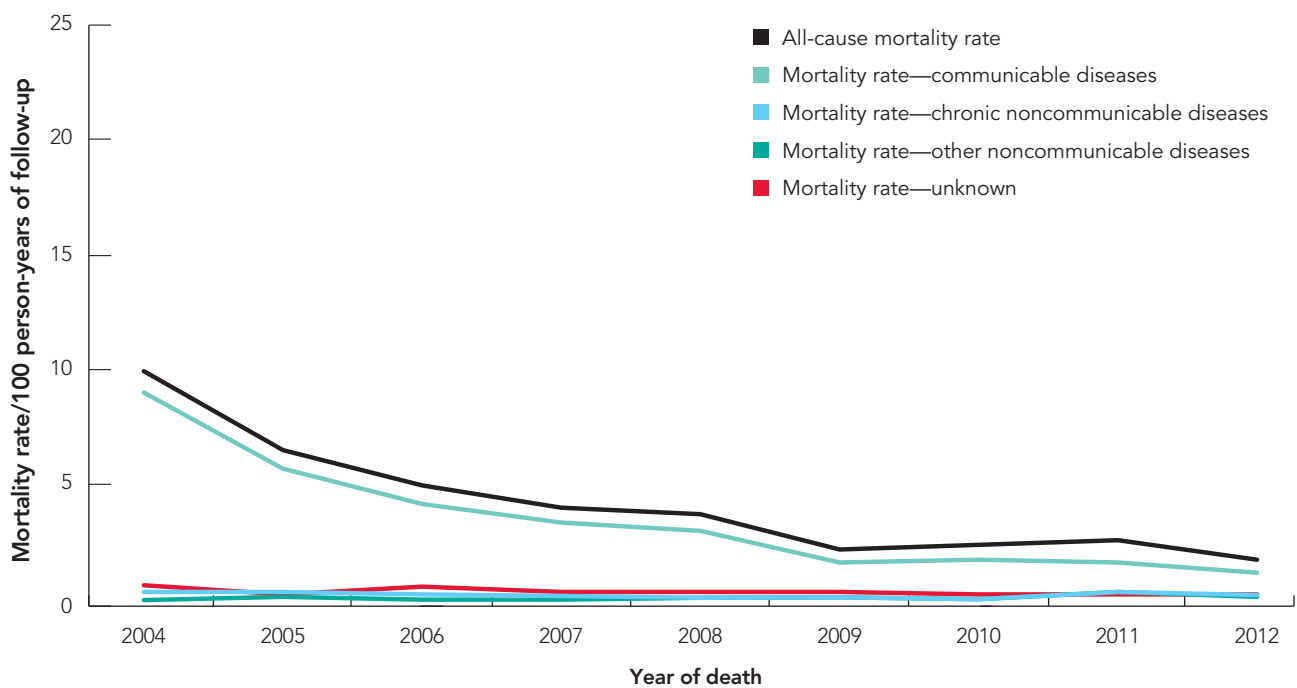
Trends in causes of deaths among people living with HIV in Europe, Australia and the United States of America, 1999–2012



Source: Smith CJ, Ryom L, Weber R, Morlat P, Pradier C, Reiss P, et al Trends in underlying causes of death in people with HIV (D:A:D): a multicohort collaboration. *Lancet*. 2014;384:241–248.

**Figure 3**

Mortality rate among people living with HIV in Uganda in the era of ART—2004–2013<sup>1</sup>



Source: Cox JA, Kiggundu D, Elpert L, Meintjes G, Colebunders R, Alamo S. Temporal trends in death causes in adults attending an urban HIV clinic in Uganda: a retrospective chart review. *BMJ Open*. 2016;6:e008718.

<sup>1</sup> **Communicable diseases:** HIV, tuberculosis, diarrhoeal disease, respiratory tract infection or respiratory symptoms, meningitis, malaria, Kaposi's sarcoma, other AIDS malignancy, infection not specified, other communicable specified.

**Chronic noncommunicable:** non-AIDS-defining malignancy, cardiovascular disease, cerebrovascular event, chronic respiratory disease, gastro infection and hepatic disease, neurological or psychiatric disorder, diabetes, chronic renal disease, chronic alcohol abuse.

**Other noncommunicable:** pregnancy related condition, accidents, suicide, assault, pulmonary embolus, other condition not specified.

# Why care and support is important

*“Care and support is important for the following reasons:*

- *To facilitate **immediate access to treatment** when a person is diagnosed with HIV.*
- *To support adherence to treatment in order to attain viral suppression for people living with HIV, for the sake of their own health and to prevent infecting other people with HIV.*
- *To enhance the **prevention and management of HIV-related infections**.*
- *To enhance coping with the challenges of living with HIV.”*

Care and support refers to key non-antiretroviral therapy clinical services, prevention and treatment of HIV-related infections, and non-clinical services that in combination with antiretroviral therapy contribute towards the reduction of rates of ill health and HIV-related deaths among, and increase the well-being of, people living with HIV (14). Care and support is important for the following reasons:

- To facilitate immediate access to treatment when a person is diagnosed with HIV.
- To support adherence to treatment in order to attain viral suppression for people living with HIV, for the sake of their own health and to prevent infecting other people with HIV.
- To enhance the prevention and management of HIV-related infections.
- To enhance coping with the challenges of living with HIV.

Table 1 shows the different care and support services adapted from the PEPFAR care and support framework (14). Care and support services indicated in the “universal” category in Table 1 are proven to contribute towards the reduction of ill health and number of deaths and to improve the well-being of people living with HIV. These services are necessary for all people living with HIV and include:

- Linkage to care for rapid initiation of antiretroviral therapy for people newly diagnosed with HIV, followed by regular clinical and laboratory monitoring and, where possible, CD4 count and viral load measurement.

- Screening for active tuberculosis (TB), with referral for diagnosis and treatment as appropriate.
- Cotrimoxazole prophylaxis for people living with HIV eligible as per country guidelines.
- Evidence-informed clinical and non-clinical services that optimize retention in care and adherence to antiretroviral therapy.

Effective counselling and testing with linkage to durable antiretroviral therapy for people newly diagnosed with HIV, regardless of CD4 count,

remains the gateway to care and support. For people with severe or advanced HIV disease (WHO clinical stage 3 or 4, and adults with a CD4 count below 350 cells/mm<sup>3</sup>), the priority should be to start HIV treatment (1). Thereafter, access and adherence to HIV treatment, basic nursing and end-of-life care, access to social grants, psychosocial and mental health support, livelihood-strengthening activities and food security continue to be critical pillars of care and support in the HIV response (15).

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## Table 1

Care and support services<sup>1</sup>

Universal	<ul style="list-style-type: none"> <li>▪ Linkage to care for immediate initiation of antiretroviral therapy for people newly diagnosed with HIV, with clinical and laboratory monitoring, including viral load monitoring</li> <li>▪ Tuberculosis screening</li> <li>▪ Cotrimoxazole prophylaxis</li> <li>▪ Optimization of retention in care and adherence to antiretroviral therapy</li> </ul>
Contextual	<ul style="list-style-type: none"> <li>▪ Clinical care</li> <li>▪ Physical care</li> <li>▪ Social support</li> <li>▪ Pain and symptom management and end-of-life care</li> <li>▪ Mental health and substance (including alcohol) abuse services</li> <li>▪ Nutrition assessment, counselling and support</li> <li>▪ Legal support</li> </ul>

<sup>1</sup> Services are not listed in any particular order.

All other services that are not universal are contextual and applicable by country context and population group. These include screening for and treatment of cervical cancer for women living with HIV, especially in high-prevalence areas of sub-Saharan Africa; access to mental health services and services for harmful substance use, including alcohol and tobacco; screening for and treatment of hepatitis, especially among key populations living with HIV; and legal support.

Since geographical areas with HIV incidence also have a high prevalence of noncommunicable diseases (e.g. diabetes, cancer, cardiovascular disease), food insecurity and the effects of endemic infections (e.g. malaria, TB, diarrhoea) (16), many of the contextual care and support services are required in different situations.

# The changing landscape requires a dynamic response

*“The changing HIV landscape means approaches to care need to evolve towards a more holistic, coordinated and integrated care and support approach. Antiretroviral therapy remains the mainstay for treating HIV infection, but care and support is integral to antiretroviral therapy.”*

An integrated and comprehensive care and support approach is essential to meet the increasingly complex needs of people living with HIV and ensure they live long, healthy, fulfilling and independent lives. The changing HIV landscape (Figure 4) means approaches to care need to evolve towards a more holistic, coordinated and integrated care and support approach (17). Antiretroviral therapy remains the mainstay for treating HIV infection, but care and support is integral to antiretroviral therapy. Care and support extends beyond medicines and formal health-care systems and requires adoption of new strategies that take into account the comprehensive and different needs of people living with HIV.

In the pre-antiretroviral therapy era, there was a clear presence of HIV-related illnesses and increasing numbers of deaths among people living with HIV. HIV affected mainly young adults and children in countries with a high HIV prevalence, which led to low life expectancies in these groups. Key populations, including sex workers, men who have sex with men, transgender people and people who inject drugs, were the groups most affected in many parts of the world. Now there are more people on antiretroviral therapy, and fewer HIV infections among adults and children are occurring. However, adolescent girls and young women in eastern and southern Africa and key populations continue to have disproportionately higher HIV burdens (5).

Before the advent of antiretroviral therapy, in many countries, especially low- and middle-income countries, health systems were unable to manage

**Figure 4**

The evolving HIV epidemiology, prevention and treatment landscape

	Past	Present	Future
Immune status among people living with HIV	<ul style="list-style-type: none"> <li>Severe immune deficiency in untreated patients</li> <li>Partially restored immune deficiency in treated patients</li> <li>AIDS-defining illnesses and tuberculosis</li> <li>Antiretroviral therapy toxicity from early antiretroviral therapy combinations</li> </ul>	<ul style="list-style-type: none"> <li>Partially restored immune system with antiretroviral therapy</li> <li>Persistent inflammation contributing to incomplete health restoration</li> <li>Increasing importance of cardiovascular, liver, renal and cognitive complications of HIV</li> </ul>	<ul style="list-style-type: none"> <li>Restored immune function through earlier initiation of antiretroviral therapy, functional cure in some patients</li> <li>Morbidity reflecting age as seen in general population</li> <li>No increased risk for tuberculosis</li> </ul>
Care and support model	<ul style="list-style-type: none"> <li>Hospital-based care of symptomatic patients</li> <li>Home-based care, palliative care and end-of-life care</li> </ul>	<ul style="list-style-type: none"> <li>Clinic- and hospital-based</li> <li>Move towards integrated HIV care cascade</li> </ul>	<ul style="list-style-type: none"> <li>Community-based and clinic-based integrated HIV care model with speciality HIV cure services</li> <li>Point-of-care technology widely used and informing patient care</li> <li>Decentralized care</li> <li>Routine viral load monitoring</li> </ul>
HIV epidemiology	<ul style="list-style-type: none"> <li>Exponential increase in new HIV infections</li> <li>Disease affects mainly young adults</li> <li>Disproportionate burden of new infections in high-risk populations</li> <li>Life expectancy of less than two years after AIDS illness</li> <li>Low proportion of people with access to antiretroviral therapy</li> </ul>	<ul style="list-style-type: none"> <li>Fewer new adult infections, but more people living with HIV</li> <li>Disease increasingly common in middle-aged people</li> <li>Reduced number of children living with HIV</li> <li>Disproportionate burden of new HIV infections in high-risk populations and in serodiscordant couples</li> <li>Greater proportion of people treated with antiretroviral therapy</li> <li>Life expectancy of decades in treated people</li> </ul>	<ul style="list-style-type: none"> <li>Few new HIV infections</li> <li>Elimination of HIV infections in children</li> <li>Disease spans age spectrum, with growing burden of disease in geriatric populations</li> <li>Reduced risk for tuberculosis</li> </ul>

Source: Deeks SG, Lewin SR, Havlir DV. The end of AIDS: HIV infection as a chronic disease. Lancet. 2013;382:1525–1533.

the high numbers of people falling ill. The majority of people living with HIV turned to their families, communities and faith-based organizations to access HIV care and support. Support groups that offered a range of services or referrals for psychosocial support, basic clinical care, nutrition

assessment and counselling, and legal and economic support, were vital to the HIV response. New evidence shows that these structures remain relevant in improving the health and well-being of children and adults living with, at risk of or affected by HIV (18).



# Care and support needs of people living with HIV

*“Meeting the multiple needs of people living with HIV is essential to link and retain people in care. Combining innovative HIV testing strategies, including home- and community-based testing, self-testing and point-of-care diagnosis (including in infants), with care and support can increase HIV testing rates and linkage to HIV treatment.”*

## **Accelerated antiretroviral treatment enrolment**

Immediate initiation of antiretroviral therapy and care is vital for health and life. The WHO recommendation to offer antiretroviral therapy to all people who test positive for HIV, regardless of CD4 count, will make little difference if people testing positive fail to initiate antiretroviral therapy immediately. People living with HIV who present to HIV care services with an AIDS-defining illness, even if they have a high CD4 count, tend to fare more poorly than people living with HIV with no AIDS-defining disease. Similarly, people with a CD4 count below 200 cells/mm<sup>3</sup> at enrolment in HIV care tend to progress more quickly to AIDS or die earlier than people with more robust immunological profiles (1).

Prompt referral, immediate enrolment and retention in clinical care, and care and support, are vital for improved health and quality of life for people living with HIV. Even when people come for counselling and testing, they may not be linked and enrolled in HIV care and treatment promptly. Linkage to care can be defined as confirmation of an HIV-positive diagnosis and first HIV clinic visit (19). Studies conducted in southern Africa show that the gap between diagnosis and linkage to care can be alarmingly wide: these studies reported that between 8.5% and 69% of people diagnosed with HIV made it into care within 90–180 days of diagnosis (20–23).

The lengths of the intervals between diagnosis and linkage to care and between diagnosis and starting antiretroviral therapy are especially critical

in infants and people with lower CD4 counts, where delayed initiation of treatment is associated with a high risk of acquiring HIV-related infections and death. A modelling exercise using South African data estimated that a delay in initiating antiretroviral therapy of 70 days would lead to a 34% increase in the 12-month death rate. Delaying antiretroviral therapy not only deters people living with HIV from starting

antiretroviral therapy but also jeopardizes the health of people who do start antiretroviral therapy (24).

There are many reasons for people not being linked to care or dropping out of care. Table 2 shows the frequent predictors of attrition from care and the barriers to accessing care from a systematic review of risk factors, barriers and facilitators for linkage to antiretroviral therapy care.

**Table 2**  
Predictors of attrition from care and barriers to care

Factor		Predictor of attrition	Barrier to care
Economic	▪ Transport	Yes	Yes
	▪ Distance to provider	Yes	Yes
	▪ Unable to take time off for clinic visits due to employment		Yes
	▪ Food shortage		Yes
Psychosocial	▪ Stigma and fear of disclosure		Yes
	▪ Fear of drug toxicity		Yes
	▪ Perceived good health		Yes
Health systems	▪ Long clinic waiting times		Yes
	▪ Poor services from health-care workers		Yes
	▪ Shortage of health-care workers	Yes	Yes
	▪ Inconvenient clinic hours		Yes
Medical	▪ Advanced immunodeficiency	Yes	
	▪ On tuberculosis therapy or coinfecting with tuberculosis	Yes	Yes
	▪ Pregnancy	Yes	
	▪ Severe malnutrition	Yes	
Other	▪ Male sex	Yes	
	▪ Younger age	Yes	
	▪ Low level of education	Yes	

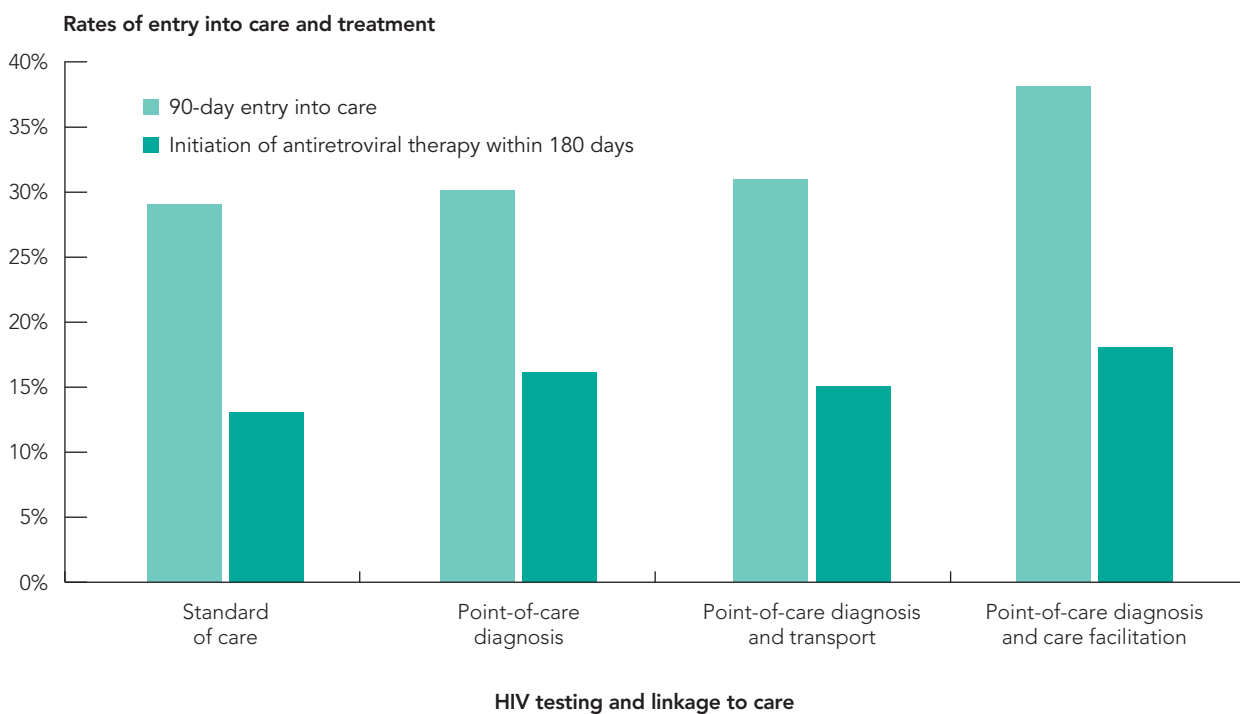
Source: Govindasamy D, Ford N, Kranzer K. Risk factors, barriers and facilitators for linkage to antiretroviral therapy care: a systematic review. *AIDS*. 2012;26:2059–2067.

Meeting the multiple needs of people living with HIV is essential to link and retain people in care. Combining innovative HIV testing strategies, including home- and community-based testing, self-testing and point-of-care diagnosis (including in infants), with care and support can increase HIV testing rates and linkage to HIV treatment. In South Africa, linkage to HIV treatment increased by 40%

when people living with HIV were offered point-of-care diagnosis and facilitated care to overcome personal barriers, including fear of stigma of an HIV-positive diagnosis, fear of disclosure and lack of self-confidence in accessing HIV treatment, compared with standard HIV counselling and testing (Figure 5) (25).

### Figure 5

Rates of entry into care within 90 days and initiation of antiretroviral therapy within 180 days



Source: Hoffmann C, Mabuto T, Ginindza S, Fielding KL, Kubeka G, Dowdy D, et al. A randomized trial to accelerate HIV care and ART initiation following HIV diagnosis. Abstract 113LB. Presented at the Conference on Retroviruses and Opportunistic Infections, Boston, MA, 22–25 February 2016.

In another study in South Africa, offering single-visit antiretroviral therapy initiation to people living with HIV increased uptake of antiretroviral therapy by 36% and increased viral suppression by 26%. Accelerated initiation of antiretroviral therapy combined compressed and accelerated clinic procedures with point-of-care laboratory testing technology, including a physical examination, education and counselling, allowing people living with HIV to begin antiretroviral therapy on the same day. From provision of informed consent to dispensing of the first supply of antiretroviral medicine, rapid initiation took a median of 2.4 hours [2.1–2.8 hours]. This interval was shorter for people living with HIV who had their CD4 count results available (median 2.25 hours); the interval was longer for people who required a TB test and initiated antiretroviral therapy on the same day (median 4.5 hours).

Standard treatment initiation followed a schedule requiring three to five additional visits over a period of two to four weeks. The rapid initiation approach increased the proportion of people living with HIV who initiated antiretroviral therapy within 90 days from 25% to 97%. In addition, 100% of people living with HIV who needed TB treatment were not delayed for TB treatment. More people living with HIV dropped out of care after starting antiretroviral therapy in the standard initiation group, highlighting the essential need for adherence counselling. Overall, the rapid initiation group had better health outcomes (24).

Stronger post-test counselling, support groups of people living with HIV and empowerment programmes are essential to connect and retain

people living with HIV in care. Linking people living with HIV to services providing transport vouchers or reimbursements and transport systems that are free at the point of use for clinic appointments are important approaches to reduce out-of-pocket expenses for people living with HIV and retain them in care. Use of mobile units providing antiretroviral therapy services such as point-of-care laboratory services and home-delivered antiretroviral therapy improves linkages to care. Financial incentives, career development paths, enhanced management, personal recognition and improved working conditions are critical for retaining and sustaining health-care workers in the public sector and retaining people living with HIV in care (28).

Due to staff shortages, services may not be accessible or may be of poor quality. Poor-quality services and negative attitudes of some health facility workers, especially towards adolescents and key populations, may discourage ongoing access to HIV services (26). Addressing the negative attitudes, such as prejudice, lack of knowledge and fear of HIV infection, of health facility workers, including doctors, nurses and others, by providing knowledge, information and adequate tools and supplies to perform their work is essential to increase access to and retention in HIV care (19).

### **START-ART strategy increased antiretroviral therapy initiation in Uganda**

In Uganda, 80% of people living with HIV participating in the Streamlined Antiretroviral Therapy Start Strategy (START-ART) started antiretroviral therapy within 14 days of diagnosis

compared with 38% of people receiving treatment in a standard HIV programme. At 90 days after diagnosis, 90% of people in the START-ART strategy were on antiretroviral therapy compared with 70% of people in the standard care programme. The START-ART approach aimed to change prevailing health-care worker behaviours, focusing on knowledge, attitudes and beliefs that affect behaviour; enabling factors consisting of skills and materials that make the desired behaviour easier; and reinforcing anticipated consequences following a behaviour.

Barriers to starting antiretroviral therapy include the widespread belief that delays to initiation of antiretroviral therapy are not harmful; overnight processing of laboratory results requiring multiple clinic visits before antiretroviral therapy is initiated; and standard practices demanding up to three counselling visits and the need for treatment supporters before antiretroviral therapy is initiated.

The START-ART approach included training about the clinical and behavioural consequences of waiting to offer antiretroviral therapy; coaching visits on clinical considerations; introduction of a revised counselling approach that relaxes strict requirements for treatment supporters and emphasizes that people living with HIV should be assessed for readiness for initiation of antiretroviral therapy rather than application of one-size-fits-all multiple adherence counselling sessions; and application of point-of-use machines to enable health-care workers to offer real-time results. The decision to offer antiretroviral therapy was left to doctors and nurses working under

programme conditions, showing that the approach is positioned to be acceptable and adoptable in routine care (27).

### **Clinical care for other illnesses**

TB is the most frequent HIV-related infection among people living with HIV, regardless of whether they are on HIV treatment (1). TB remains the leading cause of hospitalization and in-hospital deaths among adults and children living with HIV. Of all children living with HIV who are hospitalized, 8% of cases are attributed to TB. Among adults living with HIV, the rate of hospitalization due to TB is 10% across all regions except Europe. The rate of in-hospital deaths due to TB is 25% among adults living with HIV and 30% among children living with HIV (29). Almost half (45.8%) of TB infections in people living with HIV are undiagnosed at death (30). Among people living with HIV with multidrug-resistant or extreme drug-resistant TB, the rate of death reaches 72–98% (31).

WHO recommends accelerated implementation of its “three I” strategy for TB prevention and control—intensified TB case-finding, isoniazid preventive therapy and infection control—at all clinic encounters for people living with HIV (1). This strategy includes antiretroviral therapy and isoniazid preventive therapy for people living with HIV. WHO recommends that people living with HIV in areas of high TB infection, and all people with latent TB infection or exposure to TB regardless of where they live, take isoniazid preventive therapy and begin taking antiretroviral therapy immediately after an HIV-positive diagnosis.

Cytomegalovirus, cryptococcosis, Kaposi's sarcoma, non-Hodgkin's lymphoma, human papillomavirus, other HIV-related malignancies and non-AIDS cancers<sup>1</sup> are also important causes of death among people living with HIV (12, 32). A study in the United States found an increase in the proportion of Kaposi's sarcoma and non-Hodgkin's lymphoma diagnosed following initiation of antiretroviral therapy. Rates of diagnosis of Kaposi's sarcoma increased from 55% during 1996–2001 to 76% during 2007–2011. This increase was driven by more people receiving effective antiretroviral therapy and having higher CD4 counts and suppressed viral loads rather than by increases in cancer risk in the subgroups. The proportion of people receiving antiretroviral therapy diagnosed with non-Hodgkin lymphoma remained high and stable, at 83% (33).

It is essential that people living with HIV and health-care providers are aware that people living with HIV on effective antiretroviral therapy with high CD4 counts and achieving viral suppression may still develop Kaposi's sarcoma, non-Hodgkin's lymphoma and other cancers and take steps to address the risks.

For women living with HIV, the risk of pre-cancer and invasive cervical cancer is high, especially if their immunity is compromised. Women living with HIV remain at risk as they access antiretroviral therapy and live longer, requiring organized and timely screening and treatment of pre-cancer lesions. Although screening and prompt treatment would be

expected to reduce pre-cancer lesions and rates of cervical cancer among women living with HIV, more data are needed to confirm the benefit (34, 35).

People living with HIV, regardless of whether they are on HIV treatment, are at increased risk of developing a range of noncommunicable diseases, including cardiovascular diseases, diabetes and chronic lung diseases (1). Although not related to HIV, cardiovascular diseases, in particular heart attack, stroke and heart failure, continue to be among the top causes of death among people living with HIV. WHO recommends lifestyle changes to address cardiovascular risks (1) by addressing factors such as blood pressure, smoking status, obesity, unhealthy diet and lack of physical exercise for all people living with HIV.

People living with HIV, regardless of whether they are on HIV treatment, are at increased risk of acquiring malaria and infections such as pneumonia, influenza, meningitis and sepsis, especially if they live in poor sanitary and economic conditions. People living with HIV, including children, show higher rates of clinical malaria, with increased rates of death among people with advanced immune suppression. Pregnant women living with HIV and infected with malaria are at increased risk of adverse birth outcomes and other complications (36). WHO recommends people living with HIV to take cotrimoxazole to reduce ill health and the number of deaths associated with a number of common coinfections (1).

<sup>1</sup> Non-AIDS cancers include lung cancers, prostate cancer, anal cancer, head and neck cancers, Hodgkin's lymphoma, primary liver cancers (excluding hepatitis-related cancers), gastrointestinal cancers, breast cancers, uterus cancers, testicular cancers, penile cancers, bladder cancers, kidney cancers, primary bone tumours (except non-Hodgkin's lymphoma), unknown primary tumours and acute or chronic leukaemia (12).

In settings where malaria or severe bacterial infections are prevalent, cotrimoxazole prophylaxis is recommended for people living with HIV, including pregnant women, regardless of their CD4 count. Cotrimoxazole prophylaxis can be effective in preventing several HIV-related infections, including TB, bacterial pneumonia and *Pneumocystis carinii* pneumonia. Additional benefits of cotrimoxazole relate to the prevention of malaria and severe bacterial infections among adults and children living with HIV (1). The following categories of people in resource-limited settings are recommended to take cotrimoxazole prophylaxis:

- Infants and children who have been exposed to HIV.
- People living with HIV, including adolescents.
- People living with HIV with a history of *Pneumocystis carinii* pneumonia.

### **Physical care and support**

Physical care is mainly delivered by community caregivers and volunteers, who are often women living with HIV (37). A range of physical care is delivered in homes, communities and health facilities. Physical care involves:

- Support with washing and basic hygiene.
- Assisting with mobility.
- Treating sores and cuts.
- Collection of antiretroviral medicines and administering basic medicines.

- Referring to advanced clinical care and other care and support services (15).

Poor economic and unsanitary conditions may predispose people living with HIV to community-acquired bacterial and waterborne diseases. Even if they are on antiretroviral therapy, people living with HIV experience more severe diarrhoea, hospitalization and deaths from diarrhoea because of waterborne pathogens compared with people who are not living with HIV. Household water treatment and safe storage, sanitation and personal hygiene have been found to be effective in reducing the risk of diarrhoeal diseases among people living with HIV. Diarrhoeal diseases among people living with HIV can reduce absorption of antiretroviral medicines, compromising the effectiveness of antiretroviral therapy.

A randomized control trial in Uganda found that a household water treatment and safe storage programme led to 25% fewer episodes of diarrhoea; there was a 67% reduction in diarrhoea among people living with HIV when the service was used in conjunction with cotrimoxazole. Additionally, there was a 44% reduction in viral load among people living with HIV who received the service compared with people living with HIV who did not receive the service, emphasizing the importance of strengthening water sanitation and hygiene services in the care of people living with HIV (38).

Other critical physical care needs include accessible distribution points for antiretroviral therapy, appropriate information about antiretroviral regimens and associated side-effects, uninterrupted

supply of antiretroviral medicines (15), and information on positive health prevention and dignity programmes, including condom use.

Since the many care and support services cannot easily be provided by one provider and in one location, physical care also involves referrals to a diverse range of on- and off-site services. Support with transport vouchers, access to insurance, linkage to mental health services, and housing and food assistance are also part of active referrals (28).

Active referrals are feasible and preferred by people living with HIV, health-care workers and other providers compared with non-active referrals. Active referrals include activities where people living with HIV, particularly young people, women and homeless people, receive a dedicated case manager, assistance in scheduling appointments, follow-up reminders, and help in navigating and getting enrolled into care.

Non-active referrals, on the other hand, include providing the person with HIV literature or the telephone number for an HIV centre, or telling the person they should make an appointment, with no direct assistance from a counsellor, test administrator or case manager to access care.

For effective physical care, there is a need to ensure sustained action towards integrated care and support provided by a diverse range of professional, motivated and appropriately remunerated health-care providers and community caregivers, including domestic workers who provide physical care. These cadres should be trained in comprehensive HIV care and treatment, and should be well managed and

motivated through accreditation into the formal health-care structure and be offered appropriate incentives and career paths.

### **Social support**

Retention in clinical care and antiretroviral therapy adherence can present major social, economic and psychological challenges. New evidence shows that social support can improve adherence to antiretroviral therapy and prevention of mother-to-child transmission services and improve the quality of life of people living with HIV. Key social support provisions include:

- Economic strengthening activities.
- Food provision;
- Parental monitoring for paediatric and adolescent populations.
- Emotional support.
- Psychosocial counselling or support networks.

Support groups of people living with HIV are often a primary forum through which social support is provided to people living with HIV. Such groups are formed for the purpose of sharing experiences, encouraging disclosure, reducing stigma and discrimination, improving self-esteem, enhancing coping skills and psychosocial functioning, and supporting medication adherence and improved retention in HIV care. Support groups can also be distribution points for food; platforms for income-generating activities; referral points to different services; and advocacy settings on matters relating



to the welfare of people living with HIV, such as medicine stock-outs and reduction of stigma and discrimination.

Support groups are also considered a programme in the management of mental health issues, including use of alcohol and other substances. Support groups are generally initiated and supported by nongovernmental, civil society or community-based organizations and may convene in a health facility or in the community.

Evidence shows the positive impact of social support, including support groups, on mothers living with HIV and their children while receiving prevention of mother-to-child transmission of HIV services and during infancy. Engagement in women's support groups shows reductions in the number of perinatal and maternal deaths (39). Psychosocial support can increase adherence (measured by viral suppression) and retention in antiretroviral therapy (40, 41). Mother-to-mother mentoring increases height-for-weight z-scores of infants living with HIV, adherence to infant antiretroviral therapy and exclusive breastfeeding (42, 43). New evidence on adolescents living with HIV shows that attending an HIV support group and parental supervision reduces non-adherence (from 54% to 27%), viral load and opportunistic infections among adolescents living with HIV. This research also shows that a combination of care and provision of at least two meals per day ("cash plus care") reduced non-adherence further to 18% (44).

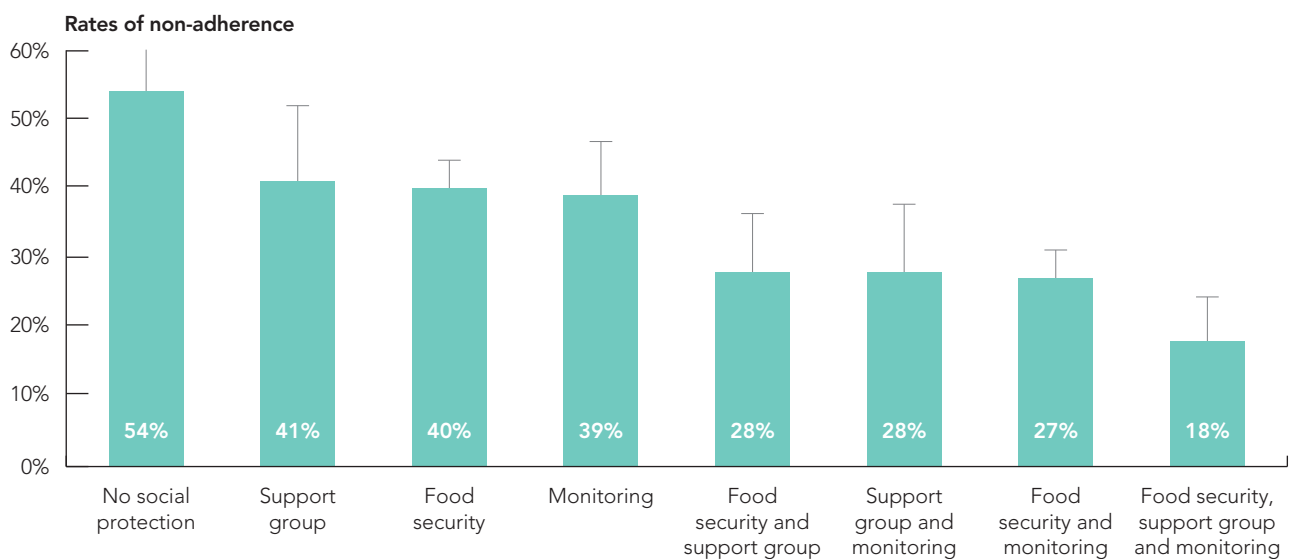
Figure 6 shows a reduction in rates of non-adherence to antiretroviral therapy due to a

combination of care and support services. More than half (54%) of adolescents living with HIV in South Africa who did not receive social protection, care and support services did not adhere to HIV treatment. Participation in a support group of people living with HIV, having at least two meals a day and supervisory parental monitoring of adolescents independently reduced the proportion of adolescents living with HIV who did not adhere to HIV treatment. When the adolescents living with HIV received a combination of care and support services including two meals a day, attended a support group and were supervised by their parents, the proportion of adolescents who did not adhere to HIV treatment was reduced to 18%, emphasizing the importance of social support in increasing adherence to HIV treatment. Social support in this case included having at least two meals a day, participating in a support group and supervisory monitoring by parents.

Since not all people living with HIV need or want to participate in support groups, and community and health facilities may not be able to accommodate all people living with HIV who want to benefit from support groups, the benefits of support groups can be maximized if they are formed around specific populations, such as men who have sex with men, pregnant women, adolescents or couples in serodiscordant relationships. Support groups require a physical meeting space away from crowded health facilities; they may also require telephone credit, transport support and refreshments during meetings (45). Capacity-building of members in facilitation skills, including effective management of support

**Figure 6**

Rates of past-week adolescent antiretroviral therapy non-adherence, by food security, HIV support group and parental monitoring/supervision (marginal effects controlling for sociodemographic co-factors)



Source: Cluver L, Toska E, Orkin FM, Meinck F, Yakubovich A, Sherr L. Achieving equity in HIV-treatment outcomes: can social protection improve adolescent ART-adherence in South Africa? *AIDS care*. 28(suppl. 2):73–82.

groups, is especially important to improve the effectiveness of these groups.

### **Pain management**

Pain remains a key symptom of HIV disease for people living with HIV that is often not managed adequately, regardless of whether they are on treatment (1). Pain may be due to immune suppression associated with HIV infection or

HIV-related opportunistic infections or it may have no clear origins. It can affect any part of the body. Other factors identified to be associated with increased risk of pain in people living with HIV include depression, anxiety, lack of social support and lower level of education. History of injecting drug use, being female and being of African-American descent are associated with increased risk of pain among people living with HIV in developed countries (46).

Through all stages of HIV infection, people living with HIV can experience pain and discomfort (1). They may experience two or three different types of pain at any given time. Types and levels of pain vary by person and by stage of HIV infection. A study among people attending an HIV outpatient centre in the United Kingdom of Great Britain and Northern Ireland found that in the early stages of infection, around 30% of people living with HIV with a CD4 count above 500 cells/mm<sup>3</sup> experience pain, while up to 75% of people with a CD4 count below 200 cells/mm<sup>3</sup> or diagnosed with AIDS experience pain. Almost all people in very advanced stages of HIV infection experience pain (1, 47). Pain can negatively affect functional ability and quality of life, and hinder access and adherence to HIV treatment.

It is essential that health-care professionals and people living with HIV be trained in pain relief and management, and the relevant medicines for pain management be available. Appropriate psychosocial services should be made available, in a form that is acceptable and accessible to people who need them.

### **Depression among people living with HIV**

Chronic depression is highly prevalent in people living with HIV. Depending on the study method used and the population studied, depression in people living with HIV ranges from 18% to 81%. Women living with HIV are four times more likely to experience depressive symptoms than women of the same age who do not have HIV (19.4% versus 4.8%). Depression can occur as a complication of HIV disease or as a result of HIV infection, such as

stigma, discrimination or social isolation, and it can remain unrecognized and untreated among people living with HIV (48). Specific groups of people living with HIV face additional risk factors for depression, including:

- Women living with HIV, particularly during the prenatal and postnatal periods, where maternal guilt, fear of infecting the baby, stigma, insufficient social networks, poverty and interpersonal relations are additional risk factors for depression.
- Adolescents living with HIV, who experience a four-fold risk of developing depression compared with their peers not living with HIV, with high rates of depression being closely associated with treatment failure (49, 50).
- Key populations, including people who use drugs, for whom the risks of developing depression are pronounced (34).

People living with HIV may also experience disproportionately high rates of mental health problems, harmful use of alcohol, anxiety, panic attacks, drug dependence and substance use compared with the general population. This may be due in part to living with HIV and being on HIV treatment, and the social and economic conditions that result from perceived or real HIV infection, such as HIV-related infections, negative emotional reactions to a diagnosis of HIV due to stigma associated with HIV, and harmful use of alcohol and other substances (51).

Depression may have a negative impact on the health and quality of life of people living with HIV and may increase the rate of death by disrupting access and adherence to HIV treatment (51). The severity of depression is associated with a more rapid CD4 cell decline and increased rate of death. Compared with people living with HIV without depression, people living with HIV with depression require twice as long to reach viral suppression than people living with HIV who do not have depression (52). Depression may also increase the incidence of risky sexual behaviours (53).

Therapeutic interventions, including psychological, psychotropic, psychosocial and physical therapy, are required to prevent and manage chronic depression in people living with HIV (48) and in key populations. Diagnosis and management of depression is an integral part of HIV care (54). Diagnosis and management of depression is essential for improved linkage and retention in care. Services to diagnose and manage depression and psychiatric conditions through different therapeutic programmes, including psychotherapy, cognitive behavioural therapy, psychiatric evaluation, and referral to other medical and social services, are necessary for improved access and retention in HIV care among people living with HIV.

### **Food and nutrition support**

Food and nutrition services play an important role in the management of HIV. Adequate nutrition is essential to maintain the immune system, manage HIV-related infections, enhance the effectiveness of HIV treatment, sustain healthy

levels of physical activity and support an optimal quality of life (1). Food and nutrition programmes contribute to preventing AIDS-related deaths. People living with HIV who are malnourished when they start antiretroviral therapy are two to six times more likely to die in the first six months of treatment than people living with HIV who are not malnourished (55).

Linking food to HIV prevention and HIV and TB treatment programmes is a powerful incentive to access HIV services. In South Africa, adolescent girls who received cash or a voucher to spend on food were 50% less likely to have transactional sex than adolescent girls who did not receive cash or a food voucher (56). A household food voucher worth US\$ 5 increased consent to home-based HIV testing by 29 percentage points. The effect of the food incentive persisted one year after the programme. People who received the food voucher continued to have more home-based HIV testing and consent rates one year after the voucher was given compared with people who did not receive a voucher, indicating the long-term impact of the food incentive on increasing HIV counselling and testing rates (57).

The efficacy of antiretroviral therapy is greatly increased by good nutrition (58). At the very least, people living with HIV need guidance on achieving optimal nutrition and, in more resource-constrained settings, may need access to additional social security, including food security programmes. In South Africa, adolescents on HIV treatment experiencing food security were 61% more likely to

adhere to HIV treatment than their peers who were experiencing food insecurity (59).

Antiretroviral therapy leads to initial weight recovery among people living with HIV who are undernourished, but many people living with HIV taking antiretroviral therapy continue to gain weight with the belief that being heavier is healthier; obesity can then elevate their risk for cardiovascular disease, stroke and diabetes (16).

Nutrition assessment counselling support—a spectrum of services to manage under- and over-nutrition—is important in the care and treatment of people living with HIV. Nutrition assessment counsellors support people living with HIV to manage their diet and lifestyle to tolerate and adhere to their medications, restore their immunity and health, and prevent early onset of noncommunicable diseases. People living with HIV may also require support in the form of nutritious food and household livelihood support (60).

### **Stigma and discrimination**

Stigma and discrimination are among the foremost barriers to accessing HIV services. Stigma and discrimination undermine HIV prevention and treatment efforts by making people afraid to seek or adhere to HIV services and discouraging them from disclosing their status to family members and sexual partners. These mechanisms are especially

prominent in settings of extreme poverty, where treatment barriers are highly prevalent and social ties may be essential for survival (61). Common causes of stigma and discrimination and their manifestations are remarkably similar across cultures and include (62):

- Lack of awareness regarding stigma and its harmful consequences.
- Irrational fears and lack of sufficient knowledge regarding HIV infection.
- Social judgements, prejudices and stereotypes against people living with HIV and key populations.
- Lack of laws and policies to address stigma and discrimination.

People living with HIV and members of their communities may need assistance in addressing stigma and discrimination associated with HIV. They may need support to access a range of services to overcome stigma, such as information-based approaches that include written information on the facts and myths of HIV, skills-building programmes to reduce negative attitudes associated with HIV, counselling support such as support groups of people living with HIV, and facilitated contacts between people living with HIV and the public to address negative attitudes associated with HIV (63).

# Care and support implications of when to start antiretroviral therapy and pre-exposure prophylaxis for HIV

*“Pre-exposure prophylaxis and antiretroviral therapy should be provided with comprehensive care and support, including adherence support, counselling and testing, legal, social and economic support, mental health and emotional support, and access to contraceptive and health services.”*

The 2016 WHO *Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection* (1) recommend immediate initiation of antiretroviral therapy for everyone living with HIV, regardless of CD4 count. People with advanced HIV disease — clinical stage III or IV disease or a CD4 count below 350 cells/mm<sup>3</sup> — should be prioritized for starting antiretroviral therapy. Pregnant and lactating women living with HIV should initiate antiretroviral therapy regardless of their CD4 count and should continue lifelong antiretroviral therapy; for these women, Option B+ becomes the norm. Children and adolescents living with HIV should start antiretroviral therapy regardless of their CD4 count.

For populations at substantial risk of HIV, defined as populations with an HIV incidence of 3%, which may include serodiscordant couples and key populations, WHO recommends pre-exposure prophylaxis as an additional HIV prevention option alongside combination prevention services, including condoms and lubricants, harm reduction, HIV counselling and testing, and linkage to antiretroviral therapy. The 2016 WHO guidelines recommend that: pre-exposure prophylaxis and antiretroviral therapy to be provided with comprehensive care and support, including adherence support, counselling and testing, legal, social and economic support, mental health and emotional support, and access to contraceptive and health services.

In the context of accessing and retaining people living with HIV in treatment, people living with HIV can be divided into four broad categories:

- Early: people newly started on HIV treatment who present well and with higher CD4 counts.
- Stable: people who have been taking HIV treatment for at least one year with no adverse drug reactions that require regular monitoring; apart from HIV they have no illnesses, are not pregnant or breastfeeding, and have a good understanding of lifelong HIV treatment.
- Delayed: people living with HIV who access HIV treatment with advanced HIV disease and a CD4 count below 200 cells/mm<sup>3</sup>.
- Treatment failure: people taking HIV treatment and not presenting well. They may have one or more illnesses, may experience adverse drug reactions and may need careful monitoring (1).

Table 3 highlights the key differentiated care and support packages for these four categories of people living with HIV.

Differentiated care involves providing different antiretroviral therapy and non-antiretroviral therapy care packages to people living with HIV based on their needs, type and frequency of services, and location and provider of services. These services vary depending on the country's health system (1). For people presenting early for treatment, the key priorities are starting antiretroviral therapy followed by screening for TB and administration of cotrimoxazole prophylaxis, isoniazid preventive therapy, and screening and management of

noncommunicable diseases, including assessment of cardiovascular risk by addressing modifiable factors such as blood pressure, smoking, obesity, diet and physical exercise. Screening and management of depression, harmful use of alcohol and other substances, and other mental disorders should also be conducted for this group. Screening and treatment of sexually transmitted infections and access to family planning services, including condoms, are essential services for people living with HIV who present early for treatment. The main operational priorities for this group are to ensure that people remain in care and adhere to HIV treatment.

People living with HIV who are taking antiretroviral therapy and are stable may receive the basic package of services for early presenters, but with less frequent (once every three to six months) visits for clinical monitoring and collection of medicines, including viral load testing where available. Specific attention should be focused on retention of people in HIV services and adherence to antiretroviral therapy.

People living with HIV in the "delayed" and "treatment failure" groups may in addition need close and intensified management and follow-up. Strong active referrals may be prioritized for people in the "delayed" group, since these people may present with a range of problems that need to be addressed by different providers for effective retention in care (1).

**Table 3**

Key care and support packages across categories of people living with HIV

Treatment initiation	Treatment continuation
<p><b>Early</b></p> <p><b>Clinical priorities</b></p> <ul style="list-style-type: none"> <li>Sexually transmitted infection screening and treatment, access to family planning and sexual and reproductive health services</li> <li>Screening and management of mental health disorders</li> <li>Screening and management of noncommunicable diseases</li> <li>Tuberculosis (TB) screening/cotrimoxazole prophylaxis/intermittent preventive therapy (IPT)</li> </ul> <p><b>Operational priorities</b></p> <ul style="list-style-type: none"> <li>Retention services</li> <li>Adherence support</li> </ul>	<p><b>Stable</b></p> <p><b>Clinical priorities</b></p> <ul style="list-style-type: none"> <li>Sexually transmitted infection screening and treatment, family planning and access to reproductive health services</li> <li>Immunization</li> <li>Nutrition support</li> <li>TB screening/cotrimoxazole prophylaxis/IPT</li> </ul> <p><b>Operational priorities</b></p> <ul style="list-style-type: none"> <li>Retention services</li> <li>Viral load monitoring</li> <li>Adherence support</li> <li>Frequency of visits</li> <li>Frequency of dispensing antiretroviral therapy</li> </ul>
<p><b>Delayed</b></p> <p><b>Clinical priorities</b></p> <ul style="list-style-type: none"> <li>Treatment education</li> <li>Antiretroviral therapy initiation</li> <li>Opportunistic infection screening, diagnosis and management (cryptococcal infections, cytomegalovirus)</li> <li>TB screening, diagnosis and treatment/cotrimoxazole prophylaxis/IPT</li> </ul> <p><b>Operational priorities</b></p> <ul style="list-style-type: none"> <li>Referral network</li> </ul>	<p><b>Treatment failure</b></p> <p><b>Clinical priorities</b></p> <ul style="list-style-type: none"> <li>Opportunistic infection screening and management (cryptococcal infections, cytomegalovirus)</li> <li>Screening and management of mental health disorders</li> <li>TB screening, diagnosis and treatment/cotrimoxazole prophylaxis/IPT</li> </ul> <p><b>Operational priorities</b></p> <ul style="list-style-type: none"> <li>Retention programmes</li> <li>Viral load monitoring</li> <li>Adherence support</li> <li>Frequency of visits</li> <li>Frequency of dispensing antiretroviral therapy</li> </ul>

Source: Adapted from: Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: recommendation for a public health approach, second edition. Geneva: World Health Organization; 2016.



# HIV care and support needs for selected populations

*“Although many of the needs of people living with HIV are common across all groups, more nuanced **care and support approaches are required to meet the specific needs of children living with HIV, key populations and older people living with HIV.**”*

The need to provide care and support, including mental health services, to counter stigma and discrimination and to offer legal services has not changed fundamentally. Although many of the needs of people living with HIV are common across all groups, more nuanced care and support approaches are required to meet the specific needs of children living with HIV, key populations and older people living with HIV.

## **HIV care and support needs for children and adolescents living with, at risk of or affected by HIV**

An orphan or other vulnerable child is defined as a child below the age of 18 years who has lost one or both parents or is living in a family or community affected by HIV. According to this definition, there are 153 million orphans worldwide (64); of these 13.4 million lost one or both parents to an HIV-related death; 10.8 million of these children live in sub-Saharan Africa.<sup>2</sup> Although the clinical programmes required to reduce the number of children newly infected with HIV are well articulated (1), social and economic barriers continue to hinder access, uptake and retention in care for children. Children in families affected by HIV are vulnerable. Millions of children live in families affected by HIV, with an increased risk of poverty, ill health, homelessness, school dropout, discrimination and loss of life opportunities, regardless of whether the children themselves are living with HIV.

Analysis of 20 Demographic Health Surveys (DHS) conducted between 2003 and 2012 of 13 African countries showed that in families where a parent,

<sup>2</sup> UNAIDS 2016 estimates.

particularly the mother, is living with HIV, children are three times more likely to die by the age of five years than children whose mothers are not living with HIV. The relative risk of death ranged from 1.5 in Cameroon in 2011 to 3.6 in Swaziland in 2006 (65). Children living in a family affected with HIV who survive beyond five years experience poorer health and human development outcomes, including increased risk of HIV infection. This effect can be even more pronounced for children of key populations—in particular, sex workers and, in some contexts, immigrants, who may face discrimination and stigma attached to their parents' work, social practices or identity (66).

For mothers living with HIV, access to effective mother-to-child HIV prevention services can reduce the risk of the child being infected during pregnancy, labour, delivery or breastfeeding to less than 5% (67). However, HIV-exposed uninfected infants born to mothers living with HIV may experience higher morbidity and mortality compared with HIV-unexposed uninfected infants and require systematic follow-up, care and support (68).

The impact of HIV on children can be mitigated by focusing on services that address children's health, social and economic needs resulting from HIV infection. Such services include providing tailored clinical and nutritional services, developing parenting skills, encouraging parents to appropriately disclose their HIV status to their children, offering access to HIV counselling and testing and enrolment into HIV treatment, and reducing disparities and barriers to education among school-age children through sustainable efforts such as school block grants (69). School

block grants are targeted support to schools in a community with general provisions as to how the grants are used, such as enrolling a specific number of orphans and other vulnerable children in a school for a period of time in return for a grant.

Referring families affected by HIV to access social protection, including cash transfers, enables families to have their children treated and vaccinated against common illnesses, meet their children's nutritional needs, enrol and retain their children in school (66), and reduce the intergenerational transfer of poverty (70). It is essential to eliminate barriers for children to access and remain in care (34) and to open up social and economic opportunities for them (69).

Actions to increase access to and retention in care for children include:

- Actively refer families affected by HIV in need to access household economic strengthening activities to empower families to meet the essential needs of their children through asset and money promotion and management services.
- Identify and eliminate social and economic barriers, including exposure to violence and stigma, that impact on children's service uptake and retention in care.
- Increase access to legal services, including removing age restrictions in accessing HIV counselling and testing (parental consent to HIV counselling and testing in some countries is required for children under 18 years of age), birth registrations, protection of inheritance rights, and basic rights to improve access to social and economic opportunities.

## **HIV care and support needs for key populations**

Key populations are defined as gay men and other men who have sex with men, sex workers and their clients, transgender people and people who inject drugs. These four main population groups suffer from punitive laws or stigmatizing policies and are among the most likely to be exposed to HIV. Countries should define populations that are key to their epidemic and response based on the epidemiological context and may include people in prisons or other closed settings, serodiscordant couples and adolescent girls and young women in eastern and southern Africa (71).

The majority of care and support needs for key populations living with HIV are similar to those for people living with HIV in general. There are some particular needs for key populations, however, including adolescents, who face greater barriers to access care and support services. Key populations may experience higher rates of medical and psychosocial problems due to factors such as:

- Persistently high or increasing HIV incidence among key populations (34).
- In some contexts services are not available. Where they are available, services are delivered by staff who do not have experience and training in providing care for key populations, and therefore lack the sensitivity required to work with key populations.
- Laws that criminalize behaviours such as drug use, sex work and same-sex relationships marginalize young people and perpetuate their

social exclusion from their communities and essential support services (72).

Key populations living with HIV more commonly have comorbidities and other coincidental problems, such as cancer, TB and hepatitis; drug, alcohol and tobacco dependence; lack of pain management; and mental health problems. These factors have a negative effect on adherence to antiretroviral therapy and retention in care. Providing access to care and support services, including opioid substitution therapy, for key populations living with HIV who need them can stabilize the lives of key populations, improve their health and well-being, and increase their adherence to antiretroviral therapy (73). Table 4 shows the additional care and support services for key populations recommended by WHO.

The combination care and support services for key population are interdependent. The health sector services yield the most benefit when they are provided in combination and when an enabling environment is in place. These services should not be delayed because an enabling environment is missing, however.

Although an enabling environment may be outside the control of health-care providers, it is important that health-care providers address the enabling environment jointly with other sectors. In addition to the services listed, people from key populations need access to broader medical, socioeconomic and legal services so they can access the highest standard of health care possible (34).

## Table 4

### Care and support services for key populations

Health sector services	Essential services for an enabling environment
Comprehensive condom and lubricant programming	Supportive legislation, policy and financial commitment, including decriminalization of behaviours of key populations
Harm reduction programmes <sup>a</sup> for substance use (in particular, needle and syringe programmes <sup>b</sup> and opioid substitution therapy)	Addressing stigma and discrimination facing key populations
Behaviour programmes	Community empowerment
HIV counselling and testing	Addressing violence against people from key populations
HIV treatment and care	
Sexual and reproductive health programmes <sup>c</sup>	
Prevention and management of coinfections and other conditions, including viral hepatitis, tuberculosis and mental health conditions	

Source: Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: recommendation for a public health approach, second edition. Geneva: World Health Organization; 2016.

<sup>a</sup> This package is the same as the package for HIV prevention, treatment and care for people who inject drugs. For people who inject drugs, the harm reduction component of the package, and in particular the implementation of needle-syringe programmes and opioid substitution therapy, remains the first priority.

<sup>b</sup> Needle-syringe programmes are important for people who inject drugs and also for transgender people, who require sterile injecting equipment to safely inject hormones for gender affirmation.

<sup>c</sup> Including contraception, diagnosis and treatment of sexually transmitted infections, cervical screening and others.

## HIV care and support needs for older people

The “maturing” of the HIV epidemic requires the AIDS response to address many physiological and psychological implications of ageing. An estimated 5.8 million [5.4 million–6.3 million] people aged 50 years and over were living with HIV in 2015.<sup>3</sup> In the United States in 2013, 18% of HIV diagnoses were among people aged 50 years and over (74), and the median age of people living with HIV has crossed over 50 years in settings such as the United States Veteran Health Care System in New York and San Francisco (75). In a multi-site study across nine African countries, 11.4% of people living with HIV starting antiretroviral therapy were aged 50 years or over (76).

The changing profile of the HIV epidemic and the fact that older people also have HIV risk behaviours account for the increasing number of older people living with HIV (77).

Three main factors accounting for the ageing of the AIDS epidemic are:

- Success of antiretroviral therapy in prolonging the lives of people living with HIV.
- Decreasing HIV incidence among young adults, shifting the disease burden to older people.
- People aged 50 years and over exhibiting many of the risk behaviours of younger people.

People aged 50 years and over living with HIV face different kinds of challenges and may fare worse

on HIV treatment than younger people living with HIV. Older people living with HIV may have other illnesses related to ageing (78). They may experience on average five years of accelerated ageing, increasing the risk of dying by 19% compared with their peers who are not living with HIV, with no difference between people recently infected with HIV and people who have lived with HIV for 12 years or more (79).

Compared with younger people, older people generally have more health issues and require more use of general health-care services. Health professionals sometimes miss an HIV diagnosis because symptoms may mimic those of other common conditions of ageing, such as mental confusion, weight loss, fatigue, high blood pressure, kidney and liver problems, and arthritis. All of these can also be linked to the long-term side-effects of HIV treatment (80). Compared with younger people, older people living with HIV are likely to have been infected with HIV for a long time and yet present relatively late, or have been taking HIV treatment for longer.

Older people with advanced HIV-related illnesses may not wish to disclose their diagnosis to their families and carers, for fear of abandonment and isolation. Caregivers and family members may be concerned about the level of care needed for an older person living with HIV and may limit their contact as a consequence. Older people living with HIV are overall more likely to be worse off in terms of money, work and housing than their peers without HIV. Since older people are less likely to be economically active, they may need access to state

<sup>3</sup> UNAIDS 2016 estimates.

benefits such as pensions, health support that is free at the point of use, housing, help in the home and transport schemes (81).

Key actions to increase access and retention of older people living with HIV in care include:

- Encourage routine HIV counselling and testing, with linkage to HIV treatment for adults, including people aged 50 years and over, since older people are often unable to reliably estimate their risk of acquiring HIV infection.
- Increase access to psychosocial support that addresses the mental, emotional and social

needs of older people living with HIV, including promoting lifestyle factors known to maximize health, such as exercise, diet, maintaining low blood pressure, lowering cholesterol and avoiding substance use.

- Increase access to integrated HIV testing, treatment, care and support, with active linkages to geriatric care programmes and services.

It is essential that HIV services take into account the needs of older people, such as reliable self-assessment of HIV risk (80) and lifestyle changes to minimize the risk of cardiovascular diseases and other noncommunicable diseases (82).

# Conclusion

*“It is necessary to increase access to care and support services for people living with HIV, at risk of contracting HIV and affected by HIV. There is also an essential need for improved child and adolescent care and development of up-to-date chronic care systems, including for key populations and older people living with HIV.”*

HIV care and support is central to assist people living with HIV to access HIV counselling and testing and immediate linkage and retention in HIV treatment and to attain the highest possible standard of well-being. Through the UNAIDS Fast-Track response, a big push on care and support is required so that 90% of people living with HIV know their HIV status, 90% of people who know their HIV-positive status are accessing treatment, and 90% of people on HIV treatment have suppressed viral loads, contributing to the elimination of stigma and discrimination and the reduction of new HIV infection to fewer than 500 000 by 2020.

Focusing on improving access for children, adults and key populations who need care and support services in key locations is essential to attain the Fast-Track targets. To achieve durable viral suppression, uptake and adherence to HIV treatment need to be improved. To do this, people will need improved counselling and testing and effective pathways to start HIV treatment early. In particular, the gaps that have persisted need to be closed, including access to:

- Clinical care.
- Physical care.
- Social support.
- Pain relief.
- Mental health services.
- Food and nutrition support.
- Legal support.

It is necessary to increase access to these services for people living with HIV, at risk of contracting HIV and affected by HIV. There is also an essential need for improved child and adolescent care and the development of up-to-date chronic care systems, including for key populations and older people

living with HIV. This can be done by building the capacity of health-care workers and community caregivers, including incentivizing, remunerating and developing career paths for community caregivers and updating these workers on the changing needs of people living with HIV.



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**UNAIDS**  
**Joint United Nations**  
**Programme on HIV/AIDS**

20 Avenue Appia  
1211 Geneva 27  
Switzerland

+41 22 791 3666

[unaids.org](http://unaids.org)