AGING
WELL

ENSURING THE WELL-BEING AND QUALITY CARE OF PEOPLE LIVING WITH HIV OVER 50

In 2023, among the 163,500 people receiving HIV care in France, **more than half were over 50 years old** — including 26,900 over 65, and more than 7,000 over 75[1]. This age group also represented **22% of new HIV cases in France**, often diagnosed at advanced stages of infection[2].

Thanks to antiretroviral treatment, their life expectancy can be equivalent to that of the general population. However, their quality of life is not comparable. Early and more frequent comorbidities, isolation, and discrimination create additional challenges for people aging with HIV. These issues were highlighted during the national conference of people living with HIV, held in May 2024 in Paris[3].

The aging of the French population living with HIV requires **public policies that specifically address and adapt to their needs**.

Members of the Aging Well group therefore call on public authorities to guarantee the well-being and quality care of people aging with HIV.

OUR **REQUESTS**

Ensuring prevention of comorbidities and providing appropriate, quality care

Despite effective treatment, living long-term with HIV causes persistent residual inflammation, which accelerates the onset of comorbidities and has harmful effects on the body: cardiovascular disease, cancers, neurological and metabolic disorders, diabetes, kidney failure, etc. These conditions typically appear 5 to 10 years earlier than in the general population[4].

These comorbidities significantly affect people living with HIV (PLWHIV). They often result in polypharmacy, which can cause drug interactions and toxicities, and they contribute to premature cognitive aging and neurocognitive disorders[5]. Around 35% of PLWHIV over 55 live with neurocognitive disorders, compared to 24% in the general population.

To better identify frailty and prevent comorbidities, members of the Aging Well group call on public authorities to:

- Provide infectious disease departments and hospital services with the resources to conduct an **annual check-up assessing general health, comorbidities, and complications** for PLWHIV over 50, as recommended by ANRS Emerging Infectious Diseases and the National Council for AIDS and Viral Hepatitis in their 2024 guidelines, approved by the French Health Authority (HAS)[6].
- Implement **geriatric consultations for the most vulnerable PLWHIV** within infectious disease departments, to assess comorbidities, frailty, polypharmacy, autonomy, neurocognitive disorders, nutrition, and more.
- **Guarantee equal access to primary care physicians and specialists across the country** within reasonable timeframes (maximum 15 days), without additional fees.
- Apply a **"long consultation" billing code for PLWHIV, regardless of age**, to ensure optimal follow-up (care coordination, prevention advice, etc.).
- Establish a **healthcare coordination system** with a designated contact responsible for liaising and ensuring communication between HIV specialists and other healthcare providers, particularly regarding comorbidities and aging (current coordination mechanisms remain insufficient).
- Allocate additional funding in the Social Security Financing Act, through regional health agencies and local authorities, for **mental health prevention and treatment** (depression, anxiety, etc.) and **to reduce isolation** (psychological support, outreach programs, empowerment initiatives in hospitals and community organizations).
- **Implement hospital discharge support programs**, such as PRADO (Return Home Program), for PLWHIV over 50.
- **Train all professionals working with older adults** (healthcare workers, social service providers, nursing home staff, community organization workers, etc.) on HIV-related issues, including health and social challenges, as well as seniors' sexual health and sexuality, in order to fight prejudice and prevent misconceptions about HIV transmission[7].
- Launch **comorbidity prevention campaigns** (physical activity, nutrition, smoking cessation, etc.), **expand targeted screenings**, and guarantee access to non-pharmacological interventions.
- Ensure **financial coverage of prescription-based physical activity** for people with chronic conditions.
- Allow **shared medication reviews in pharmacies for all individuals on ARV therapy and taking multiple medications**, regardless of age. Currently, these reviews are limited to people over 65 with chronic illnesses.

Ensuring the respect, protection, and fulfillment of the economic and social rights of people aging with HIV

Those infected in the 1980s and living with HIV for 30 or 40 years have often experienced difficult life courses: **medications with severe side effects, repeated bereavements, and shortened professional careers. As a result, many face isolation and insecurity, often worsened by the absence or loss of rights**. Housing is a major concern, especially when anticipating a loss of autonomy: *Where will I grow old? With what resources?* For example, nursing homes with in-house pharmacies may refuse to admit PLWHIV due to the high cost of treatment[8]. Such concerns worsen mental health issues and limit access to healthcare and rights.

Persistent negative social perceptions surrounding HIV add to these difficulties. Many PLWHIV continue **to hide their status** to avoid discrimination. Aging makes disclosure even more complicated, as increasing numbers of caregivers become involved and autonomy decreases. People may face discrimination, insults, or denial of care due to their HIV status, especially outside specialized HIV care[9]. Nearly one in four PLWHIV over 50 has at some point been refused a medical consultation because of their status[10].

To ensure respect, protection, and fulfillment of economic and social rights for people aging with HIV, members of the *Aging Well* group call on French public authorities to:

- Run public **information and awareness campaigns on HIV-related discrimination**, including viral suppression, to fight serophobia and improve quality of life.
- Develop a **national strategy to prevent and fight discrimination in healthcare and public services**, as recommended by the Defender of Rights[11]. This should include a national observatory on discrimination to ensure equal access to services, including healthcare and housing. The strategy must address serophobia[12], ageism, homophobia, transphobia, rejection of drug users, sex workers, and migrants.
- **Guarantee confidentiality of HIV status** in all services, procedures and communications, especially as confidentiality protections are increasingly weakened, e.g. in applications to MDPH (Departmental House for Disabled People) or for home help.
- **Ensure the right to housing**: enable people to age in place as much as possible or access suitable housing, respecting individual choice. The right to enforceable accommodation (DAHO), introduced in French law, must be applied as a priority for people living on the streets, without requiring the two current conditions (application request for shelter and lack of an offer suited to needs).
- Provide **evaluation mechanisms during the implementation of the Departmental Public Service for Autonomy** (SPDA), based on user experience, to determine if it effectively fulfills its role as a one-stop shop for information, support, and pathway coordination. Services must remain accessible physically, not only online, and there must be an appeals process in case of dysfunction.
- Review **the organization and distribution of responsibilities among departmental support systems for older people and those with disabilities**, to improve complementarity, clarity, and accessibility, and to provide practical responses to users' needs.
- Designate **dedicated contacts within health insurance funds, retirement insurance funds, and prefectures** to support social sector professionals, particularly community organizations, in navigating procedures for those they assist.
- Guarantee **non-discriminatory access to nursing homes and specialized facilities for PLWHIV**, including those younger than typical residents. Replace the current special funding system, managed by regional health agencies, for costly chronic treatments, with an automatic funding system, so nursing homes with in-house pharmacies cannot refuse PLWHIV due to treatment costs.
- Fund and promote **the deployment of health mediator positions** to improve healthcare access for isolated people and/or those without family caregivers.
- Incorporate socioeconomic, psychological, emotional, and sexual dimensions, along with the mechanisms of accelerated aging with HIV, into HIV research and studies, to better identify the needs of older PLWHIV.

MEMBERS OF THE AGING WELL GROUP

- Act Up Paris
- Act Up Sud-Ouest
- Actions Traitements
- AIDES
- ALS
- Arcat
- Association Marie Madeleine
- Basiliade
- Comité des Familles
- Da ti seni
- ENVIE
- Ikambere
- Les Actupiennes
- Les Petits Bonheurs
- PASTT
- Relais VIH
- Réseau Santé Marseille Sud
- Sidaction
- Sol En Si
- TEMPO
- Utopia_BXL
- Vivre

1 - https://www.assurance-maladie.ameli.fr/sites/default/files/2023_fiche_infection-par-vih.pdf

2 - https://www.santepubliquefrance.fr/maladies-et-traumatismes/infections-sexuellement-transmissibles/vih-sida/documents/bulletin-national/vih-et-ist-bacteriennes-en-france.-bilan-2023

3 - https://etats-generaux-vih.org/egpvvih-2024-plus-de-160-personnes-seropositives-interpellent-les-decideurs-ses-publics-ques-avec-10-mesures-pour-ameliorer-leur-qualite-de-vie /

4 - Cross-sectional Comparison of the Prevalence of Age-Associated Comorbidities and Their Risk Factors Between HIV-Infected and Uninfected Individuals: The AGEhIV Cohort Study | Clinical Infectious Diseases | Oxford Academic (oup.com) et Antiretroviral exposure and comorbidities in an aging HIV-infected population: The challenge of geriatric patients (archives-ouvertes.fr)

5 - https://www.ird.fr/vieillir-avec-le-vih-associe-un-risque-accru-de-developper-des-deficiences-cognitives

6 - https://cns.sante.fr/sites/cns-sante/files/2024/10/VIH-Suivi-PVVIH_Recommandations_Rapport-dexperts_-20241120.pdf

7 - https://www.has-sante.fr/upload/docs/application/pdf/2022-06/note_de_cadrage_vie_affective_et_sexuelle_dans_le_cadre_de_laccompagnement_en_essms_vas.pdf

8 - https://documentation.ehesp.fr/memoires/2020/phisp/magali_cognet.pdf et https://sante.gouv.fr/IMG/pdf/Rapport_Etude_PVVIH_vieillissantes_mars_2013_DGS_Pleinsens.pdf

9 - Rapport discriminations 2020 | Aides et https://pubmed.ncbi.nlm.nih.gov/29360097

10 - https://admin.moipatient.fr/files/d24b307ebdb329b872620bef533487991abcd607.pdf

11 - https://www.vie-publique.fr/rapport/298446-defenseur-des-droits-prevenir-discriminations-dans-les-parcours-de-soins

12 - sondage - VIH/sida - sérophobie | Crips Île-de-France (lecrips-idf.net)