



International Community of Women Living with HIV/AIDS (ICW) Access to Care, Treatment and Support (ACTS) Briefing¹

This briefing for ICW members frames key issues and advocacy messages based on the findings of our project work on HIV positive women's ACTS. ICW briefing papers on violence against women and sexual and reproductive health and rights are also available. Your feedback on this briefing is welcome.

ACTS refers to HIV positive women's ability to gain consistent access to all available care, treatment and support services, including:

Supportive environments	Health services and information	SRHR, VAW and ACTS
Supportive environments at home, in the community, workplace, place of learning, public and health service institutions - understanding and recognition of HIV positive women's health and rights issues.	Non-judgemental, confidential, voluntary, informed, comprehensive and appropriate treatment and related services.	Diagnosis, prophylaxis and treatment for opportunistic infections, STIs and reproductive health matters with advice and treatment for side effects or complications of medication.
Workplace policies in all settings (e.g. factories, shops, schools, banks, agricultural cooperatives etc.)	All staff in the health care setting understand the barriers that HIV positive women face in accessing services and acting on advice and treatments given.	Non-judgemental, comprehensive Information, advice and services on healthy pregnancy and motherhood.
Home based care and other care-in-the-community programs and palliative care initiatives.	Free anti-retrovirals with advice and treatment for side effects, including lipodystrophy, and complications of medication and regular monitoring of treatment.	HIV treatment policies and programmes recognise the impact of violence or fear of violence on positive women's ability to access care, treatment and support.
Financial support to meet related costs such as for transport and nutrition	On-going support in the form of counselling and referrals.	HIV treatment services, staff policies and programmes recognise the connection between SRHR issues and ACTS.

ICW recognises that gender inequalities can constrain HIV positive women's access to care, treatment and support as well as their ability to use treatment, information and advice to improve the quality of their lives. We also recognise that the care, treatment and support needs of HIV positive women are different to that of men.

Barriers to care, treatment and support include:

Gender Inequalities and Limited Access to Treatment

- Limited range of service locations and knowledge of treatment options and trials that may be available.
- Even when anti-retrovirals (ARVs) are free women have found that costs associated with travel, good nutrition, childcare and treatment for related health problems puts the chance of leading a healthy life with HIV out of their reach. *We have been having some changes and interruptions in our treatment regimes because many times when we go for ARVs clinic we are being asked for some money so we tend to miss the dose even for a week or month till we get some money to pay for that service. Another problem is lack of enough food especially to us women who are under treatment. The consequences were; not finishing my dose which caused infections, staying without a dose till the clinic day and lie to the service provider that I have finished my dose, fighting with my husband or even chasing me out of the house when I refuse giving him my dose.* (ICW member Tanzania)
- Lack of decision-making power - a woman may have to ask relatives for permission to access services.
- Stigma, discrimination and violence can prevent an HIV positive woman accessing services, and being able to act on advice and treatment given. *We face a common problem that our husbands or partners tend to force us to give them our ARVs dose while he has not tested for HIV and doesn't know his CD4 counts. They do not want to go for testing while they show all HIV symptoms. Even if you refuse he will find where you keep your medicine and steal them.* (ICW member Tanzania).
- Family healthcare demands - if a woman's children (and other relatives) are not on treatment she is likely to feel guilt or pressure to share her treatment.
- The demands of looking after a family often preclude one's own health care needs and our members also report selling medication on the black market to pay for much needed food.

¹ Adapted from ICW fact sheet on ACTS (2005) developed for the Global Coalition on Women and AIDS (GCWA). Updated 2008.

Lack of Quality, Comprehensive Care and Services

- Gender-related stigma and discrimination are sometimes reflected in the attitudes of staff in health settings.
- Limited healthcare provider knowledge about the health needs of positive women.
- Lack of treatment literacy that specifically address women's treatment issues, including gender- or age-specific side effects and opportunistic infections and STIs, healthy pregnancy/motherhood and family planning options.
- Lack of women, race and age-specific clinical research and health centre data availability exacerbates the knowledge gaps and confusion concerning treatment options for women.
- Data on client sex and age are normally collected at health centre level but often get 'reaggregated' further up the ladder.
- Lack of comprehensive care, treatment, support, monitoring and referrals for such problems as STIs, violence, reproductive health issues, human papilloma virus (HPV), cervical cancer and other HIV-related health factors, including side effects and complications of ARVs and other treatments.
- ARV treatment conditional on acceptance of injectible contraceptives or sterilisation.
- Overburdened healthcare services that impacts the availability of qualified personnel and comprehensiveness and quality of services, including regular supplies of treatments.

Care and support

- Lack of positive women's leadership within HIV positive people's support groups.
- Gender, age and other areas of discrimination within support groups.
- Women, especially HIV positive women and girls are over-burdened by care work which is generally voluntary and unrecognised.

Recommendations:

Gendered and generation-specific research and data reporting

- Different treatment and care regimes call for the development of proper gender equitable and age-related research trials, and client data reporting, both on drugs and on other aspects of care and treatment.
- More research into opportunistic infections specific to women and HIV related conditions such as cervical cancer, and more research and investment into screening and treatment options for these.
- Research into the interactions between hormonal contraceptives and ARVs.

Equitable access

- Train health staff to understand the treatment and support needs of HIV positive women and girls and the challenges they face accessing treatment of any kind.
- Ensure that appropriate treatment and services are available (including in mobile and decentralized locations) and that treatment is monitored.
- Provide accessible screening and treatment for opportunistic infections, STIs and other HIV-related conditions, as part of the treatment package for HIV positive women and girls.
- Ensure that HIV positive women have accessible information about their rights and about available treatment and services.

Meaningful involvement

- HIV positive women are consulted, trained and employed to help develop treatment, care and support programmes including ARV distribution and literacy.

Care and support – not just drugs

- Develop on-going programmes which promote care, support and respect for HIV positive people within communities and health services.
- Support holistic comprehensive approaches to quality of life issues, covering psychosocial, physical, nutritional and material support, as well as SRHR.
- Support programmes which recognise women's roles as care givers and the traumatic impact of death and illness on them.

Workplace policies

- Encourage the involvement of HIV positive women in workplace policy development and implementation, which promotes the retention and employment of HIV positive staff, including women, and which ensures that benefits to staff include a range of appropriate care and support, which is not just drug specific.
- Promote a proactive awareness of the way in which HIV can affect all our lives throughout the whole management and staff body.

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