

Declaration of rights for people living with HIV/AIDS

Created 18 Nov 2005 - 7:50pm

Life • Love • Participation

The National Association of People Living with HIV/AIDS (NAPWA) is Australia's peak non-government advocacy organisation representing PLWHA community based groups from each of Australia's States and Territories.

WORLDWIDE, approximately 40 million people live with the human immunodeficiency [virus](#) [1]A small infective organism which is incapable of reproducing outside a host cell. (HIV), which causes AIDS. Half of all adults living with HIV/AIDS are female and in sub-Saharan Africa, the most affected region, the figure is nearly 60 per cent¹. Twenty million people have died from AIDS since the first cases were identified in 1981. More than 14 million children have become AIDS orphans, and despite [antiretroviral](#) [2]A medication or other substance which is active against retroviruses such as HIV. therapy that has significantly reduced AIDS-related deaths, the HIV population has expanded alarmingly, increasing by more than 50 per cent since 1991².

The need to find effective ways to deal with the transmission of HIV, in all nations, rich and poor, is now greater than it has ever been. And with more people living with HIV than at any time in our past, the need to protect their health and human rights is also greater than it has ever been.

Human rights are fundamental to the response to HIV, for three reasons: *ethical*, because all human beings have a right to health, to life and all other human rights; *legal*, to implement the International Declaration on Human Rights and the many other international and national laws and guidelines on human rights, and for *pragmatic* reasons, because it is beyond doubt that a human rights based response, which empowers our whole community to avoid infection, and which treats those with HIV with respect and inclusion and aims to properly manage their health, is significantly more effective in reducing the spread of HIV than a response of silence, discrimination or exclusion³.

The Rights we now declare uphold not only the rights of those with HIV and AIDS, but are made for the greater good of our community in their promotion of its ethical and physical health. These Rights implement the self-evident precepts, embraced in international law, [ethics](#) [3](In clinical trials) The process of determining that a proposed clinical trial conforms to a wide range of moral, scientific and ethical standards, to ensure that participants in the trial are not abused, mistreated or unfairly taken advantage of. Before a clinical trial can go ahead, it must be given approval via an independent ethics process. and basic common sense, that no one human is more human than another, that no one human being has more worth than another, and that all human beings have equal human rights.

These Rights are declared to improve the quality of our *Life* and the *Life* of the community at large. They are centred in *Love*, as this is the ultimate foundation of all human rights. They will be carried out through our *Participation* in all aspects of the consultative and decision making processes in relation to them.

These Rights are firmly anchored within existing human rights laws and guidelines, and adopt, in large measure, the *International Guidelines on HIV/AIDS and Human Rights* of the United Nations Commissioner for Human Rights (UNHCR) and the Joint United Nations Program on HIV/AIDS ([UNAIDS](#) [4]Joint United Nations Programme on HIV/AIDS. UNAIDS is the main advocate for accelerated, comprehensive and coordinated global action on the epidemic.), revised in 2002 after extensive worldwide consultations and chaired by eminent Australian jurist, Mr Justice Michael Kirby⁴.

We, the peoples in Australia living with, and affected by HIV/AIDS, through our National and State representative bodies, CONFIRM our Right to Life, Health and the other Rights enshrined in the *Universal Declaration of Human Rights*, and DECLARE, for ourselves and for the good of our Society in general, our RIGHTS as follows:

1 (Full Rights)

The full complement of human rights under international law, those most relevant to HIV/AIDS — including the Right to:

- life
 - liberty and security of person
 - participate fully in public and cultural life, including freedom to practice spiritual and cultural beliefs
 - the highest standards of physical and mental health
 - non-discrimination, equal protection and equality before the law
 - share in scientific advancement and its benefits
 - freedom of opinion and expression
 - freedom of movement
 - privacy and confidentiality
 - freedom of association
 - work
 - marry, form relationships and have a family
 - equal access to education
 - social security, assistance and welfare
 - a reasonable standard of living
 - seek asylum
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- be free from torture and cruel, inhuman or degrading treatment or punishment.

2 (Co-ordinated Response)

The Right to a coordinated and effective response from all levels of government in Australia to the HIV/AIDS pandemic.

3 (No Discrimination)

The Right to live free from harmful discrimination or stigma which in any way relates to our positive HIV status, and to be treated with respect and dignity.

4 (Sex)

The Right, as consenting adults, to a full and satisfying sex life.

5 (Participation)

The Right to:

- participate at every level of consultation, decision making and implementation regarding HIV/AIDS advice, policy, laws, treatments, funding, research, education, resourcing and financing, and all other matters relevant to the HIV/AIDS response;
- be represented in the governance of all organisations that are involved with HIV/AIDS or which provide any service in that regard; and
- form autonomous, self-governing organisations of people living with HIV/AIDS and for those organisations to be consulted and listened to in all levels of HIV/AIDS decision making.

6 (Testing)

The Right to confidential and comprehensive pre- and post-test counselling and to give [informed consent](#) [5]The process of learning the key facts about a clinical trial before deciding whether or not to participate. It is also a continuing process throughout the study to provide information for participants. To help someone decide whether or

not to participate, the doctors and nurses involved in the trial explain the details of the study.. The Right to HIV testing and monitoring without coercion. This includes an enabling environment for the upholding of privacy and the protection of confidentiality.

7 (Treatment)

The Right to the highest quality and standards of specialist medical treatments of our choice. The Right to refuse treatments if we so choose.

8 (Care)

The Right to any quality and specialist medical care, palliative care and support services suitable and acceptable to the individual including:

- the Right to life-saving and life-prolonging health care;
- the Right to have our psycho-social needs addressed as well as our biomedical needs, and in particular, the Right to quality and specialist psychological and mental health services;
- the Right to make fully informed and voluntary decisions about our participation in clinical trials, to access quality care regardless of our agreement or refusal to participate in HIV/AIDS research;

- and in each case we have these Rights without regard to our ability to pay or the absence or type of health insurance and coverage.

9 (Medications)

The Right to access HIV/AIDS medications and treatments as and when we need them, and regardless of our capacity to pay. This includes the Right, protected through legislation, to access and advocate for new and emerging medications, as clinically necessary and through emergency access measures.

10 (Family and Relationships)

The Right to marry, to form and maintain family and partnership arrangements, and care arrangements as we choose, including:

- the Right of HIV positive women and HIV positive men to have children and to make fully informed decisions in that regard;
- the Right to adopt children, and to maintain custody of our own children; and

- the Right to require that Australian Governments protect and promote these Rights in the legal system and create supportive and enabling environments for women, men, children and the family and the partnership arrangements we have described herein.

11 (Housing)

The Right to acceptable standards of housing, including the Right for people with life- threatening HIV/AIDS to have priority access to public housing.

12 (Education)

The Right to education, at all levels within the community, unrestricted on the basis of HIV status.

13 (Prisoners)

The Right to community standard health and treatments for those with HIV/AIDS in custodial settings. The Right to health for those in custody. This includes the Right to access, treatment prevention technologies, condoms, clean needles and the like free of charge.

14 (Injecting Drug Users)

The same Right to health as any other Australian. Access to programmes which protect the health of people who inject drugs and reduce HIV transmission (such as needle syringe programmes, substitution and rehabilitation therapies) are a human right. Laws must be enacted by Australian Governments to protect that right and in so doing the public health of the community.

15 (Indigenous)

The same Right to health as any non-Indigenous Australian, and the same Right to the same standards of health as any non-Indigenous Australian, delivered in a culturally appropriate way, which reflect the differing and particular needs of Indigenous Australians.

16 (Multicultural)

The Right to receive all information and services, and to attain all of the Rights which we now declare, provided in a culturally acceptable manner and spoken and written in the language of their choice, and through an interpreter if necessary.

17 (International)

The Right to require that all governments, organisations, corporations and other bodies in Australia share their knowledge and experience regarding HIV/AIDS issues and promote and protect our Rights at the national and international level. This includes the fulfilment of Australian international commitments through specific HIV/AIDS programs and in the programs of all groups involved in the Australian international HIV/AIDS response.

18 (Freedom of Movement)

The Right of people living with HIV/AIDS to freedom of international movement and migration privilege, as accorded any other individuals. This also includes the Right to seek asylum and not be refused on the basis of their HIV status.

19 (Death)

The Right to die with dignity and in the manner the individual chooses.

20 (Implementation)

The Right to secure, through policy and legislation, protection in both the public and private sectors for those with HIV/AIDS. This should be achieved through enforceable codes of conduct and professional practice.

21 (Accountability and Enforcement)

The Right to require that Australian Governments enact and adopt monitoring and enforcement mechanisms to

implement our Rights, with appropriate penalties where that is not done, together with affordable and effective administrative and civil remedies to enable and ensure our Rights are appropriately enforced. The Right to require Australian Governments to review, enact and reform legislation to protect and promote each of our Rights which we now declare.

*Declared by people in Australia living with HIV/AIDS, through their National, State and Territory representative bodies at the Tenth Biennial NAPWA Conference, Adelaide, South Australia on Friday November 18, 2005.

¹ United Nations Population Fund, International Conference on Population and Development, *Program of Action*, September 1994

² UNAIDS 2004 *Report on the Global AIDS Epidemic*, July 2004.

³ Dr Peter Piot, UNAIDS Executive Director, Speech to the 59th Session of the UNHCR, Geneva, 19 March 2003; see also Ralf Jürgens, *Human Rights for People Living with HIV/AIDS*, Partnership to fight HIV/AIDS in Europe and Central Asia, Dublin, 24 February 2004, with numerous references.

⁴ UNAIDS and UNHCHR, *HIV/AIDS International Guidelines on HIV/AIDS and Human Rights* 1998.

Attachment	Size	Type
Declaration of Rights [6]	254.16 KB	 PDF

- [discrimination](#)
- [human rights](#)
- [privacy](#)

Links:

[1] <http://www.napwa.org.au/glossary/term/125>

[2] <http://www.napwa.org.au/glossary/term/122>

[3] <http://www.napwa.org.au/glossary/term/498>

[4] <http://www.napwa.org.au/glossary/term/396>

[5] <http://www.napwa.org.au/glossary/term/496>

[6] http://www.napwa.org.au/files/declaration_of_rights.pdf