



Testing, Treatment and Detention of People living the HIV/AIDS (PLWHA)

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1. Preamble

The Public Advocate is committed to working collaboratively with people living with HIV / AIDS (PLWHA) under guardianship or for whom the Office of the Public Advocate (OPA) is providing advocacy. OPA also endeavours to work in collaboration with partners, family and relevant stakeholders, to bring about outcomes that benefit PLWHA when making decisions in these areas or advocating courses of action.

The Office of the Public Advocate recognises there are significant social, psychological and legal implications associated with decision making in the areas of HIV testing and treatment for HIV or AIDS related illnesses. The Public Advocate is also aware of the possible discrimination, human rights violations and restrictive practice responses that may arise in relation to a positive HIV test result or a person suspected to be at risk of exposure to HIV.

Due to issues of stigma and discrimination, the term that is currently used to describe this group is people living with HIV/AIDS.

2. Resources

Relevant Legislation

- *Guardianship and Administration Act 1986* – appointment of a guardian and the Person Responsible provisions
- *Medical Treatment Act 1988* – refusing medical treatment
- *Mental Health Act 1986* – on the detention of people to have compulsory psychiatric testing
- *Disability Act 2006* – services for PLWHA
- *Public Health & Wellbeing Act 2008* – Assessment & Treatment Orders & Public Health Orders
- *Charter of Human Rights and Responsibilities Act 2006*

Relevant Rights and Responsibilities

- Victorian Charter of Human Rights and Responsibilities
- UN Convention on the Rights of People with Disabilities

Relevant Sections from the Victorian Charter of Human Rights and Responsibilities

Section 8 Recognition and equality before the law 8(1) (2) (3) (4)

Section 9	Right to life
Section 10	Protection from torture, cruel, inhuman and degrading treatment 10(a) (b)(c)
Section 12	Freedom of expression
Section 13	Privacy and reputation 13(a)(b)
Section 15	Freedom of expression 15(1)(2)(3)
Section 19	Cultural rights 19(1)(2)
Section 21	Right to liberty and security of the person 21(1)(2)(3)(4)(7)
Section 22	Humane treatment 22(1)(2)(3)
Section 24	Fair hearing 24(1)(2)(3)

Relevant Articles from the United Nations Convention on the Rights of Persons with Disabilities

Article 5	Equality and non-discrimination 5(1)(2)(3)(4)
Article 6	Women and Disabilities 6(1)(2)
Article 10	Right to life
Article 12	Equal recognition before the law 12(1)(2)(3)(4)
Article 13	Access to justice 13(1)(2)
Article 14	Liberty and security of the person 14(1)(2)
Article 15	Freedom from torture or cruel or inhumane or degrading treatment or punishment 15(1)(2)
Article 16	Freedom from exploitation violence or abuse 16(3)(4)
Article 17	Protecting the Integrity of the person
Article 18	Liberty of movement and nationality 1(c)
Article 21	Freedom of expression and opinion and access to information 21(a)(b)(c)(d)(e)
Article 22	Respect for privacy 22 (1)(2)
Article 25	Health 25(a)(b)(c)(d)(e)(f)
Article 26	Habilitation and Rehabilitation 26 (1)(2)

Relevant Policy Guidelines:

Australian Government

- The National HIV/AIDS Strategy 2005 - 2008
- National HIV testing Policy 2006
- National Guidelines for the Management of People with HIV Who Place Others at Risk 2008
- National Guidelines for Post Exposure Prophylaxis after Non – Occupational Exposure to HIV 2007.

Please note: For the latest Australian Government, Department of Health and Ageing Health HIV publications please refer to the following website: www.health.gov.au

Please note: For the latest HIV community based responses and publications please refer to the Australian Federation of AIDS Organisations: Australian Federation of AIDS Organisation: www.afao.org.au

Victorian Government

Guidelines for the management of people living with HIV who put others at risk (October 2008)

3. Issues

The Office of the Public Advocate (OPA) may be involved with cases where the appointment of a guardian is sought for a person with a disability who also has, or is believed to have Human Immunodeficiency Syndrome (HIV) or Acquired Immune Deficiency Syndrome (AIDS).

An application may be made for the purpose of appointing a substitute decision-maker under the *Guardianship and Administration Act 1986* (GAA 1986).

An appointment for a guardian can be sought for:

- 1) A person with a cognitive impairment who has or is believed to have HIV.
- 2) Where a person's disability impairs their decision-making by reason of HIV related dementia or a significant disturbance of thought, mood, perception or memory, provisions under the Mental Health Act 1986 (MHA 1986).

Specifically guardians have been appointed with healthcare authority to consent to testing for HIV and for consent to treatment.

OPA may also provide individual advocacy for people who have a cognitive disability who also have HIV and are in need of services.

Context for Decision Making in 2009

The advent of HIV medications mean that people living with HIV (PLWHA) are living longer and healthier lives. Within this context there are three broad areas of decision making for a guardian:

- **Consent to Testing:** Regular viral load screening and t-cell count testing and compliance with medication remain key strategies for ensuring good health and longer lives for PLWHA. PLWHA are able to achieve undetectable viral loads (this means that through viral load testing there is no evidence of viral activity in the blood) and healthy t-cell range (t-cells – the indicators of a healthy immune system) are within the normal adult range.
- **Access to Treatment and Compliance with Medication:** Compliance with medication is a key factor in ensuring that People Living with HIV are able to achieve longer and healthier lives.
- **Civil Detention:** If PLWHA pose a risk of transmission to others in the community due to behaviours then the person can be detained under a Public Health Order made under the Public Health & Wellbeing Act 2008 (section 117).

4. Guidance for OPA staff

The guidance provided in this practice guideline concerns three areas:

1. Testing for HIV
2. Treatment for HIV
3. Civil Detention

1. Testing

There are **five** mechanisms whereby testing can be carried out for people with a cognitive disability who are unable to provide consent.

1. Testing where there is a risk to Public Health

Where the person is considered a risk to public health and is refusing testing, testing can be carried out under an Examination and Testing Order made by the Chief Health Officer under section 113 of the *Public Health & Wellbeing Act 2008*.

2. Testing where there is a risk of Exposure

When an ***incident*** occurs in which a care-giver or custodian may have been exposed to a specific infectious disease, the Chief Health Officer (under the *Public Health & Wellbeing Act 2008*) or a senior medical officer¹ may, under section 134, order the testing of a person.

A testing order may be made for a person who is refusing to be tested or who is unconscious or does not have the capacity to consent to be tested for the disease. A person is treated as not having the capacity to consent even if the lack of capacity is temporary or there is another person who has the capacity to consent to testing on that person's behalf.

3. Testing for treatment - The Person Responsible

The person responsible provisions in s39 of the GAA 1986 could be used to provide substitute consent to testing when it is clear that the testing is in the best interests of the person with a disability. An example of this is when a person is ill or unwell and provisional diagnosis suggests HIV / AIDS.

The person responsible may be the domestic partner of the person and this would include a person of the same sex. The person responsible would need to determine that the testing was in the best interests of the person with a disability as set out in section 38 of the *Guardianship and Administration Act 1986* and not for some other reason.

4. Testing for treatment - Section 42K Notice

Where a person is unable to consent to the testing procedure, and there is no person responsible, and the procedure is being conducted in the best interests of the person with a disability, the process of authorisation under section 42K of the GAA 1986 would apply.

In the absence of a person responsible to give consent to medical treatment and where there is a dispute between parties which cannot be resolved through advocacy, guardianship may be required e.g.: the person is refusing to be tested and there are serious health problems, a guardian may be needed to determine if the person should be forcibly tested and treated.

5. Testing for treatment - Guardianship

As guardian, the Public Advocate has responsibility to promote the best interests, health and well-being of the person with a disability. Guardianship is clearly intended to promote and assert the rights and interests of the person with a disability rather than the interests of others. Circumstances under which a statutory guardian would give consent to testing of a represented person include:

- Situations in which the represented person will benefit from the testing.

¹ Section 137 - senior medical officer applies to a senior medical officer who is—

(a) employed or engaged by, or performs work for, a denominational hospital, multi purpose service or public hospital and is authorised by that hospital or service or the chief executive officer of that hospital or service to make orders or authorise testing for the purposes of this section; or

(b) employed or engaged by, or performs work for, a private hospital that is—

(i) registered under Part 4 of the **Health Services Act 1988**; and

(ii) approved by the Secretary for the purposes of this section—

and is authorised by the proprietor or chief executive officer of that private hospital to make orders or authorise testing for the purposes of this section.

- Situations in which the guardian believes that negative ongoing consequences may apply to the person as a result of refusing a test.

Requests for consent to HIV testing that arise from an organisation's infection control or occupational health and safety guidelines, are unlikely to demonstrate a benefit to the person under guardianship. In these cases, consent should be withheld. When OPA declines consent to HIV testing on the grounds that there is no benefit to the client, it may be appropriate for those seeking consent to seek further advice about risk assessment and prophylactic treatment options.

It is important to note that testing for HIV can enable access to HIV specific care, management and treatment. However, OPA is opposed to routine or mandatory testing for HIV/AIDS for people with disabilities.

Investigations for the Guardianship List should clearly identify the grounds for HIV testing to ensure that the testing will promote the health and well-being of the person with the disability.

Factors to be considered by guardians before making a decision about HIV testing

1) **Views of the RP and the Treating Practitioner**

- What are the person's views? Pre-test discussion between the treating practitioner and the person under guardianship is essential to determine the views of the person regarding HIV testing and disclosure of results. This may include identifying the views expressed by the person before he/she lost capacity.
- What approach did the treating practitioner take to explain the issues of testing and disclosure to the person having regard to his/her abilities?
- What are the views of the treating practitioner regarding the person's need for and benefit from HIV testing?

2) **Planning and the Provision of Support**

- Has the service provider developed an appropriate plan to support the person in the event the HIV testing result is either negative or positive?
- Support plans may include:
 - 1) Consideration of the person's cultural and linguistic needs
 - 2) The person's access to a HIV specialist for pre- and post-test counselling
 - 3) A follow-up plan in the case of a negative result that addresses on-going educational needs of the person
 - 4) A proposed treatment plan in the case of a positive result
 - 5) Approach to care and treatment including any proposed restrictive practices or coercive strategies
 - 6) An assessment of the person's current supports including her/his emotional and/or advocacy support
 - 7) Information regarding who will advise the person and/or the guardian about the test results, when and how;
 - 8) Strategies for the prevention of inappropriate self-disclosure and support to assist the person to understand the consequence of this
 - 9) If required, the person's on-going specialist HIV management
 - 10) A commitment to continued service provision from the agency or individual responsible for the person's on-going care
 - 11) Proposals for addressing the person's sexuality education needs.
- Does the service provider's policy on the management of confidential records include strategies to prevent inappropriate disclosure of HIV and AIDS related information to another person?

3) Questions for the Treating Practitioner

- Does the person's illness remain undiagnosed despite extensive investigation?
- Do clinical indicators for HIV related illnesses exist (remembering that there may be no existing clinical indicators)?
- What evidence is there that a person may have been exposed to HIV?
- Has the treating practitioner clarified who will receive the test results, whether those results are positive or negative?

Other relevant issues

- Is there clear evidence that the person has had a high-risk exposure to HIV? If so, advice can be sought from a registered medical practitioner or the Post Exposure Prophylaxis (PEP) Hotline 1800 737 669. PEP must begin within 72 hours for it to be effective.
- HIV antibodies will not be detectable immediately after HIV infection as it can take up to six weeks for measurable quantities of HIV antibodies to be produced by the immune system. Consequently, a test taken during this three-month "window period" may not be accurate and may indicate a negative result. To confirm the reliability of this result, a second test should be undertaken three months later. The results of both tests remain unreliable if a person has continued exposure to HIV through engaging in high-risk activities
- OPA considers issues of confidentiality and disclosure of information relating to HIV to be of major importance. The Public Advocate will view with caution any suggestion that anyone involved in the person's care has the right to know a person's HIV status and considers that all reasonable steps to prevent disclosure of the information to another person will be taken.

2. Treatment

An OPA guardian or as the person responsible may be required to consent to access to anti-retroviral treatment for a person with a cognitive impairment who is HIV positive.

Background and Issues

- Anti-retrovirals are the standard current pharmaceutical response to living with HIV / AIDS in 2009.
- Anti-retrovirals are generally prescribed by a doctor and administered orally
- Different treating regimes may be necessary depending on a range of health factors including treatment resistance, side effects, the progression of the illness, capacity to adhere to complex medication regimes as well as the choice of the individual
- There are differing opinions in the treating community as to when to start treatment but it is generally accepted that treatment should occur once a person's t-cells drop below 400
- Complete compliance with treatment is necessary for treatment to be successful
- If PLWHA are not 100% compliant then the virus can mutate and treatment resistance develop

3. Civil Detention

The Office of the Public Advocate has an expectation that if a person under guardianship is presumed to be engaging in "at risk" behaviours, such as repeated unprotected sex or known sharing of needles which places others at risk of transmission, then service providers will take all reasonable steps to support that person to minimise the potential for negative consequences of such behaviours.

Responses to ‘at risk’ behaviours are outlined under the Section 117 of the *Public Health & Wellbeing Act 2008* or in the Department of Health as “Guidelines for the management of people with HIV who place others at risk”.

Responding to this group of people is the responsibility of the Chief Health Officer through the Department of Health. This officer can be contacted on **9347 1899**.

The Chief Health Officer is responsible for making decisions about civil detention of a PLWHA who is knowingly placing others at risk.

A guardian may be required to advocate on behalf of a PLWHA with a cognitive impairment who is being detained.

Key Considerations for a PLWHA Who Is Being Civilly Detained

1. Guardians should not be making treatment, accommodation or detention decisions for a person with a cognitive disability and HIV who is considered to be a risk to others by recklessly and wilfully spreading HIV. Part 8 of the *Public Health & Wellbeing Act 2008* allows for the Chief Health Officer to make an order to ensure that a person with HIV is examined, tested, counselled and their movements restricted or isolated in accordance with the Act.
2. A Public Health Order may require that the person reside at a specified place of residence at all times or during specified time². This would constitute detention. Detention should only be used as a last resort and be proportionate to the risk that the person poses to public health³. The Public Health Department has a responsibility to ensure all persons infected with HIV are managed under five progressive stages in accordance with the 2008 guidelines. As these guidelines also apply to persons with a disability, guardianship should not be used for this purpose.

Brief summary

OPA staff acting as advocates or guardians for people with HIV/AIDS should seek to work positively within the community of the person with a disability, support networks and in a manner that is respectful of their relationships. In particular, the importance of involving the person’s partner and friends may need to be emphasised by the advocate or guardian.

Applications to the Guardianship List for the appointment of a guardian to consent to health care, accommodation and lifestyle matters for persons who have HIV should be supported by OPA only on the basis of the person’s disability, capacity and need, not simply as a consequence of their HIV status.

Issues concerning needle-stick injuries to other people by a represented person who is HIV positive should be treated compassionately and advice sought on how to provide a considered reply to the person who has suffered the needle-stick injury.

If there are any circumstances in which an OPA staff member has any concerns regarding a request for HIV testing or a dispute about healthcare or accommodation, the matter should be discussed with their Team Leader or Manager

Office of the Public Advocate

² Section 117(5)(f)

³ Section 117(4)(b)

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