

POSITIVE CARING

*A handbook for people caring for older people living with HIV,
and a guide for people living with HIV*

Developed for the Senior Voices Project, Living Positive Victoria
in partnership with the Royal District Nursing Service Limited

OCTOBER 2015

Positive Caring-a handbook for carers of older people living with HIV, and a guide for people living with HIV is published by:

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ISBN: 978-0-646-94799-0

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Funded by the Australian Government Department of Health and Ageing, Aged Care Service Improvement and Healthy Ageing Grant.

Design: Ography

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PREFACE

Welcome to Positive Caring, a handbook for people caring for older people living with human immunodeficiency virus (HIV), and a guide for people living with HIV.

Over three decades have passed since the HIV epidemic was first recognised. Now, more than 35 million people are living with HIV worldwide. In Australia, about 26,800 people were living with HIV at the end of 2013.¹

Since the introduction of better treatments in 1996 and the ongoing rollout of more effective treatments since then, the lives of people living with HIV (PLHIV) have improved dramatically. Today, many PLHIV are entering their 60s, 70s, and beyond, which comes with its own challenges. Some people have lived with HIV for over 30 years. Others have been diagnosed with HIV in their older years. Both groups can face difficult issues in their older years, which, in turn, affects those who provide care and support to them.

Best practice in caring for older people means supporting all those involved in the 'care team' (the person living with HIV, their families and friends, volunteers, paid care staff, and health professionals).

Who is this handbook for?

This handbook is for anyone involved in caring for a person or people living with HIV. Care may be provided in the person's home, in residential care, or in community settings. As a member of the person's care team, it is important that you have information and support in your role. You may be a partner or spouse, family member or friend (carer), volunteer/community visitor, paid care worker, health professional, or any other person who provides services or support to PLHIV.

Using the handbook

The way you use the handbook will vary depending on your caring role and the setting. However, there are common questions that people caring for PLHIV frequently ask, whatever the setting. The content aims to address concerns and questions you may have about your caring role and to provide clear and practical information. It aims to:

- address important features of HIV disease and issues commonly experienced during care
- provide you with a guide to HIV-related resources in Victoria

Who developed the handbook?

People living with HIV, their family and friends, care workers, volunteers and health professionals all contributed to the development of this handbook. It draws directly on the experiences of PLHIV, through Living Positive Victoria and partner organisations. Living Positive Victoria is the statewide body representing PLHIV in Victoria. It is a community-based organisation that works to advance the human rights and wellbeing of PLHIV.

The handbook also draws from many years of experience of Royal District Nursing Service (RDNS) HIV specialist nurses. RDNS, through its HIV Nursing Program, provides home nursing, care, support, and health promotion to PLHIV in metropolitan Melbourne and the Mornington Peninsula, in partnership with the Victorian AIDS Council (VAC). Since 1985, RDNS has provided care and support to PLHIV, their carers, partners, friends, and families.

¹ The Kirby Institute. (2014). *HIV, viral hepatitis and sexually transmissible infections in Australia: Annual Surveillance Report*. Sydney: University of New South Wales. 37.

ACKNOWLEDGMENTS

This handbook was developed as a joint project of Living Positive Victoria and the Royal District Nursing Service Limited (RDNS). It has been developed and adapted from *Positive Caring: a guide for carers of People living with HIV/AIDS (2004)*, written by RDNS HIV Clinical Nurse Consultants, Karyn Gellie, Nigel Aberdour and Andrea Edwards, originally funded by the Jonathon Greening Memorial Fund. Key elements of the original manual have been revised, adapted and updated with permission of RDNS and new sections have been developed.

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Dr. Elizabeth Crock, Royal District Nursing Service HIV Program, revised and updated sections 1-7.

Hilary Knack, a Victorian lawyer with over 10 years' experience in HIV health promotion – sections 8-13.

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Positive Women Victoria

Straight Arrows Victoria

Carers Victoria

Funding:

We express our gratitude to the Australian Government Department of Health and Ageing which made production of this resource possible through an Aged Care Service Improvement and Healthy Ageing Grant.

ACRONYMS

ACP	Advance Care Planning	HAND	HIV-associated neurocognitive disorder
ADC	AIDS Dementia Complex	HARP	Hospital Admission Risk Program
AFAO	Australian Federation of AIDS Organisations	HBV	Hepatitis B virus
AIDS	Acquired immune deficiency syndrome	HCV	Hepatitis C virus
ANZANAC	Australian and New Zealand Association of Nurses in AIDS Care	HIV	Human immunodeficiency virus
ANMF	Australian Nursing and Midwifery Federation	HPV	Human papilloma virus
ART	Antiretroviral therapy	KS	Kaposi's sarcoma
ASHM	Australasian Society for HIV, viral hepatitis and sexual health medicine	LGBTIQ	Lesbian, gay, bisexual, transgender, intersex, queer (see Glossary for more information)
ASM	Active Service Model	LPV	Living Positive Victoria
BBV	Blood-borne virus	MHSS	Multicultural Health and Support Service
cART	Combination antiretroviral therapy	MSM	Men who have sex with men
CAN	Country Awareness Network	MAC	Mycobacterium avium complex
CAT/CATT	Crisis Assessment and Treatment (team)	NRCP	National Respite for Carers Program
CD4 (cells)	Cluster of differentiation 4	nPEP	Non-occupational post-exposure prophylaxis to HIV
CMV	Cytomegalovirus	PEP	Post-exposure prophylaxis to HIV
CNC	Clinical nurse consultant	PJP	Pneumocystis jiroveci pneumonia
EPA	Environment Protection Authority	PLHIV	People living with HIV
ELISA	Enzyme-linked immunosorbent assay	PML	Progressive multifocal leukoencephalopathy
GLHV	Gay and Lesbian Health Victoria	PrEP	Pre-exposure prophylaxis to HIV
HACC	Home and Community Care	RDNS	Royal District Nursing Service (Limited)
HAD	HIV-associated dementia (also known as AIDS Dementia Complex)	STI	Sexually transmissible infection
HALC	HIV/AIDS Legal Centre	TB	Mycobacterium tuberculosis
		VAC	Victorian AIDS Council
		WHO	World Health Organization

GLOSSARY

Terms relating to carers and staff

Carer: Friends, family, or community members who provide unpaid care and support to the person living with HIV. This may involve a few hours a week or 24/7 care and is sometimes referred to as 'informal support'.

Care team: Often used to refer to the team of professional services involved in a person's care. However, good practice views everyone involved in a person's care as part of the care team and involves them in planning and making decisions to make sure the wishes and needs of the person living with HIV are well supported.

Care worker: Paid care staff in community settings, home care, and residential facilities.

Health workers: Registered nurses, social workers, and other professional staff, including district or community nurses.

Standard precautions: Universal, common-sense infection control and prevention practices used by health care workers to limit and/or prevent the spread of infections, regardless of the conditions a person might have.

Volunteers: People who volunteer to work for an organisation such as an AIDS council, Carers Victoria, or other organisations and are unpaid.

Terms relating to HIV and treatment

AIDS-defining illness: One of a range of infections and conditions that can occur in HIV-positive people when their immune system is damaged by HIV. If a person with HIV gets one of these conditions, a diagnosis of AIDS is confirmed and then can be treated. In most situations, the person recovers if they are treated. Most important to their recovery is to be on effective anti-HIV treatments.

CD4 count: Number of CD4 or T-helper cells per cubic millimetre (mm³) of blood. CD4 cells are critical for immunity as they help fight off infections.

Co-morbidity: The existence of two or more health issues at the same time. For example, a person with HIV may also have diabetes, or may be living with hepatitis C. Each of these conditions would be called a co-morbidity

ELISA: Enzyme-linked immunosorbent assay – an initial blood test done to look for HIV infection. If this test is reactive (or *positive*), further testing is done to confirm an HIV diagnosis.

Opportunistic illness: Illnesses that occur in people with immune systems that have been severely weakened by HIV. These illnesses are said to take advantage of the 'opportunity' presented by the weakened immune system. Formerly referred to as *opportunistic infections*.

PEP: Post-exposure prophylaxis – a course of antiretroviral medicine taken to reduce the risk of HIV infection after an exposure to HIV. PEP needs to be started within 72 hours of the exposure and taken for one month to be most effective. PEP is available for occupational exposures to HIV (such as needlestick injury) and for non-occupational exposures (such as high risk sexual exposure or sharing injecting equipment with an HIV positive person).

Non-occupational PEP is referred to as NPEP.²

² Australasian Society for HIV Medicine. (2013). *Post exposure prophylaxis after non-occupational and occupational exposure to HIV*. Sydney: Australasian Society for HIV Medicine.

PrEP: Pre-exposure prophylaxis – antiretroviral medicine taken by a person who does not have HIV but is at high risk of getting HIV. The goal of PrEP is to prevent HIV taking hold if the person is exposed to the virus. Even if a person takes PrEP, it is recommended that other prevention methods such as condoms are used. In Victoria, PrEP is currently available through a research trial, but can also be imported from online medication providers, or at full cost from pharmacies that dispense HIV medication.

See <http://www.vicprep.csrh.org> and http://endinghiv.org.au/nsw/wp-content/uploads/2015/02/PrEP_Access_Options_Paper1.pdf

Prophylaxis: To prevent a disease or an infection.

T-cells: A type of white blood cell that helps the body fight off illness and infection. Also known as CD4 cells.

Undetectable: The term to describe extremely low levels of HIV virus in the bloodstream. Depending on the test used, this can be fewer than 20 or fewer than 50 copies of HIV per millilitre of blood. A person who has an undetectable viral load is significantly less likely to pass on the virus.

Viral load: Number of copies of HIV per millilitre of blood.

Western Blot: The second type of blood test performed to diagnose HIV if ELISA test is reactive or positive. The Western Blot is used to confirm a diagnosis of HIV.

Terms relating to sexuality and gender identity (*Adapted from the National LGBTI Health Alliance*).

Ally: Typically any non-LGBTI (see below) person who supports and stands up for the rights of LGBTI people. LGBTI people can also be allies, such as a lesbian who is an ally to a transgender person.

Asexual: A person who generally does not feel sexual attraction or desire to any group of people. Asexuality is not the same as celibacy.

Bisexual: A person who is sexually attracted to people of their own gender and another gender.

Celibacy: the act of abstaining from sexual relations.

Cisgender: A person whose gender identity corresponds with his or her biological sex. For example, a person born with female genitals who also identifies as female.

Gay: A person who is sexually and emotionally attracted primarily to members of the same sex, although it can be used for any sex (e.g. gay man, gay woman, gay person). *Lesbian* is the preferred term for women who are attracted to women.

Gender: The socially defined roles assigned to females and males. This is a distinct concept from a person's biological sex at birth.

Gender identity: A person's own self-identification as female, male, or another gender.

Heterosexual: A person who is only attracted to members of the opposite sex; also called *straight*.

Homophobia/transphobia: A range of negative attitudes and feelings toward homosexuality, transsexuality or people who are identified or perceived as being LGBTI. It can be expressed as antipathy, contempt, prejudice, aversion, or hatred, may be based on irrational fear, and is sometimes related to religious beliefs. It is associated with discrimination and sometimes violence.

Homosexual: A clinical term for people who are sexually attracted to members of the same sex. Some people find this term offensive.

Intersex: A person whose sexual anatomy or chromosomes do not fit with the traditional markers of 'female' and 'male.' For example, people born with both female and male anatomy (penis, testicles, vagina, and uterus), or people born with additional X or Y chromosomes.

Lesbian: A woman who is primarily sexually and emotionally attracted to other women.

LGBTI, LGBTQI, LGBTQA: These acronyms refer to lesbian, gay, bisexual, transgender, queer or questioning, intersex, and asexual or ally. Although all the different identities within LGBTIQ are often placed together, specific needs and concerns are related to each individual identity. This handbook uses the term LGBTI for consistency.

Pansexual: A person who experiences sexual, romantic, physical, and/or spiritual attraction for members of all gender identities/expressions, not just people who fit into the standard gender binary (i.e. men and women).

Queer: An umbrella term sometimes used by LGBTI people to refer to the entire LGBTI community.

Questioning: For some, the process of exploring and discovering one's own sexual orientation, gender identity, or gender expression.

Sexual orientation: The type of sexual, romantic, and/or physical attraction someone feels toward others; often labeled based on the gender identity/expression of the person and who they are attracted to; common labels are lesbian, gay, bisexual, pansexual, etc.

Stigma: The shame, disgrace, and embarrassment attached to a characteristic or conditions considered unacceptable or undesirable. Stigma can be internal or come from external sources. Many, if not most, LGBTI people and people with HIV experience some form of stigma.

Transgender: This term has many definitions. It is frequently used as an umbrella term to refer to all people who do not identify with their assigned gender at birth or the two gender system. Some transgender people feel they exist not within one of the two standard gender categories, but rather somewhere between, beyond, or outside of those two genders. This includes Trans male/trans man, Trans female/trans woman, Indigenous Brotherboy, Indigenous Sistergirl, non-binary/gender fluid, transsexuals, genderqueer, 'Two spirit' people, 3 and others.

Transsexual: A person who is in the process of seeking, or who has completed, sexual reassignment surgery.

Adapted from the National LGBTI Health Alliance
<http://lgbtihealth.org.au/lgbti/>

INTRODUCTION

Since the human immunodeficiency virus (HIV) epidemic began over 30 years ago, enormous progress has been made in HIV treatment, care, and prevention. People living with HIV (PLHIV) are living longer and healthier lives. Many are entering older age and some are requiring support and care at home or within residential aged care services. The time is right for health workers and care workers in the aged care sector to gain the knowledge and skills to care for the diverse and vibrant community of people living with HIV.

In the early days of the HIV epidemic, fear was widespread, and PLHIV, especially gay men, often experienced stigma, blame, and discrimination. Although discrimination on the basis of a person's HIV status may have reduced over time, PLHIV still sometimes experience poor treatment within health services and in the community, and can be reluctant to ask for help for fear of rejection. Negative reactions to PLHIV from family, friends, health workers, and care workers are usually based on lack of knowledge about the virus, fear of infection, and negative attitudes about sex and sexuality. Once people learn about the condition, they usually become less fearful.

This handbook was designed as a guide for carers, care workers, volunteers, and health workers who may provide care and support to PLHIV in the home and community settings, and in residential aged care. The handbook is divided into two parts. In Part 1, Sections 1-8 cover the disease processes involved in HIV and the practical aspects of caring for a person with HIV. In Part 2, Sections 9-13 cover rights and responsibilities for clients, carers, health professionals and services. It includes legal, policy and complaints information.

Section 1 examines community attitudes, stigma and discrimination. It highlights some of the effects that stigma and discrimination can have on PLHIV and on those who provide care to them, offers guidance on addressing

stigma and discrimination, and discusses implications for care.

Section 2 outlines basic information about HIV, how the virus is transmitted, how it reproduces inside the human body, its effects on the body and on the immune system in particular.

Section 3 describes safe practices in community settings when caring for PLHIV. Topics covered include the use of 'standard infection control precautions', including hand hygiene and general cleaning protocols. This is essential to equip those providing care with clear advice and practical skills on infection control and prevention.

Section 4 looks at specific issues for people ageing and living longer with HIV, such as the effects of long-term treatment, co-morbidities (other medical conditions that people may have along with HIV), and specific health issues they may face.

In *Section 5*, the focus is on current treatments and on the role of carers, health workers, volunteers, and care workers in maximising people's ability to take treatments successfully. Strategies that can be used to support adherence to treatment are outlined.

Section 6 provides information on a range of symptoms, side effects, and health issues commonly faced by PLHIV and practical guidance on how those caring for them can help them maintain their independence and health. A person- and family-centred approach is taken, focusing on individualised care, empowerment, partnership, and collaboration. Diversity and inclusiveness are emphasised.

Section 7 addresses caring as a shared community responsibility and the importance of caring for oneself as a carer, with suggestions and further resources.

Part 2 of the handbook addresses the rights and responsibilities of clients and health professionals in health and ageing services.

It aims to raise awareness of the appropriate level of care and considerations specific to working with PLHIV. Information on advanced care planning and future preparations is also provided for PLHIV and carers. Finally, this section provides an overview of complaints mechanisms for both clients and health professionals. It is designed to speak directly to PLHIV and their carers, health professionals, and managers of health and ageing services. The sections addressing client rights, discrimination, and disclosure have been divided into three sections to provide information on these topics specifically for PLHIV and carers, health professionals, and management and service settings.

Section 8 addresses client rights and responsibilities, providing an overview of human rights in Victoria and the various charters that protect the rights of clients, carers, and health professionals in health, ageing and aged care services.

Section 9 focuses upon HIV and discrimination for PLHIV who are clients, carers, and employees in health, ageing and aged care services.

Section 10 provides an overview of the disclosure, confidentiality, and privacy obligations for clients, health professionals, and service providers. This section highlights when disclosure may be required in health care settings and how clients can access health records.

Section 11 provides an overview of the process of Advanced Care Planning, Enduring Power of Attorneys, Guardianship Appointments, and information on Wills and Estates. The section is designed to give PLHIV and their carers information on things to consider when planning for the future.

Section 12 focuses on the workplace policies that aim to reduce HIV transmission in the workplace, and addresses procedures relating to clients and employees living with HIV.

This section also provides an overview of State and Commonwealth strategies related to HIV and ageing.

Section 13 provides an overview on the complaints-making process for State and Commonwealth-funded health, ageing, and disability services. This section provides information and resources for clients, carers, and health professionals, including a referral list of legal and advocacy services.

The handbook includes answers to some frequently asked questions, a resources section and a bibliography.

1 HIV AND AIDS – STIGMA, DISCRIMINATION & COMMUNITY ATTITUDES



The word **stigma** comes from a Greek word meaning a mark of disgrace or shame.⁴ Stigmatisation leads to discrimination, or being treated less favourably than other people on the basis of a personal characteristic; in this case, on the basis of a person's HIV status.

Stigma has been associated with some of the ways that HIV transmission occurs, such as unprotected sex between men, injecting drug use, and sexual transmission itself. This has resulted in people living with HIV (PLHIV) being stigmatised and experiencing discrimination in many areas of their lives, for example in the workplace, in health care settings, and even within their own families and communities. It is important to understand some of the possible effects of HIV-related stigma on PLHIV who need services and care as they enter older age groups. Its effects are not necessarily obvious but can result in harm and poorer health.

EFFECTS OF STIGMA ON PEOPLE LIVING WITH HIV ACCESSING CARE AND SERVICES

While public perception of HIV has improved in recent years, PLHIV can still face barriers to receiving services and care. Sometimes fear of discrimination or negative past experience prevents PLHIV from accessing services. Lack of knowledge of HIV and lack of experience with HIV by health workers, care workers, or volunteers can lead them to display attitudes or make comments that are discriminatory, unfair, and unprofessional, even if they are unintentional. When a person is unwell or needs services to help them stay at home, experiencing discrimination in the form of negative attitudes, behaviours, or comments can be very upsetting. Once a person has had a negative experience with a service, they will often avoid it altogether.

Most common forms of discrimination

The most common forms of discrimination reported by PLHIV in health care in Australia are denial of treatment or care, the use of excessive infection control precautions (such as a nurse wearing gloves to take a person's temperature), and avoidance by staff, care workers or volunteers.⁵

Judgmental attitudes and discriminatory behaviour are not acceptable in any setting, but beliefs and attitudes can be slow to change or may not be well-informed. For example, **Harry**, a 75-year-old HIV-positive man, says:

'When I was on a ward in hospital, unwell with a kidney infection, I asked the nurse to bring my HIV medication in to me. When she returned she was wearing a mask and gloves. I was very upset, but I then felt I had to teach her that there was no risk to her in giving me my tablets.'

An HIV-positive woman, **Deb**, described the following:

'When I was waiting for my blood to be taken, I heard the nurse say to another nurse "the next one has got HIV", with a worried look on her face as if it was a warning. Everyone in the waiting room heard that and I was very angry and embarrassed'.

Fear of discrimination

Sometimes people are discriminated against in their own community and may be fearful of telling anyone of their HIV diagnosis, even close family members. This can mean that support may not be as easily available for them as it may be for people with other illnesses or disabilities. PLHIV may fear that care may be refused, or that they will experience negative responses and rejection.

3 Goffman, E. (1963) *Stigma: Notes on the management of spoiled identity*. New York: Simon and Schuster.

4 Grierson, J., Pitts, M., & Koelmeyer, R. (2013). *HIV Futures Seven: The Health and Well-being of HIV Positive People in Australia*. Melbourne: Australian Research Centre in Sex, Health and Society, La Trobe University.

Jeremy, a 48-year-old gay man living with HIV says:

‘Not being judged is everything to me. In the past couple of months I’ve had two times where I have been discriminated against in hospital...one nurse asked how I got it... is there somewhere else I could have gone for treatment?’

People with HIV in Australia come from a wide range of cultural and religious backgrounds. In many communities there is limited discussion about sex and little or no sex education. Talking about sex at all may be taboo in some communities, and HIV stigma is very strong in others. Amongst some ethnic groups, and in rural and remote areas, or in small communities, PLHIV may be reluctant to reveal their HIV diagnosis to anyone, because privacy can be hard to ensure.

Abi, a 32-year-old HIV-positive man from Somalia living in an Australian city says:

‘If anyone from my community knows I have HIV, I worry that they won’t come and spend time with my family. That’s why I don’t want anyone to see the tablets I am taking because they will know that they are for HIV.’

Mariam, a 45-year-old HIV-positive Muslim woman from a rural area says:

‘Confidentiality is important in regional areas and small towns. I worry that my HIV status will remain confidential.’

IMPLICATIONS FOR CARE

Staff, care workers, and volunteers may also come from diverse backgrounds and have diverse beliefs and values. However, whatever the situation or context, all such workers and carers have a *special* responsibility to ensure that people in their care are treated with respect and their rights upheld. PLHIV need to be able to trust that their health information will be kept private and confidential, and shared with others only with the person’s consent, and only if it is necessary for their care.

Being sensitive to the feelings and potential fears of PLHIV is important to gain their trust and develop a working relationship. Understanding the impact of stigma on PLHIV, and its origins in lack of knowledge, fear, and prejudice, can help provide you with greater capacity to provide empathy and a better quality of care and support. It is the key to the ethical care of PLHIV.

Sylvester, a 53-year-old gay man living with HIV, talking of his care by staff at a community agency, says:

‘The respect you are given makes you feel that they understand that you are worthy of respect. There is nothing worse than being disrespected.’

Brian, a 67 year old client of a community support agency says:

‘It is so important to be made comfortable and not judged.’

Frank, a 52 year old gay man, long term survivor of HIV, says:

‘I have never felt judged [by the district nurse]. Everyone else judges me’⁵

5 Crock, E. (2013). *The Royal District Nursing Service HIV Program in a changing epidemic: an action evaluation*. Unpublished evaluation report: Melbourne. 62.

PRIVACY AND MAINTAINING CONFIDENTIALITY

The right to privacy means that people have a right to expect that information about them is kept safe and protected from disclosure.

As a volunteer, unpaid carer, care worker, or health worker, you may come to know a lot of private information about a person you are caring for, including health information such as their HIV diagnosis and which medicines they are taking.

No one is permitted to discuss a person's health status without the person's consent. This is based on the legal and ethical principle of confidentiality, where information provided in confidence to a professional should not be disclosed without the person's agreement. The requirement to maintain confidentiality is closely linked with the concept of privacy and with the obligation you have to respect the rights of the person you are caring for. See **11. Disclosure, confidentiality and privacy** in Part 2 of this handbook for further information.

The duty to maintain confidentiality may place added stress on you as a carer. For example, neighbours or family members might ask you questions about the person you are caring for. You shouldn't discuss anything about the person you are caring for without their consent.

Lee, a volunteer from Victorian AIDS Council (VAC) who cares for an older gay man living with HIV in public housing comments:

'The neighbours sometimes ask me what is wrong with Michael; they ask who I work for and why I visit every week. I usually respond simply that I am not able to discuss my client's health with other people. I think they respect that once they realise that I am professional in the way I work.'

Peter, a 66-year-old married man living with HIV, comments:

'I always feel confident that confidentiality will be maintained by the nurses'

It is important to remember that carers also need support, because it can be difficult to keep your experiences to yourself, especially when difficult issues or crises occur. If you come across difficulties as a carer or just need to talk things through, it can help to talk to an experienced person or counsellor on the phone.

Penny, a carer, says:

'Caring for yourself – you've got to have time out. You're only as good a carer as you are at looking after yourself. A lot of us are weak at doing that.'

WORKPLACE POLICIES

All workplaces, community care/visitor schemes, and residential services have policies and protocols in place to ensure that discrimination does not occur and that confidentiality is maintained. Guidelines and policies such as standard precautions (see **What are standard precautions?** on page 11) are in place to prevent the spread of infection, without discriminating against those who have HIV or any other infection. Community-based organisations such as Living Positive Victoria and the VAC also have their own policies and procedures which volunteers are expected to adhere to. Familiarise yourself with the policies and procedures of your own organisation, as these will support you in providing the best care.

For examples of best practice organisational policies and procedures, please visit:

<http://www.livingpositivevictoria.org.au/about/governance>

USEFUL CONTACTS

**Victorian AIDS Council
Community Support:**
<http://www.vac.org.au/>

Carers Victoria:
<http://www.carersvictoria.org.au/>

**Multicultural Health
and Support Services:**
<http://www.ceh.org.au/multicultural-health-support-service/>

WHAT CAN I DO IF DISCRIMINATION OCCURS?

If you believe the person you are caring for has been discriminated against or if their confidentiality has been breached, you or the person themselves can make a direct complaint to the organisation concerned. Other options include:

- contacting the Office of the Health Services Commissioner
<http://www.health.vic.gov.au/hsc>
- contacting the Victorian Equal Opportunity & Human Rights and Equal Opportunity Commission
<http://www.humanrightscommission.vic.gov.au/>
- seek legal advice

See **14. Complaints and advice for clients and service providers** for further information.

If you have concerns about getting specific services for the person you are caring for, ask for help from a health professional, social worker, carer, support worker, or support group. You do not have to disclose the person's HIV status when seeking advice. There are many agencies set up for PLHIV that understand their concerns and offer a supportive environment.

ETHICS AND HEALTH PROFESSIONALS

Health professionals are responsible for adhering to their professional codes of ethics. Codes of ethics identify the standards and values of a profession, provide them with guidance on ethical decision-making and practice, and indicate to the community the ethical values it can expect the profession to uphold⁸. Breaching a Code of Ethics can result in disciplinary action and, at worst, deregistration of a health practitioner.

As an example, key principles of the Australian Nursing and Midwifery Council's Code of Ethics include:

- recognising the universal human rights of all people
- safeguarding the dignity and equal worth of everyone
- valuing and respecting diversity
- providing quality nursing care for all people
- facilitating informed decision-making
- safeguarding cultural safety
- maintaining confidentiality and privacy

All health workers should be familiar with their profession's code of ethics.

See, for example, <http://www.nursingmidwiferyboard.gov.au/Codes-Guidelines-Statements/Codes-Guidelines.aspx> – codes of ethics.

Volunteers and community visitors have their own codes of conduct. Organisations may also have values, protocols, or guidelines that workers and volunteers must follow, as well as professional codes of conduct.

CARERS' RIGHTS

Friends and family members who are carers also have rights. These are outlined in the National Carer Strategy and through State and Federal legislation (*Carer Recognition Act 2010* (Cth)). In Victoria, there is information about your rights and how you should be treated as a carer in:

- *The Victorian Charter Supporting People in Care Relationships* (Department of Human Services, 2012)
http://www.dhs.vic.gov.au/_data/assets/pdf_file/0010/738667/91-The-Victorian-charter-supporting-people-in-care-relationships.pdf

7 Johnstone, M.J. & Crock, E. (2015). Dealing with ethical issues in nursing practice. In E and Daly, J Chang (Eds.), *Transitions in Nursing: preparing for professional practice*. Chatwood, NSW: Elsevier.

- *Carers Recognition Act 2012* (Vic)

<http://www.dhs.vic.gov.au/about-the-department/documents-and-resources/policies,-guidelines-and-legislation/carers-recognition-act-2012>

See **7. Just for carers – taking care of yourself** and **9. Human rights, HIV and clients’ rights** for more information on rights and carers’ responsibilities.

FURTHER INFORMATION AND SUPPORT

Further information and support for people living with HIV and their carers is available from:

Living Positive Victoria (LPV) represents people living with HIV in Victoria. LPV provides peer support, health promotion and prevention education.

<http://www.livingpositivevictoria.org.au>

The Victorian AIDS Council (VAC) provides a range of services, which include treatment and care of PLHIV, counselling, and education about HIV prevention. VAC also provides support and advice to carers at the Positive Living Centre in Prahran and phone support to people living with HIV and carers, both locally and nationally.

<http://www.vac.org.au>

Positive Women Victoria provides support, information and advocacy for women in Victoria living with HIV.

<http://www.positivewomen.org.au>

Straight Arrows offers peer support, information, advocacy, health promotion and referrals for HIV-positive heterosexual men and women, and their partners and families.

<http://straightarrows.org.au>

The Multicultural Health and Support Service (MHSS) supports refugee and migrant communities in the areas of sexually transmissible infections and blood-borne viruses. It also offers training and resources to health service providers.

<http://www.ceh.org.au/multicultural-health-support-service/>

2 ABOUT HIV AND AIDS

Over the last 30-plus years, there have been major scientific advances in knowledge about HIV, leading to much better understanding of its effects on the body. HIV can now be treated effectively with a wide range of medicines. While there is still no cure for HIV, most people living with HIV can live a normal lifespan if they take treatments as prescribed and look after their health. Still, some groups have specific care needs, especially those who have lived many years with HIV and are now growing older, or have other medical conditions as well as HIV (referred to as *co-morbidities* or *multi-morbidities* meaning many illnesses).⁹

It is important for people who provide care and support to PLHIV to understand how the virus can affect the person's body.

If a person is not on treatment, or if treatments stop working, HIV can lead to serious health problems and even early death. Some people are diagnosed late (for example, they have never been tested for HIV, and they only have an HIV test when they become very sick) and have therefore missed out on the benefits of starting treatment early. In other cases, some people choose to delay starting treatment or stop taking their medicines for various reasons. For a person who is not on treatment, HIV can cause serious damage to the body's immune system.

WHAT IS THE IMMUNE SYSTEM?

The immune system, a system of organs and cells throughout the body, protects us from disease by attacking and destroying infections. The immune system is composed of many different types of white blood cells called lymphocytes. One particular type of white blood cell – called *T-cells* or *CD4* cells – is targeted by HIV. These cells are critical for immunity to help fight off infections.

WHAT IS HIV?

HIV stands for human immunodeficiency virus. A virus is a very small organism that can only grow and reproduce itself by using the cells of the person who has contracted it. HIV is classified as a blood-borne virus, meaning it is spread through contact with blood which contains HIV. It can also be passed from person to person in body fluids including semen, breast milk, and vaginal fluids (see **How is HIV transmitted?** on page 9 for more information on how HIV can be passed from one person to another).

Once inside the body, HIV enters CD4 cells and uses them to make copies of itself. Over time, numbers of CD4 cells decline and the immune system is unable to fight infections effectively.

WHAT IS ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS)?

Acquired immune deficiency syndrome (AIDS) describes the diseases that may occur when the immune system has been severely damaged by HIV. *Acquired* simply means it is not inherited genetically from parents. A person with HIV can develop AIDS if they are not treated and their immune system is not working properly (it is *deficient*).

AIDS is defined as an advanced stage of HIV disease, when the person is affected by specific medical conditions called *opportunistic infections* or *illnesses*, or by some types of cancers. Even if a person has developed AIDS, with effective treatment the immune system may recover, and the person may remain well for many more years. Today in Australia, it is rare to see people with AIDS.

8 Broom J., Sowden D., Williams M., Taing K., Morwood K., & McGill K. (2012). Moving from viral suppression to comprehensive patient-centered care: The high prevalence of comorbid conditions and health risk factors in HIV-1-infected patients in Australia. *Journal of the International Association of Providers of AIDS Care*, 11(2), 109-114.

HOW IS HIV DIAGNOSED?

HIV is diagnosed through blood tests.

First, a simple blood test called the ELISA test is done. The ELISA tests for antibodies to HIV. Antibodies usually take from two to eight weeks to develop in the human body following infection with HIV. If the ELISA test comes back positive, another test called a Western Blot test is performed to confirm the diagnosis. It can take up to two weeks to obtain the result of the Western Blot (see **Glossary** on page ix on for an explanation of ELISA and Western Blot).

Rapid tests are now available that can give a result in about 20 minutes; however, a positive result to a rapid test needs to be followed up by laboratory testing before an HIV diagnosis can be confirmed.

See the Australian Federation of AIDS Organisations' website, <http://www.afao.org.au/about-hiv/hiv-test> for more on HIV testing and diagnosis.

For more information please visit <http://www.mshc.org.au> and search "HIV testing and results"

WHAT ARE 'OPPORTUNISTIC ILLNESSES?'

Immune deficiency offers microorganisms (for example, bacteria and viruses) the *opportunity* to cause illness that a normally functioning immune system would prevent or suppress. This is why the illnesses associated with HIV infection are called *opportunistic*. Opportunistic illnesses can develop if the person's immune system is severely damaged by HIV.

What types of illnesses are recognised as 'opportunistic?'

Over time, usually about 10 years, most people with HIV, if they are not on treatment, will eventually develop immune deficiency that can lead to infections and cancers in any part of the body. Examples of opportunistic illnesses and cancers include:

- candidiasis or thrush – a fungal infection, which usually appears as white patches on the surfaces of the mouth, throat, or in women, the vagina
- cerebral toxoplasmosis – may cause brain (neurological) symptoms such as difficulty speaking, headaches, seizures (fits), and blurred vision
- cytomegalovirus (CMV) – can cause disease in the eye that can lead to blindness if untreated (may also affect the gut, lungs, and nervous system)
- mycobacterium avium complex (MAC) – a type of bacterial infection that causes fatigue, night sweats, high fevers, and diarrhoea
- mycobacterium tuberculosis (TB) – can affect the lungs or other part of the body; seen more commonly in people who are diagnosed late in HIV disease or come from countries where TB is common; sometimes a diagnosis of TB is a clue that the person may have HIV
- pneumocystis jiroveci pneumonia (PJP) – a lung infection that can lead to a cough, fever, and difficulty in breathing. Sometimes known by its former name, pneumocystis carinii pneumonia (PCP).
- progressive multifocal leukoencephalopathy (PML) – a brain infection that can result in strokes, blindness, or other disabilities due to damage to the brain

- cryptococcal meningitis – a fungal infection of the brain that can result in headaches and seizures
- lymphoma – a type of cancer affecting the lymph glands, the brain, or other organs.

Other HIV-related conditions include:

- peripheral neuropathy – HIV can directly damage nerves in the extremities (periphery of the nervous system) such as feet, legs and hands. Some medicines used to treat HIV can also contribute

to this condition. People affected by peripheral neuropathy experience a range of sensations including numbness and burning, ‘pins and needles,’ and in some cases severe pain.

- HIV-associated neurocognitive disorder (HAND) and HIV-associated dementia (HAD) – These conditions can affect memory, behaviour, personality, and mobility. HAND and HAD can be improved and their progression reversed or slowed with effective treatment of HIV.

WHAT ARE THE PHASES OF HIV DISEASE?

Table 1: The phases of HIV disease

PHASE	DESCRIPTION
Phase 1: Acute HIV	‘Acute HIV’ is defined as the period (roughly 2-4 weeks) after a person first contracts HIV. During this time, the virus is very active, producing many new copies of itself. Some people may develop a flu-like illness (fever, headache, rash) or have other symptoms. Some people recall no symptoms at all at this stage. Transmission risk is highest during Phase 1. The acute illness usually resolves within 14 days.
Phase 2: Asymptomatic chronic illness	During this stage, HIV continues to reproduce but at low levels. The person may have few or no symptoms. With treatment, people may live in this phase with ‘clinical latency’ (which means their immune system is keeping the virus under control) for many years. Without treatment, this period lasts on average ten years. A small but significant number of people live even longer without becoming unwell (known as ‘long-term non-progressors’). Transmission is possible during this phase.
Phase 3: Symptomatic chronic illness	CD4 count continues to fall and the person becomes immunodeficient. They may develop an opportunistic illness or condition (AIDS-defining illness). Without treatment, people typically survive about three years. Transmission risk is high at this stage because there are high levels of the virus present in blood and body fluids.

Adapted from.¹⁰

9 Kelly, M. (2009). Natural history of HIV infection. In Lewin, S., Post, J.J., Street, A., and Hoy, J. (Eds.), *HIV Management in Australasia: a guide for clinical care* (pp. 37-47). Sydney: Australasian Society of HIV Medicine.



HOW CAN HIV BE MONITORED?

HIV is monitored by blood tests. The two most important blood tests currently available for PLHIV are tests for *viral load* and *CD4 count* (also called T-cell count). Other tests include resistance testing to see whether a certain combination of medicines is still effective.

If a person is on treatment and their test results are stable, they may need these tests less frequently than someone who is not on treatment.

What is the CD4 count?

The CD4 count is a blood test that measures the number of CD4 cells a person has in their blood. The number of CD4 cells in a healthy adult's blood is usually between 600 to 1500 per cubic millimetre or mm^3 (on average, $1000/\text{mm}^3$).

If HIV entering and destroying the CD4 cells damages the immune system, the CD4 count falls. The lower the CD4 count, the greater the damage to the person's immune system.

Once the CD4 count falls below 200, the person becomes increasingly at risk of opportunistic illnesses and cancers. Health professionals can use this information to monitor whether the treatment is working well. If treatment is working, the CD4 count should gradually increase.

What is the viral load count?

The viral load blood test measures the amount of HIV circulating in the blood stream, in copies per milliliter of blood. If treatment is working, the viral load should decrease to an *undetectable* level – that is, current tests cannot detect the virus below a certain level (for example, some viral load tests in Australia cannot detect the virus at levels below 20 copies per millilitre of blood).

If a person's viral load is increasing over time, it means that the virus is reproducing itself rapidly. A *high viral load* is over 100,000 copies per ml; a low viral load is less than 10,000 copies per ml.¹⁰ If the person is taking HIV medicines and the viral load keeps increasing, it may mean that the virus has developed resistance to the medicines being used, with subsequent loss of effectiveness of these medicines. In this case the doctor may consider changing the medicine to a different combination.

HOW IS HIV TRANSMITTED?

HIV is present in certain body fluids of people who have HIV: blood, semen, vaginal fluids, and breast milk. Other body fluids, such as urine and saliva, are not considered a risk for HIV transmission unless they are contaminated with blood.

HIV can be passed from one person to another if one of the body fluids containing HIV comes into contact with a mucous membrane or damaged tissue, or is injected directly into their blood stream. This can occur through:

- Sexual contact: condomless sexual activity, particularly anal or vaginal sexual intercourse without condoms or sharing sex toys
- sharing drug-injecting equipment such as needles and syringes
- needlestick injury
- transmission from an HIV-positive mother to her baby, either during pregnancy, during birth or via breast milk. If the woman is on treatment, these risks can be greatly reduced

¹⁰ Australian Federation of AIDS Organisations. (2009). *HIV Tests and Treatments*. Sydney: Australian Federation of AIDS Organisations and National Association of People with HIV/AIDS.

HIV is not transmitted by:

- social interaction, such as shaking hands
- touching, hugging, or kissing
- sharing food, dishes, drinking glasses, or cutlery
- being coughed, sneezed, or cried on
- toilet seats, drinking fountains, swimming pools, or communal gyms
- animal or insect bites

Globally, HIV is mainly spread through heterosexual sex – that is, condomless sex between women and men – while the most common means of transmission of HIV in Australia is condomless sexual contact between men. Growing numbers of people in Australia have contracted HIV in recent years through heterosexual contact.

The best way to prevent HIV transmission when caring for a person with HIV, either at home or in a work setting, is through the use of what are called *standard infection control precautions*. Standard precautions also prevent transmission of infections from carers to PLHIV. Standard precautions are explained in **3. Hygiene and Safety** on page 11.

People generally prefer to stay in their own home and community as they grow older, and older people living with HIV (PLHIV) are no different. Caring for a person with HIV in the home and community setting does not pose a risk to carers or family. PLHIV may receive services from their local council, community or district nursing services and volunteer-based services such as the Victorian AIDS Council (VAC) and Carers Victoria.

Some PLHIV may eventually require residential aged care services. In all settings, the same principles for infection control and prevention apply. Carers, care workers and health workers need a sound understanding of how to prevent the spread of infection from person to person regardless of one's HIV status. Knowing these principles, and putting them into practice consistently, helps prevent the spread of all types of infections.

Michael, a 72-year-old HIV-positive man with a disability who receives care and support at home and attends a day care centre, comments:

'HIV is very, very difficult to catch, it's very specific. From a carer's point of view, good hygiene and human interaction is needed when working with someone who is HIV positive.'

HOUSEHOLD CLEANING

There is no need for special cleaning of the home when caring for a person living with HIV. Crockery and cutlery can be shared and washed as usual. Household members can share the bathroom, toilet, and laundry, which should be cleaned regularly with usual detergents. Personal items such as towels, face washers, toothbrushes and razors should be kept for individual use and not shared.

Alex, an HIV-specialist district nurse comments:

'Sometimes people living with HIV who I have cared for have described family members refusing to eat with them or providing them with paper plates when the rest of the family is eating. This is unnecessary and upsetting for the HIV positive person as there is no risk at all from sharing food and using the same utensils and crockery. Once I have explained this to families, and people understand, everyone is happier and no longer fearful.'

PREVENTING THE TRANSMISSION OF MICROORGANISMS

Infections can be spread in many ways. We don't always know whether a person has a viral or other infection, so protecting yourself at all times is the best policy. Practices known as standard precautions should be used in all settings.

WHAT ARE STANDARD PRECAUTIONS?

Standard precautions refer to practices that are applied to the care of everyone, regardless of their known or perceived infection, to minimise the risk of transmission of microorganisms. Standard precautions prevent transmission of infections from person to person. Standard precautions apply in all settings and can be practised easily and effectively by carers, staff, and volunteers in the home, the community, and in respite and residential settings.

Standard precautions are used when you anticipate contact with:

- blood
- all other body fluids (excluding sweat) regardless of whether they contain visible blood
- non-intact skin
- mucous membranes

Using standard precautions means:

- effective hand washing
(see <https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/handwashing-why-its-important>)
- the use of personal protective equipment, for example:
 - wearing gloves if contact with blood or body fluids is likely
 - wearing a plastic apron if splashes are likely to occur
- safe handling and disposal of sharps such as needles or razor blades
- cleaning and disinfecting blood or body fluid spills
- safe disposal of waste and used equipment
- appropriate handling of soiled linen ^{12, 13}

The rule is to treat all blood and body fluids from any person, not just those with a known diagnosis, as potentially infectious.

Gerry, a manager at a supported accommodation facility for PLHIV, says:

‘Infection control isn’t an issue here. Carers treat the clients and each other the same way – as though we could all be HIV positive. Standard precautions for all.’

HAND HYGIENE

Hand washing (or *hand hygiene*) is the most important way to prevent the spread of infections. Skin is a natural barrier against infection. There are two effective methods of hand hygiene:

1. routine hand wash (water and soap); and
2. use of an alcohol based hand rub.

Routine hand wash is necessary when hands are visibly soiled; otherwise either hand wash or alcohol-based hand rub may be used.

Routine hand wash means:

- Wet your hands under running water and apply soap
- Rub your hands together for at least 15 seconds, ensuring fingertips, thumbs and the areas between your fingers are washed
- Rinse your hands under running water then dry them thoroughly on disposable paper towel or a clean towel

If running water is not available when hand washing is required, use neutral detergent hand-wipes to clean your hands.

Use of alcohol-based hand rub means:

- Apply alcohol-based hand rub into the palm of your hand
- Place your hands together to apply it to each palm
- For each hand, place your fingertips together and rotate your nail tips through the alcohol based hand rub in the opposite palm (to distribute the gel under and around fingernails)
- Run the remaining alcohol based hand rub over all surfaces of both hands
- Continue rubbing until your hands are dry

Caution: Do not apply alcohol-based hand rub to wet hands, as it dilutes the alcohol and makes it ineffective. Store alcohol-based hand rub out of direct sunlight or heat, as it is flammable and can leak or become ineffective.

Hand hygiene should be practised:

- before eating
- after using the toilet
- before and after attending to the personal needs of the person you are caring for, such as helping them to use the toilet

11 Royal District Nursing Service Limited. (2014). CP E21 Hand Hygiene. *Policies and Procedures*. Melbourne: Royal District Nursing Service Limited.

12 Royal District Nursing Service Limited. (2014). CP E22 Standard and Transmission-based Precautions and Personal Protective Equipment. *Policies and Procedures*. Melbourne: Royal District Nursing Service Limited.

- after accidental contact with blood or body fluids
- after wearing gloves
- after blowing your nose
- after handling contaminated material or waste¹⁴

When should you wear gloves?

Use gloves when:

- you anticipate contact with blood or body fluids
- handling equipment or surfaces that have blood or body fluids on them

- you have broken skin such as cuts, eczema or sores
- handling soiled linen or clothing

Remove gloves after care is completed and wash your hands. Continuing to work wearing the same pair of gloves on is just like not washing your hands at all.

For the home, buy a box of disposable gloves from the supermarket or chemist.

In residential and healthcare settings, these are provided by the employer.

FOR MORE INFORMATION

See **Hand Hygiene Australia**

<http://www.hha.org.au/home/5-moments-for-hand-hygiene.aspx>

Table 2: Five moments of hand hygiene (used in residential facilities and in clinical practice)

1. Before touching a client or resident
2. Before a procedure
3. After a procedure or body fluid exposure risk, including after removing gloves, and if moving from a contaminated body site to a clean body site during client care
4. After touching a client
5. After contact with a client's surroundings (including animals).¹⁵

Skin care

Intact skin is a natural barrier against infection. Care for your hands, especially when washing them frequently, by using moisturiser or barrier cream. Cover cuts or breaks in the skin with a waterproof dressing.

HOW DO YOU CLEAN UP SPILLS OF BLOOD OR BODY FLUIDS?

Use protective clothing and equipment when cleaning up spills of blood or body fluids. Depending on the environment and size of the spill, protective equipment may simply mean gloves, or in a clinical environment, may include eyewear (such as goggles) and a waterproof apron. Eyewear should be worn if there is a risk of splashes into the eyes.

First, restrict access to the affected area if other people are around.

- Assess the situation and ensure you have all necessary items. It is helpful to have a supply of items such as paper towels, tissues, plastic bags, buckets, gloves and detergent
- For hard surfaces, mop with cold water and soap (or household detergent) and allow it to dry. If the spill is large (greater than 10cm), after absorbing it with paper towels, wipe with a freshly prepared disinfectant solution

¹³ Royal District Nursing Service Limited. (2014). CP E06 Occupational exposure – Needlestick, blood or body substances. *Policies and Procedures*. Melbourne: Royal District Nursing Service Limited.

¹⁴ *ibid.*

- On soft surfaces, such as carpet and furniture, thoroughly sponge the area with cold water and soap (or detergent) and allow it to dry. Carpets may be steam cleaned after a large spill
- Use paper towels or tissues to remove blood or body fluids then place into a plastic bag. Tie the bag, place in another plastic bag, then discard it into the rubbish. Wash your hands again

Use of bleach

The Victorian Department of Health notes: 'It is generally unnecessary to use bleach for managing spills, but it may be used in specific circumstances. Health care workers/members of the public may feel reassured that the risk of infection [from a range of organisms] is reduced if bleach is used. However there is no evidence of additional benefits...'

See the Victorian Department of Health publication: <https://www2.health.vic.gov.au/public-health/infectious-diseases/infection-control-guidelines/manage-blood-body-fluid-spills>

Handling linen

Unsoiled clothing and linen may be washed in the usual way with laundry detergent and water. When handling soiled linen or clothing:

- wear gloves
- take a bucket to where the soiled linen or clothing is, and carry it back to the laundry to avoid spilling its contents

If clothing or linen is soiled with solid waste, e.g. faeces, remove it using gloves and paper towels or tissues before rinsing it under cold running water. Soak soiled items in a detergent solution for about 30 minutes then wash them in the washing machine.

Cleaning of equipment

Take care to avoid splashes when emptying the contents of vomit bowls, bedpans, or urinals into the toilet. Wear gloves and clean the equipment with detergent and water. Dry the equipment using paper towels.

DISPOSAL OF WASTE AND SOILED MATERIALS

In the home, if you have materials such as incontinence pads, tampons, or paper towels to dispose of, put them in a plastic bag, tie the bag, place it inside another bag, and tie the top. Place the bag in the rubbish bin.

If you are working in a healthcare setting, follow your organisation's protocol for dealing with infectious waste. This usually involves placing waste in appropriately marked plastic bags, and disposing of it in line with Environment Protection Authority (EPA) regulations. Hand hygiene should then be carried out.

HANDLING AND DISPOSAL OF 'SHARPS' SUCH AS NEEDLES AND SYRINGES

- Never try to put a cap back on a used needle or to bend or break a needle; you might prick your skin with it
- Always hold a syringe by the barrel
- Wear gloves
- Do not remove a needle from the barrel
- Needles and syringes should be disposed into an approved sharps container (clearly labelled, puncture- and leak-proof). Contact your health care professional or local council for an approved sharps container
- Take the sharps container to the sharp item rather than carrying the item around
- If it is necessary to dispose of a needle and syringe and there is no sharps container, place it in a rigid-walled plastic container with a screw-top lid, such as a household detergent or fruit juice container. Don't use a glass jar or bottle as this may break. The syringe in the plastic container should then be disposed of appropriately after contacting your local council or health professional for advice
- Make sure sharps containers are stored in a secure place out of reach of children

ACCIDENTAL CONTACT WITH BLOOD AND BODY FLUIDS

- **Skin:** Immediately wash away the blood or fluid from the affected area using soap and running water. Alcohol-based hand rub can be used if soap and water are not readily available. Apply a waterproof dressing if required. If bleeding continues, apply pressure through the dressing. Do not squeeze the affected area
- **Eyes:** If your eyes are contaminated, rinse them under running tap water (keep eyes open while rinsing) for at least 30 seconds
- **Mouth:** Spit out then rinse mouth with water several times

Then promptly contact your general practitioner or hospital for further advice.

Care workers and volunteers should follow their organisation's policy and procedures regarding occupational exposures

Needlestick or sharps injury

If you have a needlestick injury or are cut with a sharp object contaminated with blood or body fluids when caring for a person living with HIV, perform first aid as described above: immediately wash away the blood or body fluid from the affected area using running water. Seek medical attention, ideally within two hours.

If you work in a healthcare setting, report accidental contact with blood and body fluids or needlestick incident to the appropriate staff member, and follow your organisation's policy and procedure.

There is evidence that people with HIV who are on ART and have an *undetectable viral load* are highly unlikely to transmit HIV.

There is also treatment available for occupational exposures to HIV that can help reduce the risk further. This is known as *post-exposure prophylaxis* or *PEP*.

Post-exposure prophylaxis (PEP)

Post-exposure prophylaxis (PEP) means a course of medicine taken after a high-risk exposure to HIV to reduce the risk of infection. HIV needs to enter the blood stream to cause infection. A health professional will assess the level of risk to determine whether PEP is needed. It is not given routinely to people who have had a possible exposure because it can cause side-effects and needs to be taken consistently for one month. Recommendations state that PEP should be started within 72 hours of the exposure, but preferably as soon as possible after exposure, to maximise its effectiveness.

See <http://www.afao.org.au/about-hiv/hiv-prevention/post-exposure-prophylaxis>

There is a 24-hour Victorian PEP info line 1800 889 887 or www.getpep.info

What about other infections?

Using standard precautions and proper hand hygiene and are the most effective methods of preventing infections from spreading. Some infections may be passed on in other ways such as by coughing and sneezing. Remember the person you are caring for might have impaired immunity so avoid contact with common infections when possible. The person's doctor may recommend vaccinations (such as the flu vaccine) to protect them from some infections. Specific advice should be sought regarding travel to other countries or for any other concerns about exposure to infections.

FOOD PREPARATION AND HANDLING

Basic food handling guidelines should be followed when caring for a person living with HIV. These guidelines are the same for anyone you may be caring for:

- Wash your hands with soap and water before handling food or utensils
- Keep cooking utensils and preparation areas clean and wash with warm soapy water before and after preparing food
- Use a separate chopping board and other utensils when preparing raw meat, fish, or poultry; then wash the board thoroughly with warm, soapy water
- Wash all fruit and vegetables well
- Store food at the correct temperature in the fridge or freezer
- Don't reheat food more than once
- Don't refreeze food once it has been defrosted
- Use food by its use-by date

4 LIVING LONGER AND AGEING WITH HIV



Due to the great advances in treatment made in the last 30 years, a large group of people living with HIV is now entering older age. The average age of Australians living with HIV is now over 45 and the number of people over 60 has been increasing at 12 per cent per year since 1995.¹⁷ In Australia, the proportion of PLHIV over age 55 increased from 2.7 per cent in 1985 to 11.2 per cent in 2000 and 25.7 per cent in 2010, with a predicted further increase to 44.3 per cent by 2020.^{18,19} Most in this group are long-term survivors of HIV.

Between 2012 and 2014, 17 per cent of new HIV diagnoses in Australia have occurred in people 50 years and over.²⁰ People diagnosed with HIV when they are over 50 tend to have more advanced disease and experience greater HIV-related illness.²¹ This group of older people who are newly diagnosed can have quite different needs to those who are long term survivors.

The topic of ageing with HIV is a relatively new area of research and health care, and information is constantly developing. Ageing brings new challenges for PLHIV, as does taking antiretroviral medicines long-term.

WHAT IS KNOWN ABOUT HIV AND AGEING?

There is some evidence that HIV contributes to a faster or earlier ageing process,²² and some PLHIV describe feeling physically 'older' than they might without HIV. So, for example, they may be frailer than a person of similar age who does not have HIV.^{23,24} They may experience bone problems such as osteoporosis or arthritis, memory difficulties, or unsteadiness when walking. Some women living with HIV may experience early menopause, which is associated with an increased risk of osteoporosis and heart problems.²⁵

It is now known that chronic inflammation caused by HIV over a long period can result in problems similar to those seen in people as they grow older. Some HIV medicines can also increase the risk of problems that are

commonly associated with ageing such as bone loss. HIV and the ageing process may compound each other.^{26,27} Also, as people age, they experience a natural ageing of the immune system, with loss of T-cells (CD4 cells) and reduced immune responses.

Use of antiretroviral therapy (ART) long term suppresses the virus, so AIDS-related conditions are now rare, although they may be seen in people whose HIV was diagnosed late. However, because PLHIV now have a much longer life expectancy, other complications associated with ageing are naturally becoming more common.²⁸

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- 15 Murray J., McDonald A., & Law M. (2009). Rapidly ageing HIV epidemic among men who have sex with men in Australia. *Sexual Health*, 6(1), 83-86.
 - 16 Roberts, J., McDonald, K., & Elliott, J. (2013). Services for People Ageing with HIV in Victoria: A Mapping Study. Infectious Diseases, Alfred Hospital. s.l.: Monash University.
 - 17 McDonald, K., Elliott, J., & Saugers, L. (2013). Ageing with HIV in Victoria: Findings from a Qualitative Study. *HIV Australia*, 11(2), 13-16.
 - 18 The Kirby Institute. (2014). p. 37
 - 19 Smibert, O.C., Ananda-Rajah, M. O'Brien, J., & Visvanathan, K. (2014). Age: HIV knows no boundary. *The Medical Journal of Australia*, 201(8), 481-482.
 - 20 del Rio, Carlos. (2011). HIV and Clinical Manifestations of Accelerated Aging. *NEJM Journal Watch AIDS Clinical Care*. Retrieved from <http://www.medscape.com/viewarticle/754989>.
 - 21 Smibert, O.C., Ananda-Rajah, M. O'Brien, J., & Visvanathan, K. (2014).
 - 22 Piggott, D., Muzaale, A.D., Mehta, S.H., Brown, T., Patel, K.V., Leng, S.X., & Kirk, G.D. (2013). Frailty, HIV Infection, and Mortality in an Aging Cohort of Injection Drug Users. *PLOS ONE*. Retrieved from <http://www.journals.plos.org/plosone/article?id=10.1371/journal.pone.0054910>.
 - 23 Smibert, O.C., Ananda-Rajah, M. O'Brien, J., & Visvanathan, K. (2014).
 - 24 Murray J., McDonald A., & Law M. (2009).
 - 25 Peate, I. (2013). The health-care needs of the older gay man living with HIV. *British Journal of Community Nursing*, 18(10), 492-495.
 - 26 Baker, D., Ebeling, P.R., Gowers, A., Gracey, D., Grulich, A., Matthews, G., Nolan, D., Shields, M., Tee, B.K., Watson, J., Willcox, J., & Wright, E. (2012). *HIV Life Plan Clinical Guide: A clinician's guide to assessing and managing HIV-related comorbidities*. Melbourne: Adrenalin Healthcare.

*** NOTE:**

There are two main forms of diabetes – type 1 and type 2. Type 1 diabetes usually affects children and young adults and is caused by the body's immune system attacking insulin-producing cells in the pancreas – known as an 'autoimmune disease.' Type 2 diabetes is more common and usually occurs in adults over 30. A person with type 2 diabetes may produce enough insulin but not use it effectively (insulin resistance) or they may not produce enough insulin.²⁹ Eventually, they will develop high blood sugar levels and over time, damage to other body systems can result.

OTHER ILLNESSES AND CONDITIONS

Most PLHIV who need services, whether at home or in residential settings, have a number of other medical conditions requiring specialist support (sometimes referred to as *co-morbidities* or *multi-morbidities*).²⁸ Managing their care may require different approaches (models of care). They may have other infections such as hepatitis C or hepatitis B. Some PLHIV have disabilities such as mental health problems or intellectual disabilities. This section discusses common conditions people with HIV may experience, provides information for people in caring roles and provides resources available for support.

Metabolic complications

Long-term use of ART can contribute to what are known as metabolic complications such as diabetes (raised blood sugar levels), hyperlipidemia (too much fat in the blood), and lipodystrophy (abnormal body fat distribution). These, in turn, can lead to heart disease and strokes. The benefits of ART are considered to greatly outweigh these risks, but it is important to be aware of them so that you can help the person you are caring for. You can help the person to minimise lifestyle risk by supporting them to stop smoking, to eat healthily, and to take part in physical activity and exercise.

<http://www.health.gov.au/internet/main/publishing.nsf/Content/phd-physical-choose-health>

http://www.afao.org.au/_data/assets/pdf_file/0003/4593/Dec09_factsheet_giveupsmoking.pdf

Diabetes

Some HIV medicines can increase a person's blood sugar levels (blood glucose) over time, which can eventually lead to type 2 diabetes*. It is thought that some HIV medicines make the body resistant to insulin, the hormone that helps the body process sugar, which is needed for energy. Symptoms of insulin resistance include drowsiness after meals, mood swings, or extreme hunger, but often people have no symptoms at all. Insulin resistance can lead to high cholesterol and triglyceride levels (high levels of fat in the blood).

Risk factors for diabetes include being overweight, lack of exercise or physical activity, and a family history of diabetes. Symptoms of diabetes include being thirsty, increased urination, unexplained weight loss or weight gain, and excessive tiredness. Diabetes, in turn, can lead to other problems if it is not controlled, such as heart disease, nerve damage, kidney damage, and blindness.

In many cases, type 2 diabetes can be controlled by eating a healthy diet, regular exercise (30 minutes most days of the week) and medication. A healthy diet is low in fat, salt, and sugar, and contains a range of vegetables and fruits, high fibre, and lean protein. A doctor may prescribe medicines if diet and exercise are not enough to lower the person's blood sugar to normal levels.

27 Baker, D., Ebeling, P.R., Gowers, A., Gracey, D., Grulich, A., Matthews, G., Nolan, D., Shields, M., Tee, B.K., Watson, J., Willcox, J., & Wright, E. (2012).

28 Youle, M. & Murphy, G. (2010). *Coming of Age: A guide to ageing well with HIV*. s.l.: justri.

Lipid abnormalities

Hyperlipidaemia is an excessive amount of fat (cholesterol and triglycerides) in the blood.

Cholesterol is a fatty substance found in animal-derived foods and is also produced by the liver. Triglycerides are also found in foods and are produced by the body.

Hyperlipidaemia has been associated with some ART. If untreated, high levels of fat in the blood can lead to heart disease and pancreatitis (inflammation of the pancreas, the organ that produces insulin). Other factors that can contribute to hyperlipidaemia include:

- alcohol
- family history
- high-fat diet
- diabetes
- obesity
- smoking

Lipid levels can be monitored by the person's doctor. Lifestyle changes such as exercise (30 minutes most days of the week); maintaining a low-fat diet with fresh fruits, vegetables, and whole grains; minimising animal fat; and reducing smoking and alcohol can all help. Lipid-lowering medicine may be used if lifestyle changes are not enough to lower fat levels to acceptable levels. The person's doctor will help choose the medicine that works best with their HIV treatment.

Body shape changes – 'lipodystrophy'

Lipodystrophy is a condition which results in abnormal changes in body fat distribution. It is associated with some ART and can result in increased blood fat levels, such as cholesterol and triglycerides. Newer HIV medicines are less likely to cause lipodystrophy.

Lipodystrophy develops from a disturbance in the way the body produces, uses and stores fat. Fat can be lost from some parts of the body, such as from the face, arms and legs or buttocks, in which case it is called *lipoatrophy*. Alternatively, it can accumulate in some areas – typically, the back of the neck or shoulders, abdomen, and breasts ('lipohypertrophy'). The medicines associated with lipoatrophy of the face, arms, buttocks, and legs are rarely used these days or can be avoided. Other risk factors for lipodystrophy include:

- age (the risk increases with age)
- very low CD4 count
- gender (men tend to experience fat loss in arms and legs, and women tend to experience a gain in abdominal and breast fat)
- duration of HIV infection (meaning the longer a person has had HIV, the greater the risk)
- ageing

Along with diabetes and lipid abnormalities, lipodystrophy is also linked with cardiovascular disease.

A good balanced diet is recommended, and exercise may help to build muscle mass where fat loss has occurred, but these actions may have little effect on reversing lipodystrophy. Some people may want more aggressive medical treatment for lipodystrophy to try and reverse its effects. Cosmetic treatments (such as liposuction or surgery to remove excess fat, or skin fillers for facial lipoatrophy) might be suitable for some people.²⁹ It's best to advise the person you are caring for to talk to their health care professional about what their options may be.

²⁹ Youle, M. & Murphy, G. (2010).

Cardiovascular disease

The risks of cardiovascular disease (heart disease and stroke) increase with age. PLHIV are at higher risk. This can be due to lifestyle factors such as higher rates of smoking amongst PLHIV³¹, amphetamine use, and insufficient exercise. Cardiovascular disease can sometimes be related to HIV itself and to long-term use of some ART.

Once again, you can help the person to minimise lifestyle risk by supporting them in stopping smoking, eating healthily, and engaging in physical activity and exercise. High cholesterol and high blood pressure can be treated by the person's doctor and monitored regularly.

Information on lifestyle changes and diet for preventing cardiovascular disease is available from the Heart Foundation:

<http://www.heartfoundation.org.au>.

Individual advice from an HIV specialist dietitian is available through the Melbourne Sexual Health Centre

<http://mshc.org.au>. Other dietitians can be found through <http://daa.asn.au/for-the-public/find-an-apd/>

Local community health services also have dietitians who can provide individualised advice:

<http://www.health.vic.gov.au/pch/commhealth/directory.htm>

Bones

As people age, bones can become thinner (known as osteopaenia), and osteoporosis can develop. Osteoporosis means porous bones. Some ART can increase this risk. If women have undergone menopause, they are more likely to develop osteoporosis. Women living with HIV sometimes experience early menopause and can develop osteoporosis earlier than other women.

Vitamin D is important for bone health.

The person's doctor can check their vitamin D level with a blood test and may order a bone density test to determine the strength of their bones and their risk of fractures.

Diet, exposure to sunlight (which stimulates vitamin D production), exercise, and attention to the person's risk of falls are important. Some people may need assessment by an occupational therapist or physiotherapist to provide advice on safety at home or on mobility aids such as electric scooters, walking sticks or frames. The person's district nurses or local doctor can request further assessments if needed, in order to access additional supports or equipment.

Frailty

Older PLHIV can be at greater risk of becoming frail than older people who do not have the virus³¹. Frailty is related to muscle loss, weakness and fatigue, and sometimes a slowing of physical and mental agility.³² It can result in falls, bone fractures,³³ and reduced mobility,^{34,35} and can lead to a loss of independence.

30 Broom J., Sowden D., Williams M., Taing K., Morwood K., & McGill K. (2012).

31 Brothers, T.D., Kirkland, S., Guaraldi, G., Falutz, J., Theou, O., Johnston, B.L., & Rockwood, K. (2014). Frailty in people aging with human immunodeficiency virus (HIV) infection. *Journal of Infectious Diseases*, 210(8), 1170-1179.

32 Piggott, D., Muzaale, A.D., Mehta, S.H., Brown, T., Patel, K.V., Leng, S.X., & Kirk, G.D. (2013).

33 Yong, M.K., Elliott, J.H., Woolley, I.J., & Hoy, J.F. (2011). Low CD4 count is associated with an increased risk of fragility fracture in HIV-infected patients. *Journal of Acquired Immune Deficiency Syndromes*, 57(3), 205-209.

34 Brothers, T.D., Kirkland, S., Guaraldi, G., Falutz, J., Theou, O., Johnston, B.L., & Rockwood, K. (2014).

35 Gebo, K.A., & Schrack, J.A. (2014). The Accentuated Challenges of Aging with HIV. *Infectious Disease Special Edition*. Retrieved from http://www.idse.net/ViewArticle.aspx?d=Special%2BEdition&d_id=395&i=September+2014&i_id=1104&a_id=28270

Dylan, a 48-year-old gay man who has lived with HIV for 20 years, says:

'As I get older, I fear I'll become frail.'

Gary, another long term survivor with HIV says:

'HIV has made me see lots of hardships and I have become frail. I make sure I walk a lot and keep active to help maintain my strength.'

To maintain muscle strength, it is important to exercise. Australian guidelines recommend 30 minutes of exercise every day. To prevent muscle loss, exercise should include weight-bearing exercises or strength training twice or three times a week. Exercises that help to maintain and increase flexibility (stretching, gardening, dancing, yoga) and balance are also very important for older people.³⁷

<http://www.health.gov.au/internet/main/publishing.nsf/Content/phd-physical-choose-health>

Eating food with protein at each meal also helps maintain muscle.

Protein foods include:

- lean meat (lamb, beef, chicken, pork)
- fish (fresh, canned, frozen)
- beans and legumes (kidney beans, chickpeas, lentils, split peas, tofu)
- eggs (boiled, scrambled, poached, in a quiche)
- dairy products (milk, yoghurt, cheese)
- nuts (almonds, walnuts, brazil, cashew, pecan)
- seeds (linseeds, sunflower seeds, pumpkin seeds)

See also www.eattocheatageing.com

HIV-related issues may also have an impact on frailty.³⁷ These may include how long the person has lived with HIV, when ART was started, adherence to treatment and the actual medicines taken, low CD4 counts, high viral load, and other illnesses or infections the person has.

Brain-related problems

Memory decline is common as people age. Older people can also take longer to learn new skills. PLHIV can develop problems with thinking and concentration if they develop a condition known as HIV-associated neurocognitive disorder (HAND). About 20 per cent of older PLHIV may develop this condition. They may have difficulty managing finances, planning ahead, driving, or they may just be forgetful. HAND can respond well to early identification and treatment, and memory and thinking problems can improve.

Carers or volunteers may sometimes be the first to notice subtle changes, such as personality changes that interfere with relationships, or difficulties in handling social situations. Prompt assessment and treatment may help slow down progress of cognitive problems or prevent more advanced memory problems such as dementia. Seek advice from the person's health professional if you are concerned about such changes.

Alzheimer's Australia has developed specific resources for carers about HAND:

<https://vic.fightdementia.org.au/about-dementia-and-memory-loss/resources/dementia-and-chronic-conditions-series-toolkits>

36 Commonwealth of Australia. Department of Veterans Affairs & Department of Health and Ageing. (2008). *Choose Health Be Active: A Physical Activity Guide for Older Australians*. Retrieved from <http://www.health.gov.au/internet/main/publishing.nsf/Content/phd-physical-choose-health>

37 Piggott, D., Muzaale, A.D., Mehta, S.H., Brown, T., Patel, K.V., Leng, S.X., & Kirk, G.D. (2013).

Cancers

PLHIV have a higher risk of some types of cancers than people who do not have HIV infection. This is thought to be due to several factors, including HIV's effects on the immune system, higher rates of smoking amongst

PLHIV,³⁹ and infection with other viruses such as human papilloma virus (HPV) or hepatitis virus.⁴⁰ Some cancers can be prevented. The table below provides a summary of some of the more common cancers experienced by PLHIV.

Table 3: Cancers and HIV

TYPE OF CANCER	WHAT IS IT?	PREVENTION AND RESOURCES
Lymphoma	A cancer of the lymphatic system. The lymphatic system carries white blood cells around the body to fight infection.	ART
Cervical cancer (women) Anal cancer (women and men)	Human papilloma virus, the virus associated with warts, is known to be the main cause of cervical cancer in women. It is also a risk factor for throat and neck cancers, and anal cancer. Older men and women with HIV are at higher risk for anal cancer than people who do not have HIV. In many cases, abnormalities may clear spontaneously, especially if the person is on ART. Smoking is also a risk factor for developing these cancers.	Prevention of cervical and anal cancer is possible with regular screening. PLHIV should discuss screening for these cancers with their doctor or nurse. The HPV vaccine will help to prevent many such cancers in the future. Quitting smoking will also help prevent these cancers developing.
Kaposi's Sarcoma	A cancer of the cells that line the lymph or blood vessels under the skin or in mucous membranes. It is related to infection with human herpes virus type 8 and HIV	ART

38 Broom J., Sowden D., Williams M., Taing K., Morwood K., & McGill K. (2012).

39 Grulich, A.E., van Leeuwen, M.T., Falster, M.O., & Vajdic, C.M. (2007). Incidence of cancers in people with HIV/AIDS compared with immunosuppressed transplant recipients: a meta-analysis. *Lancet*, 370(9581), 59-67.

TYPE OF CANCER	WHAT IS IT?	PREVENTION AND RESOURCES
Lung cancer	PLHIV can be at higher risk	<p>PLHIV who smoke can reduce dramatically their risk of lung cancer by quitting smoking. If the person you are caring for smokes, you can encourage them to speak to their doctor about nicotine replacement treatments or to attend a Quit Program.</p> <p>Living Positive Victoria runs Quit Programs tailored specifically for people living with HIV.</p> <p>http://www.livingpositivevictoria.org.au/programs/quit</p> <p>See Quitline, http://www.quit.org.au or call 13 78 48.</p>
Liver cancer	Hepatitis viruses cause inflammation of the liver and over time may lead to liver damage and liver cancer. In Australia, about 6 per cent of PLHIV have hepatitis B and around 12 per cent have hepatitis C. Higher rates of liver cancer in PLHIV are mostly related to more frequent infections with hepatitis viruses (B and/or C) and alcohol use.	<p>There is a vaccine to prevent hepatitis B.</p> <p>Effective treatments are available for hepatitis B and C. People can discuss with their doctor or health professional whether the treatment for hepatitis B or C virus is an option for them.</p> <p>Some medicines can be used to treat both hepatitis B virus and HIV, and there are treatments available that can cure hepatitis C.</p> <p>If a person knows they have previously been infected with hepatitis B or C, reducing alcohol consumption is recommended.</p> <p>For useful resources on viral hepatitis, see the Hepatitis Victoria website, http://www.hepcvic.org.au/</p> <p>See also the St Vincent's Hospital publication, The Hepatitis B Story, http://www.svhm.org.au/gp/Documents/The%20Hepatitis%20B%20Story.pdf</p>

What is a disability?

Disability includes 'long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their [people's] full and effective participation in society on an equal basis with others.' (Article 1, *UN Convention on the Rights of Persons with Disabilities*)

DISABILITY AND HIV

People with HIV may have disabilities that existed before they contracted HIV or they may develop a disability afterwards. For example, the person may develop impairment as the disease progresses, or they may have long-term physical or mental, intellectual or sensory impairments. Others might experience episodic disability, as their illness fluctuates.

Some people may have been at risk of HIV because of their disability; for example, they may have had limited or no access to education about HIV due to low literacy, or hearing or vision impairment.

People with HIV and other disabilities may benefit from service models such as community rehabilitation, case management or other relevant services. Some may be eligible for services under the National Disability Insurance Scheme (NDIS). The NDIS will be a new way of providing individualised support and community linkages to people with permanent and significant disabilities, their families and carers. For further information, see:

National Disability Insurance Scheme

<http://www.ndis.gov.au/>

Australian Government website for the public, People with Disabilities section,

www.healthdirect.gov.au/search-results/Disability%20Support%20Services

World Health Organization, Disability and HIV Policy Brief, 2009

http://www.who.int/disabilities/jc1632_policy_brief_disability_en.pdf

DENTAL AND ORAL HEALTH

Taking care of the mouth and teeth is a very important, yet an often overlooked part of maintaining general health. Oral health refers to the condition of teeth, gums, mouth, tongue, and throat. Oral health can significantly affect physical and emotional wellbeing, including comfort, appearance, self-image, self-esteem, interpersonal relationships, diet, and speech, and can

further impact upon other health conditions and the body's ability to fight HIV.

People with HIV can be at risk of poor dental health due to the side effects of some medicines leading to tooth decay. Bone problems related to HIV infection as well as ART can affect dental health.

Why is it important to have a healthy mouth?

PLHIV may experience a number of changes to their oral health.

Some of the common changes include taste changes which can occur as a common side effect from some ART and other medications. These can be caused by gum infections, abscesses, or certain fungal infections.

Encourage the person to:

- rinse the mouth clean with a neutral tasting alcohol-free mouthwash (before eating may be useful). This kills bacteria responsible for bad breath, reduces plaque, and helps prevent gum disease
- thoroughly brush teeth, at least twice a day or after meals; use toothpaste or rinses that contain fluoride
- floss after meals
- drink plenty of water (2-3 litres a day) and stimulate saliva by chewing sugar free gum between meals to avoid a dry mouth
- visit the dentist regularly (at least every 6 months), where dentures or other dental prosthetics are fitted (crowns, bridges, braces), correct cleaning and maintenance is also important. Dentures that are poorly fitted can also negatively impact upon oral health, comfort and nutrition
- find a dentist who has experience of HIV and whom the person living with HIV can feel comfortable
- regularly inspect the inside of their mouth for signs of infection or sores

The publication, *HIV & Oral Health*, published by Living Positive Victoria, has more information about maintaining oral health for people living with HIV.

<https://livingpositivevic.worldsecuringsystems.com/LiteratureRetrieve.aspx?ID=63547&A=SearchResult&SearchID=57744753&ObjectID=63547&ObjectType=6>

SEXUAL HEALTH, SEXUALITY AND GENDER ISSUES

People living with HIV may identify as gay, lesbian, straight (heterosexual), bisexual, pansexual, asexual, transgender or intersex (see the Glossary on page viii). In Australia, the HIV epidemic has mostly affected gay men, and this is the largest group of people with HIV who is now ageing. However, there is great sexual and gender diversity amongst PLHIV.

If people disclose their sexuality or gender identity to carers or staff, it best to ask them how they prefer to be referred to. For example, a transgender person may wish to be referred to as 'she' or 'he', depending on their gender identity; an intersex person may prefer a gender neutral term if they do not identify as male or female.

See: <http://www.genderqueer.org.au/basics-pronouns/>

Health workers and care workers sometimes undervalue the importance of sexuality and the level of, and desire for, sexual activity among older adults, let alone those living with HIV. They may have personal beliefs or attitudes that are non-accepting of diverse sexualities or they may simply not be aware of issues faced by transgender and intersex people.⁴¹ Some older people of diverse sexualities feel they cannot be open or speak about their sexuality or partners within aged care services:

'I couldn't tell the staff I'm gay.'

*'I keep my mouth shut. I have to be careful what I say. I have no conversation. I can't talk to the staff in here'*⁴²

Sexually active older adults with HIV can be at risk of other sexually transmissible infections and can experience sexual dysfunction. People will share their concerns only if they feel comfortable to do so. Open and non-judgmental attitudes are the key to developing therapeutic relationships with older people living with HIV.⁴³

Sexual dysfunction can be a side effect of medicines, particularly antidepressants. It can be associated with past medical history, surgery, or with other social or emotional factors, such as past history of sexual abuse or stigma. There are many forms of treatments and support available for sexual dysfunction for people of all genders and sexual orientations.⁴⁴

Positive sexual health – meaning not just the absence of disease or dysfunction, but a positive and respectful approach to sexuality and relationships – is important to people's quality of life⁴⁵. It helps protect against stressors that come from living with a chronic illness⁴⁶. Affirmation and positive recognition of a person's sexual orientation and/or gender identity can help promote good sexual health⁴⁷. Carers, care workers, and health workers can support PLHIV of diverse sexualities and gender identities by keeping an open mind and being aware of resources that might be useful to the person.

40 Peate, I. (2013).

41 Barrett, C., Harrison, J., & Kent, J. (2009). *Permission to Speak: determining strategies towards the development of gay, lesbian, bisexual, transgender and intersex friendly aged care services in Victoria*. Melbourne: Matrix Guild Victoria, Inc., and Vintage Men Inc. 45.

42 Peate, I. (2013).

43 World Health Organisation. Special Programme of Research, Development and Research Training in Human Reproduction. (2006). *Defining sexual health: report of a technical consultation on sexual health, 28-31 January 2002, Geneva*. Retrieved from http://www.who.int/reproductivehealth/publications/sexual_health/defining_sexual_health.pdf

44 *ibid*.

45 HIVAge.org. (2014). *Sexual Health in HIV and Aging*. Retrieved from <http://hiv-age.org/2014/07/16/sexual-health-hiv-aging/>

46 Peate, I. (2013).

Tools are available that can assist organisations and services in addressing sexuality issues for older people, including training and support needs of staff and care workers. See, for example:

<http://www.agedcare.org.au/publications/agendas-docs-images/sexuality-assessment-tool-sexat-for-residential-aged-care-facilities>

<http://lgbtihealth.org.au/lgbti/>

In the healthcare setting, the same policies, procedures and practices should be applied to same-sex couples wanting to live together as for heterosexual couples. Older LGBTI couples need private time and to show affection for one another, as do heterosexual couples.

“A person’s rights do not diminish with age, nor are they lesser for people of diverse sexual orientation, gender identity or those living with HIV.”

Pre-exposure prophylaxis or ‘PrEP’ is a daily dose of antiretroviral medicine that can be taken by a person who does not have HIV before sexual activity to prevent them from contracting HIV.

USEFUL CONTACTS:

Val’s Café (a Melbourne group established in 2009, as part of a La Trobe University-based project to improve the health and wellbeing of older LGBTIQ people) <http://www.valscafe.org.au> has links to a wide range of resources for older people of diverse sexualities and gender identities.

Melbourne Sexual Health Centre <http://www.mshc.org.au>

Transgender Victoria <http://www.transgendervictoria.com>

International Intersex Organization <http://oiiinternational.com/>

Hon. Susan Ryan, Age Discrimination Commissioner, in a speech to an HIV and Aged Care Forum, Melbourne, 27 March 2014

In coming years, the availability of better treatments and pre-exposure prophylaxis may have an impact on sexual confidence and sexual activity of older people with HIV.⁴⁹

PLANNING IN ADVANCE

Planning for the future is important for everyone. This includes thinking about where and how a person will live and what supports they need, financial planning, writing a will, organising powers of attorney and advance care planning. You can encourage the person you are caring for to plan ahead by talking about some of these matters.

Some people like to know that there is someone appointed who will make decisions on their behalf should they become unable to make decisions for themselves. Both you and the person you are caring for have a right to be involved in care planning at all stages of the journey and to have your wishes heard and respected.

Policy and legal assistance organisations and social workers can help with these matters (see **12. Advance Care Planning, Enduring Powers of Attorney, and Wills and Estates** on page 74 for further information.)⁴⁷

All stages of the HIV and ageing journey have their own challenges for PLHIV and their carers. Your caring role will change as the person ages or if they lose some of their capacity to manage their condition and activities of daily living. Some changes may be sudden and unexpected, others may be gradual or anticipated. Wherever possible, it is important to consider and plan for the impact of potential changes on your life and your capacity to continue in your caring role.

For family and friends in caring roles, discussions about changing care needs can be confronting and difficult to start, especially if the person isn’t ready or if there is conflict between their needs and wishes and the opinions of family or others involved in care. As a carer, you may require help to support the person you care for to think through their goals, wants and needs, support requirements, and living options at different times.

Think about who you may be able to get support from and how to have these hard conversations while maintaining a positive relationship with the person you are caring for. Good communication will also help you build positive relationships with workers and services. These skills are just as important to develop as the practical, ‘hands-on’ skills. The time line below provides some ideas about issues you may need to discuss at different stages. Note that the person may move back and forth through the stages and stages may be repeated as their condition changes or progresses.

Discussions about advance care planning, powers of attorney, wills and end of life preferences are best had with the PLHIV and their ‘care team’ at the earliest stage possible and may need to recur throughout this journey as changes occur.

Table 4: A ‘planning in advance’ timeline

SYMPTOMS	DIAGNOSIS	CARE PLANNING	CHANGES IN CONDITION (e.g. decreased/ lost capacity)	TRANSITION TO NEW CARE OPTIONS (e.g. increased dependence, respite)	END OF LIFE	DEATH & DYING	BEREAVEMENT
<ul style="list-style-type: none"> Recognise signs that things are not right Ask a health professional (community nurse, GP) for advice Get a medical review 	<ul style="list-style-type: none"> Identify questions you need answered Seek more information about HIV & its effects Discuss treatment options Acknowledge feelings and fears Seek counselling if required 	<p><i>These stages may be repeated several times as the condition progresses</i></p> <ul style="list-style-type: none"> Make decisions about treatments and care needs Identify formal and informal supports ('care team') Discuss goals for future (short, medium and long-term) Advocate for PLHIV and your needs Agree to review care plan regularly 	<ul style="list-style-type: none"> Recognise changes Ask a health professional (community nurse, GP) for advice Get a medical review Review care plan, including increased carer support needs Acknowledge feelings and fears Seek counselling if required 	<ul style="list-style-type: none"> Establish good relationships with extended care team /new services Clearly explain what your needs and wishes are Get support to make the transition easier & overcome reluctance to ask for help (in PLHIV and/or carers) Ensure additional carer supports are in place Acknowledge feelings and fears Seek counselling if required 	<ul style="list-style-type: none"> Discuss palliative care options Acknowledge difficult decisions and respect PLHIV's wishes Consider where person wants to be cared for and capacity of 'care team' Establish good relationships with extended care team /new services Negotiate new care supports/changes to carers' role Acknowledge feelings around loss and grief Seek counselling if required 	<ul style="list-style-type: none"> Consider how the person wishes to die and what happens after death Seek professional help with arrangements Get support to address potential concerns (e.g. family conflict, cultural needs, fear of dying, etc) Recognise carer loss and grief impacts Seek counselling if required 	<ul style="list-style-type: none"> Recognise ongoing carer loss and grief impacts Get help to manage financial/legal matters Plan for and get support for transition to 'post-caring' life Seek counselling if required

As can be seen by this timeline, there is a range of planning activities carers can consider with PLHIV while they still have cognitive capacity (that is, they are still mentally capable of making independent decisions), to improve their current and future quality of life. This is important for managing stressful events and challenges in the

present and will help you recognise and seek support for your own changing needs, as well as supporting the person living with HIV into the future (see **7. Just for carers – taking care of yourself**).

5 HIV TREATMENTS

This section provides basic information about current HIV treatments to help carers and care workers support people living with HIV to take their treatment correctly and remain well. To understand how the treatment works, it is helpful to remember how HIV grows in the body – see **2. About HIV and AIDS** for more information.

THE HIV LIFECYCLE

The HIV lifecycle, during which the virus makes copies of itself (known as replication), involves several steps. HIV enters the human CD4 cell (or T-cell) and starts using it to make copies of itself. The new viruses then leave the cell and infect other CD4 cells. This ultimately destroys the CD4 cells and damages the immune system over time.

For a fact-sheet on how HIV replicates, see <http://aidsinfo.nih.gov/education-materials/fact-sheets/19/73/the-hiv-life-cycle/> (US Department of Health and Human Services AIDSinfo website).

WHAT IS ANTIRETROVIRAL THERAPY?

Antiretroviral therapy (ART) drugs are different classes of medicines that directly attack HIV. They are used to achieve a sustained reduction in the viral load. Different classes of ART attack the virus at different stages of its lifecycle to slow down viral replication. This allows the immune system to start recovering.

With successful treatment, the CD4 cell count increases and the viral load decreases, ideally to an undetectable level. Undetectable means a level that cannot be detected with current blood tests. If a person has an undetectable viral load, we now know that it is extremely unlikely that they will pass on the infection to another person,⁴⁹ though it is still theoretically possible.

What is combination antiretroviral therapy?

Antiretroviral medicines to work most effectively when three or four drugs from different classes are taken in combination – known as combination antiretroviral therapy (cART) or more simply, ART. Taking combination antiretroviral therapy helps prevent the virus becoming resistant to the medicines. ART is not a cure.

Who prescribes antiretroviral therapy?

General practitioners who have done a specific course are qualified to prescribe ART, as the medicines belong to a group of highly specialised drugs (referred to as S100 drugs). Infectious disease specialist doctors (usually hospital-based) also prescribe them. In Australia, the medical practitioners who can prescribe ART are referred to as S100 prescribers. Registered nurses who have done specific training can prescribe ART in some circumstances (such as PEP).

How are antiretroviral medicines taken?

ART mainly come in tablet form or as capsules. Some are available in liquid or syrup form or as injections. As for all medicines, it is very important to take ART as instructed by a doctor, pharmacist, or registered nurse. There may be special instructions such as ‘to be taken with food’ or ‘take on an empty stomach.’ Following these instructions enables the medicines to work most effectively. HIV is very adaptable if given the opportunity – it can develop resistance to the medicine if it is not taken correctly. See, **Resistance to antiretroviral medicines** on page 29. Taking ART correctly is referred to as *adherence*.

Viral load is the term used for the amount of HIV circulating in the blood stream. It is measured in the number of copies of HIV per millilitre of blood

48 Rodger, A., Bruun, T., Cambiano, V., Vernazza, P., Estrada, V., Van Lunzen, J., Collins, S., Geretti, A.M., Phillips, A., & Lundgren, J. (2014). *HIV transmission risk through condomless sex if HIV+ partner on suppressive ART: PARTNER Study*. Abstract 153LB. Paper presented at 21st Conference on Retroviruses and Opportunistic Infections, Boston, 3-6 March 2014.

Adhering to the therapy

ART is currently a life-long commitment and needs to be taken as prescribed, usually once to twice a day. Some medicines are better taken with food and there can be some restrictions (for example, not to be taken at the same time as other medicine). If the person is not able to self-manage their medicines – for example, due to memory problems – carers or care workers may assist by reminding them or prompting them. Therefore, carers and care workers need to understand the requirements for each medicine and follow the advice of health professionals. District or community nurses can come to the person's home and provide education, support, and practical assistance with adherence strategies if necessary.

Good adherence to ART means taking it as the doctor has prescribed. If people skip doses of medicine, HIV has the opportunity to mutate, or change, and become resistant to medicines, making them ineffective. Research has shown that PLHIV need to take their medicine at least 95 per cent of the time for it to remain effective. This is equal to missing only one dose per month of a daily medicine. Carers can assist by encouraging and supporting the person to take their medicine correctly.

'My adherence went through the window when I was fed up with all the pills and the cost. When my GP phoned me and gave me a kick in the arse, I improved my adherence' **James**, 51-year-old man, long term survivor

Resistance to antiretroviral medicines

Just like antibiotic resistance, if a person misses doses, stops taking the medicines, or has frequent breaks in their treatment, the virus can become resistant to the ART, meaning ART loses its effectiveness. This may mean that the doctor needs to change their drug combination to a different one. If this happens many times, they may have no drug options left that work for them and may become unwell.

Side-effects

People often experience side-effects of medicines when they first start taking them. For example, nausea, diarrhoea and difficulty sleeping may occur. These usually settle down after a few weeks.

If you notice a change in a person's behaviour or wellbeing, for example, if they develop a rash, start vomiting, lose their appetite, or complain of diarrhoea, especially after starting new medicines, report this to a health professional as these problems may be medication-related. Practical suggestions for managing side-effects are included in this section and in **6. Care and support in the community**.

Long-term effects of antiretroviral therapy

Some of the long-term effects of ART that can occur in PLHIV were discussed in **4. Living longer and ageing with HIV**. These include metabolic problems such as body fat changes and type 2 diabetes.^{49,50}

MANAGING MEDICINE

Most people with HIV now only require a few medicines to remain well, and prefer to maintain independence by taking responsibility for their own medicines. Those who have lived longer with HIV may have other conditions (see **4. Living longer and ageing with HIV** on page 17) and may take a range of different medicines. There are often specific instructions with these medicines.

Medication may become more difficult to manage if the person has mental health or memory problems. Suggestions to help the person manage complex treatments include:

49 Broom J., Sowden D., Williams M., Taing K., Morwood K., & McGill K. (2012).

50 Youle, M. & Murphy, G. (2010).

- using cues to prompt taking medicine, such as linking it with usual times for brushing teeth or with meal times
- leaving medicines in a visible place as a reminder
- medicine timers, alarms on smartphones or watches, or a diary to prompt, especially if away from home or regular routine
- a medicine dispenser, medicine pack ('blister pack') or dosette box (a box that contains a week's supply of medicine set out in compartments for the appropriate times)

Polypharmacy and ageing

As people age their risk of drug-drug interactions and toxicities can increase. If they are taking several medicines (polypharmacy) this risk can be even greater. Some medicines need dose adjustments if the person has kidney or liver disease.

RDNS or other local community nursing services (in rural or regional areas) can assist with medicine management. Medicine packs may be prepared by a pharmacy to be administered by staff or carers (for example, in a residential facility or in the home).

Your role may include encouraging or prompting the person to take the medicine they are prescribed. Ultimately, the person you are caring for must decide if he or she wishes to take their medicine. Supportive approaches work best. Positive reinforcement of adherence and practical help with organising prescriptions and collecting medicines can promote confidence and independence.

'I would not be able to get to the doctor and other health appointments, and to get my medication, without the volunteers from VAC... I'd get much sicker than I am'

David, 55-year-old HIV positive man.

What medicines might a person with HIV be taking besides antiretroviral therapy?

People living with HIV may be prescribed a range of other medicines for:

- controlling symptoms or conditions including diarrhoea, nausea or pain
- treating high blood pressure
- treating high cholesterol levels
- treatment of depression or anxiety
- prevention or treatment of opportunistic infections (such as antibiotics, anti-fungal or other anti-viral medicine)

Quality use of medicines and safety with medicines

As for all medicine management, the following should be considered:

- Ask the general practitioner or pharmacist for a current list of the person's medicines which they can refer to when needed.
- Ensure any doctor prescribing medicines is aware of what medicines or other drugs (including recreational drugs) the person you are caring for is already taking. Keep an up-to-date list of all medicines and the doses and times taken, including herbal or other complementary therapies. Some medicines may react with other medicines. For example, recreational drugs such as ecstasy and methamphetamines, and the opioid substitution drug methadone can interact with ART. Herbal supplements such as St John's Wort, can react with some ART. Check with the person's doctor or pharmacist first before using over-the-counter or complementary medicines
- Encourage the person to have a system of reminders about what to take and when.
- Ideally medicines should stay in their original packaging.

- Dosage administration aids (DAA, including dosette boxes and blister packs) can be useful systems for some people. The person may be on several medicines and it can be hard to remember what was taken. A properly labelled DAA can serve as a reminder of what they have taken and when.
- Keep medicines in a safe place, away from children or inappropriate use, stored correctly. Follow special instructions for storage of medicines such as in a dark, cool cupboard or in the fridge.
- If the person forgets to take a medicine or makes a mistake, contact their pharmacist or registered nurse to ask what to do. Medicines can be dangerous if taken incorrectly. Follow directions given by health professionals.
- Ensure the correct medicine is being taken. All medicines have a pharmaceutical name and a brand name. There may be multiple brands of the same medicine. Check with the person's doctor, pharmacist or nurse if unsure.
- Know how often medicine needs to be taken. For example, some medicines only need to be taken when there is a symptom, such as diarrhoea or nausea.
- Know how the drug should be taken, for example, swallowing, or applying to skin.
- Follow any specific instructions, such as taking medicines with meals or on an empty stomach.
- Understand what effects a drug may have. All medicines have possible side-effects. Most are minor, but some medicines have specific effects to look for, and if noted, to report to a doctor, as they may be serious (such as a rash).
- Check the expiry dates on the medicine's packaging and return to a pharmacy for disposal if out of date.⁵²

POST-EXPOSURE PROPHYLAXIS

Post-exposure prophylaxis (PEP) was discussed in **3. Hygiene and Safety** in relation to occupational exposures to HIV on page 11. PEP is also available if people have engaged in behaviour involving significant HIV transmission risk, such as sharing needles with an HIV-positive person. This is referred to as *non-occupational post exposure prophylaxis* (NPEP).

NPEP is a 28 day course of antiretroviral medicine begun within 72 hours of exposure to HIV with the aim of reducing the risk of HIV transmission. NPEP is taken primarily for sexual and injecting drug use exposure and is reserved for cases where the HIV risk is assessed as being significant by a health professional. Information is available via the Victorian NPEP Service.

<http://www.alfred.org.au/npep/> or www.getpep.info
or 1800 889 887

WHAT ABOUT A VACCINE FOR HIV?

There is no vaccine that prevents HIV, though research is underway.

See <http://www.niaid.nih.gov/topics/hivaids/research/vaccines/Pages/default.aspx> for the latest updates on HIV vaccine research.

There are multiple clinical trials underway testing various possible vaccines and prevention methods. Details about the trials can be found by searching for 'HIV vaccine' here:

<https://clinicaltrials.gov/>

51 Commonwealth of Australia. Department of Health. Australian Pharmaceutical Advisory Council. (2006). Guiding principles for medication management in the community. Retrieved from <http://www.health.gov.au/internet/main/publishing.nsf/Content/apac-publications-guiding>

6 CARE AND SUPPORT IN THE COMMUNITY

A wide range of people provide care and support to people living with HIV (PLHIV). As mentioned throughout this handbook, they may include family and friends, neighbours, paid workers in aged care settings, volunteers, community visitors, local council workers or health workers, including district and community nurses.

This section provides practical advice, suggestions and links to resources that should prove useful for all who provide care and support. Key to this care are the concepts of a team approach to care, person and

family-centred care and diversity-inclusive practice. Recommendations for further reading are included at the end of the handbook.

WHAT IS PERSON AND FAMILY CENTRED CARE?

Person and family-centred care means that care and support are organised around the person and their chosen carer(s), rather than the person being expected to fit into existing services. For the person living with HIV, 'family' may mean family of birth, their partner and friends, or whomever they choose.

What are the principles of person centred care?

- Getting to know the person: Get to know the person beyond the diagnosis and build relationships with them and their carers.
- Sharing power and responsibility: Respecting preferences and treating people as partners in setting goals, planning care and making decisions about care, treatment or outcomes.
- Accessibility and flexibility: Meeting people's individual needs by being sensitive to values, preferences and expressed needs. Giving them choices by providing timely, complete and accurate information they can understand, so they can make choices about their care.
- Coordination and integration: Working as a team to minimise duplication and provide each person with a key contact at the health service. Teamwork allows services providers to maximise people's health outcomes and provide positive experiences.
- Environments: physical and organisational or cultural environments are important, enabling staff and carers to be person-centred in the way they work.

Source: Victorian Department of Health <https://www2.health.vic.gov.au/primary-and-community-health/community-health>

For further information for health workers on implementing person centred care in your practice, go to <http://www.health.vic.gov.au/older/toolkit/02PersonCentredPractice/docs/Guide%20to%20implentating%20Person%20centred%20practice.pdf>

See also the Australian Institute for Patient and Family Centred Care: <http://www.aipfcc.org.au/>

Inclusive care

People living with HIV come from a wide range of communities, including the LGBTI community, and from all cultural and religious backgrounds. Older LGBTI people have sometimes raised concerns about how they may be treated within aged care services.

A person and family-centred approach includes understanding and consideration of sexual, gender and relationship diversity.

One way for services to promote inclusive care for people of diverse sexualities and gender identities is through accreditation on standards of LGBTI-inclusiveness, e.g. through the Rainbow Tick process.

The Rainbow Tick

The Rainbow Tick is a process to accredit services that can demonstrate that they are able to meet the needs of LGBTI clients.

It is a collaboration between Gay and Lesbian Health Victoria and the Quality Improvement Council (QIC). The aim is to improve the health and wellbeing of LGBTI people by establishing a formal process for implementing and

accrediting standards related to the capacity of services to meet the needs of LGBTI people. Service providers including Stonnington Council, City of Port Phillip, Melbourne City Mission and Mitchell Community Health Services have undertaken an accreditation (training and workshops) to receive a Rainbow Tick, indicating that they are LGBTI aware and provide access for potential clients to their respective services.

Achieving a Rainbow Tick

The Rainbow Tick consists of six standards against which services can be formally accredited to demonstrate LGBTI-inclusive practice and service delivery. Services can include the six standards as part of their cycle of service accreditation or can apply to do the Rainbow Tick as a stand-alone assessment, subject to ongoing reassessment and quality review.

The Rainbow Tick is a world first and was developed by Gay and Lesbian Health Victoria (GLHV) in consultation with the Quality Innovation Performance (QIP) organisation.

Services are assessed against six standards:

1. organisational capability
2. consumer consultation
3. LGBTI cultural safety
4. disclosure and documentation
5. professional development
6. access and intake

Services that receive the Rainbow Tick have the opportunity to be listed in a national register of LGBTI accredited organisations.

See <http://www.glhv.org.au/lgbti-inclusive-practice>

There is a practical guide to LGBTI-inclusive practice published by the Victorian Department of Health.

It can be downloaded from the GLHV website, http://www.glhv.org.au/files/WellProud_updated2011.pdf.

AT-HOME CARE

Caring for a person at home usually involves a team approach. Team members may vary depending on the needs and wishes of the person living with HIV and those close to them. The care team may include:

- family/friends/partner
- district or community nurses
- general and specialist medical practitioners
- other health professionals such as a case manager, social workers, occupational therapists, dietitians, pharmacists, physiotherapists
- volunteers such as those from the Victorian AIDS Council
- local council workers, for example home help and Meals-on-Wheels
- community visitors
- complementary therapists
- spiritual supporters, pastoral care workers
- multicultural services
- palliative care services

Supporting someone at home or in the community can be rewarding. However, it is not uncommon for challenging issues to arise. This section provides practical information about important aspects of supporting and caring for a person living with HIV. While there are some issues relevant for most people, it is important to recognise that each person (and each carer) may need specific advice and support.

HEALTHY MEALS AND EATING

Good food is important for health and well-being, and to support and strengthen the immune system. A nutritious diet helps prevent heart disease, diabetes and cancers, so, for PLHIV who are getting older and can be at higher risk of these problems, it is especially important.

Healthy weight

For some people who have lived with HIV for many years, increasing or maintaining weight can be challenging. HIV can affect the lining of the intestine, making it difficult to absorb nutrients. People with other co-infections such as hepatitis C, which attacks the liver, can have additional problems because the liver plays a key role in processing foods and medicines.

Older people have unique nutritional needs and there is often poor awareness of the risk of malnutrition in older age groups and of the importance of nutrition in maintaining strength, mobility and independence.⁵²

For those experiencing unexpected weight loss, a medical review is advisable, because weight loss can often be prevented or treated. A health professional can arrange a referral to an accredited practising dietitian who can make an assessment and provide individualised advice. Some naturopaths also specialise in nutrition. Simple changes to eating habits can also help.

'My health has improved because I have committed to eating lunch regularly.'

Bill, 35-year-old man

'Having eggs is terrific for me. I can always cook an egg if I am too tired.'

Fiona, 57-year-old woman

'Nutritious food always boosts my energy and, personally, I need extra protein in the diet. A good multi-vitamin helps and simple things like the sun and the beach, trees. Soaking up nature always invigorates me.' **David**, 47-year-old man

⁵² Hobbins, N. (2014). *Eat to Cheat Ageing*. Northbridge, NSW: Citrus Press.

Carers are often involved in meal preparation. Ask the person you are caring for what they would like to eat. Regular meals with simple but nutritious ingredients can be helpful.

Poor appetite can be a problem for some PLHIV. It is important to seek advice early, as problems are easier to manage at that stage. There are some things you can do to help the person's appetite:

- Try sharing meals with others, as eating is a social occasion
- Suggest grazing or eating small meals throughout the day; try to have lots of snacks available as large meals can be overwhelming
- Serve meals on small plates
- Eat outside in the fresh air

Altered taste or difficulty eating can occur due to dental or gum problems. Seek medical advice for chewing or swallowing difficulties. For those experiencing difficulties:

- Good mouth care and regular dental care reduces the risk of problems that may affect eating (see also **Dental and oral health** on page 24)
- Use a straw for drinking
- Avoid hot or spicy foods
- Some people use complementary therapies, or marijuana to stimulate appetite (although marijuana use is illegal in Australia)
- A limited amount of alcohol such as a small glass of wine or nip of spirits can stimulate the appetite. Large amounts of alcohol can be harmful to health
- Ensure good management of pain and nausea. Encourage the person to talk to their doctor (see **Pain management** on page 37 for more details)

- Eat additional high-energy foods or take nutritional supplements. It is best to seek advice from an accredited practising dietitian who can advise on the most appropriate supplements
- People with HIV and chronic hepatitis C or B can be at greater risk of poor health through high rates of insulin resistance and metabolic syndrome. They have an even greater need to have a healthy diet, undertake regular exercise and to avoid alcohol⁵³

Some PLHIV, on the other hand, are now finding that they are gaining too much weight or have changing body shapes due to lipodystrophy. If you are caring for someone with lipodystrophy, with a buildup of body fat in some areas and loss of fat in others, unplanned weight gain, and high levels of sugar and fats in the blood, you can encourage them to talk to a health professional for specific nutritional advice. See **4. Living longer and ageing with HIV** for more details about these conditions.

Implications for carers

Being responsible for another person's nutritional needs can be daunting. You may need support to plan and prepare meals if the person becomes less able to do this for themselves. If you have been caring for the person for a long time, you may feel frustrated trying to encourage healthy and adequate eating. You may be worried that you are not providing enough nutrition. Ask a dietitian for advice and plan to share the care of providing meals with others – for example, roster family and friends to cook and shop, contact Meals on Wheels through your local council, or other community service.

FURTHER INFORMATION ON NUTRITION IS AVAILABLE FROM:

Australian Dietary Guidelines

<http://www.eatforhealth.gov.au/>

Improving appetite Department of Human Services Tasmania

http://www.dhhs.tas.gov.au/publichealth/community_nutrition/health_and_community_workers/older_people/material_for_older_people/appetite_for_life/nourishing_food_ideas2/improving_appetite

FOR INFORMATION ON ALCOHOL USE, SEE:

Australian Alcohol Guidelines

<http://www.nhmrc.gov.au/health-topics/alcohol-guidelines>



⁵³ Purnomo, L. (2010). *HIV/HCV Coinfection and Nutrition*. *HIV Australia*, 8(1), 36-39.

SUPPORTIVE CARE AND SYMPTOM MANAGEMENT

Some PLHIV experience nausea, fatigue, diarrhoea, pain and/or other symptoms at different times. It can be distressing to see the person you are caring for in discomfort. However, most symptoms can be controlled with correct advice and management.⁵⁵ Seek assistance from health professionals because untreated symptoms affect the quality of life of the person you are caring for and, indeed, your own quality of life.

Nausea and vomiting

Nausea and vomiting are sometimes experienced by people living with HIV. They may be due to infection, a side-effect of medicine or other causes. As with all symptoms, assessment by a health professional is usually needed and the underlying causes should be addressed if possible.

If the person you are caring for has nausea, you can help by:

- encouraging them to eat and drink when they are hungry
- being flexible about meal times
- minimising the effect of cooking aromas that may trigger nausea by opening windows, using an exhaust fan or preparing meals that don't require cooking or don't have strong odours
- avoiding fatty foods or others that may trigger nausea
- providing small, frequent meals rather than large serves
- encouraging regular brushing of teeth and/or mouthwashes to keep a fresh mouth and improve taste
- encouraging them to walk around after meals to assist digestion.⁵⁶

If nausea and vomiting are an ongoing problem, it is advisable for the person you are caring for to see their health professional. Nausea and vomiting can lead to weight loss, malnourishment, dehydration and even depression.

Some people may take anti-nausea medicine ('anti-emetics') regularly or occasionally. Others prefer complementary therapies to control nausea and stimulate appetite. Some people choose to use marijuana to manage nausea (although marijuana use is illegal in Victoria).

Travel sickness

If the person you are caring for is prone to nausea or vomiting while travelling, you can prepare by:

- arranging for them to sit in the front seat of the vehicle
- opening the window
- speaking to a health professional about preventative measures such as medicines or complementary therapies

If travelling, it is a good idea to carry some equipment in case the person vomits, such as:

- a container with a lid such as an ice-cream container
- disposable gloves
- a small towel
- a small bottle of water and soap or hand wipes
- a plastic bag to place the ice cream container in after use

54 University of California. School of Nursing. (2004). *Symptom Management Manual: Strategies for People Living with HIV/AIDS*. San Francisco: University of California.

55 *ibid.*

Pain management

Not everyone with HIV will experience pain, but for those who do, the impact on their quality of life can be severe. PLHIV have sometimes endured pain such as peripheral neuropathy for many years. It can be stressful to see the person you are caring for in pain. It is important to seek professional advice, as effective pain relief is usually possible.

Pain may have many different causes, so it needs to be assessed and managed on an individual basis. Sometimes a combination of strategies is used. Pain management may involve a range of health service providers, such as specialist pain clinics, nurses, doctors, physiotherapists, occupational therapists and complementary therapists.

Approaches to pain management include:

- taking medicines such as pain relievers ('analgesics') to treat specific types of pain
- taking medicine regularly as prescribed (such as 4-hourly or 12-hourly)
- modifying activities that cause or intensify pain
- using equipment or aids to increase comfort such as pressure-relieving cushions or mattresses
- using complementary therapies such as massage, relaxation techniques, acupuncture, hypnosis and music therapy
- encouraging social contact and reducing isolation
- referral to a counsellor and/or pastoral or spiritual care worker if the person has emotional pain or distress (see the Resources section under mental health)

Opiates (such as morphine or codeine) can be effective pain relievers for some types of severe pain such as that caused by peripheral neuropathy or bone pain. Sometimes carers and clients can be fearful when opiates are prescribed – they sometimes worry about possible addiction or side effects. Addiction to opiates is not common when used appropriately for pain⁵⁶ and is unlikely to occur if medicines are managed in consultation with a health professional. Most side-effects can be managed well. Discuss any concerns about opiates or other medicines with a health professional.

Diarrhoea

Diarrhoea has a number of possible causes such as infection, anxiety, medication, or nutritional problems. As with all symptoms, the cause should be investigated first by a health professional. Diarrhoea can interfere with a person's ability to carry out their usual activities.

Untreated HIV itself can cause diarrhoea and once the person starts ART, it usually stops after a week or two. If diarrhoea is chronic, due to other illnesses for example, it can have a serious impact on weight maintenance, self-esteem and confidence.

Strategies to prevent or manage diarrhoea include:

- adjusting the diet or taking supplements such as soluble fibre (seek further specific advice from health professionals)
- avoiding or reducing fried foods, alcohol and caffeine as they may worsen diarrhoea
- anti-diarrhoeal medicine (often most effective if taken regularly, depending on the frequency and severity of the diarrhoea; seek specific advice)

⁵⁶ Edlund, M.J., Steffick, D., Hudson, T., Harris, K.M., & Sullivan, M. (2007). Risk factors for clinically recognized opioid abuse and dependence among veterans using opioids for chronic non-cancer pain. *Pain*, 129(3), 355-362.

- planning for outings (for example, knowing where toilets are and having an incontinence pad and/or clean clothes available)

There are many ways to increase the comfort of the person you are caring for, such as using:

- continence aids, a mattress protector, and other protective linen. The person's district nurse or other health professional can provide advice on appropriate items and where they can be obtained
- aids such as a commode chair, which can make life easier if getting to the toilet in time is a problem, especially at night

Sometimes diarrhoea can cause painful skin irritation. It is best for the person you are caring for to have this checked by their health professional because irritation can also be caused by infection or other conditions that may require treatment. Ease skin irritation by using:

- a barrier lotion on the area, such as zinc and castor oil cream. This helps to protect the skin
- extra soft toilet paper or baby wipes
- a plastic squeeze bottle or a jug of warm water when the person is on the toilet and gently patting the area dry

If a person requires continence aids such as washable or disposable pads on a long-term or permanent basis, government funding may be available to pay for them through the Continence Aids Payment Scheme.

The person's district nurse or general practitioner can help organise this.

See: <http://www.humanservices.gov.au/customer/services/medicare/continence-aids-payment-scheme> for details about the scheme.

Fatigue

Fatigue is a feeling of severe tiredness and lack of energy. It is commonly experienced by people with HIV, even those with viral suppression and good immune function who are taking ART.^{57,58} It can have many causes, for example:

- HIV itself causes fatigue, and high HIV viral load is associated with fatigue. Starting ART can often improve people's energy
- Some ART cause sleep disturbances. This usually settles down a few weeks after starting treatment. If it persists, the person should discuss their treatment with their doctor, as other options may be available.
- Other drugs such as antidepressants, pain medicines or cholesterol-lowering medicine can contribute to fatigue.
- Inadequate diet, resulting in low levels of some vitamins and minerals. It may help the person to see their doctor for a blood test to check for low levels of red blood cells (anaemia), or vitamin and/or iron deficiencies. It is also important for a dietitian to review the diet and give advice about nutrition and suitable supplements.
- People who have difficulty sleeping, due to stress, anxiety, sleep apnoea or other issues, often experience day-time fatigue.
- Other medical causes, e.g. low testosterone or underactive thyroid, can be a cause.
- Long-term HIV can contribute to fatigue.

57 Jong, E., Oudhoff, L.A., Epskamp, C., Wagener, M., van Duijn, M., Fischer, S., & van Gorp, E.C.M. (2010). Predictors and treatment strategies of HIV-related fatigue in the combined antiretroviral therapy era. *AIDS*, 24(10), 1387-1405.

58 Payne, B.A.I., Hateley, C.L., Ong, E.L.C., Premchand, N., Schmid, M.L., Schwab, U., Newton, J.L., & Price, D.A. (2013). HIV-associated fatigue in the era of highly active antiretroviral therapy. *HIV Medicine*, 14(4), 247-251.

Managing fatigue

There are many things that you and the person affected can do to help manage their fatigue. First, encourage the person to discuss their fatigue with their health professional. Some useful ways to manage or reduce fatigue include:

- Report medication side-effects to a doctor or nurse and ask for specific advice
- Breaking large tasks down into smaller components
- Limiting sugary foods, fast foods, and high fat foods
- Reducing intake of caffeine, alcohol, and other drugs
- Eating whole grain foods, fruit, and raw vegetables⁶⁰

Tips for better sleep and managing insomnia

Support the person to:

- establish a routine to balance work, relaxation, exercise, sleep and socialising
- develop a regular wake and sleep pattern
- avoid napping during the day
- avoid stimulants before bedtime, e.g. alcohol, nicotine, or caffeine,
- avoid large meals close to bedtime
- undertake vigorous exercise early in the day rather than later
- consider relaxing exercise, e.g. yoga, before bed to help promote restful sleep
- get adequate exposure to natural light during the day and keep their bedroom dark enough at night
- consider complementary therapies (see those listed in Complementary therapies in the next section)

For other helpful suggestions, see the Victorian Government Better Health Channel website page on sleep hygiene: http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Sleep_hygiene

'Fatigue has been a fact of life for me, living with HIV. It usually hits in the mid-late afternoon and I'll need to lie down for an hour. It's often an emotional/psychological thing too. I'm emotionally raw and mentally fragile when I'm physically fatigued. Sometimes I find gritting my teeth and pushing through works.'

James, 39-year-old man

'Hitting the gym can boost my energy and clear my head, even if I start out feeling depleted.' **Barry**, 42-year-old man

'Practices like yoga and meditation are beneficial for me when I am fatigued.'
Max, 52-year-old man

'Getting a good night's sleep is very important. Fatigue is often present when I haven't had enough sleep. Then I need to give in, stay close to home and do the bare essentials that need to be done.'

Carol, 63-year-old woman

COMPLEMENTARY THERAPIES

People living with HIV may use different approaches to manage their HIV illness and/or symptoms. A number of complementary therapies are available. People may choose a mix of conventional and complementary therapies or a single approach. Preferred treatments may change, depending on effectiveness, needs, individual beliefs and philosophies, and new advances in treatment and care. Some carers can feel uncomfortable deviating from either traditional or alternative approaches to care, depending on their personal beliefs. Try to respect the beliefs and choices of the person you are caring for and seek further information if you need it.

A number of PLHIV use complementary therapies to help manage symptoms or the side effects of treatment. Complementary therapies may include Reiki, naturopathy, Chinese herbal medicine, acupuncture, acupressure, meditation, massage, nutritional regimes, yoga, vitamin supplements, shiatsu, reflexology, iridology, and aromatherapy. As with any care or treatment, it is important to find a reputable practitioner with appropriate experience and qualifications.

See http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Complementary_therapies?open for more information on complementary therapies

The Positive Living Centre offers a range of complementary therapies including yoga, naturopathy, and massage for PLHIV.

See <http://www.vac.org.au/complementary-therapies/>

In Victoria, funding can be requested to assist with the costs of complementary therapies through the John Marriott Fund.

Contact the Victorian AIDS Council's Positive Living Centre for more information <http://www.vac.org.au>

MENTAL HEALTH

Grief and loss

Many PLHIV who lived through the early days of the HIV epidemic have experienced extreme emotional stress, losses and trauma. These experiences can affect their mental health in the long term. Some describe feeling like they have post-traumatic stress disorder, having lost many friends under devastating circumstances. They now find themselves ageing with HIV and in some cases, alone and isolated. Listening, understanding, and validating their experiences are very important. Social support and counselling through a range of agencies is available. You can help by directing the person to these services if necessary (see Mental health in the Resources section).

See <http://www.grief.org.au/>

It is important to recognise and get support for your own grief, loss, and trauma issues when caring for a person living with HIV. Caring for a friend or family member who is ageing can also raise many issues for the carer, such as loss of shared hopes and dreams, anticipatory grief about the future, loss of self, or shared trauma if you are a partner or part of a community in which many people have died. It can be important to get support for your own mental health in order to be able to continue in your caring role (see Carer Support in the Resources section).

VAC has individual counselling services for PLHIV, friends and carers, as well as group sessions.

See: <http://www.vac.org.au/counselling-services>

Phone: (03) 9865 6700 or 1800 134 840 (free call for country callers) Monday to Thursday 10 am to 4 pm.

Living Positive Victoria and the VAC run workshops called *In the Loop* for carers, friends, family and colleagues for a greater understanding about HIV and how to provide support.

<http://www.livingpositivevictoria.org.au/programs/in-the-loop>

Carer counselling is available on 1800 242 636 through Carers Victoria.

It is important to access counselling and support before things become a crisis. If a crisis point is reached, call Lifeline on 13 11 14.

Depression and anxiety

The aged care sector recognises the importance of the diagnosis and clinical management of depression and anxiety as it is commonplace for many older people, whether living at home or in residential care.

Depression and anxiety can occur in many PLHIV who are ageing. As mentioned earlier, some have accumulated losses of relationships, social support, self-esteem, earning capacity, and a sense of hope for the future.

Having experienced multiple losses makes people more likely to develop depression and may also make symptoms more severe. Lesbian, gay, bisexual, transgender, and intersex men and women are also more likely to experience depression and anxiety than the wider population and can be at a greater risk of suicide and self-harm.

See: <http://www.beyondblue.org.au/resources/for-me/lesbian-gay-bi-trans-and-intersex-lgbti-people>

<http://resources.beyondblue.org.au/prism/file?token=BL/0648>

Factors that contribute to anxiety, depression, and self-harm amongst LGBTI populations include discrimination, abuse (both verbal and physical), exclusion and prejudice. These can lead to the person becoming isolated and withdrawn.

'My depression would be helped by not feeling abandoned. Having a social group would be good for me.'

Bill, 35-year-old HIV-positive gay man living in a country town.

Signs of depression

Signs of depression include loss of pleasure or interest in activities previously enjoyed, weight loss or gain, change in sleeping patterns, fatigue, lack of concentration, indecisiveness, anxiety, loss of sexual desire or sexual difficulties, feelings of hopelessness, and recurrent thoughts of death or suicide. People sometimes cry a lot, or find they are unable to cry. A medical review is essential, as depression can be treated. A range of psychological and medical treatments can help. Depression can also be confused with other illnesses, as some symptoms (such as poor appetite) can occur in other health conditions.

Supporting a depressed person

Caring and supporting a person with depression can be very hard. Understanding what depression is and seeking support from others is essential. It can be difficult to understand how it feels to be depressed. You can help a person with depression if you:

- discourage them from using drugs or alcohol
- encourage them to eat healthily, get enough sleep, and exercise
- encourage friends and family to invite them to social events and to stay in touch
- letting the person know you understand they are having a difficult time
- trying to separate the person from the illness and recognise depression as a treatable condition
- giving the person positive feedback and messages encouraging them and being prepared to listen and be supportive
- understanding that the person is not able to simply 'snap out of it'

Francesca, 63-year-old Italian woman living with HIV and depression, speaking of the volunteers who provide her with social support comments:

'It's so important to see a friendly smile, because in between, when you're alone, there is just nothing, nothing there.'

More information about caring for a person with depression and/or anxiety can be found on the Beyond Blue website, <http://www.beyondblue.org.au/> or by calling 1300 22 46 36

Suicide risk

Anyone who discusses suicide needs to be taken seriously. Danger signs can include isolation and withdrawal, changes in behaviour (such as doing things that are out of character), saying goodbye or giving away possessions, feelings of hopelessness, and actually threatening suicide. If you know or suspect a person is considering suicide, seek assistance urgently. Reduce access to any potential tools such as medicine, guns, or razors. Seek support for yourself as well.

Free professional and anonymous support is available 24 hours a day across Victoria on 1300 651 251 and online at <http://www.suiceline.org.au/>

If you believe the person is in immediate danger:

- Call 000 (or 112 from a mobile phone) and request an ambulance. If the person is aggressive, request the police too; or
- If they agree, take them to the local hospital emergency department; or
- Call the local Public Emergency Mental Health Service-There are mental health emergency services (Crisis Assessment and Treatment (CAT) Teams) in all regions of Victoria. Find the contact details for either metropolitan or rural areas.

See RHS column. <http://www.health.vic.gov.au/mentalhealth/services/adult/index.htm>

These emergency services are trained to support people in crisis.

Mood and behaviour changes

Any changes in behaviour, thoughts or personality of the person you are caring for requires medical assessment. Illness or infection may be the cause and treatment may be available. Mood changes are not uncommon in PLHIV who are unwell.

Sometimes mood and behaviour changes cannot be resolved with treatment.

It is important to have a plan to deal with these. A health professional or counsellor may assist you with developing strategies.

Some suggestions include:

- Give the person you are caring for time and space to be alone.
- Identify early warning signs so you can put your plan into action as early as possible.
- Develop a plan of action for responding to the person's mood or behaviour. Sometimes it can be helpful to both of you to set boundaries about what is acceptable behaviour.
- Take time out for yourself.
- Remember you have rights as a carer and shouldn't be abused.

Christopher, a 40 year old HIV positive man who attends a community support centre for PLHIV says:

'Not many people understand HIV. Because everybody's different, if your behaviour is not appropriate, the staff at the community centre understand and say, "he's just going through that."'

Carer coping skills

Support groups can help carers feel supported and less alone. Talking to others who may have experienced similar difficulties can be encouraging and they can offer helpful suggestions. Counselling can help you to develop coping skills and strategies. If you are the main carer at home, having breaks from caring (respite) is essential (see also **7. Just for carers – taking care of yourself**).

David, a 52-year-old carer of his partner living with HIV and disability, says:

'You've got to make sure you get things in place, e.g. getting respite from the local council and going to the beach for a couple of hours. Being a carer 24 hours a day, seven days a week is not good. You need to get the balance right.'

DRUG USE AND HARM REDUCTION

Drug use is common in all parts of the world. Most Australians have used at least one or more types of drugs in their lifetime.⁶¹ Alcohol and tobacco are the most widely-used drugs in this country. Other frequently used drugs include those prescribed by doctors, such as diazepam (commonly known as 'Valium'), sleeping tablets and pain medicines.

In recent decades a growing number of Australians have used other types of drugs. Marijuana is the most common of these (although it is illegal in Victoria); some PLHIV use marijuana to alleviate pain, such as that caused by peripheral neuropathy, to reduce anxiety or nausea, or to help them sleep. Other drugs illegal under Australian law, such as methamphetamines (sometimes called speed, 'Tina', crystal meth, or 'ice'), cocaine, ketamine, ecstasy, and heroin, are also used by some people.

All drugs, both legal and illegal, have health consequences. Some drugs can have serious mental health effects, and their use can affect adherence to ART. Excessive use of some drugs can affect memory and thinking, leading to anxiety, paranoia, and depression. Such effects are not always reversible.

There can also sometimes be interactions between ART and drugs used recreationally, or between ART and substances used to treat drug dependence, such as methadone. For example, one ART medicine can interact with methadone and lead to higher levels of methadone in the blood stream. This can become life threatening by leading to methadone overdose. Older PLHIV may be at greater risks of such effects as their kidney and liver function tends to decline with age, meaning their bodies may not break down or eliminate drugs so well. It is therefore important for PLHIV to discuss their recreational drug use with their doctor or another trusted health professional.

See **5. HIV treatments** for more information about safe use of medicines.

The most effective policies around recreational drug use are based on the principles of harm reduction. Harm reduction is a way of preventing drug related harm and promoting health for people who use drugs.

It emphasises reducing risks and negative health consequences of unsafe drug use. The principles include a non-judgmental approach, enhancing quality of life for people who use drugs (rather than trying to stop all drug use) and recognising other factors that affect health (such as poverty and discrimination against people who use drugs). Some harm reduction activities that have been successful in Australia include needle and syringe programs, voluntary testing for HIV and viral hepatitis, and pharmacotherapy for drug dependence, such as methadone and suboxone.

If you are concerned that the person you are caring for is having problems related to their drug use, you can help them to access resources that may help if they want to address their problem. Whether it be it alcohol, tobacco, or an illegal substance, support and treatment are available. Consider discussing this with the person you care for and/or a trusted health worker in this field.

For help and support, call Direct Line 1800 888 236, a confidential alcohol and drug counselling and referral line.

VAC also provides alcohol and other drug counselling and support for PLHIV.

See: <http://www.vac.org.au/AODServices/>

Information for carers, family and friends is available through the National Drugs Campaign website <http://www.drugs.health.gov.au/>, including services in your local area.

www.hrvic.org.au/ or call (03) 9329 1500

www.healthdirect.gov.au/how-to-help-someone-with-a-drug-problem/

60 Commonwealth of Australia. Australian Institute of Health and Welfare. (2013). *National Drug Strategy Household Survey detailed report 2013*. Retrieved from <http://www.aihw.gov.au/publication-detail/?id=60129549469>.

Occupational health and safety

Safety must be considered not only for the person being cared for but also for carers, care workers, health workers, and volunteers.

Seek advice from a health professional if you are concerned about a person's mobility or risk of falling. They can advise you on the best way to assist without risking hurting yourself too.

SAFETY AND MOBILITY

Some PLHIV may become less able to move about safely or may have difficulty standing or walking due to pain, advanced HIV disease, osteoporosis and/or weight loss.

Assessment should be undertaken by a health professional who can advise on matters such as installing handrails in the shower or toilet. Occupational therapists, physiotherapists, and district nurses are an invaluable resource when a person's mobility is limited. They are able to advise on and assist with everyday activities such as showering and avoiding falls and injuries. They may recommend equipment, strategies, or exercises to promote independence and safety.

It can be difficult for a person to adjust to changes in their mobility, as reduced mobility can result in a loss of independence. Encourage them to do whatever they can manage, to promote confidence and wellbeing.

If the person living with HIV is no longer able to move about independently, it may mean that other care options need to be considered. This can be challenging for the person and their carers. Seek assistance from friends or other family members or volunteers to help relieve the pressure. Seek professional support to help you and the person you care for to make the necessary adjustments.

ACCESSING ADDITIONAL SERVICES

Home and Community Care (HACC) services are funded by the Australian and Victorian governments and can provide additional services for people whose capacity to stay living independently at home is at risk, or for those who are at risk of premature admission to long-term residential care. The Commonwealth government is expected to take full funding and administration responsibility for Victorian HACC services for people aged 65 years and over (and 50 years and over for Aboriginal and Torres Strait Islander people) under the new

Commonwealth Home Support Program from July 2015. The Victorian Government will continue to fund and manage services for people aged under 65.

There can be a big demand for these services and eligibility is assessed according to priority guidelines, so there can be a waiting period.

The main types of services available through HACC include:

- home help or essential cleaning (not housekeeping)
- personal care such as showering or bathing
- nursing (district or community nursing, home nursing)
- allied health services (physiotherapy, podiatry, dietetics)
- Meals on Wheels and centre-based meals
- planned activity groups
- property maintenance and minor repairs
- respite services
- linkages or Home Care Packages (discussed further below)
- community visiting, Telelink services (a free service for isolated people to talk together over the phone), respite, and transport services provided by volunteers

More details are available in the Department of Health *Victorian HACC Program Handbook 2013*.

HEALTHY AGEING AND SELF-MANAGEMENT

A key initiative of the HACC Programs is the Active Service Model (ASM). Its goal is to assist people to live in the community as independently as possible for as long as possible. It aims to increase people's capacity to self-manage their daily activities and make decisions about their life.

This model emphasises autonomy, a holistic view of people's needs, and person-centred care and support. It is focused on wellness

and active ageing, on people's strengths, and on collaborative partnerships.

The HACC Program is also committed to respecting the diversity of people in Victoria, and aims to reduce barriers to services that some people may experience. Some groups are identified as having special needs (Aboriginal and Torres Strait Islander peoples, people from culturally and linguistically diverse backgrounds, people with dementia, people who are homeless or at risk of homelessness, and people in rural or remote areas). Similarly, LGBTI people and PLHIV are often marginalised or disadvantaged, and the commitment to diversity aims to improve their access to care and support.

See: http://www.health.vic.gov.au/hacc/prog_handbook/downloads/part2.pdf

Useful tools to support self-management

The National Association of People with HIV Australia (NAPWA) has developed a tool known as 'iPlan' that can be useful for people in self-managing.

See <http://napwaha.org.au/publications/iplan>

The Australian Federation of AIDS Organisations (AFAO) has a website which includes many tools, resources, and useful links to assist people with HIV to live healthy lives. One of these resources is the Your Body Blueprint for HIV and Healthy Living publication,

<http://www.yourbodyblueprint.org.au/index.php>.

HOME CARE PACKAGES AND CONSUMER-DIRECTED CARE

Home Care Packages are funded by the Commonwealth Government to provide coordinated services tailored to people's specific needs. Following assessment by the Aged Care Assessment Service, a person may be offered a package of care from level 1 (basic) through to level 4 (high level).

Aged Care Assessment Services help older people and their carers identify what additional supports they may need and will conduct an assessment in the home.

This is required before people can access Home Care services, residential aged care, and some forms of respite care.

A range of services may be provided in a Home Care Package, including:

- personal services – help with showering, bathing, dressing and mobility
- support services – such as help with washing and ironing, house cleaning, gardening, basic home maintenance, home modifications related to the person's care needs, and transport to help them do shopping, visit their doctor, or attend social activities
- nursing and other health support, such as physiotherapy (exercise, mobility, strength and balance), dietitian (nutrition assessment, nutrition advice), and hearing and vision services

Social support can also be provided through the community visitors' scheme.

From 1 July 2015, all Home Care Packages will be delivered on a Consumer Directed Care basis – this means that people will have more choice over how their Home Care Package is managed and provided, by whom and how the care it is delivered.

For more information, see <http://www.myagedcare.gov.au/aged-care-services/home-care-packages>

RESPITE CARE

When caring for a person at home or in the community, there are many services that can assist. Taking a break or respite for you as carer, or for the person living with HIV, is important. If taken regularly, it may help you to continue in your caring role.

Horizon Place (managed by the Alfred Hospital) offers short-term and intermittent respite for PLHIV in Victoria. District or community nurses, general practitioners, or Carers Victoria can advise on other local options.

The Commonwealth Home Support Programme can provide respite in the home of the person you are caring for, in a community centre, in a friend's or other family member's home or in an aged care centre. You can find out more about the program and getting an assessment via the Australian Government website.

Visit <http://www.myagedcare.gov.au> and search for 'Commonwealth Home Support Programme.'

Ray, a 50-year-old man living with HIV says:

'When I go into respite it is just an empty space where everything is taken care of. I don't have to think about anything. Respite works.'

TRANSITION FROM HOME TO SUPPORTED ACCOMMODATION OR RESIDENTIAL CARE

If the person you are caring for needs support in a healthcare setting (such as supported accommodation home or a nursing home), you can be helped throughout the process. The Commonwealth government website <http://www.myagedcare.gov.au/> is a great place to start in seeking assistance to navigate the aged care system.

The Victorian HIV Consultancy supports people transitioning from home, hospital or other settings to a healthcare setting and continues to provide support once the person is in a nursing home. This includes negotiating placement, HIV education to staff, supporting the person through disclosure issues, maintaining links to specialised HIV care and blood monitoring, support with ART management and links to ongoing social support.

Victorian HIV Consultancy: <http://www.alfred.org.au/Department.aspx?ID=406>

Or phone (03) 9076 3658. See the Resources section for other contacts that may help with such transitions.

Anxiety about transitioning from home

Transition to a health care setting can be confusing and can cause anxiety. Many PLHIV and LGBTI people have expressed fear and concern about the possibility of entering aged care services, often worried they will face stigma and discrimination by workers. One health service manager has spoken of an HIV-positive gay man's fear of stigma around his sexuality when he was advised that he required placement in a nursing home:

'...so he went off his antiretrovirals. He chose death rather than go to a nursing home. Powerful, isn't it? Again issues of sexuality, ageing, and HIV/AIDS... He chose death rather than go to a nursing home.'

Joseph, health services manager.⁶¹

On the other hand, when services are prepared in advance for a person living with HIV's care needs, with education and support to care workers and nursing staff, the transition can be smooth and the care exemplary. An elderly disabled Vietnamese HIV positive man commented simply, upon entering an aged care service and being warmly welcomed by all personnel at the facility:

*'I have good life here'*⁶²

61 Barrett, C., Harrison, J., & Kent, J. (2009). 45.

62 Crock, E., Walklate, T., & Sztrajt, S. (2011). 'I have good life here': A Vietnamese Man's Journey to Access Services. *HIV Australia*, Vol. 9(1), 20-22. 21.

TRANSITIONING TO PALLIATIVE CARE

Palliative care is an approach that improves the quality of life of people and their families facing life-threatening illness. By identifying and treating illness, pain, and other physical, spiritual and psychosocial problems, palliative care can aid in the prevention and relief of suffering.⁶⁴ It can help provide people with support for help them live as actively as possible until death.

Palliative care can be provided in the home setting, residential care or a hospice environment, and should be applied early in the person's illness to manage symptoms and distress. If the person you are caring for requires palliative care, services are available which will work with the person and their chosen carers, and with their existing service such as RDNS, VAC, and the Victorian HIV Consultancy to coordinate care in their chosen setting. For more information, ask your health professional or see:

www.health.gov.au/palliativecare

PROMOTING EXCELLENCE IN CARE FOR OLDER PEOPLE LIVING WITH HIV

The rights of PLHIV are the same as those of every other person. The Commonwealth Department of Health developed a *National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy* in 2012. This strategy aims to ensure that people from diverse sexualities and gender identities can access services specific to their care needs. The strategy emphasises empowerment, respect, access, equity, and quality. Knowing that these values are acknowledged at the highest levels can help you to advocate for the person you are caring for.

63 World Health Organisation. (2015). *WHO Definition of Palliative Care*. Retrieved from <http://www.who.int/cancer/palliative/definition/en/>

7 JUST FOR CARERS – TAKING CARE OF YOURSELF

Being a carer is a major commitment and responsibility. It can be extremely rewarding, but it can also be demanding and difficult. Carers may experience considerable stress at times, which may prevent them from continuing to care. Carer burn-out is common, so you need to look after yourself.

BENEFITS OF CARING

People who care for a family member or friend say there are many rewards. These include:

- strengthening the relationship with the person you care for
- the satisfaction of knowing you have done the best you could to improve another person's quality of life
- the opportunity for personal growth and the development of new skills
- proving to yourself that you can meet new challenges
- being acknowledged in your caring role

CHALLENGES OF CARING

Caring can also have its challenges. Some of these include:

- increased financial hardship
- impacts on your physical and emotional health and wellbeing
- mental health impacts (grief, loss, depression, etc.)
- social isolation and breakdown of relationships
- missed opportunities and disadvantage in work, education or other areas of life
- loss of spontaneity and freedom

Susan, a care worker for a community-based organisation says:

'Caring is making sure you're there, or someone else is there 24/7. I don't know how some people do it.'

Research has found that carers have the lowest wellbeing of any large group measured by the Australian Unity Wellbeing Index. Carers often ignore their own health and are 40% more likely to suffer from a chronic health condition. Some health problems may be directly linked to the caring role.

<http://www.australianunity.com.au/about-us/Wellbeing>

<http://www.carersvictoria.org.au/facts/impact-of-caring>

SIGNS OF CARER STRESS

Watch for:

- increasing impatience
- irritability and anger
- increasing tiredness
- difficulty with sleeping or changed sleeping habits
- inability to take care of personal matters
- feeling neglected by others, or neglecting yourself
- missing your own appointments
- realising that you haven't been alone or had social contact with anybody but the person you care for
- inability to keep on top of family or business matters

Afia, 45-year-old carer for her husband, Emanuel, says:

'It means putting yourself second. That is the reality. You are restricted in your freedom to do whatever else you might want to do.'

What to do

Finding the time and resources to look after yourself is not always easy. You may need to take some time to reflect on your own needs and how to get them met, and to research options that are easy to access and affordable for you. While it can be hard to do, it is important to plan the support you need – it won't just happen by itself.

Here are four areas you may want to consider:

- **Plan a social life:** It is often beneficial for you and the person you are caring for to stay connected to the real world. Laughing, having fun, and relaxation are all good for your health.
- **Plan breaks:** Caring for someone 24 hours a day, seven days a week, without a break, can be exhausting and stressful. Even a short break, such as meeting a friend for coffee, can be valuable. Ask your friends, family, or respite services for help. It may also benefit the person you are caring for to see a new face and it means you can have some time to yourself.
- **Plan for health:** To stay well you need exercise, rest, and to eat nutritious food. Plan your day so that you get all three.
- **Plan your financial or legal issues:** Ask for help if you are worried. You may be eligible for a Carer Payment or Benefit.

It may help to think about short, medium, and long-term goals. Start small. Ask for help and be realistic about what you can achieve. A carer support worker, counsellor, or social worker may be able to help you think about your goals and how you might achieve them.

It is not selfish to have your own needs met. Recognise the limits of your own endurance and strength. Ask your family, friends and community to help you.

‘We all think we are coping in providing care, however the toll on physical and emotional well-being is incremental and I was not recognising my own needs – rather I put my partner first. It was the RDNS nurses who suggested I needed a break. Irrespective of the guilt I felt in taking time out for me, it allowed me the opportunity to regain a sense of self-awareness to continue and ask for additional support from the care team.’
Max, carer for partner, aged 42.

WHAT IS RESPITE?

Respite means having a break from caring. It may take many different forms, depending on individual needs. It may be planned or unplanned, such as in response to a crisis or emergency. It can be regular or it may be occasional. It can be in your own home, for example, a volunteer or care worker coming for a few hours while you go out. It may be residential, where the person you are caring for spends a weekend or week in a respite house or hospital respite unit.

Seek advice from a social worker, nurse, doctor, or volunteer coordinator for the options available to you. Regionally-based carer programs can provide advice and help. Some regions also offer emergency after-hours respite care if you need to be away from home urgently and the person you are caring for cannot be left alone. See also **Respite care** on page 45 for information about the National Respite for Carers Program.

Greg, 49, carer of his partner Tony, says:

‘Having volunteers from the Victorian AIDS Council is fantastic. They are able to spend time with Tony and take him out for a break. They also help to take him to some of his doctor’s appointments when I can’t get time off work.’

Angela, a coordinator of a respite centre for people living with HIV, says:

‘Family members who provide full time care to a relative should be entitled to regular periods of respite. Respite supports that relationship to survive and remain healthy.’

CARERS’ RIGHTS AND RESPONSIBILITIES

You have the right to:

- a full and satisfying life
- information, education, training and support to help you in your caring role
- care for yourself

- a safe environment
- be consulted about treatment and care for the person you are caring for, if they agree
- make choices about the amount and type of care you provide
- experience and express your own emotions
- have a break from caring
- make a complaint (see, Footnote at the bottom of this page for an example)⁶⁵

<http://www.myagedcare.gov.au/caring-someone/counselling-and-support-carers>

<http://www.carersvictoria.org.au/advice/advocacy-rights-change>

You have the responsibility to:

- Respect the worth and dignity of the person you are caring for
- Consider the opinions of professional and other staff and recognise their skills in providing care and treatment for the person living with HIV⁶⁶

Alana, carer of her brother Michael, says:

‘Always take time out for yourself to be with an understanding friend or support group.’

SUPPORT FOR CARERS

Caring is a shared community responsibility but too often family and friends feel they are carrying the responsibility of caring alone. Support and advisory services can help you decide what help you need and how you might achieve a more sustainable mix of caring supports.

Support for carers includes:

- information and advice
- respite
- services to help support the person you care for in their home
- emotional support and counselling
- carer education and training
- advocacy

Contact VAC on 9865 6700 or 1800 134 840 or Carers Victoria on 1800 242 636 for more information.

Hoa, nurse manager of an aged care facility, says:

‘One of the best ways a service can deliver good care to their clients is to provide a positive environment for the staff and volunteers. Carers and care workers deserve that consideration.’

POSITIVE CARING

Whatever your role may be, as a family member, partner, care worker, volunteer, or health professional, if you have taken on the care of an older person living with HIV, you may be experiencing a demanding journey as you learn more about HIV and the specific needs of the person you are caring for.

Sometimes you may find it very rewarding and satisfying. At other times, you may be tested to your limit. RDNS and Living Positive Victoria hope that this handbook will provide you with practical information, support, and resources that can help you to ensure the best quality of life for you and for the person living with HIV for whom you are caring.

Rob, a 50 year old long term survivor, comments:

‘I’ve been lucky to have a close network of volunteers and nurses over the years to help me stay at home. It’s been a safety net for me. Now I’m getting older I know I’ll be looked after.’

64 Mental Health Carers ARAFMI NSW. (2013). *Carers’ Rights and Responsibilities*. Retrieved from <http://www.hnehealth.nsw.gov.au/mh/Documents/NG15.pdf>

65 *ibid.*

8 HIV – FREQUENTLY ASKED QUESTIONS

How is HIV transmitted?

HIV can be transmitted sexually-through sexual fluids (semen and vaginal fluids), blood to blood, e.g. needle sharing or unsafe tattooing, and from mother to child if the mother is untreated. HIV is a fragile virus which dies soon after exposure to the environment outside the body, changes in temperature and exposure to ultraviolet light.

HIV can be transmitted via needlestick injury from an HIV positive person. The risk is estimated to be around 3/1000 (0.3%). This compares with 20-40% for hepatitis B and 2-10% for hepatitis C. Post-exposure prophylaxis or PEP medicine is available to people including care workers and health workers who are exposed to HIV through workplace injury such as needlestick injury. It is also available to people exposed to HIV through other means, such as sex without a condom or sharing needles with an HIV-positive person. PEP can reduce the risk of infection.

Are standard precautions enough to protect me from contracting HIV?

Yes.

Care workers and health workers do not know the infectious status of all people they may be caring for, so standard precautions are the best protection; that is, thorough hand washing or use of alcohol-based hand rub, use of personal protective equipment (protective eyewear, gloves etc.) when handling body fluids, cleaning up spills and disposing of sharps appropriately (see **3. Hygiene and Safety** in this handbook).

Do not assume that, just because you have not been informed of a person's medical condition, a client is HIV-negative (or free from other blood-borne virus). For every 100 HIV diagnoses in the community, it is estimated that there are 10 to 20 people undiagnosed.⁶⁷ The rates are higher for other blood-borne viruses. This is another reason why standard precautions are the best policy.

Should I put an alert on the computer at work or in our workplace records for a person with HIV so that others can protect themselves from contracting the virus?

No.

Standard precautions are all that is required to protect workers and care workers from contracting HIV or other viruses or bacteria. Using standard precautions means thorough hand washing or use of alcohol-based hand rub, use of personal protective equipment when handling body fluids, cleaning up spills, and disposing of sharps appropriately. There is no reason to place an alert on a person's file simply because of their HIV status. It is, in fact, discriminatory to do so.

In most health workplaces, alerts may be relevant for concerns such as:

- behavioural issues (for example, the person has been aggressive to staff or a partner or family member displays threatening behaviour)
- environmental (cluttered environment, cleanliness issues)
- communication (lack of insight into health issues due to memory problems, frequently cancel home visits)
- health status (chronic illness, frailty, co-morbidities)

Do volunteers or staff have a right to know a client's HIV status so that they can protect themselves?

No.

There is no right to know another person's diagnosis. Workers do not know the infectious status of all people they may be caring for, and it is impossible to test everyone for every known infection. Standard precautions are the best protection in any case, i.e. thorough hand washing or use of alcohol rub, use of personal protective equipment (protective eyewear, gloves and so on) when handling body fluids,

EXAMPLE:

It may be that the person is socially isolated, has dementia and frequently cancels health worker and care worker visits, or has a chronic illness along with a number of other illnesses, and is therefore at risk. Alternatively, the person may have a family member or friend who visits frequently who may be aggressive to visiting care workers or health workers. These issues are relevant to any client in the community and may justify an alert being noted on their file.



⁶⁶ Wilson, D. (2011). *Undiagnosed HIV in Australia*. Paper presented at the Australasian HIV/AIDS Conference 2011, Canberra, 26-28 September 2011.

cleaning up spills and disposing of sharps appropriately (see **3. Hygiene and Safety** on page 11 of this handbook).

Do not assume that, just because you have not been informed of a person's medical condition, a client is HIV-negative, is free from other blood-borne viruses, or has no other infections. This is another reason why standard precautions are the best policy.

Is it okay for a pregnant health worker or care worker to provide care for HIV clients?

Yes.

Pregnant care workers or health workers can make home visits and provide care to PLHIV. Standard precautions provide the best protection against occupational exposures. If the person with HIV is on cytotoxic medicine (such as chemotherapy for cancer that can be very toxic if handled incorrectly), care workers and health workers (including pregnant women) should follow standard precautions and workplace policies and procedures where these apply. Pregnant carers should also be informed of and understand such risks.

Do I have a duty to tell other agencies, volunteers, or staff about a client's HIV diagnosis when making a referral?

No.

People are NOT required to disclose blood-borne viruses to health care professionals, volunteers, or staff. The best practice is to protect yourself by using standard precautions with every client. All agencies are required to practise standard precautions.

Any disclosure of a person's HIV (or other blood-borne virus) status should be with the client's informed consent. Please consider need to know rather than right to know when referring clients to other services. There is no right to know a person's diagnosis.

There are many documented incidents where PLHIV have experienced stigma and discrimination, which has compromised their care and/or engagement with health care, when their HIV status has been unnecessarily disclosed.

Can I get opportunistic illnesses (such as toxoplasmosis or CMV) from a person living with HIV?

No.

As an example, toxoplasmosis is common in the community but usually doesn't make people sick unless they have a weakened immune system. It is transmitted through ingestion of cat faeces or undercooked meat that may contain the toxoplasmosis organism's 'eggs'. Many people have contracted toxoplasmosis as children but have developed antibodies to the organism and do not become unwell. It is an *opportunistic illness*, meaning that the toxoplasmosis organism takes the *opportunity* to multiply inside the body when the immune system is damaged. PLHIV who have a damaged immune system may develop toxoplasmosis but they cannot infect others.

The same is the case with other opportunistic illnesses. It is the person living with HIV who is at risk, due to damage to the immune system, not the carer or health worker. If the person is on ART and their immune system has recovered, they are at much lower risk of opportunistic illnesses.

Is it okay to drink from a cup in the home of a person with HIV?

Yes.

There is no risk of contracting HIV from a cup. HIV is transmitted through blood-to-blood contact or through unprotected sexual intercourse with an HIV-positive person (through semen or vaginal fluids).

See **3. Hygiene and Safety** and in particular, *What are standard precautions?* on page 11 for more information.

Can I put people with HIV at risk of other infections because they are immunosuppressed?

Yes.

PLHIV can be vulnerable to infections due to damage to their immune system caused by the virus. If they take antiretroviral medicine, their immune system can recover and they are no longer at so much risk. If you are unwell, it is best not to visit the person or provide care until you have recovered.

Can I refuse to care for a person with HIV?

No.

All people are entitled to receive care without discrimination or fear of discrimination, and you cannot refuse to care for someone on the basis of their HIV status. However, if you think your beliefs or attitudes about PLHIV may negatively affect your ability to care for them, please make this known to your employer or agency. All people deserve and require care delivered with professionalism, and with an understanding of them. If you cannot do this, it may be better for another person to be assigned to their care.

Education and support should be available if you have concerns in your workplace. See the Resources section of this handbook (Information and education) for organisations providing HIV education.

What do I do if I get a needlestick injury or other exposure?

If you have a needlestick injury, are cut with a sharp object contaminated with blood or body fluids, or other exposure to blood or body fluids (such as a splash in the eye or mouth) when caring for a person living with HIV, immediately perform first aid in the following manner:

- **Skin:** Immediately wash away the blood or fluid from the affected area using soap and running water. Alcohol based hand rub can be used if soap and water are not readily available. Apply a waterproof dressing if required. If bleeding continues, apply pressure through the dressing. Do not squeeze the affected area.
- **Eyes:** If your eyes are contaminated, rinse them under running tap water (keep eyes open while rinsing).
- **Mouth:** If you have received a splash of body fluid/blood into the mouth – spit out then rinse mouth with water several times.

Seek medical attention, ideally within two hours, but 72 hours at most.⁶⁷

If you work in a healthcare setting, report accidental contact with blood and body fluids or needlestick incident to the appropriate staff member, and follow your organisation's policy and procedure.

There is evidence that people with HIV who are on ART and have an undetectable viral load are unlikely to transmit HIV. There is also treatment available for occupational exposures to HIV that can help reduce the risk further. This is known as post-exposure prophylaxis or *PEP*.⁶⁸

What is PEP?

PEP stands for post-exposure prophylaxis, a course of antiretroviral medicine taken to reduce the risk of HIV infection after an exposure to HIV. PEP needs to be taken within 72 hours of exposure, and must be taken for one month to be most effective. PEP is available for both occupational exposures to HIV (such as needlestick injury), and non-occupational exposures (such as high risk sexual exposure or sharing injecting equipment with an HIV-positive person). Non-occupational PEP is referred to as *NPEP*.⁶⁹

⁶⁷ Australasian Society for HIV Medicine. (2013).

⁶⁸ *ibid*.

⁶⁹ *ibid*.

I am very worried about visiting HIV-positive people who inject drugs; aren't they a high risk to others?

No.

Many people have experienced and engaged in drug use at some time in their lives. This is usually a private issue. Drug paraphernalia is usually kept private. When assessing risks, it is best to use questions such as, 'Is the home environment safe for care workers or visiting nurses?' or 'Are there any risks for the visiting staff?'

These questions should elicit information without being confronting. Be sensitive and respectful when asking questions. The first priority in providing care to HIV-positive clients is to gain their trust and engagement in their care. This promotes better health outcomes for them and has benefits for public health and HIV prevention. For further information about drug use <http://www.adf.org.au/> and the Resources section of this handbook.

What is a CD4 count?

The CD4 cell is the cell which the HIV virus attacks. It is in CD4 cells that the virus replicates.

The CD4 cell count of an HIV-negative person is between 600-1500 cells/cubic millimetre of blood (average 1,000).

People with compromised immune function, especially with a CD4 count below 200, are at risk of viral and bacterial infections and developing opportunistic illnesses. If you are unwell with an infection you should not attend their care.

SECTION 2

Rights and responsibilities for clients, carers, health professionals, and service providers. It includes legal, policy and complaints information.

Section Two of the handbook addresses the rights and responsibilities of clients and health professionals in health and ageing services.

It aims to raise awareness of the appropriate level of care and considerations specific to working with people living with HIV (PLHIV).

Information on advanced care planning and future preparations is also provided for PLHIV and carers.

Finally this section provides an overview of complaints mechanisms for both clients and health professionals. It is designed to speak directly to PLHIV and their carers, health professionals, and managers of health and ageing services.

The sections addressing client rights, discrimination, and disclosure have been divided into three sections to provide information on these topics specifically for PLHIV and carers, health professionals and management and service settings.

GENERAL DISCLAIMER

This handbook was compiled to assist people caring for PLHIV, to support them in the community and/or in residential aged care. The information should not be considered exhaustive, nor is it intended to be medical advice.

The authors have sought to provide the most current material, but information changes rapidly. Users are therefore encouraged to access the most up-to-date information.

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The legal material in this handbook is designed to provide general information on legal topics.

The contents do not constitute legal advice, are not intended to be a substitute for legal advice and should not be relied upon as advice.

You should always seek legal advice in relation to any legal questions you have.

As laws change from time to time you should seek assistance from a lawyer for the most up to date applicable laws.

While we have used our best endeavours to create helpful and accurate information, some or all of the information, from time to time may become outdated, be amended, or otherwise be inaccurate.

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9 HUMAN RIGHTS, HIV AND CLIENTS' RIGHTS

PEOPLE LIVING WITH HIV: HUMAN RIGHTS, HIV AND CLIENT CHARTERS

In Victoria our human rights are protected through the Charter of *Human Rights and Responsibilities Act 2006 (Vic)* ('Victorian Charter'). It is used to ensure that the Victorian government and other public authorities, including all State-funded public health, ageing, and aged care services, comply with and consider our human rights when making decisions.

In aged care settings, the Victorian Charter can be used to question decisions, practices and policies of services and health professionals, to ensure you maintain connections to your community, retain your freedom and autonomy and ensure that you don't experience discrimination.

The Victorian Charter defines twenty distinct human rights. Below is a list of some of those rights that may be relevant for people living with HIV (PLHIV) in aged care settings:

- Right to equality before the law and protection against discrimination
- Right to life
- Right to protection from torture and cruel, inhuman and degrading treatment
- Right to freedom of movement
- Right to privacy
- Right to freedom of thought, conscience, religion and belief
- Right to freedom of expression
- Right of a person to practice and enjoy his or her culture, religion and language
- Right to liberty and security of person

The Victorian Charter is used to ensure that the decisions of State government departments, aged care facilities, hospitals, local councils, and other public authorities do not infringe upon your human rights regardless of HIV and health status, age, sexuality, or gender.

You cannot use the Victorian Charter to take legal action for a breach of human rights on its own. However, you can use it to support pre-existing legal actions. It can also be used to make a complaint to the Victorian Ombudsman, the Disability Services Commissioner or the Health Services Commissioner. For further information see **14. Complaints and advice for clients and service providers.**

Client Charters of Rights

The Client Charters outline the rights and obligations of clients and health professionals. They do not provide clients with further complaint mechanisms; however, they do highlight the standard of care clients can expect from services and outline clients' obligations when accessing them.

There are three main client charters that support people accessing aged care services:

- *Charter of Care Recipients' rights and responsibilities* – Residential Care: for all Commonwealth funded residential care services
- *Charter of Care Recipients' rights and responsibilities* – Home Care: for all Commonwealth funded home care services
- Australian Charter of Healthcare Rights: for all health care services

Client Charters are used to ensure that client's receive an appropriate level of care, respect, and dignity as both a client and an individual. The charters seek to embrace and support the diversity of people accessing aged care services.

The charter for residential care facilities also protects your right to access services, activities, and friendships, whether inside or outside the facility, without fear of criticism or being restriction.

Client Charters guarantee the right to:

- Safe and quality health care
- Respect, dignity, and consideration
- Be included in the decisions about your health care
- Be clearly informed about services
- Treatment options and costs
- Privacy and confidentiality
- Be informed on how to make comments and complaints



Human rights have been central to the development of HIV treatment, care, and prevention strategies in the global response to the HIV. The *United Nations Declaration on Human Rights* and the *International Covenant on Economic, Social and Cultural Rights* have reinforced the right to health, access to appropriate health care, equal treatment before the law, and freedom from discrimination for people living with HIV.

VICTORIAN CARERS CHARTER

The *Victorian Charter Supporting People in Care Relationships* is for people in a care relationship. It promotes respect and inclusion of both the carer and the person receiving the care in decisions relating to care plans, treatment options, and service delivery. It aims to ensure that care organisations and services respect the role of carers in our community.

Both carers and people that are being cared for have the right to:

- support
- recognition and respect, both as individuals and as people in a care relationship
- be encouraged to take part in care planning and making decisions about care
- have your views, needs, and cultural identity taken into account in decisions and matters related to your care relationship

FURTHER INFORMATION

Charter of Care Recipients' rights and responsibilities – Residential Care

www.myagedcare.gov.au/financial-and-legal/rights-and-responsibilities-residential-care

Charter of Care Recipients' rights and responsibilities – Home Care

www.myagedcare.gov.au/financial-and-legal/rights-and-responsibilities-home-care

Australian Charter of Health Care Rights

www.safetyandquality.gov.au/national-priorities/charter-of-healthcare-rights/

Victorian Charter Supporting People in Care Relationships

http://www.dhs.vic.gov.au/_data/assets/pdf_file/0010/738667/91-The-Victorian-charter-supporting-people-in-care-relationships.pdf

HEALTH PROFESSIONALS: HUMAN RIGHTS, HIV AND CLIENT CHARTERS

HIV care and treatment focus upon the human rights and dignity of PLHIV. Australia's *Seventh National HIV Strategy 2014-2017* focuses upon human rights, access and equity as guiding principles to ensuring care, treatment and prevention are effectively developed within our health care system.

Human rights are an important consideration in the care and treatment of HIV. They ensure that the impact of stigma and discrimination is recognised and addressed in the provision of appropriate health care for PLHIV.

The *Seventh National HIV Strategy 2014-2017* also recognises the ageing population of PLHIV and the implications for the health care system and current HIV models of care.

For further information, see Table 4 and Table 5.

Table 5: Commonwealth policies on HIV and ageing for priority populations of people living with HIV

STRATEGY	RELEVANCE	FURTHER INFORMATION
<p>Seventh National HIV Strategy 2014–2017</p>	<ul style="list-style-type: none"> • Guides Australia’s HIV prevention, health promotion, treatment and care, surveillance, research and evaluation. • Recognises the impact of that ageing and HIV will have on health care system and current care and treatment models • Identifies workforce development and strategies to support people living with HIV access care and support services 	<p>To view the <i>Seventh National HIV Strategy 2014–2017</i>: http://www.health.gov.au/internet/main/publishing.nsf/Content/ohp-bbvs-hiv</p>
<p>Fourth National Aboriginal and Torres Strait Islander Blood-borne Viruses (BBV) and Sexually Transmissible Infections (STI) Strategy 2014–2017</p>	<ul style="list-style-type: none"> • Guides Australia’s BBV and STI prevention, health promotion, treatment and care, surveillance, research and evaluation within Aboriginal and Torres Strait Islander community • Recognises increased rates of HIV and specific modes of HIV transmission in Aboriginal and Torres Strait Islander communities • This policy is read alongside the <i>Seventh National HIV Strategy 2014–2017</i>. 	<p>To view the <i>Fourth National Aboriginal and Torres Strait Islander Blood-borne Viruses (BBV) and Sexually Transmissible Infections (STI) Strategy 2014–2017</i>: http://www.health.gov.au/internet/main/publishing.nsf/Content/ohp-bbvs-atsi</p>

STRATEGY	RELEVANCE	FURTHER INFORMATION
<p><i>National Lesbian, Gay, Bisexual, Transgender and Intersex Ageing and Aged Care Strategy</i></p>	<ul style="list-style-type: none"> • Highlights the impact of stigma and discrimination on the way older LGBTI people are seeking to access ageing and aged care services • Recognises the need for equitable access to appropriate ageing and aged care services • Developing inclusive ageing and aged care services through workforce development and policy response • Addressing the needs of LGBTI older people. 	<p>To view the <i>National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy</i>:</p> <p>https://www.dss.gov.au/sites/default/files/documents/08_2014/national_ageing_and_aged_care_strategy_lgbti_print_version.pdf</p>
<p><i>National Ageing and Aged Care Strategy for People from Culturally and Linguistically Diverse (CALD) Backgrounds</i></p>	<ul style="list-style-type: none"> • Recognises a large proportion of older people in Australia were born overseas and how this will impact upon the provision of appropriate ageing and aged care services • Increase CALD communities knowledge and ability to make informed choices regarding ageing and aged care services • To develop inclusive and equitable ageing and aged care services through workforce development and policy response 	<p>To view the <i>National Ageing and Aged Care Strategy for People from Culturally and Linguistically Diverse (CALD) Backgrounds</i>:</p> <p>http://fecca.org.au/wp-content/uploads/2015/06/national-cald-aged-care-strategy.pdf</p>

Table 6: Links to Victorian Aged Care Policies

POLICY	LINK
Victorian HACC strategic directions and expenditure priorities 2012-2015	http://www.health.vic.gov.au/hacc/plan_fund/index.htm
Regulation of Supported Residential Services	http://www.health.vic.gov.au/srs/role/
Service planning and development framework for the Public Sector residential aged care	http://health.vic.gov.au/agedcare/policy/resicare/psracs_planning.htm
Victorian Dementia Action Plan 2014-2018	http://docs.health.vic.gov.au/docs/doc/Victorian-dementia-action-plan-2014-2018
Recognising care and support relationships	http://www.dhs.vic.gov.au/about-the-department/documents-and-resources/policies,-guidelines-and-legislation/carers-recognition-act-2012
Administration of medication in residential aged care	http://health.vic.gov.au/agedcare/policy/medication.htm

VICTORIAN CHARTER OF HUMAN RIGHTS AND RESPONSIBILITIES

The Victorian Charter can be used to advocate for the rights of PLHIV and question the decisions made by health care services.

In Victoria, the *Victorian Charter of Human Rights and Responsibilities* (Victorian Charter) is used to ensure decisions made by the Victorian government and all State-funded health care services consider and protect the human rights of their clients. All policies, programs and decisions must support and promote the rights in the Victorian Charter. Health professionals and advocates can use it to advocate for the rights of their clients. The Victorian Charter has 20 individual rights based on International Covenant of Civil and Political Rights.

Below are some of the rights from the Victorian Charter that could be used to support PLHIV in aged care settings;

- Right to equality before the law and protection against discrimination

- Right to life
- Right to protection from torture and cruel, inhuman and degrading treatment, freedom of movement
- Right to privacy
- Right to freedom of thought, conscience, religion and belief
- Right to freedom of expression
- Right of a person to practice and enjoy his or her culture, religion and language
- Right to liberty and security of person

SENIORS RIGHTS VICTORIA CASE STUDY

Seniors Rights Victoria used the *Victorian Charter of Human Rights and Responsibilities* to advocate for the right of a man who was living in an aged care residential service to be able to leave the facility without supervision. The residential service would not allow him to leave on his own because his doctor thought it was too risky. The residential service considered this was part of their duty of care to ensure that he was safe.

FURTHER LINKS

The Victorian Charter on Rights and Responsibilities

www.humanrightscommission.vic.gov.au/index.php/the-charter

Seniors Rights Victoria questioned the decision and outlined the human rights that the service needed to consider, which included:

- the right to recognition and equality before the law, including the right to enjoy other human rights without discrimination on the basis of age or disability
- the right to freedom of movement, including the right to move freely within Victoria
- the right to privacy, including the right to personal autonomy
- the right to liberty and security of person
- the right to humane treatment when deprived of liberty, including being treated humanely with respect for the dignity of the person

Even though the residential service had made these decisions in regard to the man's safety, he was able to have the decision overturned when considering the rights that needed to be considered under the Victorian Charter. He is now allowed to leave the premises when he chooses and at his own risk.

This case study was adapted from: The Victorian Equal Opportunities and Human Rights Commission Report on *How human rights can influence and support risk management for public authorities in Victoria* 2014

The Victorian Charter can be used to make a complaint to the Victorian Ombudsman, the Disability Services Commissioner, or the Health Services Commissioner. However a person cannot bring a legal action for a breach of human rights alone. For further information see **Section 14 Complaints information for clients and service providers.**

Client Charters

There are three client Charters that outline the rights and obligations of clients and carers in aged care settings;

- *Charter of Care Recipients' rights and responsibilities* for Commonwealth funded residential care
- *Charter of Care Recipients' rights and responsibilities* for Commonwealth funded home care
- *Victorian Charter Supporting People in Care Relationships*

These Charters highlight the roles, rights and obligations between clients and health professionals. They can be used as useful tools to develop rapport with clients, outlining general rights and expectations of both clients and health professionals. Moreover, they can address specific concerns that a person living with HIV may have, such as an increased concern for confidentiality, respect, and the inclusion of diverse relationships and communities.

Under the Charters, health care services are expected to ensure that clients are:

- provided with safe and appropriate quality health care
- treated with respect, dignity and consideration
- included in the decisions about their health care
- clearly informed about services, treatment options and costs
- provided with privacy and confidentiality
- informed on how to make comments and complaints

The charters can also be used to highlight the obligations that clients have in treating health professionals with respect and ensuring that they provide the appropriate information for their care and treatment needs.

The Australian Health Care Charter is another client charter that is intended for all health care services, not just aged care services.

MANAGEMENT AND SERVICE SETTINGS: HUMAN RIGHTS, HIV, AND CLIENT CHARTERS

Human rights have been central to the development of HIV care and treatment initiatives. They are crucial to ensuring that the impact of stigma and discrimination is recognised and addressed by services supporting PLHIV.

In Victoria, the *Victorian Charter of Human Rights and Responsibilities* (Victorian Charter) aims to ensure that all decision-making processes, policies, programs and services provided by the Victorian public authorities, including State-funded health services, adhere to the human rights outlined in Victorian Charter. This means that the State government and public authorities have an obligation act in a way that is consistent with the human rights listed in the Victorian Charter. There are 20 individual rights that all State government and other public bodies are required to comply with and consider when making decisions. However some rights that may be limited in certain circumstances, if it is necessary and reasonable.

Rights in the *Victorian Charter of Human Rights and Responsibilities* those services should consider when making decisions that could impact upon clients living with HIV include:

- Right to equality before the law and protection against discrimination
- Right to life
- Right to protection from torture and cruel, inhuman and degrading treatment, freedom of movement
- Right to privacy
- Right to freedom of thought, conscience, religion and belief
- Right to freedom of expression

- Right of a person to practice and enjoy his or her culture, religion and language
- Right to liberty and security of person

The Victorian Charter can be used to make a complaint to the Victorian Ombudsman, the Disability Services Commissioner or the Health Services Commissioner. However a person cannot bring a legal action for a breach of human rights on their own. For further information see **Section 14 Complaints information for clients and service providers.**

See the Seniors Rights Case Study in section **9.2 Health professionals: Human rights, HIV and client charters** for an example of where the Victorian Charter was used to challenge the decisions of an aged care facility about one of its clients.

Client Charters

A range of client and carer charters exist, which highlight the expectations and obligations that exist between clients and health care providers within residential and home care settings. The charters can be used as tools to ensure that aged care services have the appropriate policies, systems, and processes in place to ensure that clients are receiving an appropriate level of care from health professionals. They can also be used as advocacy tools to support, both clients and health care providers. The Charters themselves do not create further complaints mechanisms.

In addition to the aged care charters the Australian Charter of Healthcare Rights also seeks to inform clients of their rights and ensure that they are receiving the most appropriate level of health care. It focuses on clients' right to access services, the government's human rights commitments to health, respect for the cultural diversity and the different ways people live in our society. The Charter applies to all health care services in Victoria and throughout Australia. Services can adopt and tailor the Charter to the appropriate needs of their clients and services.

For further information see Table 7 on page 64.

FURTHER INFORMATION

The Victorian Charter on Rights and Responsibilities
<http://www.humanrightscommission.vic.gov.au/index.php/the-charter>

Rights in focus: Reports on the rights of older Victorians 2012
<http://www.humanrightscommission.vic.gov.au/index.php/our-resources-and-publications/charter-reports/item/301-rights-in-focus-report-on-the-rights-of-older-victorians>

How human rights can influence and support risk management for public authorities in Victoria
<http://www.humanrightscommission.vic.gov.au/index.php/our-resources-and-publications/reports/item/828-rights-and-risk-how-human-rights-can-influence-and-support-risk-management-for-public-authorities-in-victoria>



Table 7: Patient Charter Rights for Aged Care Settings

CHARTER	SERVICES	RIGHTS FOR PATIENTS	RIGHTS FOR HEALTH PROFESSIONALS	LINKS TO FURTHER INFORMATION ON CHARTERS
<p><i>Australian Charter of Health Care Rights</i></p> <p>Endorsed by Australian Commission on Safety and Quality Health Care 2008.</p>	<p>All health care services can adopt the charter and tailor it to the services needs</p>	<ul style="list-style-type: none"> · Access · Safety · Respect · Communication · Participation · Privacy · Comment 	<p>Not applicable</p>	<p>Using the Australian Patient Charter in Victoria</p> <p>http://health.vic.gov.au/patientcharter/healthcare-rights-inVictoria/index.htm</p>
<p><i>Charter of Care Recipients' rights and responsibilities</i> for Commonwealth funded residential care</p> <p><i>Aged Care Act 1997</i> (Cth)</p>	<p>Residential facilities (Commonwealth funded)</p>	<ul style="list-style-type: none"> · Access rights, dignity, respect and no discrimination · Quality care · Health and treatment information · Privacy, safe, secure, homelike environment · Freedom of movement in and out of facility · Maintain relationships, access services and activities without criticism or restriction · Accept personal responsibility for actions and choices · Make decisions about daily life and affairs · Consulted on living arrangements · Information on rights, care, accommodation and complaints · Free from reprisal for taking action 	<ul style="list-style-type: none"> · Respect the rights and needs of other people in the residential care service, and residential care service community as a whole; · Respect the rights of staff · To care for your own health and well-being, · To inform medical practitioners about your relevant medical history and current state of health. 	<p><i>Charter of Care Recipients' rights and responsibilities</i> – Residential Care</p> <p>www.myagedcare.gov.au/financial-and-legal/rights-and-responsibilities-residential-care</p>

CHARTER	SERVICES	RIGHTS FOR PATIENTS	RIGHTS FOR HEALTH PROFESSIONALS	LINKS TO FURTHER INFORMATION ON CHARTERS
<p><i>Charter of Care Recipients' rights and responsibilities for Commonwealth funded home care</i></p> <p><i>Aged Care Act 1997 (Cth)</i></p>	<p>Commonwealth aged care packages or HACC</p>	<ul style="list-style-type: none"> Respect, privacy and confidentiality Involvement in decisions Written agreements with service provider Review of care and services Complaints information Fees determined in a fair manner A copy of Charter 	<ul style="list-style-type: none"> Respect the rights of care workers Give information to develop and deliver care plan follow written agreement Allow safe, reasonable and timely access Pay fees in written agreement. 	<p><i>Charter of Care Recipients' rights and responsibilities – Home Care</i></p> <p>http://www.myagedcare.gov.au/financial-and-legal/rights-and-responsibilities-home-care</p>
<p><i>Victorian Charter Supporting People in Care Relationships</i></p> <p><i>Carers Recognition Act 2012 (Vic)</i></p>	<p>State government departments, councils, and organisations funded by government to provide programs and services to people in care relationships.</p>	<p>As a carer:</p> <ul style="list-style-type: none"> Respect, recognition and support as an individual, a carer and someone with special knowledge of the person in your care for Your efforts, dedication and contribution to the community Have your views and cultural identity taken into account with the best interests of person being cared for Your social wellbeing and health recognised in matters relating To the care relationship Your participation in employment and education considered in your role as a carer <p>As a care recipient:</p> <ul style="list-style-type: none"> Be respected, recognised and supported as an individual and as a person in a care relationship Have your views taken into account, with your needs, cultural identity and best interests Have your changing needs considered and taken into account in how you are cared for 	<p>Not applicable</p>	<p>Victorian Charter Supporting People in Care Relationships go to</p> <p>www.dhs.vic.gov.au/about-the-department/documents-and-resources/policies,-guidelines-and-legislation/carers-recognition-act-2012</p>

10 HIV AND DISCRIMINATION IN HEALTH AND AGEING SERVICES

HIV and discrimination

- It is against the law to discriminate against someone on the basis of their HIV status
- HIV is recognised as a disability in Commonwealth and Victorian discrimination laws
- People living with HIV are protected from discrimination whether or not HIV is visibly affecting their health
- It is possible to be discriminated against on the basis of HIV if people have assumed someone is living with HIV when they are not
- People can be discriminated against directly on the basis of their HIV status and indirectly by imposing unreasonable conditions or policies and practices that treat people differently

PEOPLE LIVING WITH HIV: HIV AND DISCRIMINATION

What is discrimination?

Discrimination happens when you are treated less fairly or bullied because of a personal characteristic you have, are presumed to have or people you associate with have. As a result people who do not have this characteristic are treated better than you. Discrimination is unlawful when the characteristic that is used to discriminate against a person is protected from discrimination by law.

HIV and discrimination

It is unlawful to discriminate against someone on the basis of HIV status or related illness. HIV is recognised as a disability in both Commonwealth and Victorian discrimination law. This means the law protects people living with HIV from being treated unfairly or being bullied on the basis of living with a disability.

People are protected from discrimination related to HIV even if:

- their health is not visibly affected by HIV
- they do not have HIV but other people have assumed that they are living with HIV
- they are treated unfairly because they may contract HIV in the future

This also means that carers are able to seek protection from discrimination on the basis of HIV. A carer may be treated unfairly because they are presumed to be living with HIV or likely to contract HIV in the future because the person they care for someone living with HIV.

Commonwealth and Victorian discrimination laws also prohibit discrimination on the basis of gender, race, religious beliefs, sexual orientation, and gender identity.

Can discrimination occur in aged care settings?

Discrimination laws protect PLHIV from being discriminated against when accessing health services, aged care facilities, or being treated less favorably by health professionals and aged care workers.

However, discrimination on the basis of disability may be acceptable if:

- there is a real risk to your health, safety, or property (or to other people's) and the discriminatory measures are needed to protect you or necessary to protect public health or
- the discriminatory measures were taken to assist people with special needs or disabilities

It should be noted that in Victoria religious bodies can still discriminate against people on the basis of gender identity and sexual orientation, to ensure that the religious beliefs or principles of their organisations are followed. However, religious organisations that are Commonwealth-funded aged care services are not allowed to discriminate against people on the basis of sexuality or gender identity.

HEALTH PROFESSIONALS: HIV AND DISCRIMINATION

What is discrimination?

Discrimination occurs when people are treated less fairly because they have a personal trait or are associated with people who have a personal trait, such as a religious belief, which others don't have. As a result people without that trait are treated better than those who have or are assumed to have that trait.

Discrimination can happen as a direct result of a personal trait or indirectly as a result of an unreasonable requirement, condition, policy, or procedure that results in people being unfairly disadvantaged.

HIV and discrimination

HIV is protected under the ground of disability in both Commonwealth and State discrimination law. This means the law protects people living with HIV from being treated unfairly or bullied on the basis of living with a disability.

PLHIV are protected from discrimination relating to their HIV status even if:

- their health is not visibly affected by HIV
- they do not have HIV but other people have assumed that they are living with HIV
- they are treated unfairly because they may contract HIV in the future

It is also unlawful to treat someone unfairly or discriminate on the basis of their sexuality or gender identity.

Health professionals and discrimination

Health professionals and services cannot treat PLHIV less favorably or refuse to provide care or treatment on the basis of their HIV status. They need to ensure that they do not indirectly discriminate against clients on the basis of their HIV status or sexual orientation. This can happen by having policies and/or procedures that disadvantage people or treat them unfairly.

However discrimination on the basis of disability may be acceptable if:

- there is a real risk to your health, safety or property (or to other people's) and the discriminatory measures are needed to protect you or necessary to protect public health or
- the discriminatory measures were taken to assist people with special needs or disabilities.

It should be noted that in Victoria religious bodies can still discriminate on the basis of gender identity and sexual orientation

to ensure that the religious beliefs or principles of their organisations are conformed with.

However religious organisations that are Commonwealth-funded aged care services are prohibited from discriminating against people on the basis of sexuality or gender identity.

Health professionals living with HIV

Employers cannot discriminate against an employee on the basis of their HIV status except if;

- an employer would have to make unreasonable adjustments to their workplace or work situation so that you could apply for, or perform a job or;
- a person living with HIV could not adequately perform a job even if an employer made reasonable adjustments to the workplace or work situation.

Discrimination, bullying and harassment on the basis of an employee's HIV status is unlawful in the workplace.

Religious bodies in Victoria, with the exception of Commonwealth funded aged care services, can still discriminate on the basis of a person's sexuality or gender identity. This could possibly result in the service lawfully refusing to employ an openly gay or transgender health professional.

MANAGEMENT AND SERVICE SETTINGS: HIV AND DISCRIMINATION

HIV status is protected from discrimination under both Commonwealth and State laws on the grounds of disability. People are protected from discrimination on the basis of HIV even if:

- their health is not visibly affected by HIV
- they do not have HIV but other people have assumed that they are living with HIV
- they are treated unfairly because they may contract HIV in the future

FURTHER INFORMATION

Victorian Equal Opportunity and Human Rights Commission

www.humanrightscommission.vic.gov.au/index.php/discrimination

Human Rights Commission Australia

www.humanrights.gov.au

Disability

discrimination

www.humanrights.gov.au/our-work/disability-rights/guides/brief-guide-disability-discrimination-act

Different types of discrimination

Discrimination happens when people are treated less favourably than other people because:

- they have a personal characteristic, or
- they are perceived to have a personal characteristic, or
- they associate with people who have a personal characteristic.

You may be discriminated against directly or indirectly on the basis of a personal characteristic.

Direct discrimination: This happens when someone is treated unfavourably because of a personal characteristic protected by the law. It often happens when people make unfair assumptions about what people with certain personal characteristics can and cannot do.

Indirect discrimination: This happens when there are unreasonable requirements, conditions, or practices imposed that disadvantage a person or group of people because of a personal characteristic. These discriminatory behaviours can become an entrenched part of an organisation or community and can be reinforced by policies and procedures.

Health professionals and discrimination

Health professionals and services cannot treat PLHIV less favorably or refuse to provide care or treatment on the basis of their HIV status. Health professionals and services need to ensure that they do not indirectly discriminate against PLHIV. This can happen by having policies or procedures that disadvantage people or treat them unfairly.

Discrimination may be acceptable if:

- there is a real risk to your health, safety, or property (or to other people's) and the discriminatory measures are needed to protect you or necessary to protect public health or

- the discriminatory measures were taken to assist people with special needs or disabilities.

It should be noted that in Victoria religious bodies can still discriminate on the basis of gender identity and sexual orientation, to ensure that the religious beliefs or principles of their organisations are conformed with. However, religious organisations that are Commonwealth-funded aged care services are prohibited from discriminating against people on the basis of sexuality or gender identity.

Health professionals living with HIV

Employers cannot discriminate against an employee on the basis of their HIV status except if:

- an employer would have to make unreasonable adjustments to their workplace or work situation so that you could apply for, or perform, a job or
- a person living with HIV could not adequately perform a job even if an employer made reasonable adjustments to the workplace or work situation

Discrimination, bullying, and harassment on the basis of an employee's HIV status is unlawful in the workplace. Religious bodies in Victoria, with the exception of Commonwealth-funded aged care services, can still discriminate against a person on the basis of their sexuality or gender identity. This could possibly result in the service lawfully refusing to employ an openly gay or transgender health professional.

11 DISCLOSURE, CONFIDENTIALITY AND PRIVACY

PEOPLE LIVING WITH HIV: DISCLOSURE, CONFIDENTIALITY AND PRIVACY

Disclosing your HIV status to trusted health professionals can ensure you receive the highest standard of care and treatment possible.

Disclosing your HIV status

People living with HIV do not have to tell health professionals about their HIV status. There is no legal requirement to disclose HIV status before undergoing any type of medical examination or treatment. Health professionals are expected to use the same standard precautions for all clients regardless of their HIV status.

However, it can be useful for client's to disclose their HIV status to health professionals to ensure that HIV medications do not interact with any other medications, and that HIV will not affect the progression or treatment of any other medical conditions.

Disclosure of a client's HIV status by health professionals

In Victoria health professionals can only disclose a client's HIV status if:

- it is made with the express consent of the person
- it is expressly authorised, permitted, or required by law
- the information is required for medical treatment or is disclosed by medical staff to next of kin or a family member in accordance with recognised medical practices
- it is required by the Australian Red Cross Society for the purposes of tracing blood or blood products

There would be very few situations in which a health professional would need to disclose a client's HIV status. For example:

- If a needle stick injury has occurred, resulting in a real risk of transmission, and it is not possible to conceal the identity of the client who has refused to consent to the disclosure of their HIV status, or

- If there is a need to know a client's HIV status for treatment purposes that would benefit the client if they have been in an emergency situation or are unconscious.

Client confidentiality and privacy

Health professionals are bound by the same professional and ethical duties to maintain client confidentiality as they are for all other clients. Specific provisions exist to ensure that:

- health professionals maintain client confidentiality
- no information can be disclosed that could identify someone as a client of that service
- privacy of all health information and records collected

Commonwealth and Victorian privacy laws cover all private and public health services in Victoria. This includes hospitals, community health centres, aged care facilities, palliative care services, disability services, and pharmacists.

The right to privacy is also protected under the *Victorian Charter of Human Rights and Responsibilities*. This means that all public authorities, including Victorian government departments, public hospitals, and local councils, are compelled to act in a way that will protect your right to privacy.

Access to your health information

Clients can access their health information that is held in public and private health services in Victoria. Clients also have the right to a say what happens to this information.

If a health service does not provide a client's full health record when seeking to access them the health record can be applied for under Freedom of Information laws.

Any complaints regarding access to health records should be directed to the Health Services Commissioner. For further information see **Section 14. Complaints information for clients and health professionals.**

FURTHER INFORMATION

Freedom of Information
www.foi.vic.gov.au

Health Services
Commissioner
www.health.vic.gov.au/hsc

In Victoria health care workers can only disclose the HIV status of a client if:

- it is made with the consent of the person;
- it is expressly authorised, permitted or required by law (criminal court proceedings or in a public interest matter)
- it is required for the provision of health care treatment
- it is required in accordance with recognised medical practices to the next of kin or family member
- to the Australian Red Cross Society for the purposes of tracing blood or blood products

HEALTH PROFESSIONALS: DISCLOSURE, CONFIDENTIALITY, AND PRIVACY

Disclosure is a client's choice

People living with HIV (PLHIV) are not required to disclose their HIV status to health professionals, regardless of the type of medical examination or treatment it may concern. However client disclosure can be important.

If a client discloses their HIV status to health professionals it can:

- ensure they receive the highest level of care and treatment
- ensure a holistic approach to their care and support is provided
- relieve their anxiety about receiving negative reactions about living with HIV
- it can build trust and confidence in each other

Building rapport and trust with PLHIV is crucial to enable clients to disclose their HIV status.

Disclosing a client's HIV status

Careful and limited disclosure of a client's HIV status may be required if it is directly necessary for the treatment or care of that person, or there is an imminent risk to another person's health or safety.

Such disclosure must only ever occur in accordance with the relevant laws.

Examples of health professionals disclosing a patient's HIV status without consent:

- a needle stick injury has occurred resulting in a real risk of transmission, and it is not possible to conceal the identity of the client who has refused to consent to disclosure
- if there is a need to know a client's HIV status for treatment purposes that would benefit to the patient if they have been in an emergency situation or is unconscious

- if there are real concerns the person is placing others at risk of HIV transmission

As health professionals are required to use standard precautions when in contact with a client's blood or bodily fluids there will be very limited circumstances that you would need to disclose a client's HIV status.

Health professionals disclosing their HIV status

Health professionals only have to disclose their HIV status to an employer if it means that they cannot do their job or part of their job as a result of their HIV status. An example of when health professionals need to disclose their HIV status is if they are required to undertake procedures that have a high risk of HIV transmission (exposure-prone procedures). However, disclosure in any other situation is not legally required. If decisions regarding work practices and duties are being made on the basis of a person's HIV status, where there is extremely low risk of transmission, it could be discrimination and legal advice should be sought.

Privacy and confidentiality

If a client tells you they have HIV, or you find out in the course of your work, this should not be discussed with anyone else, including their family or carers, except in very limited circumstances.

Health professionals have an ethical and legal duty to maintain client confidentiality and privacy. Confidentiality is extremely important to PLHIV due to the high levels of stigma, discrimination and fear that still exists towards HIV in our community. The protection of confidentiality in small communities and cultural groups can be of even higher importance to ensure that person is able to continue to live in those communities.

In Victoria, health professionals' duty to maintain client confidentiality and privacy includes:

- not disclosing information that could identify that a client uses the service
- ensuring the security and privacy of all health information and records collected
- only collecting the necessary and relevant information from clients
- not using or disclosing for any purpose other than why it was collected
- ensuring clients can access health records and information if requested

Commonwealth and Victorian privacy laws apply to all private and public health services including hospitals, community health centres, aged care facilities, palliative care services, disability services and pharmacists.

MANAGEMENT AND SERVICE SETTINGS: DISCLOSURE, CONFIDENTIALITY, AND PRIVACY IN HEALTH CARE SETTINGS

Services should be aware that clients and residents have no obligation to disclose their HIV status to health professionals. Although disclosure would ensure that clients receive the most appropriate and holistic form of care and treatment, many clients will be unwilling to do this. Concerns relating to breaches of confidentiality, stigma, and discrimination that clients may have experienced, or fear experiencing, may prevent their disclosure.

Creating a culture of trust, inclusion, and respect for diversity within service settings may assist a client's willingness to disclose their HIV status. Ensuring clients build rapport and confidence with not only health professionals but all staff in the service may assist in clients disclosing this information.

The table below outlines disclosure obligations for clients, health professionals living with HIV, and health professionals and services disclosing the HIV status of clients.

Table 8: HIV and disclosure in health care settings

PEOPLE LIVING WITH HIV	HEALTH PROFESSIONALS LIVING WITH HIV	HEALTH PROFESSIONALS AND SERVICES
<ul style="list-style-type: none"> • There is no legal obligation upon clients to disclose their HIV status to health professionals or services 	<ul style="list-style-type: none"> • Must disclose their HIV status if it prevents them from completing work duties, e.g. conducting exposure-prone procedures • If their HIV status does not impact upon their ability to carry out their work duties, there is no obligation to disclose their HIV status 	<ul style="list-style-type: none"> • If the person living with HIV has consented to disclosure; • If authorised, permitted or required by law in criminal court proceedings or for a public health matter • If it is required for the provision of health care treatment that will benefit the person living with HIV • In accordance with recognised medical practices to disclose to the next of kin or family member • To the Australian Red Cross Society for the purpose of tracing blood or blood products

Confidentiality and Privacy

Confidentiality is extremely important to PLHIV due to the high levels of stigma, discrimination and fear that still exist in our communities.

The protection of confidentiality in small communities and cultural groups can be of even higher importance to ensure that person is able to continue to live in those communities. The same level of importance for confidentiality can be placed on aged care services and residential facilities, which form their own small communities.

Health services have the same ethical and legal duties to maintain client confidentiality and privacy for PLHIV as for any other clients. In Victoria these obligations include:

- not disclosing information that could identify that a client uses the service
- ensuring the security and privacy of all health information and records collected
- only collecting the necessary and relevant information from clients
- not using or disclosing for any purpose other than why it was collected
- ensuring clients can access health records and information if requested

Commonwealth and Victorian privacy laws apply to all private and public health services including hospitals, community health centres, aged care facilities, palliative care services, disability services, and pharmacists.

For further information refer to Table 9 below.

Table 9: Privacy legislation that affects the health sector

PRIVACY LEGISLATION	PROVISIONS	LINK
<i>Health Records Act 2001</i> (Vic)	<ul style="list-style-type: none"> • Protects privacy rights of patients and their personal information in both public and private sectors • Allows the lawful disclosure of patient information in certain circumstances • Provides complaint procedures and legal action to be taken for breaches • Health Privacy Principles: how organisations use and disclose health information 	<p>Information on <i>the Health Records Act 2001</i> www.health.vic.gov.au/healthrecords</p> <p>Information on the Health Privacy Principles www.health.vic.gov.au/hsc/downloads/hppextract.pdf</p>
<i>Health Services Act 1988</i> (Vic)	<ul style="list-style-type: none"> • Protects patients' right to confidentiality in public and private hospitals, day procedure centres and community health centres • Ensures services cannot indirectly or directly disclose identity of patients accessing services • Allows the lawful disclosure of patient information in certain circumstances • Privacy provisions apply to health services, its board and those employed or engaged by services 	<p><i>The Health Services Act 1988</i> www.austlii.edu.au/au/legis/vic/consol_act/hsa1988161/</p>

PRIVACY LEGISLATION	PROVISIONS	LINK
<i>Public Health and Wellbeing Act 2008</i> (Vic)	<ul style="list-style-type: none"> • Protect the confidentiality of people living with HIV when disclosing test results • Enables Court orders to be requested for closed court or tribunal hearings and the restriction of the publication of any part of legal proceedings related to disclosure of a person's HIV status 	<p>The <i>Public Health and Wellbeing Act 2008</i> www.austlii.edu.au/au/legis/vic/consol_act/phawa2008222/</p>
<i>Privacy Act 1988</i> (Cth)	<ul style="list-style-type: none"> • Provides privacy protections for patients accessing both government and non-government agencies • Allows the lawful disclosure of patient information in certain circumstances • Provides complaint procedures and legal action to be taken for breaches • Australian Privacy Provisions: regulates handling of personal information by government organisations and private organisations with a minimum annual turnover of \$3 million 	<p>Information on the <i>Privacy Act 1988</i> www.oaic.gov.au/privacy/privacy-act/the-privacy-act</p> <p>Information on the Australian Privacy Provisions www.oaic.gov.au/privacy/privacy-act/australian-privacy-principles</p>
<i>Charter of Human Rights and Responsibilities Act 2006</i> (Vic)	<ul style="list-style-type: none"> • Section 13 provides the right privacy, which is consistent to the privacy defined in <i>the Health Records Act 2001</i> (Vic) 	<p>Information on Privacy and the Charter on Responsibilities and Human Rights www.privacy.vic.gov.au/privacy/web2.nsf/files/privacy-and-the-charter-of-human-rights-and-responsibilities</p>

12 ADVANCE CARE PLANNING, ENDURING POWERS OF ATTORNEY, AND WILLS AND ESTATES

ADVANCE CARE PLANNING

If your choices for future health care are known, they can be respected.

Advance care planning (ACP) helps people prepare and record decisions about the health care they want if they find themselves no longer able to communicate their wishes or decisions. It aims to ensure people's dignity is respected and to prevent suffering. It may also include end of life decisions.

ACP ensures there is a clear statement outlining clients wishes that health professionals can follow. You can also nominate an advocate to ensure your wishes are adhered to. If there is no clear statement outlining your wishes, doctors must treat you in the most appropriate way.

Steps to consider in Advance Care Planning

1. **Discuss:** Talk with health professionals, carers and family about the likely progression of illnesses or injuries and treatment options. This information will help inform your choices about future health care.
2. **Nominate:** Nominate someone to act as a substitute decision maker. This person will discuss health care options with medical professionals when you are no longer able to. They can be a friend, family member, or someone you trust. When nominating a substituting decision maker consider whether that person will be able to carry out your express wishes during a difficult time and always act in your best interests.
3. **Record:** A clear set of instructions should be recorded and provided to the substitute decision maker to follow. These instructions should include the preferred future treatment and care options and outline any unacceptable outcomes, including circumstances that are not considered dignified or may cause prolonged and unnecessary suffering.

Advance Care Planning documents can include:

- an Advance Care Directive/Statement of choices
- an enduring power of attorney (medical treatment)
- a letter to the person you nominate as your substitute decision maker
- an entry in your medical record with clear instructions which outline your views

Table 10: Advance Care Planning documents

DOCUMENT	PURPOSE	LINKS TO FORMS
Advanced Care Planning/ Advance Care Directive/ Statement of choices	These documents outline a person’s wishes regarding medical and treatment options to assist the substitute decision maker and doctor to make decisions when a person is no longer able to.	<p>Advanced Care Plan form http://advancecareplanning.org.au/library/uploads/documents/vic/ACP_Aged_Care_Oct_2012_v14.pdf</p> <p>Advance Care Plan/ Statement of choice form http://advancecareplanning.org.au/library/uploads/documents/vic/Vic_Advance_Care_Directive_CP.pdf</p> <p>Advance Care Plan/ Statement of Choices (non-competent person) http://advancecareplanning.org.au/library/uploads/documents/vic/Non_competent_SOC_Vic_Oct_2010.pdf</p>
Enduring power of attorney (Medical Treatment)	<p>This document appoints a substitute decision maker for medical treatment and care decisions if a person is unable to make these decisions.</p> <p>Consider writing to the substitute decision maker a letter outlining care and treatment wishes.</p>	<p>Enduring Power of Attorney (medical treatment) form http://www.publicadvocate.vic.gov.au/our-services/publications-forms/enduring-powers-of-attorney/enduring-power-of-attorney-medical-treatment/98-enduring-power-of-attorney-medical-treatment-form</p>
Refusal of Treatment Certificate	This document refuses treatment generally or of a particular kind for a current condition. It also allows the appointment of an agent or substitute decision maker who can refuse treatment.	<p>Refusal of Treatment Certificate – Competent Person http://www.publicadvocate.vic.gov.au/our-services/publications-forms/medical-consent/refusal-of-treatment/81-refusal-of-treatment-certificate-competent-person</p> <p>Refusal of Treatment Certificate – Incompetent Person http://www.publicadvocate.vic.gov.au/our-services/publications-forms/medical-consent/refusal-of-treatment/82-refusal-of-treatment-certificate-agent-or-guardian-of-incompetent-person</p>

FURTHER INFORMATION

Take control tool kit: how to make powers of attorney and guardianship
www.publicadvocate.vic.gov.au/publications/121

Advanced Care Planning
<http://advancecareplanning.org.au>

Decision assist: palliative care and advanced care planning
www.caresearch.com.au/caresearch/tabid/2583/Default.aspx



FURTHER INFORMATION

Legal Aid provides further information on the powers of attorney www.legalaid.vic.gov.au/find-legal-answers/free-publications-and-resources/take-control-kit-for-making-powers-of-attorney-and-guardianship

POWERS OF ATTORNEY

The information below reflects the legal position in Victoria after 1 September 2015.

Principals and Attorneys

The person making the enduring power of attorney or supportive attorney is known as the *principal* and the person being given the power to make decisions on behalf of the principal is known as an *attorney*.

Enduring Powers of Attorney

An enduring power of attorney is a legal document that allows a person (the principal) to choose who can make decisions on their behalf when they no longer have the mental capacity to do so. These decisions can include financial, legal, and personal decisions.

An enduring power of attorney can only act on behalf of the principal if the principal no longer has the mental capacity to make these decisions.

More than one attorney can be appointed as an enduring power of attorney. Attorneys can be appointed to make specific decisions such as dealing with financial issues or day-to-day decisions, or they may be authorised to make all necessary decisions within the enduring power of attorney.

Supportive Attorney

A principal can appoint a *supportive attorney*. A supportive attorney will assist and support principals to make and implement their own decisions when they still have the mental capacity to do so.

A supportive attorney cannot make decisions for the principal. However they may be able to;

- Access, collect and obtain personal information about the principal
- Communicate or assist in communicating information about decisions made by the principal

- Do anything that is reasonably necessary to implement these decisions, unless they are significant financial transactions.

More than one supportive attorney can be appointed. A principal may appoint a supported attorney to provide support regarding specific decisions or all financial and personal matters under the power of attorney.

Making a power of attorney

A power of attorney must be completed in a prescribed form and signed by the principal and witnesses. The Office of the Public Advocate Take Control tool kits provides information on how to make a power of attorney or guardianship <http://www.publicadvocate.vic.gov.au/>

Cancelling a power of attorney

The principal is able to cancel a power of attorney if they still have the mental capacity to make decisions. A revocation form must be completed by the principal and reasonable steps must be taken to inform the attorney that their position has been cancelled.

Once the principal loses their ability to make their own decisions they will not be able to cancel an enduring power of attorney.

Appointment of a Guardian

A guardian is a person or organisation that is appointed to make personal lifestyle decisions for someone with a disability, who no longer has the mental capacity to make these decisions themselves. These decisions may include living arrangements, work arrangements, medical treatment and access to services.

An Administrator is a person or organisation that is appointed to make legal and financial decisions for a person with a disability who does not have the mental capacity to make their own decisions any longer.

When is a Guardian or Administrator appointed?

If an enduring power of attorney has not been appointed and a person with a disability, such as HIV, loses their mental capacity to manage their affairs a guardian or administrator may be appointed by Victorian Civil and Administrative Tribunal (VCAT).

For example a guardian and administrator may be appointed if someone living with HIV develops a cognitive impairment such as dementia and has not appointed an enduring power of attorney.

Before a guardian or administrator is appointed several factors are considered:

- your ability to manage your own affairs
- any relevant medical or health conditions that might affect your ability to make decisions, such as dementia, intellectual disability, mental illness, or acquired brain injury
- whether it is in your best interests to have a guardian or administrator appointed

Guardians have also been appointed make decisions regarding HIV testing and treatment for a person who no longer has the mental capacity to consent to this themselves.

Who can be a guardian?

VCAT can appoint a family member, friend, or organisation to act as a guardian.

WILLS AND ESTATES

A will is a document that states a person's wishes regarding the disposal of their property when they die. It is always advisable to have an up-to-date will, regardless of how much property will be included.

If you die without a will

If a person dies without a will they are said to have died intestate. This usually means that their inheritance would be divided between their blood relatives or domestic relationship and family members.

However, it can mean that friends will have very little claim to anything in the estate. This is especially important if your blood relatives have little contact with extended friendship networks.

Please note that same-sex partners are also recognised as domestic partners and will have inheritance rights in Victoria if you die without a will.

Making a will

Anyone can make their own will. Forms are available in news agencies. However, if the estate is large, or the arrangements are complex, it is worthwhile seeking legal advice.

Know where your will is!

Make sure that your will is stored in a safe place and that your executor, who is the person you have nominated in your will to carry out your wishes after you die, knows where it is kept.

An up-to-date Will ensures:

- you can consider how you would like your possessions distributed
- your wishes are clear and current
- disputes about your estate may be reduced

FURTHER INFORMATION

Office of the Public Advocate, Guardianship and Principles and Practice Guidelines
<http://www.publicadvocate.vic.gov.au/>

Legal Aid information on wills and estates
<http://www.legalaid.vic.gov.au/find-legal-answers/wills-and-estates>

Legal information on making a will
www.liv.asn.au/For-the-Community/Legal-Fact-Sheets/Wills-and-Estates

13 HIV WORKPLACE POLICIES AND STRATEGIES

FURTHER INFORMATION

Australian Guidelines for the Prevention and Control of Infection in Healthcare (2010)
www.nhmrc.gov.au/guidelines/publications/cd33

Australian National Guidelines for the Management of Health Care Workers known to be Infected with Blood-Borne Viruses
www.health.gov.au/internet/main/publishing.nsf/Content/cda-cdna-bloodborne.htm

PEP guidelines for occupational exposure – further reading for managers
<http://www.ashm.org.au/pep-guidelines>

HEALTH PROFESSIONALS: WORKPLACE POLICIES AND HIV TRANSMISSION

Policies on HIV and the workplace provide guidance on how to reduce the risk of HIV transmission to both health professionals and patients through prevention, control and management strategies.

Prevention and control of HIV in workplaces

HIV prevention and control guidelines should be followed by all health professionals who have contact with;

- blood
- bodily fluids
- broken skin, and
- the surfaces of eyes, nose, and mouth

To reduce the risk of HIV infection health professionals are expected to treat all blood and bodily fluids as potentially infectious. This is called using a *standard precautions* approach. A standard precautions approach:

- provides a high level of protection against HIV and other blood borne viruses
- ensures the same precautions and work practices are used regardless of information or assumptions about a person's HIV status
- reduces the impact of discrimination and stigma towards people living with HIV

Examples of routine standard precautions to minimise the risk of HIV infections in the workplace include:

- always using and disposing of needle sharps appropriately
- always using synthetic or latex gloves when blood or bodily fluids are involved
- always sterilising reusable equipment

Health professionals should be using standard precautions on a routine basis. However, there will be circumstances where additional precautions are needed to reduce the risk of HIV transmission. Further precautions may be recommended when PLHIV have other complicating health issues such as tuberculosis.

All health professionals performing high risk procedures

Procedures that have a high risk of HIV transmission are those where an injury to a health professional could result in their blood contaminating the open tissue of a patient. They are called exposure-prone procedures (EPPs).

Examples of EPPs include:

- procedures involving a sharps (scalpels, needles, etc.)
- procedures involving internal examinations, the health professional's hands being in a body cavity
- surgery and dental procedures

Health professionals performing exposure prone procedures should:

- always know whether they have HIV or any other blood borne virus
- be tested for HIV and other blood borne viruses each year and
- be re-tested immediately if there has been an incident that could result in HIV

Health professionals living with HIV

Due to the high risk of HIV transmission health care professionals who are HIV positive are not allowed to perform EPPs. The scope of restrictions on their work practices depends upon the likelihood that an EPP will form part of the duties of the field of work undertaken.

Occupational Health and Safety

Incidents involving needle stick injuries and other incidents involving blood or bodily substances are the main causes of occupational hazards related to HIV for health professionals.

All employees, people at work, and members of the public are entitled to the highest level of protection against risks to their health and safety. Workers in the health care sector are

covered by Commonwealth and Victorian occupational health and safety laws (OHS), sometimes known as workplace health and safety laws (WHS). Both employees and employers have obligations to prevent and manage risks for your own and other people's health and safety. The table below summarises our obligations to reduce and prevent risks on the workplace.

Table 11: Occupational Health and Safety obligations to prevent risks in the workplace

EMPLOYEE OBLIGATIONS	EMPLOYER OBLIGATIONS
<ul style="list-style-type: none"> To take reasonable care for their own health and safety To take reasonable care of the health and safety of anyone else who may be affected by their actions in the workplace, and To protect themselves from risks by co-operating with your employer's health and safety obligations, such as following workplace policies and procedures, attending workplace health and safety training and identifying workplace hazards and risks. 	<ul style="list-style-type: none"> To monitor employee health Keep information and records on the health and safety of employees Employ or engage qualified persons to provide health and safety advice, and Monitor workplace conditions to identify, eliminate or reduce any risks to health and safety as far as is practicable.



The Guidelines on the management of people living with HIV who place others at risk

The *Guidelines on the management of PLHIV who place others at risk* provide support and guidance to health professionals managing people that are accused of putting others at risk of HIV transmission. Client confidentiality is very important. However, if health professionals are concerned there is a real risk that a client is putting others at risk of HIV transmission it is lawful to disclose this information, including their HIV status, to the Department of Health and Human Services. A management program of education, support and behavior change will be implemented with further interventions put in place if necessary.

For further information go to Table 2: Workplace policies to control, prevent and manage the risk of HIV transmission.

MANAGEMENT AND SERVICE SETTINGS: WORKPLACE POLICIES AND HIV TRANSMISSION

There are four main policies that focus on reducing the risk of HIV transmission in health care settings:

- Australian Guidelines for the Prevention and Control of Infection in Healthcare (2010)
- National Guidelines for the Management of Health Care Workers known to be Infected with Blood-Borne Viruses

- National guidelines for post-exposure prophylaxis after non-occupational and occupational exposure to HIV
- Guidelines for the management of people living with HIV who put others at risk

All health care services should have an effective infection control strategies to provide a safe working environment and minimises the risk of sharps injuries, exposure to blood or bodily fluids, and prevents HIV transmission

for both health professionals and patients. The various prevention and control guidelines apply to all health professionals who have contact with blood, bodily fluids, broken skin and the surfaces of eyes, nose, and mouth. Health care services should ensure that all health professionals are using a standard precautions approach to reducing the risk of HIV transmission, and adhering to their own obligations if they are undertaking EPPs that involve a high level of risk of HIV transmission.

Table 12: Prevention, control and management strategies for HIV in health care settings

UNDERTAKING STANDARD PRECAUTIONS	HEALTH PROFESSIONALS' OBLIGATIONS WHEN CONDUCTING EXPOSURE PRONE PROCEDURES (EPPS)
<ul style="list-style-type: none"> • Provides a high level of protection against HIV and other blood borne viruses • Ensures health professionals treat all blood and bodily fluids as if they are infectious • Ensures the same precautions and work practices are used regardless of information or assumptions about a patient's HIV status • Reduces the impact of discrimination and stigma towards People with HIV. 	<ul style="list-style-type: none"> • Health professionals living with HIV cannot perform EPP • Must know whether they have HIV or any other blood borne virus • Should be tested annually for HIV and other blood borne viruses • Be re-tested immediately if there has been an incident that could result in HIV transmission and consider accessing PEP medication.

Guidelines for the management of people living with HIV who put others at risk

The *Guidelines on the management of people living with HIV who place others at risk* ('the Guidelines') provide a public health management guide on how to manage people accused of putting others at risk of HIV transmission. The guidelines provide health care workers support and guidance on how to manage challenging clients.

Client confidentiality is always a high priority. However, these protections may be limited when there is a duty to a third party who may have been exposed to HIV, and disclosure is necessary to manage a serious HIV public health risk. The limited disclosure and use

of confidential information may also be necessary to manage a person living with HIV who is putting others at risk. This should only occur if there is a very clear public health need. This allows health professionals to notify the Victorian Department of Health and Human Services if they believe a client living with HIV is putting other people at risk of HIV transmission. The Guidelines provide guidance on how to manage such sensitive situations effectively.

Health professionals concerned that a person is putting others at risk of HIV infection may request assistance from the Chief Health Officer, who will employ a public health approach to manage this risk, through the *Public Health and Wellbeing Act 2008* (Vic).

This request is managed by the Partner Notification Officers (PNOs) in the Health Protection Branch of the Department of Health and Human Services. The framework provides five levels of intervention. The majority of people who place others at risk are effectively managed using this approach that focuses

upon achieving long-term behavioural change to reduce future risk.

Below in Table 13 is a summary of the main workplace policies that provide guidance and strategies to prevent, control, and manage the risk of HIV transmission.

Table 13: Main workplace policies that provide guidance and strategies to prevent, control, and manage the risk of HIV transmission

Five intervention levels for people putting others at risk of HIV transmission:

Level 1: Counselling, education and support

Level 2: Providing formal support to the individual's primary health care provider.

Level 3: Letter of warning: advises the expectations of the Chief Health Officer, that persons with HIV take all reasonable steps to eliminate or reduce the risk of any other person contracting HIV

Level 4: Public Health Order (behaviour): Counselling, education, psychological assessment, order to refrain from behaviours and visiting specific places if appropriate

Level 5: Public health order (detention or isolation): The Chief Health Officer may order the isolation or detention of person subject to the order

PRIORITY

The *Seventh National HIV Strategy 2014–2017* sets the direction for Australia's response to HIV. Alongside the Strategy's six priority populations it recognises that people living with HIV are living longer. The strategy acknowledges that the ageing nature of the population will have important implications on the health care system and the current models of care and treatment. This includes being able to effectively address the co-morbidities of ageing populations and HIV and long-term impacts of living with HIV.

- People living with HIV
- Gay men and other men who have sex with men (MSM)
- Aboriginal and Torres Strait Islander people
- People from high HIV prevalence Countries and their partners
- Travellers and mobile workers
- Sex workers
- People who inject drugs
- People in custodial settings

Table 14: Workplace policies to control, prevent and manage the risk of HIV infection

POLICY	CONTENT	IMPLICATIONS	LINK TO POLICIES
Australian Guidelines for the Prevention and Control of Infection in Healthcare (2010)	Provide strategies on preventing and controlling HIV in health care settings.	Providing training and effective systems to ensure health professionals apply a standard precautions approach to all procedures involving blood, bodily fluids, surfaces of the eye, mouth and nose.	www.nhmrc.gov.au/guidelines/publications/cd33
Australian National Guidelines for the Management of Health Care Workers known to be living with blood-borne viruses	Provides strategies on reducing the risk of HIV transmission for both health professionals and clients during high risk procedures.	Implement systems to assist health professionals undertaking EPPs fulfil obligations to know HIV status, annually undertake HIV testing and ensure health practitioners living HIV are not involved in EPPs.	www.health.gov.au/internet/main/publishing.nsf/Content/cda-cdna-bloodborne.htm
Guidelines for the Management of people living with HIV Who Place Others at Risk	Provides guidance on managing people who may be putting others at risk of HIV.	Disclosing information to the Victorian Department of Health and Human Services if there are real concerns regarding the risk clients living with HIV may be putting others in and process of managing these clients.	http://docs.health.vic.gov.au/docs/doc/Guidelines-for-the-management-of-people-living-with-HIV-who-put-others-at-risk
National guidelines for post-exposure prophylaxis after non-occupational and occupational exposure to HIV	Provides guidance on the administration of post-exposure prophylaxis after exposure to HIV	Provides guidance in the assessment of risk and necessary prescription of PEP to prevent HIV transmission.	http://www.ashm.org.au/pep-guidelines

HIV and Ageing strategies

There will be implications on the healthcare system and current HIV models of care and support due to the ageing population of people living with HIV.

The strategy also recognises that developing the workforce and creating supportive environments is a priority action area to support for both health professionals and ensure people living with HIV access appropriate care and support.

Table 15: Seventh National HIV Strategy 2014 – 2017 Action areas to improve access to services and appropriate care and support

ENABLING ENVIRONMENTS TO SUPPORT CLIENTS	WORKFORCE DEVELOPMENT
<ul style="list-style-type: none"> • Removing stigma and discrimination in community and healthcare settings and empowering priority populations. • Removing barriers to equality of care for people living with or affected by HIV in the health sector. • Addressing legal barriers to evidence-based prevention strategies across jurisdictions. • Establishing a dialogue between health and other sectors to reduce stigma and discrimination against HIV Positive and affected individuals and communities. 	<ul style="list-style-type: none"> • Ensuring HIV testing and treatment providers have adequate training and support. • Working with organisations to ensure responsive and coordinated training, continued education, and professional support programs are delivered. • Improving collaboration between mental health, drug and alcohol, disability, clinical and community services to address the care and support needs of people with HIV. • Supporting the capacity and role of community organisations to provide education, prevention, support, and advocacy services to priority populations.

FURTHER INFORMATION

The Seventh National HIV Strategy 2014–2017
www.health.gov.au/internet/main/publishing.nsf/Content/ohp-bbvs-hiv

There are several national strategies that address the needs of key populations that are affected by HIV and ageing.

For further information see Table 4 on page 59.

14 COMPLAINTS AND ADVICE FOR CLIENTS AND SERVICE PROVIDERS

FOR MORE INFORMATION ON ACCESSING AN AGED CARE ADVOCATE CONTACT:

National Aged Care Advocacy Line
1 800 700 600; or
Elder Rights Advocacy
Victoria on (03) 9602 3066 or 1 800 700 600 (free call)

CONTACT THE HEALTH SERVICES COMMISSIONER TO MAKE A COMPLAINT:

Ph: 1 300 582 113
E-mail: hsc@health.vic.gov.au
Web: www.health.vic.gov.au/hsc

Online form
<http://docs.health.vic.gov.au/docs/doc/Complaint-form--Office-of-the-Health-Services-Commissioner>

In writing
Health Services Commissioner, Complaints and Information
26th Floor, 570 Bourke Street, Melbourne
Victoria 3000

This section provides information on how to make a complaint about the health, ageing, and disability services. It provides an overview of the complaints process for the main State and Commonwealth complaints bodies, and provides information and resources on dealing with complaints for both clients and health professionals. This section also provides a contact list to legal and advocacy services that support seniors, carers, and people living with HIV.

AGED CARE ADVOCATES

An aged care advocate supports seniors making decisions, provides information on your rights and responsibilities, and supports you when making complaints or raising concerns with service providers. An advocate can be a friend, family member or from an advocacy service.

MAKING A COMPLAINT ABOUT VICTORIAN HEALTH SERVICES

The Health Services Commissioner (HSC) is a free and confidential service that handles complaints about health care providers and health services in Victoria, including complaints about the disclosure of and access to health information.

Who can make a complaint?

- Clients
- Users of the health services
- Service providers
- A relative, friend or guardian can make a complaint on someone's behalf

Who can complaints be made against?

Complaints can be made against Victorian health professionals or health services regarding:

- an unsatisfactory level of care
- a lack of appropriate information or choices regarding care
- being treated without respect and dignity
- any other reason.

How to make a complaint

1. If you cannot resolve your complaint directly with the health professional you can make a written complaint to the HSC.
2. The HSC telephone advice line can help you write your complaint or if the complaint involves a hospital you can contact a liaison officer or patient representative from the hospital to discuss your concerns before contacting HSC.
3. The written complaint will be sent to the health professional or service asking for a response to be provided within two weeks.
4. HSC will send the complainant a copy of the response and ask you to consider it. The complaint may resolve at this stage.

Many complaints are resolved with an explanation or an apology where needed. Most people want to know what went wrong and why, and that there have been improvements made to prevent similar incidents in the future.

If the health professional or services response was not satisfactory the HSC will assess what action should be taken. The HSC may decide:

- to take no further action
- hold a conciliation meeting with the complainant and the health care provider or
- if the complaint relates to unprofessional conduct it may be referred to the Australian Health Practitioner Regulation Agency.

Most complaints that are unresolved after initially seeking further information or an apology from the health professional or service are either closed or referred for conciliation.

Possible outcomes of complaints

- an explanation of what happened or the provision of further information
- an opportunity to discuss your concerns in a face-to-face meeting
- an apology
- changing the system or procedures to avoid similar incidents
- provision of remedial treatment
- payment of compensation

Making a complaint regarding aged care homes and Home Care Packages subsidised by the Commonwealth government

The Aged Care Complaints Scheme is a free and confidential complaints service regarding the standard of services delivered by aged care services subsidised by the Australian Government.

This includes aged care homes and Home Care Packages but not HACC services in Victoria.

Who can make a complaint?

Anyone can make a complaint, including;

- clients
- family, friends, aged care advocates
- service providers

What can a complaint be made about?

Complaints relate to any matters that are the responsibility of the service providers, including;

- quality of care
- choice of activities
- personal care
- meals
- communication between you and staff
- physical environment, comfort, and safety

Making a complaint under the scheme

1. First discuss the complaint with the service or access the internal complaints mechanism. If you are not comfortable doing this seek support from an aged care advocate.
2. If you are not able to resolve the complaint with the health care service you can make a complaint to the scheme online, over the phone or in writing. Complaints may be confidential and/or anonymous.
3. The Aged Care Complaints scheme will contact you to discuss the complaint once it has been lodged, if the complaint is not anonymous.
4. The scheme will work directly with the complainant and the service to resolve the complaint or if this is not possible the scheme will examine the complaint by liaising between the service and the complainant.
5. The scheme will write to the complainant and service to notify them of the result. If you are not happy with the result the scheme will assess if the complaint can be resolved through conciliation, mediation or further investigation.
6. If you are not happy with the final outcome you are able to seek a review of the decision. If you are not satisfied with how the review has been handled you can submit a complaint to the Aged Care Commissioner or the Commonwealth Ombudsman.

Possible outcomes of the complaint include:

- the service addressing the issue appropriately
- the service demonstrating how they will meet their responsibilities
- referring the complaint to the Department of Health and Ageing Compliance Section for action
- no further action

FURTHER INFORMATION

Health Commissioner Victoria
www.health.vic.gov.au/hsc

For clients and carers Information for people wanting to make a complaint

www.health.vic.gov.au/hsc/resources/infosheet.htm

How to make a complaint with the Health Services Commissioner
www.health.vic.gov.au/hsc/patient/complaint.htm

For services

Guide to complaint handling for health service providers
www.health.vic.gov.au/hsc/resources/guide.htm

Information for service providers when a complaint has been made
www.health.vic.gov.au/hsc/provider.htm

CONTACT THE AGED CARE COMPLAINTS SCHEME:

P: 1800 550 552
<http://agedcarecomplaints.govspace.gov.au>

In writing
Aged Care Complaints Scheme
Australian Department of Social Services
GPO Box 9820
Melbourne VIC 3000

FOR FURTHER INFORMATION

Office of the Aged Care Commissioner

www.agedcarecommissioner.gov.au/complaints

For clients and carers

Advocacy services

<http://www.myagedcare.gov.au/how-make-complaint/advocacy-services>

Consumer rights in the Aged Care Scheme

www.myagedcare.gov.au/financial-and-legal/protecting-consumer-rights

For services

Aged Care Complaints Scheme Complaint Handling kit for aged care services

<https://www.dss.gov.au/our-responsibilities/ageing-and-aged-care/programs-services/complaint-handling-toolkit/better-practice-guide-to-complaint-handling-in-aged-care-services>

Policy on Preventing and Managing

Unreasonable Conduct for aged care services

<https://www.dss.gov.au/ageing-and-aged-care/programs-services/policy-on-preventing-and-managing-unreasonable-conduct>

VICTORIAN OMBUDSMAN

The Victorian Ombudsman (the Ombudsman) investigates complaints about Victorian government departments and agencies, including breaches of the Victorian Charter of Rights and Responsibilities.

Who can make a complaint

Anyone, as an individual or as a group of persons, can make a complaint.

Who you can make a complaint about

Complaints about the treatment received from a Victorian public body, generally have to be made within 12 months and include;

- Local councils,
- State government departments
- Victorian aged care services
- Public hospitals
- A private agency that carries out statutory responsibilities of government

Making a complaint

1. Before making a complaint to the Ombudsman, the complainant should try to resolve the concerns with the public body. If you cannot resolve the complaint then contact the Ombudsman.
2. The Ombudsman can investigate informal complaints made over the phone however any formal complaints need to be sent in writing.
3. The Ombudsman will initially seek a response to the complaint and an explanation of the public body's actions. Some matters are resolved at this point and the Ombudsman will notify the complainant if it is finalised at this stage.
4. If your complaint is substantiated the Ombudsman may recommend that the public authority take some action to address the complaint. The Complainant will be informed of the outcome of the complaint.

The Ombudsman cannot advocate for you, provide you with legal advice nor act on your behalf as a legal representative.

CONTACT THE OMBUDSMAN TO MAKE A COMPLAINT

Email: ombudvic@ombudsman.vic.gov.au

Ph: (03) 9613 6222 or

toll free (regional areas only) 1800 806 314

www.ombudsman.vic.gov.au

In writing

Victorian Ombudsman

Level 1 North Tower

459 Collins Street

Melbourne VIC 3000

FURTHER INFORMATION

What the ombudsman can investigate

www.ombudsman.vic.gov.au/Complaints/What-We-Can-and-Cannot-Investigate

For clients and carers

Tips on making complaints to public authorities

www.ombudsman.vic.gov.au/Fact-Sheets/For-Complainants/Fact-Sheet-2-Tips-for-making-a-complaint-to-Victor

For Services

Information for public bodies and agencies – Ombudsman complaints

www.ombudsman.vic.gov.au/Fact-Sheets/For-Respondants/Fact-Sheet-4-Information-for-public-bodies-and-age

How to handle complaints for service providers

www.ombudsman.gov.au/pages/publications-and-media/better-practice-guides/complaint-handling.php

How to manage unreasonable complaints

www.ombudsman.gov.au/pages/publications-and-media/better-practice-guides/unreasonable-conduct.php

DISABILITY COMMISSIONER VICTORIA

The Disability Services Commissioner (the DSC) is a free and confidential service that assists people living with a disability in Victoria, which includes people living with HIV, making complaints about services.

Who can make a complaint?

Any person can make a complaint, including:

- people living with a disability
- family members and
- service providers

Who can you make a complaint about?

- Any registered Victorian disability service providers
- Disability services provided by the Department of Health and Human Services
- Services that provide aids and equipment services or financial intermediary services for people living with a disability, that are contracted by the Victorian government
- Funded disability service providers including advocacy and information services

Making a complaint

1. A complaint about the provision of services or how a service handles your complaint to the DSC. A complaint can be made in writing, verbally or any other way which is appropriate. The DSC is able to assist you in making a written complaint as well.
2. The DSC will assess the complaint by either:
 - talking to the service and possibly asking them to respond to the complaint
 - working with the complainant to fully understand the complaint, the desired resolution, and relaying the services response to the complaint; or
 - working with the complainant and the service to resolve the complaint

Possible outcomes:

- allow further time for resolution
- refer the complaint to conciliation
- refer the complaint to investigation
- the Commissioner can decide that no further action by our office is possible

CONTACT INFORMATION FOR LEGAL, ADVOCACY, AND COMPLAINT SERVICES

This section provides information on services that provide legal information, advocacy assistance and complaints mechanisms for all seniors and people living with HIV.

AGED CARE COMPLAINTS SCHEME

To make complaints about Commonwealth funded aged care homes or home care packages.

Ph: 1800 550 552

Web: <http://agedcarecomplaints.govspace.gov.au>

Post: Aged Care Complaints Scheme, Australian Department of Social Services

GPO Box 9820, Melbourne Victoria 3000

AUSTRALIAN HUMAN RIGHTS COMMISSION

Make complaints and find out information about discrimination and human rights.

Ph: 1300 656 419 (Complaints) or 1300 369 711 (General enquiries)

Web: www.humanrights.gov.au

Post: Australian Human Rights Commission, Level 3, 175 Pitt St, Sydney, NSW 2000

DISABILITY LEGAL SERVICE

This is a community legal service that specialises in disability discrimination and provides free legal advice and information.

Ph: 03 9654 8644

Email: info@ddls.org.au

Web: www.communitylaw.org.au/ddls

Post: Ross House Association Inc.

2nd Floor, 247 Flinders Lane, Melbourne, Victoria 3000

CONTACT THE DISABILITY SERVICES COMMISSIONER

Level 30, 570 Bourke Street, Melbourne, Victoria, 3000 Australia

Phone for enquiries or complaints: 1800 677 342 (free call from land lines)

Email for enquiries or complaints: complaints@odsc.vic.gov.au

www.odsc.vic.gov.au

FURTHER INFORMATION

For clients and carers

Information sheets on how to make a complaint:

This includes information for complainants as well as service providers and services that are receiving complaints against them.

<http://www.odsc.vic.gov.au/information-sheets>

For services

Good practice guide for handling complaints
<http://www.odsc.vic.gov.au/good-practice-guide>

Everything you wanted to know about complaints

<http://www.odsc.vic.gov.au/ComplaintsBooklet>

Investigations guidelines for service providers

<http://www.odsc.vic.gov.au/Investigations-guidance-for-service-providers>

ELDER ABUSE

Elder abuse can take various forms such as physical, psychological or emotional, sexual or financial abuse. It can also result from intentional or unintentional neglect. Seniors Rights Victoria provides information, support, advocacy and legal advice for seniors, family members and concerned service providers regarding elder abuse. Seniors Rights also provides a free, confidential elder abuse helpline

Ph: 1300 368 821.

Web: <http://seniorsrights.org.au>

ELDER RIGHTS ADVOCACY VICTORIA

Free and confidential service advocating for the rights of seniors.

Ph: (03) 9602 3066 or 1800 700 600 (freecall)

Email: era@era.asn.au

Web: www.era.asn.au

Postal: Elder Rights Advocacy Victoria, Level 2, 85 Queen Street, Melbourne, Victoria 3000

FEDERATION OF COMMUNITY LEGAL CENTRES – VICTORIA

The Federation of Community Legal Centres provides economically and socially disadvantaged clients access legal information. The service can locate a Community legal service near you that will provide free legal advice.

Ph: (03) 9652 1500

Email: administration@fclc.org.au

Web: www.communitylaw.org.au

Postal: Federation of Community Legal Centres, Level 3, 225 Bourke Street, Melbourne Victoria 3000 Australia

HEALTH SERVICES COMMISSIONER

The Health Services Commission deals with complaints about Victorian health service providers or health services.

Ph: 1300 582 113

Email: hsc@health.vic.gov.au

Web: www.health.vic.gov.au/hsc

Postal: Health Services Commissioner, Complaints and Information

26th Floor, 570 Bourke Street, Melbourne Victoria 3000

HIV/AIDS LEGAL CENTRE NSW

HIV/AIDS Legal Centre, New South Wales, provides free legal advice and resources for people living in HIV in Australia. HALC is part of the AIDS Council of NSW. HALC operates from Monday to Friday, 10am – 6pm.

Ph: (02) 92062060

Email: halc@halc.org.au

Web: www.halc.org.au

Post: PO Box 350, Darlinghurst NSW 2300

HIV/AIDS LEGAL CENTRE VIC

HIV/AIDS Legal Centre (HALC) provides free legal advice to PLHIV in Victoria. It is part of VAC and is run by professional volunteers. HALC is only open on Thursdays from 6:30 – 9:30pm. The service operates within the Positive Living Centre and is part of the Victorian AIDS Council.

Ph: (03) 9863 0406

Email: legal@vac.org.au

OFFICE OF THE PUBLIC ADVOCATE

Phone: 1300 309 337

Web: www.publicadvocate.vic.gov.au

Post: Office of the Public Advocate, Level 1, 204 Lygon St, Carlton, Victoria 3053

SENIORS LAW VICTORIA – JUSTICE CONNECT

Seniors Law provides free legal assistance to older Victorians who cannot afford to pay for a lawyer in regard to elder abuse and other issues associated with ageing.

Ph: (03) 8636 4400

Web: www.justiceconnect.org.au/our-programs/seniors-law

Post: Seniors Law Victoria, PO Box 16013, Melbourne, Victoria 3007

SENIORS RIGHTS

Service provides a free, confidential information and advocacy on elder abuse and seniors rights.

Elder Abuse helpline: 1300 368 821.

Web: <http://seniorsrights.org.au>

Post: Level 4, 98 Elizabeth Street, Melbourne, Victoria 3000

VICTORIAN EQUAL OPPORTUNITY AND HUMAN RIGHTS COMMISSION

Make complaints and find out information about discrimination and human rights in Victoria

Ph: 1300 891 848

Email: complaints@veohrc.vic.gov.au

Web: www.humanrightscommission.vic.gov.au

Post: Victorian Equal Opportunity and Human Rights Commission, Level 3, 204 Lygon Street, Carlton, Victoria 3053.

VICTORIA LEGAL AID

Legal Aid can provide free or affordable legal advice on criminal, family and civil law matters. The service is means tested. It also provides extensive legal resources for Victorians.

Ph: 1 300 792 387

Web: www.legalaid.vic.gov.au

VICTORIAN OMBUDSMAN

To make complaints about Victorian public authorities such as the Department of Health, public hospitals or local councils.

Ph: (03) 9613 6222 or toll free (regional areas only) 1800 806 314

Email: ombudvic@ombudsman.vic.gov.au

Web: www.ombudsman.vic.gov.au

Post: Victorian Ombudsman, Level 1 North Tower, 459 Collins Street, Melbourne, Victoria 3000

RESOURCES

CARING FOR PEOPLE WITH HIV AND COMPLEX NEEDS

Models of care for people living with HIV in the community in Victoria include care coordination by HIV specialist nurses, general practitioners and hospital specialists. The following organisations and practitioners are involved in collaborative care arrangements and can be called upon for advice and support at any stage:

THE ROYAL DISTRICT NURSING SERVICE (RDNS) HIV PROGRAM

The HIV program, located with RDNS Homeless Person's Program, provides home and community-based care and care coordination in partnership with the Victorian AIDS Council in metropolitan Melbourne and the Mornington Peninsula

Contact

Telephone: 1300 33 44 55 (ask for an HIV Clinical Nurse Consultant)

Website: <http://www.rdns.com.au/services-we-provide/individuals/services-we-provide/hivaids-support-services>

VICTORIAN HIV CONSULTANCY

The Victorian HIV Consultancy is a small multidisciplinary team comprising an infectious diseases physician, a clinical nurse consultant & a clinical nurse specialist in HIV.

Originally established to support end-of-life care needs for people living with HIV/AIDS (PLHIV), the service now includes the continuing care needs of PLHIV, especially those with limited access to mainstream HIV services. This includes rural clients, individuals with a history of disengagement from mainstream health care, those from culturally and linguistically diverse (CALD) backgrounds, aging PLHIV and women.

Referrals can be made by health or allied health professionals or by individuals themselves.

Contact

Fairfield House
55 Commercial Road
Melbourne VIC 3004

PO Box 315 Prahran
VIC 3181 Australia

Telephone: (03) 9076 6097

VICTORIAN AIDS COUNCIL

The Victorian AIDS Council (VAC) is a community organisation dedicated to HIV prevention, the health and wellbeing of the LGBTI community, and the care and support of people living with HIV. Among the services offered to PLHIV are counselling services, community and peer support services, and some financial and legal assistance.

In addition, VAC runs the Positive Living Centre, a community hub providing various services for PLHIV. These include meals and nutrition services; complementary therapies like massage and yoga; and community and peer support services.

Contact

VAC
6 Claremont Street
South Yarra VIC 3141

Telephone: 03 9865 6700 or 1800 134 840

Website: <http://www.vac.org.au>

POSITIVE LIVING CENTRE

51 Commercial Road
South Yarra VIC 3141

Telephone: (03)9863 0444

MELBOURNE SEXUAL HEALTH CENTRE

The Melbourne Sexual Health Centre provides free services related to sexual health. In addition, it runs a specialist HIV clinic called The Green Room. All the doctors and nurses in the Green Room are specialists in HIV medicine. In addition to providing routine blood tests for PLHIV, they also HIV treatments through their onsite pharmacy, and referrals to other health services.

Contact

580 Swanston Street
Carlton VIC 3053

Telephone: (03) 9341 6200 or 1800 032 017

Telephone (The Green Room): (03) 9341 6214

TTY: (03) 9347 8619

Website: <http://www.mshc.org.au>

HOSPITAL ADMISSION RISK PROGRAM

HIV specialist nurses are available at the following hospitals:

- Monash Medical Centre
- Royal Melbourne Hospital/RDNS
- St Vincent's Hospital
- Barwon Health (Geelong)

Website: <http://www.health.vic.gov.au/sexualhealth/harp.htm>

To refer, see: <http://www.health.vic.gov.au/harp/services.htm#how/>

Clinics

The following are HIV specialist general practitioners in primary care, and HIV practice nurses in clinics who treat high numbers of people living with HIV. They also provide care coordination in collaboration with other health professionals, and work in close collaboration with hospital specialists to provide care for people living with HIV in Victoria:

THE CENTRE CLINIC

The Centre Clinic is run by the Victorian AIDS Council, and is a safe, friendly LGBTI general practice. It provides general health care for gay men, lesbians and trans people, as well as specialist medical care for people living with HIV and expert sexual health screening and treatment.

The Centre Clinic has an informal, friendly and relaxed atmosphere. The doctors are all registered general practitioners, meaning they are able to provide healthcare and specialist referrals for all health related matters.

The Centre Clinic has strong links with a range of LGBTI-friendly allied health services throughout Victoria, including dentists, podiatrists, psychologists, counsellors, dieticians, physiotherapists, chiropractors, osteopaths and other specialists.

Contact

77 Fitzroy Street (Rear)
St Kilda VIC 3182

Telephone: (03) 9525 5866

Website: <http://www.vac.org.au/centre-clinic>

PRAHRAN MARKET CLINIC

Prahran Market Clinic is a medical general practice, supported by allied health providers. Particular focus is placed on sexual health, and gay, lesbian and gender diverse health. The clinic is well regarded and respected for its involvement in HIV clinical research trials and for the teaching of medical students.

Contact

Pran Central Shopping Centre
Mezzanine level
325 Chapel Street
Prahran VIC 3181

Telephone: (03) 9514 0888

Website: <http://www.prahranmarketclinic.com>

NORTHSIDE CLINIC

Northside Clinic is a general practice owned and staffed by a number of GPs with years of experience working in Melbourne's inner north. The clinic is open to all, but has a particular focus on sexual health, as well as providing quality medical care in a safe and friendly environment for the gay, lesbian, bisexual, trans and HIV positive communities in Melbourne's north. The clinic provides comprehensive testing for and management of sexually transmitted infections (STIs) and HIV, as well as a full range of general practice and allied health services.

Contact

370 St Georges Road
Fitzroy North VIC 3068

Telephone: (03) 9485 7700

Website: <http://www.northsideclinic.net.au>

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