



HIV-ASSOCIATED NEUROCOGNITIVE DISORDERS (HAND)

**A toolkit for
community care workers**

**ALZHEIMER'S IS ONE FORM OF DEMENTIA
AUSTRALIA IS TACKLING THEM ALL**

Acknowledgements

This booklet is part of the Dementia and Chronic Conditions Series: HIV-Associated Neurocognitive Disorders Toolkit, which has been designed primarily for community care workers. The information and recommendations it contains are based on independent research, expert opinion and scientific evidence available at the time of writing. The information was acquired and developed from a variety of sources, including but not limited to collaborations with the Burnet Institute and Living Positive Victoria.

Funding from the Commonwealth and Victorian Governments under the HACC Program supported the development of this resource.

We would also like to acknowledge the following individuals and organisations who contributed to the development of the toolkit: Associate Professor Edwina Wright, Ian Muchamore, Dr Eric Glare, the Burnet Institute, Living Positive Victoria, Royal District Nursing Service HIV Clinical Nurse Consultants Dr Liz Crock and Nalla Burk, and the Positive Speakers Bureau.

We also extend our gratitude to all the people living with HIV and community care providers who reviewed this document and shared their thoughts prior to its publication.

Privacy and disclosure

Protecting the privacy of a person's HIV status is very important because of the stigma, prejudice and discrimination often attached to HIV. People living with HIV have their right to privacy about their HIV status protected by the law in Australia. People living with HIV are not required to disclose their status to anyone if they do not want to (except in rare circumstances when there is no other way to avoid danger or harm to another). This means they do not have to tell their partner, family, friends, employer, work colleagues, health and care providers or any other people except in rare circumstances and job roles.

If a person discloses their HIV status to you, this is an act of trust on behalf of the person. You should never disclose this information to other people without first getting permission of the person living with HIV. The only exception to this is when there is serious risk of harm to the person or to another person.

Contents

Introduction	3
How to use this resource	3
Understanding HAND	5
Key messages	5
What is an HIV-associated neurocognitive disorder (HAND)?	6
What is the cause of HAND?	7
What are the signs and symptoms of HAND?	7
How is HAND diagnosed?	9
Treatment of HAND	9
Supporting someone who is living with HIV and HAND	11
Person-centred care	11
Education	12
Communication	15
Emotional support	16
Practical support	19
Case study	20
Further information	21
Test yourself	22
Notes	24



Introduction

HIV is a virus that weakens the immune system. When a person's immune system is weakened, they have an increased risk of infections and cancers. For basic information on HIV, visit the Victorian Government Better Health Channel website or contact an HIV community organisation. Links are provided at the end of this booklet.

Most people with HIV are male; however, people with HIV are of all genders, sexual orientations and ages. Furthermore, HIV does not discriminate between ethnicity, culture or religion. People living with HIV come from all walks of life, and the population of Australians living with HIV is constantly changing.

In 2014 there are approximately 6500 people with a diagnosis of HIV living in Victoria. About 90% are men and 14% live outside metropolitan Melbourne. The average age of people living with HIV in Victoria is 47 years.

Approximately 92% of the people living with HIV in Australia are male, and 83% are gay men. The average age in this population is 49 years.

Most people living with HIV in Australia were born in Australia (78%); however, this figure is likely to be biased in favour of people who speak English, and may underestimate the number of people born overseas who are living with HIV in Australia.

This toolkit is about medical conditions associated with HIV, known as HIV-associated neurocognitive disorders (HAND). HAND affects cognitive (thinking) abilities such as memory, language, attention, concentration, planning, judgement and organisation.

This toolkit is for paid and volunteer workers in community care settings who support people with HIV. The toolkit provides information to increase knowledge and understanding of the cognitive issues of HIV and their impact on self-care. It helps workers identify and address these issues to support better health outcomes for people with HIV and HAND.

Service providers can use this toolkit as a stand-alone resource. Although this toolkit is mainly about community care, it may help in other settings, such as residential care.

How to use this resource

This booklet has information on the following:

1. Understanding HAND
2. Supporting someone who is living with HIV and HAND
3. A case study
4. Self-test questions
5. Sources of further information

The information in this booklet will be useful at different times, as HAND affects people differently, and the support needs of a person living with HAND, and their partner, family and carers vary over time.

The toolkit also includes a consumer information booklet and four separate help sheets that workers might find useful when providing information to people with HIV and HAND.

The toolkit is designed to help you (as a worker):

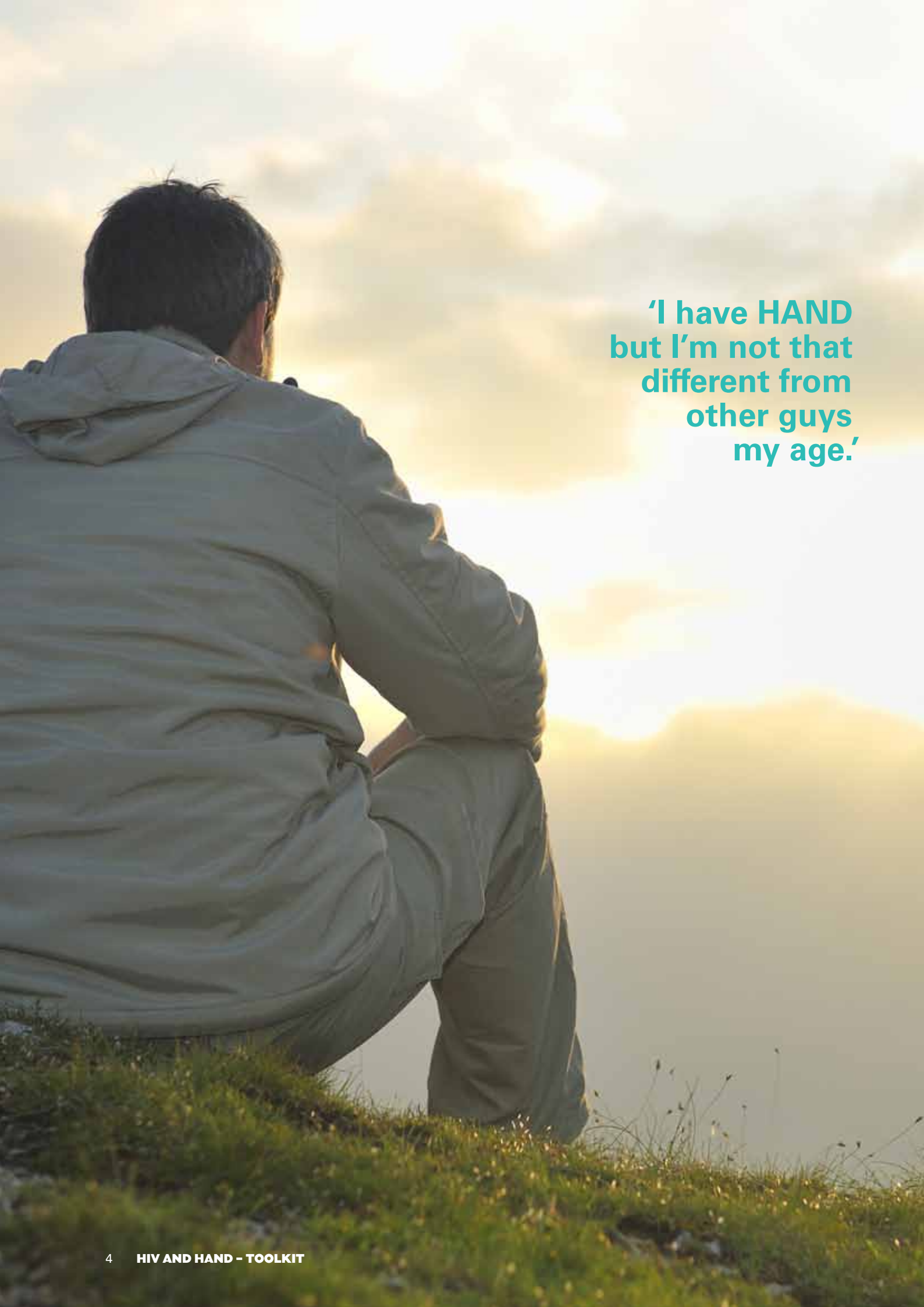
- build trust with the person living with HAND and their partner, family and friends
- understand the characteristics of cognitive impairment and dementia associated with HIV
- give concrete management suggestions and emotional support
- facilitate access to relevant support services.

Familiarise yourself with the information and resources in the toolkit at the start of your care relationship and keep the toolkit for future reference.



Support tools

This icon is used to identify different tools that may be useful to support service delivery.

A man with dark hair, seen from behind, is sitting on a grassy hill. He is wearing a grey, quilted jacket. He is looking out over a body of water towards a bright, hazy sky where the sun is either rising or setting, creating a warm, golden glow. The clouds are soft and white against the bright light.

**'I have HAND
but I'm not that
different from
other guys
my age.'**

Understanding HAND

Key Messages

- HIV can damage the brain. This can lead to a range of medical conditions called HIV-associated neurocognitive disorders (HAND). Symptoms vary from person to person. For most people with HAND, the symptoms are mild. In a small number of people, symptoms can be severe and they are said to have HIV-associated dementia (HAD).
- **Most people with HIV do not develop HAND; HAND affects approximately one in five, or 20%, of people living with HIV.**
- **HIV treatment is the best way to prevent HAND.**
- Early diagnosis of HAND and its treatment can lead to regaining abilities.
Be familiar with the signs and symptoms of HAND, and help someone follow up any concerns as soon as possible.
- **HIV medicines can reduce severity of HAND and allow recovery of functions.**
- **The severe type of HAND is different from other types of dementia, such as Alzheimer's disease. The symptoms are different and HAND is treatable.**
- Signs of HAND may include forgetfulness, lower performance in work, difficulty with finances or organising meals, and reduced driving ability.
- Many symptoms of HAND can occur in a person with HIV for other reasons, including depression, anxiety, medicines, or alcohol and recreational drug use.
- **HIV and dementia both carry stigma, risk of prejudice and discrimination.** People living with HIV are likely to have faced stigma in many areas of their life, including discrimination by health care professionals. This can make people less likely to report problems or to access support services, and it affects their mood and quality of life. **Peer support and professional counselling by people experienced in this area can be vital support services for this group.**
- People living with the most severe type of HAND need support in managing medicines, getting to appointments and performing other daily activities. People with mild symptoms are better able to manage their care tasks by following regular routines, and using pillboxes and memory prompts.



What is an HIV-associated neurocognitive disorder (HAND)?

HAND is a broad range of conditions. HAND affects cognitive (thinking) abilities such as memory, language, attention, concentration, planning, judgement and doing difficult things. HAND can reduce the independence and quality of life of people living with HIV.

HAND can be mild to severe, depending on seriousness of symptoms and their impact on daily life:

- **Asymptomatic neurocognitive impairment (ANI)** mildly affects cognitive functions and is only identified with special medical tests. The person living with ANI and those around them do not notice any symptoms.
- **Minor neurocognitive disorder (MND)** affects cognitive functions to a noticeable extent and may mildly interfere with activities of daily living.
- **HIV-associated-dementia (HAD)** seriously affects cognitive functions and significantly interferes with activities of daily life.

HAND affects approximately one in five, or 20%, of people living with HIV. The most common type of HAND is the mild type (MND); the next most common is ANI. So it is likely that most people with HAND have mild symptoms or no noticeable symptoms. In Australia, where most people who are HIV-positive have access to HIV antiretroviral treatment, the most severe type of HAND (HAD) is rare.

HAND is different from other more common types of cognitive impairment and dementia, such as Alzheimer's disease. Other types of dementia usually cause a permanent decline in ability; this is not the case with HAND. If a person diagnosed with HAND receives the right HIV medicines, their cognitive function can be stabilised and can improve.

What is the cause of HAND?

HIV infects certain cells in the brain. The infection can cause cell damage, inflammation and the production of chemicals that harm other cells in the brain. Damage in the brain can build up over time. Eventually this can have an impact on parts of the brain involved in information processing and thinking.

Excessive alcohol consumption and recreational drug use or medical problems such as diabetes, high blood pressure and high cholesterol may add to the damage that occurs in the brain, in addition to the effects of HIV.

People with HIV are now living longer, and new information suggests that living with HIV for a long time *itself* may have an impact on cognitive function.

If a person you are supporting is worried that HIV is affecting their cognitive function, they should have this investigated.

What are the signs and symptoms of HAND?

The onset of HAND may be gradual or sudden. The signs and symptoms of HAND vary from person to person and can change from day to day.

Cognitive signs and symptoms include:

- difficulty planning and organising events or tasks, especially if they are complex (e.g. organising meals, managing finances)
- difficulty following medical advice and taking medicines
- slowed thinking and slowed reaction times
- difficulty with attention and concentration (e.g. when watching television or reading)
- difficulty finding words when speaking or writing
- difficulty remembering names of people, places or objects
- difficulty with memory (e.g. needing to make lists on what to do)
- difficulty performing complex tasks at work, or lower work performance
- difficulty learning new skills (e.g. learning how to use a new mobile phone, or computer).

Motor signs and symptoms include:

- clumsiness (e.g. dropping things easily)
- difficulty with fine motor tasks (e.g. fastening buttons on clothes)
- slowed walking speed
- slowed fine motor movements
- tremor (rare).

Behaviour and personality changes can also occur in some people with HAND, especially in the most severe type.

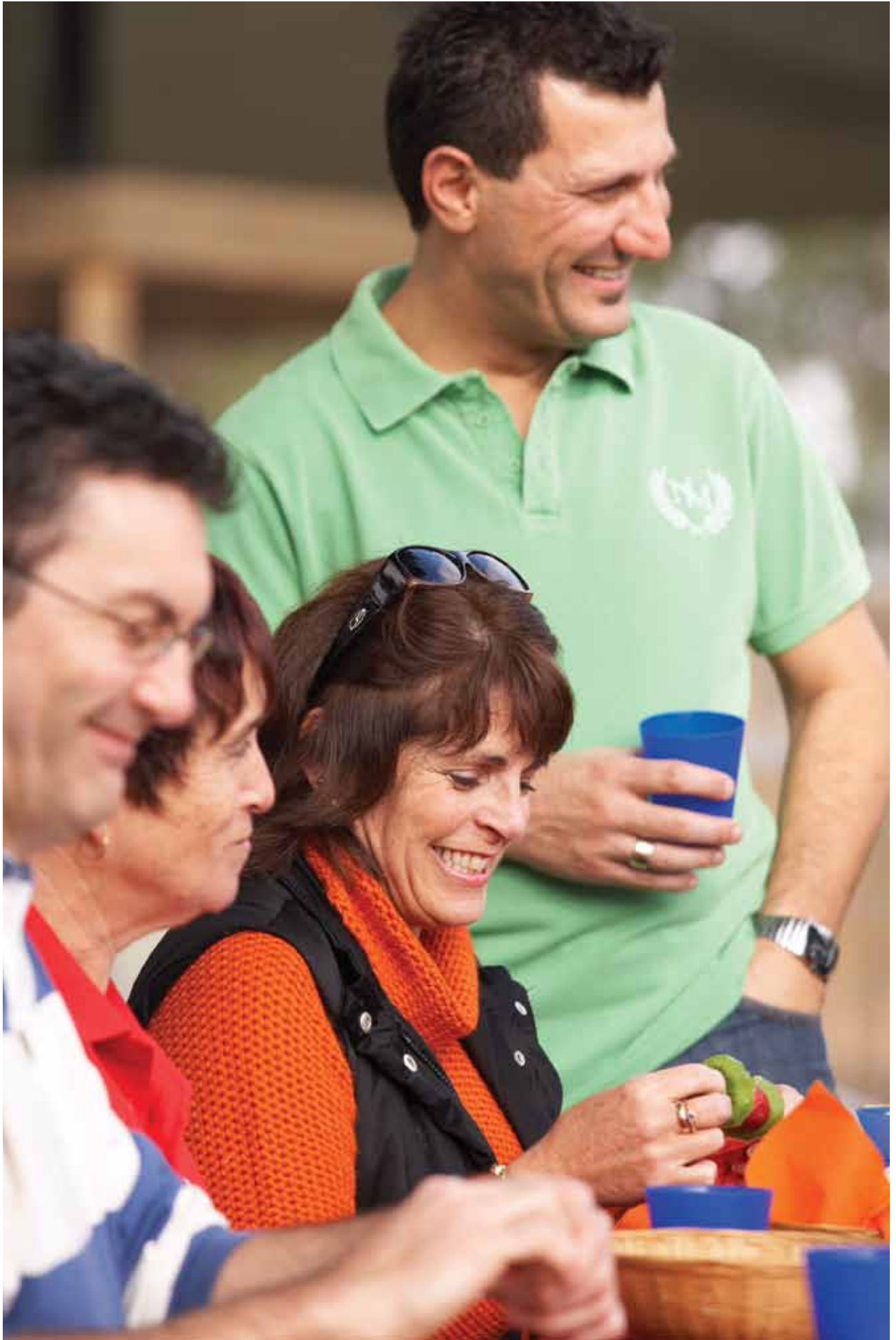
The signs and symptoms listed above can occur for other reasons in a person living with HIV.

Experiencing these signs and symptoms does not always mean the person has HAND. Other possible causes of these signs and symptoms include depression, anxiety, other brain disorders, serious medical illnesses such as stroke, or use of alcohol and recreational drugs.

Such cognitive changes can leave a person confused, frustrated, anxious or depressed. This can make cognitive symptoms worse.

If you notice changes in a person you are supporting, or have any concerns about their cognitive function, discuss your concerns with the person and encourage them to speak to their doctor or HIV specialist.

Document any observed changes or concerns and follow up as soon as possible.



How is HAND diagnosed?

To be diagnosed with HAND, the person needs to be referred to a specialist. The person's doctor knows the appropriate referral process. HIV community organisations in your state can also give advice about where HIV specialists are located. The diagnosis is usually made by ruling out other possible causes of symptoms.

Diagnosis of HAND involves the specialist obtaining a person's medical history and performing a medical exam, including blood tests and a brain scan. The person may be referred to a neuropsychologist for a series of tests and questions. These tests measure how well the brain is functioning. For some people, a lumbar puncture might be recommended to look at the cerebrospinal fluid, which surrounds the brain and spinal cord.

No single test can diagnose HAND. Instead, the specialist makes an assessment based on the person's medical history and the results of the tests mentioned above. An early diagnosis can rule out other illnesses common to people with HIV, many of which are treatable. If a diagnosis of HAND is made, appropriate treatment can be given.

Treatment of HAND

HIV medicine

Taking HIV medicine is the best way to prevent and treat HAND. People with HAND need to receive HIV medicines that are good at getting into the brain. The doctor who prescribes treatment knows how to choose these.

For people who already take HIV medicine and are diagnosed with HAND, other medicines or treatments can be tried.

In some people, their HIV treatment is effective against HIV in the blood but not against HIV in the brain. If testing confirms this, the doctor may change the HIV medicines to others that work against the virus in both the brain and the blood.

If testing is not conclusive, the doctor may still recommend changing HIV medicine to ones that are good at reaching the brain, just in case there is a small amount of HIV infection present in the brain. Alternatively, the doctor may add an extra HIV

medicine to the treatment to try and control any low-level HIV infection in the brain.

The good news is that HIV medicines can reduce problems, and people with HAND can recover well with HIV medicines.

Other things to consider

- People with HIV who have high blood pressure, diabetes or high cholesterol should be encouraged to carefully manage these conditions.
- Reducing or avoiding alcohol and recreational drug intake can help protect the brain's function.
- Medicines such as antidepressants may be needed to treat depression or anxiety.
- Non-medicine therapies, such as counselling and learning strategies, can help with reduced abilities in thinking and processing and how to manage the emotional impact of these changes.
- Peer support services can connect the person with others who have faced similar challenges and issues. One-on-one peer support as well as peer support groups and workshops are delivered in Victoria by Living Positive Victoria and the Positive Living Centre.
- Organisations such as Alzheimer's Australia support people with a cognitive impairment of any type, including HAND.

People living with HIV and HAND have complex care needs, so referral to other support professionals who have good knowledge and experience in this area is recommended. HIV community organisations can give information about services available in the local area.

'I feared getting dementia but testing told me that was not happening and worrying was just making things worse!'

Medical card

Name _____ Surname _____

Gender _____ Date of birth _____

Address _____

Date of call _____ First call ☐ Second call ☐

Sign _____

Analysis _____

Diagnosis _____

Date of filing _____

Number _____

Supporting someone who is living with HIV and HAND

Person-centred care

Person-centred care places the person at the centre of their own care. Person-centred care respects the person's values, preferences and choices. It also considers the needs of the person's partner, family and friend carers.

The principles of person-centred care should be applied to all aspects of supporting people living with HIV.

Principles of person-centred care:

1. Get to know the person with HIV and HAND beyond these diagnoses.
2. Support the person to set goals, plan and make decisions about their care.
3. Be sensitive to values, preferences and expressed needs.
4. Give complete and accurate information in a way the person understands so they can make choices about their care.
5. Work together to minimise duplication of services and have one key contact at your agency.

Show that you want to understand the person's life story. This helps develop trust and gives insight into the person's situation and beliefs. People can have very different beliefs and understanding about their illness and medicines. Health beliefs can determine a person's use of medicines as well as other health-related behaviours.

Signs and symptoms of HAND vary from person to person and can change over time. Speak to the person with HAND and, if they agree, to their partner or close friend or family, to find out:

- what signs and symptoms the person experiences
- how signs and symptoms affect the person's daily life
- what the person already does to manage their signs and symptoms
- how you can support independence and quality of life
- other information that they wish to share with you that will make your job easier.

Your role as a care provider is to build a good working relationship with the person you are supporting and their partner, family and friend carers. Be prepared to be flexible to fit the needs of the person on any particular day.



Service Coordination Tool Template: Health and social needs

A screen for service providers on a person's broad health and social needs.



Service Coordination Tool Template: Health and chronic conditions

A screen for service providers on a person's health, chronic conditions, falls history/risk, nutritional risk, vision and advance care planning.



National Association of People With HIV Australia (NAPWHA) iPlan:

A resource designed to help people living with HIV become active partners in their health care.

Education

You and your organisation are encouraged to use this toolkit to support your educational requirements.

Being knowledgeable about HIV and HAND builds respect and trust between you and a person you are supporting. By being well informed, you are better able to support people and show understanding.

Cognitive and motor signs and symptoms of HAND are listed in the 'Understanding HAND' section of this booklet. This information helps you to identify cognitive changes and decline. You must document any changes you observe or concerns that you have. Follow your organisation's policy for making referrals to medical or allied health professionals.

Organisations that can provide you with further information about HIV and HAND are listed at the end of this booklet.

Sharing information

You can help support a person with HAND to understand their condition and treatment. This can make them feel more in control and be better able to manage their lives.

The consumer resources in this toolkit contain condition information, and advice for self-care and brain health promotion. The amount of information that people request varies. Be guided by the person's requests for information, and ask them what they know already and if they have any unanswered questions. Try to adapt information you provide to the needs of each person.

You should consider the person's:

- education level
- current understanding and capacity
- language spoken
- cultural differences and sensitivities.

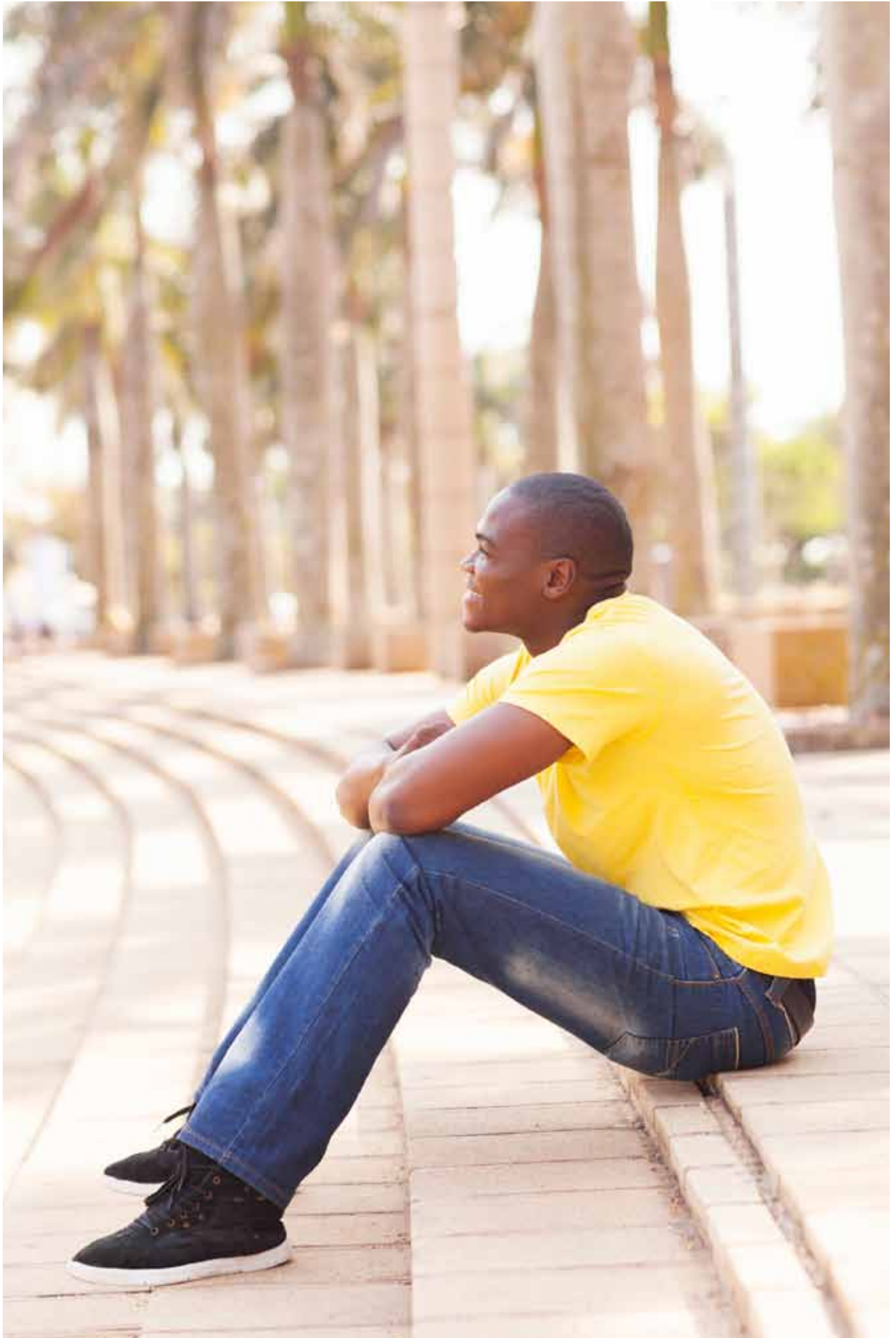
If you are uncomfortable or do not have the knowledge to answer any questions that might be raised, you should refer to one of the appropriate services listed at the end of this booklet.



Living with HIV-associated neurocognitive disorders (HAND)

Condition-specific information about HAND for people living with HIV and their loved ones.





Communication

HAND can cause slowing in language and communication. These symptoms are more common and problematic in people with the most severe type of HAND. Changes that may occur include trouble finding the right words and some slowness in understanding what other people say.

The following suggestions may help cope with changes in language and communication:

- Keep sentences short and simple when discussing or explaining something.
- Reduce background noise and distractions when having a conversation.
- Allow plenty of time for what you have said to be understood and do not rush a response.
- Ask a question to check that the person has understood any information you have shared.
- Try not to interrupt the person when they are speaking.
- Give the person time to come up with a word or thought.
- Don't order the person around or argue.
- Respect the person's rights and wishes. Having HAND does not mean people are incapable of speaking for themselves.
- Consider the person's literacy level when providing written information.

More than 20% of people with HIV in Australia were born overseas. You may need to consider using a telephone interpreter. Always get consent from the person before engaging an interpreter.

Talking about HAND

The risk of developing a cognitive impairment is a sensitive subject for people living with HIV. When discussing HAND or providing sensitive information, consider your approach. The following suggestions might help in what may be difficult conversations

- Choose an appropriate environment; conversations need to be in a private place. You should both be sitting down and able to talk privately with each other.
- Choose your words carefully; ask the person's permission before you share any concerns that you have.

There is something I am a bit concerned about.

Is it OK if I talk to you about something I've noticed?

- Ask the person for their opinion or reaction to any observations you make.
Have you noticed any changes/problems yourself?
Do you think this is something you could discuss with your doctor?
- Offer hope and reassurance; remember that if it is HAND, HIV medicines can reduce severity and improve cognitive function.
- If the person is willing, help them to work out a plan for what to do next.
- Reassure the person that you will not be sharing their information with people who are not in their care team.
- Write up the conversation and plan to follow up with the person within a week.

Emotional Support

Stigma, prejudice and discrimination

HIV and dementia both carry stigma, with a risk of prejudice and discrimination. People living with HIV are likely to have faced stigma in many areas of their life, including for some being rejected by their own families or community. People also report experiencing discrimination by health care professionals. These negative experiences can mean that people living with HIV are less likely to report problems and access support services, and they may be fearful of sharing their story. HIV-related stigma can also be internal, where the person with HIV has feelings of shame or inferiority.

Similarly, people with cognitive impairment and dementia can experience rejection and discrimination based on prejudice or misunderstandings about the condition.

HAND can create fear about the loss of key roles, such as employment, and the ability to live independently. People with HAND may experience social isolation. These issues can have a major impact on the mood and wellbeing of the person with HIV and their loved ones.

Consider your own beliefs and attitudes about HIV, sexuality and dementia. Negative beliefs may affect your ability to show empathy and to provide good support. Try to view the situation from the perspective of the person living with HIV.

Supporting the person with HAND

There are higher rates of depression and anxiety among people with HIV disorders than in the general population. Listen to the person. If someone reports being depressed or anxious, encourage them to share those concerns, and seek professional support and counselling. Because of the complex nature of HIV and HAND, it is best to find professionals with experience in these areas. HIV community organisations can give advice about services in the local area.

People living with HIV may benefit from peer support and education. HIV community organisations including Living Positive Victoria, Straight Arrows, Positive Women, and the Victorian AIDS Council also offer peer support services where people can meet with others who have faced similar challenges and issues.

Supporting partner, family and friend carers

For the people personally involved in the life of someone with HAND, feelings of depression, guilt and frustration are common. Partner, family and friend carers are dealing with the practical issues of HIV and HAND, and also are coping with changes in their loved ones. Carers are also likely dealing with their own, and their loved one's fears, and possible stigma.

Encourage partner, family and friend carers to look after themselves too; there are services and supports, including carer allowances and peer support groups for carers, partners and family. Respite care may be useful and appropriate for people caring for a loved one who has HAND.



Relationship Circle A sheet identifying partner and people inside and outside the family who can offer emotional and practical support to the person.



Service Coordination Tool Template: Social and emotional wellbeing

A screen for service providers on social and emotional wellbeing needs, including for anxiety and depression.



Service Coordination Tool Template: Care relationship, family and social network Assistance for service providers to understand care relationships and partner, family and support networks, such as friends and significant others who are involved in the person's life.

**'If I plan things and
choose the right
moment my brain
works very well.'**





Practical support

To prevent or manage HAND, people living with HIV need to take the right medicines at the right time and in the right way, and attend regular health-related appointments. People living with HAND may experience cognitive and behavioural changes that make it difficult for them to plan and organise these tasks.

If cognitive problems are severe, the person may no longer be able to manage their own care and may need daily assistance. Even people with mild symptoms may need help to stay independent. Encourage people living with HAND to seek support from their partners, families or close friends in managing their daily self-care, especially around medicine-taking.

Supporting use of medicines

People living with HIV can experience problems taking medicines, such as side effects (e.g. sickness or diarrhoea), difficulty remembering to take the medicines, or following a complicated dose schedule.

If the person you are supporting is experiencing side effects from their medicine, they should speak to the person who prescribed the medicine. If the person is having other problems managing their HIV medicines, you may be able to offer support. For example, you may be able to:

- identify barriers to taking their medicines (such as side effects)
- work with the person to create a plan that supports taking their medicines
- help set up a regular daily routine for taking their medicines
- encourage the use of a pillbox and/or memory prompts, such as diaries, calendars and phone alarms.

Tips for managing medicines and a medicine planner are included in the consumer resource.

Supporting healthy lifestyle choices

Support and encourage the person with HIV to:

- participate in regular physical activity and optimise cardiovascular health
- eat nutritious foods

- maintain a healthy weight
- have good sleep habits
- drink plenty of water
- avoid smoking, recreational drugs and excessive alcohol use
- stay mentally active and socially engaged
- look after their emotional wellbeing
- get treatment for conditions such as diabetes, high cholesterol and high blood pressure, as these conditions can affect cognitive function.

Recommendations for healthy lifestyle choices to support cognitive health are included in the 'Protecting your brain health' section of the consumer resource in this toolkit.



Tips for managing medicine A tips sheet with hints for people with HIV and HAND on managing medicines



Medicines planner A daily planner for people with HIV and HAND to use for their medicines



Protecting your brain health Tips on how to look after your brain, for people with HIV and HAND



Service Coordination Tool Template: Alcohol, smoking and substance involvement screening (ASSIST)

A screen for service providers on hazardous harmful and dependent use of alcohol, tobacco and other psychoactive drugs.



Service Coordination Tool Template: Need for assistance with activities of daily living A screen for service providers on need for assistance with activities of daily living.



Service Coordination Tool Template: Accommodation and safety arrangements A screen for service providers on risk of homelessness and safety needs, including family violence and personal emergency planning.

Case study



Martin is a 52-year-old retired man who lives alone in Melbourne. He has previously worked as an IT project officer. Martin was diagnosed with HIV nine years ago in Brisbane. At the time of diagnosis, Martin was very ill due to advanced HIV infection; he was hospitalised for several weeks and treated for severe pneumonia. At this time, Martin was also diagnosed with HIV-associated dementia (HAD).

Following successful treatment and initiation of HIV medicines, Martin's physical health and cognitive function steadily improved over the next twelve months and Martin returned to work full-time. When working, Martin developed strong organisational skills and strategies to manage his daily tasks and his health.

In the last two years Martin's physical health has declined and he is no longer able to work. In addition to physical health concerns, Martin has a diagnosis of HAND. HAND makes self-care of his complex health issues more difficult. Martin is worried that his cognitive problems are getting worse and that he is losing his independence.

Martin left Brisbane after his initial diagnosis and no longer has regular contact with his family there; in Melbourne he has a few contacts but sometimes feels isolated. Martin enjoys spending time with other people; he loves to cook and enjoys walking his dog. Martin has previously found yoga useful for managing his sense of wellbeing; however, he does not regularly attend a class.

Providing support to Martin

Martin has been living with HIV for many years. Invite Martin to share information about his experiences over that time. This will give you a better context for understanding his situation.

Martin is concerned that his cognitive function is declining. Discuss what Martin can do to have this investigated. Martin can raise these concerns with his HIV specialist or, with Martin's permission, he can be referred to a memory clinic where his cognitive function can be assessed and monitored.

Reassure Martin that there are different things that can be tried to improve or stabilise his cognitive function, and to maintain his independence.

Martin has managed his health successfully in the past, and may be able to use approaches he developed previously to manage his daily activities now. Explore what Martin did in the past to stay organised, what challenges he has now and whether any strategies he has used in the past could be helpful. Provide Martin with the tips for managing daily activities, and support Martin to put in place any ideas that suit him.

Martin does not have family support or the support of a partner. With Martin's permission, use the relationship circle tool to identify the people who are involved in Martin's life, and work out a plan to increase his social contact. Encourage Martin to consider accessing a peer support service at a local HIV community organisation. This will put Martin in touch with other people who have faced similar difficulties, and may be a way to expand his social network.

Martin reports increasing difficulty in managing his medicines. Offer to support Martin to fill in the medicine planner tool and provide Martin with the tips for taking medicines.

Martin reports finding yoga to be good for his wellbeing. Identify barriers to participation and support Martin to find and attend a yoga class. The Positive Living Centre offer exercise classes including yoga.

Further information

For more information and training on neurocognitive disorders and dementia

Alzheimer's Australia Vic

www.fightdementia.org.au

Offers accredited programs and a broad range of dementia-specific workshops and seminars for care workers.

National Dementia Helpline

1800 100 500 (business hours).

A telephone information and support service available across Australia. The Helpline is available for people with dementia, their carers, families and friends, as well as people concerned about memory loss. It is also used by health professionals, service providers and community organisations.

Dementia Behaviour Management Advisory Service (DBMAS)

1800 699 799 (24 hours a day, 7 days a week)

Support for carers and care workers of people with dementia who experience behaviours of concern that may have an impact on their care.

For more information on HIV

Living Positive Victoria

www.livingpositivevictoria.org.au

Offers peer support and health promotion programs for people living with HIV.

Victorian AIDS Council

www.vicaids.asn.au

Positive Living Centre

www.vac.org.au/community-centre-plc

Better Health Channel

www.betterhealth.vic.gov.au

For emotional or crisis support

Lifeline 13 11 14

SuicideLine 1300 651 251

beyondblue www.beyondblue.org.au

Further education

Carers Victoria www.carersvic.org.au

Offers professional development and accredited training to help community care staff work in partnership with partners, families and friends of their client.

Test yourself

Complete these self-assessment questions to check your recall and understanding of the information presented in this booklet.

Answer in your own words. Compare your answers with the information in the manual to check for accuracy and completeness.

1. Describe the three categories of HAND.

2. What cognitive signs and symptoms might a person with HAND have?

<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>

3. What motor signs and symptoms might a person with HAND have?

<hr/>	<hr/>
<hr/>	<hr/>

4. What other health problems could be causing some of the signs and symptoms above (other than HAND)?

<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>

5. How is HAND different from Alzheimer's disease?

6. How is HAND diagnosed?

7. How is HAND treated?

Complete the table below to assess your practice and consider how you can find ways to improve your rating.

1 Strongly disagree

5 Strongly agree

I know about the person's life beyond their diagnosis	1	2	3	4	5
I treat the person as a partner when setting care goals	1	2	3	4	5
I know what signs and symptoms of HAND the person has and how they affect their life	1	2	3	4	5
I use positive and supportive language	1	2	3	4	5
I do not correct or argue	1	2	3	4	5
I am patient and flexible	1	2	3	4	5
I listen carefully	1	2	3	4	5
I encourage the person to talk about their feelings	1	2	3	4	5
I know who else is involved in the person's life	1	2	3	4	5
I use familiar routines	1	2	3	4	5
I support taking medicines at the right time in the right way	1	2	3	4	5
I support healthy lifestyle choices to protect brain health	1	2	3	4	5
I am familiar with resources and support available to the person	1	2	3	4	5

Notes

[illegible]

'After surviving an infection on my brain, I had problems with my speech. I got support for my HAND and I went back to public speaking. It is the best thing I did for myself.'



National Dementia Helpline 1800 100 500
www.fightdementia.org.au

**ALZHEIMER'S IS ONE FORM OF DEMENTIA
AUSTRALIA IS TACKLING THEM ALL**