



Partners, family, friends & carers of people living with

# **HIV ASSOCIATED NEUROCOGNITIVE DISORDER**

**PositiveLifeNSW**  
the voice of people with HIV since 1988

## Acknowledgements

The results of published research *Developing resources assisting people living with HIV Neurocognitive Disorder (HAND)*, 2016. [www.positivelife.org.au/images/PDF/2016/PLNSW-HAND-Report-2016.pdf](http://www.positivelife.org.au/images/PDF/2016/PLNSW-HAND-Report-2016.pdf) identified key areas for resource development to assist people living with HIV (PLHIV) to talk about HAND and for healthcare workers, service providers and significant others on how to respond meaningfully when addressing or raising concerns about the possibility of HAND with PLHIV. The idea for this research arose from questions raised at a meeting in Sydney 2015 of the 'HAND Think Tank', a group comprised of HIV specialist clinicians, healthcare workers, nurses and community representatives.

Positive Life NSW would like to acknowledge and thank the members of the 'HAND Think Tank' who contributed to the development of the resource. We would also like to thank the Multicultural HIV/AIDS Services for their feedback and editing to make the resource accessible for those from culturally and linguistically diverse backgrounds (CALD). We pay special acknowledgement to those people living with and affected by HIV who contributed their valuable time to complete the survey and thank those people caring for someone living with a HAND diagnosis who participated in the final focus testing of the resource. Positive Life NSW also acknowledges the work in the development of this resource by:

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Denise Cummins, Clinical Nurse Consultant, Sydney District Nursing, Community Health, Sydney Local Health District.

David Crawford, Treatments Officer, Positive Life NSW.

*Images used in this publication are sourced stock photography and are used for illustrative purposes. They do not imply any particular HIV status, sexuality, attitudes or behaviours.*

# USING THIS BOOKLET

The booklet is designed to give partners, family, friends or carers the right support and practical advice as they assist a person living with HIV Associated Neurocognitive Disorder (HAND). This includes information on where to seek more assistance and get further information. It is not intended to give a diagnosis of HAND. The resource can be read in short sections using the headings as a guide and can also be read in conjunction with the 'HIV Associated Neurocognitive Disorder' booklet for further information.



# WHAT IS HAND AND WHY IS IT IMPORTANT FOR PARTNERS, FAMILY, FRIENDS OR CARERS TO KNOW ABOUT HAND?

Sometimes, the *human immunodeficiency virus* (HIV) can get into the brain of people living with HIV (PLHIV). In simple terms HIV can cause inflammation of the brain affecting the way a person acts and responds. If this happens, people who are close to the person living with HIV are usually the first to notice changes in their behaviour. Some symptoms listed (pages 3–4) can also indicate the possibility of another diagnosis. However, if a diagnosis is made where HIV is affecting the brain, it is called HIV Associated Neurocognitive Disorder (HAND).

While these changes are slight to begin with, the impact on partners, family, friends or carers can be concerning and often leaves them not knowing what to do or say because they don't know how to approach the topic. Sometimes they just hope the person will get better on their own. The reality is that early treatment with new and improved antiretroviral drugs may result in improvement and a better outcome for the person living with HAND.



## **WHAT MIGHT I NOTICE IN SOMEONE WHO IS LIVING WITH HAND?**

Generally, any changes tend to be out-of-character for the person. These include changes in mood such as being more anxious, depressed, frustrated and angry about things that were not a problem for them before. The person may withdraw from doing things they previously enjoyed doing or react in a negative way to noise or other people around them.

They may talk about always feeling tired, or they might behave like they are feeling exhausted. They could talk about decreased energy levels or their sleep patterns might change.

## **Examples of the kind of behaviour that you might notice include:**

- Finding it hard to organise things
- Becoming angry and easily agitated
- Becoming more easily upset or excited
- Not finishing planned tasks
- Being more forgetful than usual
- Missing appointments
- Missing meals
- Missing a lot of tablets or medication
- Saying things that don't make sense in a conversation
- More often losing track of what they were saying or not finding the right word
- Coming up with solutions to problems that don't make sense
- Uncharacteristically losing track of time or getting lost in doing things
- Unexplained bruises, bumping into things, tripping or falling over more than usual
- More mistakes or accidents while driving
- An increase in driving related offences e.g. speeding fines
- Not paying bills, spending more money than usual or uncharacteristically getting into debt
- Getting into trouble with the law.

## **If the person is working, you might notice that they:**

- Cannot do the things they could do well before
- Constantly respond to work situations negatively
- Make more mistakes when under pressure
- Are not interested in their work anymore
- Need to use reminders and diaries more than usual
- Are not finishing jobs on time
- Getting into trouble at work.

# SUPPORTING SOMEONE TO LIVE WELL WITH HAND

As a partner, family member, friend or carer you can play a critical role in helping someone with HIV live well, even with a diagnosis of HAND.

If a person is diagnosed with HAND it can be a time of uncertainty if they are working full or part time. Fear of making mistakes and missing things can be stressful. HAND does not mean they need to stop working, but they may need to re-think the kind of work they do, like considering changing to a less demanding role or reduce the number of hours they work.

Make sure the person has spoken to the HIV/AIDS Legal Centre (HALC) before disclosing a diagnosis of HAND, agreeing to any changes to their work arrangements, or deciding to resign from work. They should be well informed and supported – so seek legal advice or the support of a peer organisation from those listed at the end of this booklet.

Your friend or loved one may also have questions about disclosing their diagnosis to co-workers or employers. While disclosing at work is not always possible, if your friend or loved one chooses to disclose they have HAND, the employer is obliged to help them adjust their workload or job description to make things easier. Changes to work arrangements may only need to be temporary, but it will be important to have the right people supporting them to understand the law and what these changes mean. This will be a time for the person to talk about any adjustments they might need to stay employed and to involve services that are able to assist and support them. Some of these services are listed at the back of this booklet.

## What can you do if you notice these changes in someone living with HIV?

It's important to be sure the changes you notice are *actually* changes due to HAND and **not due to temporary stressors**. From time to time, everyone can show some differences in behaviour due to other stressors (e.g. bereavement, financial debt, relationship or family pressures, work problems, an undiagnosed mental health condition etc.) or changes in routine. If you notice these symptoms are occurring more frequently over the last 6 to 12 months, then it is time to raise these concerns so they can be checked out by a doctor. The changes from HAND can be barely noticeable and slow at first.

Get your friend or significant other to contact their doctor sooner rather than later, as the outcome will be better if they act as soon as possible.

Offer to go with them to their doctor's appointment if you think this will assist the person to actually make the appointment. Always assure them of your support and care, especially during these visits to the doctor.

## How to talk about these changes with someone

It is hard to start a conversation about HAND with someone we care about. Friends and family are often worried about what to do or say. In a Positive Life NSW survey about HAND, people said that they often feel dismissed or unheard when they try to talk about what they are experiencing.

It's okay to be unsure when something seems wrong or different. It is difficult to see a loved one struggling and not know what to do, how to respond or where to get help. You may also be worried that they might react badly or angrily if you say something about the changes. Keep in mind that if HAND is found and treated early, it can often be reversed, slowed down or made better with the right support and treatment.



## **What can I do if the conversation does not go well?**

Sometimes the conversation may not go the way you expect – you haven't done anything wrong by raising the subject. Denial or confusion can also be part of the response and this is also okay.

Do not force the issue with them and make sure they understand that you are only concerned for them. Seek the support of a doctor, healthcare worker or peer support worker if you need additional assistance.

### **Here are some practical tips to help you:**

- Take notes that list the main behaviours you notice
- Collect more information
- Make a plan
- Make a list of people and services who can help
- Talk to other trusted members of the family and their friends
- Talk to a doctor, nurse, counsellor or peer worker
- Set aside plenty of time to talk to the person
- Pick the best time of day to talk
- Pick a quiet and safe environment
- Ask them if they have been noticing anything within themselves
- Start the conversation by telling them that you care about them
- Try to let the person take the lead and answer honestly any questions they have
- Be gentle, patient and supportive
- Be clear about what you are seeing
- Do not give them too many examples of what you are seeing e.g. three or four are plenty to start with.

# LIVING WITH A PERSON WITH HAND?



## **Here are some simple steps you can take to assist you living with a person with HAND:**

- Discuss strategies on how you can work together
- Keep a calendar or diary for appointments and other social engagements
- Agree on where to keep important items like keys, wallet/handbag, glasses etc.
- Use whiteboards or the fridge door to record upcoming appointments and social engagements or things that both of you need to replace e.g. milk, bread, medication etc.
- Encourage them to take time to respond to questions
- Give them time to think, process and reflect

- Do not interrupt or make suggestions as this can add to their confusion and embarrassment
- If the blank space becomes too long and they begin to look embarrassed or upset, say “take your time” or “let me know when it comes back to you”
- Remain calm and supportive
- Being tired, stressed and rushing are times where they are more likely to make more mistakes leading to further frustration so try and avoid adding to this pressure
- Take note of the times of the day they function better and focus on the more complex and demanding jobs then
- Allow plenty of time to get appointments as rushing can be stressful
- Plan only one or two activities on the same day
- Link mobile phone calendars or diaries with a friend, family or partners
- Encourage the person to do as much for themselves as they can e.g. cooking meals and doing other household chores
- Install a timer switch or another reminder to check that the appliance has been turned off. It is better not to chastise the person for having forgotten to do this but a gentle reminder and finding other strategies will help to reduce the risks of fire.

### **Are there other things that will be important to think about?**

- Make sure all the legal affairs are in order, talk to a legal advisor like HALC, a doctor or healthcare worker or a peer to get further direction on what needs to be in place
- Get help managing finances or getting out of debt
- Speak to a financial planner or counsellor e.g. Bobby Goldsmith Foundation (BGF)
- Seek extra help earlier – ignoring problems can make them more difficult to sort out later.



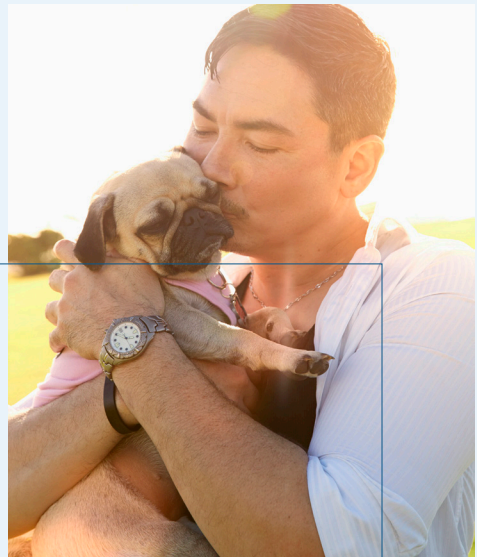
## TAKING CARE OF YOURSELF

Family members, partners, friends and carers who have inadequate supports tend to only seek help and support when the situation has become too much to handle. Managing angry outbursts and frustrating behaviours on your own can lead to a breakdown in the relationship with the person you care about.

Fatigue and stress can set in if you are attempting to resolve problems without support for yourself. If the person living with HAND has lost the capacity to reason and they cannot see the harm that HAND is causing in their life and yours, keep in mind it is the illness that is changing the person's behaviour. The sooner you find support, the better position you'll be in to support them and find positive solutions for both of you.

## What things can I do to take care of myself?

- Take regular breaks from the situation at home
- Avoid becoming too tired and worn out
- Take time to relax apart from the person diagnosed with HAND
- Find other friends, family members or a carer to help you out
- Include the person living with HAND in any plans and talk about involving other carers or support people
- Ask healthcare professionals about strategies that can support you or respite services.



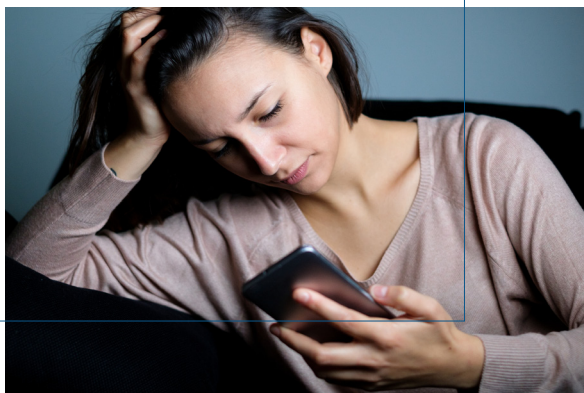
## Respite Care

Taking care of someone living with HAND can be exhausting. You may not want to put them into long term care but you might need to take a break, take a holiday or take care of business. There are services in NSW that can provide short term support including accommodation for the person living with HAND. Contact Adahps or the Ankali Project to talk more about accessing these support services.

## Where can I get help and who can I talk to?

Healthcare workers are there to support you and they understand the drain these kinds of demanding situations place on people. There is no shame in reaching out for help. The earlier you do this, the better the outcome will be for everyone.

- Adahps (a specialised service in NSW for people with complex HIV needs like HAND)
- Your own GP
- The local mental health care team
- A peer support worker.



# INFORMATION AND SUPPORT

## **Adahps**

Provides assessment, support, and referral service for people living with HIV and complex needs.

301 Forbes St, Darlinghurst

Hours: 8.30am – 5pm, Mon – Fri

**p** (02) 9382 8600

**e** [adahps@health.nsw.gov.au](mailto:adahps@health.nsw.gov.au)

**w** [www.health.nsw.gov.au/adahps](http://www.health.nsw.gov.au/adahps)

## **Positive Life NSW**

Provides peer support and is an advocacy organisation representing people living with HIV in NSW

Level 5, 414 Elizabeth St, Surry Hills

Hours: 8.30am – 5pm, Mon – Fri

**p** (02) 9206 2177 or

1800 245 677 (freecall)

**e** [contact@positivelife.org.au](mailto:contact@positivelife.org.au)

**w** [www.positivelife.org.au](http://www.positivelife.org.au)

## **Bobby Goldsmith Foundation**

Provides case management, financial counselling and support service addressing long term social and economic poverty for people living with HIV.

111–117 Devonshire St, Surry Hills

Hours: 8.30am – 5pm, Mon – Fri

**p** (02) 9283 8666

**w** [www.bgf.org.au](http://www.bgf.org.au)

## **HIV/AIDS Legal Centre Inc. (NSW) (HALC)**

Provides a free and comprehensive legal assistance to people in NSW living with HIV and Hepatitis

Level 5, 414 Elizabeth St, Surry Hills

Hours: 10am – 6pm, Mon – Fri

**p** (02) 9206 2060

**e** [halc@halc.org.au](mailto:halc@halc.org.au)

**w** [www.halc.org.au](http://www.halc.org.au)

## **Ankali Project**

Provides emotional and social support to PLHIV in Sydney who are dealing with social isolation, mental health challenges and the use of alcohol or other drugs.

150 Albion St, Surry Hills

8.30am – 5.30pm, Mon – Fri

**p** (02) 9332 1090

**e** [ankali@thealbioncentre.org.au](mailto:ankali@thealbioncentre.org.au)

**w** [www.thealbioncentre.org.au/ankali/the-ankali-project/](http://www.thealbioncentre.org.au/ankali/the-ankali-project/)

## **ACON**

An organisation addressing HIV prevention, providing HIV support and health matters for lesbian, gay, bisexual, transgender and intersex (LGBTI) communities.

414 Elizabeth St, Surry Hills

9am – 6pm, Mon – Fri

**p** (02) 9206 2000

**e** [acon@acon.org.au](mailto:acon@acon.org.au)

**w** [www.acon.org.au](http://www.acon.org.au)

**This resource has been made possible  
with the support of:**

$$\left[ \begin{array}{c} \text{TEST} \\ \text{MORE} \end{array} \right] + \left[ \begin{array}{c} \text{TREAT} \\ \text{EARLY} \end{array} \right] + \left[ \begin{array}{c} \text{STAY} \\ \text{SAFE} \end{array} \right] = \left[ \begin{array}{c} \text{END} \\ \text{ING} \\ \text{HIV} \end{array} \right]$$



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