

Condition Insight Report (CIR)

Human Immunodeficiency Virus (HIV)

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Completed in collaboration with
NAT

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Overview

What is the condition usually called / any abbreviations used?

HIV (Human Immunodeficiency Virus)

Brief overview of the condition

HIV (human immunodeficiency virus) is a virus that damages the cells in your immune system and weakens your ability to fight everyday infections and disease.

HIV and AIDS are not the same, though the terms are used interchangeably by some people and in some countries. AIDS (acquired immune deficiency syndrome) is the name used to describe a number of potentially life-threatening infections and illnesses that happen when your immune system has been severely damaged by the HIV virus.

Some people living with HIV may be diagnosed with AIDS if they are diagnosed with one of a specific list of illnesses which are associated with a compromised immune system due to advanced HIV.

What is the generally preferred term for someone with this condition?

An individual living with HIV.

Please avoid: 'HIV sufferer/carrier' and 'AIDS victim/patient'

Presenting Symptoms

A 2011 survey by National AIDS Trust (NAT) found the fluctuating symptoms most commonly reported by people living with HIV were:

- Fatigue, exhaustion or lack of energy
- Depression or anxiety
- Gastro-intestinal problems (such as nausea, vomiting and diarrhoea, weight loss)
- Insomnia or difficulty sleeping
- Neuropathy

Some of these symptoms relate to the HIV infection; others are treatment side-effects – although it can be hard to disentangle the exact cause in some cases.

Some of the other symptoms which may be present are:

- **Breathlessness** due to repeated fungal pneumonia infections
- HIV related **neurocognitive impairment** that can affect memory, concentration and co-ordination
- **Pain** related to neuropathy (nerve pain) particularly in the hands and feet
- Pain related to lipodystrophy (fat redistribution), especially on the pads of the feet when walking and buttocks when sitting
- **Osteopenia and osteoporosis**
- **Frailty**
- **Anxiety** in social situations
- **Side-effects of medication** including chronic diarrhoea, nausea, fatigue, loss of concentration, insomnia and sleep disturbance

A common misconception is that it is possible to see the impact of HIV; this often stems from ideas about the presentation of particular AIDS-defining illness and symptoms of advanced HIV, such as wasting or skin conditions. HIV is largely an unseen condition, and while some people applying for PIP may have visible barriers around mobility, for example, it is inappropriate to draw evidence from how well or unwell someone appears.

Fluctuations

The cycle of fluctuation can be within a day, or over a longer period of time. It can be difficult to ascertain whether the fluctuation is caused by the HIV, HIV treatment or a combination of both.

Think about exploring things like:

- Do their symptoms change and if so how often, to what degree, how long does this last, what is more frequent for them, how much difference is there?
- How is breathlessness impacting them? Does this increase with minimal or excessive activity?
- How are their pain levels or neuropathy symptoms? Where do they experience the symptoms, is this hands and feet or other areas and how does this impact on functionality? Does anything increase the level of pain they experience?
- Is the claimant experiencing any of the common side effects of the medication?

Reliability

What specific areas should be covered to ensure a complete, reflective report?

SAFETY 

Do they have any symptoms which could cause a safety consideration?

For any symptoms which are reported to have a safety implication get clear information about how they manage these risks for each activity it is relevant to.

TIMELY 

For any activities where restriction is reported how long does it take them to complete these activities? Has how long it takes them changed over time?

Fatigue can have an impact on some and side effects of the medication can mean that some tasks take longer. Where this is reported, ensure to explore to what extent in all activities.

ACCEPTABLE 
STANDARD

How have they adapted to completing tasks over time – is this different to what might be considered 'normal'?

Changes to someone's HIV medication or interactions between HIV medication and treatment for other health problems can also have significant side effects.

REPEATEDLY 

Are they able to repeat a task as often as required? Is this the same every day?

For example, during a given day, someone may have problems with gastric and continence issues following the taking of medication in the morning, through to difficulty sleeping after taking medication at night. For others it can fluctuate over longer periods of time, so someone can feel well for a period before developing pain and fatigue, and then feeling well again several weeks later.

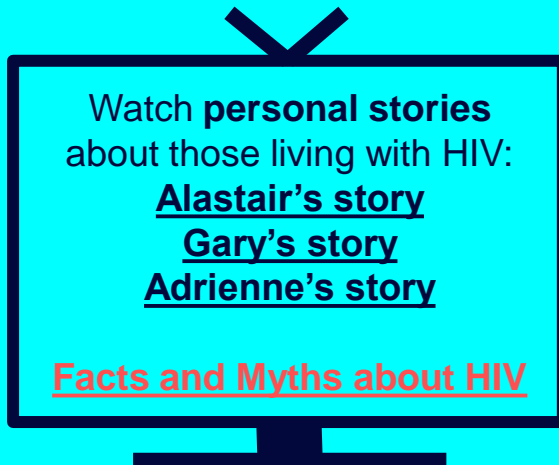
Sensitivities

What areas might they find difficult to mention or perhaps understate the impact of?

Assessors should be aware that many people living with HIV have experienced stigmatising reactions to their condition from others, in both personal and professional settings. This can include people working within health and care services. For this reason, someone living with HIV may be apprehensive about discussing their condition with a stranger, even a health professional.

Specifically in relation to symptoms, some people living with HIV may feel uncomfortable mentioning the following:

- The common problem of persistent severe diarrhoea and incontinence.
- Their full mental health history, particularly relating to depression and suicidal ideation.



Customer Care

How is it best to ask about any sensitive topics and what are the common courtesies?



In general

- The key courtesy to show someone living with HIV is to treat them with the same ease and respect as someone with any other condition.
- **Avoid using stigmatising language or displaying judgemental attitudes** relating to HIV. Using preferred terminology ('people living with HIV'), rather than inaccurate or loaded terms ('AIDS patient', 'victim' or 'carrier'), is one way of avoiding stigmatising behaviour.
- **Do not ask someone living with HIV how they acquired their condition.** This is an intrusive question which adds no value to the consultation.
- A significant proportion of people living with HIV in the UK were born in sub-Saharan Africa and some came to the UK as refugees. It is worth keeping in mind that some will have experienced trauma, physical and sexual violence. Special care should be made to gather background information about this in a sensitive manner.

During face to face interactions

- Signpost individuals to toilets and exits
- Confirm they can get up and move around should they need to



Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 1: Preparing food

Fatigue, neuropathy and breathlessness may impact their physical ability to complete the task depending on the extent of their symptoms, as well as any neurocognitive impairment and associated mental health conditions.

Remember in PIP...

You must explore reliability. If they are cooking, how long does it take? Does this increase their fatigue or breathlessness? How do they feel after? How long can they stand for? Can they chop food and lift pans? If they have associated MH conditions, are they motivated to cook on the majority of days? Are they safe cooking?

Activity 2: Taking nutrition

Some can have very poor appetite and have lost significant amounts of weight. Some need nutritional supplements and support to manage their weight and ensure they are having sufficient intake.

Remember in PIP...

If they lack appetite, do they require prompting to eat? If so, is this throughout the duration of the meal? Do they require any nutritional supplements? Do they need prompting to take these? Do they have co-existing mental health conditions which may impact motivation to eat?

Activity 3: Managing therapy and monitoring a health condition

People should be asked about the side effects of the medication. As the treatment is life saving, stopping treatment is not an option. Some side effects are similar to HIV – chronic diarrhoea, nausea, fatigue, loss of concentration, insomnia, frequent nightmares and night sweats.

Remember in PIP...

Are they able to independently manage their own medication? Are they motivated to take it? Do they have any therapies in the home environment? If so, do they require assistance with these and is this on the majority of weeks?

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 4: Washing and bathing

Fatigue, neuropathy, breathlessness may impact their physical ability to complete the task depending on the extent of their symptoms as well as any neurocognitive impairment and associated mental health conditions.

Remember in PIP...

You must explore reliability. When they are washing, how long does it take? Does this increase their fatigue or breathlessness? How do they feel after? How long can they stand for? Can they wash upper and lower body? Do they require any aids? If they have associated MH conditions, are they motivated to wash on the majority of days?

Activity 5: Managing toileting needs and incontinence

Gastro-intestinal problems can be a common symptom. Some may struggle to manage their hygiene and even be incontinent.

Remember in PIP...

If the claimant is incontinent, how frequent is it and is this of both bladder and bowel? Can this be managed with pads independently or do they need assistance to maintain hygiene?
How do they transfer on/off the toilet? Can they reliably clean themselves after using the toilet?

Activity 6: Dressing and undressing

Fatigue, neuropathy, breathlessness may impact their physical ability to complete the task depending on the extent of their symptoms as well as any neurocognitive impairment and associated mental health conditions.

Remember in PIP...

You must explore reliability. When they are dressing, how long does it take? Does this increase their fatigue or breathlessness? How do they feel after? Does being seated reduce their symptoms? Can they dress upper and lower body? Do they require any aids? If they have associated MH conditions, are they motivated to dress on the majority of days?

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 7: Communicating verbally

Consider any comorbid/cognitive conditions.

Remember in PIP...

The scope of the activity is the ability to express and understand verbal information. They must be able to do both. Can they speak to people? Can they utilise a mobile phone? Can they provide responses in context?

Activity 8: Reading and understanding signs and symbols

Consider any comorbid/cognitive conditions.

Remember in PIP...

What can they read? Could they read a household bill, appointment letter or text message?
Can they understand what they have read?

REMEMBER: Complex written information is anything more than one sentence.

Activity 9: Engaging with others face to face

Anxiety in social situations can be common.

Remember in PIP...

If someone reports their condition has impacted their mental health, does that impact their ability to engage? Who are they engaging with regularly? How do they engage with unfamiliar people? Do they experience anxiety? If so, how do they overcome this? Do they require specific support?

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 10: Budgeting

Consider any neurocognitive impairment and any associated mental health such as anxiety.

Remember in PIP...

Can they manage household budgets? Are they motivated to do this? How would they cope with a new bill? Can they do online banking or shopping? Would they understand change in a shop?

Activity 11: Planning and following a journey

Consider any neurocognitive impairment and any associated mental health issues such as anxiety.

Remember in PIP...

Can they plan and follow the route of a journey? Are they safe when completing journeys? If they report associated anxiety, does this meet the OPD threshold? If so, how often do they go out of the home? Do they require support? If any neurocognitive impairments reported, could they manage diversions? Could they complete an unfamiliar journey safely?

Activity 12: Moving around

Fatigue, neuropathy and breathlessness may impact their physical ability to move to an acceptable standard, in a timely manner and repeatedly.

Remember in PIP...

Individuals may struggle to provide specific information. Try to use examples to help or things in their area they might be able to refer to. You must explore whether any journey discussed is repeatable, where possible how long it takes them, how they feel whilst doing it, and any incidents of note such as falls in the past 12 months?

Additional reading or other resources

EXTERNAL

- Basic facts, myths and FAQs about HIV: www.nat.org.uk/we-inform/do-i-understand-hiv , www.nat.org.uk/we-inform/FAQs-%26-Myths
- Free e-learning module on HIV for health and care workers: www.nat.org.uk/we-inform/training-and-learning/e-learning
- For further information see NHS Conditions and Treatments: <https://www.nhs.uk/conditions/hiv-and-aids/>

INTERNAL

- Desktop Aid – MSE, Breathlessness, Fatigue

Version control