

LIVING WITH HIV



WHAT IS HIV?

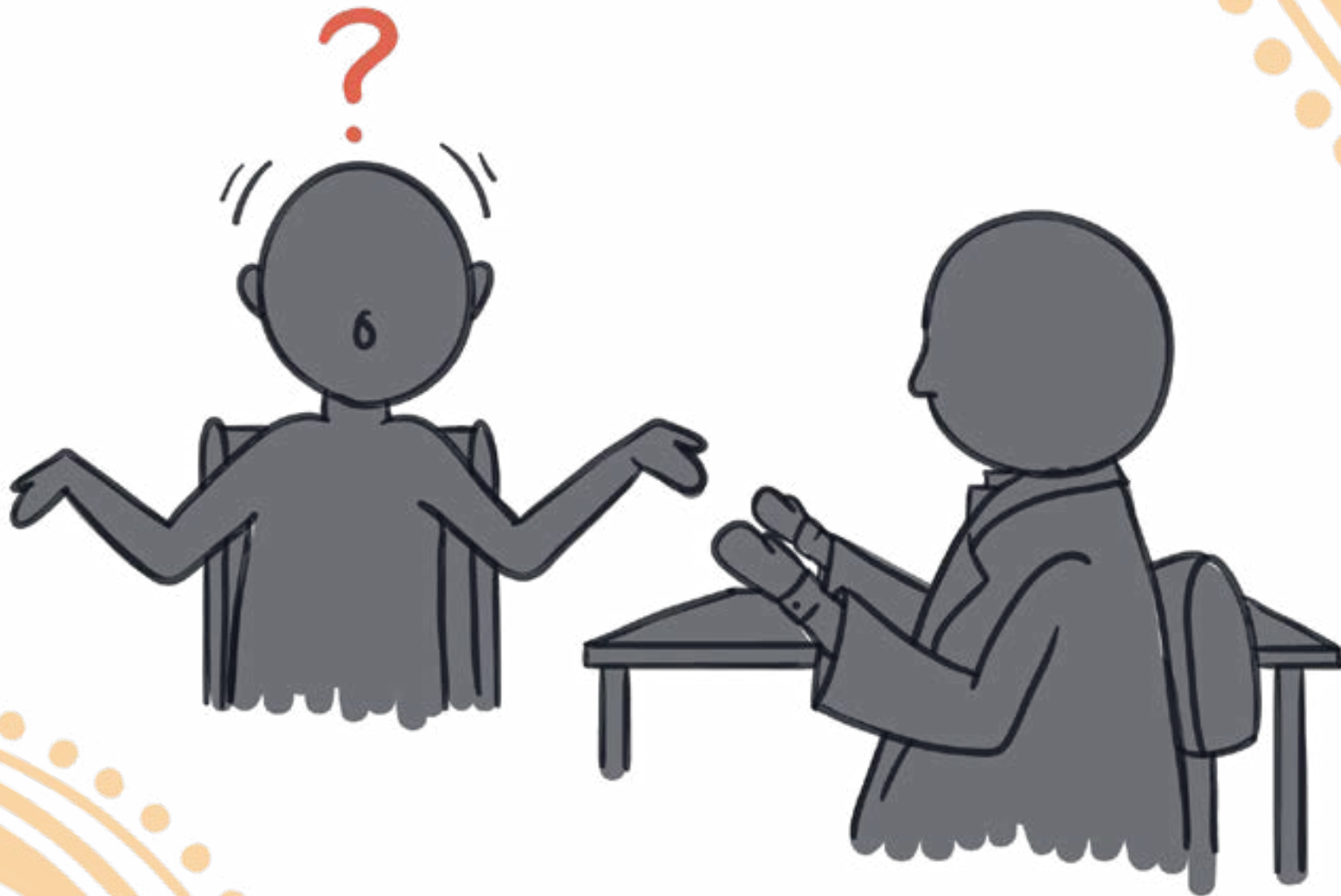
Provide the patient with a high-level overview of HIV.

Key points checklist:

- HIV is a sickness that people can get and it can make them very sick.
- HIV is the short name for human immunodeficiency virus.
- HIV is not the same as AIDS.
- **If a person with HIV does not get treatment, their immune system gets weak, and they can develop AIDS. AIDS is when the body cannot fight germs and the person gets very serious infections.**



WHAT IS HIV?



FEELINGS

Check in with the patient about how they are feeling.

Key points checklist:

- It is normal for people to feel shame, confused, worried or angry when they find out they have HIV and that is okay.
- **It is important to note that you and your service are available to help and will continue to provide care for them.**
- Invite the patient to ask questions they may have. Reassure the patient that you are available to answer any questions they have as they come up.

HOW ARE YOU FEELING?



Shame



Confused



Worried



Angry

HIV IN THE BODY

It can be useful to describe HIV in more detail so the patient understands the virus better and how and why medication helps and sets you up to discuss nuanced health messaging such as undetectable = untransmissible.

Key points checklist:

- **HIV is a tiny virus that gets into the blood.**
- **When people do not take medication, HIV makes more of itself in the body.** This means there is more and more of the virus in the body.
- Over time **HIV makes the immune system weak** – this is the part of the body that fights off sicknesses.
- Eventually the immune system gets so weak that germs and infections the body fights off every day can get into the body and those infections make people very sick and they may even die.

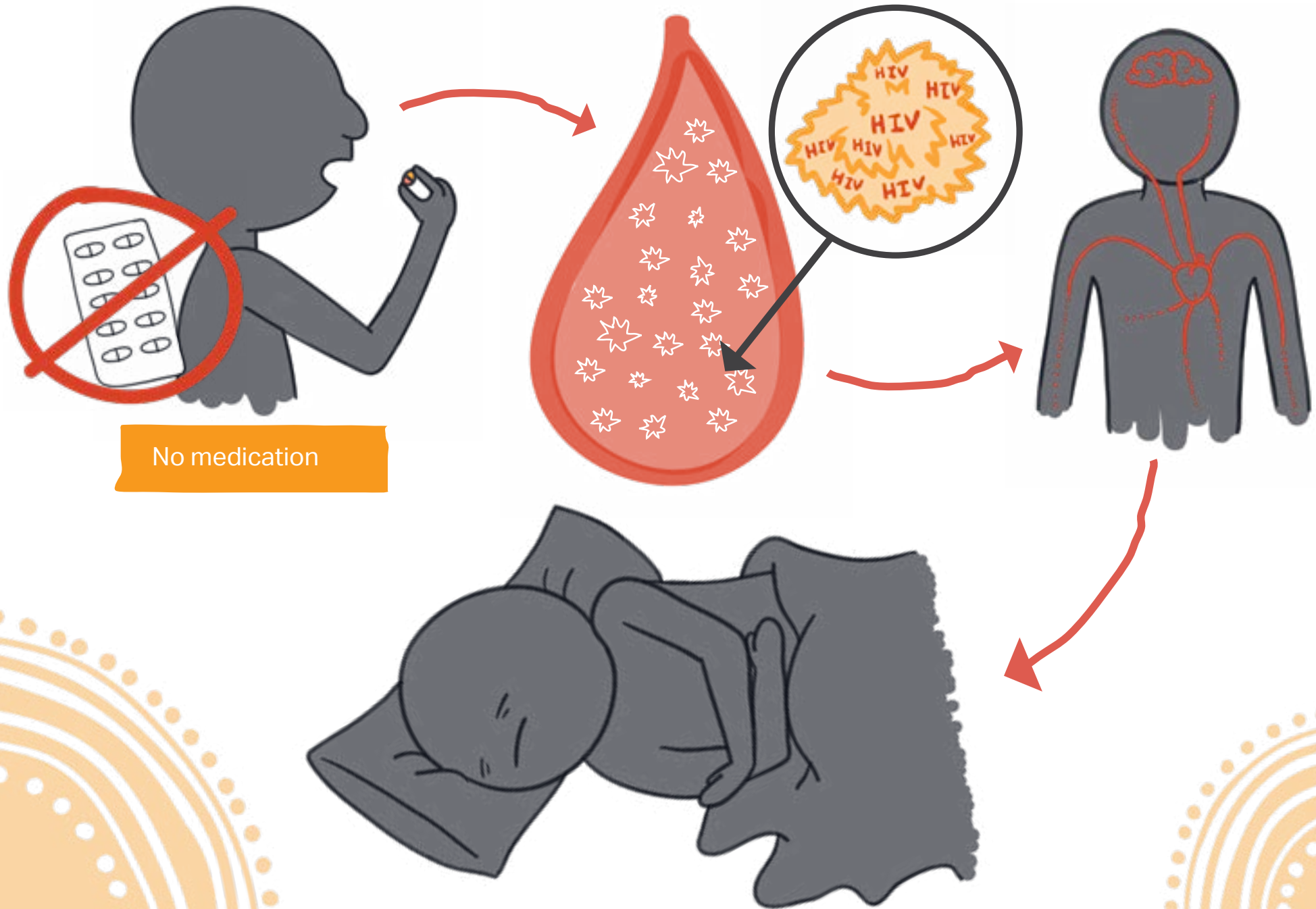


Explaining the immune system:

The body has an immune system which protects people from sicknesses. It is made up of special cells in the blood which fight sicknesses and keep people well.

HIV uses these immune cells to make more of itself.

WHAT DOES HIV DO TO THE BODY?



HIV TREATMENT

For patients to take care of their own health and to stop other people getting HIV, it is important they start treatment early and stay on the recommended treatment to stop HIV from making more of itself.

Key points checklist:

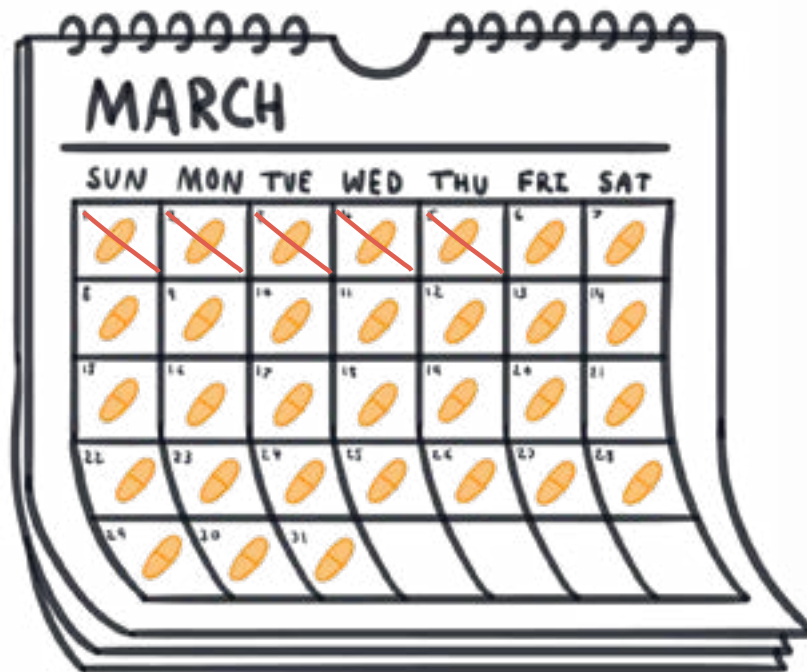
- **There is no cure for HIV**, and once someone has HIV it will be in the body forever.
- **There are very effective (strong) medicines people can take** which reduce the amount of HIV in the body. They do this by stopping HIV from being able to make more of itself.
- **Medicines will help keep the body strong** and helps the immune system to protect people from infections.



Different treatment options:

Taking oral tablets every day is the most used treatment for HIV in Australia. There are also long-acting injectable (needles) HIV treatments which are given once every two months instead of taking tablets every day. A person needs to have taken tablets to treat their HIV before they can use injectable treatment. If your patient is interested in injectable treatments, or you as a health worker think the patient may benefit by changing from tablets to injectable treatments, you can ask their doctor to contact Royal Perth Hospital Immunology or Fiona Stanley Infectious Diseases Department to see if it would be suitable for them.

TAKING STRONG MEDICINES FOR HIV



Need to take medication every day



VIRAL LOAD AND ACHIEVING VIRAL SUPPRESSION

Patients will need to get regular blood tests to measure the HIV viral load in the body. Talk to the patient about why these blood tests will happen, and what is being measured.

Key points checklist:

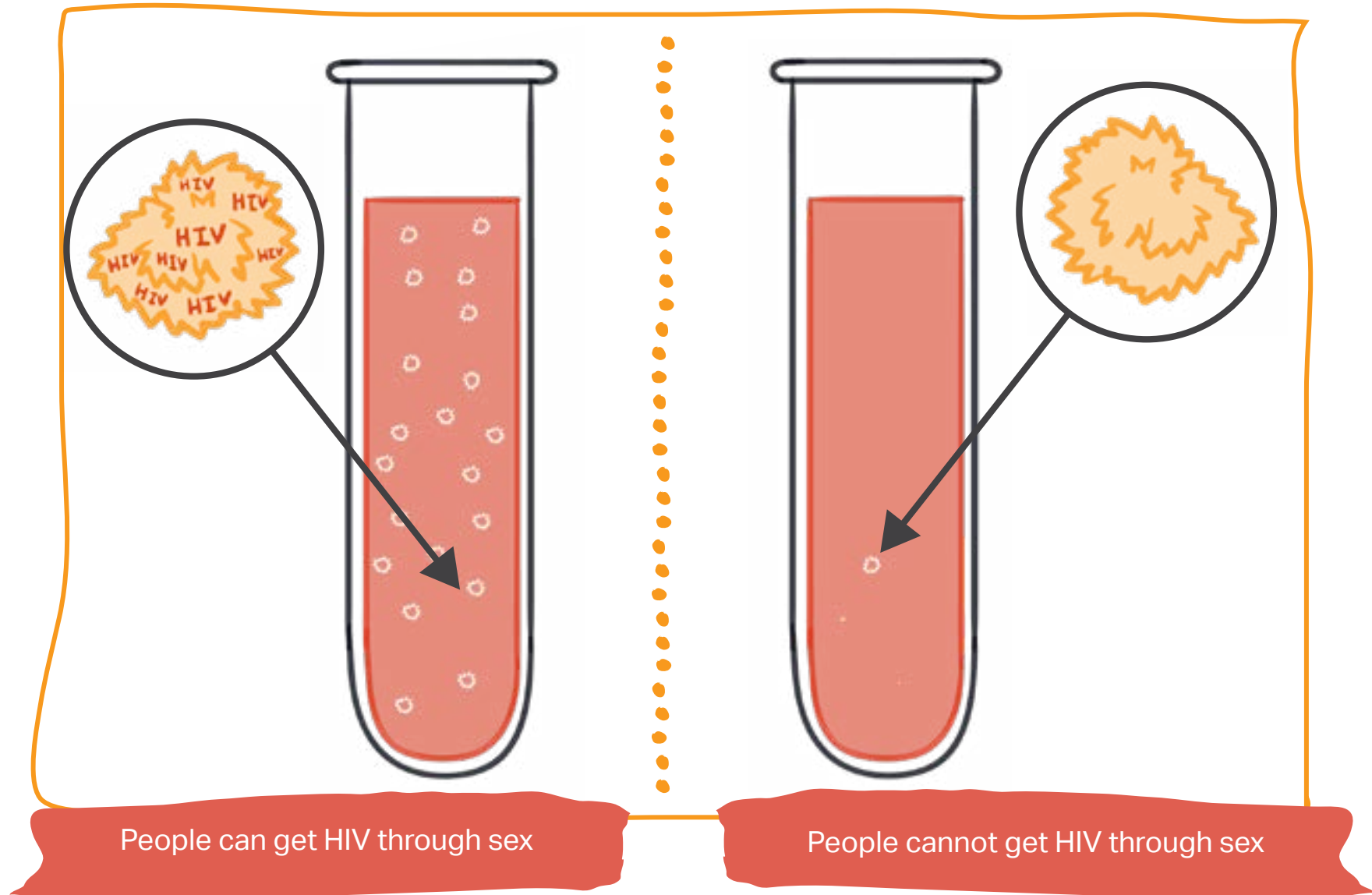
- **Patients will need to get regular blood tests** to measure how much of the virus is in the body. The amount of the virus in the body is called the viral load.
- **By taking HIV medicine** as instructed by a health worker, **patients can reduce the amount of HIV in the body**, so it won't show up in blood tests. When this happens, the patient has achieved viral suppression or has an undetectable viral load. This is what we want to happen.
- The **patient will still have HIV inside their body**, and they will need to keep taking HIV medicine as instructed by a health worker, **but the patient will not be able to pass HIV on to anyone else through sex** which will keep themselves and their sex partners safe.



Undetectable = untransmissible:

It has been well proven through research that people with a sustained undetectable viral load are unable to pass HIV to other people through sexual contact. Undetectable = untransmissible can help decrease and remove stigma towards people living with HIV and can often help decrease patients' concerns about giving the virus to people they know. This message may be very different to what patients have heard about HIV.

DETECTABLE VS UNDETECTABLE



LIVING WITH HIV

By taking HIV medication people can continue to live their life. Patients will need to change the way they do a few things, like attending regular appointments and taking medicine as instructed by their health worker, which will help to keep themselves and other people safe.

Key points checklist:

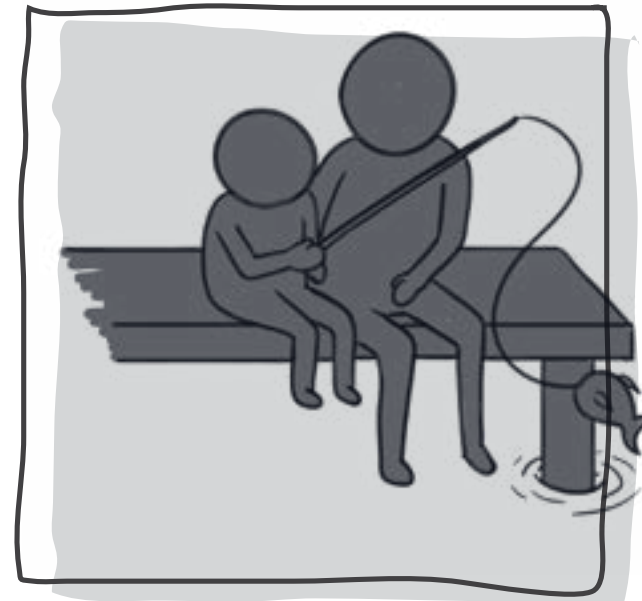
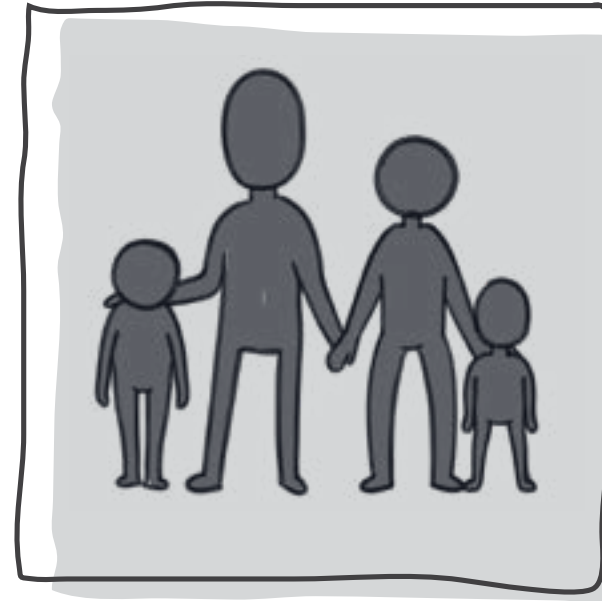
- **HIV is a manageable sickness with medication.**
- **People with HIV can still:**
 - **have relationships** • work
 - **have sex** • play sports
 - **have kids** • go fishing and hunting.
- People may need to change the way they do a few things to keep themselves, their family and their community safe. This will be elaborated on later in the resource.



Considerations for language:

Be cautious using 'live a long and healthy life.' People may not be living 'healthy lives' and may not want to live a 'healthy life'. Wording like this may make people feel like they have to dramatically change their lifestyle like the way they eat, how much alcohol they drink, their smoking habits, cease drug use etc. Although these things are good for general health, the key message is that **with medication, having HIV will not dramatically impact the way patients live their lives.**

LIVING WITH HIV



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HOW TO STOP PEOPLE FROM GETTING HIV



BODY FLUIDS THAT CONTAIN HIV

HIV is transmitted through body fluids which contain HIV. Understanding which body fluids contain HIV helps patients understand what activities can result in transmission.

Key points checklist:

- **People can get HIV** when **one or more of these body fluids from a person who has HIV** enters another person's body.
- The body fluids are:
 - **blood**
 - **anal (bum) fluid**
 - **semen or cum**
 - **breast milk.**
 - **vaginal fluid**
- To stop other people from getting HIV, people need to not come in contact with these body fluids.

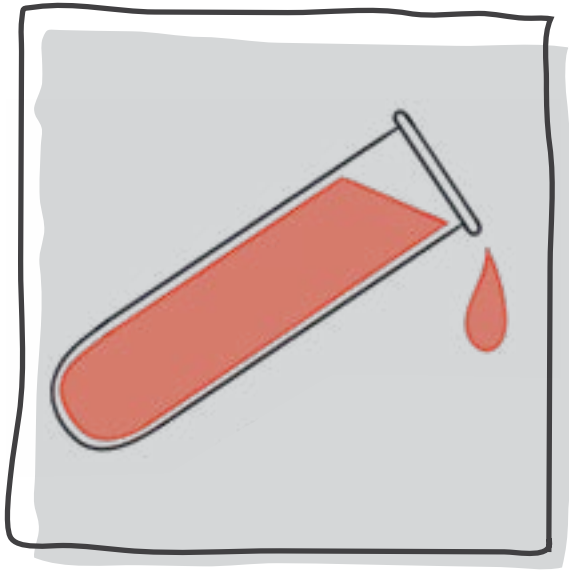


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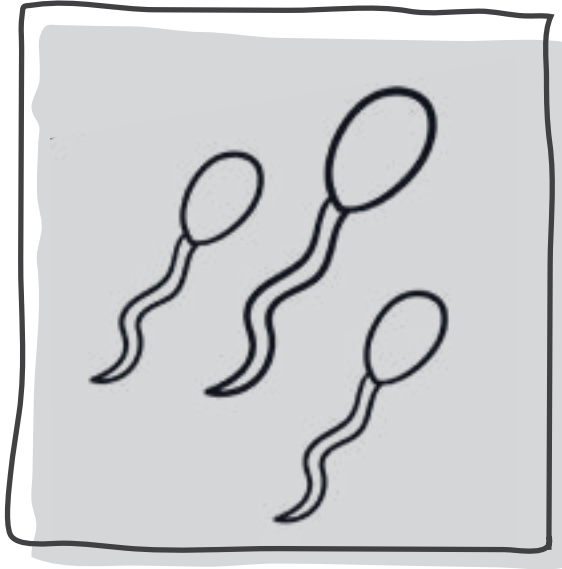
Ask the patient what situations may result in coming in contact with these body fluids.

After they have identified a few ways, ask the patient ways that they might be able to prevent coming into contact with these body fluids, or ways they may be able to reduce the likelihood of exposing other people to these body fluids.

BODY FLUIDS WHICH CONTAIN HIV ARE



Blood



Semen (Cum)



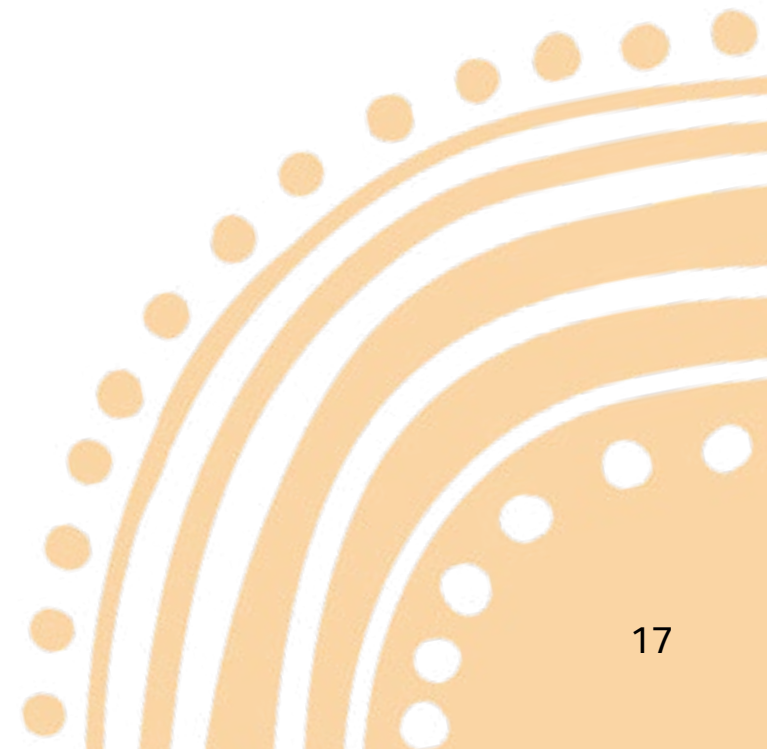
Vaginal Fluid



Anal (Bum) Fluid



Breast Milk



COMMON WAYS PEOPLE CAN GET HIV

Key points checklist:

- **HIV can be passed on from mother to child**, this can happen during pregnancy, through childbirth or through breastfeeding.
- **HIV can be passed on through all types of sex**,* including oral sex, vaginal sex, or anal (bum) sex.
- HIV can be passed on through blood-to-blood contact, normally through sharing injecting drug equipment.
- Having an **undetectable viral load will stop you from passing HIV on through sex, but even with an undetectable viral load people can't share injecting drug equipment, and they should use formula to feed their babies.**



*Health worker note:

Talking about HIV transmission through sex has become very nuanced with advancements in prevention such as PrEP, PEP and undetectable = untransmissible. 'People can get HIV through sex where a person is not using either a condom or dental dam, or is not taking medicine to stop them from getting HIV. For a person to get HIV through sex they need to have sex with a person who has HIV and who has detectable amounts of the virus in their body.'

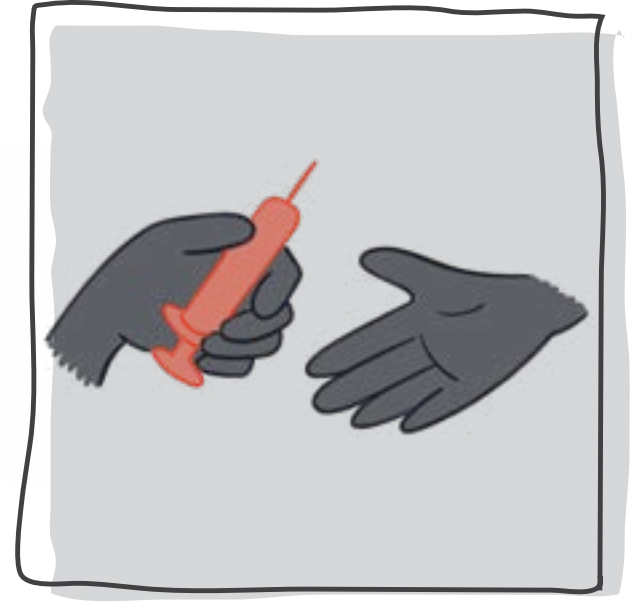
WAYS PEOPLE GET HIV



Can be given to babies during birth or breastfeeding



Is spread by sex without condoms (unprotected sex)



Is spread by sharing syringes and needles

WAYS TO STOP GIVING HIV TO OTHER PEOPLE

A patient who is newly diagnosed will need to take additional steps to prevent HIV transmission, particularly at the beginning when their viral load is high.

Key points for people who are newly diagnosed:

- There are things you can do to stop giving someone else HIV.
- Wear condoms and use water-based lube every time you have sex. This will also stop you getting other STIs.
- Have regular appointments with your health worker and get blood-tests regularly. It is good to get tested regularly for other STIs (like chlamydia, gonorrhoea, and syphilis) and BBVs (like hepatitis C and hepatitis B)
- Take medicine as told by your health worker.
- ask your sex partners if they are on pre-exposure prophylaxis (PrEP).

Key points for people who are negative or don't know if they have HIV:

- There are things you can do to stop getting HIV.
- Wear condoms every time you have sex. This will also stop you getting other STIs.
- Have regular appointments with your health worker and get tested regularly for STIs (like chlamydia, gonorrhoea, and syphilis) and BBVs (like hepatitis C, hepatitis B and HIV).
- ask your health worker about strong medicines that you can take to stop yourself from getting HIV (PrEP and PEP).

DO



See your health worker



Wear condoms



**Take medicine as told
by your health worker**

WAYS TO STOP GIVING HIV TO OTHER PEOPLE (Continued)

Key points for people who are newly diagnosed:

- Don't share injecting drug equipment, even with family.
- Don't share personal hygiene items like razors.
- Don't get home piercings or tattoos.

Key points for people who are negative or don't

know if they have HIV:

- Don't share injecting drug equipment, even with family.
- Don't share personal hygiene items like razors.
- Don't get home piercings or tattoos.

- A woman can have a baby without passing HIV on to her baby. For a woman to stop giving HIV to their baby they should have an undetectable viral load, take medicine as told by their health worker and have regular appointments with their health worker.



Having an undetectable viral load will greatly decrease the likelihood of transmission of HIV through injecting drug use and from mother to child. Even with an undetectable viral load, a person can still give other people HIV by sharing injecting drug equipment so patients should be told to never share injecting drug equipment, personal hygiene equipment, or get home tattoos or piercings. Some communities may use ceremonial tools which can be a risk of HIV transmission. If this is relevant for the communities you work with, discuss this with the patient.

DON'T



**Share injection
drug equipment**



**Share personal
hygiene equipment**



**Get home tattoos
or piercings**

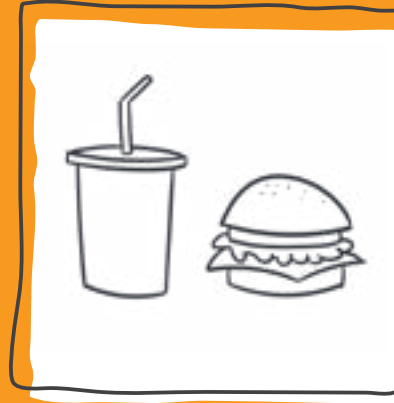
HIV MYTHS

Patients can have misconceptions about what can spread HIV. It is important to spend time myth busting with patients. We have shown some common myths.

Key points checklist:

- Sometimes people think HIV can be passed on in ways that it can't.
- **People won't get HIV from hugging or by having a relationship with someone.**
People also cannot get HIV from kissing, this is because HIV is not in saliva (spit).
- **People can't get HIV from sharing drinks or food.**
- **HIV is not spread through coughing or sneezing** because it is not in mucous (snot).
- **HIV is not spread through mosquito bites.**
- **People cannot get HIV from toilet seats.** It is not in urine (wee) or faeces (poo).

PEOPLE WITH HIV CAN



PEOPLE WILL NOT GET HIV FROM

CONFIDENTIALITY AND CONTACT TRACING

It's important to initiate contact tracing when it's appropriate. It's important to maintain rapport with the patient so ensure that you take into consideration their comfort and willingness to engage in contact tracing.

Key points checklist:

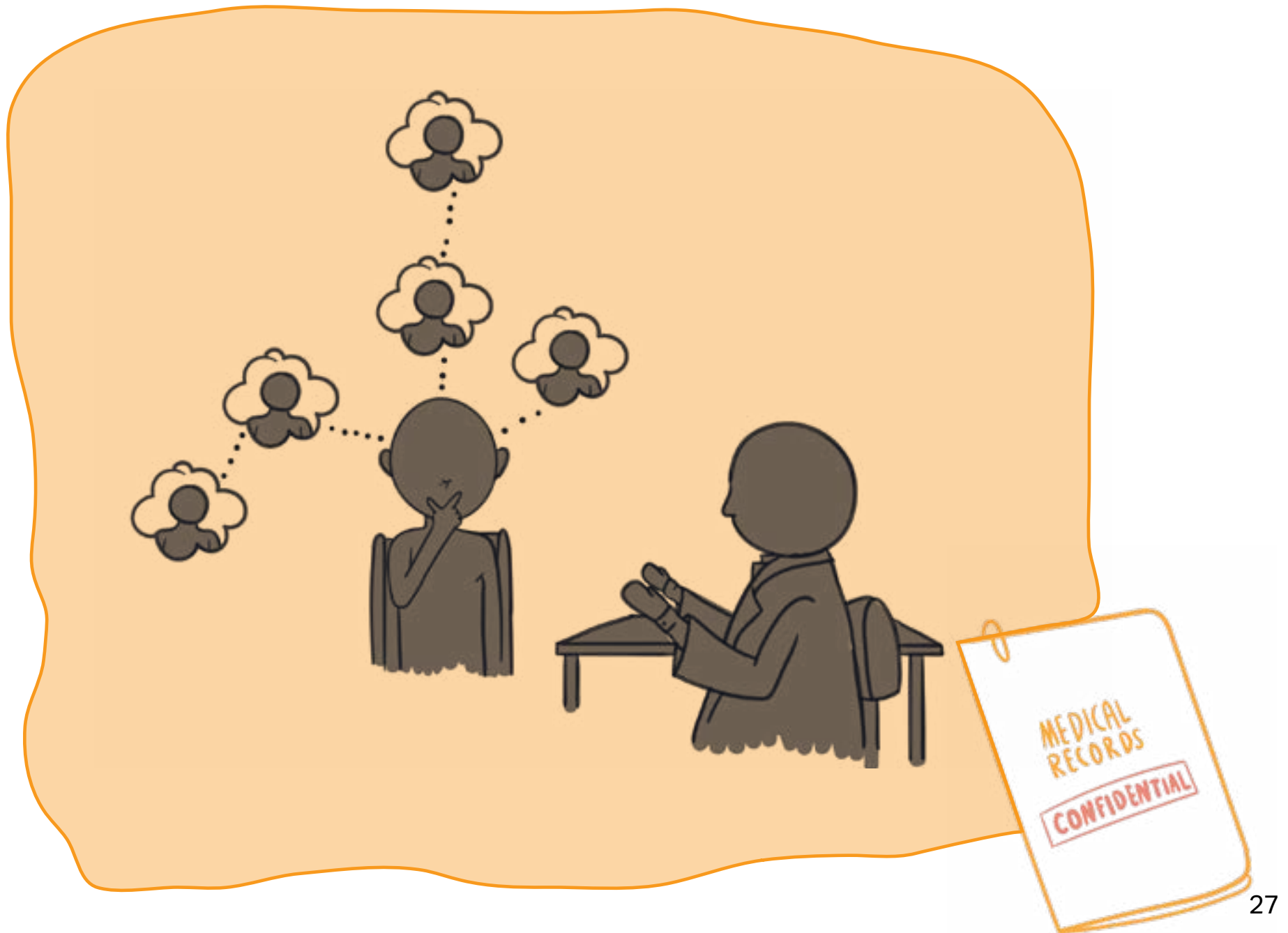
- To **ensure that health workers can test people who may have been exposed to HIV, patients with HIV will need to think about who they may have had sex with, or who they may have shared injecting drug equipment with.**
- It is good to ensure the patient understands this is important so that the people can get tested, and if they are positive, they can also get HIV medicine.
- **Health workers can tell the patient's sex partners and people they may have injected drugs with. It is confidential** which means the patient's details will be kept hidden from them, their details will also be kept private as well.
- **Only medical and health workers who treat the patient will need to know.** Other staff in the clinic and people in community will not be told.
- If the patient is worried about their regular sex partner getting HIV, there are effective (strong) medicines people can take to lower their risk of getting HIV. This is called PrEP. When a person without HIV takes PrEP as instructed by a health worker, it is extremely effective at stopping a person from getting HIV.



What is contact tracing:

Contact tracing is the process of identifying sexual and injecting drug use contacts of a person with an STI or BBV, and ensuring they are aware of their exposure, and they need to be tested. Contact tracing is an important part of STI and BBV care and prevention.

WHO NEEDS TO KNOW?



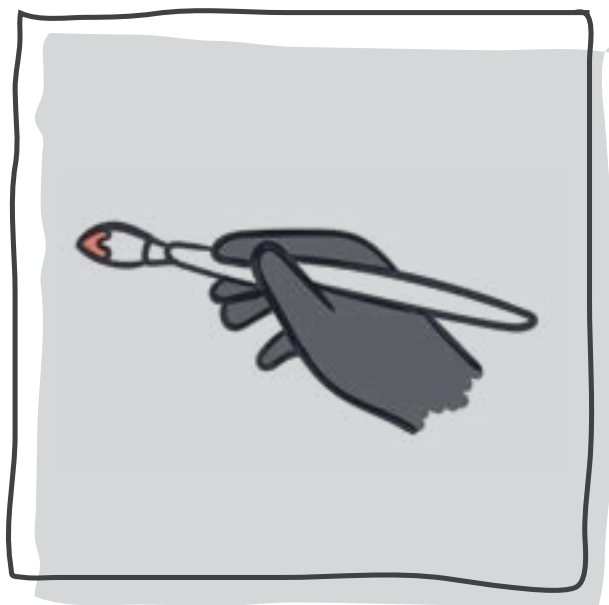
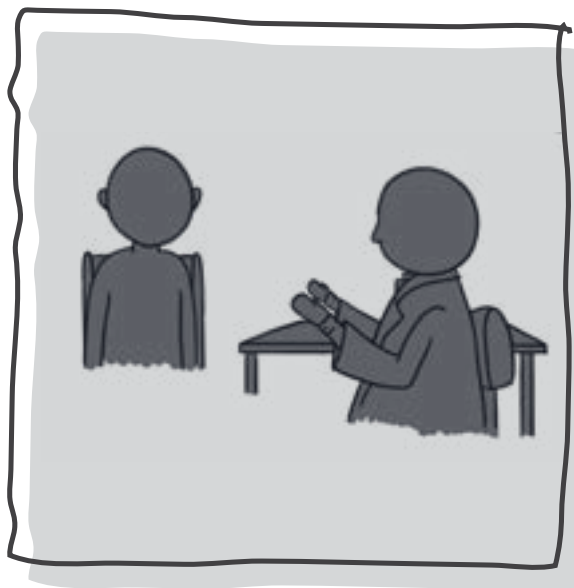
SELF-CARE

This can be a stressful time for people who are newly diagnosed. **The patient may be feeling anxious, nervous, scared, confused etc. It is important to remind people to take care of their mental health.**

Key points checklist:

- People can have a lot of feelings about being told they have HIV. It is important that people do things they love to care for themselves.
- Things that people can find may help are:
 - eating well
 - doing exercise or playing sport
 - spending time with friends, family or community
 - speaking to a health worker
 - doing a hobby like painting or fishing.

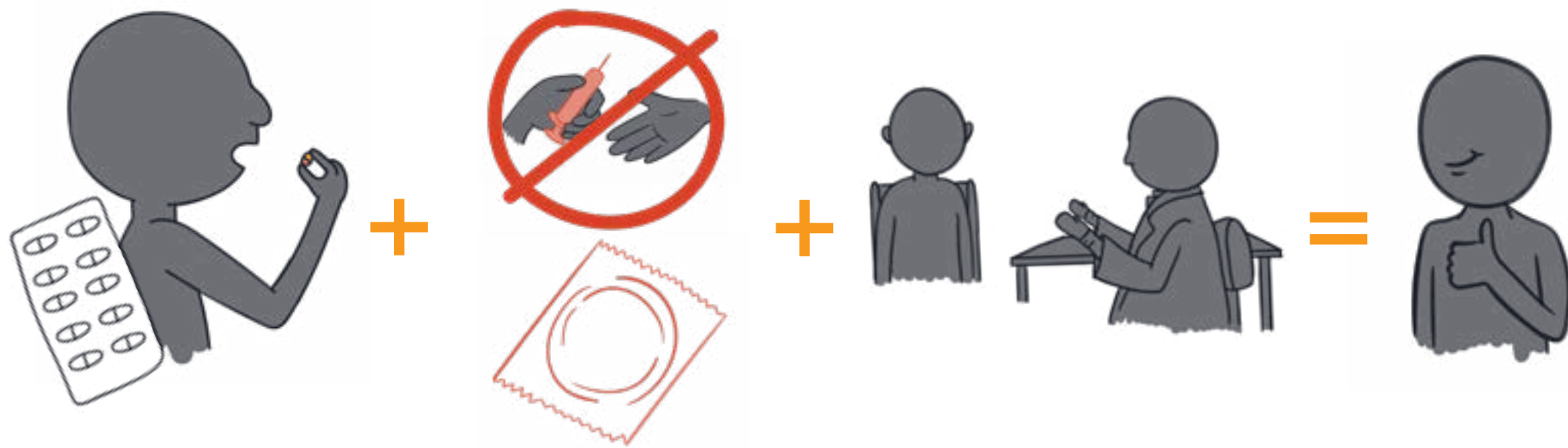
TAKING CARE OF YOURSELF



KEY MESSAGES

- The patient should get medicine for HIV and take it as told by a health worker.
- They should use condoms and not share injecting drug equipment.
- Their sex partners or people they may have shared injecting drug equipment with will need to be told. Health workers can do this for patients.
- They will need to see their health worker regularly.

By doing this someone newly diagnosed with HIV can keep themselves, their family and their community safe.



Illustrations by Crawl in Crocodile

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