# HIV: Training for care providers





These notes are designed to accompany the Powerpoint presentation available on NAT's website. The bullet points for the slides are also included within the notes below. By the end of the training people should have an understanding of:

- What HIV is and why it is relevant to care providers
- Myths and facts about HIV
- Confidentiality and HIV

- HIV and infection control
- Medical and psychological care
- Relationships, sexual health and rights
- Supporting employees with HIV

The training contains a number of case studies for group discussion and a quiz at the end. It is designed so you can pick and choose which areas you cover to meet the needs of staff and the time you have available. NAT has also developed a resource *HIV: A guide for care providers* which is available to download for free from our website.



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#### **SLIDE 1: WHY DO CARE WORKERS NEED TO KNOW ABOUT HIV?**

When HIV was first discovered there was no effective treatment and many people died from AIDS related diseases before they reached older age. That all changed in the mid 1990s with the discovery of effective medication. Now if someone is diagnosed on time and receives treatment they can expect to have a normal life expectancy.

This, and the fact that a growing number of people are getting HIV in older age, means that it is more likely that you will be providing care for someone who is living with HIV in the future. Data from Public Health England shows that one in six of people living with HIV is over 55.

If you aren't completely up-to-date about HIV you won't be alone! Research shows that the general public as a whole are confused about how the virus is passed on, and even some GPs and healthcare professionals have a poor understanding.

# WHY DO CARE WORKERS NEED TO KNOW ABOUT HIV?

#### WHY DO CARE WORKERS NEED TO KNOW ABOUT HIV?

Slide



- People with HIV now living longer normal life expectancy
- First generation of people living with HIV reaching older age - 1 in 6 over 55
- Care sector hasn't had experience of providing care for this community
- There's a lot of public mis-understanding about HIV
- Things have changed since the 1980s!

Living with HIV





HIV (Human Immunodeficiency Virus) is a virus that attacks and damages the body's immune system. It makes the body's immune system less effective over time so that it can no longer protect itself against diseases which it would normally be able to fight off. People who are undiagnosed and have been living with HIV for a considerable time can develop serious illnesses such as pneumonia, TB and certain types of cancer.

But what is the difference between HIV and AIDS? The terms HIV and AIDS (Acquired Immunodeficiency Syndrome) are sometimes used interchangeably. However, this is misleading - they are not the same.

HIV, if left untreated, can lead to the development of AIDS. People diagnosed as having AIDS will have one of a number of different illnesses, depending on the infection they develop. This is why AIDS is not considered a disease, but a syndrome – a collection of different signs and symptoms, all caused by the same virus, HIV.

Since the development of effective treatment, as long as people with HIV are diagnosed in time, it is very unlikely that they will develop AIDS. With treatment, even if someone has AIDS, health can be restored and the long term prognosis can be excellent.

# HIV AND AIDS, WHAT IS THE DIFFERENCE?

#### HIV AND AIDS, WHAT IS THE DIFFERENCE?

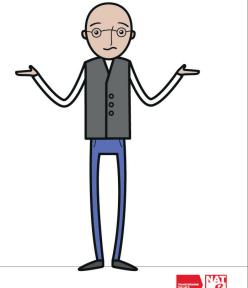
Slide

**HIV** = Human Immunodeficiency Virus

**AIDS** = Acquired Immunodeficiency Syndrome

HIV and AIDS are not the same!

Only if someone is living with HIV and is not diagnosed or on treatment will they develop AIDS





HIV affects quite a lot of people! There are over 100,000 people living with HIV in the UK. That's about the same as the number of people living with multiple sclerosis. Worldwide there are an estimated 37 million people living with HIV.

In the UK some people are more likely to be affected by HIV than others. Gay and bisexual men and black African people are the most affected communities. One in every twenty gay and bisexual men is living with HIV in the UK. However, it's worth remembering that HIV can affect anyone.

How do people get the virus? In the UK it's essentially all about sex. In some parts of the world a lot of people living with HIV got it through sharing injecting drug

equipment, and this is the case for a few people living with HIV here - in Scotland in 2015, 52 people acquired HIV from injecting drug use (though this was an unusually high number). But over 95% of UK infections are sexually transmitted.

Some health and care workers are at first anxious about caring for someone living with HIV because they think there's a risk they might get the virus. It's really important to understand that HIV is quite difficult to pass on and you cannot get the virus from every day care activities like washing someone or assisting them with dressing or eating. HIV is not passed on through contact with saliva, faeces or vomit and you can't get HIV from social contact such as kissing, hugging, coughing or sneezing.

## THE BASICS: WHAT EVERYONE SHOULD KNOW ABOUT HIV

# THE BASICS: WHAT EVERYONE SHOULD KNOW ABOUT HIV Slide Over 100,000 people living with HIV Over 95% of people are infected in UK through sex Dlack African men and women and gay and bisexual men are the groups most affected You cannot get HIV from everyday 95% infected care activities such as washing through sex someone or dressing them TEANSFORMING NAT

#### **SLIDE 4: THE BASICS: WHAT EVERYONE SHOULD KNOW ABOUT HIV**

Managing HIV is actually a fantastic success story because we now have effective treatment.

Not only does this mean people can lead long, active and fulfilling lives, it also means that the vast majority of people doing well on treatment are not infectious. This is because the treatment reduces the amount of virus in their body to very low levels so it can't be passed on. Most people you come across in care who have

diagnosed HIV will be on treatment and not infectious.

However, lots of people don't understand how HIV is passed on or the impact of treatment on infectiousness. And for that reason there is still a lot of stigma and discrimination about HIV. Unfortunately people living with HIV often experience this within a healthcare setting and that's why it is so important that health and social care staff have up-to-date knowledge about HIV.

## THE BASICS: WHAT EVERYONE SHOULD KNOW ABOUT HIV

#### THE BASICS: WHAT EVERYONE SHOULD KNOW ABOUT HIV

Slide



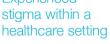
- HIV treatment is extremely effective
- Most people on treatment have a very low level of virus in their body which means they are not infectious
- A third of people living with HIV have experienced stigma and discrimination, half within a healthcare setting.

#### Living with HIV



## Living with HIV







#### **SLIDE 5: HIV AND AGEING**

How does ageing impact on people living with HIV? The answer is that we are still finding this out! There are several international studies following older people living with HIV as they age so we can learn what people's needs are. A lot is still unclear but it seems that people living with HIV are likely to experience symptoms of ageing at an earlier age. They are more likely to suffer

from more than one health condition than their HIV negative peers (for example heart conditions, dementia, osteoporosis). They are also more likely to experience depression and mental health issues. We still don't know whether these things are caused by HIV itself or are side effects of taking HIV medication for many years.

## **HIV AND AGEING**

**HIV AND AGEING** 

- People living with HIV experience signs of ageing at a younger age
- People living with HIV are more likely to have several health conditions to manage (e.g. heart condition, dementia, osteoporosis etc) than people who don't have HIV
- People are more likely to have depression
- Long term impacts of HIV/HIV treatment still emerging.







So what does all this mean for you if you become a carer for someone living with HIV? The short answer is not much! The most important message is that nearly all caring duties will be the same for someone whether they have HIV or not.

So for example people don't need their own cutlery or disposable cutlery. They don't need additional hygiene processes such as disinfected rooms or being given the last bath of the day. And certainly they should not have their personal things labelled or marked out because they have HIV. Nobody ever got HIV from sharing a sofa or a cup! People should never be left out from group activities or told they cannot use shared facilities like a swimming pool or communal toilet because they have HIV.

However there are a few things which need careful attention and that is what we're going to look at in this training.

### CARING FOR SOMEONE LIVING WITH HIV

#### CARING FOR SOMEONE LIVING WITH HIV





- You don't need to treat people living with HIV differently! There's no risk of transmission
- People don't need separate or disposable cutlery
- People don't need to have their rooms disinfected or washing done separately
- People don't need to be washed differently or given the last bath of the day
- Some people have specific requirements around medication, confidentiality and diet



There are some things you can do to make people feel safe and comfortable in your care. Being sensitive to each individual is the most important thing.

For example, globally evidence suggests trans\* people are at higher risk of HIV although we don't yet have data on this in the UK. If you are providing personal care to a trans\* person it's important to understand that their body many not seem to match the way they dress or their name (their gender identity). It's important that people are respectful of this. You can find out more about providing care to trans\* people from the guide listed on the final slide.

Because many people living with HIV have experienced discrimination and poor treatment related to their HIV, they may not want to talk about their HIV status. It is up to each individual to decide how they manage their HIV and some people will not want to discuss it. In which

case there's no need to bring it up unless you need to for their medical care.

Using the right language can really help. Most people never develop AIDS now we have effective treatment and people prefer to talk about HIV rather than AIDS. The term 'homosexual' has also lots of negative associations for people and people tend to talk about gay and bisexual people instead.

People also rarely want to talk about how they got the virus - this is very personal and so unless someone wants to speak about it, avoid asking this type of auestion.

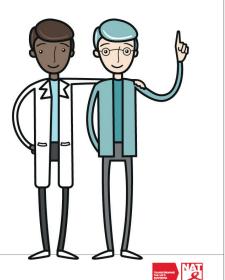
If you see someone being treated badly, left out of activities or called names, you must tell a manager immediately.

# CARING FOR SOMEONE LIVING WITH HIV

#### CARING FOR SOMEONE LIVING WITH HIV



- There's no need to discuss someone's HIV status unless this is for medical reasons or because they raise it with you
- Think carefully about language: it's usually more appropriate to talk about HIV rather than AIDS
- Never ask someone how they got HIV
- Act quickly if you see other members of staff or residents discriminating against someone living with HIV



# **CASE STUDY**

CASE STUDY Slide 8

#### Rita is living with HIV.

She is the first person living with HIV to move into her new care home. She is always given the last bath/shower of the day and is given separate cutlery from the other residents. She has been told to stay in her room and avoid the communal living areas.

#### **Discussion**

- Are the care staff doing anything wrong?
- ♦ How might Rita feel?
- Why is Rita being treated like this?
- How could things be done differently?







#### **SLIDE 9: CONFIDENTIALITY**

Confidentiality is one of the most important things for people living with HIV. People think long and hard about who they tell about their HIV status and people's approach will vary - some will be very open, others very private. What's important is that people living with HIV feel in control of who knows and who doesn't.

Once you understand that there is no risk of HIV transmission from everyday social contact, it is clear that other residents in a care home do not need to know if another resident has HIV. In fact to share this information would be a breach of the Data Protection Act. It is important that someone's medical care is managed

carefully so that other residents are not made aware that someone has HIV. For example making sure attendance at HIV clinic appointments is kept confidential.

Care staff do not need to know that someone they are looking after has HIV unless they are involved with their medical care and support.

If you are aware someone you care for has HIV, don't assume that their friends and family know, they may not. You should always check with someone living with HIV before mentioning it to someone else.

#### CONFIDENTIALITY

# CONFIDENTIALITY Slide 9 There's no need to tell other residents that someone has HIV. Staff not involved in medical care don't need to know - keep medical records securely Don't assume that people's relatives or friends know they have HIV Always check with the individual before mentioning their HIV status to someone Think about how someone's treatment and medical appointments are managed to safeguard confidentiality

# **CONFIDENTIALITY**

"Things got off to a bad start as all the staff at the home were informed of my client's HIV status, although this was completely unnecessary."

HIV social worker



## CONFIDENTIALITY

CONFIDENTIALITY

Slide 11

"The person living with HIV is in control of their information. Apart from their care manager, nobody else has access to their file. The care manager has to get written consent from the person living with HIV before sharing this information."

Care provider





When you understand how HIV is and isn't transmitted, you understand why there is no need for extra precautions when caring for someone living with HIV. Universal precautions/Standard Infection Control Precautions (SICPs) should always be used to guard against a range of infections and this is all that is necessary. You are far less at risk from someone who has been diagnosed with HIV and is doing well on treatment (and is therefore non-infectious) than from someone who doesn't know they have HIV - that is why universal precautions/SICPs should always be used.

If you think you might have been exposed to HIV, for example from a needlestick injury, you should go to A&E and get medical advice. They may decide to give you PEP (Post Exposure Prophylaxis) which is HIV treatment that can be taken to stop you getting the virus but it must be taken as soon as possible, definitely within 72 hours. However, it is worth remembering the risk is very low.

## **HIV AND INFECTION CONTROL**

#### HIV AND INFECTION CONTROL



- Universal precautions/Standard Infection Control Precautions (SICPs) should be taken when supporting any individual in a care setting
- Universal precautions/SICPs are all that are needed when caring for someone living with HIV
- Remember most people on HIV treatment are non-infectious
- PEP Post Exposure Prophylaxis is HIV treatment that can be taken to stop someone getting the virus
- If someone has been exposed to HIV (e.g. needle stick injury) get medical advice as soon as possible, definitely within 72 hours, in case PEP is required.





# **CASE STUDY**

**CASE STUDY** Slide 13

# Guy has recently been discharged from hospital and now needs a carer to help him.

The carer always wears extra gloves when washing and moving him. She has asked him questions about how he got HIV even though he doesn't want to talk about it. She also informed his neighbours that he has HIV when they came to visit him with their young child.

#### **Discussion**

- Are the care staff doing anything wrong?
- ♦ How might Guy feel?
- Why is Guy being treated like this?
- How could things be done differently?







You are probably tired of hearing that essentially people living with HIV need the same high quality care as everyone else! There are a few differences. Confidentiality is a key one but there also some specific points around managing HIV treatment and care.

HIV treatment is very effective but for it to work it must be taken regularly as prescribed - adherence is vital to its success. So it's important that people are given their treatment at the right time, in the right way (this can be before food or with food depending on the drug). You should ask people about their diet and how this interacts with their medication - a nutritious diet is particularly important for people living with HIV as they may have a damaged immune system.

Some people do experience side effects from their medication - for example diarrhoea, tiredness, nausea but these usually go away after a while. People who were diagnosed before effective treatments were available may have more serious side effects for example peripheral neuropathy (damage to the body's nerves).

Most people will have been taking their treatment

independently for years and years so it's important to try and allow people to be in control of their medication for as long as possible.

The relationship with the HIV clinic is important. Most people living with HIV have a close relationship with their HIV clinician and making sure people attend their medical appointments is crucial. In the past many people got all their medical care from their HIV doctor, but now most people will see their GP for routine health problems.

Another important point is treatment interaction - many older people living with HIV will have several health conditions and may need lots of different medications. Sometimes these can interfere with HIV treatment so it's really important to make sure there won't be a problem before giving someone a new medication. You can always check with someone's HIV clinician or on the website www.hiv-druginteractions.org which is constantly updated.

If someone is moving to a different care setting or back to their own home, it's important to make sure they have their HIV medication with them before they go.

# **MEDICAL CARE**

**MEDICAL CARE** 

- People's relationship with their HIV clinic is crucial - make sure people attend their appointments
- Good adherence taking treatment at the right time in the right way - is vital to the success of HIV treatment
- Make sure people take their medication exactly as prescribed by their doctor
- People may need support with side effects from their medication
- Be aware of possible treatment interactions – if unsure always check!
- If someone moves to a different care setting make sure they have their medication with them





# **MEDICAL CARE**

Slide 15 **MEDICAL CARE** "We have an excellent relationship with the HIV clinic, organising transport to get patients to their vital clinic appointments and communicating regularly about any medication or health need."

Care Home Manager









#### **SLIDE 16: PSYCHOLOGICAL SUPPORT**

This is another area where people living with HIV might need additional help. Research shows people living with HIV are more likely to have depression and some may not have the same support networks as other people. Older gay men are less likely to have children and some black African people may have fewer family members living in the UK.

However there are HIV support organisations that offer support for people living with HIV. There are examples of care homes that take residents living with HIV to attend weekly support groups where they can get the additional support they need. NAM has a webpage that will tell you what's available in your area (http://www.aidsmap.com/eatlas/uk/)

### **PSYCHOLOGICAL SUPPORT**

#### **PSYCHOLOGICAL SUPPORT**

- People living with HIV are more likely to experience depression
- Some people won't have the same support networks as other residents - they may not have children or other close family
- Support groups are available for people living with HIV find out what's available in your area







# **PSYCHOLOGICAL SUPPORT**

**PSYCHOLOGICAL SUPPORT** 

Slide 17

"Our home has a number of residents living with HIV, including some younger adults who have HIV related dementia. We make sure that they get the support they need including taking people to peer support sessions at the local HIV service."

Care Home Manager







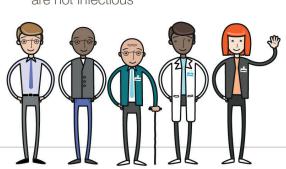
Older people have the right to have sex! And this includes older people living with HIV. We've stressed the fact that HIV treatment means that most people who are diagnosed and on treatment will not be infectious. Plus condoms are also an effective prevention method that should be available.

Many older people living with HIV will be gay and bisexual men. Many have spoken about their fear about being open about their sexual orientation in a care setting or in front of a carer in their own home. If carers can help put people at ease by making it clear that same sex partners are valued in the same way as other friends and family, this will help people feel comfortable about who they are.

#### **RELATIONSHIPS AND SEXUAL HEALTH**

#### **RELATIONSHIPS AND SEXUAL HEALTH**

- Older people have the right to have sexual relationships
- Most people living with HIV on treatment have a very low level of virus in their body which means they are not infectious



- Oreate an atmosphere where people feel able to be open about their sexual orientation - make sure same sex partners feel welcome
- Ensure people can access condoms and sexual health advice





End of life care for people living with HIV is very different from the early days of the epidemic. Most care will be exactly the same as for other people reaching the end of their life. It is important to remember that some people will have partners as well as family and they should be included in the decision making process.

Sometimes people who had HIV when they died face discrimination from funeral directors. There is no risk of HIV transmission from the washing and preparing of bodies for burial or cremation and bodies can be viewed just like anyone else. Embalming is also possible, the current Health and Safety Executive guidance is being revised to reflect this.

## **END OF LIFE CARE**

**END OF LIFE CARE** 



- Involve people's partners as well as their families in end of life care decisions
- The bodies of people living with HIV can be washed and prepared for viewing just like anyone else
- Health and Safety Executive guidance which advises against embalming when the person had HIV is being revised.





# **END OF LIFE CARE**





Care workers want to provide high quality care because they want the best for the people they are supporting. People living with HIV also have a right to appropriate care which is set out in law.

Although many people living with HIV may not think of themselves as having a disability, HIV is a disability under the Equality Act 2010. This means people are protected from discrimination - so it would be illegal to not provide someone with a service just because they are living with HIV, or to charge them more for a care service just

because they have HIV but not additional care needs.

People should also be protected from harassment and abuse from other residents in the care home. People whose care is funded by local authorities also have protections under the Human Rights Act.

As well as making sure people's rights are protected, make people feel included by creating an environment where different cultures and lifestyles are accepted and celebrated.

### **RIGHTS**

RIGHTS
Slide 21
HIV is a disability from the point of diagnosis under the Equality Act 2010
This means people are protected from discrimination
Never refuse someone a service or access to an activity because they have HIV
Protect people from harassment related to their HIV status
Generate an atmosphere where diversity is celebrated

# **CASE STUDY**

CASE STUDY Slide 22

This chain of care homes makes sure residents living with HIV have the opportunity to attend local community groups that supports people living with HIV.

They provide food from different cultures after residents said they would like the menu to include food from their country of origin. They have set up an LGBT staff and residents group to make sure new residents feel welcome and have a space to raise concerns.

#### **Discussion**

- What is this provider doing right?
- Why is that important?
- What could you do within your care setting to build on this?





When thinking about HIV, it's not only people you care for you need to consider. Many people living with HIV will be working in the care sector.

As you'll realise by now, there's no risk of transmission from providing or receiving care and so there is no reason why someone living with HIV shouldn't have a career in care, and many do. Sometimes when people are newly diagnosed or adjusting to medication they can need a bit of time off or flexibility at work. They are

entitled to reasonable adjustments from their employer to help them manage. These are usually simple and easy to manage.

As with a resident or client living with HIV, confidentiality is also very important and there is no need to share someone's HIV status with other employees or residents. Employees living with HIV, like residents, are protected from discrimination under the Equality Act 2010.

# **WORKING WITH HIV**

#### **WORKING WITH HIV**

- People living with HIV can work in social care
- There is no risk of transmission to those they care for
- Some people may want to access reasonable adjustments to make it easier for them to manage their HIV at work these are usually very simple and easy to accommodate
- Maintaining employee's confidentiality about their HIV status is very important







#### **SLIDE 24: FURTHER INFORMATION**

This training has just covered the basics. There's a lot more information out there to help. This final slide has the details of resources where you can find more details about some of the areas covered in this training.

## **FURTHER INFORMATION**

#### **FURTHER INFORMATION**



- NAT resource:
  - HIV: A guide for care providers www.nat.org.uk
- NAT e-learning resource: What you need to know about HIV www.nat.org.uk
- Stonewall: Lesbian, gay and bisexual people in later life www.stonewall.org.uk
- Royal College of Nursing: Older people in care homes – sex, sexuality and intimate relationships www.rcn.org.uk
- NAM: Nutrition www.aidsmap.com
- NAT: HIV@Work www.nat.org.uk
- Public Health Wales: It's just good care: a guide for health staff caring for people who are trans\* www.publichealthwales.wales.nhs.uk





This quiz is made up of ten statements. Ask people whether each statement is true or false. The answer sheet provides the answers as well as information to explain briefly each statement.

#### Quiz

1. If someone is diagnosed with HIV in good time and on treatment they can expect to have a normal life expectancy.

True or false?

2. There are about 40,000 people living with HIV in the UK

True or false?

3. You cannot get HIV from everyday care activities such as washing or dressing someone.

True or false?

4. The majority of people living with HIV in the UK are young heterosexual people aged under 25.

True or false?

5. People living with HIV who are doing well on treatment are not infectious.

True or false?

6. Health and social care workers should wear two sets of gloves plus face mask to protect themselves from HIV transmission at work.

True or false?

7. You can take a drug - PEP (Post Exposure Prophylaxis) - to prevent HIV infection if you have been exposed to the virus.

True or false?

8. All residents in a care home have the right to know if someone there is living with HIV.

True or false?

9. HIV is not a disability.

True or false?

10. People living with HIV can act as care workers just like anyone else.

True or false?

#### If someone is diagnosed with HIV in good time and on treatment they can expect to have a normal life expectancy.

**ANSWER:** True

A person diagnosed with HIV in good time and who responds well to treatment can expect to live a normal lifespan. However, if a person is diagnosed late (after the point at which treatment should have begun) the chances of ill health are increased.

# 2. There are about 40,000 people living with HIV in the UK

**ANSWER:** False

There are about 100,000 people living with HIV in the UK. Public Health England publishes UK wide data on HIV every year and the latest data is available on their website.

#### You cannot get HIV from everyday care activities such as washing or dressing someone.

**ANSWER:** True

You cannot get HIV from any routine caring activity, such as washing or dressing people. In fact sex without a condom is the most common route of HIV transmission in the UK. Over 95% of HIV cases in the UK are transmitted through sexual contact. Condom use during anal or vaginal sex should always be recommended to all sexually active men and women to prevent HIV transmission.

# 4. The majority of people living with HIV in the UK are young heterosexual people aged under 25.

**ANSWER:** False

Although anyone can get HIV, in the UK the community most affected by HIV are gay and bisexual men, with one in twenty gay and bisexual men in the UK living with HIV.

# 5. People living with HIV who are doing well on treatment are not infectious.

**ANSWER:** True

HIV treatment reduces the amount of virus in the body to very low levels so it can't be passed on. Most people you come across in care who have diagnosed HIV will be on treatment and not infectious.

6. Health and social care workers should wear two sets of gloves plus face mask to protect themselves from HIV transmission at work.

**ANSWER:** False

No additional precautions are needed when working

with HIV positive patients. Universal precautions should be taken with all patients, regardless of HIV status. The use of extra gloves, for example, is unnecessary and stigmatising.

# 7. You can take a drug - PEP (Post Exposure Prophylaxis) - to prevent HIV infection if you have been exposed to the virus.

**ANSWER:** True

There is a very small possibility of HIV transmission from a needlestick injury involving someone living with HIV who is not on treatment. If you think you have been exposed to HIV you should go to A&E where you will be given a risk assessment and prescribed PEP if appropriate. PEP must be accessed as soon as possible, definitely within 72 hours.

# 8. All residents in a care home have the right to know if someone there is living with HIV.

**ANSWER:** False

Confidentiality is one of the most important things for people living with HIV. Other residents and visitors do not need to know about someone's HIV status, nor do other care workers unless they are directly involved in someone's medical care. Always check with an individual before mentioning their HIV status to someone.

#### 9. HIV is not a disability.

**ANSWER:** False

Although many people may not think of themselves as having a disability, HIV is a disability under the Equality Act 2010 and this means people are protected from discrimination (for example it would be illegal to refuse to care for someone just because they have HIV).

# 10. People living with HIV can act as care workers just like anyone else.

**ANSWER:** True

There's no risk of HIV transmission from providing care and many people living with HIV have successful careers in the care sector. Employees living with HIV are also protected from discrimination at work under the Equality Act 2010.



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