Our strategic goals

All our work is focused on achieving five strategic goals:

- effective HIV prevention in order to halt the spread of HIV.
- early diagnosis of HIV through ethical, accessible and appropriate testing.
- equitable access to treatment, care and support for people living with HIV.
- enhanced understanding of the facts about HIV and living with HIV in the UK.
- eradication of HIV-related stigma and discrimination.

Our vision

Our vision is a world in which people living with HIV are treated as equal citizens with respect, dignity and justice, are diagnosed early and receive the highest standards of care, and in which everyone knows how, and is able, to protect themselves and others from HIV infection.

NAT is the UK’s leading charity dedicated to transforming society’s response to HIV.

We provide fresh thinking, expertise and practical resources.

We champion the rights of people living with HIV and campaign for change.
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Foreword - Care Inspectorate Scotland

The Care Inspectorate welcomes the opportunity to be part of the development of this significant publication from the National AIDS Trust (NAT).

This practice guide can be used across both health and social care services across Scotland to support continued improvement. It will also help ensure that residents, people using services, and their families are all confident about the levels of care and support they are entitled to and should expect.

The values inherent in this guide mirror the Care Inspectorate’s own values, where we strive to be person centred and operate in a fair and respectful manner with integrity and efficiency at the heart of what we do.

Being person centred means the services, and scrutiny and improvement bodies, must focus on the individual needs of people using care services, and ensure that people’s rights are protected and enhanced.

This guide is timely as we begin to develop in partnership with Scottish Government, Healthcare Improvement Scotland, stakeholders and people who use services and their carers, new national care standards which will stretch across social care and health. We expect these to be based around human rights and people’s wellbeing, and so practice guides like this will become very important in giving effect to the standards and ensuring that all people have safe, high-quality, compassionate care.

While the majority of care services perform well, this guide will also be a useful reference point to support care scrutiny and ensure that effective practice is seen universally in care services.

I am therefore pleased to recommend this guide for residential and domiciliary care in Scotland and we will help ensure that staff, service providers and other external stakeholders can use it to improve their care and practice.

Karen Reid
Chief Executive Care Inspectorate, Scotland
Foreword - The Care Quality Commission

The Care Quality Commission (CQC) welcomes this guide from the National AIDS Trust (NAT) as a valuable resource for residential and domiciliary care services, on a subject matter that does not always get recognised as relevant or important for older adults. But as this guide clearly identifies, with more adults living into older age with HIV, providers of services and all staff should be educated and mindful of how they can best ensure their services are ‘HIV ready’, to enable them to provide equitable high quality services to everyone.

As the Chief Inspector for Adult Social Care in England, I want us to always ask ourselves, ‘is this good enough for my mum? Or anyone I love? Is it good enough for me?’ If it is, that’s great. If it’s not, we need to do something about it. Addressing inequality is at the heart of CQC’s purpose to make sure health and social care services provide people with safe, effective, compassionate, high quality care and encourage care services to improve.

We take our regulatory role seriously, and we are committed to ensuring that everyone receives high quality care, regardless of their equality characteristics. We have incorporated equality into our new approach and will continue to work hard to ensure fairness for all. This guidance helps to tackle some of those misunderstandings and myths about HIV that can otherwise result in unfair and discriminatory behaviour, or services that do not adapt to meet people’s needs - not always through intention but by ignorance.

We have published new handbooks which set out how we will monitor, inspect and regulate adult social care services. These describe what we expect from providers, what we expect good care to look like, and set out the characteristics of the new performance ratings for each provider. We have also published guidance for providers on meeting the new fundamental standards of care, set out in the regulations, which came into force in April 2015.

We all want the same – a caring, well informed, skilled and competent workforce, who are empowered with the right values and behaviours as well as learning and development, to provide high quality, compassionate care, for the benefit of those they support day in, and day out. Without prejudice or ignorance. People using services and staff alike deserve nothing less and NAT’s new guide has an important role in making sure this happens.

Andrea Sutcliffe
Chief Inspector of Adult Social Care, CQC
Who is this guide for?

This guide is intended for care workers and people who commission, manage or deliver residential or domiciliary care.

It can also be used by people living with HIV (and those supporting them) when they are thinking about residential or domiciliary care to give them an understanding of what they should be able to expect from care services.

Why is it needed?

Improvements in HIV treatment mean people living with HIV in the UK are living longer and most can expect to have a normal life expectancy. In 2013 one in four adults living with HIV were aged 50 and over, compared to only one in eight in 2003.

As people living with HIV live to an older age, a greater number will require residential care or support in their own homes. It is important that care providers are ready to offer people living with HIV the services they need.

Historically many people living with HIV did not live into old age so this is not an area where many older people’s services have experience. For this reason many people living with HIV have expressed anxiety about whether they may face discrimination from providers who misunderstand the condition. NAT (National AIDS Trust) has also had a growing number of questions from care providers and staff who are unsure how to support people living with HIV. This guide is designed to answer those questions, providing a practical resource to support the delivery of high quality care.

What does it cover?

This resource is designed to ensure care services for older people are ‘HIV ready’. It includes information everyone providing or commissioning care should know about HIV, as well as dealing with the common myths and misunderstanding.

It will assist with developing training and internal policies on key areas including confidentiality, infection control, equality, sexual health and legal obligations.

There are key points boxes in each section which provide essential information on each area.

HIV and ageing

As people age, they tend to have an increasing number of health problems. This is also true for people living with HIV, but evidence suggests people living with HIV experience more severe problems or problems at an earlier stage.

One study of people over 50 living with HIV found that just under two thirds were on treatment for other long term conditions, and the number of these conditions was almost double what would have been expected in the general population at this age.¹

Common health conditions faced by older people living with HIV include:

- cardiovascular disease;
- diabetes;
- high blood pressure;
- osteoporosis;
- kidney disease;
- dementia and other neuro-cognitive impairments.

Mental health problems and depression are also more common amongst older people living with HIV than the population as a whole.

So whilst advances in treatment have increased life expectancy for most people living with HIV, many will face greater health challenges as they get older.

Research into the impact of the virus on ageing, the side effects of treatment and the way HIV medication interacts with other medication is ongoing and many questions remain unanswered.

What we do know is that people need to be given appropriate support to manage their HIV and other care needs as they grow older.
Section 1.

What everyone should know about HIV
With the changing age profile of people living with HIV, providers of residential and domiciliary care are more likely to come into contact with people living with HIV. It is therefore essential that care workers and other staff have a basic understanding of the virus.

This section provides the facts about HIV people need to know. It should be used for staff training and induction and to inform relevant policies. Providing accurate information will reduce anxiety about HIV transmission and ensure that staff support people living with HIV appropriately. More detailed information on HIV transmission is provided in section four, HIV and infection control.

What is HIV?

HIV (Human Immunodeficiency Virus) is a virus that attacks and damages the body’s immune system. In the UK, HIV is no longer a death sentence, but a long-term manageable condition. If diagnosed on time and on treatment, most people living with HIV will have a normal life expectancy.

What is the difference between HIV and AIDS?

Sometimes the terms ‘HIV’ and ‘AIDS’ (Acquired Immunodeficiency Syndrome) are used interchangeably. This is incorrect and misleading. HIV if left untreated can lead to the development of AIDS, which is a collective term for one or more conditions (for example pneumonia or some types of cancer) which occur when someone’s immune system has been seriously damaged by untreated HIV.

If people with HIV are diagnosed and start treatment when they need to, it is very unlikely that they will develop AIDS. Even if someone is diagnosed late with an AIDS diagnosis, improvements in treatment mean that they may well return to good health.

AIDS is not a term that is used very much now in the UK and some people living with HIV find it stigmatising.

Key points

- There are over 100,000 people living with HIV in the UK.
- Black African men and women and gay and bisexual men are the groups most affected.
- 1 in 4 people accessing HIV care are over 50. People living with HIV are likely to experience problems associated with ageing at an earlier stage and are more likely to have mental health problems.
- Over 95% of people are infected through sex.
- You cannot get HIV from everyday care procedures, for example washing or moving people.
- HIV treatment is now extremely effective and most people diagnosed on time can expect to have a normal life expectancy.
- Most people on HIV treatment have a very low level of HIV in their body - this means they are effectively non-infectious.
- A third of people living with HIV have experienced stigma and discrimination, half within a healthcare setting. Stigma remains a key concern for many people living with HIV.
HIV in the UK

There are over 100,000 people living with HIV in the UK. One in four people living with HIV are undiagnosed and don’t know that they have the virus.

The two groups most affected by HIV in the UK are gay and bisexual men and black African communities. These people can face multiple prejudices related to their ethnicity, sexual orientation and HIV status.

The number of people living with a diagnosed HIV infection who are aged 50 and over has increased in recent years. In 2013, one in four adults seen for HIV care were 50 years of age or older.

HIV transmission

Myths about how HIV can be passed on are still widespread causing unnecessary fear.

HIV cannot be passed on through contact with bodily fluids such as saliva, urine, faeces or vomit. You cannot get HIV from social contact such as touching, kissing, coughing or sneezing. You cannot get HIV from caring for someone, for example when moving them or washing or dressing them. Nor can people get HIV from sharing facilities or equipment, for example sharing toilet seats or cutlery.

HIV is passed on through infected semen, vaginal fluids, rectal secretions, blood or breast milk. However, you cannot get HIV when you come into contact with these fluids if your skin is intact.

The most common ways HIV is passed on are through sex without a condom, or sharing infected needles, syringes or other injecting drug equipment. In the UK, over 95% of people are infected through sex.

Treatment and infectiousness

It is important to understand the impact of HIV treatment on infectiousness. If someone has been diagnosed with HIV and is doing well on treatment it is extremely unlikely they can pass the virus on. This is because treatment significantly reduces the amount of HIV in the body and this reduces infectiousness to a very low level.

Clinics can measure the amount of virus in someone’s blood, and when this falls to below 50 copies per millilitre they are said to have an ‘undetectable viral load’ and are effectively non-infectious. The vast majority of people on treatment in the UK have an undetectable viral load.

Stigma and discrimination

HIV remains a stigmatised condition, often because people misunderstand the way it is transmitted and have misplaced fear about contracting the virus.

One study found that a third of people living with HIV had faced discrimination, half of which occurred in a healthcare setting. Because of this many people living with HIV have concerns about residential and domiciliary care and what prejudices they may face.

For this reason it is particularly important that care workers are given the knowledge and training to treat people living with HIV confidently and with respect.
Testing for HIV

HIV can be detected four weeks after an exposure incident if the most up-to-date laboratory tests are used (available in all sexual health clinics). HIV is not detectable immediately after transmission and this short initial period, known as the ‘window period,’ is the time in which a test would not detect HIV. If someone has been at high risk of infection they may be recommended another test after eight weeks if their initial test result is negative.

You can get a free HIV test in a variety of clinical or community settings including any walk-in sexual health clinic. You can find out where you can get a test near you by entering your postcode in the service finder here: www.aidsmap.com/e-atlas. Self-tests you can buy and use at home are now also available. Waiting times for test results depend on the type of test, with some tests providing an immediate result.

HIV treatment

HIV treatment has improved beyond recognition in recent years and is now extremely effective. Many people now only need to take one or two tablets a day although adherence to treatment (taking it as directed, when directed) is extremely important. Even missing one dose a month can impact on its effectiveness. Some people do experience treatment side effects but these are usually moderate and can be effectively managed. For more information about managing treatment see section five.
Section 2.

Caring for someone living with HIV
When caring for someone living with HIV it is important to know how to treat them in a supportive and responsive way. This section attempts to answer the basic questions care workers or providers may have when supporting someone living with HIV for the first time.

How and when to talk about HIV

You may be aware of someone’s HIV status but if they do not mention it, there is no need to bring it up unless it is necessary in relation to their medical care.

Many people living with HIV have experienced stigma and discrimination and so may feel uncomfortable or nervous talking about their status. They may just feel that it isn’t relevant to their care.

It is also important not to ask someone how they contracted the virus. How they got HIV (in this case potentially many years ago) is not relevant to their current care needs and they may not want to share this information with you. Respecting confidentiality is vital and this is covered in more detail in section three.

Some people living with HIV will want to disclose and talk about their experiences. If they do, it is important to listen to them and give them a chance to speak, not to try to change the subject out of embarrassment or awkwardness about how to respond.

To help create a supportive environment, use language that will make them feel comfortable. It is usually more appropriate to talk about HIV rather than AIDS, as thanks to the huge advances in treatment, very few people in the UK will develop AIDS. Many older people living with HIV will be gay or bisexual men. The term ‘homosexual’

"I am personally committed to making sure our care is appropriate for people living with HIV. Residents living with HIV are treated both equally and as individuals, with no unnecessary additional ‘health and safety’ procedures or separate facilities.”

Care Home Manager

Key points for care workers

☐ There is no need to discuss someone’s HIV status if they do not wish to do so, unless necessary for medical reasons.

☐ If someone wants to speak about their status, listen and give them space to do so.

☐ Always use appropriate language when talking about HIV and never ask someone how they acquired the virus.

☐ There is no risk of HIV transmission from everyday care procedures – you do not need to use extra precautions when caring for people living with HIV.
is now considered out-of-date and can cause offence. Instead, ‘gay and bisexual’ is more accepted. Listen to the language the individual uses themselves and take your cue from them. In addition, make sure that the language you use and forms you provide do not assume that everyone is heterosexual — so rather than asking about somebody’s wife or husband, speak about their partner.

Creating an environment where people living with HIV feel safe and comfortable is very important. If residential care providers are aware of staff or other residents using homophobic, racist or stigmatising language they should take steps to address this immediately. Developing a policy on how to handle this situation will ensure a consistent approach and that all residents can enjoy a tolerant atmosphere. Stonewall and Age UK have guidance on this listed in section 12.

**What do I need to do differently?**

The answer to this is very little. Of course everyone is different so when providing care to anyone it is important to consider their individual needs. And there are some specific requirements around HIV and diet, medication, confidentiality and psychological support that are covered later in this guide. But in terms of essential everyday care there is no need to treat someone living with HIV any differently to any other resident or client. This is because there is no risk of HIV transmission from the day-to-day activities that take place during residential or domiciliary care.

For example, if it isn’t general practice for everyone, people living with HIV should not be given separate or disposable cutlery or bedding, nor should things they use be labelled as there is no risk of HIV transmission from contact with everyday possessions.

When moving, washing, changing dressings or taking someone’s temperature there is no HIV risk and someone living with HIV should be treated in the same way as anyone else.

When cleaning someone’s room, bedroom or bathroom facilities no additional steps are required. And there is no need to dispose of things in a different way if they have been used by someone living with HIV. When someone leaves or dies, a room does not need to be specially cleaned or disinfected just because someone living with HIV may have occupied it. Sometimes care workers bathe people living with HIV last so that they can clean the bath thoroughly afterwards. This is completely unnecessary.

In fact to do these things would be discriminatory and an infringement of someone’s rights. For more information about the law and protecting people’s rights see section 10.

"I know because of my HIV status they were reluctant to help me with the shower. I would keep asking but they would just leave me, I kept reminding them but they were really reluctant."  

Care Home Resident

**Key points for managers**

Act quickly if staff or residents are discriminating against someone living with HIV and make sure you have a policy in place to deal with this.
“When I raised my concerns, the manager reacted straight away and I know now the same thing won’t happen again.”

HIV Social Worker
Section 3.

Confidentiality
The use and storage of personal data to support an individual's care is an important part of any care provider’s role. Care providers in both residential and domiciliary settings will have confidentiality policies and procedures, based on the Data Protection Act 1998 and related social care guidance and regulations. This section explains why confidentiality is so important to people living HIV, and how to avoid unintentional breaches.

Confidentiality and HIV

Confidentiality is important for people living with HIV because of the impact breaches can have. Many people respond well if they find out someone has HIV, but this is not always the case. A breach of confidentiality can lead to unpleasant gossip, negative and discriminatory comments and information being shared without the consent of the person living with HIV. HIV remains a highly stigmatised condition and people living with HIV may have faced stigma or discrimination in the past.

NAT’s recent report on confidentiality in the NHS showed that healthcare settings are one of the main places where people face discrimination, and this may affect how they feel about disclosing their status to organisations or individuals providing care. For this reason, if someone discloses their HIV status it is important that this is not disclosed to a third party without their consent.

Explaining confidentiality policies

It is important to discuss confidentiality policies and procedures with a resident or client so they understand how any information they provide will be used. People should be reassured that the information they provide, including their HIV status, will not be shared with anyone who is not involved in their immediate medical care without their consent and there should be a shared understanding of how it will be used. People living with HIV will then be able to make an informed decision about whether and to whom they may wish to disclose their HIV status.

GPs and disclosure

Whilst people living with HIV will have disclosed their status to their HIV specialist clinic where they are receiving care, they may not have disclosed to other medical professionals involved in their care.

They may have disclosed to their GP but this is not always the case. Some people can be more reticent if they live in a small community where GPs or practice staff may know their friends or family or if they have previously had a bad experience when disclosing to a healthcare worker. Whilst it is generally advisable for a GP to know someone’s status because of potential treatment interactions, it is up to each individual to decide if they disclose. Do not assume that a GP will know about a patient’s HIV status and never disclose to a GP without someone’s consent.
Who needs to know?

Care staff that are not directly involved in meeting the medical care needs of someone living with HIV do not need to know someone has HIV. Sometimes people think that if they are working with someone living with HIV, they have a right to know their status because of a perceived transmission risk. There is no transmission risk and sharing this information would be a breach of confidentiality.

Staff involved in more general care that does not involve supervising medication or clinic appointments do not have any reason to know someone’s HIV status. There is absolutely no reason why cleaners, cooks and other general staff should be informed about someone’s HIV status and to inform them without someone’s consent would be a breach of confidentiality.

There may be circumstances when a care provider will need to share someone’s confidential information with a colleague who is, or is about to, provide them with direct clinical care to make sure they get the best possible treatment. However only information which is relevant in that instance should be shared and only if the person living with HIV consents (either explicitly or through implied consent). In cases where someone does not have capacity to consent, this is more complex, but the individual’s partner or relative or someone who has been given power of attorney could provide consent in these circumstances.

Whilst some administrative staff who deal with record maintenance or arranging medical appointments may need to know about someone’s status, the same standards of confidentiality apply to them as to other staff. All administrative staff who have access to records should receive training on confidentiality and the same strict expectations of confidentiality should apply to them as to other health and social care workers.

"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. It is then up to each individual what information they choose to give to the care workers who come to their home."

Home Care Provider

Some people will feel comfortable talking about their HIV status with other residents or with care workers who come to their home. However, disclosing this information is entirely up to the individual concerned. It would never be appropriate for all residents to be informed of someone’s HIV status. Don’t assume that because someone was happy to tell you about their status, that they would be happy for you to tell others.

Keeping records confidential

Providers will obviously need to keep records for people they provide care for and so it is important that appropriate processes are in place to safeguard people’s confidentiality. There should be a clear policy on who has

Key points for care workers

- Do not assume that other care workers, the GP, friends, family or neighbours know about a person’s HIV status – always check with the client before discussing it with a third party.
- Make sure people’s treatment and medical appointment are managed appropriately so as not to disclose their status to others.
- Make sure you understand your employer’s confidentiality policy and what this means in terms of storing records securely.
access to records and records should never be left out or accessible on a computer for others to see. This includes records kept in an individual’s home – care should be taken so they are not left somewhere visible to visitors.

In many cases, an individual’s care plan may not need to include any reference to their HIV status. If the care provided simply relates to assistance with washing and dressing or food preparation there is no need to include any details of the individual’s HIV status.

Confidentiality breaches

Confidentiality can be difficult to manage. Sometimes confidentiality breaches occur when people are acting with the best of intentions. For example when someone thinks they are doing the right thing by telling others about a person’s HIV status because they misunderstand the way the virus is transmitted and think others need to know.

Other examples of possible breaches include talking about a person’s HIV treatment or clinic appointments in the presence of other residents or staff who do not know about that person’s status or leaving out medical records for public view that refer to an individual’s status. The provision of HIV medication needs to be done in a sensitive way so that someone’s status is not accidently disclosed.

"They broke my confidentiality, telling the other residents that they shouldn’t come and see me in my room because I had HIV. I was lucky because my social worker helped me move to a new home where things are much better. They respect my confidentiality here."

Care Home Resident

Key points for managers

- Ensure your confidentiality policy is up to date and reflects the needs of people living with HIV – all new staff should be inducted in the policy and understand its importance (and current staff may need a refresher in relation to HIV).
- Ensure that people’s records are kept confidential and that domiciliary care workers understand the need for files kept in people’s homes to be stored appropriately. Remember that in many cases there is no need for someone’s HIV status to be mentioned in their care plan.
- Ensure people living with HIV understand your confidentiality policies and that you have a shared agreement about who will be told about their status.

Staff should also not assume that someone’s friends or family know about their HIV status. If domiciliary care workers are in the home of someone living with HIV when someone visits, they should not assume that the visitor knows about the person’s HIV status. Many people living with HIV will have shared their status with some close family and friends, but not everyone will have. Always check with the person before talking about their HIV status.

Domiciliary care workers should never speak to a neighbour or other care or support worker that visits their client’s home about their client’s status. And of course it is never appropriate for a member of staff or indeed residents to gossip or speculate about someone’s HIV status.
Section 4.

HIV and infection control
While the risk of HIV transmission can be a concern to people working in health and social care, in reality HIV is difficult to pass on, and over 95% of cases in the UK are transmitted through sexual contact.

It is important that care workers and other staff have the information they need to be safe and protect themselves from HIV at work. This information is provided here and also in NAT’s e-learning resource for health and social care workers, What you need to know about HIV.6

Care providers’ induction processes should ensure that staff understand the risks of infections, and this should include HIV. However, it is also important that occupational health and blood borne virus policies and training materials do not overstate the risk of HIV transmission and cause unnecessary concern. In fact the main reason to provide the information is to reassure people that the risk of transmission is extremely low, in most cases non-existent.

All residential and domiciliary care infection control training and occupational health materials should emphasise the importance of universal precautions, and state clearly how HIV can be transmitted and how it is not transmitted. This will help to avoid unnecessary anxiety that staff are at risk if they are caring for someone living with HIV.

Importance of universal precautions

Staff and care workers should be reassured that if they follow universal precautions they will not be at risk of acquiring HIV at work. The General Medical Council’s (GMC) guidelines outline how universal precautions are all that are necessary to protect someone from HIV transmission, even when conducting more invasive procedures or surgery.7

Providers will have standard training on universal precautions for all new staff as part of the induction process. Routine procedures should include precautions such as wearing gloves when taking blood or when handling other bodily fluids and making sure any cuts or skin infections are properly covered. Training should also look at the prevention of sharps injuries, for example ensuring needles aren’t re-sheathed after use but disposed of directly into a sharps container and having a clear procedure for responding to sharp injuries, including access to PEP (see below).

These procedures are important regardless of the HIV status of the person you are caring for. If someone’s HIV status is known they are likely to present a low risk. This is because people with diagnosed HIV are likely to be on treatment. Treatment significantly reduces the amount of the HIV virus in the blood stream and this reduces infectiousness to an extremely low level.8 However, one in four people living with HIV are unaware of their status and more likely to be infectious.

It is vital that you do not overstate the risk of HIV transmission when someone known to be living with HIV is in your care or act in a way that would be discriminatory by using ‘extra’ precautions that you would not use for an HIV negative person, for example double gloving when taking blood or giving injections because someone has HIV. The information below should reassure staff about the low risk of transmission.

The main routes of HIV transmission

HIV can be transmitted through semen, anal mucus and vaginal fluid, blood, and breast milk. However, it is important to remember even if your skin is in contact with one of these fluids, if your skin is intact there is no risk of transmission.

HIV is transmitted through anal or vaginal intercourse without a condom or through the sharing of injecting equipment. It is possible to transmit HIV through unprotected oral sex but the risk is significantly lower.

It is also possible for a mother living with HIV to transmit HIV to her child during pregnancy, childbirth or when breastfeeding. However, in the UK effective screening of pregnant women for HIV and provision of HIV treatment to those who have HIV has reduced the risk of a mother passing the virus on to her child to 0.5%.
Situations where there is no risk of HIV transmission

HIV is not transmitted through contact with bodily fluids such as saliva, urine, faeces or vomit.

You cannot get HIV from social contact such as touching, kissing, superficial scratching, coughing, sneezing, sharing seating or a bedroom, sharing washing facilities or toilet seats, handling or moving someone, toothbrushes, or cutlery. You cannot get HIV from spitting.

There is also no risk of transmission from cuts or grazes from broken glass, other sharp materials, or knives if there is no blood on them.

Situations where there is a very low risk of HIV transmission

There are some situations where there may be a theoretical risk of HIV transmission but the risk is extremely low, or may not exist at all.

Biting presents a theoretical risk if a bite is so severe as to puncture the skin, and if the person biting has their own blood in their mouth, and is highly infectious (either because they are recently infected or because they have late stage HIV illness). These are circumstances that people providing care in either a residential or domiciliary care setting are unlikely to face. If someone is living with HIV and on effective treatment there is virtually no risk of transmission. Indeed there has never been a reported case in the UK of infection from biting and only a handful of possible cases around the world.

Blood in the eye. There is an extremely low risk of HIV transmission from blood which comes into contact with a ‘mucous membrane’ for example blood in contact with an eye. If blood comes into contact with someone’s eye then it is important to follow universal precautions and rinse the eye with water or saline solution. The very small risk is reduced even further if the person living with HIV is on treatment.

Resuscitation. The risk of infection from mouth-to-mouth resuscitation is extremely low and there would only be a risk if the person living with HIV had blood in

Key points for managers

- Ensure infection control training for all staff includes HIV so people understand the low risk of HIV transmission in a care setting.
- If someone has been exposed to HIV ensure they should seek medical advice as soon as possible, definitely within 72 hours, in case PEP is required.

"When my client was discharged from hospital he was too ill to go back to his flat and so was temporarily placed in a care home. He was made to feel very uncomfortable about the fact that he had HIV and was not treated in the same way as the other residents – for example made to have the last bath of the day and given separate cutlery. When I spoke to the care home about this, it became clear that the staff had no understanding about HIV and how it is and isn’t passed on"

Social Worker

Key points for care workers

- Always use universal precautions.
- Universal precautions are all that are necessary when caring for someone living with HIV, taking extra unnecessary precautions would be discriminatory.
their mouth and even then the risk would be very small. Resuscitation is normally required because of cardiac arrest and it should not be delayed because of concerns around contracting HIV.

For all the above scenarios it is advisable to get medical advice, but mainly to address other possible infection risks.

**Needle stick injuries**

There have been five cases of occupational transmission of HIV through a needle stick injury in healthcare settings in the UK, but none since 1999. The Department of Health Guidance on occupational exposure to HIV in a healthcare setting notes that the risk of transmission is low, with a transmission risk of about 3 per 1,000 in needle stick injuries involving someone known to be HIV positive. If the person were on HIV treatment there would be virtually no risk. There have been no reported cases of HIV transmission in a social care setting.

**Post-exposure Prophylaxis (PEP)**

If you are concerned that you have been exposed to HIV, you should seek medical advice straight away. If an assessment indicates a significant risk of HIV exposure, PEP will be recommended. PEP is a month-long course of HIV medication taken to prevent HIV infection following exposure to the virus.

If PEP is needed it should be started as soon as possible – within hours of exposure – and certainly within 72 hours. PEP will not normally be recommended after 72 hours as it is much less likely to be effective after this point. PEP is available from A&E departments and sexual health clinics. People who have been prescribed a course of PEP will be told to take an HIV test after four weeks.

PEP can have side-effects, so health and social care workers will be advised to take it only when there is a real risk of occupational exposure. In fact it would only be in very rare circumstances that PEP would be recommended to someone working in a care setting. For example, recent PEP guidance from the Expert Advisory Group on AIDS (EAGA) states that PEP should not be provided for needle stick injuries when the patient living with HIV is on treatment because the risk of infection is so low.
This section looks at the interaction between the care worker, the HIV clinic and the GP, and the administration of HIV medication.

The HIV clinic

People living with HIV will be receiving care from an HIV clinic. This may be a large specialist HIV centre, a smaller clinic that is linked to a sexual health clinic or a centre for tropical diseases/infections.

The relationship between the person living with HIV and their clinic is the most important part of their clinical care. It is at the clinic that HIV treatment decisions are made, including whether to start treatment and the types of drugs prescribed. It is also where the effectiveness of treatment is regularly monitored.

How regularly a person needs to visit their clinic will vary but it is usually at least every six months. These visits and the relationship with the clinic are very important, not just in terms of clinical care, but also for the wider support on offer through the clinic.

"I was self-medicating and at first they used to remind me at the right time to take my medication but then they stopped reminding me which made it much more difficult and I ended up in hospital."

Care Home Resident

For people in residential care, it will be important to ensure that residents attend clinic appointments when they are supposed to. This will involve ensuring that staff are available to accompany someone to an appointment if necessary, or that transport is arranged if required. This needs to be done in a sensitive way to maintain the confidentiality of the person's HIV status (some HIV clinics are within sexual health clinics and people may not want other residents to know where they are going).

In many instances both the patient and clinician want to continue an existing relationship when someone moves into a care home, even if there is a nearer or more convenient HIV clinic. In these circumstances the residential care provider should take steps to ensure this happens if at all possible.

Depending on the type of support provided, a domiciliary care worker can have an important role in reminding people about forthcoming appointments and assisting with arranging transport if needed.

HIV treatment: medication, adherence and self-administration

If someone is in your care, it is important to find out if they are on treatment. If they are, make sure they can access their treatment as strict adherence - taking medication exactly as prescribed - is vital to its success. HIV medication has to be taken at least once a day. Even missing one dose in a month can risk the treatment becoming ineffective (good adherence is considered to be taking medication as prescribed at least 95% of the time).

Commissioners and providers will have policies and processes for the safe and effective use of medicines for people who are in their care. These policies should include arrangements to ensure that records are accurate and up to date. A process should also be in place for sharing information about someone’s medication when they move from one care setting to another (for example from residential care into hospital). This is particularly important for people living with HIV because of the importance of adherence if HIV treatment is going to be effective.

When someone has the capacity to look after and take their own medication this is often referred to as ‘self-administration.’ Those in residential care or supported at
SECTION 5: 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

home should have the same opportunities to be involved in decisions about their treatment and care as anyone else. Unless a risk assessment has indicated otherwise, residents in care homes should be able to self-administer their HIV treatment.10

This does not mean that people should not be supported to ensure they take the correct dose of their medication at the right time. It will be important to keep records of when people are supplied with their HIV medication and that they have been reminded to take it at the correct time. It is also vital to check that people have enough medication to last between appointments at their HIV clinic and if they do not, to ensure that more is obtained so there is no break in the person’s treatment.

Medicines for self-administration should be stored appropriately (for example in a lockable cupboard or in the resident’s drawer) and should be easily accessible to the resident when they need to take them. Residents’ confidentiality about their HIV status should be carefully considered when storing medication.

It is important that if for any reason someone refuses to take their HIV medication this is closely monitored and recorded. If this occurs then the person’s HIV clinician may need to be contacted and options discussed given the importance of adherence.

Older people living with HIV are likely to have more than one health condition. Careful records of the different drugs they are taking should be kept. If there are any concerns about treatment interactions these should be noted and raised with the person’s HIV clinician.

Interaction between primary care and HIV care

Day-to-day non-HIV related health care is now provided by someone’s GP. This is a change as until recently people living with HIV often went to their HIV clinic for their wider healthcare needs. Despite this change, not all people living with HIV will have disclosed their status to their GP so don’t assume that someone’s GP knows about their status.

Given the change in the role of the GP in providing care to people living with HIV, it would be helpful for a GP to be aware of someone’s status and this might be something you wish to discuss with a resident or client, particularly in a residential care setting where the GP will often be coming directly to the home.

If a resident does not want to disclose their HIV status to the GP even after discussion, you may need to support them in speaking to their HIV clinician about any drug interactions from treatment they may have been prescribed by their GP for a different health issue.

Key points for managers and care workers

- The relationship with the HIV Clinic is crucial – make sure the person in your care has regular appointments and support to attend them.
- HIV treatment requires good adherence – make sure people living with HIV are taking their treatment and keep good records.
- Support people to self-administer their medication if possible.

Key points for care workers

- Remember that someone’s GP may not be aware of their HIV status.
- Be aware of potential treatment interactions – if you are unsure check with the HIV clinician.
- If someone moves care settings – for example from a residential home to hospital, make sure they take their treatment with them.
Section 6.

Psychological support
Caring for people living with HIV goes beyond ensuring they have their medication and attend regular clinic appointments. Evidence shows that one impact of HIV is poorer mental health, with depression thought to be about twice as common in people living with HIV as in the general population.

For this reason it is important that those involved in caring for people living with HIV also consider their psychological wellbeing. This may mean looking for different types of support than those usually offered to other residents or people you provide care to.

If you have concerns, discuss these in a sensitive way. Encourage the person to raise these issues with their HIV clinician or GP who will have expertise in this area.

Peer support

Some people with HIV will benefit from contact with peer support services for people living with HIV. This is a chance for them to discuss the issues unique to living with the virus, things that they may not feel able to share with other residents or friends.

Some people living with HIV may be more isolated than other older people. For example research shows that gay men are more likely to live alone, to be childless and to have less contact with their family. Some African people may not have the same support networks as other older people if a lot of their family are living abroad. This is another reason why it is important to ensure that people living with HIV have the opportunity to access support services.

"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

Key points

- People living with HIV are more likely to experience depression.
- Some people living with HIV will not have the same support networks as other older people.

Key points for managers

- Support groups are available and can play an important role for people living with HIV – look at how you can work with these services to support people you are providing care for.

Key points for care workers

- Look out for signs of depression in people that you care for, and if you have concerns, discuss these in a sensitive way.

There may be a variety of services from those specifically for older people, for gay men or from African communities. There are many local HIV support services across the UK, some of whom will offer to come to visit people or run groups that people can access. To find out where your nearest HIV support service is enter your postcode into the service finder here: www.aidsmap.com/e-atlas
Section 7.

Relationships and sexual health
People living in care homes or receiving care in their own home have the right to continue current, or develop new, relationships. Older people are often concerned about isolation and it is important for their health and well being to support social interaction and preserve existing relationships and social networks.

For gay men who may not have children of their own, friends and other HIV positive people may have a more important role to play than traditional family networks. Care providers should ensure that visitors who are not immediate family are made welcome. This is particularly important as many older gay men are anxious about being open about their sexual orientation.

Care workers and providers should make clear that they celebrate diversity and create an atmosphere where gay men feel able to be open about their sexual orientation and their HIV status. Social events should be diverse and inclusive reflecting the experience of residents. Stonewall and Age UK have developed resources on sexual orientation, ethnicity and care provision which will help providers meet people’s needs.

Sexual relationships

Not all care settings will have residents who want to/are able to have sexual relationships. However some will. Sexual relationships have a positive effect on health and wellbeing and do continue into later life.

People living with HIV in residential care settings or receiving domiciliary care are entitled to have sexual relationships with whom they wish, without fear of stigma or breaches of their confidentially (assuming that both parties are adults and able to consent to such a relationship). If they are on effective treatment then they are extremely unlikely to be able to pass on HIV to a sexual partner. While it is important to ensure people have access to condoms and sexual health advice, neither family members nor staff should try to stop someone having a consensual sexual relationship or disclose their status to others.

The Royal College of Nursing (RCN) has produced a guide, Older people in care homes: sex, sexuality and intimate relationships, which covers these issues in detail.

Key points
- Older people have the right to have sexual relationships.
- Most older people living with HIV will be on treatment so they will be virtually non infectious.

Key points for managers
- Ensure people living with HIV can maintain relationships with friends and partners beyond traditional family networks.
- Create an atmosphere where people feel able to be open about their sexual orientation and HIV status.
- Ensure residents can access condoms and sexual health advice.
Section 8.

Diet and HIV
A good diet is important for all older people. For people living with HIV, diet can play an important role in ensuring that they stay well. Certain HIV treatments need to be taken with food, after food or alongside a diet that contains enough calories. Diet can also be used to help with other long term conditions people living with HIV may have, for example osteoporosis or cardiovascular disease.

As people get older and less active their appetite can change and they may want to eat less. This makes it even more important that people living with HIV eat well and that their diet is monitored. Monitoring diet is particularly important for older people living with HIV and dementia as they can sometimes forget to eat properly.

In residential care settings where food is provided there is clearly a duty on the provider and staff to give residents a suitable diet that can help maintain health and wellbeing. Someone living with HIV may have specific needs around their medication and it is important they are discussed with them and fully understood by the care provider.

If domiciliary care workers are assisting with people’s shopping and cooking, they should monitor how much food people are eating. If the care worker knows that an individual has HIV, they should make sure they take their medication in line with food requirements. Many people living with HIV may also be affected by poverty – if someone cannot afford to buy the food they need to stay well, care workers should highlight this to their manager and consider referring them to a benefits advisor, support organisation or a food bank.

"The food was out of this world! They knew what he needed and liked to eat – he used to say ‘this is a good hotel’ so that has to be positive praise!"

Relative of Care Home Resident

Key points for managers

- Ensure that nutrition is discussed as part of the resident induction process for residential care so people have a diet that meets their needs.

Key points for care workers

- Ensure that people’s dietary needs around medication are noted and followed.
- Domiciliary care workers helping with shopping or food preparation should discuss people’s dietary needs.
- If someone cannot afford the food they need, domiciliary care workers should refer them to additional help.
In the 1980s end of life care was an area of expertise for people caring for those living with HIV because of the absence of effective treatment. When antiretroviral treatment became available in the mid 1990s things started to change as HIV became a long term manageable condition. Now as people are living into older age, end of life care needs will become more relevant again.

Someone’s HIV clinician and GP or hospital will manage the medical elements at this time. Decisions need to be made about how long people continue to take antiretroviral treatment, weighing up the benefits of the treatment against the burden of taking medication (potentially in addition to medication for other conditions) and any side effects. Pain management also needs careful consideration, particularly for those that may previously have been injecting drug users. These patients need careful needs assessment and potentially higher doses of pain relief as a result of increased tolerance to opioids.

Care workers can have an important role in monitoring people’s condition and supporting people living with HIV and their families. At this time it is important to ensure the involvement of all the loved ones of the person living with HIV; for some older gay men this may mean ensuring a partner or close friend is included in discussions and the decision making process around care, not just immediate family.

When someone living with HIV dies, the process for certifying the death is no different from that for anyone else. Funeral directors should agree to care for a deceased person who had HIV, and refusal to do so would be discriminatory. Some funeral directors can have concerns around HIV transmission when handling the deceased but these are misplaced. All funeral homes should agree to prepare a body for viewing and burial or cremation. Some guidance does say that the body of someone who had HIV cannot be embalmed, but this is out of date and is currently being revised. In addition, there are embalmers in the UK who will embalm someone who had HIV.

Key points

- The bodies of people who had HIV can be washed and prepared for viewing just like anyone else.
- Some out-of-date guidance advises against embalming when the person had HIV but this is currently being revised.

Key points for managers and care workers

- Involve people’s partners and/or close friends – if this is the wish of the person with HIV - in decisions about end of life care, not just family members.

"Everything from beginning to end was well handled. They dealt with the funeral parlour and it was exactly as he would have wanted – his HIV status was never even raised."

Relative of Care Home Resident
“We need to think ahead – now is the time to look at end of life care for people living with HIV and how we can meet their needs.”

Palliative Care Nurse
Section 10.

Protecting people’s rights
People receiving care have rights which are protecting in law. This section sets out what these rights are and how they relate to people living with HIV.

Equality Act 2010

People living with HIV are protected under the Equality Act 2010 (HIV is defined as a disability from the point of diagnosis), which means they must be treated fairly, with dignity and with respect.

For those providing care to people living with HIV who have some or all of their care funded by local authorities or the NHS, there is also an additional requirement to act in accordance with the duty in the Act to advance equality of opportunity, foster good relations and eliminate discrimination. This means that providers are legally required to ensure that residents and staff can live and work in a supportive environment. Although this applies only to those funded by a local authority, all providers should take steps to implement this duty as a matter of good practice.

What does this mean in practice?

Under the Equality Act, it would be unlawful to decline to offer goods or services to someone living with HIV because of their status. For example, it would be unlawful to not offer a place in a residential care home or refuse to provide care to someone in their home because they have HIV.

In most cases someone’s HIV status will be incidental to the care they need. Any additional cost related to HIV status must be clearly justified because of additional care needs, for example additional care needs due to HIV-related dementia. It would be unlawful to charge someone extra for a service just because they have HIV.

Unlawful discrimination also includes ‘harassment’ which means violating someone’s dignity because of their HIV status or ‘creating an intimidating, hostile, degrading, humiliating or offensive environment’ for an individual. Domiciliary and care home providers must ensure that their staff treat people living with HIV with respect.

It is also unlawful to treat someone living with HIV differently from other residents – for example stopping them using shared facilities such as a bathroom or fitness area or preventing them from taking up activities offered to other residents because of their HIV status.

The Human Rights Act 1998

In addition to the Equality Act 2010, the Human Rights Act 1998 applies to care provided for people who are funded by a public authority – i.e. a local authority or the NHS. Indeed all providers should ensure their care protects these rights regardless of how it is paid for as a principle of good practice.15

"Jim faced discrimination and delay in getting the support he needs with washing and dressing. At the beginning of December the service said that they would be able to help him. Usually they would start within 48 hours but he was still waiting at the end of January because they said additional assessments were required. When pushed they admitted that this was not necessary and care should have started immediately."

Social Worker
Rights that commissioners and providers should particularly consider include:

Article 2 “Right to Life” – Providers must ensure that people living with HIV are not put in danger as a result of consistently poor treatment by care workers and must ensure that people’s lives are protected by providing sufficient support and care, for example ensuring HIV treatment is taken as prescribed.

Article 3 “No one shall be subject to inhuman or degrading treatment” – Providers must take steps to make sure people living with HIV are not caused physical or mental harm or humiliated, for example by not being provided with proper care because of misplaced fears around transmission or HIV related stigma.

Article 5 “Right to liberty and security” – Providers must allow people living with HIV to leave and return to their home when they wish to (for example to attend HIV support groups), they should not be locked inside their home without lawful process being followed, for example through application of the Deprivation of Liberty safeguards in England.

Article 8 “Right to a private and family life, home and correspondence” – Providers should take steps to allow people to live their life as they choose, for example older gay men living with HIV should be allowed to have visits from partners and sexual relationships if they choose.

Article 14 “Right not to be discriminated against in the way your human rights are protected” – The rights above cannot be breached because someone has HIV (Article 14 can only be used in relation to the other articles within the Human Rights Act).

Key points

- HIV is a disability from the point of diagnosis under the Equality Act 2010 offering people living with HIV legal protection from discrimination.

Key points for managers

- Never refuse someone a service or access to an activity just because they have HIV.
- Don’t charge extra for services because of someone’s status unless this can be justified.

Key points for managers and care workers

- Protect people in your care from harassment related to their HIV status and generate an environment where diversity is celebrated.
Section 11.

Employees living with HIV
Best practice around HIV in a care setting is not just about caring for people living with HIV. It is also important to ensure that managers and staff are aware of their responsibilities for employees living with HIV.

People living with HIV are able and entitled to work in the care industry just like anyone else. While staff in the residential and domiciliary care sector may be in close contact with people when providing their care, as long as universal precautions are followed, there is no risk of HIV transmission. In the past there has been misplaced concern that if a resident bit a care worker who was living with HIV there may be a risk of transmission. In fact, it is very likely that the member of staff would be on treatment, in which case there would be no risk at all. Even if they were not on treatment, the risk is extremely low and there has never been a reported case in the UK of infection from biting.

Given that there is no risk of HIV transmission through everyday work contact, it is unnecessary for an employer, colleague or someone receiving care to ask someone living with HIV to disclose their status in the workplace. It would also be inappropriate and illegal for an employer to disclose someone’s HIV status. The decision for someone to disclose their status should be entirely voluntary.

Reasonable adjustments

Disabled employees have a right to reasonable adjustments at work. Reasonable adjustments make it easier for disabled people to continue to work. They may help a person with HIV to attend clinic appointments, take medication at set times or adjust to treatment side-effects. An employer must provide these adjustments to a member of staff living with HIV unless it would be unreasonable to do so. What is ‘reasonable’ is determined on a case-by-case basis and will depend on the size of the employer but in most instances the adjustments required by someone living with HIV will be minor. When making reasonable adjustments it is important to remember to maintain confidentiality.

Equality Act and recruitment

People living with HIV in work are protected from discrimination under the Equality Act 2010 (HIV is defined as a disability from the point of diagnosis in the legislation). The Equality Act provides protection from direct discrimination, indirect discrimination, discrimination arising from disability and discrimination by association/perception.

The Equality Act also prohibits the use of pre-employment health questionnaires, which means it is unlawful to ask any questions about a candidate’s health or disability prior to making a job offer. You can ask them to complete a health questionnaire after they have been offered a position, but if you were to use this information against someone, for example to withdraw the offer of a job, this could be unlawful and used as evidence against you in a tribunal.

Key points

- People living with HIV can work in social care and there is no risk of transmission to those they care for.
- People are protected from HIV discrimination in employment by the Equality Act 2010.

Key points for managers

- You cannot ask people questions about their HIV status during the recruitment process until you have offered them a job.
- Some people may wish to access reasonable adjustments to make it easier to manage their HIV at work.
- Maintaining employees’ confidentiality about their HIV status is vital.
HIV Confidentiality and Employment

Maintaining confidentiality when it comes to HIV is very important and this applies equally to employees as to people being cared for. Some employees may be very open about their status, others may think it is irrelevant to their colleagues or have previously had negative reactions and so choose not to disclose.

If someone does disclose their status to you, for example so they can access reasonable adjustments, it is vital that you keep this information confidential and reassure them that you will do this. The Data Protection Act (DPA) 1998 specifies that written consent is needed for personally sensitive information to be passed on. You should not assume that anyone else in the workplace knows about someone’s HIV status.
References

6. For more information about HIV and health and social care see NAT’s e-learning resource, What you need to know about HIV at http://www.hivaware.org.uk/resources/e-learning.
8. BHIVA/ EAGA, (January 2013), Position statement on the use of antiretroviral therapy to reduce HIV transmission, January 2013, see: www.gov.uk
10. For more information see: NICE. (March 2014). Managing medicines in care homes, see: www.nice.org.uk
14. NAM have developed a booklet to answer some of the most commonly asked questions about food, nutrition and living with HIV. See NAM (2014) Nutrition at www.aidsmap.com
16. For more information about the different types of discrimination and how to avoid acting unlawfully please see NAT’s guide: HIV@work:Advice for employers at www.nat.org.uk.

Still got questions about HIV? Visit www.hivaware.org.uk
Links to the training and regulatory framework in the UK

**England:** The CQC has five inspection questions which contain within them key lines of enquiry. This table sets out how providers and care workers can show they are meeting the CQC key questions in relation to HIV, linking back to chapters in this guide. The table also shows how the Care Certificate standards developed by Skills for Care relate to HIV care.

<table>
<thead>
<tr>
<th>CQC question for services</th>
<th>CQC key line of enquiry</th>
<th>Relevant chapter in this guide</th>
<th>Care Certificate standard (numbers 1 – 15)</th>
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<tbody>
<tr>
<td>Are they safe?</td>
<td>How are people protected from bullying, harassment, avoidable harm and abuse that may breach their human rights?</td>
<td>See ‘Caring for someone living with HIV’ p11</td>
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<td>See ‘Protecting people’s rights’ p35</td>
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<td>How are people’s medicines managed so that they receive them safely?</td>
<td>See ‘Medical care’ p23</td>
<td>10. Safeguarding adults</td>
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<td>How well are people protected from prevention and control of infection?</td>
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<tr>
<td>Are they effective?</td>
<td>Is consent to care and treatment always sought in line with legislation and guidance?</td>
<td>See ‘Medical care’ p23</td>
<td>5. Work in a person centred way</td>
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<td>How are people supported to eat and drink enough to maintain a balanced diet?</td>
<td>See ‘Diet and HIV’ p30</td>
<td>8. Fluids and nutrition</td>
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<td>How are people supported to maintain good health, have access to healthcare services and receive ongoing healthcare support?</td>
<td>See ‘Medical care’ p23</td>
<td>5. Work in a person centred way</td>
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## CQC question for services

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| Are they caring?          | How are positive caring relationships developed with people using the service? | See ‘What everyone should know about HIV’ p7  
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See ‘Protecting people’s rights’ p35 | 4. Equality and Diversity  
5. Working in a person centred way  
6. Communications |
|                           | How does the service support people to express their views and be actively involved in making decisions about their treatment care and support? | See ‘Medical care’ p23  
See ‘End of life care’ p32 | 5. Work in a person centred way  
6. Communication  
7. Privacy and dignity |
|                           | How is people’s privacy and dignity respected and promoted? | See ‘Confidentiality’ p15  
See ‘Relationships and sexual health’ p28 | 7. Privacy and dignity  
14. Handling information |
|                           | How are people supported at the end of their life to have a private, comfortable, dignified and pain free death? | See ‘End of life care’ p32 | 7. Privacy and dignity |
| Are they responsive?      | How do people receive personalised care that is responsive to their needs? | See ‘Caring for someone living with HIV’ p11 | 4. Equality and Diversity  
5. Work in a person centred way  
6. Communication  
7. Privacy and dignity  
9. Awareness of mental health, dementia and learning difficulties  
14. Handling information |
### SECTION 13: LINKS TO THE TRAINING AND REGULATORY FRAMEWORK IN THE UK

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<tr>
<td>Are they well led?</td>
<td>Is there a positive culture that is person centred, open, inclusive and empowering?</td>
<td>See ‘Caring for someone living with HIV’ p11</td>
<td>Skills for Care and the Social Care Institute for Excellence have developed a resource Care Improvement Works which links to training resources for managers mapped to the CQC’s five questions and the Care Certificate - see <a href="http://www.careimprovementworks.org.uk">www.careimprovementworks.org.uk</a></td>
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<td>See ‘Protecting people’s rights’ p35</td>
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<td>See “Employees living with HIV” p38</td>
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<tr>
<td>How does the service work in partnership with other agencies?</td>
<td></td>
<td>See ‘Medical care’ p23</td>
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**Northern Ireland:** The Regulation and Quality Improvement Authority inspects care providers on the basis of Minimum Standards. This table sets out how providers and care workers can show they are meeting these standards in relation to HIV, mapping each chapter to the relevant standards. The table also shows how the current Induction Standards and related training for social care workers relate to HIV care.

<table>
<thead>
<tr>
<th>Section of NAT guide</th>
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<tr>
<td>Caring for someone living with HIV</td>
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<td>Induction Standard 1: Understand the principles of care (especially 1.3 person centred approaches)</td>
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<td>Standard 16: Residents are protected from abuse</td>
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</tr>
<tr>
<td>Confidentiality</td>
<td>Standard 22: Clear documented systems are in place for the management of records in accordance with professional and legislative requirements</td>
<td>Standard 10: Clear, documented systems are in place for the management of records in accordance with legislative requirements</td>
<td>Induction Standard 1: Understand the principles of care (especially 1.2 Confidentiality)</td>
</tr>
<tr>
<td>HIV and infection control</td>
<td>Standard 35: There is a managed environment that minimises the risk of infection for staff, residents and visitors</td>
<td>Standard 16: The agency has systems that ensure safe and healthy working practices</td>
<td>Induction Standard 3: Maintain safety at work (especially 3.5 Infection prevention and control)</td>
</tr>
<tr>
<td>Medical care</td>
<td>Standard 9: The health and social care needs of residents are fully addressed</td>
<td>Standard 7: The agency has arrangements in place to ensure that care workers manage medicines safely and securely</td>
<td>Induction Standard 3: Maintain safety at work (especially 3.6 Medication and health care procedures)</td>
</tr>
<tr>
<td>Psychological support</td>
<td>Standard 2: Contact with family, friends and the local community is facilitated for residents. Standard 13: The home offers a structured programme of varied activities and events, related to the statement of purpose and identified needs of residents</td>
<td></td>
<td>Induction Standard 1: Understanding the principles of care (especially 1.3 Person centred approaches)</td>
</tr>
<tr>
<td>Relationships and sexual health</td>
<td>Standard 2.5: Each resident’s right to develop and maintain intimate personal relationships with people of their choice is respected unless a resident is assessed as lacking the capacity to consent to such a relationship</td>
<td>Standard 1.1: The values underpinning the standards inform the philosophy of care and staff of the agency consistently demonstrate the integration of these values within their practice. (These values include dignity and respect, rights, equality and diversity, privacy and confidentiality)</td>
<td>Induction Standard 2: Understand the organisation and the role of the worker (especially 2.1.4 Your role as a worker)</td>
</tr>
<tr>
<td>Diet and HIV</td>
<td>Standard 12.1: Residents are provided with a nutritious and varied diet, which meets their individual and recorded dietary needs and preferences</td>
<td></td>
<td>Induction Standard 1: Understand the principle of care (especially 1.3 Person centred approaches)</td>
</tr>
<tr>
<td>Section of NAT guide</td>
<td>Relevant Minimum Standards for Residential Care Homes</td>
<td>Relevant Minimum Standards for Domiciliary Care Agencies</td>
<td>Related training</td>
</tr>
<tr>
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</tr>
<tr>
<td>End of life care</td>
<td>Standard 14: The death of a resident is respectfully handled as they would wish</td>
<td></td>
<td>Level 2 and 3 diplomas in health and social care (adults) Wales and Northern Ireland, specifically: EOL201 – Awareness of working in end of life care; HSC3048 – Support individuals at end of life</td>
</tr>
<tr>
<td>Protecting people’s rights</td>
<td>Standard 1.1: The values underpinning the standards inform the philosophy of care and staff consistently demonstrate the integration of these values within their practice. (These values include dignity and respect, rights, equality and diversity, privacy and confidentiality)</td>
<td>Standard 1.1: The values underpinning the standards inform the philosophy of care and staff of the agency consistently demonstrate the integration of these values within their practice. (These values include dignity and respect, rights, equality and diversity, privacy and confidentiality)</td>
<td>Induction Standard 1: Understand the principle of care (especially 1.1 the values)</td>
</tr>
<tr>
<td>Employees living with HIV</td>
<td>Standard 19: Staff are recruited and employed in accordance with relevant statutory employment legislation</td>
<td>Standard 11: Staff are recruited and employed in accordance with relevant statutory employment legislation</td>
<td>A Level 5 diploma in leadership for health and social care services (Adults’ residential care/adults’ management) Wales and Northern Ireland: O16 – Recruitment and selection within health and social care or children’s and young people’s settings. SHC53 – Champion equality, diversity and inclusion</td>
</tr>
</tbody>
</table>
Scotland: The Care Inspectorate inspects care providers on the basis of the National Care Standards for Scotland (although these are currently being reviewed). There are separate standards for care homes and for broader support services. This table sets out how providers and care workers can show they are meeting the standards in relation to HIV, mapping each chapter to the relevant standards. The table also shows how current training relates to HIV care.

<table>
<thead>
<tr>
<th>Section of NAT guide</th>
<th>Relevant Minimum Standards for Residential Care Homes</th>
<th>Relevant National Care Standard for Support Services</th>
<th>Related training</th>
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</thead>
<tbody>
<tr>
<td>What everyone should know about HIV</td>
<td>Standard 5: Management and staffing arrangements</td>
<td>Standard 2: Management and staffing arrangements</td>
<td>Level 2 SVQ Social Services and Healthcare at SCQF level 6, specifically:</td>
</tr>
<tr>
<td>Caring for someone living with HIV</td>
<td>Standard 6: Support arrangements</td>
<td>Standard 4: Support arrangements</td>
<td>H5L5 04 – Develop your own knowledge and practice</td>
</tr>
<tr>
<td>Confidentiality</td>
<td>Standard 16: Private life</td>
<td>Standard 14: Daily life</td>
<td>Level 2 SVQ Social Services and Healthcare at SCQF level 6, specifically:</td>
</tr>
<tr>
<td>HIV and infection control</td>
<td>Standard 4: Your environment</td>
<td>Standard 5: Your environment</td>
<td>H5P9 04 – Uphold the rights of individuals</td>
</tr>
<tr>
<td>Medical care</td>
<td>Standard 14: Keeping well – healthcare</td>
<td>Standard 16: Keeping well</td>
<td>Level 2 SVQ Social Services and Healthcare at SCQF level 6, specifically:</td>
</tr>
<tr>
<td>Psychological support</td>
<td>Standard 12: Lifestyle – social, cultural and religious belief or faith</td>
<td>Standard 8: Making choices</td>
<td>H5P9 04 – Support individuals to participate in recreational activities</td>
</tr>
</tbody>
</table>

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## Section 13: Links to the Training and Regulatory Framework in the UK

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<thead>
<tr>
<th>Section of NAT guide</th>
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</thead>
<tbody>
<tr>
<td>Diet and HIV</td>
<td>Standard 13: Eating well</td>
<td>Standard 15: Eating well</td>
<td>Level 2 SVQ Social Services and Healthcare at SCQF level 6, specifically: H5NK 04 – Support individuals to meet their domestic and personal needs; H5NN 04 – Provide food and drink to promote individuals’ health and wellbeing</td>
</tr>
<tr>
<td>End of life care</td>
<td>Standard 19: Support and care in dying and death</td>
<td></td>
<td>Level 2 SVQ Social Services and Healthcare at SCQF level 6, specifically: H5NS 04 – Help address the physical comfort needs of individuals; H5PA 04 – Contribute to the care of a deceased person</td>
</tr>
<tr>
<td>Protecting people’s rights</td>
<td>Standard 10: Exercising your rights</td>
<td>Standard 11: Exercising your rights</td>
<td>Level 2 SVQ Social Services and Healthcare at SCQF level 6, specifically: H5P9 04 – Uphold the rights of individuals</td>
</tr>
<tr>
<td>Protecting people’s rights</td>
<td>Standard 5: Management and staffing arrangements</td>
<td>Standard 2: Management and staffing arrangements</td>
<td>SVQ 4 Care services leadership and management at SCQF level 10, specifically: H7LM 04 – Actively engage in the safe selection and recruitment of workers and their retention in care services; H7M9 04 – Manage the conduct and performance of workers in care services</td>
</tr>
</tbody>
</table>
Wales: The CCISW inspects care providers on the basis of the National Minimum Standards for Wales. There are separate standards for care homes and for domiciliary care providers. This table sets out how providers and care workers can show they are meeting the standards in relation to HIV, mapping each chapter to the relevant standards. The table also shows how the current training requirements relate to HIV care.

<table>
<thead>
<tr>
<th>Section of NAT guide</th>
<th>Relevant National Minimum Standard for Care Homes for Older People</th>
<th>Relevant National Minimum Standard for Domiciliary Care agencies in Wales</th>
<th>Related training</th>
</tr>
</thead>
<tbody>
<tr>
<td>What everyone should know about HIV</td>
<td>Standard 23: staff training</td>
<td>Standard 19: Development and training</td>
<td>Level 2 and 3 diplomas in health and social care (adults) Wales and Northern Ireland, specifically:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>HSC027 – Contribute to health and safety in health and social care settings</td>
</tr>
<tr>
<td>Caring for someone living with HIV</td>
<td>Standard 6: Service user plan</td>
<td>Standard 4: Service delivery plan</td>
<td>Level 2 and 3 diplomas in health and social care (adults) Wales and Northern Ireland, specifically:</td>
</tr>
<tr>
<td></td>
<td>Standard 8: Autonomy and choice</td>
<td>Standard 7: Responsive services</td>
<td>SHC24 – Introduction to duty of care in health, social care or children’s and young people’s settings;</td>
</tr>
<tr>
<td></td>
<td>Standard 14: Personal care: privacy and dignity</td>
<td>Standard 8: Privacy and dignity</td>
<td>SHC23 – Introduction to equality and inclusion in health, social care or children’s and young people’s settings;</td>
</tr>
<tr>
<td></td>
<td>Standard 32: Protection</td>
<td>Standard 14: Protection of the person</td>
<td>LD202 – Support person centred thinking and planning</td>
</tr>
<tr>
<td>Confidentiality</td>
<td>Standard 7: Record keeping</td>
<td>Standard 6: Confidentiality</td>
<td>Level 2 and 3 diplomas in health and social care (adults) Wales and Northern Ireland, specifically:</td>
</tr>
<tr>
<td></td>
<td>Standard 12: Confidentiality</td>
<td>Standard 16: Records kept in the service user’s home</td>
<td>HSC028 – Handle information in health and social care settings</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Standard 24: Record keeping</td>
<td></td>
</tr>
</tbody>
</table>
### Section 13: Links to the Training and Regulatory Framework in the UK

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</tr>
</thead>
<tbody>
<tr>
<td>HIV and infection control</td>
<td>Standard 18: Safe working practices&lt;br&gt;Standard 40: Hygiene and control of infection</td>
<td>Standard 11: Safe working practices</td>
<td>Level 2 and 3 diplomas in health and social care (adults) Wales and Northern Ireland, specifically:&lt;br&gt;IC01 – The principles of infection prevention and control&lt;br&gt;IC02 – Cause and spread of infection</td>
</tr>
<tr>
<td>Medical care</td>
<td>Standard 6: Service user plan&lt;br&gt;Standard 7: Record keeping&lt;br&gt;Standard 15: Health care&lt;br&gt;Standard 17: Medication</td>
<td>Standard 10: Medication and health related activities</td>
<td>Level 2 and 3 diplomas in health and social care (adults) Wales and Northern Ireland, specifically:&lt;br&gt;HSC2004 – Contribute to monitoring the health of individuals affected by health conditions&lt;br&gt;HSC3047 – Support the use of medication in social care settings</td>
</tr>
<tr>
<td>Psychological support</td>
<td>Standard 9: Social contact and opportunities&lt;br&gt;Standard 10: Community contact</td>
<td></td>
<td>Level 2 and 3 diplomas in health and social care (adults) Wales and Northern Ireland, specifically:&lt;br&gt;SHH 302 – Understand mental wellbeing and mental health promotion;&lt;br&gt;HSC2010 – Provide support for leisure activities</td>
</tr>
<tr>
<td>Relationships and sexual health</td>
<td>Standard 9: Social contact and opportunities&lt;br&gt;Standard 10: Community contact</td>
<td>Standard 8: Privacy and dignity</td>
<td>Level 2 and 3 diplomas in health and social care (adults) Wales and Northern Ireland, specifically:&lt;br&gt;HSC3013 – Support individuals in their relationships</td>
</tr>
</tbody>
</table>
## Section of NAT guide | Relevant National Minimum Standard for Care Homes for Older People | Relevant National Minimum Standard for Domiciliary Care agencies in Wales | Related training
---|---|---|---
Diet and HIV | Standard 16: Meals and meal time | Standard 2: Needs assessment | Level 2 and 3 diplomas in health and social care (adults) Wales and Northern Ireland, specifically: FSN201 – Contribute to promoting nutrition and hydration in health and social care settings
End of life care | Standard 19: Dying and death | | Level 2 and 3 diplomas in health and social care (adults) Wales and Northern Ireland, specifically: EOL201 – Awareness of working in end of life care; HSC3048 – Support individuals at end of life
SHAPING ATTITUDES
CHALLENGING INJUSTICE
CHANGING LIVES

You can help us continue to make a difference.
NAT relies on the support of people like you to continue our important work - shaping attitudes, challenging injustice and changing lives.

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www.HIVaware.org.uk

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www.nat.org.uk

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