care inspectorate

TRANSFORMING THE UK'S RESPONSE TO HIV

NAT

Care of people living with HIV

Practice note

HAPPY TO TRANSLATE

Care of people living with HIV

This practice note is for inspectors, service providers and staff working in care homes, care at home, housing support and other registered care services.

Its purpose is to support inspectors to identify good and weak practice in the care of people living with HIV, support improvement and ensure the best possible outcomes for people experiencing care. Providers and staff can also use this to make sure they are implementing good practices and to show what a good quality care service should be like.

This is linked to the National Aids Trust: HIV: a guide for care providers and the National Health and Care Standards (2017).

Context

People aged 50 and over now make up over a third of all those accessing HIV care in the UK, and this proportion will increase to more than half of people living with HIV by 2028.

While those who access modern antiretroviral treatment early will not experience serious HIV-related illnesses, not everyone is diagnosed in a timely way and there continues to be younger people living with HIV with significant care needs.

Care providers need to be prepared to meet the needs of a diverse population of people living with HIV. In the UK, the groups disproportionately affected by HIV continue to be gay and bisexual men, African women and men and people who currently or previously have injected drugs.

HIV is a complex and not always well-understood condition. This can lead to poor care of people living with HIV, including discriminatory practices and behaviour which does not respect people's rights or dignity.

Key points

Good care of people living with HIV is grounded in respect for rights and dignity. People living with HIV are legally protected against discrimination from the point of diagnosis.

HIV does not pose a risk to care providers, their staff or other people receiving care in a residential or domiciliary care environment and infection control can be achieved through universal application of standard infection control precautions. Effective treatment also means that the virus cannot be passed on.

The specialised healthcare and wellbeing needs of people living with HIV is best supported by good relationships between care providers and specialist clinicians.

Good care for people living with HIV will support their relationships and support networks, in the context of a care environment which celebrates diversity.

Further resources and training

NAT (National AIDS Trust). 2015. HIV: a guide for care providers (developed with the Care Inspectorate)

Free training materials to accompany NAT guide:
- Training guide
- Powerpoint

Indicators of good practice: People living with HIV in care homes and receiving care at home or housing support services

	Component of care	Good practice and sources of evidence	Identifying weak practice	Links to Health and Social Care Standards – My support my life (2017)	Information and resources
1.	**HIV infection prevention and control and risk management**	Standard infection control precautions (SICPs) are in place, without additional practices for those known to be living with HIV (e.g. Single pair of gloves always worn when in contact with blood or body fluids). System for safe disposal of sharps including needles in place (if healthcare is provided). Procedure in place for immediate staff referral to HIV post-exposure prophylaxis (PEP) in case of possible exposure (e.g. needle stick injury (If healthcare is provided).	SICPs not used universally but only for people experiencing care known or suspected to have a communicable infection. Special risk assessment and additional precautions (beyond SICPs) adopted for care of people living with HIV. (e.g. providing separate crockery, double-gloving, alerts on documentation systems / folders). People living with HIV isolated from other people experiencing care.	Dignity and respect 3.2 3.4 3.14 3.18 4.11 4.14 4.17	GMC Supplementary Guidance: Confidentiality – disclosing information about serious communicable diseases. 2009. Section 1: What everyone should know about HIV. HIV: a guide for care providers. NAT, 2015. Section 4: HIV and infection control. HIV: a guide for care providers. NAT. 2015. National Infection Prevention and Control Manual Ch 1: 1.9 Safe disposal of waste (including sharps) Ch1: 1.10 Occupational safety. Prevention and management (including sharps) http://www.nipcm.hps.scot.nhs.uk/ NHS Education Scotland http://nes.scot.nhs.uk/education-

		Staff are offered and attend training on HIV and situations in which transmission does or does not occur. This could form part of mandatory infection control training.	People living with HIV refused usual assisted services (e.g. assistance when bathing). People living with HIV refused usual equipment access (e.g. shower bath, lounge chairs). Confidential medical information about HIV status shared with third parties. Staff sent for HIV PEP following incidents which do not involve exposure to HIV (e.g. spitting).		and-training/by-theme-initiative/public-health/health-protection/blood-borne-viruses-and-sexual-health.aspx
2.	**Confidentiality**	Personal medical or care information is stored securely. Personal medical or care information is accessed only by those directly involved in clinical aspects of care who have	Personal medical information not stored securely/ accessible by staff not directly involved in care. Information about HIV status shared routinely with staff not directly	Dignity and respect 3.8 4.17 4.18	GMC Supplementary Guidance: Confidentiality – disclosing information about serious communicable diseases. 2009. Section 3: Confidentiality. HIV: a guide for care providers. NAT, 2015.

		a need-to-know (e.g. anyone prescribing or administering medicine). System is in place for explaining confidentiality policies and data-sharing procedures to people using the service. Personal medical information (e.g. HIV positive status) is not discussed with third parties (including family and friends) without prior consent from the person. Arrangements for medical/healthcare appointments handled sensitively to avoid sharing of confidential information.	involved in clinical aspects of care. Personal medical or care information discussed with family or friends of service user without prior consent. Information about HIV status shared with any other third party.		Your choice: A guide to confidentiality and HIV in Scotland. HIV Scotland and NAT. 2016.
3.	**Clinical care and support**	Access to specialist HIV clinical care facilitated (e.g. travel to appointments at specialist clinic). Care home settings have	Routine clinical appointments are missed. Health crises occur due to poor communication between in-house staff	Responsive care and support Health and Social Care Standards 1.9 1.12	British HIV Association Standards of Care for People living with HIV. 2013. Section 5: Medical care. HIV: a guide for care providers. NAT, 2015.

		protocols in place for both routine and urgent communication with GPs and, where preferred by the service user, specialist HIV clinicians (consultants, nurses and pharmacists). People living with HIV consulted about preferences for communication with GPs.	and specialist clinicians. People living with HIV not consulted about whether staff may discuss HIV status with their GP.	1.13 1.14 1.15 1.24 2.12 2.24	Section 9: End of life care. HIV: a guide for care providers. NAT, 2015.
4.	**Managing medicines**	People living with HIV supported to self-administer antiretroviral treatment, where possible, including support with dosage and timing where needed. Where self-administration is not possible, antiretroviral treatment is provided consistently at the dosage and precise timing agreed with specialist clinicians. People with HIV are supported by care	People experiencing care are not permitted to self-administer any medication, irrespective of individual risk-assessment. Self-administration is not offered to individuals if they need some support to do so (e.g. care staff providing reminders / prompting about dosage and timing). Medication provision schedule reflects	Be included Responsive care and support Wellbeing 1.18 2.23 4.27	HIV drug interactions checker: http://www.hiv-druginteractions.org/. University of Liverpool. British HIV Association Standards of Care for People living with HIV. 2013. Section 5: Medical care. HIV: a guide for care providers. NAT, 2015.

		providers to seek medicines reviews from healthcare professionals in response to concerns around side-effects, polypharmacy, pill burden etc.	organisational preferences, not persons clinical or care needs.		
5.	**Psychological support**	Screening and provision of services for psychological support recognise the specific needs of people living with HIV. People living with HIV are supported to access peer support or other relevant support services in the community.	No systems in place for identifying and meeting psychological support needs of people experiencing care. Care providers will not facilitate access to HIV-relevant specific groups and other sources of support in the community, where these are available (e.g. by providing transport).	Responsive care and support Wellbeing Compassion 1.5 1.6 1.7 1.25 3.8 3.9	British Psychological Society (BPS), British HIV Association (BHIVA) and Medical Foundation for AIDS & Sexual Health (MedFASH) Standards for psychological support for adults living with HIV. 2011. HIV Scotland pages on Peer support available around Scotland. Positively UK. National Standards for Peer Support in HIV. 2017. Section 6: Psychological support. HIV: a guide for care providers. NAT, 2015.
6.	**Relationships and sexual health**	People living with HIV are supported to maintain relationships including and beyond family networks (e.g. friends and partners) and including healthy sexual relationships.	Relationships with broader support networks are not supported by organisational approach to visitors/travel. Negative approach	Be included Wellbeing Responsive care and support 1.1	Royal College of Nursing. Older people in care homes: sex, sexuality and intimate relationships. 2011. Section 7: Relationships and sexual health. HIV: a guide for care providers. NAT, 2015.

		Care environment celebrates diversity in all forms, including sexual orientation and relationships. People living with HIV experience a physical environment that maintains their relationship in a dignified and respectful manner (have access to private area/room that they can secure). People's individual sexual health needs are met, including access to health promotion materials (condoms and sexual health advice) and clinical services, when needed.	towards same-sex relationships and non-traditional relationships (e.g. verbal or documentation communication evidences episodes of bias, discrimination or judgement). People living with HIV are not supported to have healthy sexual relationships.	1.2 2.18 5.8	
7.	**Protecting rights**	Policies and procedures in place which recognise that HIV positive status is a protected characteristic (disability) under the Equality Act 2010, from the point of diagnosis.	People living with HIV experience disability-related discrimination (e.g. subject to unnecessary infection control or breeches of confidentiality).	Dignity and respect 1.1 1.2 2.2	Your rights: A Guide to Human Rights and HIV. HIV Scotland and NAT, 2016. Section 10: Protecting people's rights. HIV: a guide for care providers. NAT, 2015.

		Reasonable adjustments made when requested. Active steps taken to prevent discrimination or harassment related to HIV status. Diversity is celebrated in the care environment, including of race, sexual orientation, gender and disability. Staff are trained in equality and human rights law.	Reasonable adjustments are not made when requested (e.g. dietary needs). People living with HIV experience violation of dignity and/or an intimidating, hostile, degrading, humiliating or offensive environment. Appropriate action is not taken in response to breaches of equality of human rights law.		
8.	**Continuous Improvement / Quality Management Systems**	Monitoring and/or auditing/survey systems are in place to capture feedback on the effectiveness of the service provision for people with HIV. There is a culture of continuous improvement which supports the persons lifestyle preferences, choices and aspirations. People experiencing care feel	There is no measurable or monitoring mechanism for staff or others to report system or service delivery issues in the area of HIV (e.g. no infection control audits exist that test / measure items 1-8). There is no feedback mechanism for people experiencing care (e.g.	Be included Responsive care and support Wellbeing Be included Responsive care and support Wellbeing 1.17 3.14	

		confident to give feedback on their care experiences or raise any concerns. Where there are adverse incidents or areas for improvement identified, there is a clear improvement plan in place which addresses this. Training resources include methods to measure learning (e.g. competency-based system demonstrating putting learning into practice).	no comment or complaint system that is accessible or confidential; no satisfaction surveys of people's views or experiences taken into account and acted on). There is no clear improvement plan in place to support a lessons learned approach to adverse incidents or feedback which will help to improve practice and outcomes for people. Training is not measured for effectiveness (e.g. only attendance or enjoyment / satisfaction measured).	4.19	

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