

HIV as a long-term condition and role of the annual health review

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Abstract

Living with HIV has changed. Over the past 30 years HIV has developed from an acute illness with a poor prognosis to a long-term condition with a near normal, if not enhanced, lifespan. HIV healthcare professionals have developed with these changes from supporting and managing acute, unwell people living with HIV, developing their palliative and terminal care skills, to today where they are now developing skills in preventative health and promotion of desirable healthy lifestyles. HIV as a long-term condition is now a reality for people living with HIV and healthcare professionals who manage, support and care for them. This continuing professional development (CPD) article will define long-term health for people living and ageing with HIV, describe the types of interventions available as well as discussing how we can best manage them; defining and discussing the role of the nurse in supporting self-care and self-management, and also looking at the annual health review and the nurse's role in monitoring and developing this.

Keywords: HIV, long-term condition, house of care, prevention, self-care, self-management, annual health review

A. Revalidation

This article has been prepared with continuing professional development (CPD) in mind and can be used to support your revalidation. It is estimated that 2.5 hours of CPD activity will be required for completion of the reading, 'time out' activities, the quiz and writing a brief reflective account in relation to your learning and its applicability to your practice. There is a self-assessment quiz at the end of this article for you to assess what you have learnt.

B. Aims and intended learning outcomes

This article aims to increase your knowledge about HIV as a long-term condition and the role of the annual health review in assessing long-term health. It would be useful to work through some of the previous CPD articles [1-5]

After reading this article, undertaking the activities and completing the self-assessment quiz you should be able to:

- understand and define the concepts of HIV as a long-term condition;
- list and discuss at least three issues associated with HIV and long-term conditions;
- show awareness of your own role within management of HIV as a long-term condition;
- describe and discuss the terms 'self-care' and 'self-management' and the role of the expert patient;
- discuss the role of an annual health review for people with HIV; and
- review your current practice and guidelines around providing annual health reviews.

C. Introduction

Living with HIV has evolved as the HIV epidemic has developed over the past 30 years from a life-limiting illness with periods of acute ill health, complicated drug regimens and a health and social care service designed to holistically manage and support the individual to a chronic long-term condition with single tablet treatments, a near normal life span and reduced health and social support. In the early day of the HIV story, discussions about long-term health were unrealistic and much of the talk was around enjoying life to the full, with no pressure to stop lifestyle choices such as smoking, drinking and drug taking unless they were seen as problematic or the person with HIV asked for help to stop or cut down. Today where, thanks to the use of increasingly sophisticated antiretroviral therapy (ART), HIV has been redefined as a long-term condition, but an illness that has and will incorporate issues of ageing where management and support remains fragmented across primary, secondary and tertiary care services [6]. For many HIV will remain a long-term, manageable illness requiring annual clinic appointments, email and telephone appointments and home delivery of medications, others are more complex [5]. Comorbidities are associated with the natural ageing process, but an increased risk of comorbidities in older patients with HIV has been linked to the long-term use of ART, chronic inflammation associated with HIV and persistent immune activation [7]. People living with HIV have higher prevalence of comorbidities than the general population: 64% of people living with HIV have at least one other comorbidity and 38% have multiple comorbidities [8]. Over one-third (38%) of people living with HIV are aged ≥ 50 years and by 2028 this figure is projected to rise to more than half

(54%). The acquisition of both HIV-related and non-HIV-related comorbidities among this ageing population creates a new dimension for the management of long-term conditions among people living with HIV. For example, among people living with HIV, high cholesterol will increase from 19% in 2103 to 29% in 2028 and hypertension will increase from 13% to 21% [9]. Therefore interventions are needed to reduce lifestyle risk factors. Data from a study in the Netherlands by Smit *et al.* show that the proportion of people living with HIV aged ≥ 50 years will increase from 28% in 2010, to 73% by 2030 with the proportion of people living with HIV with at least one noncommunicable illness such as hypertension, hypercholesterolemia, myocardial infarction, stroke, diabetes, chronic kidney disease, osteoporosis, and non-AIDS malignancies estimated to increase from 29% in 2010, to 84% by 2030 [10]. They also estimated that by 2030, 28% of people living with HIV will have more than three noncommunicable illnesses and that 54% will be on medications to treat these conditions. However, long-term health is not only about ageing with HIV but should clearly focus upon living 'healthily' with HIV from the day of diagnosis onwards, regardless of age. As nurses working in HIV we need to think holistically about all aspects of a person's life that can positively and negatively impact on their long-term health, some of these have been covered in previous CPD articles [1-4]. Obvious lifestyle issues such as diet and weight management, smoking, alcohol and recreational drug use, exercise and fitness can be time consuming and challenging to address, particularly if you have limited appointment times and more so if the patient has other more pressing concerns that they want to discuss. We also need to consider genetics and take a family history to get an overview of potential issues ahead. In the general population chronic diseases are now the most common cause of death and disability in England [6]. More than 15 million people have a long-term condition such as hypertension, depression, asthma, diabetes, coronary heart disease, chronic kidney disease, or other health problem or disability for which there is no cure. These people tend to be heavy users of healthcare resources, accounting for at least 50% of all GP appointments, 64% of outpatient appointments and 70% of all inpatient bed days [11]. But how do you talk about living to old age and adopting a healthy lifestyle to a young person living with HIV who wants to live in the moment and not think about their life 40 years on?

Time out activity 1

Think about a patient you know. List the issues they have now and potential issues they may have in the future. Think about not only their physical health (family history, weight, alcohol intake, diet, exercise, drug use) but also psychosocial health, such as housing and finances. Have you discussed concerns around long-term health with them, if not why not?

What motivates them (and you) to make changes in life style?

D. Defining HIV as a long-term condition

Long-term conditions have been defined as 'health problems that require ongoing management over a period of years or decades' [12]. However Eaton *et al.* stated that this definition fails to reflect the personal, social and economic burden on the individual, their families, and the wider community; or acknowledge that people with long-term conditions spend just a few hours a year interacting with clinicians and health-care services and more than 99% of their lives managing their conditions themselves [13]. HIV and its management, I would argue, have been under the long-term care banner for many years and we already provide tailored care for, predominantly, well informed, empowered people living with HIV.

However, management and care of long-term conditions still tends to be seen as the clinician's responsibility rather than a collaborative endeavour with active patient involvement and effective self-management support. There have been several initiatives to support long-term health for people living with HIV such as the positive self-management programme (Livingwellhiv.com) and locally run 'recently diagnosed' courses. The British HIV Association (BHIVA) standards (2018) have recognised this for many years and support self-management initiatives [14]. With the latest standards stating:

'People living with HIV should have equitable access to services that promote self-management of HIV including provision of support and information:

- *about HIV, treatment, healthy living with HIV, diet and lifestyle, and optimisation of general health including rehabilitation services*
- *on maximisation of entitlement to health services and support*
- *to enable people to optimise their entitlement and access to financial and housing support, and to optimise their ability to maintain/gain/regain employment'*

The NHS forward view looks to the house of care which was devised to help those working in primary care to place the patient at the heart of the delivery system. The key components are:

- People with long-term conditions are central to the process. They are supported by health and social care professionals to express their own needs and decide on their own priorities through a process of information-sharing, shared decision-making and action planning.
- Self-management support and the development of collaborative relationships between patients and professionals are at the heart of service delivery shifting the focus onto the roles and responsibilities of patients as well as professionals, and the systems that are needed to support them to fulfil these roles with the ultimate aim that people should have the knowledge, skills and confidence to manage their condition effectively in the context of their everyday life.
- Tackling health inequalities is a central aim of the house of care. The number of long-term conditions and their burden falls disproportionately on people

with poor health literacy and those in lower socio-economic groups. Tools, skills training and ongoing support must be available to identify those who find it harder to engage with health issues and may need extra support to do so.

- The house of care delivery system aims to ensure that each individual is involved in a unified, holistic care planning process with a single care plan. A common set of relevant skills and processes reduces the burden of training.
- Quality assurance of the philosophy, core approach and skills required are essential to ensure that implementation builds on relevant evidence and experiential knowledge, which is consistently applied.
- Care planning is the gateway to personalisation and/or personal health budgets [6]. The centre of the house of care is personalised care planning, a collaborative process between patient and healthcare professional(s) to devise a tailored programme that will support and develop confidence to be an effective self-manager of their condition with the structures and processes surrounding the patient to support them, see Figure 1. Healthcare professionals who do things with people rather than do things to them can achieve so much more [6].

Clinicians need to learn to practise a consulting style that is curious, supportive and non-judgemental, which uses problem-solving and coaching techniques, and contains the following elements [15]:

- developing empathy and trust;
- negotiating agenda setting and prioritising sharing information;
- challenging and re-attributing unhelpful beliefs;
- communicating and managing risk;
- supporting deliberation;
- summarising and feeding back;
- developing action plans collaboratively;
- documenting agreed actions; and
- providing practical and emotional follow-up support.

Time out activity 2

Do you discuss long-term health with your patients? What issues do you encounter? Do you feel this is your or other members of the healthcare teams responsibility? What do you find easy and more challenging to discuss about their long-term health?

E. Self-management and self-care

Self-care has been defined as *'the actions that individuals take for themselves, on behalf of and with others in order to develop, protect, maintain and improve their health, wellbeing or wellness'* [16]. The self-care forum state that around 80% of all care in the UK is self-care. The majority of people feel comfortable managing everyday minor ailments like coughs and colds themselves; particularly when they feel confident in recognising the symptoms and have successfully treated them using an over-the-counter (OTC) medicine previously. On average, people in the UK experience nearly four symptoms every fortnight, the three commonest being feeling tired/run down, headaches and joint pain and most of these are managed in the community without people seeking professional healthcare [17]. Self-management involves people living with HIV developing an understanding of how their condition affects their lives and how to cope with the clinical, physical, psychological and social challenges it presents. Effective self-management allows people living with HIV to make the many daily decisions that improve their health-related behaviours and outcomes. Building capacity to optimally self-manage includes ways to manage current challenges and also preparedness for future challenges [14].

The Self Care Forum have devised a sliding scale continuum of self-care starting with the individual responsibility people take in making daily choices about their lifestyle, such as brushing their teeth, eating

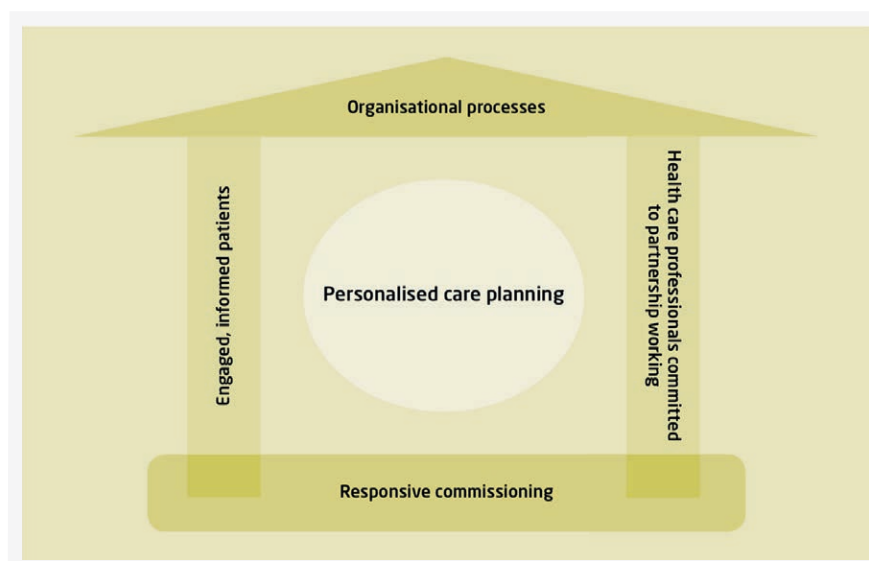


Figure 1: House of care. Image used with kind permission from The King's Fund <https://www.kingsfund.org.uk/publications/delivering-better-services-people-long-term-conditions> [6]

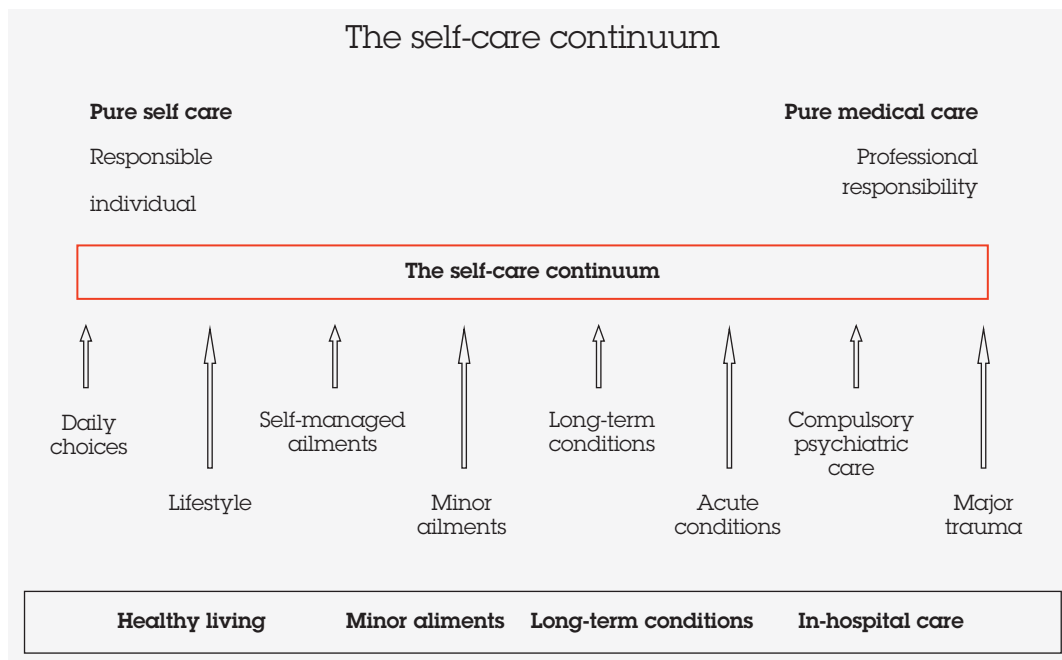


Figure 2: The self-care continuum, published with kind permission from the Self Care Forum <http://www.selfcareforum.org/about-us/what-do-we-mean-by-self-care-and-why-is-good-for-people/> [16]

healthily or choosing to do exercise, Figure 2. Moving along the scale, people can often take care of themselves when they have common symptoms such as sore throats, coughs etc., for example by using OTC remedies. The same is true for long-term conditions where people often self-manage without intervention from a health professional. At the opposite end of the continuum is major trauma where responsibility for care is entirely in the hands of the healthcare professionals, until the start of recovery when self-care can begin again [16].

Living with HIV requires lifelong adjustments and management. As with many other long-term conditions, self-management approaches can help people living with HIV to gain confidence, skills and knowledge to manage their own health better, with resulting improvements in quality of life and independence. It is important to know that resources required to effectively self-manage will change across the life course, there is no set plan that is right for everyone, so some people living with HIV will manage their illness with very little support and may gain their expertise from resources (internet, National AIDS Manual etc.) or speaking to peers, whilst others may benefit from structured expert patient type programmes with ongoing support from peers and facilitators; and there will be other people living with HIV who are more than happy for healthcare workers to manage their HIV for them. Self-management issues around key life phases and moments, for example diagnosis, starting HIV treatment, entry and re-entry into the workforce, establishing relationships, sexual debut, pregnancy and having children, coping with loss, ageing, retirement or transitioning from paediatric to adult services will require different strategies and resources and have implications for different services [14].

The role of self-care and self-management isn't new and has been used in the management of other chronic illnesses such as diabetes and arthritis for years [18]. HIV self-management has developed over the last 15 years as HIV became a 'manageable' illness and clinics changed from being 'one stop shops', where most issues were dealt with in-house, and care moved into the community meaning that people living with HIV had to take some ownership over their HIV and communicate not only with their GP but also any other healthcare professionals they encountered. Today the NHS Five year Forward View states:

'Evidence tells us that supporting patients to be actively involved in their own care, treatment and support can improve outcomes and experience for patients, and potentially yield efficiency savings for the system through more personalised commissioning and supporting people to stay well and manage their own conditions better.' [19]

They plan to support this by:

- giving patients the power to manage their own health and make informed decisions about their care and treatment; and
- and supporting them to improve their health and give them the best opportunity to lead the life that they want [20].

There is much evidence around the effectiveness of self-management for people living with HIV [21-24]. However, self-care and self-management (despite their names) cannot work in isolation, with healthcare workers and especially nurses being ideally placed to encourage patients to take control of the situation, enable them to explore the full extent of their needs and wishes, and to develop care plans that take into account physical and other needs [25]. In some studies people living with HIV stated that their doctor was their most significant health support [26], with many having

long-established relationships with their HIV doctor, which was identified as an essential component to successful self-management [27]. Recognising the central role of patients in the day-to-day self-management of their conditions, and the professional's role in supporting each patient to develop the knowledge, skills and confidence to be an expert self-manager, is the first step to professional engagement [6].

Patient empowerment and self-management are relatively new concepts for nurses and other healthcare professionals. It means that people living with HIV are provided with information about how to manage their illness, symptoms to be aware of and the risk and benefits of treatment, so they can make an informed choice and act on this, however this could also mean that they may choose not to take medications or to follow advice given [25]. The use of the internet to gain information can be both useful and challenging especially as some treatments may only be available in certain countries that can lead to frustrations if the person with HIV has symptoms that aren't responding to UK prescribed medications. Where patients choose a course of action not in keeping with professional advice, it is important they receive continuing supportive help. In many cases there should be further exploration of why they do not wish to comply with the advice given, for example, real or perceived side effects of medication, apathy about a course of action and conflicting or poor information. These reasons should be fully understood by the nurse, and support given without challenging their beliefs.

F. Patient activation

Central to the NHS Five Year Forward plan and self-management of long-term conditions is the motivation and confidence of people living with a long-term condition to make the changes needed to maintain their health. The scarily science fiction-named 'patient activation' then comes into play. People living with HIV, and any other long-term condition have different levels of knowledge, skills and confidence to assume responsibility for their own health and well-being. In order to tailor appropriate support according to their needs and to increase their capability to look after themselves more effectively, it is important to be able to measure a person's level of activation (the confidence and motivation to self-manage and make needed changes). The Patient Activation Measure (PAM) is a validated, commercially licenced tool and has been extensively tested with reviewed findings from a large number of studies [28]. It helps to measure the spectrum of skills, knowledge and confidence in patients and captures the extent to which people feel engaged and confident in taking care of their condition. Individuals are asked to complete a short survey and based on their responses they receive a PAM score (between 0 and 100). The resulting score places the individual at one of four levels of activation, each of which reveals insight into a range of health-related characteristics, including behaviours and outcomes. The four levels of activation are shown in Box 1.

Box 1. Four levels of patient activation

- Level 1: Individuals tend to be passive and feel overwhelmed by managing their own health. They may not understand their role in the care process.
- Level 2: Individuals may lack the knowledge and confidence to manage their health.
- Level 3: Individuals appear to be taking action but may still lack the confidence and skill to support their behaviours.
- Level 4: Individuals have adopted many of the behaviours needed to support their health but may not be able to maintain them in the face of life stressors.

People with high levels of activation understand their role in the care process and feel capable of fulfilling that role. Individuals with long-term conditions who are more highly activated are more likely to engage in positive health behaviours and to manage their health conditions more effectively [28]. Whereas, people with low levels of activation often feel overwhelmed with the task of managing their health and have little confidence in their ability to have a positive impact on their health. These individuals usually have previously failed to manage their health, have become passive in managing their health, misunderstand their role in the care process, have limited problem solving skills and state they would rather not think about their health. For example, if a person living with HIV is told that they are at risk of a cardiac event unless they change their diet, stop smoking, exercise more and take new medications, someone with low levels of activation may attempt to make all these changes and fail on day two or three. Supporting them to make small stepped changes may be more effective and beneficial than overwhelming them and setting them up to fail.

G. Prevention of illness; the role of the annual health review

Having discussed HIV as a long-term condition perhaps the most important issue to consider is that poor long-term health is, on the whole, preventable. The role of diet, drug and alcohol intake, weight management, exercise and ongoing engagement in care play a part in poor health outcomes. As a society our health is measured in decades with constant reminders from the GP that now you are >40, >50 or >60 years you will need to have regular screening such as cervical smears and breast examination for women and prostate checks in men as well as invitations to have a 'health check-up', this is really no different for people living with HIV and one way to monitor the ongoing health and predicted future health of people living with HIV is to carry out annual health checks. The BHIVA audit (2015) of their annual health review standards showed poor compliance and lack of clarity over what should be monitored [29]. Following on from this the National HIV Nurses Association (NHIVNA), supported by BHIVA, developed the 'Annual Health Review for people living with HIV: a good practice guide' (2017), Figure 3 [30]. The annual health review can support people living with

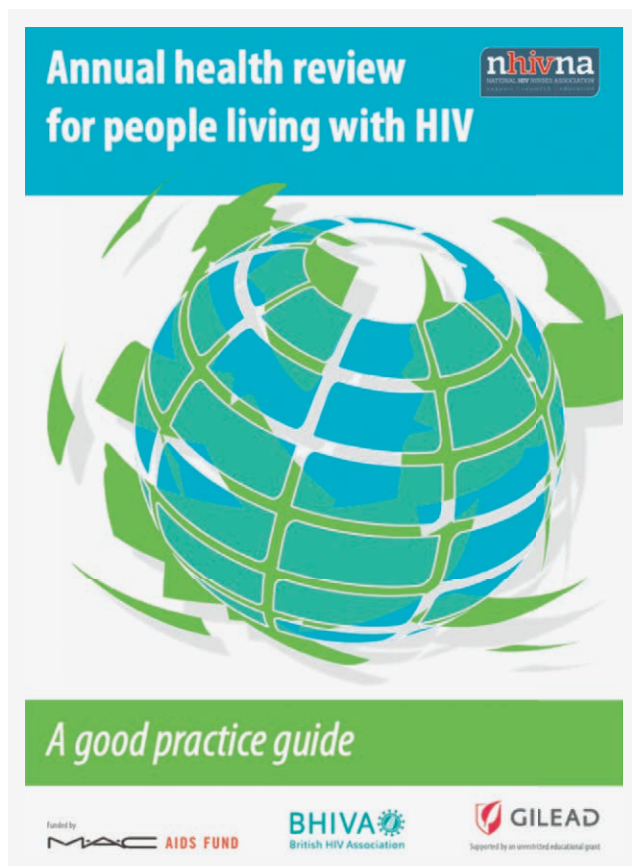


Figure 3: Cover of NHIVNA's Annual health review for people living with HIV good practice guidance annual-health-review-for-people-living-with-HIV [30]

HIV to lead healthy and fulfilling lives. It incorporates holistic needs, providing early detection and prevention of risk factors or comorbid illness. The annual health review for people living with HIV aims to:

- improve outcomes for people living with HIV who should receive optimum evidence-based care relating to their health and well-being;
- ensure that best practice becomes a standard within HIV care settings to reduce variations in care;
- improve effectiveness and efficiency in healthcare systems;
- maintain appropriate prescribing and optimise adherence to ART;
- increase appropriate prescribing of non-ART medicines across the pathway of care; and
- provide recognised audit measures and tools for service monitoring and development.

The guide encourages nurses to look at some or all of these standards and depending upon your cohort of patients you can choose which of these are the most important and who is best placed to measure and record them. This list is also not exhaustive and can be developed in an ever-changing HIV world. Nurses can use this good practice guide to hone their expertise, adding value to their practice.

Time out activity 3

Do you provide an annual health review in your place of work? If so what do you monitor and record. Look at the NHIVNA Annual health review and compare it with what you provide. Do you exceed this? Or are there areas that need development, if so which areas, and how do you think you could improve on this?

H. How do we manage long-term health?

The annual health review clearly demonstrates the tools and methods needed to highlight issues of poor long-term health. However, management of long-term health should be something discussed with the patient from the outset. Clear assessment of risk and highlighting the issues may be enough for some patients to make changes, sometimes the shock of a positive result may be the trigger needed, whilst other may not want to change their perceived 'bad' habits but it is important as people living with HIV age that risks are revisited from time to time. We are constantly bombarded with lifestyle issues from the tv, press and social media to quit smoking in Stoptober, quit alcohol in dry January, couch-to-5K initiatives and national days of no smoking and cancer awareness etc. These campaigns provide plenty of opportunities throughout the year to engage with patients and discuss issues of diet, exercise alcohol and drug use etc. Management should be dictated by the person living with HIV, with support and signposting from the nurse. Heavy-handed scare tactics may work for some but on the whole should be avoided, however telling someone they have a 10% chance of a cardiac event in 10 years may not register at all so look to other tools like checking the heart age (www.nhs.uk/conditions/nhs-health-check/check-your-heart-age-tool/), which may be more effective. Simple tools like measuring BMI (Body mass index) and discussing waist circumference as a diabetes check may also prove useful (www.diabetes.org.uk/preventing-type-2-diabetes/waist-measurement).

Key point: The annual review looks at the following nine measurable standards:

1. Cardiovascular health
2. Bone health
3. Renal health
4. Preventative medicine
5. Neurocognitive impairment
6. Mental health and psychological well-being
7. Antiretroviral (ART) and non-ART management
8. Monitoring of comorbidities
9. Sexual and reproductive health and psychological well-being

Be guided by your patient not your own judgements on what you feel is the right course of action.

I. Step by step

Know yourself – think of your own health and long-term health concerns and the blocks you put down to stop yourself making the changes needed, and the successes you have had to make changes. This will inform your care.

It's not all about HIV – long-term health is for everyone and we all have and make our own judgements and decisions about this. Think about what stops you losing weight, exercising more, stopping smoking or reducing your alcohol/chocolate intake. The challenges you face are the same for people living with HIV yet with the added pressure of healthcare workers monitoring their every move. I've had several patients change clinics or doctors because they have felt the pressure, real or perceived, to change a lifestyle or medication that they didn't want to. Even asking about cigarette use or alcohol intake can add to a person's feeling of persecution, perhaps in some situations self-reporting is needed with added levels of support and ideas of how to cut down or quit being available, but only discussed if the patient wants to.

Support self-management but understand that not everyone will want to do this. Self-management by individuals takes some degree of confidence not only in themselves but confidence in the system. Some healthcare professionals find empowered self-managers easy to work with, others struggle. Understanding that empowered people living with HIV know their illness and have their own thoughts about how they want to manage their care is important, relinquishing the 'power' that healthcare professionals can have can be challenging.

Annual reviews are important but so is your time and as we may only see a person living with HIV at their clinic once a year, squeezing in exhaustive checks may be difficult and the appointment may not leave time for the patient to discuss other issues, so be creative with the annual review and work as a team. Who can record what? Is the information centralised somewhere and who can add to this? What pre-appointment information can the patient complete and what does their GP monitor, if anything? *The Annual Health Review* guidance has a useful proforma that can be utilised and developed as a starting point. But decide what the most important standards to monitor are as an HIV team.

Time out activity 4

Think about your own long-term health? What influences your views on your health? Where did/do you get information about long-term health and how to manage this (think about media, tv programmes, magazine articles etc)?

Do you give advice to the people living with HIV that you may or may not take yourself? If not, why not and do you feel conflicted by this?

J. Conclusion

Living long term with HIV is now a reality and with that come decisions about changes in lifestyle that we all have to face. Nurses are best placed to not only monitor long-term health issues but to support people living with HIV who want to manage their own care. Monitoring and supporting long-term health will develop as the years roll on and the development of e-health and apps that support people living with HIV to record and report concerns can only enhance their long-term health.

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Conflict of interest

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