

Help and information for people who have HIV and are 50 or over

Terrence  
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TRUST



# 50+ & HIV+

Written for people with HIV, by people with HIV

Because of successful treatments, a growing number of us with HIV are living into our 50s and beyond.

For many, ageing is a happy experience. It can mean more time to spend with people we love and more time to do things we enjoy. But ageing also means that we lose some of the strength and ability we had when younger. It can be difficult, as we age, to stay healthy, to manage with less money, and to get the help we need to keep enjoying life. Having HIV can add to these difficulties.

This is a guide to where older people with HIV can get information or advice on some of the problems that we might face.

With thanks to Jonathan Grimshaw, Roy Trelvelion, Kate Charlesworth and the members of the 50 Plus Advisory group.

**“You can be old or young with HIV, you just have to **take care** of yourself.”**

Quotations are from people with HIV who took part in 50+, a national survey of ageing and HIV. The survey can be seen or downloaded at: [ttht.org.uk/informationresources/hivandaids/personal-experiences-of-hiv/50plus/](http://ttht.org.uk/informationresources/hivandaids/personal-experiences-of-hiv/50plus/)

## Healthy living

For almost everyone, getting older brings health problems that rarely affect younger people. We may have problems with the heart or the arteries that carry blood to the heart. We might get high blood pressure. We can get diseases that affect bones and joints, the liver or the kidneys. We might develop cancer.

These problems don't appear in most people until late old age, but in people with HIV they can appear earlier and more often than usual. We're most likely to get these problems if we smoke, drink too much alcohol, are overweight, eat unhealthy food and don't take enough exercise.

So, for older people with HIV, healthy living means not only taking treatments for HIV, but also doing what we can to prevent other illnesses by giving up smoking, drinking less alcohol, eating healthily and keeping fit.

**aidsmap.com** and **i-base.info** are websites with information on most medical aspects of HIV, including the health problems that occur as people with HIV get older. i-base also has a telephone helpline (0808 800 6013 Mon, Tues, Wed 12-4 pm) and you can ask questions by email or online.

'Coming of Age' is a very detailed guide to how your health will be affected by ageing with HIV and what you can do to keep well. It can be viewed online or downloaded from **www.justri.org**

**myhiv.org.uk** and **namlife.org.uk** are websites for people with HIV with information about health, sex and well-being. They have pages on alcohol, diet and exercise. Namlife has advice about giving up smoking.

**“Giving up smoking, and doing exercise would be good.”**

**“I am fed up with people saying... because there is combination therapy everyone is fine.”**

Age UK's website [ageuk.org.uk](http://ageuk.org.uk) has information about the illnesses that affect people as they get older, healthy eating, how to keep fit and active, and healthcare rights.

There are also projects specifically to help people with HIV adopt and maintain a healthier lifestyle; many will welcome older people. THT Direct can tell you what is available where you live (0808 802 1221 from 10 till 10 weekdays and from 12 till 6 weekends).

You should talk to your HIV doctor first if you're going to start doing any new exercises to keep fit, just to be sure you won't be putting too much strain on your body. Some GP practices also have information about local projects and activities for keeping fit and well.

## Mental health and emotional well-being

Living with HIV can be difficult enough, but, for some, the changes that can affect our lives as we get older may seem overwhelming.

Talking to a counsellor can help us work out the most important things we should be dealing with to try and get back in control of our lives.



THT Direct offers emotional support over the phone or online and can help you find a counsellor where you live.

Even if the counsellor doesn't have specific HIV experience, they might be able to help you cope with emotional turmoil caused by, for example, retirement, bereavement, moving home, memory loss, and health problems.

Local Age UKs, Age Concerns and MIND (listed in the phone book) also have information about local counselling services.

If feelings of anxiety or depression are getting you down, or you are worried because your brain doesn't seem to be working as well as it used to, you should talk to your HIV doctor or GP who can refer you to a psychologist if needed.



## Choosing or changing your GP surgery or HIV clinic

It is very important to have a GP that you trust because you will need to rely on them for treatment and help with a lot of the health problems that can develop as we get older.

Many people with HIV live in areas where there may be more than one GP surgery, or HIV clinic, within travelling distance and can therefore change to a different GP or clinic if they wish.

**“I am... sick of people saying that despite combination therapy, everything is still terrible.”**

Your current HIV clinic may have a list of HIV-aware GPs. THT Direct can give advice about choosing or changing a GP surgery.

THT Direct and [myHIV.org.uk](http://myHIV.org.uk) have details of all HIV clinics. Talking to other people with HIV is a good way of finding out about different HIV clinics. Good communication between your GP and HIV clinic is essential, especially as GPs become more involved in looking after us as we get older.

## Relationships

HIV can have a big impact on your relationships with family members or partners and it can affect how you make new relationships.

[myHIV.org.uk](http://myHIV.org.uk) and [namlife.org.uk](http://namlife.org.uk) have information about how to deal with a range of situations, such as having an HIV-negative partner, or talking about HIV to your children.

Many people with HIV are in happy, long-term relationships, but sometimes, as with anyone, relationships break down and you may face several problems relating to where to live, money, career, or, if with children, how to get access to them.



THT Direct can refer you to relationship agencies that might be able to help you and your partner deal with problems in your relationship. It can also help you get advice and support in dealing with the practical and emotional consequences of relationship breakdown. HIV clinics will often offer psychological support to a couple where one partner has HIV and the other doesn't. For those wanting to form new relationships, there are dating sites on the internet specifically for people with HIV (see list at the end of the leaflet). Ehow has advice about joining a dating site for people with HIV:

[ehow.co.uk/how\\_2095085\\_join-hiv-positive-dating-site.html#ixzz1CFiWQPfR](http://ehow.co.uk/how_2095085_join-hiv-positive-dating-site.html#ixzz1CFiWQPfR)

## Social support

Few of us could get through life without the company and support of friends and people we love. But fear of how others will react to HIV and getting older can mean we are alone more than we would like.

Many local HIV organisations have support groups for people with HIV and, as the number of older people with HIV grows, there will be more of us in these groups. There may also be a Patients' Group or Representative at your HIV clinic and these may be able to put you in touch with local support groups.

Organisations for older people, like Age UK, also have support groups for people who are alone or in poor health; although there may not be other people with HIV in these groups.

**“I do a lot of volunteer work. That is what is keeping me going.”**

LGBT groups for people in later life can be a source of support, as can groups for older people in African communities affected by HIV. Some people get support from their faith community. **myHIV.org.uk** has advice about telling people in your faith community that you have HIV. Doing voluntary or campaigning work for an HIV or other organisation, such as Age UK, can be a way of meeting and making friends with others, as well as a way of helping people in need.

THT Direct or your local HIV organisation can tell you about local support groups and places where you could do voluntary work. They can also give you advice if you are worried about telling other people that you have HIV.

**myHIV.org.uk** has online forums where you can chat to other people with HIV.

**“I think we just need good care and acceptance just like anybody else.”**

## Getting help at home

If you're finding it difficult to manage at home with things like washing yourself, cleaning or cooking because you or a partner can't do them, you may be able to get help. Contact your local council's Social Services HIV or Adult Social Care section and explain how your day-to-day activities are affected.

Age UK's website has useful information about finding help with general household tasks as well as help with personal care (**ageuk.org.uk**). In some areas there are 'handyperson' schemes which provide low-cost help with minor repairs and maintenance. Local AgeUKs and Age Concerns will have details.

Some local charities or groups, including your local Age UK or Age Concern, may have volunteers who can help with indoor and outdoor tasks such as gardening.

You may be worried that people who are sent to help you at home will be ignorant about HIV or might not respect you if, for example, you are gay or from an ethnic minority.

Organisations that provide care to people at home have to meet certain standards, including having the skills and competence to meet your particular needs, treating you with respect and valuing you as a person, regardless of your HIV status, sexuality or ethnic background.

Problems sometimes arise because, although people looking after you mean well, they may not know or understand some things about HIV. Giving them a bit more information could be a big help, to them and to you. THT Direct or your local HIV organisation can give you advice about how to inform other people about HIV.

**“Having not expected to live this long, it's quite a shock to have to deal with the onset of old age.”**

If you feel you are not being treated properly you should discuss it with the organisation providing help. THT Direct or your local HIV organisation can give you advice about who to contact to ensure your needs are met and your rights are respected.

## Housing

If you're finding it impossible to manage at home, perhaps because your health is getting worse, or where you live is bad for your health, you might be able to get a different place to live. You should contact your local council's HIV, Social Services or Housing section, or call THT Direct for advice.

If your local authority agrees that you need re-housing, you might be able to get housing that is built or adapted to be suitable for older people with disabilities and HIV. Many housing associations that provide housing for older people have had experience of HIV in the past.

Retirement (or "sheltered") housing for older people usually has 20 to 40 self-contained flats or bungalows grouped together. There is almost always an alarm system, someone on site to help with problems, and communal areas such as shared lounge, laundry and garden.



Some large retirement housing providers for older people, such as the Anchor Trust, have LGBT groups and there is likely in future to be more retirement housing suitable for LGBT people.

There may come a time when residential care could be your best option. **ageuk.org.uk** has advice about choosing a care home.

You can also ask your local council's HIV or Social Services section, or your local HIV organisation, if they know of care homes which have cared for people with HIV in the past.

## Work, money and benefits

Many older people want to keep working for as long as possible but those of us with HIV might be worried about whether we will be able to as we get older.

THT Direct can give you advice about how to talk to your employer or union about your concerns for the future and what your rights are.

As we get older, we often start to think about saving money for when we stop working. Age UK's website has financial advice for older people, including advice about saving and managing money (**ageuk.org.uk**). Age UK also has a booklet 'Lesbian, Gay or Bisexual: Planning for Later Life' available online.

Some older people with HIV, having lost jobs or retired early, may want to return to work. **namlife.org.uk** has advice about returning to work and THT Direct can advise too. **yourworkhealth.com** has information about staying in or returning to work if you have a long-term illness like HIV.

**“I’m more conscious of how to get the kind of support I need so that I can live as normal a life as possible.”**

If you are unable to work, or constantly struggling to make ends meet, make sure you have all the benefits you're entitled to. Your local Citizen's Advice Bureau (listed in the phone book and at [citizensadvice.org.uk](http://citizensadvice.org.uk)) will give you advice about benefits, or THT Direct can refer you to a specialist adviser.

If you're in debt, don't use a fee charging debt advice service. THT Direct can tell you where to get advice about getting out of debt and how to apply for small grants of money. The National Debtline service (0808 808 4000) can also give you advice about debt.

## Stigma and discrimination

Having HIV can be bad enough, but you might be worried that being older could make other people even more likely to reject or refuse to help you. THT Direct can help you to work out who to tell that you have HIV and how best to tell them.

New laws mean that if someone who is giving you a service, such as the services described in this leaflet, or who employs you, treats you less well than other people because you have HIV, they can be taken to court, so there should be less of this type of discrimination in future.

Laws introduced over the past few years also protect older people from discrimination at work. A new law introduced in 2011 means people can no longer be prevented from working beyond the age of 65.

**“I have a good life because I have a positive outlook on life.”**

If you have any doubts, [ageuk.org.uk](http://ageuk.org.uk) gives more information about these changes.

But a number of people with HIV continue to have problems, even with some health care workers.

If you feel you have been treated badly at a GPs or Dental surgery because you have HIV, you can talk to your local HIV organisation or THT Direct about what to do. They can suggest ways of talking to the people involved to help them respond better to people with HIV in future.

If you decide to make a complaint, you can ask for a copy of the complaints procedure. This should tell you how to make the complaint and what will happen. THT Direct can give you advice and support at each step of the procedure.

Local PALS (Patient Advice and Liaison Service) help people who have complaints about how they're treated in the NHS. PALS offices can be found in hospitals and you can find a local office through [pals.nhs.uk](http://pals.nhs.uk)

Complaining about bad treatment can be stressful but it can also help to make sure that you and other people with HIV are treated better in future. If you have any



doubts, or concerns that you are taking a risk by complaining, your local HIV organisation or THT Direct can give you advice.

If you feel you've been treated badly because you have HIV by neighbours, people at work, or when trying to get a service, talking to other people with HIV can help. They might have faced similar situations and talking to other people can take away some of the anger and pain you may have felt.

Talking to your local HIV organisation or to THT Direct can help you decide what to do about the prejudice or discrimination you face but it also means HIV organisations can argue for better education about HIV for the public and better protection for people with HIV.

**“I am... an advocate and speak for people who are HIV positive.”**

**“...life is wonderful. You can go on and do all sorts of exciting things, challenge yourself.”**

## Helpful agencies

### Advice by phone

**THT Direct 0808 802 1221** for more information on HIV and Sexual Health

Monday-Friday 10am-10pm; Weekends 12pm-6pm

**i-base 0808 800 6013** for treatment concerns

Mon, Tues, Wed 12pm-4pm

**National Debtline 0808 808 4009** for financial advice or money concerns

Monday-Friday 9am-9pm; Saturday 9.30am-1pm

### Useful websites

**myhiv.org.uk** A website about HIV including discussion boards by and for people with HIV.

**i-base.info** for treatment and health issues

**namlife.org.uk** for HIV information and research

**ageuk.org.uk** for anyone growing older

**yourworkhealth.com** Information on employment rights for people.

**citizensadvice.org.uk** for money, benefits and debt advice

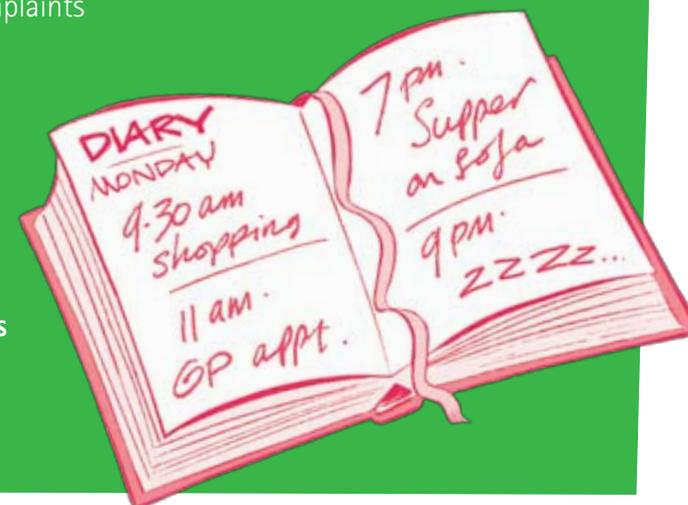
**pals.nhs.uk** for NHS complaints

Meeting and Dating websites for people with HIV

**hivmatch.co.uk**

**datepositive.net**

**meetup.com/plusfriends**



# The HIV and sexual health charity for life

**Website:** [www.tht.org.uk](http://www.tht.org.uk) **THT Direct:** 0808 802 1221

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