End of life care for people living with HIV

Support and guidance for people with a terminal illness who are living with HIV

Partnered with

Marie Curie

Terrence Higgins Trust

When you're living with an illness you could die from and you have HIV, you may have questions, concerns or wishes about the end of life.

You may be thinking about specific things because of your HIV status. It can help to have conversations and make plans early, so you can get the care and support you want and need. In this booklet, we aim to answer some of those questions and explain where to get support.

Contents

End of life care

End of life care is treatment, care and support for people who are thought to be in the last year of life. It's centred around you as a person – how you want to be cared for and what's important to you. It can involve managing symptoms, emotional support for you or your family and friends, help with tasks like washing and dressing, and planning for future care or what you want to happen after you die.

End of life care is an important part of palliative care, which is care someone can have at any stage of a serious illness.

While you're having end of life care, different health and social care professionals might care for and support you. This can include your usual HIV doctor or GP, as well as new doctors, nurses, social workers, counsellors, and people who can offer spiritual support.

Getting the right care for you

People living with HIV are more likely to have multiple health conditions, so you may already have specific care needs.

People are also living longer with HIV. As you get older, you're more likely to develop conditions related to ageing. This includes things like a weaker heart or bones, or finding it harder to remember things. HIV and HIV medicines can make some of these conditions more likely or worse.

Ideally, any healthcare professionals who support you, including your HIV doctor or GP, will work together with an end-of-life healthcare team. This helps make sure any existing conditions are managed.

Read more about end of life care at **mariecurie.org.uk/getting-care**, call the free Marie Curie Support Line on **0800 090 2309** or email **support@mariecurie.org.uk**

Your rights as someone living with HIV

HIV is defined as a disability under the Equality Act 2010. It's discrimination and against the law for a healthcare provider to do any of these things based on your HIV status:

- Refuse to care for you.
- Refuse to give you access to a service.
- Give you a worse quality of care or service than they would usually provide.
- Cause you harm.
- Behave in a way that distresses, offends or intimidates you.

Even though this is the law, you may have experienced discrimination or be worried about people discriminating against you.

Understandably, this may make it hard to ask for the care you need, meet new health and social care professionals, and talk openly about living with HIV. We explain options and how to get support if someone discriminates against you on page 4.

> *HIV is an illness, yes. But it's not something that identifies me – it's not all I am.*
>
> **Tandi, who's living with HIV**

Read more about your rights at **tht.org.uk/workplace-rights**

Telling health and social care professionals that you have HIV

You don't have to tell anyone that you are living with HIV. This includes health and social care professionals caring for you towards the end of your life.

If you do feel happy and safe to tell them, knowing about any medical needs or medications, including HIV, helps health and social care professionals give you the best possible care. They might also know that you have HIV from your health records.

Do my health records say that I have HIV?

Your HIV medicine and HIV status may be included in your health record. You should be asked for consent to share your health record and the information in it. If you do give consent, health records would be shared with health and social care professionals who give you care. It's mostly so they can make the right decisions about treatment. This means your end-of-life healthcare team may know that you're living with HIV without you telling them.

You can ask to only have core information in your health record. Core information would include any HIV medicine you're taking. Or you can opt out of having a health record.

You might find it helpful to speak with your GP or another healthcare professional about your health record. They can explain what's currently in your record, who has access, and your options.

How health and social care professionals may react

Health and social care professionals deal with different illnesses and conditions every day. You should be able to tell them about your HIV status and get the support you need. But we know that some people don't understand HIV and can act badly or with prejudice because of that.

We've spoken with people living with HIV who are worried about telling others because of a possible negative reaction. You may be worried because of bad experiences you've had before or that you've heard about.

If people do react negatively or discriminate against you, here are some things that might help:

- **Know your rights.** HIV is defined as a disability, so you are legally protected against discrimination based on your HIV status (see page 2).
- **Find out about the complaints process where you're getting care.** Hospitals, hospices or services that provide care at home will have a way for you to safely make a complaint. You could try looking on their website, or emailing or calling their patient support team.
- **Speak to someone you trust.** This could be another health or social care professional, like your HIV doctor. Or it may be a partner, family member or friend. They might be able to support you to raise an issue with the healthcare provider, or raise an issue on your behalf.
- **Get support from us.** Call THT Direct on **0808 802 1221** or email **info@tht.org.uk** for advice.

Family, friends or other visitors who don't know you're living with HIV

You may not have told everyone important to you that you're living with HIV. Talk to your HIV doctor and end-of-life healthcare teams about who knows and who you'd prefer not to know. This way, if you have visitors, your healthcare teams can make sure not to say or do anything that reveals your HIV status.

> “*I do worry about facing discrimination as I get older, more vulnerable and am less able to stand up for myself. As a Black woman, I already have to think about racism and prejudice in healthcare – and this is another thing that may affect how someone perceives me.*”
>
> **Abigail, who's living with HIV**

Taking HIV medicine towards end of life

There's no guidance around whether you should stop or continue taking HIV medicine when you're dying. It's important to speak with your HIV doctor, your end-of-life healthcare team, and anyone else supporting you before you decide.

They'll be able to explain the pros and cons, and can give you advice based on your personal situation.

Reviewing your medicine towards the end of life

During the last months, weeks and days of life, your doctor should regularly review medicines you take. They should check whether the medicines are still helping your overall wellbeing, or taking it is making you uncomfortable.

Stopping HIV medicine too early might cause you to become more ill (see page 6). So it's important that you and your doctor decide together what's best for you.

If your usual medicine becomes hard to take

You might not be able to take your usual HIV medicine. For example, if you usually take tablets but find them hard to swallow, you can ask your HIV doctor if there are other options, like having an injection.

HIV medicines and end of life medicines

HIV medicines can interact with other medicines. This is when taking two or more medicines at the same time can have a bad effect. This might include worse side effects or the medicine no longer working properly.

Your HIV doctor and end-of-life healthcare team should work together to make sure your medicines don't interact. If you do have any side effects, they can help to keep you comfortable.

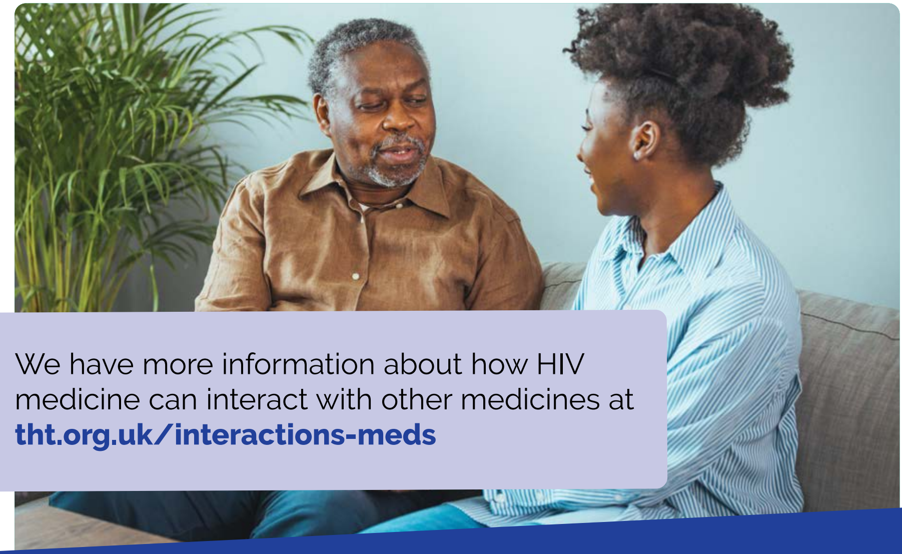
If you stop taking HIV medicine

If you stop HIV medicine, the amount of the virus in your blood (your viral load) usually increases within a few weeks.

An increased viral load makes you more likely to get infections or other illnesses. This could make you feel more unwell, and might mean you need other medicines or care to make sure you stay comfortable.

It's important to speak with your HIV doctor and end-of-life healthcare team to understand their opinion based on your medical history and the stage of your illness.

You can also talk to them about your wishes and find out what they could do to support you, if you did become more ill.



We have more information about how HIV medicine can interact with other medicines at **tht.org.uk/interactions-meds**

Making plans for the end of life

Whatever stage you're at in your life, it can be useful to make plans for the end of life. Planning can give you a sense of control, as well as making sure that other people know what's important to you.

It might not be possible for people to follow all your wishes. Some things may depend on your illness, where you live and whether care is free or you have to pay. But if your wishes are known, the people caring for you can try to follow them.

Making plans while you're well enough

There may be a time when you're no longer able to make decisions for yourself because of an illness or symptoms. This is known as lacking mental capacity. It can happen for different reasons, including:

- dementia
- a mental health illness
- when you become unconscious at the very end of life.

Here are some things you can do now:

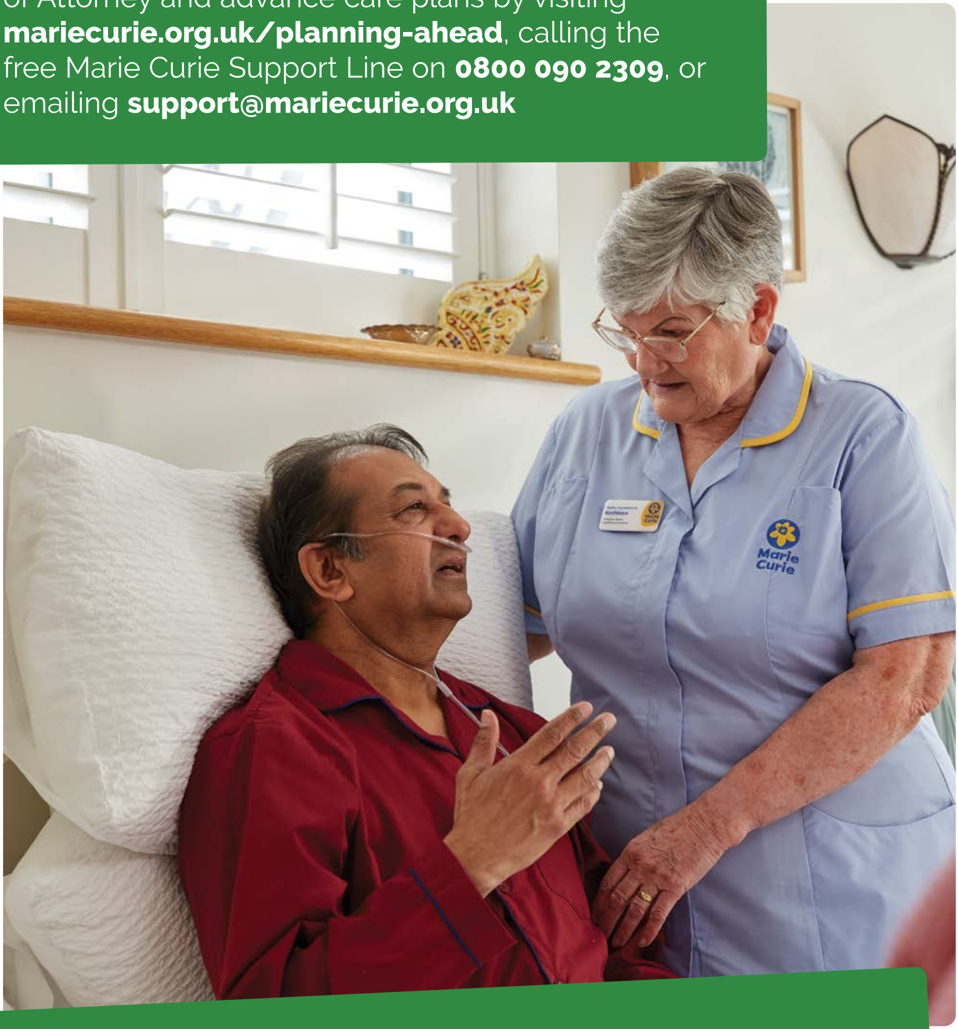
Choose someone else to make decisions on your behalf

You can choose someone to make decisions about health, welfare, money and property on your behalf, if you become unable to make them yourself.

This could be a partner, friend, family member or a professional like a solicitor. It's called a Power of Attorney. There are different types, depending on what it's for and where you live in the UK.

> *Once Roger knew he had cancer he wrote a new Will, but it never got signed. I just presumed it had been done. The new Will was a split between his children and me – luckily, they are extremely good to me and we got it sorted. But it's those sorts of loose ends that needed tying up.*
>
> **Peter, who's living with HIV and cared for his partner, Roger, at the end of his life**

Find out more about mental capacity, Power of Attorney and advance care plans by visiting **mariecurie.org.uk/planning-ahead**, calling the free Marie Curie Support Line on **0800 090 2309**, or emailing **support@mariecurie.org.uk**



Plan for future treatment and care

You can make an advance care plan to tell people how you want to be cared for in the future. This is sometimes called a future care plan or anticipatory care plan. It's not legally binding, but may mean your wishes are more likely to be followed.

This could include, for example, whether you want to be cared for at home or in a hospice. You should discuss your plan with the people important to you, as well as your doctor or another healthcare professional.

In England and Wales, an advance decision to refuse treatment (ADRT) can be part of your advance care plan. It's a written decision to refuse a specific type of medical treatment, sometimes called an advance decision or living will. You need to write it and have it signed in the correct way, as it's legally binding. An ADRT will only be used if you lose the ability to make your own decisions about your treatment.

Will HIV be on my death certificate?

HIV may appear on your death certificate, if it's thought to be related to your death. Whoever registers your death is likely to see this – this usually needs to be a family member or someone there at the time of death. Think about whether this is likely to be someone who already knows your HIV status.

You may want to leave a request for who you'd like to register your death, if there are some family or friends who don't know (see page 4).

My wishes for the end of life

You can use the space on the next page to record your wishes for the end of life. No one has to follow this by law, but it can help other people understand what's important to you.

You can keep it somewhere safe and share it with the people important to you, as well as any health or social care professionals supporting you.

Before I die, I’d like to...

Use this space for anything you’d like to do before you die – some people call it a ‘bucket list’.

I’d like to be cared for...

Put where you’d like to die in this space. It might be at home, in a particular hospice or in a care home – or you might not mind.

The things that are most important to me at the end of my life are...

Use this space for what’s personal and important to you. It could be being around certain people, listening to some favourite music, or feeling connected to your culture or faith.

My current health conditions, medicines or treatment are...

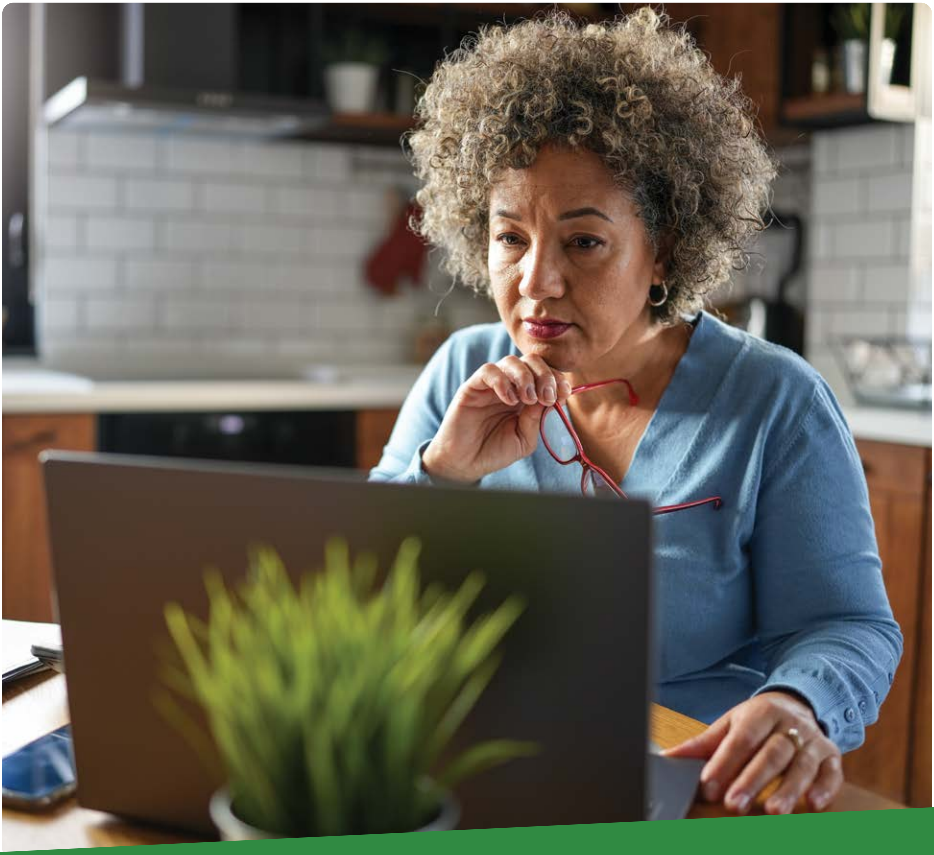
Put any health conditions or worries you feel comfortable sharing in this space.

After I die, I’d like...

Put any wishes for a celebration of life, funeral or other service you’d like in this space – or if you don’t want anything like that.

I’ve...

- ☐ written my Will
- ☐ chosen someone to make decisions on my behalf (set up a Power of Attorney)
- ☐ put important documents in a safe place – and told somewhere where they are
- ☐ spoken to my HIV doctor or another healthcare professional about an advance care plan (my wishes for treatment and care)
- ☐ told the people important to me about my wishes.



Where to find support

Asking for information and support about the end of life can be hard, especially if you're worried about telling people you're living with HIV.

There are HIV-specific health services across the UK. You can ask your GP, pharmacy or search online to see if any are local to you.

Here are some charities suggested by people living with HIV, who have found support and understanding from their information and services.

National HIV charities

Terrence Higgins Trust

We're the UK's leading HIV charity, supporting people living with HIV and ensuring their voices are heard. Visit **tht.org.uk**, call THT Direct on **0808 802 1221** or email **info@tht.org.uk** for support, advice and information about living with HIV. Our helpline is open from 10am to 6pm, Monday to Friday.

National AIDS Trust (NAT)

NAT is the UK's HIV rights charity. It provides information for people living with HIV, as well as confidential, free support for people who have faced discrimination because of their HIV status. Visit **nat.org.uk/discrimination** to find out more about the service.

> *I don't broadcast the fact that I'm HIV positive because not everybody is understanding. But at The Lawson Unit, it's treated the same as any other illness. People are so friendly and it lifts your spirits.*
>
> **Peter, who's living with HIV**

Positively UK

Positively UK offers peer-led support, advocacy, and information to empower people living with HIV. Visit **positivelyuk.org**, call **0207 713 0444** or email **info@positivelyuk.org** to learn about the support on offer. The phone line is open from 10am to 4pm, Monday to Friday.

Chiva

Chiva supports children and young adults (up to age 25) living with HIV. Find information and sign up to get support at **chiva.org.uk/chiva-support**

Find out more

For further information and resources on end of life and how to plan while living with HIV, visit our website: **tht.org.uk/palliative-care**

Marie Curie supports everyone affected by terminal illness who is thinking about or at the end of life – including people living with HIV who have a terminal illness.

You can visit **mariecurie.org.uk**, call the free Marie Curie Support Line on **0800 090 2309** or email **support@mariecurie.org.uk**

Terrence Higgins Trust

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Marie Curie

Marie Curie is the UK's leading end of life charity. Whatever the illness, wherever you are, we're with you to the end.

0800 090 2309*

Marie Curie provides free support over the phone in over 200 languages, and via webchat, to anyone with an illness they're likely to die from and those close to them. Visit **mariecurie.org.uk/information**

*Calls are free from landlines and mobiles. Your call may be recorded for training and monitoring purposes.

Trusted Information Creator
Patient Information Forum

Terrence Higgins Trust 439 Caledonian Road, London N7 9BG
Tel: 020 7812 1600 **Email:** info@tht.org.uk **Website:** tht.org.uk **THT Direct:** 0808 802 1221

Terrence Higgins Trust is a registered charity in England and Wales (reg. no. 288527). Company reg. no. 1778149 and a registered charity in Scotland (reg no.SC039986).

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