

# HIV and quality of life: guide to side effects & long-term health

April 2023

**i-base**  
0808 800 6013



HIV i-Base  
ISSN 2046-7311  
[www.i-Base.info](http://www.i-Base.info)  
Watch out for out-of-date information

**Talking to your doctor**  
**Side effects and symptoms**  
**HIV and ageing**  
**Further information**



This leaflet is for people living with HIV. It is about side effects, other health issues and getting the best quality of life.

Different QR codes link to detailed information online.



This leaflet is a guide to the online resource:  
[www.i-Base.info/guides/side](http://www.i-Base.info/guides/side)

Written and edited for HIV i-Base by Simon Collins. 8th edition 2023.

Thanks to the advisory group of people living with HIV and health professionals for help and comments.

Disclaimer: This booklet is to help with information when talking to your doctor.

Treatment decisions should always be made in consultation with your doctor.

# Introduction

<https://i-base.info/guides/side/introduction>

**Modern HIV treatment, called ART, is very safe and effective.**

**The risk of side effects is very low and these are generally mild.**

**So good quality of life also depends on other health issues, and this resource looks at these too.**

- Possible side effects of HIV treatment (ART).
- Other health issues, especially linked to getting older.

There are four main sections.

## 1. General information.

This is about getting the best health care. It includes talking to your doctor, recording and describing symptoms and changing treatment.



## 2. Individual symptoms and side effects.

This includes separate info on each symptom.

For example, weight gain, feeling tired (fatigue) or feeling sick (nausea).



It also includes important general areas like sexual health and mental well-being.

## 3. Lifestyle, quality of life and health ageing.

This includes looking after your heart and bones, and about difficult issues like cancer.



It also includes lifestyle issues like diet and exercise that can help with side effects and long-term health.

## 4. Further information and references

This section links to the main treatment guidelines. It also includes more than 400 research papers that were used in the full guide.



If you have questions, i-Base also runs a Q&A service by phone, by email and online.



<https://i-base.info/qa>



# 1. General information

<https://i-base.info/guides/side/general-info>

**This section includes general information about side effects.**

**It includes how to monitor side effects and how to report them to your doctor.**

- What are side effects and why do they occur?
- Starting treatment for the first time?
- How to talk to your doctor about side effects
- Side effects diary
- Using the Yellow Card scheme
- How side effects are graded
- Drug levels, genetics and drug level monitoring (TDM)
- Changing HIV drugs
- Side effects and adherence
- You and your doctor

## 2. Information on specific symptoms and side effects



<https://i-base.info/guides/side/symptoms>

**This section cover a wide range of symptoms but the risk of nearly all of these is still low.**

**The website includes detailed information on each one. Many of these were only problems with earlier HIV treatment.**

**Sometimes these can be side effects. Sometimes they are caused by other things.**

**Whatever the cause, please talk to your doctor about this.**

- Weight gain on ART
- Diarrhoea
- Nausea and vomiting
- Fatigue – feeling tired
- Insomnia – disturbed sleep
- Mental health and well-being
- Sexual health and well-being
- Increases in cholesterol and triglycerides
- Increased blood-sugar levels and risk of type 2 diabetes
- CNS side effects: mood changes, anxiety, dizziness,

sleep disturbance

- Kidney-related side effects
- Liver-related side effects
- HIV and fatty liver disease (NAFLD)
- Increased bilirubin and jaundice (yellow skin and/or eyes)
- Skin rash
- Abacavir hypersensitivity reaction

*Side effects linked to older drugs.*

*These are now rare.*

- Dry skin, nail problems, hair loss
- Lipodystrophy (body fat distribution)
- Fat accumulation
- Fat loss (lipoatrophy)
- Peripheral neuropathy
- Lactic acidosis and pancreatitis
- T-20: injection site reactions (ISRs) and other side effects

## 3. Lifestyle, quality of life and healthy ageing

<https://i-base.info/guides/side/lifestyle-and-quality-of-life>

This section looks at health issues that become important as we get older.



Some of the related symptoms are similar to side effects of some HIV drugs.

These health issues are closely linked to the lifestyle factors that are also included in this section.

And changes to a healthier lifestyle can be important at any age, not just as we get older.

- **HIV and ageing**

Ageing can bring new perspectives that are only possible because of our previous experiences.

This section talks about how to age well and with the best health.

- **Heart disease**

Just as in the general population, lifestyle factors can reduce your risk of heart disease and stroke.

This talks about HIV meds and ways to have a healthy heart.

- **Bone health**

Some HIV drugs can reduce bone density and this can also be a general side effect of ART.

But low bone density can be related to your age, sex, weight, menopause and smoking.

- **HIV and cancer**

Cancer is included in this guide for two reasons.

One is that people who are diagnosed late with HIV still have HIV-related cancers.

The second is that as we grow older we all have an increased risk of cancer.

- **Lifestyle factors and your health**

This section has information about the different ways your lifestyle is related to your health.

- **Diet: a balanced diet and your health**

Information about different types of foods and how to choose a healthy and balanced diet.

- **Exercise and staying active**

Information about the different ways to exercise and the related effect on your health.

## 4. Further reading and references



<https://i-base.info/guides/side/4-further-information-and-references>

**This resource includes links for further information.**

### • Further information

There are links to important reference sites that might be useful.



These include:

- Treatment guidelines - both for the UK and in other countries.
- Other community organisations that publish resources about side effects and good health.
- Important medical conferences for the latest research.
- Online calculators. These are easy ways to check things like risk of heart disease or kidney problems. Or for calculating BMI or benefits linked to stopping smoking.
- Several resources are included on HIV and ageing.

### • References

Information in this guide is compiled from evidence from many studies.



- In addition to treatment guidelines we include more than 400 published medical papers.
- References are organised by subject and some references have a brief summary of what the study reports.

## Feedback

Your feedback helps us improve these guides.

[www.surveymonkey.com/r/7CCWBW2](http://www.surveymonkey.com/r/7CCWBW2)



## Glossary

As with all i-Base guides, the online version includes a glossary to explain technical words.



## References

References are also online.



## Any questions?

If you have questions after reading this guide contact the i-Base information service by phone or email.

**0808 800 6013**

**[questions@i-Base.org.uk](mailto:questions@i-Base.org.uk)**

The EMA website includes patient information on all HIV meds in most EU languages.

It also includes the full prescribing information for each drug.

[www.ema.europa.eu](http://www.ema.europa.eu)

# Contact us on 0808 800 6013

**i-Base Treatment  
Information Phonenumber**

**Monday to Wednesday  
12 noon to 4pm**

**[questions@i-Base.org.uk](mailto:questions@i-Base.org.uk)  
[www.i-Base.info/questions](http://www.i-Base.info/questions)**

