

UK guide to PrEP

- UK access
- Testing & monitoring
- Buying PrEP online
- Dosing options

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*This guide is dedicated to our inspirational co-author Dr Mags Portman who was a leading advocate for PrEP in the UK. Mags died from mesothelioma in February 2019 aged 44 and we miss her deeply.

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Introduction

This is a UK guide to Pre-Exposure Prophylaxis (PrEP).

PrEP usually refers to a pill containing two HIV drugs: tenofovir (TD) plus emtricitabine (FTC) in a single pill.

When taken correctly, PrEP greatly reduces the risk of HIV sexual transmission.

Getting PrEP in the UK - and COVID-19

PrEP is now available free on the NHS from sexual health clinics throughout the UK.

The following links provide information for each country. This includes how to search for a sexual health clinic by post code.

Scotland: www.prep.scot

Wales: www.friskywales.org/wales-prep-project.html

Northern Ireland: www.rainbow-project.org/prep

England: www.nhs.uk/service-search/other-services/HIV-testing/LocationSearch/418

See page 11 for buying PrEP online from the UK.

The link below covers access to PrEP during COVID-19 restrictions.

<https://i-base.info/guides/prep/introduction-and-access>

Background

What is PrEP?

PrEP stands for Pre-Exposure Prophylaxis.

PrEP is usually a pill taken before and after sex, so it is pre-exposure. Prophylaxis means to prevent infection.

PrEP routinely uses oral tablets that contain two HIV drugs: TD plus FTC. A newer version using tenofovir alafenamide (TAF) instead of TD is only approved in the US, and only for men and trans women. TAF-based PrEP is rarely used by the NHS but a generic version can be bought online for personal use.

A two-monthly injection of cabotegravir as PrEP is also approved in the US, but not yet in Europe. In December 2021, PrEP studies of a monthly oral pill and a yearly implant (both using islatravir) were put on-hold.

Who should take PrEP?

If you are HIV negative and at high risk of HIV and don't always use condoms, then PrEP can stop your risk of HIV.

These other factors are linked to a high risk of HIV.

- A recent STI (especially rectal infection or syphilis).
- Recent need for PEP (post-exposure prophylaxis).
- Using recreational drugs used for chemsex (crystal meth, mephedrone and GHB).
- If your HIV positive partner isn't currently taking their HIV meds regularly.

Talk to your doctor or nurse about how these risks affect you.

You do NOT need PrEP if...

- You are HIV positive.
- You only have sex with HIV positive people who have undetectable viral load on ART. When the viral load is this low, HIV is not a sexual risk.
- You are happy and able to always use condoms.
- You don't use condoms but your partner is low risk (see p8).

How well does PrEP work?

PrEP is more than 99% effective when taken correctly.

Tens of thousands of people take PrEP in the UK. Very few HIV infections occur when taken as prescribed.

The few cases are sometimes because:

- HIV was resistant to the drugs in PrEP.
- Very recent HIV infection (six weeks before the HIV test). In this case someone is HIV positive without realising it. This can be avoided by having another HIV test six weeks after either the last risk or after starting PrEP.

PrEP and side effects

Most people taking PrEP do not get side effects.

However, like all other medicines, PrEP has the potential to cause side effects. In studies, mild nausea, diarrhoea, bloating and headache were reported in the first month by less than 1 in 10 people. These side effects then usually stop.

Occasionally, PrEP can cause more serious side effects that reduce kidney function and/or bone health.

This is why kidney tests are run before and during PrEP use.

Changes in bone structure are usually small and reverse after stopping TD/FTC. This is similar to a commonly used oral contraceptive but might be important if younger than 30 when bones are still developing. Bone strength was not fully reversed after a year in one study in adolescents aged 15 to 19.

PrEP has not been linked to bone fractures.

PrEP and drug resistance

The chance of drug resistance to PrEP is very low.

Firstly, resistance relates to HIV and not the person. So an HIV negative person can't be drug resistant. Resistance is only a risk if you become HIV positive. Even then the risk is low.

Drug resistance affects PrEP in two different ways. Both cases are very rare.

1. Drug resistance developing while taking PrEP.

- Starting PrEP without knowing that you are already HIV positive. This is why the HIV test before PrEP is essential.
- Becoming HIV positive during a break from PrEP and not retesting before starting again.
- Missing too many PrEP doses, so that drug levels are too low to prevent HIV infection.

2. Coming into contact with drug-resistant HIV.

- In this case the drug resistance will stop PrEP from working.
- Globally, very few cases have been reported of PrEP not working because of drug-resistant HIV.

PrEP and sexually transmitted infections (STIs)

PrEP does not protect against other STIs. Condoms can help prevent many other STIs.

Although STIs are mostly easy to treat, symptoms can sometimes be unpleasant and sometimes serious. This is why regular testing for STIs is a good idea.

The HPV vaccine can protect against genital warts and the virus that causes cervical and anal cancers. Please ask your clinic or GP about this vaccine.

Does PrEP interact with other medicines?

PrEP does not interact with most other medicines.

But if you routinely take other prescribed meds, always tell your doctor (including your GP) that you are taking PrEP. You can also ask a pharmacist to check for drug interactions. This includes with over-the-counter meds.

Tenofovir (TD) should also be used with caution with some other drugs that can affect the kidneys. These include some non-steroidal anti-inflammatory drugs (NSAIDs), especially diclofenac, ibuprofen and naproxen.

Routinely taking both drugs together can cause kidney problems. Avoid these meds with PrEP, or let your doctor know if you regularly need to take them.

Although currently used more rarely, TAF can interact with TB meds, anti-epileptics, St John's Wort and others. This isn't a problem with TD.

PrEP is very safe for trans and non binary people taking hormone therapy (see page 10).

See: www.hiv-druginteractions.org/checker

PrEP for women

Why should women take PrEP?

Women who are at high risk of HIV can use daily PrEP as a way to stay HIV negative.

The highest risk for HIV is if you don't always use condoms with partners who might be HIV positive and not yet know. Or if they are not on treatment or not taking all their meds.

Condoms protect against HIV. HIV positive people cannot transmit HIV if they have an undetectable viral load on treatment.

Other reasons to consider PrEP

- If condom use is difficult or impossible to negotiate.
- If you have sex for money, or receive gifts for sex.

AND

If your partner or partners might be at risk of HIV.

For example:

- If your partner is from, or travels to, a country where HIV is common.
- If your partner is bisexual or has other partners.
- If you have recently migrated to the UK.
- If you or your partners inject drugs and share injecting equipment.

Contraception

It is safe to use PrEP with all hormonal contraception (ring, patch, the pill, or an implant). PrEP will not affect your contraception. And contraception will not affect PrEP.

Pregnancy

If you are planning a pregnancy or not using contraception, daily PrEP can make sure that you don't become HIV positive.

But if you know that your partner is HIV positive, it is better for them to be on treatment first. If their viral load is undetectable, there will be no additional benefit from you using PrEP.

However, if you become pregnant while taking PrEP, please talk to your doctor about whether or not continuing PrEP will be right for you.

Breastfeeding and chestfeeding

Outside the UK, many people living with HIV use the same meds as HIV treatment during breast and chest feeding.

Only very small amounts of FTC and TD are present in breast milk. These low levels are not harmful.

Daily PrEP is very safe if you breastfeed or chestfeed.

UK website on women and PrEP

These community sites have lots of info on PrEP and women.

womenandprep.org.uk

prepster.info/prep4women

PrEP for trans and non binary people

PrEP is just as safe and effective for people who are transgender or non binary as it is for cis gender people.

Dosing choices depend on the type of sex, but generally daily dosing is recommended.

Anyone having vaginal or front hole / frontal sex needs to take daily PrEP at least six days a week. This is to make sure PrEP levels are high enough in these tissues to provide protection.

2:1:1 dosing can only be used for anal sex.

PrEP is very safe with hormone treatment. Even though you might worry about drug interactions, your hormone levels will not be affected. Daily dosing (not 2:1:1) overcomes reduced TD levels with feminising hormone therapy.

An excellent resource on drug interactions between hormone treatments and other HIV meds is this leaflet from Liverpool University:

www.hiv-druginteractions.org/printable_charts

Ongoing studies are looking at other aspects of PrEP in trans women and men.

CliniQ is a London-based specialist clinic providing sexual health and well-being services for trans people. The **56T clinic** at 56 Dean Street in London has a popular PrEP service.

cliniq.org.uk dean.st/trans-non-binary

Other trans clinics include **Clinic T** in Brighton and **Indigo Gender Service** in Manchester.

<https://brightonsexualhealth.com/service/clinic-t>
indigogenderservice.uk

PrEP and sex work

PrEP can be used for any job in the sex industry including porn.

Many sex workers look after their sexual health but their clients might not. PrEP will protect against HIV if you are pressured to not use condoms. Specialised services (that are free from stigma and judgement) are available and recommended.

www.uglymugs.org

Buying PrEP in the UK, including online

It is legal to buy generic PrEP online, from outside the EU, if this is for personal use. Personal use is defined as up to three months of daily PrEP.

Online TD/FTC costs about £20 – £40 + post for 30 tablets (depending on supplier). TAF/FTC is similar or a little more expensive, but can not be used by everyone (see page 4).

Generic PrEP contains the same meds as brand products but made by a different companies.

PrEP supplied by NHS clinics is also generic. Generics are approved by the US FDA and/or the European Medicines Agency (EMA). See FDA listing:

www.fda.gov/InternationalPrograms/PEPFAR/ucm119231.htm

Sometimes buying PrEP online might take a while for the drugs to arrive. It is best to order at least a month in advance.

You need a combined pill that contains both tenofovir (TD, TDF or TAF) and emtricitabine. For example, you need Tenvir-EM or Ricovir-EM rather than just Tenvir or Ricovir.

Several UK community websites have information about how and where to buy PrEP online.

iwantprepnow.co.uk

prepster.info

i-base.info/qa/category/prep

Some clinics will support you and provide advice and testing if you buy PrEP online. However, the NHS is only responsible for meds that it supplies. The community websites above recommend good suppliers.

Before you start

First, please talk to a health advisor, nurse or doctor at the clinic. These people can help you if you want to take PrEP, or are already taking it.

An HIV test before or as you start PrEP is essential.

PrEP can only be used if you are HIV negative. If you are already HIV positive and don't realise it, you could develop drug resistance.

Ask for a 4th generation HIV blood test. This is also called a 'antigen/antibody' test. This will tell you if you have HIV so long as you haven't had other risks in the last six weeks.

Most finger prick tests are currently 3rd generation. This test needs 2-3 months to show a positive result. Don't rely on a finger prick test before PrEP if you have a more recent risk.

If you are just starting PrEP and had a risk in the last six weeks, have another 4th generation HIV test six weeks after starting. This is to be sure an early infection is not missed.

Be careful about starting PrEP if you have flu-like symptoms *and* had a recent HIV risk. This is in case these symptoms are related to a recent HIV infection.

If you are starting PrEP after PEP, it is best to start straight away if you need to. Ideally you should have a 4th generation HIV test after you finish PEP/start PrEP. Then have another test six weeks after starting PrEP.

Check your kidneys

Kidney tests just involve a blood test for creatinine and a urine test for protein. These tests should ideally be done just before or on the day you start.

Check for other sexually transmitted infections (STIs)

Testing for HIV and STIs is a great idea for anyone with an active sex life. This is whether you use PrEP or not.

Test for hepatitis B (HBV)

Testing for hep B is essential. This is because PrEP meds are active against both HIV and HBV.

This is a good time to have this vaccine, or to boost a previous vaccine. Please ask your clinic about this.

You can still use PrEP if you have HBV, but it needs to be used more carefully. People with HBV need to take PrEP every day, with medical advice, especially if you want to stop.

Care if you have already started PrEP

Once you have started PrEP, monitoring is just as important. If you are currently using PrEP and have not been monitored, talk to the clinic about doing this now.

Every 3-4 months

- Have a 4th-generation HIV blood test. This is also called an antigen/antibody (Ag/Ab) HIV blood test.
- Have a full screen for other STIs.
- An additional blood test for kidney function (creatinine) might be needed every six months. This is if you are older than 40 or are at risk of kidney problems. Abnormal kidney results might need monitoring more often.

Every 12 months

- Have a blood test to check your kidney function.
- Test for hepatitis C if you are having sex with gay men. Some clinics do this more frequently depending on risk.

How to take PrEP (TD/FTC)

This section is about two different ways to take TD/FTC. *

1. Everyone can use daily dosing.
2. Some people can use on-demand 2:1:1 dosing. This can be used for protection during anal sex, but not by women, trans or non-binary people having vaginal or front hole sex.

In both cases PrEP is taken both BEFORE sex (to let drug levels build up) and AFTER sex (to keep levels high).

Also, each of the drugs in PrEP is different. Both drugs are needed to give full protection.

FTC (emtricitabine) is absorbed rapidly, giving protection within hours, but levels drop more quickly.

TD takes up to 24 hours to reach rectal tissue, but it then stays at higher levels for longer. TD levels are lower in vaginal tissue, which is why daily PrEP is needed for women and trans men having front hole sex. On-demand (2:1:1) dosing is very effective for anal sex or for straight men having vaginal sex (see pages 17 to 19).

TAF is absorbed more quickly than TD and stays at higher levels for longer, but is only for men and transgender women. Unless you need TAF for medical reasons, it is rarely used in the UK and is not approved in the EU. It can only be used with daily dosing.

Please talk to your doctor about the best dose and timing that will be most suitable for you.

** TAF/FTC has only been studied with daily dosing. 2:1:1 dosing is not approved for TAF/FTC.*

Daily PrEP: for anal and vaginal sex

Most PrEP studies have used daily PrEP.

Taking PrEP every day will make sure that there are protective drug levels 24 hours a day, 7 days a week. This means you can have sex anytime, without planning for PrEP.

If you generally have sex every week, daily PrEP has the advantage of being an easier routine. Also, missing an occasional dose is unlikely to make a difference.

- If you are just about to start daily dosing but think you might have a risk within the next few days, start with a double dose.
- For anal sex, four or more daily doses each week will give good protection, especially after the first week. But four doses a week does not leave room for any missed doses.
- For vaginal or front hole sex you need to take PrEP at least six days a week. PrEP needs to be taken for seven days for drug levels to reach full protection.

On-demand 2:1:1 dosing: for anal sex or straight men having vaginal sex

Instead of a daily pill, some people can just use PrEP when needed. This is called on-demand or 2:1:1 dosing (or event-based dosing).

2:1:1 dosing **can** be used for anal sex (if you are the active or passive partner). It can **not** be used by women, trans and non-binary people for vaginal or front hole sex (see page 15).

In people who can use this option, 2:1:1 dosing is just as effective as daily PrEP. It involves taking two pills before sex and two pills after (see below).

2:1:1 dosing is less expensive because you need fewer pills, but can't be used if you have hepatitis B.

On-demand dosing

1. Take a **double dose** of PrEP (two pills) before you have sex. Ideally this should be between 2 and 24 hours before sex.
2. Take a single pill 24 hours after the double dose.
3. Take another single pill the following day, 24 hours later.

Aim to take the single pills 24 hours and 48 hours after the first double-dose.

The pre dose is important for the highest protection. If you miss or are late with the pre dose, taking the double dose as soon as possible.

The next two pages show examples of on-demand dosing.

Examples for 2:1:1 dosing

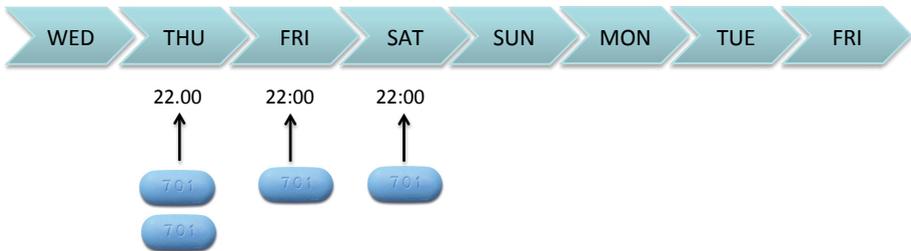
1. On-demand dosing: If you have sex once a week

BEFORE SEX

2 PrEP tablets at least 2 hours & ideally 24 hours before sex



19:00



AFTER SEX

1 PrEP 24 hours* after the 1st 2

1 PrEP 48 hours* after the 1st 2

= total of 2 tablets after sex

*2 hours before or after planned time is OK

If you might have sex on Friday or over the weekend, you could take two pills on Thursday, i.e at 10 pm.

If you have sex on Friday at 7 pm, then you would take a single pill on both Friday and Saturday at around 10 pm.

These times can be approximate. You still get good protection if you took the Thursday dose at 6 pm and had sex on Friday at 11 pm. **Even if the pre dose is only two hours before sex, or just before sex, or even after sex, some PrEP is always better than none.**

From having sex once, on-demand dosing involves four pills.

2. On-demand dosing: Sex several times over a few days

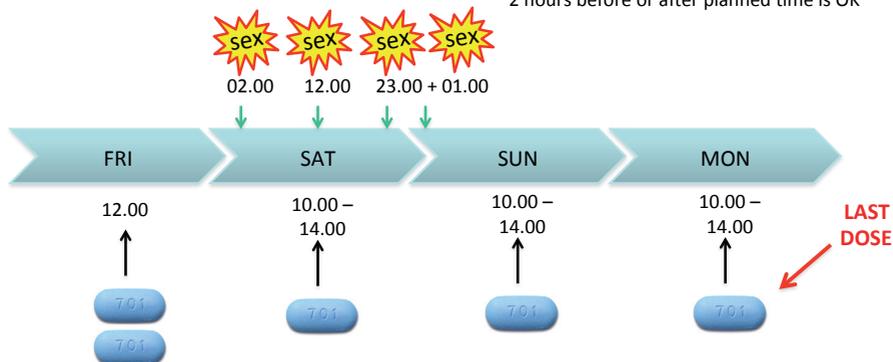
BEFORE SEX

2 PrEP tablets at least 2 hours & not more than 24 hours before sex

AFTER SEX

1 PrEP 24 hours* after the 1st 2
Take Truvada every 24 hours* **until 2 doses after your last sex**

*2 hours before or after planned time is OK



Take your double dose as usual 2 to 24 hours before sex.

If you have sex on Saturday, and a few times until Sunday at 1 am, continue to take a single pill every day at around the same time until you have had two doses after sex. Using the example above, your last dose would be on Monday.

If you don't have sex on Saturday or Sunday, but might still have sex on Monday, you only need to continue with a single pill on Saturday, Sunday and Monday. This is because you will already have good levels of PrEP. Continue taking PrEP daily until you have had two sex-free days, i.e. until Wednesday (seven pills).

If you start PrEP but then don't have sex on Saturday, and have no plans to have sex on Sunday or Monday, there is no need to take PrEP on any of these days.

If you didn't continue daily PrEP on Saturday and Sunday, restart with a double-dose to get best drug levels again.

Other tips on how to take PrEP

What to do if you miss a pill

If you miss one, or even two pills occasionally, this will be fine on a daily regimen.

Don't stop PrEP, just carry on once you remember. Drug levels will still be high enough to protect against HIV. If you are missing several doses each week, please talk to the clinic about support.

If you use daily dosing and miss more than a week of pills, you have to start again - see page 15.

This will involve either seven days of daily dosing (including for women and transgender people) or the double dose for 2:1:1 dosing.

You only need one double dose at the start.

You never need more than a total of seven pills in one week, unless you restart daily PrEP with a double dose. for earlier protection.

- A pill box makes it easy to see if you missed a dose.
- Aim for the same time each day. Link it to a routine task like brushing your teeth.

- If you have risks during a break from PrEP, it is important to have another HIV test.
- **With 2:1:1 dosing, if you miss the BEFORE dose, still take a double dose AFTER sex, and continue daily.** Contact your clinic in case PEP is recommended (see page 21). Missed doses matter more if you are using 2:1:1 dosing.

Is PEP recommended if I am on PrEP?

PEP stands for post-exposure prophylaxis and involves taking a combination of three HIV meds for one month.

PEP is now used less often. But if you need PEP, the earlier you start, the more likely it will work. PEP can be prescribed up to 72 hours after sex but the sooner it is started, the more likely it will work. **Ideally, PEP should be started within 24 hours.**

- If you have a risk when you haven't been taking PrEP, or enough PrEP, contact a clinic to discuss whether you might need PEP.
- Taking a double-dose of PrEP (if you still have some left) is a good idea as the earlier PEP is started the better it works.

Can I switch between daily and 2:1:1 dosing?

If you are able to use 2:1:1 dosing, PrEP is very easy to change if your HIV risks change.

You can stop and restart PrEP, or change the way in which you take it. PrEP can adapt to your needs at different times.

Talk to your clinic about ways of taking PrEP and about how to stop or restart when you need to.

2:1:1 dosing is NOT an option:

- If you have hepatitis B.
- For women who want protection during receptive vaginal sex, as a seven day lead-in is needed.
- For trans and non binary people who want protection from receptive vaginal or front hole sex.

Can I stop PrEP completely?

As with the flexibility for dosing, you might decide that you want to stop PrEP altogether.

Discuss your decision to stop with clinic staff.

You might want to discuss plans to stop PrEP with partner(s) and get tested for HIV and other infections together. Make sure you use a 4th generation HIV test six weeks after the last risk.

How you stop PrEP depends on how you were taking PrEP.

If you were taking daily PrEP, then continue for seven days.

If you were using on-demand dosing (2:1:1) then stopping after your last dose is okay.

If in the future your circumstances change again, it is easy to restart PrEP.

If you stop PrEP and have a risk afterwards, contact your clinic in case post-exposure prophylaxis (PEP) might be needed. In the cases when PEP is used, it needs to be started as soon as possible (see page 21).

Credits and further information

This leaflet was produced by doctors and community advocates from the following organisations.

BASHH (SIG MSM)	www.bashh.org
HIV i-Base	i-base.info/prep
iwantprepnw.co.uk	iwantprepnw.co.uk
PrEPster.info	PrEPster.info
56 Dean Street	facebook.com/56DeanStreet
Mortimer Market Centre	cnwl.nhs.uk/service/mortimer-market-centre
cliniQ: sexual health for trans people	cliniq.org.uk
Sophia Forum	sophiaforum.net
PrEP in Scotland	prep.scot
PrEP in Wales	tinyurl.com/ycm2hfbw
PrEP in N. Ireland	tinyurl.com/yytdkz3t
IMPACT trial	prepimpacttrial.org.uk
Drug interactions	hiv-druginteractions.org
Trans people and PrEP	cliniq.org.uk
PrEP guidelines	bashh.org and bhiva.org
HPV vaccine for gay men	i-base.info/htb/31151

