



Contact details:

UK guide to PrEP

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

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*This edition 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).

It was first written to support people who were buying PrEP online. This edition is also for people who are prescribed PrEP or are part of a study.

PrEP currently refers to a pill containing two HIV drugs. When taken correctly, PrEP greatly reduces the risk of HIV sexual transmission.

Access to PrEP in the UK

Free access to PrEP depends on where you live in the UK.

- NHS Scotland now provides PrEP.
For more details see: www.prep.scot
- NHS England only currently provides PrEP as part of the IMPACT trial. This study will enrol up to 26,000 people. It started in September 2017 and will run for three years.
- NHS Wales are now running a similar study called PrEPARED that currently has no cap on enrolment.
- PrEP is available in Northern Ireland in a two-year project.
- The DISCOVER study (already enrolled) is comparing current PrEP to a newer version.
- Many people are likely to continue to buy generic PrEP using online pharmacies.
- The Mags Portman PrEP Access Fund will provide vouchers for free PrEP for up to 1000 people (www.tht.org).

Background

What is PrEP?

PrEP stands for pre-exposure prophylaxis. PrEP is a pill taken before sex, so it is pre-exposure. Prophylaxis means to prevent infection. So HIV negative people can use PrEP to prevent them from becoming HIV positive.

Currently, PrEP uses oral tablets that contain two drugs: a version of tenofovir (usually TDF) plus emtricitabine (FTC).

Both TDF and FTC have been widely used to treat HIV. PrEP was approved in the US in 2012 and in Europe in 2016.

Who should take PrEP?

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

Other factors related to a high risk of HIV include:

- 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 is finding it difficult to take their HIV meds regularly.

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

Who should not take PrEP?

PrEP should NOT be used:

- By people who are HIV positive.

PrEP is usually not needed if:

- The negative person only has HIV positive partners who are on HIV meds with undetectable viral load. When viral load is this low, HIV positive people can not transmit HIV.
- If you are happy and able to always use condoms.

How well does PrEP work?

PrEP is highly effective at stopping HIV infection. In studies, PrEP was more than 95% effective when taken correctly.

Globally, tens of thousands of people take PrEP and only a few HIV infections have been reported from when people were taking PrEP. Of these, two cases were due to drug resistant HIV which is rare when using the prescribed dose (see p 7).

PrEP and side effects

The majority of 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 treatment.

PrEP and drug resistance

If you take PrEP correctly, the chance of drug resistance is very low.

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

The risks of drug resistance are from:

- 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 then not having an HIV test before restarting.
- Missing too many PrEP doses, so that drug levels are too low to prevent HIV infection.
- Contact with drug-resistant HIV. This is very rare: globally, only two 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 cervical/anal cancers. It is newly available for some gay men.

Does PrEP interact with other medicines?

PrEP does not interact with most other medicines.

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

TDF 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.

Taking both drugs together can cause kidney problems. Other NSAIDs include ibuprofen and naproxen. Avoid using these meds if you are taking PrEP, or let your doctor know if you need to take them.

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

Info on interactions between PrEP and other meds, including hormone treatment is on this site from Liverpool University:

www.hiv-druginteractions.org

PrEP for women

Why 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 a partner or partners who might be HIV positive. But only if they are either not on treatment or not taking all their meds.

Condoms protect against HIV. HIV positive people cannot transmit HIV if they have 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 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 most hormonal contraception (ring, patch, the pill, or an implant). PrEP will not affect your contraception. And the 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

Outside the UK, many women living with HIV have been using daily PrEP drugs for HIV treatment during breastfeeding.

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

This suggests that daily PrEP can be used safely if you breastfeed.

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 safe and effective for people who are transgender or non binary.

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

Anyone having vaginal/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.

On-demand dosing can only be used if your only risk is from anal sex.

PrEP is very safe with hormone treatment. Even though you might worry about drug interactions, your hormone levels will not be affected.

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 hormones and PrEP in trans women. This will hopefully also be studied in trans men.

CliniQ is a London-based specialist clinic providing sexual health and well-being services for trans people. This group is has produced new resources about PrEP.

cliniq.org.uk

Buying PrEP online

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

Generic PrEP contains the same medicine as the brand product (Truvada). It is usually made by a different company to the one that had the original patent.

PrEP supplied by NHS clinics in the UK is also generic and different brands may be available at different places and times. Generics approved by the US FDA and or the European Medicines Agency (EMA) are safe to use. 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.

Make sure that you order a combined pill that contains both TDF 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.

iwantprepnw.co.uk

prepster.info

i-base.info/qa/category/prep

There is always a caution when buying anything online. However, 56 Dean Street (a sexual health clinic in London) reported good drug levels using versions of generic PrEP listed on iwantPrEPnow. No HIV transmissions were reported from 400 people using generic PrEP for a year. [1]

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, for example, for the generic PrEP used in the IMPACT study.

The community websites on page 11 will make sure you get the right pills.

Reference

1. Nwokolo N et al. IAS 2017, Abstract WEPEC0962.
<http://programme.ias2017.org/Abstract/Abstract/5033>

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.

It is important to have an HIV test before or as you start PrEP.

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 four weeks.

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

If you are just starting PrEP and had a risk in the last four

weeks, have another 4th generation HIV test four weeks after starting. This is just to be sure an early infection was 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 four 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 STI 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.

Routine 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 may be required if you are older than 40 or are at risk of kidney problems.

Every 12 months

- Have a blood test to check your kidney function.
- Test for hepatitis C if you are having sex with gay men.

For trans and non binary people

If you have concerns about hormone interactions please speak to your doctor. Apart from ethinylestradiol (which should not be used with PrEP), hormone levels are not be affected.

However, if this is something you are worried about, it is important to talk to your doctor about your concerns.

How to take PrEP

This section discusses different ways that you can take PrEP.

This involves allowing for the time HIV needs to take hold (around 1 to 3 days). Also, to allow for PrEP to be absorbed and reach active levels (from a few hours to a day).

PrEP is likely to be most effective when both PrEP drugs are at protective levels before you have sex. However, any PrEP, even if late, will be better than none.

Drugs absorption and dosing options

Your body takes time to absorb drugs. Therefore, PrEP should be taken both BEFORE sex (to let the levels build up) and AFTER sex (to keep levels high).

Also, each drug is different. FTC is absorbed rapidly, giving early protection within hours, but levels drop more quickly. However, TDF takes up to 24 hours to reach rectal and genital tissue, but it then stays at higher levels for longer.

You can take PrEP in different ways depending on your circumstances and how often you have sex.

For vaginal sex, you need to take daily PrEP at least six days each week. You also need to take PrEP for a week to reach protective drug levels. This is because PrEP is absorbed differently in vaginal tissue compared to rectal tissue.

For anal sex, there is more evidence supporting daily PrEP. But on-demand dosing was very effective for anal sex in the IPERGAY and Prevenir studies. This involved taking two pills before sex as a double dose, a single dose 24 hours after the first double dose and another single dose, 48 hours later.

On-demand dosing is NOT suitable for women or transgender women having vaginal sex. On-demand dosing is NOT suitable for transgender men for vaginal/frontal sex. In all these cases, the longer lead in of seven days is needed to reach protective levels.

For men whose only risk is insertive sex (vaginal or anal), the double dose to start is likely to be okay, just that there is more data for daily PrEP.

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

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 do not have to plan PrEP for when you might have sex.

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 may 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.
- Remember that for vaginal/frontal sex you need to take PrEP at least six days a week.

On-demand dosing: only for anal sex

For people who do not want to take a daily pill there is an option to just use PrEP when you need it. This is called “on-demand dosing” (or event-based dosing).

Just taking PrEP before and after a risk is very effective. This option is important if you don't often have anal sex without condoms. Also, if you usually know when you will have sex.

If you are buying PrEP online, on-demand dosing will be less expensive because you need fewer pills and this might also reduce side effects. However, on-demand dosing can't be used if you have hepatitis B.

On-demand dosing involves:

1. Taking a **double dose** of PrEP (two pills) before you have sex. Ideally this should be between 2 and 24 hours before sex as this dosing was used in the IPERGAY study.
2. Taking a single pill 24 hours after the double dose.
3. Taking another single pill the following day, 24 hours later.

You should aim to take a single pill 24 hours and 48 hours after the first double-dose.

Although 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 will still give some protection.

The next three pages shows several on-demand examples.

Examples for on-demand 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

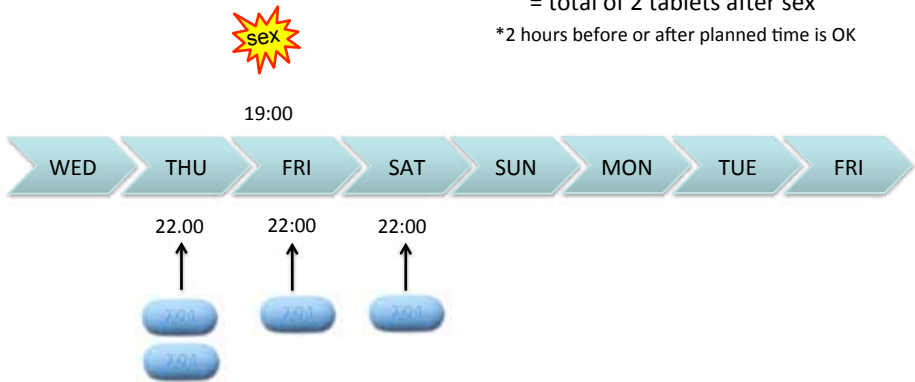
AFTER SEX

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 think 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

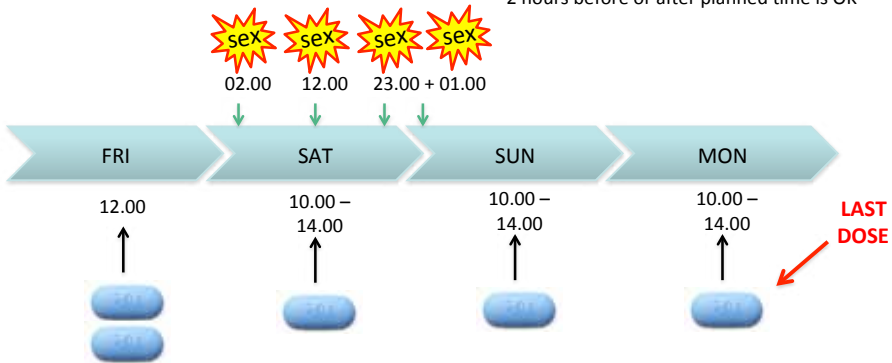
BEFORE SEX

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 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.

3. On-demand dosing: Sex several times, then more sex less than seven days after the last PrEP dose

1st PREP

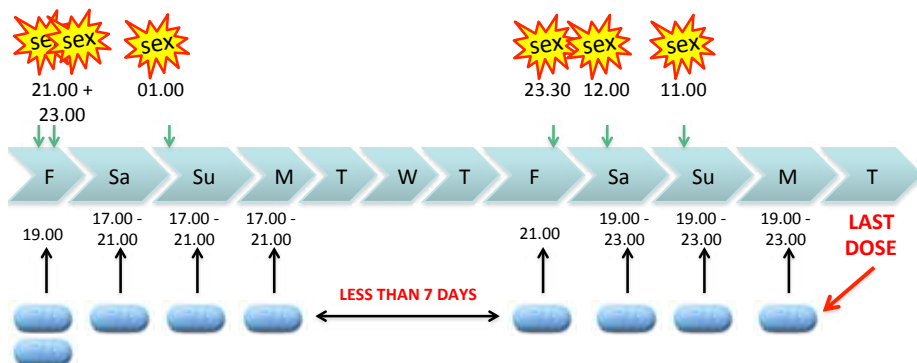
TWO PrEP tablets at least 2 hours & not more than 24 hours before sex. 1 PrEP tablet every 24 hours* until 2 tablets taken since last sex

*2 hours before or after planned time is OK

2nd PREP

ONE PrEP tablet at least 2 hours & not more than 24 hours before sex. 1 PrEP tablet every 24 hours* until 2 tablets taken since last sex

*2 hours before or after planned time is OK



If there are less than seven days between the end of one on-demand dosing period and the beginning of another, you only need to take one single PrEP tablet when you restart.

If it is more than seven days since your last PrEP dose, start again with a double dose of two pills.

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 16.

Never take more than one double dose when you start PrEP. You only need one double dose at the start.

Do not take more than a total of seven pills in one week.

- A pill box makes it easy to see whether you have taken or missed a dose. They only cost £1 or so from a pharmacy.
- Pick a regular time and try to stick to this each day. Link it to a routine task like brushing your teeth. It doesn't have to be the exact same time but it will help get you into a routine.
- If you have a break from PrEP and have risks during this time, it is important to have another HIV test.
- With on-demand dosing, if you miss the BEFORE dose completely, still take a double dose AFTER sex, and continue daily. Contact your clinic in case PEP is recommended (see below). Missed doses matter more if you are using on-demand rather than a daily 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 rarely used, but if you need it, the earlier you start PEP, the more likely it will work. PEP can be prescribed up to 72 hours after sex but is most effective if 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 on-demand based dosing?

If you are able to use on-demand dosing, PrEP is very adaptable if your circumstances change.

If your HIV risk changes, you can stop and restart PrEP, or change the way in which you take it. PrEP can be individualised to your needs at different times.

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

On-demand 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 women and trans men and non binary people who want protection from receptive vaginal/frontal 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 four weeks after the last risk.

How you stop PrEP depends on the sort of sex you last had.

Continue daily for seven days if you are protecting your vagina/front.

Continue for two more daily doses if you are protecting your bottom or penis.

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 22).

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
iwantprepnow.co.uk	iwantprepnow.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

