

TALKING TO YOUR HIV-NEGATIVE FRIENDS AND PARTNERS ABOUT PREP

This resource is for people living with HIV. It provides suggestions and advice you may want to share with friends and partners who are using or considering pre-exposure prophylaxis (PrEP).

WHAT IS PREP?

PrEP stands for Pre-Exposure Prophylaxis, where HIV-negative people take specific medications as prescribed to stop infection taking hold if they are exposed to HIV. These are some of the same medications used to control the virus in people who are already living with HIV.

NOT SURE ABOUT PREP?

Some people still have questions about where PrEP fits in relation to condom use and other risk reduction strategies. Research shows that PrEP and condoms are highly effective when they are used consistently and correctly.¹ PrEP is particularly important as a form of effective protection that may be acceptable to HIV-negative people who do not use condoms.

Keeping an open mind on PrEP will help keep open channels of communication – and you may have knowledge and skills that can help a friend use PrEP effectively.

STRONGER TOGETHER

PrEP is not just an issue for HIV-negative people: prevention is always a partnership. People living with HIV have a lot of expertise that is relevant to the challenges faced by people using PrEP, including the sometimes difficult aspects of disclosure and negotiating sex without condoms. We also know that people with HIV will be negotiating sexual encounters and relationships with people who are using PrEP. There is a lot that people living with and without HIV can learn from each other.

SIX STRATEGIES TO SHARE FOR SUCCESSFUL USE OF PREP

1. IT'S A PROGRAM NOT A PILL

Sometimes PrEP is described as 'taking a pill to prevent HIV'. However, just like HIV treatment, we know that medication will only work as part of a package.

It involves regular monitoring for HIV, sexually transmitted infections (STI) and side effects, in the context of a trusting relationship with a GP. This is very much like our experience of HIV treatment.

2. TAKING THE PILLS ON TIME

The most important factor in the effectiveness of PrEP is taking it as prescribed. As people with HIV we know that's not as simple as it sounds. We have learned to make it part of our everyday life. That's information you can share with friends using PrEP. When do you take it? How do you set reminders that work? Do you use pill boxes for daily doses and unmarked containers for travel?

3. DEVELOP A TRUSTING RELATIONSHIP WITH A GP

For many people, using PrEP may be their first experience of keeping three-monthly medical appointments and talking about issues that are complex and sensitive. People living with HIV have become 'expert patients'. It takes time, skill and courage to develop a trusting relationship with your doctor. Talk to your friends who are using or considering PrEP about how to choose a doctor, what to expect, how to ask questions and keeping that trust going.

4. DEALING WITH STIGMA

Some people oppose PrEP. Many of the comments by these people opposing PrEP have stigmatised individuals who might benefit most from using it.

People with HIV are experienced at living with stigma and use different strategies to deal with it. You can be a sounding board for friends who are encountering stigma and sex shaming. Share your own ways of understanding and responding to stigma, as well as those you have learned from other people with HIV. Talking with mates is the best way to minimise the impact of stigma.

5. KNOWING YOUR RIGHTS AND SEEKING A SECOND OPINION

Friends who are interested in PrEP may encounter judgmental or inaccurate advice from health professionals about PrEP. You can encourage them to seek advice of their own on the best way forward. Tell your friends to ask around. In particular, see page 4 for advice on the legal requirements to import generic medications into Australia.

6. UNDERSTAND THE SCIENCE

Organisations for people living with HIV continually interpret and discuss new scientific studies in terms of their implications for everyday wellbeing and prevention. Understanding the science behind PrEP can help people feel more confident in its effectiveness. It may also help to motivate people using PrEP to take each prescribed dose consistently. If you're not 100% confident in your own knowledge, do what you'd do for a positive friend – refer them to a positive organisation, AIDS Council or sexual health clinic for advice.

IMPORTING MEDICATION WITH A PRESCRIPTION

The advice here is based on the *PrEP – Access Options* paper. View it online at http://endinghiv.org.au/nsw/wp-content/uploads/2015/02/PrEP_Access_Options_Paper1.pdf

The advice reflects the reality that few people can afford the \$13,500 annual cost to purchase the brand name formulation of tenofovir and emtricitabine available in Australia.

The information provided here is for general interest and should not be taken as medical advice. Anyone considering PrEP should talk to a doctor, who is experienced in sexual health care and authorised to prescribe HIV medication, about whether PrEP is right for them.

IMPORTING GENERIC PREP

If someone cannot purchase PrEP at full price and does not have a place in a research study providing it, their doctor can legally prescribe the medication 'off label'.

However, until the medication is approved by the Therapeutic Goods Administration and Pharmaceutical Benefits Advisory Committee for use as PrEP, there is no publicly subsidised access to it.

An alternative option is to purchase a 'generic' formulation of the medication from a reliable overseas supplier and import it to Australia.

Generic means it has the same active ingredient, but has been produced under an exemption to the patent that applies to the drug.

At around \$1300 per year, the cost of importing generic medication is much more affordable than buying the brand name drug, but it will still be out of reach for many. Advocacy is underway to address this need.

The *PrEP – Access Options* paper provides instructions on how to order and import generic medication for use as PrEP.

WHAT ABOUT ME AS A PERSON LIVING WITH HIV?

PrEP may affect the medical and legal risks that people living with HIV may face when negotiating condomless sex and relationships with people who don't have HIV.

WHAT ABOUT RESISTANCE?

A person who thinks they may have acquired HIV while using PrEP should seek an HIV test as soon as possible. If someone acquires HIV due to poor adherence to PrEP, continuing to use PrEP medication could increase the likelihood of resistance developing.

There is a theoretical possibility, not seen in studies conducted to date, of a person who is living with HIV acquiring resistant virus from a person using PrEP who has been infected due to poor adherence.

DOES PREP PROTECT THE HIV-POSITIVE PARTNER FROM LEGAL RISK?

Victorian law requires people living with HIV to take reasonable steps to reduce or eliminate the risk of transmission. In the case of PrEP, the law remains untested. When negotiating sex where PrEP is the main form of protection, reasonable steps might involve asking your partner if they have missed any doses recently, and whether they are being routinely screened for HIV and other STIs. For instance, this might be an issue during a party weekend, particularly if a person on PrEP is travelling.

Don't assume that an HIV-negative partner looking for condomless sex is on PrEP. Making a diary note or taking a screen shot of a chat session can be a good way to document the conversation in case it becomes relevant at a later date.

LENDING MEDICATION

Giving HIV medication that has been prescribed for you to another person, even if they have a prescription of their own, is an offence in Victoria.^{2,3}

However, in everyday life, we know that small quantities of medication may be borrowed by friends using PrEP to maintain adherence. Consistent with the principles of harm reduction, here are some suggestions in case this occurs:

- Check there's no difference in strength (mg/pill) between the medication you take and what your friend takes.
- Do not lend other anti-HIV medications as they have not been proven to work as PrEP. In particular, they may not reach the tissues or concentrations that are needed to prevent sexual transmission of HIV.

- Do not lend other single pill combinations containing tenofovir, as their additional active ingredients can have side effects that may require urgent medical attention.
- Make sure that you have enough medication to meet your own needs.

If someone asks to borrow medication, encourage them to discuss options for importing PrEP as described on page 4.

SUPPLYING PILLS FOR SOMEONE TO USE AS PREP—WITH YOU

We strongly caution against supplying HIV medication for the purpose of having condomless sex with someone who is not currently using PrEP themselves. Your partner may already have been infected with HIV, and taking a short burst of medication could lead to resistance developing.

No studies have shown a one-off episode of medication is effective as PrEP, so this practice would not count as ‘reasonable steps to reduce or eliminate the risk of transmission’ under Victorian law. You could be putting yourself at significant legal risk, not to mention the risk of passing on HIV to your partner.

FINAL NOTE

PrEP is an effective HIV prevention strategy when taken as prescribed. It may not be everyone’s choice, but once the choice has been made, it deserves our respect and support. The best way to do that is to educate yourself, provide non-judgemental advice, and know where to refer your friends if they need further information and support.

To quote the American counsellor and advocate Damon L. Jacobs, PrEP stands for *Proactive Responsible Empowered Pleasure*. This response to people who stigmatise PrEP draws on the strategies people living with HIV have developed for expressing resistance and resilience against shame and stigma.

Living Positive Victoria
www.livingpositivevictoria.org.au

Victorian AIDS Council
www.vac.org.au/PrEP

REFERENCES

- 1 Grant, R.M., et al, iPrEx Study Team, 2010. Preexposure chemoprophylaxis for HIV prevention in men who have sex with men. *N. Engl. J. Med.* 363, 2587–2599; Baeten J, *Antiretroviral Pre-Exposure Prophylaxis for HIV-1 prevention among heterosexual African men and women: the Partners PrEP Study*. Sixth International AIDS Society Conference on HIV Pathogenesis, Treatment and Prevention, Rome, 2015, abstract MOAX0106; Molina JM et al. On Demand PrEP With Oral TDF-FTC in MSM: Results of the ANRS Ipergay Trial. CROI 2015. Oral late breaker abstract 23LB; McCormack S et al on behalf of the PROUD Study. Pragmatic open-label randomised trial of preexposure prophylaxis: the PROUD study. CROI 2015. Oral late breaker abstract 22LB.
- 2 *Drugs, Poisons and Controlled Substances Regulations 2006 (Vic)*, reg 45(1).
- 3 *Drugs, Poisons and Controlled Substances Act 1981 (Vic)* s 4 (definition of ‘supply’).