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Slaying side effects - it's all about managing the menace

As of June 2019, approximately 29,000 people in South Africa have started using oral pre-exposure prophylaxis (PrEP) to prevent HIV infection. Oral PrEP, a relatively new HIV prevention medication that keeps HIV negative people from being infected with the virus, needs to be taken daily to provide more than 90% protection. It is an incredible health intervention that puts the control around preventing HIV infection back into the individual’s hands.

Research tells us that approximately 1 out of every 10 people who use oral PrEP for HIV prevention experience some mild side effects. Let’s be honest, on the best of days, we’re simply not in the mood for any kind of inconvenience, so, how exactly have the people who remained on oral PrEP (and experienced some side effects) managed to overcome these and live their best life, uninterrupted?

DID YOU KNOW...

Every day, millions of people in South Africa need to take chronic medication. For instance, over 4.4 million people receive HIV treatment and need to take it every day.¹

Almost 50% of people with chronic illnesses do not take their medication as prescribed. The fear of side effects plays a role in a person’s decision to continue taking their medication correctly.

WHAT IS PREP & HOW DOES IT WORK?

Oral PrEP is a pill made up of two antiretroviral (ARV) medications, that, when taken once a day, can PREVENT HIV. It is PREVENTION, not TREATMENT and is only used by HIV-negative people.

A person can take oral PrEP for as long as they feel they are at risk of HIV infection. If a person no longer feels at risk, they can stop taking oral PrEP with the guidance of their health provider.

The medication in oral PrEP builds up in the body within 7 days to offer more than 90% protection against HIV, and is then maintained through daily use. It works by preventing HIV from integrating into a person’s cells and so protecting the body against contracting the infection. However, as with all medication, PrEP only works if a person takes it consistently and correctly, that is every day at more or less the same time for as long as they need to. Oral PrEP is for a season of risk, and not for the rest of a person’s life, unlike HIV treatment!

Find out if oral PrEP could be right for you by taking the online journey: PrEP Roadmap.

A little bit of background

In 2018, the Wits Reproductive Health and HIV Institute (Wits RHI), a leading partner of the OPTIONS Consortium*, in partnership with the NDoH and the Clinton Health Access Initiative, developed a
research study to understand exactly why people choose to use this fairly new HIV prevention method, what motivated them to continue using it and if they did stop, why they decide to do so.

The research was developed to listen to clients seeking health services at clinics, 299 of them to be exact. Women and men from four provinces (Gauteng, Limpopo, KwaZulu Natal and the Western Cape) across South Africa had their say. These clients were either using oral PrEP, had used oral PrEP in the past, had never even heard of it or had heard of oral PrEP but chose not to take it. More than 60% of the clients we spoke with were female and just over 30% were male, that’s right, oral PrEP works for both men and women. Almost half of the clients who shared their thoughts with us were between 25 and 34 years old, but those older and younger shared their thoughts as well.

If PrEP is such a great HIV prevention method, why did people stop using it?

There’s no doubt about it, PrEP is quite the pill. But despite the fame, it may not be for everyone. And that is perfectly okay, it’s all about finding the HIV prevention method that works for every individual, the method that makes them feel empowered to protect themselves and in control – this will be different for different people. In conversations with men and women who had previously used oral PrEP, the researchers learned that the main reason why people stopped using oral PrEP was because they had anxiety about side effects. The mere thought of side effects or when and if it would hit and disrupt life was definitely a barrier, never mind actually experiencing it.

Let the slaying commence

From our research, we found that 6 out of 10 (59%) current PrEP users had experienced side effects when they first started using oral PrEP. When asked what drove them to keep using oral PrEP, current users referred to a deep-seated desire to protect themselves and stay healthy. For those who use condoms, oral PrEP gave them an extra layer of defence against HIV, and that was inspirational to them. Users were determined to stay on oral PrEP regardless of the side effects they were experiencing. For instance, some users stayed on oral PrEP because they felt empowered by the accurate and honest information they had received from their health providers either through counselling or materials such as pamphlets and factsheets. For these users, just knowing which side effects could happen gave them a sense of control over their health and promoted their determination to keep taking oral PrEP for HIV prevention. Some users returned to their clinic or even called their health provider for advice and support when they experienced side effects, and this helped them to continue with oral PrEP.

What really piqued our interest is how some users changed things up and used clever strategies to help them take control of side effects. One user said, “...when I started taking the pill at 11am I would be stressed, because sometimes I would get nauseous; sometimes you would find that my friends would say I am moody, emotional, and easily pissed off and I didn’t know what was going on ... maybe those are the side effects of the pill. So, I told myself, “Okay, (participant name) maybe the issue here is with the time you’re taking the
pill – try and change the time and see the results” [...] when I take the pill at 8pm, there is nothing much to worry about.”

Simply changing the time they took their oral PrEP side-stepped daytime nausea or fatigue. In the end, most users said that these tactics carried them through until the side effects disappeared over time.

**Side effects associated with oral PrEP and how to kick it**

It's important to know that not everyone using oral PrEP experiences side effects. In fact, some people use oral PrEP without ever having side effects, while others, get mild side effects that go away within a few days to a month of starting it. Some common side effects reported include nausea, vomiting, and headaches. Even though that doesn’t sound like a good day, it seemed that for some, determination beat discomfort. Knowing how to manage anything menacing and uncomfortable when starting a new medication is key! We compiled a few helpful hints that could help relieve minor side effects. However, if symptoms last long and do not improve then it is advised that a health provider be seen as soon as possible.

**Nausea and/or vomiting**

Mild nausea and vomiting are possible side effects that can be managed. Try taking oral PrEP at a different time, e.g. before sleeping. You could try drinking small amounts of liquids such as water, lemon juice, lime juice or ginger. It may also be helpful to avoid drinking dairy products and eating oily or spicy foods - these could make you feel worse.

**Headache**

Headaches can be treated with medication, but you can also try drinking lots of water and getting enough sleep. Staying away from alcohol and caffeinated drinks is a great idea too.

**Loss of appetite**

When it comes to loss of appetite or a reduced desire to eat, there are simple things you can do to stimulate your appetite! Eat your favourite foods, try having small meals regularly or eating foods that are rich in calories and nutrients to compensate.

**Rash**

Getting a rash once starting oral PrEP can be uncomfortable and going back to your healthcare provider to have it checked is the best possible thing you can do!

**Remember!** The information contained here is not meant to replace the knowledge and care of health providers. If side effects continue or worsen and affect your daily activities, see your health provider immediately.

**We are the generation that will end HIV...**

It’s been over 30 years since AIDS was discovered, and in that time researchers have made significant progress towards developing an HIV vaccine, but we are still many years away from such a vaccine. Until we have an effective vaccine available, South Africa has several HIV prevention options available and oral PrEP is an important new addition. The researchers of this study found that health provider counselling, the realisation of personal risk and access to honest information play a vital role in empowering and encouraging people on their oral PrEP journey. Knowing what to possibly expect and how to manage it is power in itself.
Have more questions? Visit myprep.co.za to answer all your questions about oral PrEP. Want even more interaction, visit the South Africa MyPrEP Facebook and Twitter pages and join a community of people who believe that We Are The Generation That Will End HIV!

Want oral PrEP? Find your closest clinic in South Africa that is providing oral PrEP free of charge here. Want to know if oral PrEP is right for you? Try doing this online journey to find out: PrEP Roadmap.

*The OPTIONS Consortium is one of five microbicide projects funded by the U.S. Agency for International Development (USAID), in partnership with the U.S. President’s Emergency Plan for AIDS Relief (PEPFAR), working to accelerate and sustain access to oral PrEP.

Disclaimer: Oral PrEP is more than 90% effective at preventing HIV infection for HIV negative people only. It does not protect against other STIs or unintended pregnancy.