

# HIV HEALTH SERIES

## Dealing with diarrhoea

**Many people with HIV have experienced diarrhoea and this can have a significant impact on their quality of life. Diarrhoea can be caused by HIV itself, by viral, bacterial, or parasitic infections, by medicines or by contamination of food because of poor food hygiene. Stress and emotional problems are other causes.**

The persistence of diarrhoea as well as its severity (e.g. mild, bad) and frequency (every day all day, just at night or sometimes after meds) differ between people. Causes might not necessarily be a side-effect of HIV or treatments. In most cases there are steps you can take to control it.

This factsheet describes some lifestyle changes and offers practical tips on dealing with diarrhoea.

Diarrhoea is one of the most commonly reported treatment side-effects (along with nausea or vomiting, fatigue or lethargy and sleep disturbance).<sup>1</sup> Improved HIV treatments are less likely to cause intermittent diarrhoea or persistent diarrhoea. Prescribing practice has also changed over time. However, even with these changes diarrhoea is still a significant concern for many people with HIV.

### **Maintaining quality of life**

For people with severe and persistent diarrhoea, the negative effects are not just physical: persistent diarrhoea can significantly reduce quality of life.

**John:** It had been going on for ten years. It's ruled my life to the point where I had to see a psychiatrist to get over all the anxieties that it created. She put me on medication to reduce the panic attacks. There'd be times when it would be so bad I'd end up lining the bottom of my underpants with toilet paper as an added precaution.

**Christopher:** It comes and goes, but when you do experience it, it does take away from your enjoyment of the moment in whatever you are doing – going to the shop or having a meal with a friend.

Diarrhoea can make things like going out, socialising, or having sex difficult and stressful.

Depending on the severity of the diarrhoea, some people explore other sexual options and still have a sex life despite their difficulties.

**Christopher:** It's not like you can't have sex. If I'm a bit worried about not being able to get fucked because of a few cramps, I will just be a top for the night or stick to oral sex.

Maintaining quality of life includes having a social life. The thought of going out and socialising may be the last thing on your mind. Here are some practical tips:

- If you feel the beginning of cramps or are a bit unsettled make a quick trip to the toilet – don't wait.
- Try taking Imodium (Gastrostop) before you go out, this helps slow down the gut and may prevent accidents from happening.
- Take a spare pair of underwear and toilet paper when you go out.
- A small plastic bag for soiled underwear could help.
- Plan a trip in advance and allow extra time just in case you have to stop along the way.
- Know where the toilets are located at the regular places you visit.
- If you are away from home, try to avoid those things that you know trigger your diarrhoea (e.g. certain foods or beverages).

**John:** I'd get up the road five minutes and get cramps. I'd think: "Where am I? Am I close to a shopping centre?" If I'm not far from home I'd turn around and go back. So, when I went anywhere I'd plan in advance. I had to allow for extra time in case I'd have to stop somewhere along the way. I've got to know where all the garages or hotels are. When I go to the mall I've got to know where the loos are.

BECAUSE DIARRHOEA IS A SIDE-EFFECT OF TREATMENTS, YOUR DOCTOR MAY OVERLOOK HOW SERIOUS IT IS.

THE FIRST STEP TOWARDS CONTROL IS TO IDENTIFY THE CAUSE.

## Identify the cause

There are two main reasons why people with HIV might get diarrhoea. It may be the result of infection with a micro-organism; or it could be the side-effect of medication. The first step towards control is to identify the cause. It is now relatively uncommon for a specific cause not to be found.

Infective diarrhoea is in many cases the easiest to treat. Some of the more serious microorganisms that can cause diarrhoea include cryptosporidium, MAC, shigella and there are a few others. There can be less exotic ones such as Giardia. Antibiotic treatment is usually very effective in dealing with these infections.

If infective causes have been ruled out, it is possible that diarrhoea is a side-effect of antiretrovirals or other drugs. This may mean changing the medication which is causing it, which is possible through discussion with your doctor. It is important to remember that people can experience the various medications differently.

**John:** With the medication everyone is going to be different. This is what worked for me. I'm on a brand new drug Atazanavir. With the combination of Atazanavir, Ritonavir, Abacavir and Tenofovir there is no diarrhoea. The HIV is under control and the diarrhoea is virtually non-existent. Things are getting back to normal, but it will take a while for the anxiety issues to subside.

Diarrhoea has been reported as a common side-effect of all of the protease inhibitors (some more than others) and with a few of the nucleoside drugs. Most other anti-HIV drugs have had diarrhoea listed as a less-common side-effect. Antibiotics may also be a cause.

Because diarrhoea is a side-effect of treatments, your doctor may overlook how serious it is. Usually diarrhoea will settle down after a few days. If it persists it is important to see your doctor.

## What to do

While many people with HIV will experience diarrhoea from time to time, in most cases there are steps you can take to control it.

As diarrhoea may result in excessive loss of salts and water from the body it is important to drink plenty of fluids or special rehydration drinks. If you have bad diarrhoea, you are likely to lose valuable nutrients. Eating foods like bananas, potatoes, chicken and fish will help you replace potassium levels of which are depleted in people with severe symptoms. Soluble fibres from natural sources like oats, bananas, apples and pears have also been shown to be effective against diarrhoea.

As weight loss may accompany diarrhoea, improving your diet and getting guidance on nutrition is advisable. You might find it useful to speak to an HIV dietitian who can provide you with advice on suitable dietary changes, how to avoid losing weight and how to get adequate nutrition. If diarrhoea remains unmanageable, dietary supplements to replace the loss of nutrients may be recommended.

The temptation to stop taking drugs that are causing diarrhoea can be very strong, especially if you have just started a new treatment regime and find yourself spending a lot of time on the toilet. In many cases, the diarrhoea will settle down after a short period of time, but you need to keep taking the drug to give this a chance to occur. If the diarrhoea is serious, especially if it persists for more than two days or is accompanied by weight loss, talk to your doctor. Don't stop taking your treatment unless your doctor recommends it.

## Dietary strategies

Many mistakenly believe that when they experience diarrhoea, they should stop eating and drinking. Eating may be the last thing on your mind, especially when it can be the trigger for an attack, not to mention the anxiety this can provoke. However, reducing food intake may make the problem more serious.

KEEP TAKING YOUR DRUGS, KEEP EATING  
AND DRINK LOTS OF WATER.

IF DIARRHOEA IS SEVERE OR BECOMES PERSISTENT  
TALK TO YOUR DOCTOR.

Eating the right type of foods can make all the difference.

- Increase soluble fibre intake. Soluble fibre in the form of psyllium husks, which can be bought at the supermarket, or Metamucil from the chemist, help by absorbing water from the gut, slowing down the gut and allowing more time for the fluids to be absorbed helping create formed stools.
  - Soluble fibre is found in oats, fruits (not juices), vegetables and legumes (e.g. baked beans, kidney beans, peas, lentils). These may need to be reduced if diarrhoea is severe and reintroduced as diarrhoea settles.
  - Sprinkle a teaspoon of psyllium husks onto cereal or on top of your toast with jam or mix it with apple juice.

**Fibre supplements should be taken at least a couple of hours apart from HIV drugs or they can affect drug absorption.**

- Clear juices such as apple, pineapple or pear are good, but avoid most other fruit juices, which can aggravate the problem. Some people may have increased problems when consuming foods containing a high fructose level. If the fruit juices mentioned increase the diarrhoea, cramping or bloating then contact your HIV dietitian for advice as you may need to decrease foods containing fructose.
- Bananas and white rice are high nutrition foods with the right type of fibre. Dry white toast is an old standby, but can be hard to eat if you have a dry mouth. Clear broths and soups are usually a good bet, but watch out for packaged soups containing MSG.
- Drink plenty of fluids – at least eight cups per day to replace lost water. Dehydration will cause a dry mouth, making eating more difficult. Sports drinks like Gatorade or rehydration solutions like Gastrolyte can be helpful in replacing lost electrolytes. Contact your local AIDS Council for a recipe to make your own rehydration drinks.

- Eat small amounts of food five or six times a day instead of trying to consume normal-sized meals.
- Eat soft, mashed, moist foods such as soft vegetables and fruit, porridge, rice, bananas, mangoes, watermelon or stews with rice, barley or potatoes. Soft vegetables include squash, pumpkin, sweet potato, carrots, and vegetable soup.

Managing diarrhoea can take an individualised approach. Some people change their treatment regime or their diet, or take antidiarrheals, or take up all three options.

**Christopher:** You need to find an individual dietary plan. While you might have a model for a good diet, you need to adjust it. If you are having problems with your treatments then talk to your doctor.

## Some foods can make diarrhoea worse

Try to remove one food at a time from your diet and see if it makes a difference.

- Reduce insoluble fibre intake. Insoluble fibre can add bulk to the gut contents and speed up the process of moving waste through your digestive system, potentially making diarrhoea worse. Insoluble fibre is found in cereal and grain products (e.g. wholemeal varieties of flour, breakfast cereal, bran, bread, pasta, nuts and seeds).
- Reduce caffeinated and alcoholic drinks. Alcohol, coffee, tea and caffeine-containing carbonated drinks (e.g. Redbull, V-drinks, Coca Cola) can all make diarrhoea worse and can exacerbate dehydration. They should be replaced by other fluids such as water, herbal tea and soups.
- Minimise lactose (the sugar found in milk) intake because it may exacerbate your diarrhoea. You may benefit from reduced lactose or lactose-free milk or soy milk.
- Watch out for highly processed foods, especially those containing monosodium glutamate (MSG) often listed on the label as flavour enhancer 621. Artificial sweeteners can also have a powerful laxative effect.
- Reduce high-fat foods (e.g. deep-fried foods, fatty meats). Fats can make diarrhoea worse and cause nausea. Fat intake should then be reduced, adding

less or no cooking oil, cutting off visible fat or skin from meat and boiling or steaming food rather than frying it.

- Take care with spicy foods.

## Sometimes you need more than the right diet

If you have trouble controlling diarrhoea with diet some products available from a pharmacy may be of benefit.

- Imodium is the most commonly prescribed anti-diarrhoea drug. The effect of the Imodium is to slow down the movement in the gut, so it gives it more time to absorb the fluid that is there.

It is important to establish when the diarrhoea is at its worst (i.e. morning/night). If it is worse in the morning take Imodium before going to bed. If it is worse at night take Imodium in the morning. Try different times and amounts to find out what suits you best.

**Imodium can also have the opposite effect – making you constipated – so careful monitoring of the effects and gradual adjustment is important.**

- Calcium carbonate supplements of 500mg twice a day can help ease the diarrhoea often experienced by people taking the protease inhibitor nelfinavir (Viracept).<sup>2</sup>

## Complementary options

Many people have found that complementary options have helped with diarrhoea and improved quality of life.

Complementary therapies that can help calm diarrhoea are peppermint and ginger teas and the amino acid l-glutamine. Adding a little nutmeg to food can also help.

If you have had an infective diarrhoea which has been treated with antibiotics, it is important to replace the helpful bacteria lost from the gut. Yakult drinks are recommended. Generally the recommendation is: 2 x Yakult for 5 days, 1 x Yakult for the next 5 days and then 1 x Yakult every 2 – 3 days.

Probiotics are classed as “friendly bacteria” and may also be of benefit. They keep the gut healthy by protecting it from infection and assist in better absorption of nutrients from food. Probiotics are found most commonly in yoghurts.

## The bottom line

- The most important advice is to keep taking your drugs, keep eating and drink lots of fluids.
- Identify the cause. Diarrhoea is not always caused by HIV medication; it could be due to an infection.
- If your diarrhoea is severe and persists for more than two days, make an appointment to see your doctor. If you are having problems with your medication changing them can sometimes help with diarrhoea.
- It is a good idea to consult with your doctor and/or dietitian when making significant changes to your diet.
- Consider consulting a dietitian about the types of foods to limit and which ones to include. A dietitian can help you with an individualised approach to managing your diarrhoea.
- Practise good food hygiene (e.g. wash your hands and food before preparation, make sure food is cooked properly and is stored at the right temperature, and check the 'use by' or 'best before' dates).
- If you have got diarrhoea, it is even more important to be meticulous about hygiene, like washing your hands after going to the toilet and before you prepare your meals.
- Diarrhoea can cause anxiety and significantly reduce quality of life. At times it may be useful to consult a counsellor or psychiatrist to talk about some of these issues.

## Getting information and support

- **For treatment and complementary therapies information call ACON** (02) 9206 2000 (NSW only), 1800 063 060 (NSW only) or email [hivliving@acon.org.au](mailto:hivliving@acon.org.au)
- **For dietary needs call Albion Street Centre** (02) 9332 9600, 1800 451 600 (NSW only)
- **For regional NSW HIV and related services**  
*Contacts: a directory for people with HIV* visit [www.positivelife.org.au/contacts](http://www.positivelife.org.au/contacts)
- **The Australian National Public Toilet Map** may be useful. It locates public toilet facilities in cities, towns, rural areas, and along major travel routes. [www.toiletmap.gov.au](http://www.toiletmap.gov.au)

## References

- 1 Grierson, J., Thorpe, R. and Pitts, M. (2006). *HIV Futures 5: Life as we know it*, Monograph, series number 60, The Australian Research Centre for Sex, Health and Society, Latrobe University, Melbourne, Australia, p 18.
- 2 See [www.aidsmap.com](http://www.aidsmap.com) A–Z of Symptoms: Diarrhoea

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