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adherence & resistance

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This booklet replaces
*Adherence and HIV Drug
Resistance.*

NAM is a charity that publishes information for people affected by HIV and those working with them. We believe information helps people to make decisions about, and be in control of, their lives, health and treatment options.

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adherence & resistance

HIV treatment can mean a longer and healthier life. You'll get the most benefit from your treatment if you take it properly. This is often described as 'adherence'. If you don't take HIV treatment properly, then your HIV may become resistant to the drugs you are taking and possibly other, similar drugs.

The first part of this booklet is about adherence, and includes tips on how you can boost your ability to take treatment properly. In the second part of the booklet, the issue of resistance is looked at in more detail.

This booklet is not intended to replace discussion with your doctor. But it should provide you with a better understanding of taking HIV treatment and drug resistance and can be a starting point for discussions about these issues.

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Why taking your HIV treatment properly is so important

1

The outlook for people with HIV in the UK has never been better. The right treatment and care can mean that you have a good chance of living a long and healthy life, with a near-normal lifespan.

The currently available anti-HIV drugs (antiretrovirals) cannot cure HIV. However, treatment with a combination of these drugs (usually three) can reduce the amount of HIV in your blood (your viral load) to such a low level that it cannot be detected using laboratory tests. This is called an 'undetectable' level. An undetectable viral load is the aim of HIV treatment. Having an undetectable viral load means that your immune system can stay strong and fight off infections.

There's very good evidence that the HIV treatment available today will work against the virus in the long term and keep your viral load undetectable indefinitely.

However, for this to be the case, it's very important to take your HIV treatment properly. This is often called 'adherence' and it is the most important factor under your control in the success of your HIV treatment.

Not taking your HIV treatment properly can mean that the levels of the drugs in your blood are not high enough to properly fight HIV. If this happens, your HIV will be able to reproduce. The strains of HIV that reproduce when you're taking HIV

treatment can develop resistance to the drugs you are taking. Resistance can mean that your HIV treatment won't work properly.

Your treatment not working is likely to mean that your viral load will increase and your CD4 cell count, an important indicator of the health of your immune system, will fall. This situation increases your chances of becoming ill because of HIV.

If your viral load increases to detectable levels, then you'll need to change your HIV treatment. While there is more choice available this new treatment might be more difficult to take than the combination you were taking before and could involve a risk of more or new side-effects.

You may also become resistant to drugs similar to those you are currently taking. This is called cross-resistance and the risk varies between different classes of HIV drugs. You can find out more about the different drug classes in the NAM booklet *Anti-HIV Drugs*.

When taken properly, HIV treatment can also lower viral load in genital fluids to undetectable levels. This can reduce the risk of HIV transmission during sex. A consequence of not taking your HIV treatment properly can be that the amount of virus in your genital fluids increases, therefore increasing the risk of passing on HIV to your sexual partner(s) and the type of HIV which you pass on may be resistant to one or more of the drugs.

There's more information about resistance in the second part of this booklet between pages 21 and 30.

You can find out more about HIV treatment in the NAM booklet *HIV Therapy*. Information about CD4 cell counts and viral load is available in the booklet *CD4, Viral Load & Other Tests*.

4 What does taking your HIV treatment ‘properly’ involve?

Taking your drugs properly is often called adherence. Adherence to your HIV treatment means:

- Taking all the medicines that make up your HIV treatment combination in the right quantities.
- Taking your medicines at the right time. Taking your medicine too late can be as bad as not taking it at all.
- Following any instructions about food. Some medicines need to be taken with food so they are absorbed properly, but others need to be taken on an empty stomach.

- Checking for interactions with other medicines or drugs. This includes medicines that a doctor prescribes to you, as well as those bought over the counter. It’s also important to know that some herbal and alternative medicines can interact with some anti-HIV drugs, as can some recreational and illegal drugs.

How many doses of your medication do you need to take?

The best results of HIV treatment are seen in people who take all, or nearly all of the doses of their drugs in the right way.

Modern HIV treatment has a very powerful anti-HIV effect, but nevertheless taking

fewer than 95% of your doses correctly has been associated with an increase in viral load, a fall in CD4 cell count, and an increased risk of resistance.

What does this mean in practice?

If you take your HIV treatment once a day, then 95% adherence means missing no more than one dose of your HIV treatment a month.

If you take your HIV treatment twice a day, then 95% adherence means missing no more than three doses of your HIV treatment a month.

Many people find this demanding and don't always achieve such high levels of

adherence. Despite the difficulty, it's important to aim to take all the doses of your medication correctly, and many people find a way of making sure that they take their HIV treatment in the right way and at the right time.

What should you do if you miss a dose?

You should try and make an effort to take every dose of your medication at the right time and in the right way. But most people taking HIV treatment occasionally forget to take a dose of their treatment.

What you should do about missed doses will depend on circumstances. You should still take the dose if you remember within a few

hours. But don't take your medicine if it would mean taking the dose very late. It is a good idea to discuss this with your doctor or pharmacist, as how late you can take a dose will vary depending on the drugs you are taking. You should not take a double dose to compensate for the one you have missed.

It's important to remember that taking doses late can be as bad as not taking them at all.

If you are regularly missing doses of your medication, or taking them late, it's a good idea to mention this to your doctor. Your clinic should be able to offer advice and support.

Helping you to take your HIV treatment properly

A wide range of factors can have an influence on how well you adhere to your HIV treatment. These differ between people and can change over time. This means that there's no single magic solution that can guarantee the best possible adherence for everyone.

Instead, it's important to think about the factors that are likely to affect you. Doing this can be beneficial if you are about to start or change treatment, or if you are having problems taking your treatment properly.

Being involved in decisions about your treatment

If you are involved in decisions about starting or changing your HIV treatment, and feel comfortable about what you've decided, then you'll be more likely to take your treatment properly.

Your doctor should take time to talk through with you why you need to start or change HIV treatment. You should also be given written information to take away and read about any treatment you are considering.

Other members of the healthcare team at your clinic, particularly specialist HIV pharmacists, health advisers or health

trainers and nurses are also good sources of information and support when starting or changing treatment.

Some other reliable sources of information are:

● THT Direct

telephone 0845 12 21 200

email info@tht.org.uk

opening hours Monday to Friday,

10am to 10pm

Saturday and Sunday, 12 noon to 6pm

● HIV i-Base Treatment Phonenumber

telephone 0808 800 6013

email questions@i-base.org.uk

opening hours Monday to Wednesday,

12 noon to 4pm

- if you live in London, you can get help from a health trainer through THT's HIV Health Support Service. Health trainers work in HIV clinics, community centres or can visit you in your home and can provide information, advice and support about living with HIV, treatment and managing your condition. You can ask to see a health trainer at your clinic, by contacting THT Direct or by using the online service at www.tht.org.uk/askthetrainer.

It's a good idea to ask questions if you are unclear about anything and to keep on asking questions until you understand.

You'll probably have an opportunity to think about starting treatment over a number of weeks or even months. There's a good chance that your adherence will be better if you start taking treatment when you're ready to do so. It's important to know, however, that you're likely to be advised to start taking HIV treatment soon if you are ill because of HIV. HIV treatment is also recommended for people even if they have no symptoms when their CD4 cell count falls to around 350. If you need to change treatment because your current HIV treatment isn't controlling your viral load, it's important that you do this as soon as possible to reduce the risk of resistance.

There's more information about starting and changing HIV treatment in the NAM booklet, *HIV Therapy*.

What you think about your HIV treatment

There's evidence to show that people who understand the benefits of HIV treatment are more likely to take their treatment properly. It's good to know that the amount of illness and death caused by HIV has fallen dramatically since effective HIV treatment became available. Researchers have calculated that HIV treatment will mean that many people with the virus who take their treatment properly will live a near-normal lifespan.

There have been important improvements in HIV treatment in recent years. The side-effects of the recommended anti-HIV drugs are generally mild and either lessen or go away completely over time.

If you have questions or concerns about the effectiveness of HIV treatment or its possible side-effects, it makes sense to discuss these with your HIV doctor or another member of your healthcare team. There's more information in the NAM booklet *Side-effects*.

Your mental health and your circumstances

Mental health problems such as depression have been linked to not taking HIV treatment properly.

Depression is quite common in people with HIV. However, it can be successfully treated and a lot of support is available through your clinic as well as through HIV organisations if you have emotional or mental health problems.

Therefore it's a good idea to tell your HIV doctor if you think you are depressed, particularly if this means that you're having problems taking your treatment.

Feeling isolated or alone, or having worries about money, housing, immigration or employment, can all make it harder to take your HIV treatment properly. These concerns may seem more pressing and

important than prioritising or taking your treatment. HIV organisations can be a good place to turn to for support if you are facing any of these issues. Your HIV clinic may have a specialist social worker who can help, so it's a good idea to tell your doctor about any problems you are having.

You can find out more about mental health in the NAM booklet, *HIV and Mental Health*. A good place to find out about the services available to you is THT Direct, on 0845 12 21 200.

There are now over 20 HIV drugs available. This means that you and your doctor will usually be able to find a combination that suits your circumstances.

It makes good sense to consider any past treatment experience, as well as your needs and preferences about how often you take your medication, the chances of developing side-effects, and the risk of interactions with other medicines and drugs.

Taking your individual needs and preferences into account may mean that you are less likely to encounter problems taking your treatment later on.

Information on all of the currently available anti-HIV drugs is available in the NAM booklet, *Anti-HIV Drugs*.

Number of doses

Medicines from the three main classes of anti-HIV drugs (nucleoside reverse transcriptase inhibitors or NRTIs, non-nucleoside reverse transcriptase inhibitors or NNRTIs, and protease inhibitors) are available in forms that need to be taken just once a day. If you're starting HIV treatment for the first time, then it's likely that you will be able to choose from a number of once-daily combinations. There is even an HIV treatment that consists of just one pill, once a day.

Even if you have taken a lot of HIV drugs in the past, it's very unlikely that you will have to take your treatment more than twice daily.

If you have a preference for once- or twice-daily treatment you should discuss this with your doctor.

The NAM booklet *Anti-HIV Drugs* provides information about the dosing requirements of each of the available anti-HIV drugs.

Number of pills

Some people have difficulty taking large numbers of pills. However, HIV treatment for most people consists of a few pills once or twice a day. If you have a choice, choosing the simplest combination with the fewest pills is likely to boost your chance of taking your treatment properly.

You can find out about the number of pills involved in treatment with each of the currently available drugs in NAM's booklet, *Anti-HIV Drugs*.

Food restrictions

Some HIV drugs need to be taken with food to work properly, whereas others should be taken on an empty stomach. However, for some drugs, it doesn't matter if they are taken with or without food.

Some people find it difficult to take their HIV treatment on an empty stomach because this means not eating for a certain amount of time before or after taking their medicines. Other people prefer to not have to take their anti-HIV drugs with food because this can

reduce the amount of flexibility they have about the time they take their treatment.

If you have a preference or concerns about food restrictions it makes good sense to let your doctor know this so that you can be prescribed the most appropriate treatment.

Some HIV clinics have dieticians who can make sure you are eating enough food for your medication to be absorbed properly. There's information on the food requirements of HIV treatment in the NAM booklets *Anti-HIV Drugs* and *Nutrition*.

Side-effects

Like all medication, HIV treatment can cause side-effects, and these can be a reason

why people don't take their treatment properly.

The risk of side-effects can vary between individual drugs. It isn't inevitable that your HIV treatment will cause side-effects, and the medicines used today generally only cause mild side-effects that either become more tolerable or go away completely with time.

However, side-effects do happen. If you are concerned about the risk of developing a particular side-effect, then mention this to your HIV doctor. You'll then be able to discuss your concerns, and it may be possible to choose a treatment that doesn't cause the side-effect you are worried about.

It also makes good sense to speak to your doctor about any side-effects that you develop after starting treatment. It's nearly always possible to do something about side-effects. Don't miss doses of your treatment in an attempt to avoid side-effects. If you develop a side-effect, you shouldn't stop taking your HIV treatment without speaking to your HIV doctor first.

Dieticians can give advice on how to minimise side-effects like nausea and diarrhoea.

You can find out more about side-effects in the NAM booklets *Side-effects* and *Anti-HIV Drugs*.

Interactions

To reduce the risk of potentially harmful interactions between drugs, it makes good sense to tell your HIV doctor or pharmacist about any other medicines, supplements or drugs you are taking. This includes medicines prescribed by another healthcare professional, as well as medicines bought over the counter, some nutritional supplements, herbal and alternative drugs, and illegal and recreational drugs.

Sometimes people feel uncomfortable telling their healthcare team about drug use. Your HIV doctor is more likely to be concerned about avoiding potentially dangerous interactions than telling you off about the use of recreational drugs. It's also

good to know that support and information will be available from your clinic if you are concerned about your drug use.

The most important interactions for each drug are listed in the NAM booklet *Anti-HIV Drugs*.

Looking to the future

There have been huge improvements in HIV treatment over the last ten years or so. Compared to many older anti-HIV drugs, the ones used most widely today are more powerful, cause fewer side-effects and are easier to take. Currently available HIV treatment is highly effective for most people.

Research into HIV treatment is continuing, and this could mean that drugs will become available in the near future that don't have to be taken as frequently as the ones in use today or that require lower levels of adherence.

You can keep up with the latest developments in HIV treatment by regularly visiting NAM's websites, www.aidsmap.com and www.namlife.org, or by signing up to the e-bulletin, *HIV Weekly*. If you're personally affected by HIV, you can get a free subscription to NAM's treatments newsletter, *HIV Treatment Update*. See the end of this booklet to find out how to get these resources.

16 Some things that might help you to take your treatment properly

Simple forgetfulness is a common reason for missing doses of anti-HIV drugs. If you do forget to take your medication don't be too hard on yourself, but do try to learn from the experience about what it was that caused you to forget. If you are missing doses regularly, then discuss this with your doctor. It may be possible to make your schedule easier, or to change to a more suitable combination. Where this is not an option, talking through your concerns with your healthcare team may provide you with the support you need to manage your treatment better.

Practice

Some people have found that taking practice doses of sweets or multivitamins

for a few weeks in the same quantities, and at the same time, as you will have to take your anti-HIV drugs regimen and taking account of any dietary or other restrictions, helps them to adhere to their actual regimen when they start it.

Keeping a diary

Confusion over which pills to take when, and what times to eat or avoid food, may be a problem when starting a new combination. To avoid this, your doctor or pharmacist can provide a written daily schedule with your prescription, which you can tick off after taking your dose. Some pharmacists offer stickers for medication containers, which have the same function.

Pill boxes

Partitioned containers that you fill once a week or every few days with the individual daily doses are available. With some versions you can take out a single day's dose, or several if you may be away for some time. Your HIV pharmacist should be able to provide one of these boxes free. Make sure that the box you're getting is big enough and that you have checked with your pharmacist that all your drugs are suitable for storing out of their original container. Some pills deteriorate if not kept correctly. The bottle that *Truvada* comes in, for instance, contains a small capsule that keeps the tablets dry.

Alarms

Setting an alarm on your mobile phone or watch can serve as a useful reminder to take your pills.

Storing spares

Keeping spare doses of pills in your bag, jacket pocket, at work or college, at a friend's or in the glove compartment of your car can mean that you have a dose available if you forget to take your pills or are unexpectedly away from home.

Overcoming food restrictions

If you need to take your HIV treatment on an empty stomach, try taking your pills just before you go to bed. It's normally necessary

to have a two-hour gap between eating and taking your medication, to take your pills on an empty stomach. You should then wait at least 30 minutes before eating again.

If you have to take your HIV treatment with food, it's useful to know that it's usually not necessary to eat a full meal. A bar of chocolate or a bowl of cereal is often sufficient.

Holidays and going out

Think about how going away for a break or on holiday could impact on your adherence. This could include the effect of travel on the times you take your medication, particularly if you are travelling a long way involving a changed time zone. You should try and

ensure that you take your medication at the same intervals. Make sure that you take enough medication with you, as securing more supplies might be impossible. You should also travel with your medication in your hand luggage as this is less likely to get lost and means that your medication is close at hand should you need to take any during your journey.

If you are flying or travelling across borders consider getting a letter from your doctor giving the name and doses of the medications you are taking and explaining that you need to have the medication with you at all times. This will help ensure that you are allowed to carry the medication in your hand luggage (in case the airline is imposing any restrictions on

what can be carried) and it may help you with customs officials should you be stopped. This letter doesn't have to mention HIV.

Some countries, most notably the USA (although this may soon change), impose entry restrictions on people with HIV. There is some evidence that a small number of people travelling to the US take a break from their HIV treatment because they are worried about their medicine being found in their luggage at customs and their entry to the US denied.

Talk to your doctor before taking any break from your HIV treatment. Breaking your routine may also have an impact on

adherence as you may be away from prompts that helped you remember to take your medication. Think about what these might be and how to overcome them.

Taking your medication away from home may mean that there is an increased chance that you will have to take it with people who do not know about your health, or who you do not want to know about it. Plan in advance how you might manage this. Simple things such as having a bottle of water by your bed might give you the privacy you need to take your medication.

If you are going out for the night and think that there is a chance that you may not go home before your next medication dose or

doses, then take enough medication with you to cover that period. Be aware that door staff may not be able to recognise prescription medication and some people have been asked what their anti-HIV drugs are or have had them taken away when trying to get into some clubs. Also if you are going out and are planning to drink alcohol or take drugs which might affect your memory, then try to plan in advance how you might overcome this. This could involve setting an alarm on your watch or telling a friend to remind you when it is time to take your medication.

If you are concerned about possible interactions between your HIV medication and recreational drugs then speak to your

doctor or another member of your healthcare team. They should be able to offer advice on safely minimising interactions. Do not skip doses.

If you are having ongoing difficulties taking your medication, or are worried, ask for help immediately. Staff at your HIV clinic are there to help, and there are other sources of support (see page 7).

As has already been mentioned, one of the possible consequences of not taking your HIV treatment properly is that your HIV will develop resistance to anti-HIV drugs. This section of the booklet provides information on how resistance can develop; how to reduce the risk of resistance; cross-resistance; resistance tests; and the transmission of resistant virus.

How does resistance develop?

HIV reproduces very quickly, making billions of new viruses every day. Because the virus often makes mistakes when copying itself, each new generation differs slightly from the one before. These tiny differences are called mutations.

Some mutations occur in the parts of HIV which are targeted by anti-HIV drugs. This can

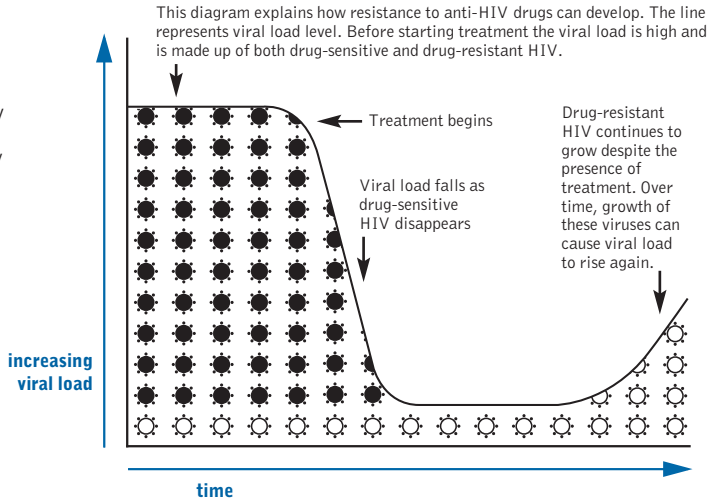
result in strains of HIV developing that are less easily controlled by the drugs. These HIV strains are called drug-resistant.

Drug-resistant HIV strains vary – some may be highly resistant to anti-HIV drugs while others may be less so. When an anti-HIV drug is started, HIV that is fully susceptible to that drug disappears rapidly and drug-resistant viruses remain. If the HIV replication is not fully suppressed, these resistant viruses can continue to reproduce themselves despite the drug's presence. The diagram on page 22 shows how this works.

Resistance is an important reason why HIV treatment can fail. Viral load, which should drop when you start a new drug combination, will increase again if drug-resistant HIV is able to emerge.

Key to symbols

- ☉ drug-resistant HIV
- drug-sensitive HIV



Take your HIV treatment

Taking your HIV treatment in the correct doses, at the right time, observing any food restrictions and avoiding interactions will reduce the risk of resistance developing.

Take the right anti-HIV drugs

Before you start HIV treatment for the first time, or change treatment because your viral load is detectable, you should have a resistance test. There's more information on these tests later.

The results of a resistance test will help you and your doctor to choose the combination of drugs that is likely to be most effective against your HIV.

Be honest

It's important to be honest with yourself and your doctor about the way you live your life. If it's probable or likely that you won't take your HIV treatment properly, then it's important that your doctor knows this. This will allow your doctor to prescribe a combination of anti-HIV drugs that has a lower risk of resistance. For example, HIV treatment that is based on a boosted protease inhibitor has a lower risk of resistance than treatment that is based on an NNRTI.

An undetectable viral load

The aim of HIV treatment is an undetectable viral load. If you have an undetectable viral load, your HIV cannot

become resistant to the anti-HIV drugs that you are taking. However, resistance can develop if your viral load becomes detectable and you continue to take anti-HIV drugs. You can find out more about viral load in NAM's booklet, *CD4, Viral Load & Other Tests*.

Changing treatment

If your viral load is still detectable six months after starting HIV treatment, or falls to undetectable levels and then becomes detectable again in two consecutive tests, you should change HIV treatment.

Changing HIV treatment promptly can reduce the risk of drug resistance.

But before you change treatment, you should have a resistance test to help select the most effective combination of anti-HIV drugs. If you are changing HIV treatment because of resistance, it's very likely that you will need to start a new combination of drugs.

Some important new anti-HIV drugs have become available for people who have drug-resistant HIV. The NNRTI etravirine (*Intence*) can work well in most people with resistance to the other NNRTIs. Another important drug is the boosted protease inhibitor darunavir (*Prezista*).

Important new classes of anti-HIV drugs have been developed. These include the integrase inhibitor raltegravir (*Isentress*), the CCR5

inhibitor maraviroc (*Celsentri*) and the fusion inhibitor T-20 (enfuvirtide, *Fuzeon*).

For more information on these drugs and your treatment options if you have drug-resistant virus, see the NAM booklets, *Anti-HIV Drugs* and *HIV Therapy*.

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Once resistance to one anti-HIV drug has developed, this may mean that your HIV is also resistant to other, similar anti-HIV drugs you haven't yet taken. This is called cross-resistance.

Cross-resistance can affect all the currently available anti-HIV drugs to some extent. However, cross-resistance isn't inevitable if you develop resistance to one drug, and the use of resistance tests will help you and your HIV doctor select the anti-HIV drugs that are likely to be most effective against your virus if resistance does develop.

Blood tests are available which detect whether the HIV in your body is resistant to anti-HIV drugs.

It's recommended that drug resistance tests are used when a person is first diagnosed with HIV in case they have been infected by a virus which is already resistant to one or more drugs. It is also recommended that everybody who is about to start HIV treatment for the first time should have a resistance test. You should also have a resistance test whenever you are changing treatment because your viral load is detectable.

Resistance tests are also recommended to help guide the choice of treatment in women who are pregnant, and in children.

Results should be interpreted by someone who is experienced in their use. Test results should be considered alongside a full treatment history, rather than in isolation. This is because drug resistance is not the only reason why HIV treatment can fail – missed doses, poor absorption and drug interactions are other possible causes to consider.

Resistance tests can now be done if your viral load is above 200 – it used to be the case that you had to wait until your viral load was 1000 or more before they could produce accurate results.

Resistance tests will also be more accurate if done while you are still taking a failing

combination rather than after you've stopped it. Once you stop taking a drug, the sensitive viruses start to grow rapidly as they are usually more 'fit' than the resistant viruses. The test may give the wrong answer as it may not be possible to detect the smaller number of resistant viruses.

There are two main methods of testing for HIV drug resistance:

- **Genotypic** tests which look for specific mutations in HIV's genes that are known to be linked with resistance to anti-HIV drugs.

- **Phenotypic** tests which measure the concentration of a drug required to reduce viral replication by a set amount. When resistance to a drug begins to develop, higher levels of that drug will be required to stop HIV growing.

There is no clear indication that one type of test is more useful than another at the moment – each has its pros and cons.

A significant proportion of people contract HIV that is already resistant to one or more anti-HIV drugs. This can happen either through sexual transmission, through contact with infected blood (e.g. through injecting drugs), or from an HIV-positive mother to her baby.

Becoming infected with a drug-resistant strain may limit your treatment options in the same way as developing resistance while taking treatments does, narrowing down the range of drugs you might benefit from.

In the UK, about 10% of people newly infected with HIV have drug-resistant virus.

If you have a detectable viral load and drug-resistant virus, then there's a risk that you could pass on a drug-resistant strain of HIV to someone else. Properly used condoms are a very good way of preventing sexual transmission of HIV.

It is becoming clear that somebody who is already HIV-positive can be infected with another strain of HIV that could be drug-resistant. This is called superinfection. It is not known how common this is, but so far it appears to be rare, and only 40 or so cases from around the world have been recorded. However, this figure is increasing as new cases are reported. If you would like to discuss any concerns you may have about this, such as

how it might affect the sex you have, a health adviser or health trainer at your HIV clinic or another member of your healthcare team should be able to help. You can also read more about superinfection in the NAM booklet in this series, *HIV & Sex*.

- Adherence means taking your pills in the prescribed doses at the right time, in the right amount and in the right way.
- Missing doses or not taking doses correctly can lead to your HIV becoming drug resistant. This will cause your treatment to fail and limit the drugs you can take in the future.
- A high level of adherence is needed for your HIV treatment to work effectively and you should aim to take every dose.
- Everyone taking HIV treatment should be offered support and advice with adherence.
- You might find adherence easier to manage if you feel ready to start treatment, and if your treatment fits in with your lifestyle.
- Keeping a diary, using a pill box, or using an alarm might help you to adhere.

- Resistance is an important reason why HIV treatment stops working.
- Developing resistance is less likely if your viral load is undetectable and you take your HIV treatment correctly. The more you miss doses, the more likely it will be that your drug combination will fail.
- Some people contract a strain of HIV which is already drug resistant.
- Resistance tests will be used to help choose the best drug combination for you.

adherence Taking a treatment exactly as prescribed.

antiretroviral A substance that acts against retroviruses, such as HIV.

CD4 A molecule on the surface of some cells, onto which HIV can bind. The CD4 cell count roughly reflects the state of the immune system.

cross-resistance When HIV that is resistant to one drug is also resistant to other, similar drugs.

genotype The genetic make-up of an organism.

mutation A single change in the gene sequence.

phenotype Trait or behaviour that results from a particular genotype.

resistance A drug-resistant HIV strain is one which is less susceptible to the effects of one or more anti-HIV drugs.

resistance test Blood test which detects resistance to anti-HIV drugs.

side-effect An unwanted secondary effect of a treatment.

superinfection If someone already has HIV, and they are then infected with HIV again, possibly with a different strain, or subtype.

viral load Measurement of the amount of virus in a sample. HIV viral load indicates the extent to which HIV is reproducing in the body.

34 Questions for my doctor

My treatment

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You could write down the drugs you're on and when you have to take them.

Notes



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HIV Treatment Update

NAM's monthly newsletter keeps you up to date with the latest news and developments about HIV, to help you talk to your doctor, and make decisions about your health and treatment.



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- Please do not send me information about NAM's full range of publications on HIV and AIDS
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NAM is unable to provide free subscriptions to *HTU* to professionals or organisations - please contact us for prices

Please complete this form and send to NAM, FREEPOST LON17995 London, SW9 6BR

Under the terms of the Data Protection Act you may advise us at any time if you do not wish to receive further mailings from NAM

What did you think of this booklet?

NAM wants to make sure this booklet is useful to you. We would be grateful if you could take a minute to provide us with some valuable feedback. The questionnaire is anonymous and confidential.

As a result of reading this resource have you learnt anything about HIV, your health and treatment?

- I have learned nothing new
- I have learnt something but it's not particularly useful to me
- I have learnt something that is useful to me
- I have learnt something that seems vitally important to me

Please tell us in your own words what you have learnt:

.....

.....

.....

As a result of reading this resource I am more likely to:
(tick all that apply)

- Discuss my treatment and care with my healthcare team
- Feel more confident talking to my healthcare team
- Feel better equipped to take decisions regarding my treatment and care
- Feel more informed about HIV treatment and living well with HIV
- Find other information and support, if I need it
- None of the above

Please tell us if there is anything else you are more likely to do or feel as a result of reading this booklet:

.....

.....

.....

Please tear off this page and post it to: NAM, FREEPOST LON17995 London, SW9 6BR. Alternatively you can complete the questionnaire at www.aidsmap.com/feedback, where you can also try our HIV treatment and health knowledge quiz, which will help ensure you have all the information you need to get the best out of your health care or treatment.

We would like to ask you a few more questions. You don't have to answer these, but if you do, it will help us make sure our information is relevant and useful to our readers.

Please circle the description that best describes you

- I am: male / female / transgender
- I live: in London / in the UK but outside London / outside the UK (please specify)
- My ethnic background is: White / Black-Caribbean / Black-African / Black – other /
Indian or Pakistani or Bangladeshi / other Asian or oriental / other or mixed
- My HIV status is: unknown / negative / positive
- (If positive) I think I got HIV as a result of: sex between men / sex between men and women / injecting drugs /
from blood or blood products / mother-to-child transmission /
other / don't know / rather not say
- I work: in the HIV field / not in the HIV field / I do not work at the moment
- I got this booklet from: nurse / doctor / clinic / THT's HIV Health Support Service /
support group / friend / family member / NAM /
other (please specify)

**Thank you very much for taking the time to fill in this questionnaire.
NAM really values your feedback. It helps make the information we provide better.**

If you have any other comments on the content of this booklet please email info@nam.org.uk

HIV helplines

THT Direct

from the Terrence Higgins Trust

telephone 0845 1221 200

opening hours Monday-Friday, 10am-10pm
Saturday & Sunday, 12pm-6pm

African AIDS Helpline

telephone 0800 0967 500

opening hours Monday-Friday, 10am-6pm

HIV i-Base Treatment Phonenumber

telephone 0808 800 6013

opening hours Monday-Wednesday, 12pm-4pm

NAM information series for HIV-positive people

The booklet series includes: ■ anti-hiv drugs ■ CD4, viral load & other tests ■ clinical trials
■ hiv & children ■ hiv & hepatitis ■ hiv & mental health ■ hiv & sex ■ hiv & stigma
■ hiv & women ■ hiv therapy ■ hiv & tb ■ nutrition ■ side-effects

More from NAM

NAM Information Forums

Free meetings offering an opportunity to hear the latest news, views and research around HIV treatments. Held in the evening at a central London location. **Call NAM for details.**

HIV Health Support Service

NAM supports THT in providing one-to-one and group skills sessions on health and treatments to people living with HIV in London. **Call THT Direct for details.**



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Call NAM on
020 7840 0050.

Donate to NAM

Every year NAM provides information resources, like this booklet, to thousands of people living with HIV, completely free of charge. To do this we really do rely on the generosity of people like you to help us continue our vital work. You can make a difference today.

Please make a donation by visiting
www.aidsmap.com/donate
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