infovihtal #1 Spring 2001

Recently diagnosed

Recently diagnosed?

Taking an HIV test and learning that you are HIVpositive can be a daunting, shattering experience. Though it may be hard to think in such terms at the time of testing, knowledge of a positive test result may extend your life.

You now have the opportunity to take advantage of regular medical monitoring and the many medical advances that have occurred recently. Whilst your HIV infection goes undiagnosed, the virus nevertheless continues to damage your immune system. For many people, this has led to serious illness which may have been avoidable.

Day one

Most testing services offer pre- and post test counselling. If, however, you feel like you need ongoing support, ask at your clinic where such help is available. Support comes in many forms: telephone helplines like 93 302 04 11 and 93 441 29 97, will be able to provide you with a list of organisations that provide help. Many of the HIV centres around the country offer one-to-one counselling free of charge.

Making decisions

The time of diagnosis is probably a difficult time for you to be making important decisions about the future. This may involve anything from starting anti-HIV treatments to disclosing your status to close friends or family. Few people need to begin HIV treatment at this point - though people who are diagnosed very soon after infection may be in a special position regarding this question. Instead it is more likely that you will begin regular monitoring of your health to give you a better understanding about how your body is coping with HIV.

Medical care

Finding a clinic that meets your needs and a doctor with whom you feel comfortable is vital. You are under no obligation to continue your care at the centre where you took your HIV test. Also, you are entitled to access care from any HIV centre in the country, not just the one in the area where you live.

Some people prefer larger centres, while others prefer smaller more informal clinics. It's generally agreed, though, that being cared for by a doctor who is experienced in managing HIV disease is very important.

Once you have chosen a clinic, you'll probably be asked to attend every three months for a check-up. At these appointments you'll be able to discuss your health with your doctor and take monitoring tests called CD4 and viral load tests. These are used to predict your risk of developing illness in the future, and to help you think about when to start anti-HIV drugs.

If you begin treatment, or if your HIV disease is more advanced, or if you join a clinical trial, you may visit your clinic more often.

Learning about HIV

At first, you are likely to come across medical terms you are unfamiliar with. Don't worry - there are lots of good sources of information which you may pursue at your own pace.

Learning about HIV will help you to take control of your health and to ask your doctor more relevant questions. It's important to watch for outdated information, and to seek advice from a range of sources: doctors, nurses, pharmacists, HIV services. Always ask for written information if you are left with questions. The internet can be a very useful information source. If you are unsure where to begin, or are worried about the quality of the information that you may find there, begin with www.gtt-vih.org from gTt.

Disclosure

Take time to decide who to tell about your HIV diagnosis, and why; and plan how you are going to tell them. What kind of support do you want from them? Can you anticipate their best or worst reaction? Begin with those around you who are most likely to be supportive, and consider waiting to tell anyone, e.g. an employer, whose reaction may not be helpful.

Meeting people

Meeting other HIV-positive people can be a remarkably supportive experience. If there's an HIV centre locally, it may have a support group aimed at people who are newly diagnosed. Here you'll meet people with a range of experiences, who are likely to have faced similar issues to you in coming to terms with their diagnosis.

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infovihtal #2 Spring 2001

Immune system cells

Immune system cells

The human immune system protects the body against foreign objects, such as micro-organisms. It is made of many different cells that are spread throughout the body, each playing different roles and moving about the body as needed.

Blood cells

There are two major types of cells in the blood. The most common are red blood cells or erythrocytes, which carry oxygen to the body tissues, and carry away carbon dioxide. The other group are white blood cells, or leukocytes. These are the immune cells.

Some white blood cells recognise specific foreign organisms to which the body has been exposed in the past. These specific immune cells are called lymphocytes. Other white blood cells are non-specific and can attack a range of different foreign organisms: these include neutrophils, eosinophils and natural killer cells.

Lymphocytes

There are two different types of lymphocytes. B-lymphocytes (sometimes just called B-cells) produce antibodies. An antibody is a protein that can lock onto a distinctive part of a specific foreign organism. When this happens, the antibody signals to other immune cells to attack the organism.

T-lymphocytes (sometimes just called T-cells) are called different names depending on the molecules on their surface. CD4 cells (also known as CD4 T-lymphocytes, or T-helper cells) play a coordinating role in the immune system. They help B-lymphocytes identify foreign organisms (which they produce antibodies against). They also secrete substances that enable CD8 cells to reproduce.

CD4 cells also activate macrophages (see below) to kill certain organisms, including many causes of AIDS diseases. When CD4 cells are destroyed by HIV, all these parts of the immune system are disrupted CD8 cells (also known as CD8 T-lymphocytes or cytotoxic T-cells) attach themselves to abnormal body cells, notably cells that have been infected by viruses, and kill them.

Other immune cells

Natural killer cells (or NK cells) attack tumour cells and virus-infected cells in a similar way to lymphocytes. But while each lymphocyte can only recognise and attack cells infected by one specific virus, natural killer cells can attack a wider range.

Eosinophils attack organisms that are too big to be eaten by a single phagocyte, like worms.

The phagocytes are cells that attack and destroy foreign cells by engulfing them. There are two main different types of phagocytes:

❍ Macrophages roam the blood and the body tissues, killing organisms that can cause AIDS-related diseases and cells infected by viruses.

❍ Neutrophils leave the blood to go to tissues where infection or inflammation is developing. They mainly attack bacteria and fungi.

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infovihtal #3 Spring 2001 Anti-HIV Therapy

Anti-HIV therapy

Anti-HIV therapy is treatment with drugs that attack HIV itself. These drugs interfere with the way the virus tries to reproduce itself inside a human cell. Although anti-HIV drugs cannot kill the virus completely, they reduce the chance of infected cells producing new HIV particles which could go on to infect even more cells.

The anti-HIV drugs that are currently available fall into two main categories:

- reverse transcriptase inhibitors
- protease inhibitors

In the past, doctors prescribed anti-HIV drugs one at a time (monotherapy). It has since been found that drugs are more effective when three or more are taken at the same time. This is called combination therapy or HAART (Highly Active Antiretroviral Therapy). It is unclear which of all the possible combinations is the most effective.

It is also uncertain when the best time to begin taking anti-HIV drugs is, although most doctors in Spain would recommend that you consider starting if you develop HIV-related symptoms or if your CD4 count is either below 350 or is falling rapidly, or your viral load is high.

HAART combinations usually include two nucleoside analogues and one other drug. Some people take four or more drugs, particularly people with advanced HIV disease, high viral load, or those who have taken several combinations before.

Reverse transcriptase inhibitors

Once HIV has locked onto and invaded a human cell, it uses a substance called reverse transcriptase (RT) to convert its genetic code into the same form as the genetic code of human cells (DNA). This viral DNA then merges with the human DNA, converting the cell into a factory for making the building blocks of new virus.

There are two different classes of anti-HIV drug that target RT. The earliest anti-HIV drugs to be developed – AZT (zidovudine, Retrovir), ddI (didanosine, Videx), 3TC (lamivudine,Epivir), d4T (stavudine, Zerit), abacavir (Ziagen) and ddC (zalcitabine, Hivid) and– all belong to the nucleoside analogue class.

The other class is non-nucleoside reverse transcriptase inhibitors (NNRTIs). Like the nucleoside analogues, they also attack RT, but in a different way. Several NNRTIs are in current use, including nevirapine (Viramune), efavirenz (Sustiva) and delavirdine (Rescriptor).

Protease inhibitors

Protease is a different HIV enzyme. After HIV has successfully merged its DNA with the human cell's DNA, the cell produces a string of protein. Protease cuts this protein string into smaller proteins that can be used to construct new HIV particles. By blocking protease, protease inhibitors help to prevent an infected cell from producing new infectious virus particles.

The protease inhibitors which are currently available are indinavir (Crixivan), ritonavir (Norvir), nelfinavir (Viracept) and saquinavir (Invirase, Fortovase). Amprenavir (Agenerase) and (lopinavir) are newer protease inhibitors which are not licensed in the UK at present.

Other treatment options

Several other types of treatment are also being studied, including adefovir and tenofovir (nucleotide analogues), hydroxyurea (a ribonucleotide inhibitor), T20 (a fusion inhibitor), and a number of immune therapies such as interkeukin-2 and remune aim to encourage an immune response against HIV.

Side-effects

Like all medicines, anti-HIV drugs can cause side-effects. Different drugs cause different side-effects. Make sure your doctor explains what side-effects you may expect from any drugs you decide to take, including mild ones that may wear off, and serious ones that you should report to your doctor straight away.

Resistance

Resistance can develop whenever HIV continues to reproduce whilst anti-HIV drugs are being taken, but can be delayed by taking drugs in powerful combinations which suppress viral load to very low levels. HIV that is resistant to one anti-HIV drug is likely still to be susceptible to some of the other anti-HIV drugs.

The risk of developing resistance may increase if you fail to take your anti-HIV drugs regularly at the recommended dose and times of day, or to follow any food restrictions. This means that you should only start anti-HIV therapy if you are firmly committed to continuing to take it.

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Adherence Tips

Adherence tips

Simple forgetfulness is a common reason for missing doses of anti-HIV drugs, and this can cause them to fail. If you do forget to take your medication don't be too hard on yourself, but do try to learn from the experience. If you are missing doses consistently, then discuss this with your doctor. It may be possible to make your schedule easier, or change to a more suitable combination.

Keeping a diary

Confusion over which pills to take, when, and when food can be eaten or is to be avoided, 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.

Jogging your memory

If the problem seems to be about needing a reminder, then you might find a timer or alarmed watch useful. There are some with programmable alarms and they are available at several high street retailers.

The alarms are stored in memory so the watch does not have to be reset every day and an eight letter message can be set to scroll across the watch face with an audible alarm. Computer scheduling programmes can also be adapted for this purpose.

You can also get hold of a pillbox with a timer. Useful if you have one set of pills that has to be taken every twelve hours and another every eight hours.

Storing & transporting pills

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 properly kept. The bottle that indinavir (Crixivan) comes in, for instance, contains small canisters that keep the capsules dry and stop them from leaking. You could also use a film canister.

Some people keep doses in the different places that they could be at when pill-taking time comes around, e.g. friend's house, handbag, car. Make sure you store medication safely out of the reach of children, and remember that extreme temperatures can damage most medications.

Overcoming difficulties

For some people, taking the pills can be a problem depending on their size, shape and texture. Always mention problems to your HIV pharmacist. There may be another preparation of the medication available, e.g. a liquid or powder that you might find easier to take than a pill.

Using a pill crusher can make some pills easier to take. These are available from your HIV pharmacist who will advise you if it is suitable for the drugs you are taking. Pill crushers look like small jars - put the pills inside and then screw on the top. This crushes the pills inside the container.

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Drug checklist

This sheet is designed to help you keep a note of the drugs you are currently taking. Use it to record any treatment you take, whether it has been prescribed by your doctor, or you have bought it yourself. By showing it to your HIV pharmacist or doctor every time you visit your treatment centre, you can help to avoid drug interactions which may be harmful.

Anti-HIV drugs

Tick any of the following anti-HIV drugs which you are currently taking:

Combivir (lamivudine + zidovudine)		**Retrovir** (zidovudine, AZT)	
Crixivan (indinavir)		**Sustiva** (efavirenz)	
Epivir (lamivudine, 3TC)		**Videx** (didanosine, ddI)	
Fortovase (saquinavir soft gel)		**Viracept** (nelfinavir)	
Hivid (zalcitabine, ddC)		**Viramune** (nevirapine)	
Invirase (saquinavir hard gel)		**Zerit** (stavudine, d4T)	
Norvir (ritonavir)		**Ziagen** (abacavir)	

Other regularly prescribed medication

List any other treatments that you are taking on a regular basis, e.g. Septrin, Viagra, oral contraceptives:

Name of drug	How often taken	How many taken

Over-the-counter medication

List any treatments you are taking which you buy without a prescription:

Name of drug	How often taken	How many taken

Vitamins, minerals, herbs & supplements

List any of these types of therapies you are taking, e.g. anabolic steroids, carnitine:

Name of drug	How often taken	How many taken

Miscellaneous

List any other drug or therapy you have taken recently.
You may also choose to make a note of any recreational drugs you have taken. You could keep this information secret by using a codeword which only you and your pharmacist know:

Warning: Do not take St John's Wort (hypericin) if you are also taking anti-HIV drug.

Name of drug	How often taken	How many taken

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