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POSITIVE LIVING



DISCRIMINATION
EXPERIENCED BY
PEOPLE LIVING
WITH HIV AND AIDS



GOOD PRACTICE AND
PHONE LISTENING

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POSITIVE LIVING

A COLLECTIVE REPORT FROM EUROPEAN
HELPLINES 2001 – 2004

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FOREWORD

ENAH is the European Network of AIDS Helplines and includes nine European countries as full members and ten associate members. ENAH's main objective, since its creation in 1999, is to examine AIDS helpline services in Europe, and to compare their experiences and to improve the quality of the services provided to the callers.

The network members formed three working groups to consider the important and recurrent themes that confronted the member organisations. The first group has developed a guide of best practice, the second group has analysed the calls received by people living with HIV/AIDS (PHA) and the third group has examined the discrimination experienced by PHA.

INTRODUCTION

This report examines the impact of HIV/AIDS helplines on the lives of HIV positive people and explores the full interactions between the service and the callers based on the experience of the organisations that constitute ENAH. It presents the full dynamics of the function of HIV helplines in the lives of HIV positive people. The report, using collective experiences, is intended as a reference to help to understand the issues facing people living with HIV/AIDS (PHA) in Europe.

The telephone has been proven to be an invaluable prevention and counselling tool. The helplines' success has been their ability to construct a safe, anonymous and confidential information and counselling service for the general public and for PHA. The efficiency, professionalism and ability of helplines' to deliver neutral information and non-directional counselling at the moment it is needed has engendered confidence in these services.

The Gay Men's Health Crisis, in response to AIDS established the first HIV/AIDS helpline in New York in 1982. This encouraged the subsequent development of helplines in Europe. With the development of combination antiretroviral therapy for HIV and the scientific and technical advances, the questions from PHA are constantly changing. The service provided by the helplines has had

to adapt their training policies as well as their recruitment criteria to remain a constant and up-to-date resource for PWLHA.

The report deals with the wide range of questions facing PWLHA in Europe today. What this report shows is that despite the advances in the field of medical treatments, or what has been called the "medicalisation" of AIDS; those questions related to psychosocial, sexual and economic problems are still an urgent priority. Helplines provide information and support (specifically through the telephone) based on the respect of the individual's rights and treating each caller uniquely. In that sense, the telephone strengthens the empowerment process of PHA. For these reasons, and because helplines have the historical legitimacy, this report reinforces the demand for a more aggressive response to tackle the obstacles still facing PHA in the European Union. The helplines bear direct witness to PHA's ever-changing experiences. This report gives accounts of the lives of HIV positive callers living in Europe and of the impact of AIDS on all aspects of their lives.

The report's analysis is based on excerpts from actual calls received by the member organisations from PHA. It focuses on two main areas: social issues including psychosocial, sexual and economic problems, and health issues.

PSYCHO-SOCIAL ISSUES

After testing HIV positive no two people will ever be confronted with the same set of issues. Their age, sex, geographic location, disease, stage in the disease process, support networks, economic position and point in career path will influence the decision model they choose. What becomes crucial is the need for a resource base to acquire the knowledge necessary for informed decision making.

This report examines the perceived and actual issues experienced by people affected by HIV/AIDS based on extracts from callers to the European helplines of ENAH.

CRISIS INTERVENTION

The social issues encountered by people affected by HIV/AIDS include:

- fears based on lack of personal knowledge about HIV/AIDS
- perceived exclusion from risk of infection (post HAART)
- false perceptions about HIV/AIDS

FEARS BASED ON LACK OF PERSONAL KNOWLEDGE ABOUT HIV/AIDS

The discovery of an HIV positive diagnosis may be perceived by some as a "death sentence" based on out-of-date information. The perception of imminent death is reinforced by the character of the irreversibility of the diagnosis and manifests itself not by a direct question but rather in the form of cries for help.

"I need to talk to somebody... I don't know what to do... I had many projects, things that I wanted to do, but now everything is over, I've got AIDS and I am going to die!"
Man, 36yrs

"Before HIV, I did not think about being a mother, but now I am positive, I can not stop thinking about it."
Woman, 27yrs

The fear of death is evidently more realistic when people discover their HIV status after a test taken in the suspicion of AIDS. This is normally expressed in the form of last wishes.

"I know that I am going to die... before I die I would like to go to the beach one last time"
Man, 32y

"I want to die at home, not at the hospital..."
Man, 45yrs

A positive test is a turning point in the life of the person. In many instances, there is a before and after.

"I've just received a positive test result, I want to know how much time I have?"
Man, 33yrs

PERCEIVED EXCLUSION FROM
RISK OF INFECTION

There is a perception among the younger generation (15-28 years) that HIV/AIDS is treatable (post HAART) and another generation's problem. Also the sense of invulnerability of the younger generation excludes them from being infected with HIV.

"Is AIDS infection still a problem I thought that now there are treatments for it?"
Man, 23yrs

"I saw a new drug on the TV last night and they said that with this AIDS had converted to a chronic illness?"
Woman, 32yrs

"When will the new AIDS vaccine become available?"
Man, 27 yrs

FALSE PERCEPTIONS

Correction of these false perceptions and the allaying of fear are possible through the helplines with clear and precise information and factual education about the life cycle of HIV disease in the light of current therapies. Explaining the implications of a positive test result and demystifying confusing or technical language. This assists the caller towards relevant structures and/or organised groups (where they exist).

"I am HIV positive but have an undetectable viral load. Does this mean I won't infect others?"
Man, 31yrs

"I get confused with my doctor, he talks about PCP, CD4 and viral loads and I don't understand him. Can you explain?"
Woman, 46yrs

TESTING POSITIVE

Getting a positive test result will be received differently by different people; however it is still a traumatic event. People may feel isolated and unable to communicate with their immediate social group. The interventional opportunity by helplines here is obvious. They can provide support, counselling and possible referral to other relevant professional social or medical resources.

"I am so shocked with the result of my test I can't even talk to my doctor, sorry to bother you with my problems."
Man, 25yrs

The psychological issues including anxiety, stress, depression, fear, amongst others, to be confronted by an HIV positive person may seem insurmountable. The helpline may allow these people to begin to come to terms with these issues, or offer a period of calm to help organise their feelings about their test result. In certain cases the psychological problems may need to be referred for appropriate professional help.

"I don't know how I got infected and now I don't know who to turn to."
Woman, 27yrs

"I can't cope with this on my own any longer; I think I am going mad."
Man, 41yrs

TELLING OTHERS

People's first affirmation of their HIV status is often to a helpline. The reasons for this are that the helpline is accessible, anonymous, non-judgemental and confidential.

accessible
not geographically dependent

anonymity
excludes the need to disclose the caller's or the listener's identity

non-judgemental
judgements are not made regarding the issues or social situation proffered by the caller

confidential
protecting the dialogue of the call from disclosure to a third party

When the person has disclosed their status to a helpline they often feel more confident to consider the possibility of disclosure to others because they have been informed of the risks and potential damage and/or benefits of telling someone else. This enables them to evaluate the best time; the most suitable person; the method; the environment and what information they need to disclose at this time.

"I have been HIV positive for 3 years and now I am starting a new relationship should I tell my partner?"
Man, 33yrs

"In all my relationships I have told my partner of my now 11 year infection, and they have all failed. Is the answer not to tell? It's so difficult not doing so."
Woman, 31yrs

In certain circumstances people do not have any suitable person to tell other than the helpline or they have disclosed their status to an unsuitable person increasing their isolation.

note
Self-discrimination and discrimination by others is considered in the report on discrimination by the third work group, (see relevant report).

"I told my new boyfriend of my HIV status and never saw him again. The same thing always happens, I feel so lonely I don't think I will meet anyone."
Man, 40 yrs

"I can't confess to anyone I am so scared of being outcast and misunderstood."
Woman, 39yrs

"At work they already hate me for being gay, if they find out about my HIV I will surely be fired."
Man, 34yrs

ACCIDENTAL DISCLOSURE

The fear of third party disclosure through careless management of medical records; simple indiscretion though social contacts; through family and friends may lead to further stress and distress. Thus creating difficulties and distrust in choosing whom to confide in with this sensitive information.

"Can the company I work for ask for an HIV test during my annual medical revision?"
Man, 36yrs

"Do company medicals include an HIV test?"
Woman, 21yrs

DEVELOPING SOCIAL STRATEGIES

Being HIV positive affects one's personal and professional relationships including a person's relationship and perception of themselves. The HIV positive person remains invisible within society while they remain healthy. This delays the need to disclose their status within their social circle. Without the proximity of HIV organisations, HIV positive people, HIV awareness campaigns, medical care and in the absence of HIV defining illnesses the onus of self-affirmation might be less relevant and avoidable. This could engender feelings of denial about one's HIV status.

"Until I became ill I never thought my HIV status and thought it would just go away."
Woman, 37yrs

A declared HIV positive diagnosis can precipitate or expose other social perceptions about sexuality or drug use that may or may not be correct. Implications beyond the simple fact of being HIV positive are an added burden to contend with. In some cases to publicise one's status implies a revelation about behavioural habits and lifestyle(s).

"I always believed AIDS was for prostitutes, homos

and junkies, now I am infected people think the same of me."
Woman, 33yrs

"I can't tell my parents I am gay how I can tell them I have AIDS."
Man, 26yrs

"HIV has brought out my homosexuality and drug habits to others I feel outcast by society."
Man, 34yrs

This responsibility while onerous may have the benefit of encouraging the acceptance of one's HIV status and sexual orientation. Conversely it may prove too oppressive when discovering one's HIV status to accept either situation. Developing a coping mechanism to negotiate these new situations can be given direction by helpline counselling and appropriate referral to other resources (when available). A number of urban European centres have well established centres for PHAs with general and specific needs with regard to sexuality, drug use, migrant groups, pregnancy or psychological difficulties.

"The only good thing about HIV is that it has made me be honest about my lifestyle to those I want to know."
Man, 23yrs

"Is there any specific gay group for HIV positive people in the area I live?"
Man, 24yrs

HIV may be seen as an inevitable event for some callers whose peer group has a higher percentage of HIV positive members who have conventionally been considered a risk group e.g. the gay community, intra venous drug users or sex workers. These groups through experience have the benefit of a greater understanding of the issues involved with HIV infection and have the ability to inform PHA on how to live well with HIV.

"It was difficult for me to tell my parents but they took my news as an almost logical result of my being an ex-drug user."
Man, 28yrs

Unfortunately while an HIV diagnosis may reinforce people's self identity and their identity within certain groups that they previously felt marginalized from, it can also further isolate and marginalize people where HIV is an unusual event within that peer group. This situation if then publicised may highlight deeper problems previously unconsidered. These considerations can call into question their own behaviour or their relation-

ships with their partners or the behaviour of those partners, including issues of fidelity or drug use that seem to be far removed from their normal range of experience. They may have no resources, support or accesses to information to allow them to start to come to terms with these new circumstances that continue developing and requiring management. Usually people respond to these abnormal situations by denial or by hoping they go away and not having to consider the implications. When people contact a helpline this indicates that they have begun the initial phase of acknowledgement.

"I feel more betrayed by my husband because of HIV than for his infidelity. Can you recommend somewhere I can get professional help?"
Woman, 53yrs

Negotiating changes in behaviour ensuring that people with HIV remain well and preventing the transmission of HIV involves becoming aware of a range of prevention techniques for the transmission of HIV and other sexually transmitted infections. A number of callers will have established their own guidelines for protected behaviour these may need reinforcement and confirmation and at times correction.

"My cousin and family are coming to stay with me do I need to take any special care so as not to infect any of them for example, in the shower or WC or with towels or cutlery?"
Man, 31 yrs

"I have a cat and want to know is if he scratches me and then scratches a friend could he or she become infected by my HIV?"
Woman, 24yrs

Prevention techniques have been updated in some countries since the emergence of HIV, because the original prevention messages were unrealistic and impractical. These techniques are multifaceted and require precise and accurate information that is available to (most) the helplines in Europe.

"The condom broke during sex, and although there was no ejaculation is there a risk of infection?"
Woman, 33yrs

"I hate using a condom all the time. Is there any other prevention technique my wife could use?"
Man, 39 yrs

"Where can I buy flavoured condoms?"
Man, 23yrs

The use of Post exposure prophylaxis (PEP) as a preventive measure in serodifferent couples varies in different countries. There are a number of controversial issues in the use of PEP. **PEP guidelines – see appendix.**

The social and legal policies regarding certain vulnerable groups vary in European countries. These national policies will affect people's reaction and management of their HIV status. Where there are more liberal and relaxed attitudes and supportive social policies towards marginalized groups it maybe easier for these people to come to terms with their HIV status and to improve their self-esteem. Where these attitudes differ there could be additional hurdles to be negotiated beyond the difficulties of simply managing HIV infection. The sharing of ideas within the member groups of ENAH has allowed less liberal member groups to realise the shortcomings within their own countries.

CRIMINALIZATION

EU members have adopted different policies regarding the criminalization of the transmission of HIV infection. This fear of legal redress is helping to drive HIV underground to a position where its transmission will thrive. Criminalization of transmission encourages people not to get tested for HIV to allow them not to have to reveal something that they simply do not know.

"I lost my husband a few years ago I was infected by a person who knew his status. A man I did not know. Just a one time encounter. Is there any legal recourse against this person?"

Woman, 43 yrs

"For two months I lived with a guy who hid his status from me. He did not talk about it I did not know. When I got HIV he left me, since then I am receiving anonymous phone calls, my bike has been broken. We talked once since but he told me that it was all my fault. He was taking his medication in secret he has not been honest with me in all that time. I cannot be around him anymore. He scares me. I hold him responsible for my seropositivity. I don't trust anyone anymore. I want to get my dignity back."

Man, 24 yrs

"I was negative before I met her. I had sex when I was drunk, the condom broke. I know this is how I got infected. She told everyone in her family that I passed the virus onto her now they all gang up on me. They drive by in a car and threaten me. Now I am on an antidepressant, my Mum has advised me to move out of town. To live in a big city. I feel awful."

Man, 31 yrs

Most countries have a large number of organisations involved with people affected by HIV/AIDS a helpline can assist these callers by orientating them through existing groups and organisations. Callers can also be encouraged to network with other positive people to share information and to become proactive to implement change.

Positive networking in Ireland

Poz Ireland formed in response to the need for information by people affected by HIV/AIDS. Poz Ireland began in 1995 from an Internet discussion group called GayPoz. This group networked people who had similar problems with treatment issues, side effects, access to treatments and other social issues. Poz Ireland began publishing an annual Treatment Directory in 1996. It also helps PHA who have similar treatment issues to network with each other in Ireland.

MIGRANTS

A number of migrant groups have great difficulty being accepted within their own community when they are HIV positive. These people face triple discrimination from within their own community group, from the general society because of their status and again as being seen as an extra burden on the health care system.

"I know I am HIV positive since 1998 - I never told my wife. I cannot because in my country, Haiti, no one drinks from a glass used by a HIV + person. I fear to be rejected. I use condoms with my wife - most of the time - I am taking treatment in secret. It's very difficult to manage. There is so much prejudice against HIV+ people in my country."

Man, 35 yrs

"I saw on TV two weeks ago that there are new treatments available. My brother who lives in the Ivory Coast told me that he's HIV+. Can I buy these medications in the pharmacy? Can I buy them and send them?"

Man, 31 yrs

"I was diagnosed HIV+ a month ago, the physician did not prescribe a treatment. Is it normal?"

Woman, 26 yrs

When a migrant group becomes aware of one of their member's HIV status sometimes they might ostracise that member. The personal strategy adopted by these people to remain part of their peer group is to be secretive or silent about their HIV status. This brings about further psychological problems for that person and affects their attitude to starting or adhering to antiretroviral treatment. This sense of isolation is not always alleviated by the helpline because the caller might not fully trust the confidentiality of the call.

A number of migrant callers enquire about the possibility of acquiring anti-HIV medications to allow them to send the medications back to their countries of origin. These requests further highlight the inequitable position regarding the accessibility and availability of anti-HIV treatments in the developing countries.

SEXUALITY

Testing positive can infer changes to one's sexual behaviour, if one chooses to adopt protected sexual practices. People's reactions to sexual practices can range from completely distancing themselves from any sexual contact to increasing their sexual contacts well beyond their normal levels which may include unprotected behaviour. The former behaviour can result from a feeling of loss of desirability and a fear of infecting others. The latter behaviour can be a life affirming reaction to their diagnosis, or self-loathing. These extreme behaviours after a time tend towards a period of adjustment reliant on the appreciation of the person's own balanced attitude towards their sexuality. These reactions can depend on the mode of infection. Some people often feel betrayed or angry after being infected with HIV.

"Because I am under treatments, I have experienced important sexual problems. I have almost no libido at this point and have difficulty in getting a hard-on. I have tremendous problems in my relationship because of that. I wonder if other people experience the same type of difficulty. Is it psychological or physiological?"
Man, 37yrs

"I am in love with a guy I met in a sauna. I am positive and I don't know how to tell him, I fear losing him. Maybe he is positive too because he fucked me without a condom, I don't want to lose this guy now but at the same time I am afraid to have infected him during our first encounter."
Man, 33 yrs

RELATIONSHIPS

"I have decided to commit suicide. I have been seropositive for a long time now - I lost my son, he was 16 ½ - I cannot go on living like this; I almost take pleasure in the idea to be with him after I die"
Woman, 39 yrs

"I was married for seven years when I discovered I was HIV+ - my wife is OK - I am very grateful that I did not infect her, but she has left me now and she wants a divorce."
Man, 41 yrs

"I cannot bear loneliness any more. My daughter does not understand what I am going through, my divorce is going through a very bad stage."
Man, 45 yrs

"My son doesn't want to see me anymore, no financial means, no social life, no more friends. Nothing. I have so much pain that I have to wear a morphine patch. I am totally lost."
Man, 52 yrs

Forming relationships can be very threatening for people with HIV. Fear of rejection keeps many people from talking about their HIV status. Every situation is different and

everybody doesn't need to be told about one's HIV status when safe sex practices are been used, and neither person is at risk of infection. However as any relationship develops it is difficult to keep this information outside that relationship. The longer ones HIV status is excluded from a relationship the more difficult it is to introduce it into the relationship.

Sooner or later in a relationship, some callers feel the need to talk about their HIV status.

"I am positive since 1998. Every time I talked about my seropositivity to the men I met they all run away. I have just met someone and I have no desire to tell him anything. What can I do to avoid putting him in a risky situation?"
Woman, 38 yrs

The responsibility for not transmitting HIV in a serodifferent relationship lies overwhelmingly with the seropositive person.

"My boyfriend is negative and we have unprotected sex from time to time. He is the top. He says he is fine

with it and that it is less risky. I wonder if it is really true? Personally, I am not comfortable with his decision, I would feel awful if I know that I am responsible for his infection."
Man, 28yrs

Not only does the seropositive person have to control their own sexual behaviour but the other partner's sexual behaviour in some cases to prevent the transmission of HIV.

"This morning during sex the condom tore and my boyfriend went to get PEP. I do not understand why the condom tore. Never happened before. I always put it on myself. I am taking Combivir and Ziagen, I think I am not really contagious, I am scared though I feel responsible for him."
Woman, 28yrs

The reduction or loss of sexual intimacy can create a feeling of a need to share a partner's experience from the seronegative partner's perspective causing an aspiration or indifference for that partner to become HIV positive.

(RELATIONSHIPS) ■

"I know that I am positive since 25 days. My partner knows it too. But I am terrified he will leave me eventually. When I talked to him the first time he told me he would stay with me no matter what! I do not easily trust people in general, do you think he will leave me anyhow? Can I go on not taking treatments? I am scared, is it normal?"
 Woman, 26yrs

This can result in the dissolution of relationships of serodiscordant couples with the seropositive person expressing a need to form intimate relationships with seropositive people exclusively. The establishment of seropositive relationships could solve the overshadowing and nonnegotiable presence of HIV within a relationship.

"I am exclusively looking for guys who are seropositive like me. It's easier... I do not use condoms any more and I do not have any moral question to ask myself afterwards."
 Man, 24 yrs

"I had a seronegative boyfriend for 2 years and he left me. He could not see a future for our relationship....I

have met someone he is also seropositive the relationship is totally different with him, every aspect of our relationship is easier to manage."
 Man, 36 yrs

PREGNANCY AND
 CHILDBIRTH

A woman learning about being HIV positive when she is pregnant brings about issues of managing the pregnancy, the diagnosis and dealing with treatments for HIV and treatments to prevent transmission of HIV to her child.

*What will happen if the child is HIV positive?
 What treatments are available for the child?*

"I have discovered my seropositivity in 1986, I was pregnant for four months. The doctor told me that I was going to deliver a child who would be dead in two years. I had a therapeutic abortion."
 Woman, 43 yrs

Serodiscordant couples who desire to have children

These couples once they have a shared desire and a willingness to have children, they are concerned with the techniques necessary to avoid transmission: 'sperm washing', treatment for mother to child transmission, surrogacy, adoption, in vitro fertilisation. Callers have raised concerns about the significance of their viral load and its implications in conception.

In the process of decision-making about conception they use a number of advice sources including family and friends. They may face rejection and a lack of support from

family and friends causing them to continue with their decision without this support and in that situation seeking out information and support from a HIV/AIDS helpline.

"I am in love with a man who is HIV positive. What can I do and not do with him? Up to now we had no sex. It is the question of death that scares me. What about having children? Can he live long enough to be a father?"
 Woman, 32 yrs

"My husband is seronegative, I collect his sperm in a condom and afterwards I inject it, with a syringe... I want a child from him, but I would not bear the responsibility to get him infected."
 Woman, 34 yrs

"I am seropositive, I want to adopt a child can it work? Is it legal? I cannot have children with my husband, it is a tragedy for both of us."
 Woman, 38 yrs

"We have just received a negative response from the hospital for the IVF because of the sperm, they need 20 million and I have only 13 million. We are very disappointed. I have a very good CD4 count - 800. My doctor does not understand the refusal either. Are there any others IVF services?"
 Man, 41 yrs

SEXUAL DYSFUNCTION

Sexual dysfunction includes reduced sex drive (a loss of interest in sex) and physical difficulties (such as loss of erection or difficulty reaching orgasm). Sexual dysfunction has been linked to HIV treatments. Under reporting is likely because many people find it difficult to talk about this aspect of their lives.

*" I have suffered impotency for the last two or three months and my doctor prescribed Viagra. Getting an erection now is not a problem but I don't reach a climax easily. Is this dangerous? A friend told me that not ejaculating could cause prostate cancer. This is also very frustrating for me and my boyfriend and the more I worry about it the more it happens."
Man, 43 yrs*

A recent study in over 900 HIV-positive people using combination therapy (80% men, 20% women) found that 38% men and 29% of women reported a decrease in sexual interest. 29% men reported a decrease in sexual potency.

CHILDREN

With the success of the treatments for the prevention of mother to child transmission of HIV the challenges of parents of HIV positive children are to overcome isolation and establishing networks. In regard to education there may be difficulty with classmates and teachers who are not aware of HIV issues.

*"One of big concern was the school environment of my kid... it took us a lot of courage and determination before we agreed to send her to school... everything was so gloomy."
Woman, 49 yrs*

HEALTH ISSUES

Testing positive for HIV means that one is infected with the virus that causes AIDS. There is no cure for HIV infection but there are many treatments that help to keep the disease under control. Without treatment HIV can weaken the immune system allowing the possibility of 'opportunistic infections' (OIs). These OIs are caused by common germs that normally do not cause infection when the immune system is healthy. The first medication for HIV was approved in 1987. Today there are more than 20 drugs that help to slow down the HIV virus. Most people with HIV disease live healthy for many years.

THE TREATMENT DILEMMA

Deciding whether or when to start treatment for HIV is a very tough choice. Then deciding which combination of drugs that is suitable, because not all drugs are not created equal in their side effects or dosing requirements, is another very difficult choice. It is very important to remember that HIV treatment is forever, a lifetime commitment that must be approached carefully.

'My doctor wants me to start on combination treatment immediately – but I have just found out I am HIV positive. I am not ready.'
Man, 28 yrs

'The hospital explained about the four drugs in the combination. But I cannot remember the details. And I don't know how they must be taken.'
Man, 36 yrs

'If I start treatment now, will I live longer?'
Woman, 39 yrs

COMBINAISON THERAPY*

Combination therapy consists of three or more drugs to treat HIV; it is also called HAART (Highly Active Anti-Retroviral Therapy). HAART has now been used for over six years with many of the individual drugs been studied for even longer. Where combination therapy is used AIDS-related deaths and illnesses have reduced dramatically. Combination treatment works for women, men and children by helping to reduce the virus in the body allowing the immune system to recover and get stronger by itself.

The length of time that any combination works depends on the development of resistance to the drugs used. When the viral load stays undetectable, the same combination may be used for many years.

At some point, most HIV-positive people will need treatment. When people will need it though, can vary a lot. HIV infection progresses in different people at very different rates. About one third of HIV-positive people will stay well for up to 10 years after infection, even without treatment. About 60% will start treatment after 4-5 years. 2-3% of people can become ill more quickly and need treatment much earlier. 2-3% can go for 15-20 years without treatment.

*See appendix – Anti-HIV drug

STARTING TREATMENT

When to start treatment is something that must be discussed with a doctor who has good experience with HIV/AIDS. It is important that people are allowed to take time to think about what they want to do and do not feel rushed or pressurised into doing something they don't understand. The helpline can help people negotiate a good relationship with their doctor or treatment provider to tell them about the different drugs that can be used and the advantages and disadvantages about each of them. The development of a good doctor/patient partnership is one of the most important elements of HIV treatment.

'There are so many drugs - what is the best combination to start with.'
Man, 31 yrs

'I feel fine why should I take tablets that may make me feel sick.'
Man, 28 yrs

'Nobody knows I am positive except my doctor. How will I be able to take all these tablets without people knowing there is something wrong?'
Man, 41yrs

Doctors, nurses and pharmacists are usually excellent sources of support and advice on all aspects of HIV treatment (including adherence and side effects). PHA and those involved in their care have certain rights and responsibilities. People should have different choices for treatment explained to them including the risks and benefits of each option. They should be included in all decisions about their treatment and care and have the right to choose whether to take part in research trials. PHA should have the right to have a second opinion about their care and to be able to change their doctor or treatment centre. These rights can be limited in certain countries due to limited resources or because of people's geographical location e.g. people in urban centres may have easier access to and more choices for their treatment centres.

'My doctor said it was my own fault that I was positive.'
Man, 24 yrs

'No one knows I am gay or HIV positive except my doctor.'
Woman, 37 yrs

'I am really OK most of the time but I have a lot of small problems. I feel sick and

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have diarrhea and I am always tired. The doctor says it's nothing to worry about but it's been over three months since this started.'
Man, 38 yrs

Callers can be advised on which treatment centres are convenient to them and what questions they should discuss with their doctor.

'I live in a small town and I cannot go to my local doctor. He knows me and my family but I don't think he knows a lot about HIV.'
Man, 25 yrs

If people do not understand any aspects of their treatment they should ask their doctor to explain it again or in a different way. Some people may be reluctant to be honest with those caring for them about their sexuality or about any other drugs that they are taking, including legal and illegal drugs or complementary treatment.

AGEING AND HIV

Ageing itself suppresses the immune systems. People over 50 have an increased risk of damage caused by HIV. However combination treatment may increase the risk of heart disease. Although the benefits of HIV treatment far outweigh the additional risks of heart disease for most people, this may not be true for everyone. The additional risks that HIV treatment may generate, means that an assessment of cardiovascular and HIV risk factors should be made before starting HIV treatment.

EARLY DIAGNOSIS AND PRIMARY INFECTION

Early treatment is usually not recommended as it limits people's choices of drugs with the development of resistance and is largely only provided in clinical trials.

LATE HIV DIAGNOSIS AND LOW CD4S

Some people, across all age ranges, only find out they are HIV-positive when they become ill and admitted to hospital. This often means starting treatment straight away, and having to contend with adherence issues and side effects.

Almost everyone considering HIV treatment worries about side effects. Most people find that taking treatment becomes an ordinary and manageable part of their life, while others find it difficult to include the routine required of the treatment into their daily lives. Also most side effects of treatment are usually mild and can often be reduced with over the counter medication that is easy to use.

'I have developed this rash that's driving me crazy. It keeps me awake at night, the only relief I can get is with antihistamines and painkillers – but they make me feel exhausted.'
Man, 28 yrs

'Every time I take my tablets – I begin to feel nauseous and that puts me off eating. But I am supposed to take food with these tablets.'
Woman, 31 yrs

'I need to go to the loo (toilet) about 10 times a day. I am afraid to go out anywhere because I feel I need to be near a loo.'
Man, 32 yrs

'I haven't had any problems or side effects with the drugs I am taking – will I?'
Man, 26 yrs

However some side effects can be serious and debilitating and these need more specialised treatment and careful monitoring. A number of callers underestimate the side effects they experience that may affect their quality of life. These people are encouraged to see their treatment providers and to carefully list the side effects they are experiencing however minor they may seem.

'Every time I inject T20 it leaves a lump and a red swollen area. Sometimes I get a large bruise. Because I have very little body fat – I find it difficult to find a place to give myself the injections without it being very sore.'
Man, 59 yrs

PHA are encouraged to ask their doctor, nurse or HIV pharmacist about the most common side effects of the drugs that they are using and how likely they are to occur.

Nausea, diarrhoea and tiredness are the most common general side effects. These often become easier after the first few weeks of treatment.

'I am tired of feeling tired. My doctor says I should exercise but I simply don't have

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the energy. I do rest a lot but it's not helping.'
Man, 41 yrs

'It's very hard to keep working – because I always am so exhausted.'
Man, 33 yrs

There are simple effective treatments for nausea and diarrhoea that should alleviate the symptoms but if these medications aren't effective, people should ask their treatment providers for stronger or more effective drugs.

LIPODYSTROPHY

Lipodystrophy refers to changes in blood fat and blood sugar levels. It also includes changes in fat cells and the distribution of body fat.

It is a set of side effects that is a worry for many people who are about to start treatment. The most severe cases of lipodystrophy are in people who have used many different drugs, or have used treatment for many years. The greater awareness of lipodystrophy today means that people are usually carefully monitored. Changing treatment is an option with low-level symptoms. New drugs for use in first-line therapy, which are less likely to cause these side effects, will hopefully reduce the incidence of lipodystrophy.

Different drugs may be responsible for fat gain and fat loss. Fat accumulation, to the stomach or breasts and/or across the shoulders, has been more linked to protease inhibitors and NNRTIs. Fat loss, from arms, legs, face and buttocks, has been linked to nucleosides. This is mainly to d4T, and to a lesser extent to AZT.

'My belly is really getting big – I look ridiculous

– I have this large belly and skinny legs and no arse.'
Man, 48 yrs

The causes of lipodystrophy are not known. Lipodystrophy usually, but not always, develops slowly over many months. Symptoms may reverse if people switch to different HIV drugs. As with HIV-negative people, the proper diet, exercise and stopping smoking help reduce the impact of lipodystrophy.

FACIAL WASTING ■

Fat loss (lipoatrophy) from the face is common in people with HIV – especially after long-term treatment. This has been linked to nucleoside analogues as well as to protease inhibitors, although neither link has been proven. Several studies have reported benefits for some people from switching d4T (or AZT) to either abacavir or other combinations of drugs.

The action of both PIs and nucleosides together may increase the risk for lipoatrophy but lipodystrophy also been reported in HIV-positive people who have not used HIV drugs.

'I've two deep hollows in my face and I am tired of people making comments about how I look tired or asking am I OK.'
Man, 37 yrs

'I don't go out much any more because I find people's comments hard to take.'
Man, 41 yrs

'I can hide the fact that I have lost weight on my legs and backside but I can't hide what's happened to my face.'
Man, 43 yrs

'I know I should be thankful that I am still here with these wonderful treat-

ments but at what price.'
Man, 31 yrs

'Is 'New Fill' treatment available with my health insurance? What are the options for treating facial wasting?'
Man, 53 yrs

Facial lipoatrophy is not life threatening but helps to erode self-image and self-esteem. It causes an anxiety around HIV disclosure forced by facial appearance that can be demoralising and depressing. Discrimination against people with facial wasting may occur in some social groups who recognise this condition.

Many people contacting helplines with facial lipoatrophy have withdrawn socially because of the condition. They stop going out and reduce their social contact to friends who know about their condition. Some people have even given up work. Some people talk of knowing that "lipodystrophic look" and associate it with the beginning of the loss of friends or loved ones through an HIV-related condition.

Most people are desperate for some resolve from this obvious distress of looking at themselves and knowing that they have this condition. A lot

of people with facial wasting are physically fit and well, having successfully assimilated lifestyle and diet changes with complex drug regimes. Then the facial effects of lipodystrophy serve to act as the daily reminder of their status.

Several people have been offered anti-depressants to overcome this distress. Others have been offered counselling and therapy. All of these treatments cost health services money, and can only offer variable success rates. Practical treatments that provide visible results bring immediate quantifiable results in the well-being of sufferers.

Other side effects

Side effects that are more serious occur rarely with most combinations. They also relate to specific drugs. It is important to be aware of those associated with the drugs that are used before they starting treatment.

ALTERNATIVES ■

If a first combination is too difficult to follow, or if the side effects have not improved after the first few weeks, people can usually change the drug or drugs that they find most difficult.

'The combination I am taking is very difficult with the job I do, I have tried but it is almost impossible to take all the doses on time every time – is there another choice.'
Man, 34 yrs

'The first combination I took was absolutely no problem but this one makes me feel sick and tired all the time. I want to change to something else.'
Woman, 35 yrs

TREATMENT BREAKS ■

Treatment breaks have received a lot of attention. Other names include STIs, which stands for Structured (or Strategic) Treatment Interruptions.

Stopping treatment may help people who are resistant to the available drugs. This is when there are no other treatment options. In this situation a treatment break should be for a short period – perhaps only for two months. One recent study showed that a break of four months was worse than not taking a break.

'Just to have a couple of weeks without being tied down to the pill box would be great.'
Man, 43 yrs

'I am travelling to the U.S and I have heard there can be problems getting meds in. If I took a break from my meds for the length of the holiday – would that be possible?'
Man, 26 yrs

'I need to start a new combination as the one I am on is failing, but I would like to take some time out to give myself a rest before I start the next set of tablets.'
Woman, 44 yrs

DRUG TRIALS ■

Many hospitals are also research centres and you may be asked to join a trial. Trials are very important for developing new treatments. They can improve our knowledge of how to use both new and existing drugs.

'Everything I have tried has failed – but I have heard about T20 – which clinic is using this?'
Man, 39 yrs

'I have run out of options and want to find out what trial drugs are around.'
Man, 53 yrs

'The combination I am taking is no problems – but my doctor wants to change me to another combination.'
Woman, 33 yrs

However, if you are recently diagnosed, or are only just finding out about treatment, you should not feel pressurised into taking part.

SALVAGE THERAPY ■

Second, third or salvage combinations are one of the most difficult challenges facing people living with HIV/AIDS and their treatment providers. The first shot at combination treatment is the most important. Medical professionals who are well experienced in HIV medicine and who have developed a good partnership with their patients should develop this first combination.

TREATMENT FAILURE

RESISTANCE ■

Resistance is the ability of HIV to overcome the effects of a drug. Resistance has been seen with every anti-HIV drug. If someone shows resistance to a drug, it does not mean that every strain of HIV in the person's body is resistant, so there might still be some merit to taking the drug, especially if there are no other treatment options. Drugs are used in combination to discourage resistance. Resistance testing* is to measure resistance of HIV to anti-retroviral drugs. Resistance testing can aid in anti-retroviral drug selection but has certain limitations.

Preliminary studies are showing that the combination use of resistance testing with TDM are providing better treatment responses.

ADHERENCE PROBLEMS ■

Adherence can be difficult with combination treatment. Information about the full extent of the dosing requirements of each drug within a combination is essential along with support from treatment providers / treatment centres or a support group. Designing a strategy for near perfect adherence when taking a salvage combination can be as beneficial as having access to new drugs.

'I've just stopped taking all my drugs they were so much trouble – I haven't been able to tell my doctor yet.'
Woman, 43 yrs

'I take my tablets when I can. I know the timing isn't right but it suits me.'
Woman, 48 yrs

'I am going on holidays and need to know how to manage the time difference with my combination.'
Man, 31 yrs

'Half my suitcase is full of medication when I go anywhere for holidays.'
Man, 34 yrs

'I have been very ill recently and didn't take any of my usual meds is it Ok to start again?'
Man, 48 yrs

MDRT OR MEGA-HAART ■

'Thought I would never have problems taking tablets twice a day but I have forgotten to take my dose twice this week.'
 Man, 31 yrs

Side effects often lead to discontinuation of treatment. Side effects vary from a simple rash to serious liver problems. Although drugs are designed to work against HIV they sometimes interfere with other ways in which the body works. The current HIV drugs are far from perfect and some do cause side effects. Most side effects reduce and disappear with time.

One hope with treatment breaks or STIs (structured treatment interruptions) is to produce an 'autoinoculation' with one's own virus that would help to jog the immune system into recognising HIV as clearly as it did when first infected. Most recently STIs are promoted not as immune boosters but as breaks from drug side effects.

MDRT calls for as many antiretrovirals as a person can tolerate. Some studies have used as many as 9 drugs. Most people within these studies had run out of drug choices with multiple resistance to all drug classes and CD4 counts as low as 20 cells/mm³.

Safety and tolerability are concerns when dealing with MDRT and TDM (therapeutic drug monitoring) is an essential component to confirm levels of each PI and NNRTI with the ability to individualise doses.

NEW DRUGS

EXPERIENCE ■

For those who continue to experience a rising viral load with MDRT (Mega-HAART) the use of new drugs may provide their best hope. Some drugs in development hold great promise but will produce better results if they are supported by other effective drugs in a combination regimen. (BETA 2002). For people who have no other options and whose clinical health is at risk then any new drug may provide an important benefit; even if only in the short term. The Modest approach – sustaining the status quo. Another salvage option is to continue with the current combination, even with a rising viral load. This option has two risks: Side effects may persist or worsen and HIV continues to evolve maybe into a more resistant form. Studies (Deeks 2001) show that people are better to remain on a failing regimen as this may keep a person clinically and immunologically stable by partially controlling viral replication and giving a less fit resistant viral population or both.

Whatever the process, the value of a failing drug regimen may fade as HIV mutates further. Staying with a poor combination makes sense if the combination is tolerable and easy to take or if the virus remains susceptible to at least one drug that is held in reserve while waiting for newer more potent salvage drugs.

The most important factor in treatment is the experience of the treatment provider. Successful salvage treatments are often the result of good partnerships between informed patients and their HIV experienced treatment providers.

'My GP is great even though she knows very little about HIV she always asks my consultant if she feels out of her depth. She is great with other health problems.'
 Man, 32 yrs

'The clinic I go to has very few HIV positive patients and I have talked to other people who have been given more choices than I get. Is it possible to change clinics?'
 Man, 27 yrs

'I went to A&E recently with a problem and the doctor who saw me prescribed something that caused a problem with the meds I was taking. I did tell them that I was HIV positive and what medication I was on. It is impossible to get any proper medical help with emergencies outside of the clinic's opening times.'
 Woman, 31 yrs

'It's great to hear my doctor say he doesn't know

and then we work on things together, or he gets a second opinion. I know I am lucky because a friend of mine constantly asks her doctor for a second opinion and he keeps blocking her requests. I've told her to change her doctor.'
 Man, 37 yrs

SURVIVORS AND SURVIVING

Mainly because of HAART therapy, many HIV/AIDS sufferers have been or have classified themselves as people living with "chronic illness", in a similar situation to those suffering from any other long term disease. This obviously implies an acceptance of the infection, passing through all of the psycho-social and medical issues previously discussed in this report and coming to the decision to take advantage of the therapies available and concentrate more on quality of life issues.

These long-term sufferers however continue to use the helplines as an information service, mainly for legal guidance, human rights issues and to some extent immigration and travel information. The reason for this is again the confidentiality offered by a helpline service rather than to seek face to face advice from a lawyer, travel agent, consul or embassy worker etc...

"I would like to go to the U.S. for a holiday with my partner, can you tell me the situation with taking my medication with me and if I should let the immigration authorities know that I am HIV+?"
Man, 34 yrs

"I need to stay in Britain for over 3 months, can you tell me where I can get my medication, if the cost will be covered by the Spanish health service and what would the procedure be if I should fall ill?"
Woman, 37 yrs

Some of these long term patients also suffer unexpected bouts of non-HIV related illness or secondary effects that are new to them or the people around them and cause concern and anxiety that "real" illness is setting in and look to the helpline for advise and comfort. One of the main topics in this area is about dealing with lipodystrophy, not only from a medical point of view but as a personal perception and corporal image problem, affecting quality of life and often leading to psychological imbalance.

"Can you tell me about facial reconstruction and infill techniques and where can I get it done?"
Man, 52 yrs

"Can you recommend some guide that will help me care for my brother if he does become ill and need my help? Until now I had never thought about this but he has had 2 colds in such a short

time and it has frightened me a little".
Woman, 27 yrs

The length of time that a person has been living with HIV/AIDS is usually related to a greater understanding of the disease they are living with and questions from these long term patients are related to new treatments information, clinical trial access and STI. These are dealt with by helplines only on an information basis and it is always stressed that these questions should always be consulted to an appropriate medical professional.

"What are the requirements for patients to go onto compassionate use of T20"
Man, 48 yrs

"Can you tell me the drawbacks and advantages of structured therapy interruption and give me some orientation on when and with whom it is possible. I want to talk to my doctor about it but need some background information so I do not feel ignorant whilst speaking to him"
Woman, 34 yrs

CONCLUSION

Health and human rights are closely intertwined especially in the context of HIV/AIDS. While human rights may exist in European Union law, the need and ability to uphold these rights at a national level is often limited for PHA. Misconceptions and ignorance like HIV itself may be incurable but also like HIV can be treated. This must provide an incentive for political changes at a European and national level for improved human rights and increased public education campaigns to help eliminate HIV-related discrimination.

The general public and parliamentary European perception that HIV/AIDS has been 'sorted' is far removed from the real experiences and demands by PHA experienced by the helplines. It is now essential that the needs of PHA, as witnessed directly by the European helplines, are given full validation and credence within current and prospective health strategies and human rights issues in the European Union.

This charter has been elaborated from the experiences of the AIDS Helplines composing the network. The European Network of AIDS Helplines welcomes other European AIDS telephone services that share its principles and objectives.

I
Ethical principles

- The AIDS helplines offer non-judgemental, non directive and personally centred listening.
- They guarantee the anonymity of the caller and insure that any information taken remains confidential.
- They promote the caller's self-esteem and also respect his/her personal beliefs.

II
Their functions are as follows

- To broaden the knowledge level of the public at large and thereby to assist in the implementation of personal strategies of risk assessments.
- To provide accurate information, support and orientation on all aspects related to HIV and AIDS.
- To support those who are directly affected by HIV and AIDS.
- To break the taboos surrounding HIV and AIDS.
- To facilitate the access to comprehensive care and the common respect of social rights.

III
Objectives of the European Network of AIDS Helplines

- To improve the quality of services provided to the callers by the participating helplines.
- To create means and structures of information and expertise exchanges within the network.
- To promote actions of prevention for all populations as well as comprehensive care (medical, psycho-social) for people with HIV in the specific arena of AIDS helplines.
- To disperse accurate and current information to all members.
- To be an observer of the HIV epidemic for the European Union.
- To apply the know-how of AIDS helplines to other health issues: i.e. hepatitis, STIs.
- To be able to refer EU citizens to national or regional services of each member country.
- To strive to provide access for all EU citizens to accurate information.
- To improve collaboration between ENAH and other networks and organisations dealing with public health issues connected to HIV.
- Sharing experiences, information and training materials (Internet, library, journal...).

IV
Means of the European Network of AIDS Helplines

- Creating working groups and collaboration on specific issues.
- Organising regular meetings between the participating helplines.
- Encouraging the AIDS helplines to give the most accurate information.
- Reflecting on the elaboration of common ethical rules.
- Initiating common training sessions on particular topics.

**POST-EXPOSURE
PROPHYLAXIS (PEP)**

Post-exposure prophylaxis (PEP) is the use of antiviral drugs as soon as possible after exposure to HIV, to prevent HIV infection. PEP can reduce the rate of infection in health care workers exposed to HIV by 79%.

Workplace exposure

PEP has been standard procedure for healthcare workers exposed to HIV. Workers start taking medications within a few hours of exposure. Usually the exposure is from a "needle stick", when a health care worker accidentally gets jabbed with a needle containing HIV-infected blood. PEP reduced the rate of HIV infection from workplace exposures by 79%. However, some health care workers who take PEP still get HIV infection.

Other exposure

In the last few years, PEP has been used after HIV exposures that are not work-related. People can be exposed to HIV during unsafe sexual activity, when a condom breaks during sex, or if they share needles for injecting drugs. Infants can be exposed if they drink breast milk from an infected woman. In a study of PEP in cases of possible sexual exposure to HIV, not one person became infected with HIV.

For serious exposures, usually a combination of three approved antiviral drugs is taken for four weeks. For less serious exposure, treatment is with two drugs: AZT and 3TC.

PEP is a four-week program of two or three antiviral medications, several times a day. The medications have serious side effects that can make it difficult to finish the program. PEP is not 100% effective; it can not guarantee that exposure to HIV will not become a case of HIV infection.

ANTI HIV DRUGS TABLE

NAME	BRAND & OTHER NAMES	TOTAL DAILY PILLS	FOOD RESTRICTIONS
REVERSE TRANSCRIPTASE INHIBITORS (RTIS)			
d4t	zerit, stavudine	2	none
azt	retrovir, zidovudine	2	none
ddi 100mg	videx, didanosine	4	do not eat for 2 hours before and 1 hour after (2 hours after for ec)
ddi 200mg	'reduced mass' ddi formula	2	
ddi/ec	'enteric coated' formula	1	
3tc (150mg)	epivir, lamivudine	2	none
3tc (300mg)	epivir, lamivudine	1	none
abacavir	ziagen, 1592	2	none
combivir	{azt/3tc together}	2	none
trizivir	{azt/3tc/abacavir together}	2	none
tenofovir	viread	1	take with food
ftc *	emtracitabine	1	none
NON-NUCLEOSIDE REVERSE TRANSCRIPTASE INHIBITORS (NNRTIS)			
efavirenz	sustiva	1	not with high-fat meal
nevirapine	viramune	2	none
delavirdine *	rescriptor	12	none
DUAL & BOOSTED PROTEASE COMBINATIONS [the most used doses - individual monitoring (tdm) of drug levels is recommended]			
lopinavir/r	kaletra, abt-378/r	6	take with food
indinavir/ritonavir	400mg/400mg	10	none
	800mg/200mg	8	none
	800mg/100mg	6	none
saquinavir/ritonavir	400mg/400mg	12	food reduces side effects
saquinavir/ritonavir	1000mg/100mg	12	food reduces side effects
[invirase, hard gel formulation of saquinavir can be used instead of fortovase soft gel capsule when using ritonavir. invirase is a smaller pill with less side effects]			
fosamprenavir*/ritonavir	700mg/100mg	none	
atazanavir*/ritonavir	300mg/100mg	3	none
SINGLE PROTEASE INHIBITORS (PIS) [some pis are used without ritonavir boosting. this is not generally recommended.]			
indinavir	crivan	6	2 hours after food and 1 hour before
nelfinavir	viracept (film coated)	10	take with meal
atazanavir	reyataz	2	take with food
ENTRY INHIBITORS (fusion inhibitors)			
enfuvirtide	t-20, fuzeon	none	
OTHER DRUGS USED IN HIV TREATMENT			
interleukin-2 (il-2)	experimental immune treatment used with combination therapy to boost cd4 counts. il-2 is given by injection for five days every 2 months and heavy flu-like side effects are expected during each five-day course.		

This table is a reference for different names of drugs, dosing, total pill count and brief details of food restrictions. Alternative doses are required for some combinations. All combinations and doses should be discussed with an experienced treatment provider.

A

Acute HIV Infection: The 4-to-7-week period of rapid viral replication immediately following exposure. The number of virions produced during primary infection is similar to that produced during several subsequent years of established, asymptomatic infection. An estimated 30 to 60 percent of individuals with primary HIV infection develop an acute syndrome characterised by fever, malaise, lymphadenopathy, pharyngitis, headache, myalgia, and sometimes rash. Following primary infection, seroconversion and a broad HIV-1 specific immune response occur, usually within 30 to 50 days. It was previously thought that HIV was relatively dormant during this phase. However, it is now known that during the time of primary infection, high levels of plasma HIV RNA can be documented.

Adherence: The extent to which a patient takes his/her medications according to the prescribed schedule (also called "compliance"). Nonadherence may jeopardise the effectiveness of a drug and lead to drug resistance.

AIDS (Acquired Immunodeficiency Syndrome): A state of severe immune suppression brought about by infection with HIV. A diagnosis of AIDS is given to a person with HIV infection who experiences an AIDS-defining illness; the condition may be an opportunistic infection like CMV or cancers like lymphoma.

Allergic Reaction (immediate hypersensitivity): An immune response to an antigen (allergen) that does not normally cause an adverse reaction (e.g., animal dander, pollen). Allergic reactions are mediated by the release of histamine by mast cells. Allergic symptoms may include runny nose (rhinitis), sneezing, skin rash, asthma or anaphylactic shock.

Antiretrovirals: A class of drugs that inhibit retroviruses like HIV.

Antiviral: A substance or process that destroys a virus or suppresses its replication (i.e., reproduction).

AZT (Retrovir®, zidovudine, ZDV): The first drug licensed to treat HIV. Today it is almost always used in combination with other anti-HIV drugs. Side effects include nausea, vomiting, and low red or white blood cell counts. Also used to prevent transmission of HIV from mother to foetus.

B

Buffalo Hump: see "Lipodystrophy"

C

Cardiomyopathy: Chronic disorder affecting the muscle of the heart. The role HIV plays in heart disease is still not fully understood. Certain antiretroviral drugs may increase a person's risk of heart disease.

CD4 Cell: Also known as «T4» or «helper T cell,» the CD4 cell is the primary target of HIV. It performs critical functions such as signalling other parts of the immune system to respond to an infection. Treatment decisions are often based on CD4 count. Normal counts range from 500 to 1500.

Centre for Disease Control and Prevention (CDC): The top US body for epidemiology and prevention. The CDC has a responsibility within the USA of defining AIDS as well as other categories of HIV infection.

Cholesterol: A fatlike material present in the blood and most tissues. A raised level of cholesterol in the blood is associated with the build-up of fatty plaques on blood vessel walls.

Chronic: Refers to symptoms and diseases that last for an extended period of time without noticeable change.

Clinical Trial: An experimental study in people to test the safety and efficacy of new drugs.

Combination Therapy: Use of more than one drug to treat a disease or infection.

Combivir®: 300 mg AZT and 150 mg 3TC, available as tablet or liquid. See "AZT" and "3TC."

Compassionate Use: A method of providing experimental therapeutics (including experimental drugs)

prior to final approval for use in humans. This procedure is used with very sick individuals who have no other treatment options.

Compliance: The extent to which a patient takes medications according to the prescribed schedule; synonymous with «adherence.»

Confidentiality: The right inherent in the contract between the health-care provider and patient that ensures that information on the patient's medical conditions will be released to a third party only after explicit permission is obtained from the patient or guardian

Contraindication: A situation that prevents use of a certain medication (for instance, using two drugs that have the same toxicity).

Controlled Trial: A clinical study in which one group of participants receives the experimental drug while another group receives either a placebo or an approved standard therapy. When participants do not know which group they are in, the trial is blinded. When the researchers and clinicians are kept from knowing, then the trial is double-blinded.

Crixivan®: see «Indinavir.»

Cross-Resistance: This refers to the development of resistance by a viral strain that makes it less susceptible to other medications in the same class.

D

ddC (Hivid®, zalcitabine): A drug that inhibits an enzyme used by HIV called «reverse transcriptase.» Side effects include pancreatitis and peripheral neuropathy.

ddI (Videx®, didanosine): A drug that inhibits an enzyme used by HIV called «reverse transcriptase.» Side effects include pancreatitis, peripheral neuropathy, and diarrhoea.

Delavirdine (Rescriptor®): A drug that inhibits an enzyme used by HIV called «reverse transcriptase,» via a different mechanism than AZT and related drugs. Side effects include temporary skin rash.

d4T (stavudine, Zerit®): Approved nucleoside analogue anti-HIV drug. Side effects can include nerve damage in the hands and feet, stomach upset, pancreatitis and liver damage.

Diagnosis: The determination of the presence of a specific disease or infection usually accomplished by evaluating clinical symptoms and laboratory tests.

Diarrhoea: Abnormally high frequency and liquidity of faecal discharges.

Dose: The measured amount of a drug to be taken at one time.

Drug-Resistance: The ability of some disease-causing micro-organisms, such as bacteria, viruses, and mycoplasma, to adapt themselves, to grow, and to multiply even in the presence of drugs that usually kill them.

Drug-Drug Interaction: A modification of the effect of a drug when administered with another drug. The effect may be an increase or a decrease in the action of either substance, or it may be an adverse effect that is not normally associated with either drug.

E

Efavirenz (Sustiva®): A drug that inhibits an enzyme used by HIV called «reverse transcriptase,» via a different mechanism than AZT and related drugs. It is taken once a day. Notable side effects are CNS disturbances.

EMA: European Medicines Evaluation Agency, the European equivalent of the FDA. (See "FDA.")

Epidemiology: A discipline concerned with the determination of the specific causes or distribution of a disease or the interrelation between various factors determining a disease.

Epivir®: see «3TC.»

Expanded Access: A general term for methods of distributing experimental drugs to patients who are unable to participate in ongoing clinical efficacy trials and have no other treatment options. Specific types of expanded-access mechanisms include parallel track, treatment IND (Investigational New Drug), and compassionate use.

F

First-Line Treatment: The preferred therapy for a particular condition.

FDA (Food and Drug Administration): A US agency of the DHHS that regulates the testing of experimental drugs and approves medical products based on evidence of safety and efficacy.

Fortovase®: Soft gel capsule formulation of Saquinavir. See «Saquinavir.»

Fusion: An integral step in the process whereby HIV enters cells. Researchers have found that in addition to the primary receptor, the CD4 molecule, other cofactors, such as CC CKR5 and CXCR4, are needed in order for HIV to fuse with the membranes of the immune system cells.

Fusion Inhibitor: A drug that is designed to inhibit binding and entry of HIV to CD4 cells. T-20 is an example of a drug in this class because it can inhibit HIV's fusion with the human cell.

G

Gene: A unit of DNA that carries information for the biosynthesis of a specific product.

Genotypic Resistance Test (Genotype testing): The genetic material of HIV is examined for the presence of changes or mutations that are usually associated with resistance to specific drugs. This test is subject to several limitations.

H

HAART (Highly-Active Anti-Retroviral Therapy): Combination anti-HIV therapy, usually involving a protease inhibitor. Combinations of drugs have been found to be highly suppressive of HIV, and this strategy helps delay or avoid the development of treatment-resistant viral mutants.

Haemophilia: Hereditary blood disorder that prevents blood from clotting due to a deficiency of factor VIII, a blood coagulation factor.

HIV Disease: During the initial infection with HIV, when the virus comes in contact with the mucosal surface, and finds susceptible T cells (see T lymphocytes), the first site at which there is truly massive production of the virus in lymphoid tissue. This leads to a burst of massive viraemia with wide dissemination of the virus to lymphoid organs. The resulting immune response to suppress the virus is only partially successful and some virus escapes. Eventually, this results in high viral turnover that leads to destruction of the immune system. HIV disease is, therefore, characterised by a gradual deterioration of immune functions. During the course of infection, crucial immune cells, called CD4+ T cells, are disabled and killed, and their numbers progressively decline.

HIV-1 (Human Immunodeficiency Virus): The causative agent of AIDS. Infection with HIV does not mean that a person has AIDS; see «AIDS» for more information. It is the predominant virus causing AIDS in the U.S. and Europe.

HIV-2: Also a virus that causes AIDS, although it may be somewhat less potent than HIV-1. It is the predominant virus causing AIDS in Western Africa.

Hivid®: see «ddC.»

Hydroxyurea (Hydrea®): An antiviral drug that is a ribonucleotide reductase inhibitor. It is taken twice a

day in combination with other antiretrovirals. It is an anticancer drug.

I

Immune Restoration: A treatment strategy that states that, in addition to riding the body of HIV, it is also necessary to repair the immune system. Various methods are being tested.

Immune System: The network of white blood cells and the chemical products they produce to protect the body from foreign «invaders.» One major division is between the «cellular» portion, which involves T cells, and the «humoral» portion, which involves B cells that make antibodies. The two parts work hand-in-hand.

Immunocompetent: 1. Capable of developing an immune response. 2. Possessing a normal immune system.

Immunocompromised, Immunosuppressed: The state of having a damaged immune system and, therefore, increased susceptibility to illness.

Indication: The purpose for which a drug is prescribed. The indications appear on the packaging insert with a drug.

Indinavir (Crixivan®): A protease inhibitor that must be taken three times a day on an empty stomach to aid absorption. May cause kidney stones and increased triglyceride levels.

Informed Consent: The process by which a healthcare provider gives a patient information, including pros and cons, about a potential new treatment; when a person is entering a clinical trial, that person must sign a document with this information, thereby providing «informed consent.»

Intravenous (IV): Within a vein.

Invirase®: see «Saquinavir.»

J

Kaletra®: A capsule that contains a fixed formulation of two protease inhibitors – lopinavir (133.3 mg) and ritonavir (33.3 mg). Normal adult dosage is three capsules twice daily with food. Side effects include mild diarrhoea and raised triglycerides.

L

Lamivudine: see «3TC.»

Lipid: This is simply fat or a class of relatively large water-insoluble compounds found in nature.

Lipodystrophy: A disturbance of fat metabolism or fat distribution in the body. It is associated with antiretroviral treatment. There is a laying down of visceral fat and a loss of peripheral (arms, legs, face) fat.

Long-Term Non-Progression: This phrase came into vogue in the late 1980s, when it became clear that some people with HIV infection did not develop progressive disease. It is non-specific, and it includes people who have responded very well to treatment, people who have mounted an effective, long-term immunologic response to HIV, and people who have a weak, non-disease-producing strain of the virus. There is no strict definition, but it usually implies that an individual has had HIV infection for a decade or longer and is clinically well, with normal or near-normal CD4 counts.

Lopinavir: A protease inhibitor used in combination with ritonavir (see Kaletra). It is taken twice a day in combination with NNRTIs plus nucleoside analogues. Side effects include diarrhoea, nausea, fatigue and headache.

M

Maintenance Therapy: This refers to long-term (perhaps life-long) treatment of an infection, to make sure it does not come back. Usually, drug doses are lower than the levels used to treat an actual case of the infection. Examples of infections that require maintenance (or «suppressive») therapy include PCP, MAC, CMV, and TB.

Metabolic disorders: A collection of disorders in which some part of the body's internal chemistry is disrupted.

Monotherapy: Medical treatment consisting of a single drug administered alone. Not recommended for the treatment of HIV or AIDS.

Morbidity: The condition of being diseased or sick; also the incidence of disease or rate of sickness.

Mortality: Death; also death rate.

N

NARTI (Nucleoside Analogue Reverse Transcriptase Inhibitor): see «Nucleoside Analogue.»

Nausea: Feeling sick.

Nelfinavir (Viracept®): A protease inhibitor that is taken three times or twice daily, with food; approved for children and adults. Most common side effect is diarrhoea.

Neuropathy: Damage to the peripheral nerves; usually manifests as pain, tingling, or numbness in the feet or, more rarely, the hands. Drugs or HIV itself may cause neuropathy. Many treatments are used for this condition.

Nevirapine (Viramune®): A drug that inhibits an enzyme used by HIV called «reverse transcriptase.» Nevirapine belongs to a class of drugs called NNRTIs (see entry), and is taken twice daily. Side effects may include fever, rash, and increased liver enzymes.

NNRTI (Non-Nucleoside Reverse-Transcriptase Inhibitor): A class of drugs that inhibit an enzyme used by HIV called «reverse transcriptase.» NNRTIs work by a different mechanism than AZT and similar drugs, which also attack reverse transcriptase. NNRTIs are more specifically targeted to HIV than AZT, etc. However, resistance develops more quickly with these drugs; to discourage resistance, NNRTIs are always used in combination with other anti-HIV drugs.

Non-Nucleoside Reverse-Transcriptase Inhibitor: see «NNRTI.»

Norvir®: see «Ritonavir.»

Nucleoside Analogue: This is a class of drugs that fight HIV by interfering with the virus's ability to make a key enzyme called «reverse transcriptase.» AZT was the first nucleoside analogue licensed, and many others, such as ddI, ddC, d4T, and 3TC have followed it. These drugs act at the DNA level. They also affect normal cell growth, such as bone marrow cells, so there can be significant toxic effects.

Nucleotide analogues: Drugs based on nucleotides that are chemically altered to inhibit production or activity of disease causing proteins. Maybe more stable and active than nucleosides.

O

Opportunistic Infection (OI): Many organisms (viruses, bacteria, fungi, etc.) are held in check by the immune system. They often «colonise» the body (i.e. they are present but not noticed) without causing disease. When someone becomes immunocompromised for any reason (HIV infection, cancer, or treatment with immunosuppressive drugs, such as certain kinds of chemotherapy), some of these organisms take advantage of the «opportunity» by growing out of control and causing disease. Common OIs in patients with AIDS include PCP, CMV, MAC, and toxoplasmosis.

P

Paediatric: Of or pertaining to children. (12 years and younger)

Palliative: Offering relief of symptoms or comfort without ameliorating the underlying disease.

Perinatal transmission: Transmission of a pathogen, such as HIV, from mother to baby during or just before birth. Also known as vertical transmission.

Peripheral Neuropathy: Damage to nerves outside of the central nervous system; neuropathy commonly affects the feet, although the hands can be involved as well. Symptoms include tingling and pain in the extremities, as well as numbness. Usually, both sides are affected. Neuropathy can be caused by HIV itself, or by drugs such as ddC.

Phenotypic Resistance Testing: In this test HIV is grown in the presence of antiviral drugs. The extent of how well the virus grows is then a direct measurement of the degree of resistance of the HIV to the drug(s) being used in the test. It takes about 3 weeks before the results are reported.

Placebo: A «look-alike» dummy pill that does not contain drug; placebos are often used in clinical trials.

Prophylaxis: Preventive therapy; «primary prophylaxis» is given to at-risk individuals to prevent a first infection by, say, PCP; «secondary prophylaxis» is given to prevent recurrent infections.

Protease: An enzyme used by HIV to process new copies of virus after it has reproduced; drugs specifically aimed at this enzyme are called «protease inhibitors.» Human cells also use protease enzymes, but they are different from the HIV protease.

Protease Inhibitors: Antiviral drugs that act by inhibiting the virus protease enzyme, thereby preventing viral replication. Specifically, these drugs block the protease enzyme from breaking apart long strands of viral proteins to make the smaller, active HIV proteins that comprise the virion. If the larger HIV proteins are not broken apart, they cannot assemble themselves into new functional HIV particles.

Q

Quality of Life: Expression used in speaking of issues relating to normalising the life of a chronically ill individual. In defining quality of life, health care providers must consider not only the physical responses to medical therapy, but also the psychological implications of illness for both the patient and family. The overriding goal of care should be to relieve suffering and increase patient well-being.

R

Regimen: Refers to the specific doses and the specified times to take medications.

Remission: Time during which a disease is inactive.

Rescriptor®: see «Delavirdine.»

Resistance: Ability of an organism, such as HIV, to overcome the inhibitory effects of a drug, such as AZT or a protease inhibitor. Resistance has been seen with every anti-HIV drug. If someone has laboratory evidence of resistance to a drug, it does not mean that every strain of HIV in the person's body is resistant, so there might still be some merit to taking the drug, especially if there are no other treatment options. Drugs are used in combination to discourage resistance.

Retrovir®: see «AZT.»

Retrovirus: A type of virus (like HIV) that encodes its genes as RNA, rather than DNA. Human cells use DNA to encode their genetic information; for retroviruses to incorporate their genes into human genes, they must be able to convert RNA into DNA. The enzyme reverse transcriptase accomplishes this conversion.

Reverse Transcriptase: A retroviral enzyme that is capable of copying RNA into DNA, an essential step in the life cycle of HIV. AZT, ddI etc. work by inhibiting reverse transcriptase.

Ritonavir (Norvir®): A protease inhibitor that needs to be taken with food. It must be kept refrigerated. Ritonavir interacts with several drugs; so be sure the doctor who prescribes it knows everything you are taking. Main side effects are nausea and diarrhoea.

S

Safe Sex: In the context of HIV infection, sexual activity conducted in such a way that there is no risk of transmission or acquisition of the infection.

Safer Sex: Sexual activity conducted in such a way that transmission of HIV infection is minimised by reducing the exchange of body fluids (e.g., consistent use of condoms, avoiding unprotected vaginal and anal intercourse).

Salvage Therapy: A final therapy for people who are nonresponsive to or cannot tolerate other available treatments for a particular condition.

Saquinavir (Invirase® and Fortovase®): A protease inhibitor; the original form of saquinavir (Invirase®) is poorly absorbed, but Fortovase® delivers 300% more drug to the bloodstream. Both forms are often taken with ritonavir, which increases the amount of saquinavir that is absorbed.

Seroconversion: The point at which the immune starts to produce antibodies to HIV, the person is said to seroconvert because they now test positive for HIV antibodies. Usually seroconversion occurs within 3 weeks after becoming infected, but in rare cases may take up to 3 months.

Seropositive: Antibody Positive.

Serostatus: A generic term that refers to the presence/absence of antibodies in the blood. Often, the term refers to HIV antibodies.

Side Effect: Any unwanted effect of a drug or treatment (also called an «adverse event», see entry). Some side effects are minor; others can be life threatening.

Sildenafil (Viagra®): An impotence drug used to treat erectile dysfunction.

Sinusitis: An infection of the sinus cavities in the head, often bacterial.

Stavudine: see «d4T.»

STI / STD: Any sexually transmitted infection / disease, like gonorrhoea, syphilis, HIV, etc.

Sustiva®: see “Efavirenz.”

Symptoms: Any perceptible, subjective change in the body or its functions that indicates disease, as reported by the patient.

T

T Cells: (T Lymphocytes.) T cells are white blood cells, derived from the thymus gland, that participate in a variety of cell-mediated immune reactions. Three fundamentally different types of T cells are recognised: helper, killer (see killer T cells), and suppressor. They are the immune system’s «border police,» responsible for finding infected or cancerous cells. The killer T cell receptors (TCR) bind to an infected cell’s distress signal - a combination of one of the cell’s own proteins and a tiny fragment of the invader’s protein. The bits of foreign protein are made with the help of enzymes inside the invaded cell that chew up the pathogens into protein fragments (peptides), which are then scooped up by the major histocompatibility complex and carted through the cell membrane.

Tenofovir: A nucleoside analogue approved for treatment of HIV. It is taken once a day 300 mg.

3TC (lamivudine, Epivir®): An anti-HIV drug that is in the nucleoside Analogue class. Now available in a

formulation with AZT known as Combivir®, 3TC is well tolerated by most patients.

Toxicity: Undesirable side effects of a drug or treatment; can range from annoying to life threatening.

Treatment Naïve: Refers to people who have never taken a particular drug(s) before. Commonly refers to people who have not taken antiviral drugs.

Trizivir®: A combination of three nucleoside analogues – abacavir, 3TC (lamivudine) and AZT (zidovudine). See entries for ABV, 3TC and AZT.

V

Vertical Transmission: Transmission of HIV from mother to foetus.

Videx®: see «ddI.»

Viracept®: see «Nelfinavir.»

Viral Load: The amount of virus in a given sample of body fluid (usually blood). Measurements are with a lab technique called PCR (see entry). Viral load measurements can be used to judge how active HIV is and if current treatment is working well.

Viramune®: see «Nevirapine.»

Virus: A particle containing genetic information and therefore able to reproduce. Its genes may be in the form of DNA or RNA (see «Retrovirus»). Technically, a virus is not a living organism, because it cannot reproduce without infecting living cells. It is notoriously difficult to design drugs that effectively treat viruses.

W

Wasting Syndrome: Progressive, involuntary weight loss associated with advanced HIV infection.

Wild-Type Virus: The prevalent type of virus in the host population before genetic manipulation or mutation; virus that is isolated from a host, as opposed to one grown in a lab culture.

Window Period: This is the time between when a person becomes infected with HIV and when the person’s blood tests positive for HIV antibodies.

Z

Zalcitabine: see «ddC.»

ZDV: see «AZT.»

Zerit®: see «d4T.»

Ziagen®: see «Abacavir.»

Zidovudine: see «AZT.»

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