



FOCUS ON LIFE



Foreword

This pamphlet has been written for people with HIV, and it provides an overview of some of the most important factors HIV-infected people need to think about. Although the pamphlet is intended for HIV-infected people, their close family and friends may also benefit from reading it.

With the right treatment you will probably be able to live an almost normal life for many years even though you have HIV. This pamphlet describes the course of treatment offered to HIV-infected people, such as when you must receive treatment, how often you need hospital check-ups and what they examine in hospital.

Having HIV is not just a question of treatment and illness. Your life will also be affected in many other ways and there are many things that need to be thought about.

This pamphlet has been written to help you through the first difficult stage as an HIV-infected person. It will not answer all your questions and will not alleviate all your problems, but you can always talk to a doctor or nurse/counsellor if there are things you don't understand or need to talk to somebody about.

You will find a list of useful addresses and telephone numbers at the back of the pamphlet.

“HIV is something I think about a little every day - when I take my medication, for example. When I go for check-ups at the clinic, it preys on my mind a bit more. But I'm not frightened about it all the time – I've got used to it”.

Woman, 22

What is HIV and what is AIDS?

HIV is the name of a virus which weakens human immune defences so that finally you may develop the illness AIDS. Usually there are many years between being infected with HIV and developing AIDS. Many people think they can tell by the look of a person if they are infected with HIV, but that is not the case. So that means they cannot see that you have HIV either.

A person has AIDS when that person is infected with HIV and has serious complications, such as pneumonia or tuberculosis. However, usually there are many years between you being infected with HIV and you developing AIDS. In our part of the world, if you *do not* receive medical treatment, the average time between contracting HIV and being diagnosed with AIDS is about 10 years. If a person receives treatment, it is often much longer than that before that person develops AIDS.

When you have been told you have HIV

An HIV test is a blood test that is examined in a special way. If the HIV test is positive, you have been infected with HIV. People react differently when they find out they have contracted HIV: many are shocked and suffer a serious crisis; they may well suffer feelings of sorrow and sadness or anxiety and loneliness. People's sex lives can be affected - for example, many people often lose the desire for sex and feelings of discomfort with one's own body are also common at the beginning.

It is important to get these many different feelings under control and it is good to talk about them. You can either talk to your doctor, the staff at the hospital or to good friends and family. Many questions arise, and although you cannot find all the answers at the beginning, many problems will gradually be resolved.

“The day after I was diagnosed, I was pretty much numb. I really don't remember much from around that time”.

Man, 25

Initially it would be a good idea to find one special friend or family member whom you trust and whom you can share your sombre thoughts and worries with.

Many will experience feelings of great guilt and perhaps feel ashamed of having the HIV infection - and many will be afraid of being rejected by other people because they have HIV. It is important to remember that anyone can contract HIV. Many people think that it is only prostitutes, homosexual men or people with many sexual partners that contract HIV, but this is not correct.

“I was afraid they'd say that I'd only got what I'd asked for. That they'd condemn me, or get angry”.

Man, 35

If you are married or have a partner, you should tell him or her that you have HIV. This is both to avoid your partner contracting HIV and also because the fact that you have HIV will most definitely affect your relationship. At first, there will probably be times when you are frightened and depressed, and for long periods many people also lose their urge to have sexual intercourse. If your partner is to understand why you are acting differently to the way you normally do, he or she needs to know the reason, and it will also help you gain the support of your partner in this difficult period.

HIV and treatment

Hospital checkups and examinations

As a person with HIV you will be offered regular checkups at a hospital. During your first examination you will be asked many questions and you will have to have many blood tests. This is because it is important to have a good picture of your situation.

Hospitals are often very busy and because of this doctors do not have a lot of time for each individual patient. Therefore, sometimes it is a good idea to work out what you want to ask in advance, perhaps writing your questions down on a piece of paper. If there are things you are not sure you have understood, remember to tell the doctor. You will also talk to a nurse each time you come, and he or she will often have more time to talk to you than the doctor has. Even if people are busy, it is important that you have understood what the doctor and the nurse tell you. If you feel nervous about going to the hospital alone, you are always welcome to bring along a friend or a family member for support.

After each visit a time will be scheduled for your next appointment at the hospital. If you later find that you cannot attend at that time, please call and cancel the appointment and arrange a new one.

Many people worry that they will be recognised by somebody while they are sitting in the hospital waiting room. However, it is important to remember that it is not only HIV patients who are examined in the hospital departments where HIV patients are examined.

The tracing of contacts

It is important to help ensure that others do not contract the HIV virus. *Tracing contacts* means finding those sexual partners you have had who may have been exposed to the risk of contracting HIV. By finding them and talking to them, you can help prevent more people contracting the HIV virus. Therefore, while you are being given advice and guidance at the hospital on your new situation as an HIV-infected person, you will also be asked whom you might have exposed to the infection.

Many people find it embarrassing to talk about their sex lives and whom they have had sex with, but the staff at the hospital are used to talking to patients about these matters. Some people decide to tell their present and former sexual partners themselves about the HIV risk, and you could, if you wished, bring them along to speak

to someone at the hospital. Others choose to let the doctor or the nurse deal with tracing contacts, i.e. any previous sexual partners you may have had. If you decide to let the doctor or nurse deal with tracing contacts, your previous partners will not be told that it is you that has given their names. In other words, you can remain anonymous in such cases.

Participation in contact tracing is voluntary.

The body's immune defences

Becoming ill with HIV is caused by a deterioration in one's immune defences - the body's ability to fight disease.

These immune defences protect us against illness and disease. The stronger our immune defences, the more able our body is to protect us against various types of illness and disease. Often the immune defences can in time completely remove a virus from our bodies (e.g. the flu virus). The immune defences can never entirely remove the HIV virus from our bodies, but they can keep the amount of the HIV virus down.

We can measure the strength of the body's immune defences: this is the so-called your CD-4 count. That is why the hospital takes blood tests to establish how high your CD-4 count is. The higher your CD-4 count, the better your immune defences. If the CD-4 count falls,

it means that the immune defences have been weakened and there is a risk of developing illnesses and diseases.

While at hospital the amount of HIV virus you have in your blood will also be measured (*the viral load*). The more virus you have in your blood, the greater the risk of falling ill. Thus, the CD-4 count and the viral load are both indicators of how strong your immune defences are and how great a risk there is of you developing actual illnesses.

Ideally, you should have a high CD-4 count and low viral load, as then there is least risk of developing illnesses.

Medicinal treatment

HIV cannot be cured but there are medicinal treatments which can keep down the viral load. This means that the time when you risk becoming ill will be delayed until later in the future.

All HIV-infected people in Denmark will sooner or later be offered medicinal treatment for their HIV infections. Treatment consists of a combination of various types of medicine and is therefore referred to as *combination treatment*. The various types of medicine each attack the HIV virus in their own way.

Usually there will be a number of years between you being infected and you being offered treatment. You will be offered treatment if:

- your CD-4 count is low,
- you suffer complications such as tuberculosis, pneumonia, fungal infections, certain types of cancer or meningitis,
- you are pregnant and wish to keep the child

Side effects

For the first few months of combination treatment some people may suffer a number of serious side effects (e.g. nausea, diarrhoea, insomnia). In the vast majority of cases these side effects will disappear after this time. If they do not disappear, tell your doctor, who will attempt to find another type of treatment that will cause you fewer side effects. Different types of side effect may appear after several years' treatment, such as altered fat distribution in the body (more fat around the neck and less on the chest and legs and other places).

“I have sickness and diarrhoea, especially in the mornings, and I'm tired. My arms and legs feel heavier, and my stomach's getting bigger”.

Man, 41

Resistance

The HIV virus can become resistant if you, for example, do not take your medicine regularly. This means that the medicine stops working in the way it should because the virus is able to “stand up to” it. Therefore, it is very important that you take your medicine regularly every day. Your doctor will tell you how much medicine you must take and when it must be taken.

If the HIV virus becomes resistant to treatment, the doctor will change the type of treatment.

If you wish to stop taking the medicine for a time - e.g. if you are going on a trip - you must always consult your doctor about it. The risk of resistance is not so great where actual “short interruptions” in taking medicine are involved. The worst thing is if you regularly forget to take your medicine every day. Tell the nurse or doctor if you think it will be difficult for you to remember to take the medicine, or if you find yourself often forgetting to take it.

Infection pathways

How is HIV contracted

To avoid infecting others with HIV it is important that you know how HIV is spread. It is also good to know how it *cannot* be spread so you can avoid unnecessary worry.

HIV can be passed on in three ways:

- Through unprotected sex
- Through blood
- In conjunction with pregnancy, childbirth and breastfeeding

The commonest way of becoming infected is through unprotected sexual intercourse, i.e. sex without using a condom. The risk is greater with anal intercourse (sexual intercourse in the rectum) than with vaginal intercourse (sexual intercourse in the vagina). There is only a slight risk of HIV infection through oral sex (mouth to genital sex).

HIV can also be passed on between drug addicts who share needles - or if you inject doping preparations and share the needle with others. HIV can also be

transmitted if HIV-infected blood gets into an open sore.

HIV can also be passed on from an HIV-infected woman to her unborn child. However, if the pregnant woman knows she is infected with HIV, she can be given medicine which will reduce the risk of the child becoming infected. The HIV virus can also be passed on if an HIV-infected mother breastfeeds her child, and therefore HIV-infected mothers are recommended not to breastfeed their children and instead use breast milk substitutes.

Even if you feel healthy in yourself or if you are receiving treatment for HIV, you can still infect others. People with HIV can infect others for the rest of their lives - including when they are receiving treatment.

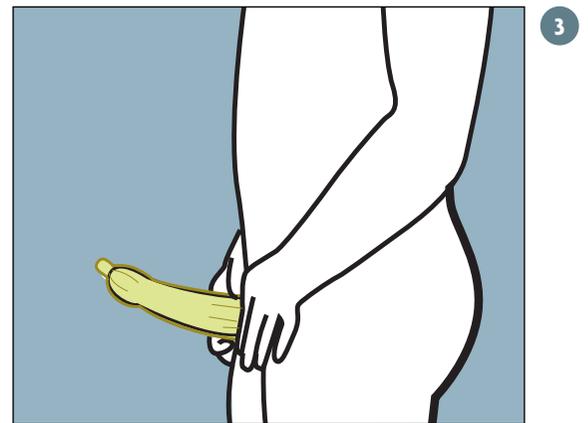
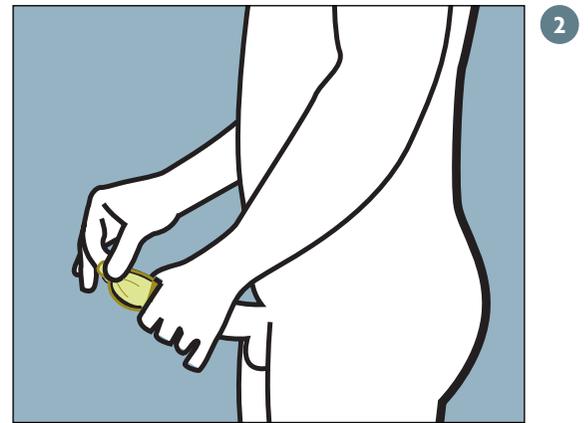
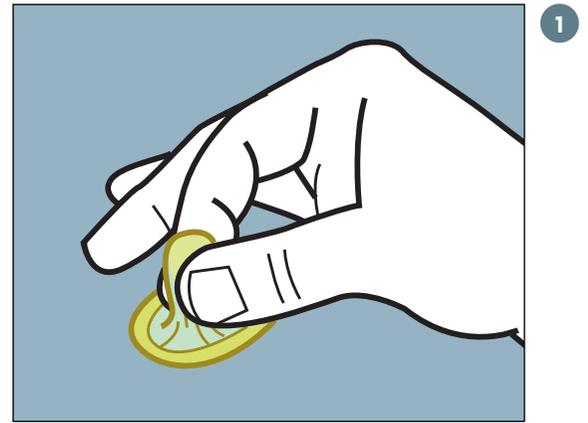
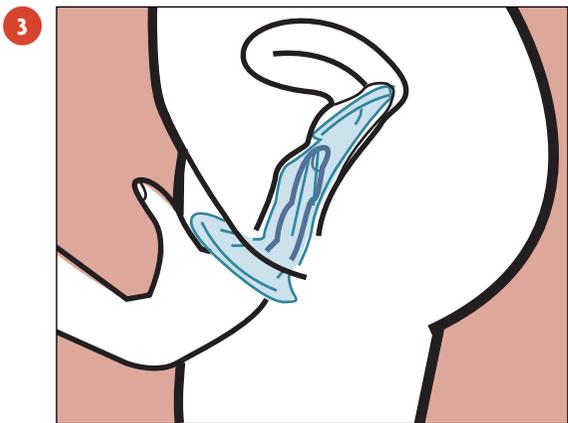
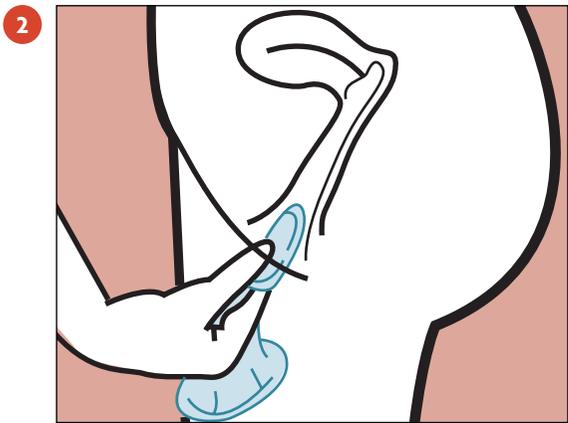
How HIV cannot be contracted

HIV *cannot* be spread through kissing, sweat, saliva or urine. You cannot be infected with HIV just by getting blood or sperm on your skin. The fact is that HIV cannot penetrate the skin.

Thus HIV does not spread through ordinary social intercourse, e.g. by using the same knives, forks and spoons or by sharing the same toilet as an HIV-infected person.

Safe sex

Many people with HIV are extremely worried about infecting others, for instance when having sex. To avoid infecting your partner you must always practice safe sex - in other words, use condoms when you have sexual intercourse. When having vaginal intercourse instead of using a condom you can use a femidom (a sort of condom for women).



Many find it hard to imagine that even though they are infected with HIV, they can still enjoy a normal sex life. And even if the urge for sex may often disappear for a while, most people recover the desire for close and intimate relations. There are many ways of making love to your partner without there being any risk: you can kiss and cuddle and massage each other anywhere on the body. It is not possible to infect the other person even if you should get sperm, sperm secretion or blood on their skin. The fact is that HIV cannot penetrate the skin. Just remember to use a condom (or a femidom) when engaging in sexual intercourse or oral sex.

You should also know that you can always talk to your doctor, your nurse or a counsellor from HIV Denmark if you are finding it difficult to have a satisfactory sex life. If you prefer to be anonymous, you can call the AIDS Hotline. Most of their counsellors speak English.

If a condom breaks there is a certain amount of risk of the other person contracting the virus. Therefore, it is important for people who are not infected to know that there are preventive treatments against HIV available if they have engaged in unsafe sex (for instance, if a condom has broken) with a person with HIV. This is known as PEP Treatment. However, there is no guarantee that this treatment will prevent infection. The treatment must be taken at the latest 24 hours after being exposed to infection. The treatment, which is in pill form, is administered at hospitals. The AIDS Hotline will be able to advise you on the nearest

hospital where such treatment is available. The treatment lasts four weeks and can cause side effects.

HIV tests

It is a good idea for your previous partners - and your present partner - to be tested for HIV if you have had sex without using a condom. This way they can discover whether they have been infected with HIV.

HIV tests are carried out by your own doctor, at hospitals or at an STD clinic (a clinic for sexually transmitted diseases). The AIDS Hotline can give you the addresses and the opening times. In Denmark everyone can be tested anonymously (i.e. without giving a name or address) and free of charge.

It normally takes between 3 and 14 days from the time of taking the blood test to being informed whether you are infected or not.

When a person has been infected it may take up to three months before it can be seen in a blood test. Therefore, you should wait three months from the time you were exposed to the risk before taking the HIV test.

You have to give your consent for an HIV test to be undertaken. This means that you are not automatically tested for HIV when undergoing other types of examination, e.g. pregnancy examinations.

Living with hiv

Your life will be affected in many ways when you find out that you have the HIV infection. During the first phase your main feeling will be one of shock, but after a while most people learn to live with the infection. For many people it is important not to spend too much time alone during the first phase. Many benefit a lot from talking to just one person whom they trust - maybe a close friend or member of the family. You can also choose to talk to the nurse at the out-patients' clinic where you go for checkups or to a counsellor from HIV Denmark.

HIV is a serious illness which you will have for the rest of your life - but you will presumably still be able to live a long and almost normal life if you receive the right treatment. Therefore it is important that you try to make the most of life and that you refuse to be preoccupied too much by fear of the illness. One way of taking responsibility for your own life is to get to grips thoroughly with what HIV implies. In other words, what symptoms may arise, when medicine will be offered to you, who needs to know that you have HIV, how HIV spreads and how it does not spread, and so on. The more you know, the easier it is for you to take decisions and act positively.

Whom should you tell that you have been infected with HIV

When you tell - and whether you will tell - your family, your friends and your workplace that you have contracted HIV is entirely up to you. It is important to think carefully when and how you will do so. It can be beneficial to talk over these matters with a person or people whom you trust. You might talk to your nurse or a counsellor from HIV Denmark. The way people around you react to you telling them varies greatly from case to case. It will often depend on how close you are to the people you tell. Some may become angry or upset, others may be frightened of being infected by you. But it is important to remember that the vast majority of people who have decided to tell others about it have had positive experiences. Many have found they get help and support from the people who know they are infected.

If you have children it is particularly important to think carefully when and how they should be told that you have HIV. Many people think that it is best for children not to know anything, but experience has shown that most children sense that "something is wrong". When children feel that "something is wrong" they spend a lot of time and energy trying to work out what it might be and whether it could be their fault in some way. Often it is a relief for them to discover the truth. In this situation, too, it may be a good idea to talk to others about how best to break the news to the children.

If you wish to have a child and you have HIV

If you are a woman and have HIV and you want to have a child, you should think about things very carefully. Given the correct medicinal treatment the risk of the child being infected with HIV can be considerably reduced, i.e. to less than one per cent. To avoid your husband becoming infected during sexual intercourse you should have artificial insemination.

If you are a man with HIV and would like to have a child with your wife (and she is *not* infected), these days you can be offered a “sperm wash”, where your sperm cells are cleaned of the HIV virus. In this case, too, the woman must be impregnated via artificial insemination to avoid her being infected with HIV.

If you are infected with HIV and are thinking of having a child, you and your partner should talk to your doctor to discuss what opportunities are available and what the problems are before you make a decision.

The relationship with your employer and your colleagues

Being infected with the HIV virus does not restrict you from doing any job you want to take on and you are not obliged to tell either your employer, your colleagues or the local authority that you are infected. For the same reason an employer may not dismiss you because you

have HIV. If you find that you are being discriminated against or dismissed because you have HIV, get in touch with your union or HIV Denmark.

“I haven't told anyone at work. I'm all right, and I don't call in sick any more often than my colleagues do. I don't think there's any reason for them to know about it”.

Woman, 28

Some jobs require you to be a member of a specific pension scheme, and you therefore have to answer various questions concerning your state of health. Pension scheme rules change all the time and therefore it is best to talk to your union or a counsellor from HIV Denmark if you are in doubt as to what to do.

By the way, the same applies if you wish to take out accident insurance. These rules are also complicated and are constantly changing.

HIV and social benefits

HIV-infected people are entitled to assistance under social security legislation. You can get in touch with your local council if you have special financial, physical or mental problems you need help with. You can also seek advice from HIV Denmark or speak to the social worker at the hospital.

Confidentiality

The same confidentiality rules apply to HIV and AIDS as to all other disorders. It is important that people with HIV feel confident in approaching the healthcare system and that they provide all the necessary information. For this reason, healthcare personnel are bound to confidentiality and may not pass on information concerning your HIV status to others besides those whom you have given consent for. Confidentiality applies to doctors, nurses, dentists and other employees in the healthcare sector. Therefore, if you have tested positive for the HIV virus somewhere else besides with your own doctor, he or she will not be informed of your HIV infection unless you give your consent or you yourself tell your doctor about it.

“If I wasn't sure that the doctors, nurses and counsellors would respect professional secrecy, I wouldn't want to talk to them about my sex life or about safe sex”.

Woman, 38

Confidentiality obligations also mean that the family and friends of people with HIV cannot obtain information from the doctor or the hospital concerning a relative - that is, unless you give your consent.

Confidentiality obligations may only be ignored under special circumstances, for example if an HIV-infected person refuses to inform his wife or her husband or partner of their infection. In cases like this, healthcare personnel are entitled to inform the wife, husband or partner of the illness, but only if the healthcare worker assesses that the wife, husband or partner has been or is exposed to an obvious risk of infection.

HIV and the penal code

The penal code states that people who “recklessly expose other people to the risk of infection with a life-threatening and incurable disease,” can be punished (section 252). These rules apply to people with HIV who expose their partners to infection without those partners knowing that they risk being infected with HIV. It does not matter whether the person in question has actually been infected or not. The rules also apply to people who have not been tested for HIV but who have good grounds for believing that they carry the HIV infection. But this also means that if you and your partner use condoms, you do not need to tell the person in question that you are carrying the HIV virus, since you are protecting your partner against infection.

The maximum penalty is imprisonment for up to eight years and you may risk losing your residence permit if you are not a Danish citizen.

You cannot be punished if you practice safe sex or if you inform your partner in advance that you have HIV.

If you tell your partner about your HIV infection and you both choose to go ahead and have unsafe sex, nobody can be punished.

The penal code also applies to the risk of infection through the sharing of needles and syringes or when donating blood.

Language difficulties and interpreters

If you do not speak or understand Danish very well it may be difficult to understand what is being said - at the hospital, by social services or at your doctor's. It may also be difficult for you to explain the things you would like to explain. If this is the case, you can ask for an interpreter to be present the next time you have an appointment. It is important for you and the personnel to understand each other. The personnel may themselves have called in an interpreter, in which case it will be to ensure that you understand each other.

Interpreters must also observe confidentiality and must therefore not talk to others about the person he or she has been interpreting for or what they talked about.

Some people wish members of their families or their children to translate, but this is not a good idea. It is best not to get your children and family involved "in your illness" in this way - and there are bound to be many words (concerning medicinal treatment, sexuality and legislation) that they will not necessarily understand.

Trips abroad

If you travel abroad, there are a number of things you must remember to think about before you travel: travel insurance, medical insurance, the implications for any residence permits you may hold etc. These rules can be complicated, so speak to a social worker from social services or a counsellor from HIV Denmark about them.

You must also bear in mind that there are some countries which do not allow free entry to people with HIV, and therefore it may be a good idea to get in touch with the embassy before travelling.

If you are taking medicine, you ought to take enough for the whole trip so you don't suddenly find that you have run out. You should also talk to your doctor about which vaccinations you need. Careful consideration should be given before administering certain vaccines to people with impaired immune defences.

It might also be wise to investigate the opportunities for obtaining advice if problems arise while you are abroad - this may involve hospital assistance or an HIV/AIDS counselling centre. In most cases the AIDS Hotline can help you with addresses of counselling centres abroad.

The AIDS Hotline
Skindergade 27
1159 Copenhagen K

Tel. +45 33 91 11 19
www.aids-linien.dk

hiv.dk
c/o HIV-Danmark
Skindergade 44
1159 Copenhagen K

Tel. +45 33 32 58 68
www.hiv.dk

HIV Denmark
Skindergade 44
1159 Copenhagen K
Tel. +45 33 32 58 68
www.hiv-danmark.dk

Counselling East
(Zealand and the islands):
Tel. +45 33 32 58 60

Counselling West
(Jutland and Funen):
Tel. +45 70 22 58 68

Provides telephone and personal counselling on HIV/AIDS and other STDs.

Email and chat counselling is also provided via the Internet. See website.

Internet portal for Danish HIV/AIDS organisations.

Here you can find the addresses of many Danish HIV/AIDS organisations, including Den Folkekirkelige Aids Tjeneste (The Aids Service of the Danish Established Church) and the HIV-pensionat (HIV residence).

The portal is also available in English.

Patient association for people with HIV and umbrella organisation for Danish HIV/AIDS organisations.

Nationwide personal counselling for people with HIV and their relatives and friends.

Arranges contact with HIV support groups.

HIVinfo.dk
Box 1132
1009 Copenhagen K

Tel. +45 33 93 10 35
www.hivinfo.dk

TICC
Training, Information and
Counselling Centre
Lille Kirkestræde 3, 2
1072 Copenhagen K

Tel. +45 36 31 08 08

HIVinfo.dk is an information and meeting place on the Internet for people with HIV and others affected by HIV.

There is information and news on medicines, support, survival, and much more: HIVinfo.dk is updated several times a day.

To date, HIVinfo.dk has been in Danish, but it also answers questions in English.

Healthcare information centre which provides information, counselling and support to Africans and their families affected by HIV and AIDS.

Personal and telephone counselling.

Arranges contact with HIV support groups.



ENGELSK



Sex & Samfund

The Danish Family Planning Association
Rosenørns Allé 12, 1. sal
1634 Copenhagen V
Tel. 33 93 10 10
www.sexogsamfund.dk

Sundhedsstyrelsen

National Board of Health
Islands Brygge 67
2300 Copenhagen S
Tel. 72 22 74 00
www.sst.dk