# Multidisciplinary Guideline HIV and work

**SUMMARY**

for daily practice

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What follows is a summary of the most important recommendations from the multidisciplinary guideline for HIV and work. The guideline was developed according to "evidence-based guideline development (EBRO)" methods (CBO, 2004). The scientific evidence and considerations on which the recommendations have been based have not been included in this summary. For the scientific argumentation, considerations and associated recommendations, we refer to the full guideline text in Dutch (www.positiefwerkt.nl).

The summary starts with a brief description of the various phases that can be differentiated during the course of infectious HIV disease. This is followed by several generic/preventive recommendations pertaining to absenteeism, returning to work, and individual recommendations extending beyond healthcare. The summary provides a framework of guidelines for addressing employment-related problems for people with HIV in various phases/working situations. It should be noted, however, that this is a generalization. Clearly, everybody with HIV is unique, can be affected differently by the disease and can face different problems.

## Phases during the course of HIV infection

In conjunction with the availability of antiretroviral treatment (HAART), we can distinguish between two groups of "patients".

### *The diagnosis of HIV infection before 1996: the pre-HAART period*

Thanks to the availability of new drugs, since 1996 it has been possible to provide adequate treatment for HIV patients. The therapy is life-long but cure is not (yet) possible. With the resources available at the time, it was not possible to offer effective long-term treatment before 1996. Resistance (decreased sensitivity) was a big problem. Patients whose treatment started before 1996 often encountered many problems finding effective treatment combinations in subsequent years. The availability of effective treatment combinations (cART) in 1996 heralded a breakthrough for HIV patients. HIV changed from being a potentially fatal infectious disease into a chronic infection.

No specific recommendations have been formulated for this group. Many of the recommendations listed below may be applicable. It is important to make a proper assessment of the situation of the person in question and analyze his or her wishes/needs so that the guidance that is provided can be adapted accordingly.

### *The diagnosis of HIV infection after 1996: the HAART period: different stages and their features*

> *The early stage;* with fear of HIV infection, justified or otherwise

> *The stage immediately after a positive HIV test,* usually followed immediately with further blood tests to ascertain, among other things, the level of immunity of the person concerned, a viral load (amount of virus bodies) and if deemed necessary, a HIV resistance test. The response of the affected person partly depends on what is found, the consequences of determining the degree of "sickness", the necessary follow-up examinations/treatment, the ability to cope, existing comorbidity, age, status and the applicable social situation. In practice, it appears to takes an average of between one and two years before an emotionally stable situation is attained in cases where there is acceptance of being HIV seropositive.

In the beginning, it is important to allow for the grieving process after hearing the diagnosis. Having to accept the loss of good health plays a role in this.

After the diagnosis of HIV, always inform working people about the possibility of seeing an occupational health physician for a preventative consultation and, if deemed necessary, seeing a counselor or company social worker. Point out to the employee that the occupational health physician, counselor and company social worker are bound by confidentiality. The preventive consultation must focus of the resilience of the employee, his or her workload, possible absenteeism risk factors and employment-related medical vulnerabilities of the HIV-infected employee.

> *The follow-up in the therapy-free stage:* there is still no question of the disease having progressed, but the person has to come to terms with the periodic results and the tension they can cause. This phase can take from several months to decades for the so-called "Elite controllers", those who hardly show any progression of the disease. For most people with HIV this period has an average duration of a few years. The period between HIV diagnosis and initial treatment is subject to change, mainly due to changing guidelines pertaining to starting the treatment. Currently, the trend is to start treatment earlier, which makes this period shorter.

> *The starting therapy phase:* A combination of factors (among them, immunity, the amount of virus in the blood (the viral load) and the HIV resistance test), together with individual factors determine whether, and when, to start with antiretroviral therapy (ART). It is possible for (short-term) side effects to manifest themselves, particularly during the period immediately after starting the antiretroviral therapy. This sometimes necessitates a change of therapy. Diminished capacity and associated absenteeism are a distinct possibility during this phase.

Be alert for diminished physical capacity and the side effects of medication, along with the repercussions these can have for the patient's participation in the working process.

> *Stable therapy phase:* Generally speaking, there are few problems in this phase. Patients visit the treating doctor an average of two to three times a year for examinations. Long-term side effects resulting from medication can affect some patients.

> *Instable therapy phase:* When there is inadequate response to the chosen therapy or problems occur due to prolonged treatment with a combination antiretroviral therapy (cART) or the chronic HIV infection. The severity of any crisis obviously depends on the situation, whether a sufficiently supportive social network is available, and how those involved are coping. Chronic HIV infection and treatment can go hand-in-hand with an increased likelihood of comorbidities such as diabetes mellitus, hypertension, heart disease, osteoporosis, skin complaints, hypercholesterolemia, reduced testosterone levels, depression, anxiety and panic attacks and certain forms of cancer.

Be alert to the possible presence of comorbidities, which can lead to the patient being less able to work. Assess whether additional attention should be paid to this.

Ask the patient about feeling excessively tired. A low energy level and tiring quickly are important indicators of a patient's capacity to participate in the working process.

If an employee with HIV has diminished capacity, as a result of comorbidity for example, and/or serious side effects from (HIV) medication, advise him or her for make an appointment with the occupational health physician. Point out to the employee that the occupational health physician is bound by confidentiality.

> *Future phase:* This depends on new insights into treatment, the availability of new treatment modalities and better understanding of the consequences of living with chronic HIV infection.

Keep an eye open for impaired cognition. The impairment of cognitive functioning of someone with a HIV infection can lead to employment-related problems.

### Generic/preventative recommendations

As a support provider, make sure that other support providers are informed in a timely manner about absenteeism and the rehabilitation process. In this way it will be possible to ensure that interventions can be coordinated, and the chance of success will thus be increased.

Be explicit about the confidentiality obligation when contacting the HIV patient, even if the subject is not broached. The carers involved must, at all times, observe this confidentiality obligation pertaining to the HIV status of a patient/client. Explain that information will, under no circumstances, be shared with third parties unless the HIV patient gives written permission by means of an informed consent form, or if the HIV patient wishes to communicate the information personally. Discuss how communication with the employer will take place.

Safeguard the privacy of the HIV patient. This privacy is of the highest priority and must be respected and safeguarded by all involved support providers. Refer to the website of the Dutch doctors' federation KNMG (www.knmg.artsennet.nl) for guidelines for handling medical data.

Ask the employee whether his or her employer is aware of the HIV infection and check how well informed the employer is about HIV and the degree of acceptance. Indicate that they are not obliged to be open about their HIV status.

Offer support in the event of (non) disclosure and the fear of stigmatization. The occupational health physician, occupational health nurse, counselor, company social worker and the employee's general practitioner can play an essential role in this respect. List the advantages and disadvantages with the employee so that you can decide on a considered course of action. If the occupational health physician has not (yet) been informed, the HIV counselor can advise. The choice of whether or not to be open about the HIV status always rests with the HIV-infected employee and disclosure cannot be made mandatory.

Make stigmatization and discrimination against HIV in the workplace negotiable, but in a responsible manner. This will make it possible to reduce the likelihood of both. A major responsibility in this respect lies with the employer and Human Resources department. To this end it is very important that employers are aware of all aspects pertaining to HIV in the workplace.

Where necessary, stimulate and support the development of self-management skills, so that patients take control of their illness, their participation in the working process and their quality of life. However, sufficient and adequate support must always be available for those who do not have the required self-management skills.

Make an inventory at an early phase of the treatment/counseling of the socio-demographic factors:

- Age (the chance of finding work diminishes as age increases)
- Gender (women lose their jobs quicker, men consider returning to work more often)
- The social and demographic situation before the HIV diagnosis (a poor situation diminishes the chance of finding work)
- Education (a higher level of education increases the chance of finding work)
- Employment situation (people who were already unemployed are more likely to remain unemployed)
- Children (having children diminishes the chance of finding work)
- Ethnic background (the chance of finding work depends on the patient's level of integration and command of the Dutch language)
- Lifestyle Inventory, (a poor lifestyle increases the likelihood of absenteeism)

To deliver effective customization every healthcare professional seeks out the determinants that are relevant for the support he or she will provide, and, together with the client, makes an assessment of the factors that will help or hinder participation in the working process. Possible (preventive) measures are then anticipated in the treatment.

Make an individual analysis of the patient's personal characteristics and style of coping. Assess whether additional attention is called for in this area.

Stay alert for depression and other psychopathological disorders that might be influenced by participating in the working process and the quality of life. Flag up any psychological problems that people might experience.

Explore how the HIV patient sees his own health situation and make sure you clarify possible ambiguities or inaccuracies.

People with HIV should be well informed about their rights and obligations as employees in the workplace, and they should make sure they are well informed about the possibilities for having their interests represented.

Occupational health physicians and other occupational health professionals, such as a labor and organizational expert, should be encouraged to adopt a proactive attitude towards the management and HRM department in the development of HIV policies.

## Recommendations in the event of absenteeism

Find out why the employee called in sick. If it's because of the HIV then consultation between the general practitioner, the occupational health physician, the HIV-nurse/HIV-physician and occupational health nurse will be necessary. The patient/employee must, of course, provide written permission.

In the event of absenteeism, distinguish between incidental, short-term absenteeism, frequent short-term absenteeism and long-term absenteeism. If it's incidental, short-term absenteeism no action is usually necessary. Consult the occupational health physician/patient/employee before adapting the support and possible use of interventions (company social worker, occupational health nurse, psychologist, general practitioner, additional consultation with the HIV therapist).

The occupational health physician assumes responsibility for the patient's participation in the working process. The occupational health physician ascertains which referral/intervention is required and what role the patient/employee is able to take on. If the occupational health physician is not up-to-speed on the situation, the HIV-nurse can play an advisory role towards the employee and possibly, with permission, towards the occupational health physician.

## Recommendations for returning to work

In the event of rehabilitation into the working process, distinguish between first-track rehabilitation (with the same employer, if necessary, in a new position), second-track rehabilitation (with a different employer) and rehabilitation from a situation in which the employee was receiving benefits of some sort. Make an analysis of the wishes and possibilities of the employee/client and adapt the interventions accordingly.

On returning to work, enquire immediately about the employee's motivation to work. Establish which factors play a role and intervene if necessary.

Take into account aspects such as transport and the financial situation for a return to work.

Bear in mind the degree of job satisfaction, as well as the prevailing company culture and the knowledge and attitude of line managers in supporting the rehabilitation process.

Also, bear in mind that the employee's career aspirations might have altered as a result of a changed outlook on life or the need for a career switch as a result of diminished resilience, for example, due to the HIV. Ask the employee how he sees himself functioning adequately.

Map out the provisions and possibilities with respect to adapting the work schedule (working hours, rest periods, spreading the work over the week) and the flexibility of the employer.

Ask the employee if he or she is afraid that work might be detrimental to his or her health.

Consider appointing a case manager to the rehabilitation processes; individual support appears to be more successful.

If problems arise around the rehabilitation process, explore the possibilities for counseling and intervention. Actions calling for self-management are preferable, as these will reinforce the impression that patient is in control.

### Recommendations transcending individual care

There should be a regional overview of carers/interventions that can be used to speed up the rehabilitation process.

Make an overview of national interventions that can be used to expedite the rehabilitation of people with HIV, and make sure it is communicated.

To promote the participation of people with HIV in the working process, customized training and support programs, such as those that were available between 1999 and 2009, could, for example, be developed and offered by the Dutch HIV Association. However, an action plan should also be made for groups that are difficult to reach.

Collate all information about the rehabilitation of people with HIV and make it accessible for other people with HIV, all relevant professionals in the occupational health care sector and employers.

While taking privacy into account, the core group recommends that the national employment status is registered. This could, for example, be registered through Stichting HIV Monitoring (the HIV Monitoring Foundation) in collaboration with Nederlands Centrum voor Beroepsziekten (Dutch Centre for Occupational Diseases). The HIV–nurse will probably play an important role in this. For the sake of consistency a national registration form should be developed.

The core group recommends making the topic of HIV broadly open to discussion through the dissemination of information through a variety of communication channels, such as (existing) websites, trade magazines and social media.

### Relevant links

Being positive works: the central place of work and HIV for employers, professional groups, intermediaries and employees (with HIV) - *www.positiefwerkt.nl* -

Arboportaal.nl: Everything about working conditions, the Ministry of Social Affairs and Employment (SZW) - *www.arboportaal.nl/onderwerpen/arbowet--en--regelgeving* -

Pre-employment medical examinations - *www.nvab.artsennet.nl or www.aanstellingskeuringen.nl* -

The Equal Opportunities Commission - *www.cgb.nl* -

The Knowledge Centre for Infectious Diseases and Working - *www.kiza.nl* -

Self-management - *www.zelfmanagement.com* -

### Relevant guidelines

Guideline for Antiretroviral Treatment 2007 - *www.nvhb.nl* -

Guideline for the prevention of HIV transmission by risk-forming medical personnel - *www.rivm.nl* -

National guideline for Needlestick Injuries - *www.rivm.nl* -

Guidelines for dealing with medical data, KNMG - *www.knmg.artsennet.nl* -

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