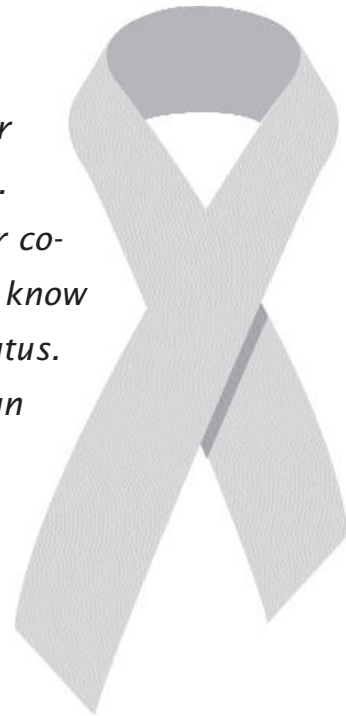


# People living openly with **HIV/AIDS in the workplace**

*HIV/AIDS remains hidden and this reduces our ability to contain its spread and to confront it. Most South Africans know of family, friends or co-workers who have died of AIDS, but few of us know people living openly with their HIV-positive status. People Living (openly) with AIDS (PLWAs) are an important exception to this secrecy. **David Dickinson** explores the importance of PLWAs at work and how they can contribute to an effective HIV/AIDS workplace programme.*



**A**lthough South African law makes it illegal to discriminate against employees on the basis of their HIV status few people have revealed their HIV-positive status at work. This is for a number of reasons.

- HIV/AIDS is a highly stigmatised disease – because of its association

with sex and death – and many people are afraid that they will be judged or blamed by others if they are known to be HIV positive.

- Despite legislation, discrimination against people who are HIV positive (or who are thought to be HIV positive) is widespread at work. This

can range from open discrimination (such as being fired) to more disguised discrimination (such as not training or promoting an employee).

- People talk or gossip about something that is sensational. It is not possible for someone to be open about their HIV status in one

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environment and be sure that this information will not spread to other situations. This raises the barriers to people being open about their status – even if it might be safe to do so in some parts of their lives.

In contrast to this reality, best practice policy responses encourage the creation of an environment in which people can choose freely whether they want to be open about their status or not. Thus, the Code of Good Practice on Key Aspects of HIV/AIDS and Employment agreed to in the National Economic Development and Labour Council (Nedlac) recommends that companies should 'create an environment that is conducive to openness, disclosure and acceptance amongst all staff.'

Open disclosure of an individual's HIV-positive status is of psychological benefit – since the individual no longer lives with this secret. It can also be of great benefit for the HIV/AIDS programme of a company since PLWAs can help everybody in the company acknowledge the reality of HIV/AIDS and get them – whether positive or negative – to take appropriate action.

#### **A vicious circle**

From the above we can identify a vicious circle. We would like HIV-positive employees to be open about their status because removing secrecy and fear will help combat stigma and discrimination around HIV/AIDS. Yet, there are very few PLWAs in our workplaces because of existing levels of stigma and discrimination.

This vicious cycle can be broken in a number of ways. Educating those who are in a position to most easily discriminate at work (such as supervisors and production management) is extremely important. Also of critical importance is how PLWAs that do come forward show they can live healthy and productive lives

#### **Pitfall One: If you do not ensure positive HIV/AIDS role models you will get negative ones**

It is not easy for people who are HIV positive to be open about their status. But if you do not ensure you have role models who can provide positive messages about being positive, you will get role models who reinforce negative messages about AIDS.

HIV-positive employees are not able to acknowledge their status and take appropriate action, such as taking antiretroviral drugs, they will become sick and die. Such people are bad role models. They may never have revealed their status, but word gets out as their health deteriorates and they take sick leave. When news comes back that they died of an AIDS-related illness the message is clear: AIDS kills. This further reinforces stigma and silence in the workplace.

and are not discriminated against. However, there are dangers and pitfalls that workers and managers should acknowledge: if you do not have positive HIV/AIDS role models at work, you will get negative role models.

#### **PLWAs from outside or inside the company?**

When companies start to address the issue of HIV/AIDS they will not be able to draw on employees who are PLWAs since they may still be firmly caught in the vicious circle described above. One solution to this is to bring in PLWAs from outside the organisation to speak at training sessions or awareness events which can be valuable as an educational tool.

Different PLWAs bring different messages depending on their experiences and situation. For example, Patience, an attractive African woman addressing a group of male mineworkers only revealed that she was HIV positive some way into her presentation. She then told the audience (to nods of agreement) that if she had not revealed her status she would have had several propositions before leaving the mine. The point that HIV could not be seen and that people should always avoid unprotected sex was powerfully made.

But important as outside PLWAs are when organisations begin to tackle HIV/AIDS they are no substitute for employees being able to reveal their status and remain at work. An outside PLWA can educate and inform, but at the end of their presentation they do not have to face the consequences of being openly positive within that particular organisations' employees do. So the willingness of employees to become PLWAs can be regarded as a fundamental test of a company's response. If a company is making good progress in combating stigma and discriminations HIV-positive employees are more likely to come forward and disclose their status. If the company is not addressing HIV/AIDS seriously (or is simply paying lip service to its responsibilities) then HIV-positive employees are not going to be open.

This test of a company's response is an important one. It is also, however, one that can be abused by managers who are in a hurry to show results. A second pitfall is 'over-exposing' an HIV-positive employee who begins to reveal his or her status. Revealing their status is a difficult decision and usually occurs over a period of time as he or she gains confidence. But managers or others promoting a company's HIV/AIDS response may want to 'fast-track' this

*Pitfall Two: Over-exposing the first PLWAs in a company*

Colin who worked in an educational institution was HIV positive and had begun to reveal his status in the classroom when talking to students about HIV/AIDS. In particular he explained how effective antiretroviral drugs had been in improving his own health. When the organisation began to respond to HIV/AIDS, Colin was asked to sit on its HIV/AIDS steering committee. The first newsletter of the steering committee, distributed to all staff members, listed the committee members and explained that Colin was an HIV positive member of staff. Suddenly, everybody knew Colin was HIV positive. He was no longer in control of how he explained his status to people. He felt threatened by the situation and angry that the committee had exposed him in this way. People who want to be open about their HIV-positive status in an organisation should be encouraged, but only if there are effective measures to ensure they will not be discriminated against. Moreover, the process by which a person reveals their status needs to be respected and carefully considered.

process to prove that their campaign is working. This is a risky strategy that can backfire on the programme and the person with HIV/AIDS.

**PLWAs and a company's response to HIV/AIDS**

If an HIV-positive employee is confident enough to reveal his/her status at work this can be of great benefit in the wider response of an organisation to HIV/AIDS. We can see this input along a spectrum of activity.

- 'Quietly' setting an example of how HIV-positive people can continue

- living healthily and working productively to fellow employees;
- Actively involved in the organisation's HIV/AIDS programmes – for example giving presentations to encourage other employees to know their HIV status through voluntary counselling and testing (VCT); and
- Being responsible for a organisation's HIV/AIDS programme.

Because PLWAs have many advantages in conveying messages around HIV/AIDS it is tempting for people to assume that a PLWA is the right person to run the company's response. But this

*Pitfall Three: Assuming that a PLWA can 'do it all'*

Mpho was brought into a large company to run its HIV/AIDS programme on the basis of being openly HIV-positive and her dynamic personality. Unfortunately, Mpho had no management experience and did not understand the politics of the company. Soon she was isolated and frustrated. Additionally, now that Mpho was in the company it was felt that any issue relating to HIV/AIDS could be given to her; having a PLWA responsible for the company's programme became an excuse for managers not to have to deal with the issue. After a few months Mpho was unable to cope and quit the company.

PLWAs need to be carefully placed within an organisation's response to HIV/AIDS. Being open about their status can be a powerful tool – but it is only one asset that needs to be combined with a range of skills and resources that makes for an effective response to HIV/AIDS. Moreover, AIDS must be seen as everybody's responsibility, dumping everything on a PLWA (or any individual) is a recipe for burnout and failure.

may not be the case. They may show tremendous courage in revealing their status – but that does not mean they have the skills to run a large and complex HIV/AIDS programme. Nor does it mean that they have the energy and time to deal with every employer who is concerned about HIV/AIDS.

So, while there are dangers of expecting too much from a PLWA the value that they can bring to a company's response to HIV/AIDS should not be underestimated. Among the most important ways in which they can contribute are:

- Education and awareness: PLWAs – whether from outside or inside the company – can provide valuable education on HIV/AIDS. As the earlier example of Patience illustrates, this can be through direct messages that they are in a strong position to communicate.
- Putting a human face to HIV/AIDS: In addition to this direct educational input, PLWAs change attitudes by putting a human face on HIV/AIDS. This, however, needs to be carefully considered if it is to be effective. The AIDS epidemic has been characterised by extensive 'othering' in which people perceive the disease to be a problem affecting other people. In still racially-divided workplaces, a black PLWA may not, unfortunately, be effective in getting white managers to take AIDS seriously. By contrast, when two white PLWAs were brought in unannounced to address the (white) management team of a company employing 600 people there was clear shock that contributed to a decision to upgrade the response to HIV/AIDS. Within the same business unit it has been an African male PLWA who has been effective in convincing his fellow (African male) workers that they should find out their HIV status.

*Pitfall Four: With only a few PLWAs individual, incorrect views can have disproportionate weight*

Bernadette, a hospital employee, had been open about her HIV-positive status for a number of years. Her example had been an inspiration to many other employees who had trained as HIV/AIDS counsellors. When Bernadette's CD4 count fell below 200 and opportunistic infections began she correctly started taking antiretroviral drugs. However, she found the side effects unmanageable and, after three months, stopped taking them. As far as she was concerned antiretroviral drugs should not be taken unless there really was no other alternative and she forcefully communicated this message. Because of her status as a PLWA other employees, including nurses, accepted her account and began communicating this when they were counselling HIV-positive patients – an incorrect message since many of these people would not experience side effects.

The experience of PLWAs is of great value, but it does not mean that they are always right. Their experience is highly personal, but because there are so few PLWAs at present it may not be possible to access a different opinion or experience. Consequently, until there are large numbers of PLWAs available as alternative role models, PLWAs need to take responsibility to give out messages that are best for everybody, not just those that are right for themselves.

- Helping to confront discrimination: PLWAs are an effective way to expose and end discrimination. When people are afraid of revealing their status publicly it is easy to discriminate against them. When they are open, discrimination is exposed and can be dealt with through appropriate disciplinary procedures. This sends a powerful message throughout the company.
- Setting an example to others: PLWAs can be direct role models for other employees by encouraging them to find out their HIV status and if they are positive, to take appropriate action such as eating well and accessing antiretroviral drugs. However, within the transitional stage we are currently in – where there are only a handful of PLWAs – there are dangers. Something that may work for most HIV-positive people may not work for a particular PLWA who could well be the only role model available. If this is the case, there is a danger that incorrect messages are transmitted.

**Thinking about PLWAs in the workplace**

We know that HIV/AIDS is surrounded by stigma and discrimination in our workplaces that, despite legal safeguards, prevents us from effectively responding to the epidemic. We want to change this situation and PLWAs can play an important role within an effective workplace HIV/AIDS programme. How effective that role is will depend on how well they are integrated into wider response structures. It is clear from some of the pitfalls raised in this article that an effective workplace response should support all those who are willing to reveal their HIV-positive status at work, but actively promoting them within the workplace should be a more carefully

thoughtout process. At a minimum, workplace PLWAs should have a number of key attributes.

- A willingness to remain in the organisation. A PLWA who remains in their normal employment provides a more accessible role model than somebody who becomes a 'full-time' AIDS worker;
- Good communication skills;
- Knowledge of HIV/AIDS;
- Understanding of the organisation's response to HIV/AIDS;
- Understanding and committed to undertaking treatment when appropriate.

Some of these can be provided through appropriate training. Others are about commitment to broader and not personal goals: the important thing is that workplace PLWAs find appropriate roles which they can carry out effectively within a well-resourced and well-supported company response to HIV/AIDS.

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**AIDS Helpline**

For basic information, counselling and referral contact the multilingual tollfree AIDS Helpline at 0800-0123-22.



The Labour Bulletin is interested in employee experiences of HIV/AIDS in the workplace.

Contributions can be sent to [salb@icon.co.za](mailto:salb@icon.co.za) or fax (011) 403-9873.