

Psychological support for adults living with HIV



Everyone living with HIV is entitled to specialist psychological support

Although many people living with HIV do not have psychological problems, specialist psychological support is available for anyone who needs it. Depression and anxiety are two of the most common types of psychological problems. They can affect anybody at some time in their life. Symptoms vary a lot but some of the most common are listed here:

ANXIETY: Feelings of panic and/or worry
 Difficulty breathing
 Restlessness/unable to relax
 Difficulty concentrating

DEPRESSION: Tiredness/ fatigue
 Low mood/negative thoughts
 Poor appetite/not hungry
 Loss of interest in everything
 Sleeping badly

People who are HIV positive are more likely to experience psychological problems than people who are HIV negative. Psychological problems can develop after HIV diagnosis or after experiencing some of the challenges of living with HIV. Many people living with HIV worry about their quality of life and issues such as their health. Some people living with HIV may experience discrimination or social isolation, which has been shown to have a negative impact on health.

If you are experiencing psychological problems, it is important that you share your concerns with your GP or HIV specialist.

How to seek psychological support

If you are living with HIV, you are entitled to regular mental health screening from your healthcare professional. You should expect to be treated with respect and dignity by all healthcare professionals and, if needed, referral to psychological support services should happen without delay and in a confidential manner.

Dealing with a long-term health issue such as HIV can affect a person's physical and psychological health. They are closely linked, and both must be managed for a happy, healthy, life.

The people closest to you are probably also affected by your diagnosis and so may also benefit from psychological support. Appropriate services for friends, family or partner can be found through organisations such as:

- GP surgeries
- Local HIV Charities
- Peer support groups.

There is also a lot of information, help and support available online. Healthcare professionals should be able to signpost you to the most reliable sources.

Psychological support can be provided in a variety of ways. An intervention is a popular and often effective way of providing psychological support for an adult living with HIV. There are many different types of intervention. For example, psychological support may be provided individually, to couples or groups of people. Health care professionals such as psychologists and health advisors are trained in providing psychotherapeutic and counselling interventions. However psychological support is also provided by qualified counsellors, support workers and groups based in the community.

This is a story of Scott, a young man who was diagnosed with HIV when he was 18.

‘Scott, who is in his early twenties, was diagnosed with HIV three years ago. The diagnosis really hit him hard. He was very worried about how people would react, expecting a lot of stigma, and found it very difficult to talk about it, even to family or close friends. He had no idea how things might work out and was scared that he would get a negative reaction from anyone who knew about his HIV status.

Scott began to feel lonely, and started to lose interest in activities that he used to really enjoy. When he started to have difficulty sleeping as well he decided to see his GP. They discussed how Scott had been feeling and he was diagnosed with depression. He was given medication and also referred for psychological therapy. He found that the psychologist really understood his problems. He was able to discuss his feelings in an open and friendly manner.

Three years later Scott has come to terms with being HIV positive. He is happy with his job, has a good network of friends and is now looking forward to what the future might bring.’

Seeking support

‘Psychological support’ refers to any form of support which is aimed at helping people living with HIV to enhance their mental health and their cognitive, emotional and behavioural wellbeing. Psychological support can be emotional support and the provision of a variety of talking therapies, cognitive rehabilitation and appropriate medication.

Psychological support is provided at different levels of complexity by a wide range of professional groups, peers and informal providers, in clinical settings and in the community. If you are living with HIV, you may need to access psychological support at some point in your life. Your needs are unique, and your needs will be different from somebody else who is living with HIV.

Psychologists suggest that there are four different levels of psychological needs. If you do suffer from psychological difficulties, the level of care that you may need will depend on the severity and complexity of your psychological problems. Each level requires a different level of provision. These problems will probably change over time, from when you are first diagnosed to when you are living with HIV long-term. It is important that you are receiving the most appropriate level of care for your needs. Your healthcare professional should assess this regularly.

1. Information and support
2. Enhanced support
3. HIV-specialist counselling and psychotherapies
4. Specialist psychological and mental health intervention

Levels of support

Level 1: Information and support

Neil was diagnosed with HIV by his GP. As his diagnosis was not entirely unexpected, he didn't feel that he needed psychological support. He conducted his own research but still had some basic questions for his GP, such as what the risk was of transmitting HIV to others. The GP referred him to the practice nurse who was able to answer most of Neil's questions and gave him some leaflets with information and details of local support organisations, where he could meet other people with HIV.

Anybody living with HIV should be able to access basic information and a basic level of support. Information and support should be provided by any healthcare professional that is directly responsible for providing care to a person living with HIV. Every healthcare professional that you may come into contact with, such as GPs, practice nurses, HIV doctors and nurses and peer support workers, should understand and have training in the basic psychological aspects of living with HIV, including stigma and confidentiality. They should provide emotional care, supported self-help, and signposting to other services. If more complex problems are identified you may be referred for specialist support. The health professionals that refer you should do so in a confidential and sensitive manner.

Level 2: Enhanced support

Linda was pregnant when she received her diagnosis. She didn't blame herself, but had a lot of questions about how to disclose to her present partner. She was advised to start HIV treatment as soon as she could as her CD4 count was low, but she was worried about her baby. She started to wonder if her baby would also be HIV positive. She visited a psychological wellbeing practitioner to explore her options about disclosure, condom use and treatment. Linda felt better for sharing her concerns and found that the psychological wellbeing practitioner was able to provide relevant and accurate information about disclosure, condom use and treatment.

Level 2 psychological support is provided by healthcare professionals with experience and training in providing psychological support for people living with HIV. They can help by providing short-term counselling on issues such as:

- Facing and coming to terms with test results
- Living with a long term illness
- Reducing sexual risk taking
- Antenatal and post-natal support
- Support for drug users
- Managing day to day life with HIV
- Information about psychological problems and how to manage them.

At this level, healthcare professionals should talk to you about your test results and discuss options for safer sex. If you are suffering from psychological difficulties such as depression or anxiety a psychological wellbeing practitioner may refer you to a specialised service which will offer specialised support for psychological difficulties.

Level 3: HIV-specialist counselling and psychological therapies

Isaac had been living with HIV for ten years and was on ARV therapy. He had a good job and had not felt that his HIV status had had much effect on his life. However, he recently discovered that his body was now resistant to the drugs that he had been taking, and his CD4 count had declined. Although the new combination of drugs that he received had been effective he had been feeling very anxious and quite depressed. He started to blame himself for the drug resistance and began to dread going into work. When he next visited his HIV specialist he was referred to a specialist HIV psychological therapy service. The sessions with the psychologist made him feel more relaxed, and helped him realise that the drug failure was not his fault. He started to accept that he could not deal with everything unaided.

Level 3 support is offered by qualified, professionally registered and supervised health professionals in providing counselling and psychological therapies. They can help with more complex psychological difficulties, such as adjustment difficulties, anxiety and depression, drug dependence or relationship problems. Specialist support may be provided through therapies such as Cognitive Behavioural Therapy (CBT). During CBT, a psychologist may help you to improve your awareness of how your thought can affect your health, to reduce negative thoughts and encourage healthier thinking patterns. At this level your health professional will assess your needs, to make sure you are receiving the most appropriate level of care for your needs. If your psychological difficulties are considered to be severe you may be referred to alternative specialist services.

Level 4: Specialist psychological and mental health intervention

Imogen was recovering from using drugs when she found out that she was HIV positive. After receiving her diagnosis she developed severe depression, and was unable to eat, sleep or get out of bed. She became paranoid that strangers in the street knew about her HIV status and she often thought about ways to end her life. The next time Imogen went to the clinic her major depression was identified by a specialist nurse who had received training in psychological health. She was referred to a psychiatrist, who prescribed her antidepressants and organised some sessions for psychological therapy. Imogen was able to start talking about her experiences and start putting her life back together.

Level 4 care covers psychological and mental health specialists such as psychiatrists, clinical psychologists and specialist psychotherapists. They work within HIV specialist services to treat more severe and complex psychological problems such as severe depression, drug dependence, personality disorder, and psychosis. If a person living with HIV has more than one of these issues or has one of these issues and is also experiencing physical ill-health, then a psychologist may work with them to identify what could be causing their psychological difficulties. A psychologist may discuss different ways of dealing with these psychological difficulties and monitor the effectiveness of each method.

If you want to know more, ask your GP or healthcare professional and other relevant community organisations in your area.

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