

DWP DISABILITY HANDBOOK AS AT FEBRUARY 2008 DMG SECTION 32

32 HUMAN IMMUNODEFICIENCY VIRUS (HIV) AND ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS)

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32.2 Introduction

32.2.1 Infection with human immunodeficiency virus occurs when infected body fluids are transmitted between individuals. This can occur during sexual intercourse, both heterosexual and homosexual, through transfusion of infected blood or blood products including shared hypodermic needles used by drug addicts and from mother to baby. The transmission from mother to baby may take place around the time of birth or through breast milk.

32.2.2 There is a world wide epidemic of HIV infection with the majority of cases occurring in the developing countries. In the early 1980s most cases in the UK were found in homosexual men and injecting drug users. An increasing proportion of new cases resulting from heterosexual transmission has been noted in the UK over recent years.

32.3 General

32.3.1 The effects of HIV infection on the body are gradual and progressive, usually over some years. The main effects of the virus are to cause a gradual reduction in the body's defence mechanisms against other infections and to compromise the body's normal protective mechanisms against the development of malignant disease. This is described as an **impairment of immunity or immunosuppression**. The types of infection which occur are often of an unusual nature resulting from organisms (germs) which do not commonly affect normal individuals, for example, severe fungal infections such as Pneumocystis carinii pneumonia (PCP), tuberculosis or parasitic infections. These infections known as **opportunistic infections** can have a grave prognosis and be difficult to treat. Similarly the malignant tumours which develop may be of an uncommon nature. The virus can also attack the nervous tissues including the brain, and this may result in the premature development of dementia.

32.3.2 Individuals with HIV infection are divided into four groups according to the stage of their infection:

Group I Primary HIV infection

Group II Asymptomatic phase

Group III Persistent generalised lymphadenopathy

Group IV Symptomatic infection (includes AIDS defining conditions)

32.3.3 Following an interval of about six weeks after the initial infection a short lived illness (group I) with fever and rash may occur. Subsequently antibodies to the virus can be found in the blood and detection of these forms the basis of the HIV test.

32.3.4 It may be many years before any further manifestations of the disease become apparent; the individual is symptom free and leads a normal life. This phase (group II) can last for ten years or more. As time passes some people may develop generalised enlargement of groups of lymph nodes (glands) in different parts of the body (group III). Many people remain symptom free and relatively well, although others may suffer from a general lack of well being and feelings of ill health. The latter group is however unlikely to have substantial care needs or restrictions in mobility.

32.3.5 As the individual's immunity starts to be compromised unusual infections occur that may be difficult to treat, persistent diarrhoea develops and there are general feelings of debility and fatigue (group IV). Skin and mouth conditions may cause symptoms. In later stages there can be profound weight loss, generalised weakness and persistent fevers and sweats. Drug treatment (see below) however can cause partial or complete resolution of these severe manifestations. Malignant disease of the lymph glands (lymphoma) and Kaposi's sarcoma - a type of malignancy, which can infiltrate the skin and other body linings with purple/blue nodules - may supervene. Other severe manifestations of the illness include tuberculosis, toxoplasmosis, cytomegalovirus, cryptosporidiosis, meningitis, encephalopathy and dementia (see **glossary**).

32.3.6 The treatment of HIV and AIDS has been revolutionised as a result of new drug treatments. Average life expectancy has increased significantly and the death rate is falling in developed countries such as the UK. Innovative **anti-viral drugs** have been developed which are given together - three, four or even more drugs are combined in a complex daily regime, which may be taken for prolonged periods of time - months or years. These drugs reduce the viral load (see below), boost immunity to infections and increase the length of symptom free existence. It is likely that the prognosis will continue to improve year on year as further drugs are developed.

32.3.7 Blood tests are used to assess the progression of the disease and the response to drug treatment. The amount of virus in the blood stream can be calculated and expressed as the **viral load**. Over 50,000 copies/ml indicates significant disease and 150,000 or more suggests that there will be severe problems. Another blood test the **CD4 count** is a measure of the body's resistance to infection. Normal CD4 count is over a 1000×10^6 cells/litre; when this falls to below 200 there is a risk of developing a severe infection such as Pneumocystis carinii pneumonia (PCP). Below 100 repeated serious infections can occur. A low CD4 count combined with a high viral load can indicate a very grave prognosis in the absence of a response to drug treatment.

32.3.8 Prior to the development of effective drug treatment the results of blood tests were a useful indicator of the progression of the disease and its severity. Results of blood tests should now be interpreted with medical advice taking into account the history of the illness and whether there has been a favourable response to drug therapy. They do not bear a direct relationship to the degree of disability or the prognosis.

32.4 Care needs

32.4.1 For a number of years HIV infected individuals remain free of symptoms and are well. As immunity decreases minor skin conditions - such as persistent warts, molluscum contagiosum, impetigo, folliculitis, seborrheic dermatitis - may develop but which in themselves will not lead to a need for attention from others.

32.4.2 Some people may describe debilitating side effects arising from the drug treatment regimes. These may include nausea, headaches, skin rashes and numbness of the hands and feet due to peripheral neuropathy (inflammation of nerves). Many of these symptoms are transient and can be controlled. More serious side effects of the drug treatment regimes do occur including weakness of the hands and feet due to peripheral neuropathy, anaemia and lipodystrophy (fat redistribution causing altered body shape). These can exacerbate disability.

32.4.3 Generalised lymph node enlargement combined with fever, malaise, sweats, weight loss and persistent diarrhoea may lead to the need for help with bodily functions in the course of the day. An individual may require help with changing bedding at night if he or she suffers from severe night sweats and general debility.

32.4.4 In more advanced disease a general poor state of health associated with repeated infections may lead to a state of overall debility and increasing care needs. Neurological complications affecting the spinal cord and peripheral nerves may lead to weakness of the limbs, pain and numbness of the hands/feet and poor balance. Help may be necessary to rise from a chair or manage at the toilet.

32.4.5 Changes in the brain may lead to poor concentration, memory loss, confusion, and fluctuating levels of consciousness and ultimately dementia. These problems may lead to a requirement for high levels of supervision. Certain infections such as cytomegalovirus and toxoplasma may affect the eyes and cause significant visual impairment.

32.4.6 The debilitating effects of tumours such as lymphomas may be exacerbated by the side effects of chemotherapeutic agents used in treatment. Anaemia and other blood abnormalities increase debility and predispose to infection and bleeding tendencies.

32.4.7 All these physical impairments may be accompanied by symptoms of anxiety and depression, which may arise following the diagnosis or become more prominent as disability increases. Disfiguring effects of the illness may exacerbate psychological impairment.

32.5 Mobility Considerations

32.5.1 Shortness of breath, neurological disease and weight loss may significantly restrict the ability to walk in the late stages of the disease. Chest infections such as pneumonia (PCP) and tuberculosis may cause breathlessness. An unusual form of tuberculosis - due to organisms such as *Mycobacterium avium intracellulare* - can be difficult to diagnose. Infections of these types however tend to respond well to conventional treatment in combination with anti-viral drugs and breathlessness can improve.

32.5.2 Significant visual impairment may contribute to the need for some guidance or supervision when walking out of doors.

32.6 Duration and Prognosis

32.6.1 With the advent of greatly improved drug treatment for HIV many individuals will live for many years without significant disability.

32.6.2 As immunity starts to diminish more serious or repeated infections, or the development of malignant disease, occurs. In assessing the degree of disability it is necessary to bear in mind the stage of the illness and the fact that some of the conditions will respond to appropriate drug treatment with improvement of function. Medical Services will be able to assist in interpreting complex hospital reports including the results of blood tests. Over time however as immunity declines care needs and mobility needs will increase.

32.6.3 As the disease progresses drug treatment may become less effective or a malignant condition such as lymphoma appears. This may indicate a much graver outlook. In determining that such a stage has been reached a factual report and advice from Medical Services are required.

32.7 Further evidence

32.7.1 Obtaining and interpreting further evidence in HIV/AIDS is of particular importance, since the condition can have varied and unusual clinical manifestations causing differing degrees of disability. For many people the life expectancy has increased dramatically with new antiviral treatments, and HIV infection should be considered to be a long-term (chronic) illness managed with medication. Interpretation of medical evidence including blood tests requires knowledge of the progression of the illness and response to treatment.

32.7.2 Most people are under the regular care of a hospital clinic, and a report can be obtained from the medical attendant or specialist nurse attached to the clinic. Those with increasing degrees of disability may have been assessed by an occupational therapist, who can provide a factual report. In some cases general practitioners have comprehensive information, but they may lack recent, up to date information if the person attends a clinic regularly. An EMP report can be useful to assess care needs or mobility when the condition appears stable and/or factual reports do not supply sufficient clinical information to enable Medical Services to advise.

32.8 Haemophilia Complicated by AIDS

32.8.1 For Haemophilia complicated by AIDS see Chapter 27