

## section 2.6.4: End stage HIV AIDS

### General description of the disease and progression

AIDS results from the late stage of HIV infection when the immune system has been badly damaged. Advanced immune deficiency is defined as a CD4 cell count below 200. At this stage, infections that only occur in people who are immune deficient may develop. These are known as “opportunistic infections” such as pneumocystis carinii pneumonia (PCP) and mycobacterium avium complex (MAC). These infections can be serious and life threatening. Cancers, eg lymphoma and Kaposi’s sarcoma, can also occur in late stage HIV.

In the past, HIV infection was viewed as a rapidly fatal disease – however significant improvements in treatment for HIV AIDS now means that patients may be infected for many years and remain well and have excellent functional status. In most people, HIV infection will progress over time to eventually cause health problems. The rate of progression varies greatly from person to person and depends on the particular medical conditions affecting the individual. The prognosis, treatment and recurrence of HIV related illness are variable and often unpredictable.

### Potential problems

- When diagnosed? How long has this patient known about his/her HIV infection? Is this a new diagnosis – many issues may need to be addressed including the patient’s psychological, emotional and mental health needs.
- **Information sharing – who knows what?** Is it documented formally? Patients with HIV infection need to have their privacy and confidentiality respected and health care staff should be mindful of this with relatives and friends. It is common for relatives and friends of people living with HIV not to be aware of the HIV status of their relative/friend.
- **HIV and mental health issues.** Depression, grief, feelings of isolation and fear can occur as with any dying person. Disenfranchised grief of same sex partners, lovers and friends may also need to be addressed.
- **Substance use and abuse.** Continued use of licit and illicit substances, apart from masking emotional pain, can cloud the physical manifestations of neurological and psychiatric illness.
- **Interaction with current medications.** Many of the antiretrovirals have major interactions with prescribed and non prescribed medications – check with Infectious Diseases Unit re changes to medications. HIV and the combination treatments used to suppress replication of HIV often cause a degree of neuropathy mainly in the lower limbs. This neuropathic pain is often difficult to control and may require use of adjuvant therapies. Other drug side effects may also require symptom control, eg nausea, anaemia, neutropenia.
- **Active treatment for complications/opportunistic disease.** Sometimes in end stage disease active treatment is undertaken to provide quality of life for dying patients. One example is the treatment of CMV to prevent retinal blindness before death.
- **Encephalopathy/dementia.** Viral replication of HIV in the brain is the main cause of encephalopathy/dementia in patients with end stage HIV infection – mild to severe memory loss, agitation, hypomania and occasionally paranoia may need to be managed.

### Identification of potential problems

- symptom managements will depend on disease stage, ie: Is this an opportunistic illness? Is this debility from end stage HIV? Does the patient have neuropathy? etc
- observe for changes in mood or memory
- ask about disturbed sleep, pain levels etc
- respect the patient’s confidential information

## **Special considerations**

No special infection control procedures are necessary for care of patients with HIV infection, however universal precautions must be used for handling of blood and body fluids. Correct disposal of "sharps" is important to prevent accidental exposure to HIV by health care workers. Refer to organisational OHS policy and procedures immediately if needle stick injury occurs.

## **Specific considerations for end stage care**

- encourage discussion with the patient about their wishes for care at the end of life as there may not be a gradual decline prior to a life threatening infection
- see Therapeutic Guidelines – Palliative Care for management of specific symptoms<sup>1</sup>
- see U.S Department of Health and Human Services – Health Resources and Services Administration web site for a comprehensive "Clinical guide to supportive and palliative care for HIV/AIDS – see <http://hab.hrsa.gov/>

## **references**

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<sup>1</sup> Therapeutic Guidelines - Palliative Care, Version 2 (2005), Therapeutic Guidelines Ltd, Victoria, Australia.