2

Managing people with HIV infection

Before you begin this unit, please take the corresponding test at the end of the book to assess your knowledge of the subject matter. You should redo the test after you've worked through the unit, to evaluate what you have learned.

Objectives

When you have completed this unit you should be able to:

- Manage a well patient with asymptomatic HIV infection.
- List ways of developing a healthy lifestyle.
- Describe ways the community can play an important role in supporting people with HIV infection.
- Provide counselling for people with HIV infection.
- Monitor the CD4 count.
- Provide care to patients terminally ill with AIDS.

GENERAL MANAGEMENT

2-1 What are the phases of managing patients with HIV infection?

1. Managing patients with acute seroconversion illness
2. Managing well people in the asymptomatic (latent) phase of HIV infection
3. Managing patients with symptomatic HIV infection
4. Preparing patients for antiretroviral treatment
5. Managing patients on antiretroviral treatment
6. Providing terminal care to patients with terminal AIDS

2-2 What are the goals of managing people who have asymtomatic HIV infection?

1. Keeping them well for as long as possible
2. Helping them live a normal, healthy lifestyle with a positive attitude
3. Preventing them spreading HIV infection to others

2-3 What is the management of well people with asymptomatic HIV infection?

It is important that attention is paid to the following:

1. Education about HIV infection and AIDS
2. Practising safer sex
3. Taking a good, balanced diet
4. Exercising regularly
5. Having adequate rest
6. Developing a positive outlook on life
7. Avoiding smoking, drinking excess alcohol or abusing drugs
8. Getting emotional support and counselling if needed
9. Providing good primary healthcare

In summary, develop a healthy, positive lifestyle. This is a very important part of managing a person with HIV infection. Each person with HIV infection needs a wellness programme.

A healthy lifestyle is very important for people who are HIV postive.

2-4 What is a wellness programme?

This is an active programme to encourage HIV-infected people to remain physically and emotionally well for as long as possible. A wellness programme promotes a healthy lifestyle. Both regular follow-up by an HIV clinic and support from the community are important. The media (radio, TV, newspapers, magazines, books) also have a role to play in promoting wellness.

2-5 Why is education about HIV infection and AIDS important?

The most important step in helping people with HIV infection is to enable them to learn about and understand their disease. They need to feel that they are still in control of their own lives and can play an active role in managing their illness. They must be empowered to make the best decisions for themselves. A good understanding of HIV infection and AIDS helps to reduce their anxiety and develop confidence and hope.

Knowledge and understanding is power.

2-6 What education is needed?

1. The natural history of HIV infection
2. How to prevent infecting others
3. Ways of strengthening the immune system through healthy living
4. The early symptoms and signs of HIV infection
5. What can be offered with antiretroviral treatment

2-7 Why is it important for an HIV-positive person to practise safer sex?

1. To prevent spreading HIV to others.
2. To avoid reinfection with HIV. Being HIV positive does not prevent further infection with other strains of HIV. The progression to AIDS is more rapid with multiple HIV infections.

It is essential that HIV-positive people practise safer sex.

2-8 What is safer sex?

The only way of totally preventing the sexual transmission of HIV is to avoid sex. However, the risk of HIV infection can be greatly reduced by changing sexual practices (safer sex). Condoms must be used every time the person has sex. Avoid multiple partners. Anal sex is particularly dangerous. Although oral sex is safer, it is still a recognised way of transmitting HIV.

The 'ABC' of safer sex is Abstinence (no sex), Be faithful (one partner only) and Condoms (always use a condom).

2-9 Are condoms adequate for contraception?

Condoms are only partially effective as contraception. Therefore some other form of contraception must be used as well. Progesterone injections (e.g. Petogen three-monthly or Nur-Isterate two-monthly) are best as some medication taken by HIV-infected people may interfere with oral contraceptives (the pill).

Any HIV-infected woman planning to fall pregnant should get advice from an HIV clinic.

2-10 Why is diet, rest and exercise important?

Having a good diet, adequate rest and keeping fit with moderate exercise help to maintain the normal function of the immune system. It is important that people in the

latent phase look after their health and wellbeing. This will prolong the period of asymptomatic HIV infection.

2-11 Why is it important to maintain normal body weight?

Because marked weight loss and poor nutrition are associated with a rapid progress to AIDS. Malnutrition weakens the immune system.

Weight loss in HIV-infected people may be due to:

1. Poverty
2. Depression
3. Poor appetite due to illness
4. Oral and oesophageal candidiasis
5. Chronic diarrhoea
6. Gut malabsorption
7. Tuberculosis

Unintentional weight loss is often an early sign of symptomatic HIV infection. It is important to maintain normal body weight for as long as possible.

2-12 What dietary advice should be given?

A balanced diet is important to provide sufficient amounts of carbohydrates, fats and protein. A diet containing an adequate supply of vitamins and trace elements may be supplemented with a daily multivitamin pill. A good calorie and protein intake helps to prevent weight loss.

First the person's present diet and pattern of eating should be reviewed. Then the person can be advised on local, affordable foods which would improve the diet. Small frequent meals are best. Alcohol intake should be reduced or stopped and smoking discouraged. The nutritional value of meals can be improved by:

1. Using starchy foods as the basis of most meals to provide calories, e.g. porridge, samp (mealies), rice or potatoes.
2. Adding 1–2 teaspoons of vegetable oil, margarine or peanut butter to provide added calories.
3. Using whole wheat or brown bread rather than white bread.
4. Providing protein with fish, eggs and meat (expensive) or beans, peas, lentils or soya products (cheaper).
5. Using only a little fat and salt.
6. Buying fruit in season (expensive) or fresh vegetables (cheaper). Do not overcook vegetables as this damages vitamins.
7. Use a variety of foods mixing starch, protein, vegetables and fruit. Cultivating a vegetable garden can save costs.

A good diet need not be expensive and helps to improve and maintain the immune system.

NOTE Good trials of dietary supplements are still needed. There is little scientific evidence that supplementation with specific nutrients is of benefit.

2-13 Can HIV infection be managed without antiretroviral treatment?

It is very important for all HIV-infected people to understand that every effort must be made to prolong the latent phase and delay the onset of symptomatic HIV infection. Antiretroviral treatment is only recommended when HIV becomes symptomatic.

Many people with AIDS do not yet have access to antiretroviral treatment and have to be managed symptomatically. Many of the symptoms of AIDS can be relieved and HIV-associated infections can be treated. However, antiretroviral treatment is the only effective management of AIDS and offers the only hope of prolonging a good quality of life.

2-14 Are herbal medications of value in HIV infection?

Many plants have an effect on the immune system. Some are believed to be helpful while others have been shown to depress the immune system. However, only very limited clinical trials have been conducted, with mixed results. It is hoped to identify herbal compounds which may strengthen the immune system and delay the onset of AIDS. Plant and other non-medical (alternative) substances can have

serious side effects. They may also interfere with antiretroviral treatment.

NOTE It has been shown that plant sterols and sterolins interact with antiretroviral drugs and lower blood levels. Until the proper tests are done they cannot be recommended.

2-15 What primary healthcare is needed by people who are HIV positive?

1. Promoting a healthy lifestyle
2. Offering primary prophylaxis when indicated
3. Providing an immunisation service
4. Monitoring the patient's weight
5. Screening for the early symptoms and signs of symptomatic HIV infection
6. Managing the minor problems associated with HIV infection
7. Helping patients obtain social support and counselling when needed
8. Monitoring the CD4 count

2-16 What is primary prophylaxis?

Most of the morbidity and mortality in HIV-infected patients are due to HIV-associated infections. Primary prophylaxis is the use of specific antibiotics to prevent some of these infections. Therefore primary prophylaxis is an important part of healthcare during the asymptomatic phase of HIV infection.

Co-trimoxazole and INH are the most important drugs used for primary prophylaxis.

NOTE Secondary prophylaxis is the use of specific preventative antibiotics in patients who have previously been infected with that organism.

2-17 What immunisations are helpful?

Most adults will have received the routine schedule of childhood immunisations. Some additional immunisations may be helpful in well people with HIV infection:

1. Hepatitis B
2. Influenza

The influenza immunisation is not effective in people with a CD4 below 200. Unfortunately these immunisations are expensive and usually not available from state clinics.

2-18 What is the risk of malaria in HIV-positive people?

The risk of severe malaria is increased in people infected with HIV. Therefore malaria is a major cause of death in HIV-infected people in some countries. If possible, they should avoid entering known malaria areas. Avoid mosquito bites by using insecticide-impregnated bed nets and insect repellents. Stay indoors from late afternoon to midmorning and wear long sleeves and trousers as well as shoes.

Prophylactic drugs are recommended. Co-trimoxazole helps reduce the risk of malaria. Treat immediately if symptoms of malaria develop within a few weeks of entering a malaria area.

NOTE Prophylaxis with mefloquine, doxycycline or 'Malanil'. Treat malaria with quinine and doxycycline or 'Coartem' (artemethet and lumefantrine).

2-19 Should HIV-positive patients bring their sexual partners to the clinic?

HIV-positive patients should bring their sexual partners, husband or wife, and children to the clinic for voluntary counselling and testing (VCT). Screening all high-risk groups of people for HIV infection is important in limiting the spread of infection. Ideally everyone should be screened.

THE ROLE OF THE COMMUNITY

2-20 Can the community play an active role in managing HIV-positive people?

If the HIV epidemic is to be controlled and patients with HIV infection adequately managed, the community will have to become actively involved in all aspects of prevention, support and care. This is difficult

where poverty, gender inequality, stigma and discrimination are common and HIV-infected people see themselves as helpless victims.

Local communities must take ownership of their joint problem and not simply rely on government providing the services. Fear, denial, stigma and discrimination will have to be overcome before a communal sense of responsibility can be developed and people believe they can contribute positively to solving the problem and make a difference.

Communities must become actively involved in addressing the enormous problem of HIV infection and AIDS.

Prevention and management of HIV infection must be seen as parts of the same integrated community programme. One will not be effective without the other.

2-21 What active role can the community play?

1. Changing sexual attitudes and behaviour
2. Reducing the stigma of HIV infection and AIDS
3. Supporting people living with HIV and their carers
4. Working with government services, non-government organisations and volunteer groups
5. Helping patients access health services and welfare grants
6. Educating the community about AIDS and helping to promote open discussion about HIV infection
7. Helping to empower women
8. Help care for AIDS orphans
9. Advising healthcare services on caring needs

The community has a very important part to play in the prevention and management of HIV infection.

2-22 Which community members can play an active role in helping?

1. Families
2. Friends and partners
3. Church groups
4. Youth clubs
5. Trade union organisations
6. HIV support groups
7. Other social groups
8. Volunteer health workers

Everyone in the community has a part to play. Without a community partnership, health services will have only a limited impact in preventing HIV infection and managing people with HIV infection.

2-23 What is an HIV support group?

One of the best ways of supporting someone with HIV infection is for them to join a group of people who also have HIV. Here they can share experiences in a safe, non-judgemental environment. Members of support groups can bring education, hope and improve the quality of life.

2-24 What are volunteer health workers?

These are members of the community who want to help people who are living with HIV. Home nursing is the greatest need. Patients need to be fed, cleaned, comforted and cared for. Help with simple chores such as cooking, cleaning, shopping and collecting water and firewood make a big difference.

Provision of knowledge, skills and support for lay health volunteers is essential. Volunteer health workers are the most realistic way of providing home-based care. They also play an important role in reducing stigma and discrimination in the community.

2-25 What is stigma?

Stigma is the negative thoughts and feelings that people have. It is a form of discrimination and has an important negative effect on people with HIV infection and their families. Unfortunately stigma is common and causes great personal

suffering. It remains one of the most difficult obstacles in tackling the HIV epidemic.

Stigma is a negative, damaging attitude towards people who are HIV positive.

2-26 What are the effects of stigma?

People with HIV who are stigmatised feel lonely, helpless and afraid. They are made to feel bad, despised, embarrassed and shameful and may hate themselves. They often feel that they are no longer respected and have brought disgrace on themselves, their family and their community because they are HIV positive. Due to stigma and discrimination, people with HIV are often avoided, feel socially isolated, and stop seeing friends and family. They may be thrown out of their homes, sacked from their jobs, abandoned by friends and even assaulted or killed.

Owing to the effects of stigma and fear of discrimination, many people refuse to be tested for HIV or deny their HIV status. This often leads to a fear of disclosure, delay in treatment and failure of preventing the spread of HIV. Many people choose to die of AIDS rather than disclose their HIV status and seek treatment. In many societies the words 'HIV' and 'AIDS' are not even used. People deny there is anyone with AIDS in their community despite the fact that everyone knows that many people are dying of HIV.

Stigma results in fear, denial and failure to prevent the spread of HIV.

Owing to the fear of stigma, the HIV status of pregnant women is often not recorded on the antenatal cards, while that of their infants is not recorded on their Road-to-Health cards. This prevents essential communication between healthcare workers.

2-27 What are the causes of stigma?

Usually ignorance and fear. The stigma towards HIV infection is usually due to the stigma surrounding sex and sexual activity. Stigma to sex is the real problem. In many societies, sex is seen as shameful and not spoken about or even acknowledged. Sex and the use of condoms are 'taboo' subjects. Negative attitudes towards sex are often promoted by the male head of the family, traditional leaders and the church. Many believe that the immorality of young women is the cause of the HIV epidemic. It may even be viewed as a punishment to society for the sin of promiscuity.

NOTE In a patriarchal society, sexual relations are controlled by men, leaving women disempowered and unable to control their own sexuality. Unequal power relations prevent women from protecting themselves and their children against HIV.

2-28 What can be done to overcome stigma?

Education, understanding, and critical and open discussion are the most effective ways of preventing and overcoming stigma. People need to learn appropriate emotional responses to sex and HIV infection. Support groups, where sexuality and HIV infection can be debated, are of great help and support.

Groups such as the Treatment Action Campaign and LoveLife have tried to make people aware of the damage that is being done by stigma to HIV. Life skills training at schools could reduce stigma to HIV by teaching healthy, open attitudes towards sexuality and the risk of sexually transmitted diseases. Government, church and community leaders, sports people and entertainers who are HIV positive need to disclose their status.

It is essential to create a social climate where people are not afraid of admitting they have HIV. Then they can openly practise safer sex and seek healthcare.

COUNSELLING

2-29 What is counselling?

Counselling is a process of education, communication and support by which a counsellor helps people to cope with difficult situations in their lives so that they are able to make important decisions and find realistic ways to solve their problems. Counselling, therefore, helps people make their own choices and supports these decisions, rather than simply giving them advice and information or telling them what to do. Counselling is far more than simply educating and is best provided by a trained counsellor.

Counselling is about empowering people to make important decisions and to solve their own problems.

2-30 What is a counsellor?

A counsellor is someone who is trained to educate, assist and give psychosocial support to people with problems. A good counsellor helps people to understand and accept their HIV status and to take the best course of action to lead a positive life.

Either a professional healthcare worker (nurse, social worker, doctor) or a lay person can be trained as a counsellor. Training large numbers of good lay counsellors is one of the major challenges facing those who care for people with HIV infection.

Both professional and lay people can be trained to be good counsellors.

2-31 What counselling may be needed?

Patients with HIV infection have many concerns about their future. Once they understand the nature of HIV infection and know that their immune system will become progressively damaged, they need to be able to speak about their worries and fears and obtain good information. They need good counselling.

2-32 When is counselling needed?

Counselling is needed:

1. When a person is being prepared for an HIV screen. Counselling is also needed when the person is told the result of the test, whether positive or negative.
2. During the asymptomatic phase of HIV infection when people are trying to practise a healthy lifestyle.
3. During the symptomatic phase when people have to learn to live with their illness.
4. During preparation for antiretroviral treatment and again while they are on treatment to ensure good adherence.
5. During terminal care when they are preparing to die.

2-33 What important skills are needed for HIV counselling?

Two essential skills are needed for HIV counselling:

1. A good knowledge of HIV infection and the personal implications of being infected with HIV.
2. The ability to communicate effectively. Communication is the basis of good counselling.

2-34 What is effective communication?

Communication in counselling is a two-way process in which information, knowledge, thoughts and ideas are passed between the person being counselled and the counsellor. The spoken word is the most important means of communication but the counsellor must be aware that people may also pass important messages by showing their emotions and in their body language (how they act). The counsellor must learn to pick up these signs as it helps in gathering information and giving appropriate understanding (empathy) and emotional support. Effective communication requires the skill of active listening.

Effective communication is a combination of active listening and using words with care and consideration.

2-35 What is active listening?

Active listening is the process of hearing not only the words people say, but also noting their body language and emotional reactions, and trying to understand the meaning behind their words and actions. In order to understand what a person is saying and to respond appropriately, the counsellor must become skilled in actively listening to people.

Active listening is the key to effective counselling.

2-36 What are the steps to good counselling?

A good counsellor should:

1. Put the person at ease so that they can feel free to talk.
2. Remove distractions and concentrate on what is being said. Close the door. Do not take phone calls, fiddle with notes or tap your pencil.
3. Speak a language that the patient can understand (or use a competent translator).
4. Do not talk too much. You cannot listen if you keep talking. Be silent when silence is needed. Do not interrupt unnecessarily or finish people's sentences.
5. Show interest.
6. Be patient and allow questions.
7. Express empathy and understanding. Try to put yourself in their place so that you can see the problem from their point of view.
8. Help people being counselled to identify problems and try to understand the causes before encouraging them to develop ways of finding solutions.
9. Always keep personal information confidential.

2-37 What are common errors which prevent good counselling?

1. Talking more than listening
2. Interrupting and arguing
3. Being judgemental
4. Concentrating only on facts, not feelings
5. Talking too fast and using complicated medical language

'If you do not listen to the person being counselled, do not expect them to listen to you.'

Good communication is blocked when the counsellor is judgemental, critical, threatening, manipulative, uninterested, or tries to control the discussion.

2-38 What else can help effective communication?

1. Choose your words carefully to ensure that what you say is what the person being counselled will understand.
2. Say what you mean and give simple messages.
3. Remember that as you can receive messages from the person being counselled from their body language, emotional reactions and tone of voice, so can you pass messages to them in the same way. Make sure you pass the 'right' message.
4. Repeat important information and make sure it is understood. Some messages may need to be repeated many times at one or more visits before they are accepted and understood.

MONITORING IMMUNE FUNCTION

2-39 What test is used to measure the degree of damage to the immune system by HIV infection?

The CD4 count. CD4 cells are lymphocytes that play a very important role in the normal functioning of the immune system. HIV

attaches to CD4 cells and kills them. As a result the number of CD4 cells gradually falls as the HIV infection progresses and more and more CD4 cells are killed. Therefore the CD4 count is the best measure of the degree that HIV has damaged the immune system.

The CD4 count measures the degree of damage done by HIV to the immune system.

2-40 What is a normal CD4 count?

The normal CD4 count in HIV-negative, healthy adults is 600 to 1500 cells/µl. A CD4 count above 500 cells/µl is usually regarded as normal. As the CD4 count falls below 500 cells/µl the function of the immune system steadily becomes worse and the patient is at increased risk of many infections.

The normal CD4 count is above 500 cells/µl.

2-41 What is the predictive value of a low CD4 count?

The lower the CD4 count, the greater the risk of symptomatic HIV infection and AIDS. Therefore, the CD4 count is the best predictor of the risk that an HIV-positive person will develop severe HIV-associated infections (i.e. AIDS).

The current South African guidelines recommend that antiretroviral treatment should be offered when the CD4 count falls below 200 cells/µl. However, antiretroviral treatment should be offered to all pregnant women and people with TB if the CD4 count is less than 350 cells/µl, whatever their clinical stage.

The CD4 count also indicates how quickly a person will progress to symptomatic HIV disease.

2-42 How fast does the CD4 count fall?

In most HIV-infected people who are not on antiretroviral treatment, the CD4 count falls each year by approximately 25 to 50 cells/µl. This will result in the CD4 count falling from 600 to 200 in four to eight years. Most HIV-positive people will have symptoms and signs of HIV infection by the time the CD4 count has reached 200 cells/µl.

In some people the CD4 count falls particularly fast (rapid progressors) while in others it falls slower than usual (slow progressors).

2-43 How accurate is the CD4 count?

The CD4 count is generally an accurate measurement. However, the CD4 count may vary, therefore the test should be repeated if the result is unexpected. Temporary falls may be due to an acute illness or recent vaccination.

2-44 How often should the CD4 count be measured?

In HIV-positive people who are well, the CD4 count should be measured every year to assess the condition of the immune system. When the CD4 count falls below 350 cells/µl it should be repeated every six months. Antiretroviral treatment should be considered when the CD4 count approaches 200 cells/µl. Regular monitoring of the CD4 count is an important part of the management of people with HIV infection.

NOTE The CD4 count is best done in stable patients who are not acutely ill with HIV-associated or other infections.

The CD4 count is the best way of monitoring the progress of HIV infection.

2-45 Should the viral load be monitored in well patients?

There is no need to routinely measure the viral load in patients with HIV infection who are not yet on antiretroviral treatment. Regular measurements of viral load are used to monitor the response to antiretroviral treatment.

NOTE A high viral load (above 100 000 copies/ml) indicates a high risk for disease progression.

There is no need to routinely measure viral load in patients who are not on antiretroviral treatment.

PALLIATIVE AND TERMINAL CARE

2-46 What is palliative care?

Palliative care is the care of patients who have an incurable disease (such as HIV infection). It aims at reducing suffering and improving the quality of life in these patients. Palliative care starts at the time of the diagnosis and addresses all the patient's physical, emotional, social and spiritual needs. Although HIV infection cannot be cured, most of the HIV-associated conditions can be prevented or adequately treated and controlled.

Palliative care addresses the physical, emotional, social and spiritual needs of people with an incurable disease.

NOTE Palliative care aims to 'heal' when a cure is no longer possible.

2-47 What is terminal care?

In contrast, terminal care is the active care of patients whose disease no longer responds to treatment, e.g. antiretroviral drugs. Terminal care is not the same as no care or poor care. Patients who are dying of AIDS need terminal care. Care should never be withdrawn because there is no longer any hope for a cure.

2-48 Do patients with advanced HIV infection need terminal care?

As HIV infection cannot be cured there is an enormous need for terminal care in these patients. Terminal care is most needed in patients who are likely to die within months or weeks.

2-49 Where should terminal care be provided?

Home care is the basis of terminal care. If at all possible these patients should be cared for in their own home where they are comfortable in their own surrounding and with their family and friends. Only if this is impossible should they be given care in an institution, preferably in a hospice.

Terminal care should be provided at home if possible.

2-50 What is a hospice?

This is a place where terminally ill patients can be cared for. Management is aimed at compassionate care and support rather than cure. Members of a hospice team also help to care for patients who are at home.

2-51 Who should provide terminal care?

As there are so many aspects to terminal care, it is best provided by a team of people who are trained in this special type of care. A multidisciplinary approach is needed to meet the many different physical, psychosocial and spiritual needs of terminally ill patients. Patients, family and friends also have a role in terminal care.

2-52 What are the goals of terminal care?

To improve the quality of care of patients, and their families, who are facing death. Terminal care offers prevention and relief of suffering. The goal of terminal care is not necessarily to prolong life, but to reduce suffering.

The goal of terminal care is to prevent and relieve suffering.

2-53 What does terminal care involve?

1. The controlling of unpleasant symptoms, especially pain
2. Reducing the side effects of drugs used
3. Treating HIV-associated infections

4. Supporting the patient as well as family and friends
5. Giving patients and families control over the management

2-54 What physical problems need to be addressed with terminal care?

1. Nutrition
2. Pain and discomfort

2-55 What are the nutritional needs in patients with terminal AIDS?

These patients are often wasted and very underweight. They may also have a poor appetite, nausea and difficulty swallowing. It may be difficult for them to obtain and prepare food.

High-calorie and protein foods are important. It is important that patients are able to choose foods which they prefer. If possible, intravenous fluids or nasogastric feeds should be avoided.

2-56 Is pain a common problem in patients with advanced AIDS?

Yes, severe pain is very common in patients who are dying of AIDS. It is likely to be under-diagnosed and under-treated. Pain significantly reduces the quality of life and results in fear and despair. Pain also causes distress to the family.

Severe pain is a major problem in patients who are dying of AIDS.

2-57 What are the principles of pain relief?

1. The correct choice and dose of analgesia (pain relief) is important.
2. Analgesics (drugs to relieve pain) should be given regularly ('by the clock') to both prevent and treat pain.
3. Oral analgesia should be used whenever possible.
4. Give clear written instructions.
5. Assess the amount of pain and review the pain management frequently.
6. Manage factors that aggravate pain such as fear, loneliness and depression.

The aim of pain management is to control pain by giving analgesia regularly so that pain can be prevented.

The aim of pain management is to prevent pain.

2-58 What common mistakes are made in treating pain?

1. Morphine is used too late.
2. The dose of analgesic is too low.
3. Medication is not given frequently or regularly enough.
4. Medication is only used to treat, rather than prevent, pain.

2-59 What common analgesics are used to control pain?

1. **For mild pain**: Paracetamol (Panado) and ibuprofen (Brufen). The dose of paracetamol is 1000 mg (2 x 500 mg tablets) every four to six hours as required. The dose of ibuprofen is 200 to 400 mg every four to six hours as needed.
2. **For moderate pain**: Codeine phosphate 30 to 60 mg every four hours. Often paracetamol or ibuprofen is used in addition.
3. **Severe pain**: Oral morphine solution starting at 5 to 10 mg every four hours.

The choice of analgesics for an individual depends on their degree of pain. As pain increases one moves up the 'treatment ladder' from step 1 (non-opioids such as paracetamol and ibuprofen) to step 2 (weak opioids such as codeine phosphate) to step 3 (strong opioids such as morphine).

NOTE Amitriptyline (an antidepressant), carbamazepine (an anticonvulsant) and steroids are often helpful for pain due to peripheral neuropathy, herpes neuralgia or nerve compression.

2-60 How is morphine used?

If possible, it should be given orally. A dose must be given every four hours as the action of morphine is short. Give an extra dose equivalent to the four-hourly dose if the pain is not controlled. Giving extra doses for 'breakthrough' pain is very important. The starting dose of 5 to 10 mg should be increased by 50% every second day until the pain is controlled (the total dose over 24 hours should be divided by two to give the amount that the daily dose should be increased). There is no maximum dose. The correct dose is the dose which is effective. Therefore the dose of morphine should be titrated against the degree of pain.

Morphine can also be given by continuous subcutaneous infusion with a syringe driver, intramuscularly or intravenously.

Frequent doses of oral morphine are the most effective form of pain relief.

2-61 What common problems occur with morphine?

1. All patients on morphine develop constipation. Fruit, bran and extra fluids are helpful. Laxatives such as liquid paraffin 5 to 20 ml daily and senna (Sennacot) 15 to 30 mg daily should be used. Constipation does not become less with continued use of morphine and is the major side effect. Morphine may be useful in controlling chronic diarrhoea.
2. Nausea and drowsiness. This improves with time (tolerance) and responds to a lower dose.

Addiction is not of concern when morphine is used to control pain in terminally ill patients. Do not stop morphine suddenly as this may result in withdrawal symptoms. Respiratory depression is uncommon when morphine is used to control pain.

2-62 What other forms of discomfort are common in advanced HIV infection?

1. Anorexia, nausea and vomiting
2. Diarrhoea
3. Constipation
4. Cough and shortness of breath
5. Itch or dry skin
6. Fatigue and weakness
7. Lack of sleep
8. Bed sores
9. Incontinence

A syndromic approach is used in terminal care when the symptoms are managed even if the underlying cause cannot be treated. Help from hospice staff is very useful in preventing and managing most of these problems.

2-63 What can be used to treat nausea?

Nausea is a common problem, especially when treatment with morphine is started. Metoclopramide (Maxolon) 10 mg orally eight-hourly is helpful.

2-64 How can treating HIV-associated infections improve the quality of life in a patient dying of AIDS?

Treating the symptoms caused by HIV-associated infections can greatly improve the quality of the last weeks of life. For exampzle, treating painful mouth ulcers, or relieving painful swallowing by managing fungal oesophagitis, or preventing blindness due to CMV retinitis.

Relief of symptoms is often best achieved by treating HIV-associated infections.

2-65 Is it worthwhile treating patients who are dying?

Yes. Patients should never be allowed to feel abandoned by their health carers. Pain, discomfort and distress must always be aggressively managed. However, sometimes it may not be realistic to treat terminally ill patients if the treatment will only prolong their suffering.

The question that must always be asked is 'will this make a difference to the quality of the person's life?'

2-66 What are the psychological aspects of terminal care?

Anxiety, fear and depression are common in terminally ill patients and are often not recognised. It is important to manage anxiety and depression as they both aggravate pain.

Anxiety, fear and depression make pain worse.

2-67 What are the signs of depression?

Withdrawal, sadness, sleep disturbances, poor appetite, depressed mood, lack of energy and interest in the world around them, and suicidal thoughts. Depression is common and unfortunately often missed. Management consists of emotional support and antidepressants. Response to medication may take a few weeks.

2-68 What is a memory box?

This is a simple box that parents can store mementos in for their children. Photographs, letters and cards are kept in the box which is given to the children when they are older to help them remember a parent who has died of AIDS. A memory box is one of the many ways that a parent can prepare themselves before death separates them from their children.

2-69 How can the spiritual needs of terminal patients be met?

Most people as they near the end of their lives need to speak to someone about their approaching death. The spiritual needs of members of a religious group usually are well attended to. However, many people who have not regarded themselves as religious also need spiritual counselling. It is important for the members of the health team to find someone suitable to meet this need.

2-70 Do the carers need care themselves?

Yes. This is often forgotten or not realised. Care of the carers is a very important part of terminal care. It is physically and emotionally exhausting to care for terminally ill patients. Practical help with lifting, turning, washing and feeding is needed, as well as emotional support.

CASE STUDY 1

A young woman with asymptomatic HIV infection is referred to a primary-care clinic where the staff have a special interest in managing HIV-positive people who are still well. She wants to learn how to live with her condition.

1. What are the goals of managing people who have asymptomatic HIV infection?

To help these people to remain well for as long as possible and teach them how to live a healthy lifestyle. They also need to prevent spreading HIV infection to others.

2. What should she do to develop a healthy lifestyle?

Take a balanced diet, get adequate rest and regular exercise. Avoid excessive alcohol, do not smoke or abuse drugs and develop a positive outlook on life.

3. How can she get help to achieve these goals?

She can join a wellness programme.

4. What is an HIV support group?

This is a group of people with HIV infection who can support each other and share experiences in a safe, non-judgemental environment. They can learn from one another how to live a healthy life.

5. What is safer sex?

Abstinence is the only way to be completely safe. However, being faithful to a single partner and using a condom are ways to greatly reduce the risk of getting or passing on an HIV infection.

6. Can HIV infection be managed without antiretroviral treatment?

Much can be done to remain well for many years after HIV infection. Minor problems can also be successfully managed. However, antiretroviral treatment is the only effective management when a patient develops AIDS. Unfortunately, it is not always available to all who need it.

CASE STUDY 2

A healthy man with asymptomatic HIV infection has been followed up at a local clinic for a number of years. At his last visit his CD4 count is 650 cells/µl.

1. Is his CD4 count normal?

Yes, as the normal range is 600 to 1500 cells/µl.

2. When should his CD4 count be repeated?

A patient with asymptomatic HIV infection should have a routine CD4 count measured every year. Once the CD4 count falls below 350 cells/µl it should be measured every six months.

3. How fast does a CD4 count fall?

The rate of fall varies from one person to another. However, the CD4 count in most HIV-infected people falls by 25 to 50 cells/µl each year.

4. Should the viral load also be measured?

The viral load is not routinely measured unless the person is being managed on antiretroviral treatment.

5. What is the value of measuring his weight at each clinic visit?

Unexpected weight loss may be an early sign of symptomatic HIV infection or tuberculosis. Maintaining a normal body weight by taking a good, balanced diet helps to prolong the latent phase.

6. Will multivitamin pills and herbal medicines help to delay the onset of symptomatic HIV infection?

There is little evidence that specific nutritional supplements help if the person is on a good diet, while herbal remedies can have serious side effects and drug interactions with the antiretroviral medication.

CASE STUDY 3

A depressed patient with AIDS is referred to a HIV counsellor. She has a good knowledge of HIV infections and is aware of the importance of her symptoms. Unfortunately, she does not have access to antiretroviral treatment.

1. What is HIV counselling?

Counselling is a method which uses education, communication and support to help a person manage their lives better, make decisions and find realistic ways to handle their problems. Counselling is more than just education.

2. Can someone who is not a health professional become a counsellor?

Yes. Many people from the community can be trained to become good counsellors.

3. What skills are needed by a counsellor?

They need to have a good knowledge of HIV infection and also be able to communicate well with people.

4. What is active listening?

Active listening notices body language and emotional reactions as well as words to understand what a person is trying to say. Active listening is the key to effective counselling.

5. What are commonly missed signs of depression?

A depressed mood, sadness, lack of interest in the world around them, sleep disturbances and suicidal thoughts. Depressed patients should be referred for assessment and possible treatment with antidepressants.

6. Is it worth treating a person with AIDS if antiretroviral treatment is not available?

Most definitely. Many of the symptoms of AIDS can be relieved and the quality of their lives improved during the last weeks and months. Patients should never be allowed to feel that they have been abandoned by the health carers.

CASE STUDY 4

A terminally ill man with AIDS is being cared for at home by his family. He has constant severe pain and the family is exhausted and can no longer manage.

1. Who should look after this patient?

It would be best if he could remain at home, but the family will need help. Failing this, it may be possible to move him to a hospice. Only as a last resort should he be admitted to hospital. Volunteer health workers could help with the many tasks needed in the home, such as cleaning and cooking. They can also help with washing and cleaning the patient.

2. Could the hospice advise on his home care?

Yes. Staff from the local hospice do home visits and are very experienced in the care of terminally ill patients.

3. What would be the best pain management for this man?

Usually analgesics for mild pain (e.g. paracetamol) and moderate pain (e.g. codeine) are tried first. However, this patient probably needs morphine for severe pain.

4. What is the preferred way of giving morphine?

By mouth every four hours. The dose of morphine is increased until the pain is controlled. The aim is to prevent pain and not to give morphine only when the pain is severe.

5. What is the common side effect of morphine?

Constipation. This can be controlled by adding fruit, bran and extra liquid to the diet. A laxative should also be given. Nausea and drowsiness may occur but they usually improve with time.

6. What is a memory box?

It is a box in which dying patients can put mementos, such as photographs, letters and cards, that can be given to their children when they are older. It enables terminally ill patients to leave something behind which will help their children remember them.