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3 Palliative Care for People Living with HIV/AIDS

Clinical Protocol for the WHO European Region

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Edited by:
Irina Eramova
Srdan Matic
Monique Munz

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Abbreviations

AFB	acid-fast bacilli
AIDS	acquired immunodeficiency syndrome
ART	antiretroviral treatment
ARV	antiretroviral
BID	twice daily
BPAD	bipolar affective disorder
CBT	cognitive behavioural therapy
CMV	cytomegalovirus
d4T	stavudine
ddI	didanosine
DSP	distal symmetric polyneuropathy
ECG	electrocardiogram
GAD	generalized anxiety disorder
HAART	highly active antiretroviral treatment
HIV	human immunodeficiency virus
IDU	injecting drug user
IM	intramuscularly, intramuscular
IV	intravenously, intravenous
MAO	monoamine oxidase
NSAIDS	non-steroidal anti-inflammatory drugs
OD	once daily
OI	opportunistic infection
ORS	oral rehydration solution
OST	opioid substitution therapy
PI	protease inhibitor
PLWHA	people living with HIV/AIDS
PO	per os (orally)
QID	four times daily
SSRI	selective serotonin reuptake inhibitor
TB	tuberculosis
TID	three times daily
VZV	varicella-zoster virus
WHO	World Health Organization

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Irina Eramova, Srdan Matic and Monique Munz
Sexually transmitted infections/HIV/AIDS programme
WHO Regional Office for Europe

I. Policy, principles and organization of services

1. Policy

Palliative care is an approach that improves the quality of life of patients and their families when facing the problems of life-threatening illness. While disease-specific (or "curative") treatment is directed at reversing the course of an illness, palliative care is primarily focused on the prevention and relief of suffering in progressive, incurable disease. Early identification, sound assessment and effective treatment of pain and other physical, psychosocial and spiritual problems are essential elements in assuring quality palliative care *(1–5)*. Ideally, palliative care and disease-specific treatment should be integrated throughout the course of chronic, life-limiting illness, rather than being divided into two completely disconnected treatment approaches. The balance between palliative and curative therapy should depend in a given situation on the etiology of the patient's symptoms and suffering, the possibility of improving these symptoms through disease-specific and/or palliative interventions, and the availability of resources in the particular country *(6)*.

- Palliative care is a core component of comprehensive HIV/AIDS care.
- Access to palliative care should not be artificially restricted due to political or social constraints. All patients needing and wanting it should receive it, without exception.
- Palliative care should be provided in accordance with the needs of the patient and WHO standards of care.
- Treatment for illnesses and conditions should not be withheld at any stage of the disease (for example, tuberculosis (TB) treatment, antiretroviral treatment (ART) or substitution therapy for injecting drug users).
- Palliative care should be incorporated as appropriate at every stage of HIV disease, and not only when the patient is dying.

2. Principles

The guiding principles of palliative care are to:

- provide relief from pain and other distressing symptoms to enhance quality of life;
- integrate the psychological and spiritual aspects of patient care;
- offer support to help patients live as actively as possible;
- offer support to help families cope during illness and bereavement;
- draw on experience and communication between the patient and health care provider (nurse, physician, family member, etc) to provide the best combination of interventions and medications;
- affirm life and regard dying as a normal process;
- strive neither to hasten nor postpone death.

3. Organization of services

- The needs of patients and their families can be addressed by a team approach, including bereavement counselling if indicated.
- Palliative care services can be provided as consultative services in hospitals at both inpatient units and outpatient clinics.
- Palliative care services can also be provided in the community, in outpatient settings and as home-based care, coordinated with hospital services as needed.
- Where available, palliative care specialists should be available to AIDS clinical services. In situations where such access is difficult, AIDS clinics should refer to other institutions where palliative care specialists and services are available.
- AIDS care providers should also be familiar with basic principles of palliative care and be able to manage routine problems without needing to refer to palliative care specialists.
- Nongovernmental organizations should be involved in delivering palliative care.

II. General considerations for palliative home care of people living with HIV/AIDS (PLWHA)

Care of patients at home and in the community is an essential component of palliative care. Caregivers' questions and concerns about safety and infection control can be readily addressed by references to simple and longstanding practices which decrease risk of contamination with HIV and other bloodborne pathogens. Standard infection control measures to prevent the transmission of HIV have been well established since the 1980s *(7, 8)*. Precautions that should be taken when caring for someone with HIV/AIDS, whether it be in the hospital, clinic or at home, should be the same. These precautions are based on the principles of standard infection control and should be in place and respected at all times. These principles minimize the risk of contamination through infected blood or other body fluids by considering all such fluids as potentially infectious and applying simple and consistent techniques for handling and disposing of them.

1. Precautionary measures at home

When palliative care is offered at home, the health care provider (doctor or nurse) should counsel the home care provider (family member, friend or other service provider) on the following points.

- Family members and other caregivers can safely care for AIDS patients. There is an extremely low risk of HIV transmission to health care providers and household contacts if the following hygienic practices are respected.
  - Wear latex gloves when in contact with blood and bodily fluids.
  - Keep wounds covered (on both caregivers and PLWHA); if they become wet with blood or other body fluids, change dressings and dispose of properly.
  - Clean up blood, faeces and urine with ordinary household bleach while wearing gloves.
  - Keep clothing and sheets that are stained with blood, faeces or other body fluids separate from other household laundry. Use a piece of plastic or gloves to handle soiled items.
  - Do not share toothbrushes, razors, needles or other skin-piercing instruments.
  - Wash hands with soap and water after changing soiled bedsheets and clothing and after any contact with bodily fluids.
- There is no risk from casual household contact (no gloves needed).
- Cutlery and other food items, unsoiled clothing and linens, toilets, baths, showers, etc. can be cleaned with ordinary cleaning products.

2. Education on management of symptoms

The attending doctor or nurse should provide clear instructions to home caregivers on the management of symptoms, including:

- explanation of symptom management;
- education in the most immediately necessary areas, teaching a few skills at a time;
- demonstration of skills, such as how to safely give an injection;
- verification of skills and knowledge by asking questions and requesting demonstrations;
- encouraging the care provider to return if there are any questions or concerns;
- ensuring that the caregivers know when and whom to call for help and how to provide back-up, especially in case of side-effects or drug interactions.

3. Psychosocial issues for affected families

When recommending palliative home care for PLWHA, the health care worker needs to consider the family's emotional state, the home environment and any socioeconomic issues that may affect the patient and family. Significant factors may include:

- frustration, sadness, grief;
- family members' fear of becoming infected if they are not already known to be;
- anger and blame for the infection that are directed towards the patient;
- stigmatization and discrimination of the patient, family members, friends and other caregivers; and
- concerns about the economic impact of life-threatening illness on the main family wage-earner(s), and the possibility of orphaning any children.

Actions to be taken include:

- assessing if the family is physically and emotionally capable of caring for the patient and other home responsibilities (may include age-related concerns);
- counselling and educating family caregivers;
- providing psychological support, referrals to HIV/AIDS psychologists and/or peer support groups;
- assisting in planning for and ensuring care of orphans;
- referral to social service agencies for financial, legal and other assistance.

III. Initial evaluation

The initial evaluation of PLWHA in need of palliative care, like the initial clinical evaluation of newly diagnosed PLWHA, should include a complete history, physical examination, general staging of the illness (i.e. WHO Categories I–IV), and assessment of any active problems or other issues requiring intervention or follow-up. (See Protocol 1, *Patient evaluation and antiretroviral treatment for adults and adolescents*.) In addition, the palliative care-focused evaluation should identify any significant physical symptoms; the types and degree of pain; any emotional, psychological or spiritual issues; and any family or social problems.

Box 1. Initial evaluation of PLWHA in need of palliative care

History

- Present illnesses and treatments administered
- Past medical history, including all comorbidities and past HIV-related complications, other major illnesses, hospitalizations, surgeries and date of HIV diagnosis
- Medication history
- Substance use and dependence history, including treatment (see Protocol *5, HIV/AIDS treatment and care for injecting drug users*)
- Family history
- Social history
- Social resources
- Financial issues
- Current symptoms (i.e. pain, weight loss, anorexia, fatigue, fevers, night sweats, insomnia, sadness, anxiety, dyspnoea, cough, nausea/vomiting, diarrhoea)
- Chronology of symptoms
- Exacerbating and relieving factors
- Current medications or other treatment for symptoms
- Cause, type and grade of pain[1]
- Symptom cause, type and characteristics
- Impact:
  - of symptoms on functional capabilities
  - of symptoms on each other
  - of specific therapies on each symptom
  - of symptoms on patient's quality of life
- Mental health history and treatment (e.g. depression, anxiety disorder, delirium, psychosis), and any current mental health problems

Physical examination

- Full clinical examination
- Systems review including:
  - constitutional (fatigue, anorexia, fevers, weight loss)
  - neurological
  - mental status
  - dermatological

Other examinations and tests as required

[1] Grading of pain should be on a 0 to 10 scale, with 0 being no pain and 10 being the worst pain imaginable.

The initial palliative care assessment should result in a staging of the HIV infection; identification of comorbidities and other relevant medical, mental health, social and environmental conditions; classification and grading of pain and other symptoms; and an initial plan for addressing the multiple needs of the patient and the patient's family in accordance with the conceptual framework of palliative care outlined in section I above.

IV. Treatment

Since early in the AIDS epidemic, patients with HIV/AIDS have been found to have a high prevalence of pain and other symptoms *(9–24)*. The source of pain (and most of the other common symptoms of HIV/AIDS) can be HIV itself, specific opportunistic infections or malignancies, medications used in the treatment of HIV, and/or other coexisting conditions. Accordingly, the most effective approach to symptom management may be treating an underlying condition, controlling HIV infection, changing medications to reduce toxicity and/or treating the symptoms themselves.

1. Pain management

Pain is generally categorized as nociceptive or neuropathic.

Nociceptive pain results in the stimulation of intact nociceptors (pain receptors), and it is subdivided into:

- somatic pain (involving skin, soft tissue, muscle and bone)
- visceral pain (involving internal organs and hollow viscera) *(25)*.

Nociceptive pain generally responds to non-opioid and opioid analgesics.

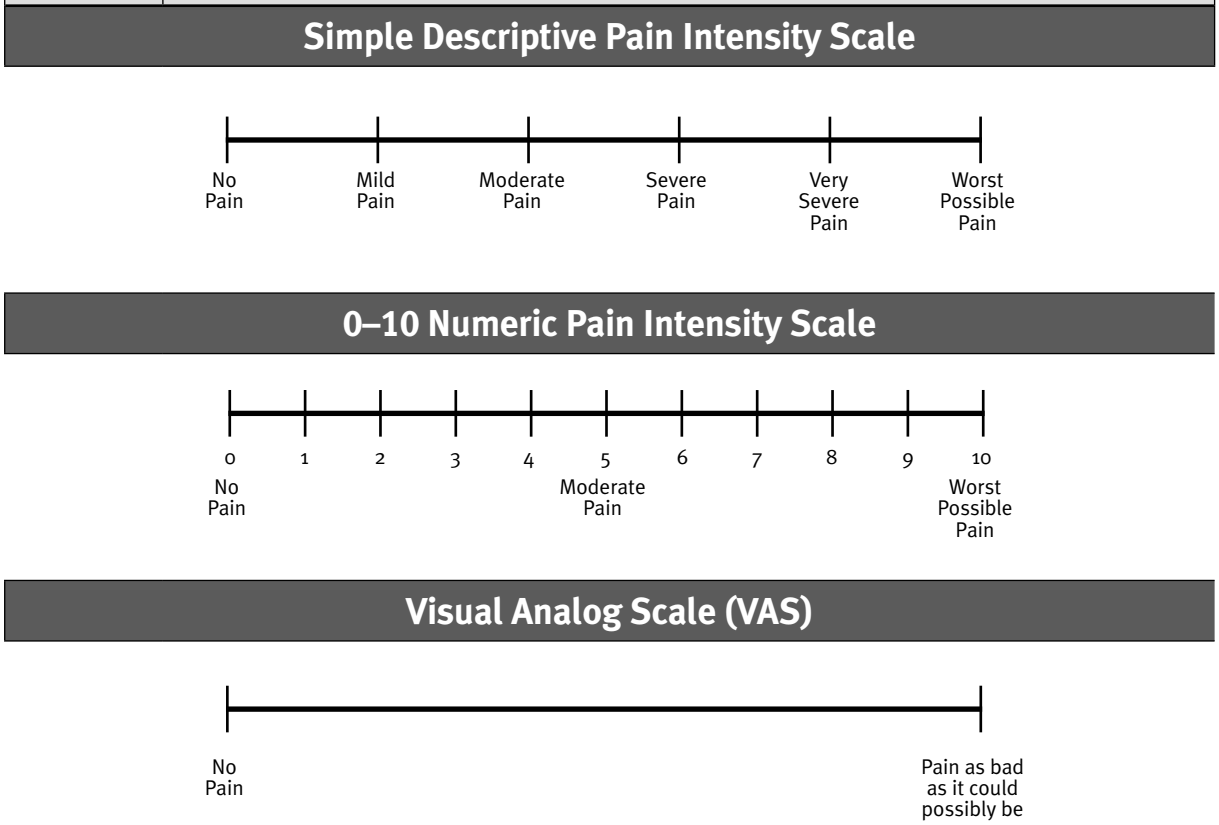
In PLWHA, neuropathic pain occurs in at least 40% of patients with advanced disease *(21)*. It is mostly due to the syndrome of distal symmetric polyneuropathy (DSP), which is an axonal neuropathy apparently caused by HIV infection itself and characterized by numbness, tingling, a "pins and needles" sensation and allodynia, especially involving the distal lower extremities and feet *(26–31)*. Neuropathic pain generally responds to non-opioid or opioid analgesics together with adjuvant medications such as antidepressants or anticonvulsants *(1, 2, 24, 29, 31, 32)*.

In addition, certain antiretroviral agents used in ART, e.g. didanosine (ddI) and stavudine (d4T), have been associated with a similar toxic neuropathy with comparable symptoms that also affect the distal lower extremities. In these cases, a change in antiretroviral agent(s) may result in some improvement, though that is not always the case.

Pain management should begin with a thorough and systematic assessment of pain, including possible etiologies, and the specific nature of pain. Important characteristics include intensity, type, interference and relief.

- **Pain intensity.** Use of a 10-point numeric scale is standard, with 0 as no pain and 10 the worst possible pain. It is particularly helpful to use the same scale over time in an individual patient, to monitor any changes on a continuing basis (see Fig. 1 below) *(33)*.
- **Pain type.** Nociceptive pain may be described as aching, stabbing, deep, dull, pulsating; neuropathic pain may be described as burning, tingling, "pins and needles", numbness or otherwise abnormal sensations. Such characterizations can help guide analgesic choice, especially for suspected neuropathic pain.
- **Pain interference.** The impact of pain on patients' functional status, ability to perform usual daily activities and emotional state should also be documented.
- **Pain relief.** Conditions or interventions which increase or decrease pain should be elicited.

Fig. 1. Pain Intensity Scales

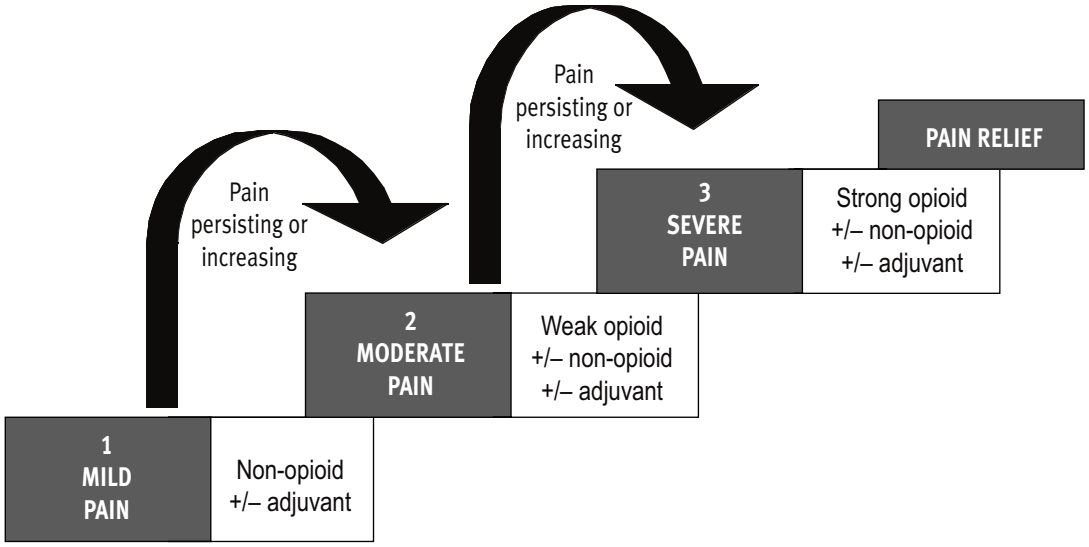


Note: a 10-cm baseline is recommended for any graphic representation of these scales.
Source: Acute Pain Management Guidelines Panel, 1992 *(33)*.

Severe chronic pain most often occurs with malignancies, chronic pancreatitis, joint problems and severe neuropathy.

A graded approach for using analgesics to treat mild, moderate and severe pain, along with the potential use of adjuvant medications at each stage, can be helpful (see Fig. 2) *(1)*. Table 1 below, expands on this approach indicating starting doses and other recommendations.

Fig. 2. WHO analgesic ladder for management of pain in PLWHA



+/–: with or without.
Mild pain: 1–3 on the 0–10 Numeric Pain Intensity Scale; moderate pain: 4–6; severe pain: 7–10.
Non-opioid analgesics: ibuprofen, indomethicin, acetylsalicyclic acid, paracetamol.
Adjuvants: amtriptyline, imipramine, gabapentin, carbamazepine, valproic acid.
Weak opioids: codeine, hydrocodone.
Strong opioids: morphine, oxycodone, methadone, hydromorphone, fentanyl.
Notes: Adjuvant medications are particularly helpful for neuropathic pain. Not all analgesics will be available in all settings.
Source: adapted from WHO, 1990 *(1)*.

Some specific considerations are worth noting.

- If possible, administer analgesics orally or (assuming no history of rectal abscesses, rectal infection, etc.) rectally. Intramuscular pain management, though sometimes required for severe pain not responding to oral regimens, can be painful in itself and may pose a risk of infection. If necessary and available, intravenous or subcutaneous infusion of strong analgesics can be used as an alternative route of administration, especially in hospital settings but also in the home if resources permit.
- Tailor the analgesic regimen to patterns of sleep, i.e. if possible do not awaken the patient to give pain medication.
- Administer analgesia before the effects of the previous dose have worn off.
- Start with a low dose and increase gradually until the patient is comfortable.
- For breakthrough pain[2], give an extra dose (50–100% of the 4-hourly dose) in addition to the regular schedule.
- While aspirin can be effective in controlling mild-to-moderate pain, care should be taken in using it due to the increased bleeding tendencies of PLWHA, especially in patients with clinically significant liver disease. Paracetamol may also be problematic in patients with active liver disease and should be used cautiously, generally not exceeding 2 g/day in such patients.

[2] Breakthrough pain is pain that "breaks through" a regular pain medicine schedule. Breakthrough pain comes hard and fast and can last up to an hour. It may be an intensified all-over dull pain, or come as a localized sharp stab or fiery sensation. Breakthrough pain differs from person to person and is often unpredictable.

Table 1. Pain management

Type of pain or treatment	Usual starting dose (adults)	Recommendations
A. Medical treatment[a]		
Step 1: *mild pain*		
Non-opioids	**Paracetamol** 500–1000 mg every 4–6 hours (also available in rectal suppositories)	Do not exceed 4 g/day. Use with careful monitoring in patients with liver disease; toxicity is dose-related.
	Ibuprofen 400 mg every 6 hours	Maximum 2.4 g/day. Contraindicated in patients with gastrointestinal bleeding and/or bleeding disorders. Use with caution in patients with liver disease.
	Aspirin (acetylsalicylic acid) 325–500 mg every 4 hours, or 1000 mg every 6 hours	Do not give to children under 12 years old. Contraindicated in patients with gastrointestinal bleeding and/or bleeding disorders. Use with caution in patients with liver disease.
Step 2: *moderate pain*[b]		
Non-opioids **Plus** **Opioids**[c]	**Paracetamol** 500–1000 mg every 4–6 hours (also available in rectal suppositories)	Do not exceed 4 g/day. Use with careful monitoring in patients with liver disease; toxicity is dose-related.
	Ibuprofen 400 mg every 6 hours	Maximum 2.4 g/day. Contraindicated in patients with gastrointestinal bleeding and/or bleeding disorders. Use with caution in patients with liver disease.
	Aspirin (acetylsalicylic acid) 325–500 mg every 4 hours, or 1000 mg every 6 hours	Do not give to children under 12 years old. Contraindicated in patients with gastrointestinal bleeding and/or bleeding disorders. Use with caution in patients with liver disease.
	Codeine 25–50 mg every 4 hours If codeine is not available consider alternating aspirin and paracetamol. Codeine is available in fixed-dose combinations with aspirin or paracetamol, with 325–500 mg paracetamol or aspirin and 25–60 mg codeine.	Maximum daily dose for pain 180–240 mg due to constipation, otherwise switch to morphine. Prevent constipation through use of a stool softener and bowel stimulant, use laxatives if needed. For IDUs, use a non-steroidal anti-inflammatory (ibuprofen) before offering codeine. Be aware of possible abuse of codeine or morphine-related drugs. Refer to Protocol 5, *HIV/AIDS treatment and care for injecting drug users*.
	Tramadol 50–100 mg every 4–6 hours	—

Type of pain or treatment	Usual starting dose (adults)	Recommendations
Step 3: *severe pain*		
Non-opioids **Plus** **Opioids**[c]	**Paracetamol** 500–1000 mg every 4–6 hours (also available in rectal suppositories)	Do not exceed 4 g/day. Use with careful monitoring in patients with liver disease; toxicity is dose-related
	Aspirin (acetylsalicylic acid) 325–500 mg every 4 hours, or 1000 mg every 6 hours	Do not give to children under 12 years old. Contraindicated in patients with gastrointestinal bleeding and/or bleeding disorders. Use with caution in patients with liver disease.
	Oral morphine[d] 10–20 mg every 3–4 hours in tablet or liquid form **IV or IM morphine** 5–10 mg every 3–4 hours Dose can be increased by 50% after 24 hours if severe pain persists. There is no ceiling dose. **Oxycodone**[d] 5–10 mg, every 4 hours Dose can be increased by 50% after 24 hours if severe pain persists. **Hydromorphone** 2–4 mg every 4 hours **Fentanyl transdermal patch** 25 mcg, replaced every 72 hours	If oral morphine is not available, and injectable morphine is used rectally, use 5 mg/5 ml or 50 mg/5 ml, according to need and rate of respiration (no ceiling; consider withholding if respiration rate is <6/minute). Prevent constipation through use of a stool softener and bowel stimulant; use laxatives if needed. IDUs: pain management is the same as for non-IDUs, only the needed dose of the analgesic is usually higher. In case of opioid substitution therapy (OST), the substitution dose should be maintained and opioid analgesics added. Be aware of possible abuse of codeine and of morphine-related drugs. Refer to Protocol 5, *HIV/AIDS treatment and care for injecting drug users*. Approximately 4–6 times more potent then morphine. Not for use in opioid-naive patients.
B. Treatment for special pain problems		
Neuropathic pain Burning pains, abnormal sensation pains, shooting pains, "pins and needles" sensation. Common causes include HIV-related peripheral neuropathies and herpes zoster.	*Use opioids with or without non-opioid analgesics, as above, along with one of the following adjuvants*	
	Amitriptyline 25 mg at night (because of side-effects, e.g. fatigue) or 12.5 mg twice daily (BID)	Wait 2 weeks for response, then increase gradually to 50 mg at night or 25 mg BID. As there is no sudden relief, wait 5 days minimum for a response.
	Gabapentin Maximum 2.4 g/d if on highly active antiretroviral treatment (HAART) regimen with protease inhibitor (PI)	Refer to Protocol 1, *Patient evaluation and antiretroviral treatment for adults and adolescents*, section on Drug interactions with ARVs.
	Carbamazepine 200–400 mg every 6 hours	Monitor white blood cell count and drug interactions.
	Clonazepam 0.5–1.0 mg 2–3 times daily	—

Type of pain or treatment	Usual starting dose (adults)	Recommendations
Muscle spasms	**Diazepam** 5–10 mg 2–3 times daily **Tetrazepam** 50 mg/day, up to 200 mg/day in 2 doses **Baclofen** Begin with 5 mg three times daily (TID), increase every 3 days up to 25 mg TID.	IDUs: before administering consider carefully the possibility of polysubstance misuse. Should only be used in the short term (6–8 weeks maximum).
In terminal care, with no referral and: • **swelling around tumour;** • **severe oesophageal candidiasis** with ulceration and swallowing problems; • **nerve compression;** or • **persistent severe headache** due to increased intracranial pressure.	**Dexamethasone** 2–6 mg per day **Prednisolone** 15–40 mg for 7 days or as provided by trained health worker	Helpful in terminal care; improves appetite and makes patient feel comfortable. Reduce dose to lowest possible. Withdraw if no benefit in 3 weeks. Dexamethasone is about seven times stronger than prednisolone. If prednisolone needs to be used, multiply the dexamethasone dose by seven. Corticosteroids may cause candidiasis.
Gastrointestinal pain from colic	**Butylscopolamine** 3–5 x 10–20 mg	Butylscopolamine has different half-lives: IV is more rapid, while per os (PO) is slower, though dosage remains the same for both. Start with IV, followed by PO; if stable PO, dose with IV for peaks.
	Codeine 30 mg every 4 hours	Codeine can cause constipation and worsening of symptoms in injecting drug users (IDU). Be aware of possible abuse of codeine or morphine-related drugs.
	Trimebutin 100–200 mg TID before meals	—
C. Non-medical treatment		
Psychological, spiritual and/or emotional support and counselling to accompany pain medication	Not applicable	Pain may be more difficult to bear when accompanied by guilt, fear of dying, loneliness, anxiety or depression. Relieve fear and anxiety by explaining events.
Relaxation techniques, including physical methods, such as massage and breathing techniques; and cognitive methods, such as music	Not applicable	Contraindicated if the patient is psychotic or severely depressed.

[a] Administer only one drug from the non-opioid and opioid choices at a time; aspirin every 4 hours can be given along with paracetamol every 4 hours by offsetting the schedule so that the patient is being given one of the two every 2 hours.

[b] See equianalgesic dose chart in Annex 1, which can be used to help select or substitute for specific opioid analgesics.

[c] If pain is controlled, reduce morphine rapidly or stop if used for only a short time; reduce gradually if used for more than 2 weeks.

[d] Morphine and oxycodone are frequently available in long-acting (sustained-release) forms; the guidelines above refer to acute pain management, which should be initiated with short-acting preparations and then converted to long-acting formula-

tions if the need for chronic analgesia persists.

Morphine and other opioids commonly cause side-effects which can generally be prevented or treated easily through dose adjustment or other simple symptom-specific interventions, as outlined in Table 2. Many of these symptoms may diminish on their own over time. Occasionally, if symptoms are persistent and treatment-limiting with a particular opioid, it may be necessary to change to another opioid medication. For equianalgesic dose equivalents for opioids, please refer to Annex 1.

TABLE 2. MANAGEMENT OF SIDE-EFFECTS OF MORPHINE AND OTHER OPIOIDS

Side-effect	Managmenet
Constipation	Increase consumption of fluids and fibre with fruits and vegetables or bran supplements. Give stool softener **(docusate 200–800 mg/d)** at time of prescribing plus stimulant (**senna** 7.5–8.6 mg tablets, 2–4 BID). If no improvement, add laxative such as **macrogol** 13.125 mg/dose once or twice a day, or **lactulose** 10–20 ml TID, and if still no improvement, **bisocodyl** 5–15 mg oral tablets or rectal suppositories as needed. Prevent by using some or all of the above measures for prophylaxis (unless chronic diarrhoea).
Nausea and/or vomiting	An antiemetic usually resolves the problem in several days; may need round-the-clock dosing.
Respiratory depression (rare if oral morphine is titrated against pain)	Usually no need to intervene if respiratory rate >6–8/min. If severe, consider withholding next opioid dose, then halve the dose.
Confusion or drowsiness (due to the opioid)	Usually occurs at start of treatment or dose increase. Usually resolves within a few days. Can occur at end of life with renal failure. Halve dose or increase interval between doses.
Itching/twitching (myoclonus – if severe or present during waking hours)	If on high dose, consider reducing or alternating doses or using two opioids. Re-evaluate pain and treatment; pain may not be morphine responsive.
Somnolence	Extended sleep can be from exhaustion due to pain. If condition persists more than 2 days after starting, reduce dose by half.

Note: Reducing morphine when the cause of pain is under control depends on the length of use. If morphine has been used

only for a short time, stop or rapidly reduce dosage. If it has been used for >2 weeks, reduce dosage gradually and watch for withdrawal symptoms.

Table 3. Oral morphine instructions for family and community care providers

Purpose	Instructions

To teach family and community care providers how to give small amounts of oral morphine with a syringe and how to deal with side-effects.	Oral morphine is a strong painkiller that is only available from specially trained health workers.
	• To administer oral morphine:
	  ◦ pour a small amount of morphine liquid into a cup;
	  ◦ draw up the exact dose into a syringe (using the ml marks); and
	  ◦ drip the liquid from the syringe into the mouth (there should be no needle on the syringe).
	• Give prescribed dose regularly every 4 hrs (by the clock or by sun/moon estimates) – do not wait for pain to return.
	• Give a double dose at bedtime.
	• If the pain is getting worse or reoccurs before the next dose is due, give an extra dose and inform the health worker – the regular dose may need to be increased.
	• **Nausea** usually goes away after a few days of morphine and does not usually come again.
	• **Constipation** should be prevented in all patients except those with diarrhoea; give local remedies or a laxative such as **senna**. If constipation does occur, see Table 2 above and section IV.11 below for management.
	• **Dry mouth:** give sips of water.
	• **Drowsiness** usually goes away after a few days of morphine. If it persists or gets worse, halve the dose and inform the health worker.
	• **Sweating or muscle spasms:** notify health worker.

Table 4. Pain management instructions for family and community care providers

Purpose	Instructions
To teach family and community care providers how to administer pain medication	• Explain frequency and importance of administering pain relief medicine regularly and of not waiting for the pain to return. • Stress that dose should be given before the previous dose wears off. • Write out instructions clearly.
To advise family and community care providers on additional methods of pain control.	Discuss how to control pain through: • emotional support; • physical methods: touch (stroking, massage, rocking, vibration), ice or heat, deep breathing; • cognitive methods: distraction, music, imagery, etc.; and • spiritual support, including meditation and prayer, while respecting the patient's beliefs.

2. Symptom management

Patients with HIV/AIDS may experience a wide range of symptoms, involving virtually every major organ system, as a result of specific opportunistic infections, malignancies, comorbidities, medication toxicity, substance abuse or HIV infection itself. Many studies from different countries have documented a high prevalence of symptoms in patients with AIDS (see Table 5) *(34)*. Table 6 summarizes some of the common symptoms in HIV/AIDS and their possible causes, grouped primarily by organ system, and it also indicates some of the disease-specific and/or palliative care interventions that may be applied in individual cases. Tables 7–26 present symptom-specific palliative care interventions in more detail, along with suggestions that may be useful for home care providers. Whenever possible, the particular condition causing the symptom should be treated

(e.g. cryptococcal meningitis that is causing headaches), but often it is just as important to treat the symptom itself (for example, loperamide or codeine for chronic diarrhoea that is not due to a specific pathogen).

TABLE 5. PREVALENCE OF SYMPTOMS IN PATIENTS WITH AIDS

Symptoms	Prevalence
Fatigue or lack of energy	48–45%
Weight loss	37–91%
Pain	29–76%
Anorexia	26–51%
Anxiety	25–40%
Insomnia	21–50%
Cough	19–60%
Nausea or vomiting	17–43%
Dyspnoea or other respiratory symptoms	15–48%
Depression or sadness	15–40%
Diarrhoea	11–32%
Constipation	10–29%

Source: based on available descriptive studies of patients with AIDS, predominantly with late-stage disease, 1990–2002, in Selwyn & Forstein, 2003 *(34)*.

TABLE 6. COMMON SYMPTOMS IN PATIENTS WITH AIDS AND POSSIBLE DISEASE-SPECIFIC AND SYMPTOM-SPECIFIC INTERVENTIONS

Type	Symptoms	Possible causes	Disease-specific treatment	Symptom-specific treatment
Constitutional	Fatigue, weakness	AIDS Opportunistic infections Anaemia	HAART Treat specific infections Erythropoietin, transfusion	Corticosteroids (prednisone, dexamethasone) Psychostimulants (methylphenidate, dextroamphetamine)
	Weightloss/anorexia	HIV Malignancy	HAART Chemotherapy Nutritional support/enteral feedings	Corticosteroids Megestrol acetate Anabolic agents (oxandrolone, testosterone)
	Fevers/sweats	DMAC Cytomegalovirus (CMV) HIV Lymphoma, malignancy	Azithromycin, ethambutol Ganciclovir, foscarnet HAART Chemotherapy	NSAIDS[a] (ibuprofen, indomethicin) Corticosteroids Anticholinergics (hyoscine, thioridazine) H_2 receptor antagonists (cimetidine)
Pain	Nociceptive pain: • somatic • visceral	Opportunistic infections, HIV-related malignancies, non-specific causes	Treat specific disease entities	*For nociceptive pain* • NSAIDS[a] • Opioids • Corticosteroids

	Neuropathic pain	HIV-related peripheral neuropathy
		CMV
		Varicella-zoster virus (VZV)
		Possible toxicity from dideoxynucleosides (didanosine, stavudine)
		Other medications (isoniazid)
			HAART
			Ganciclovir, foscarnet,
			Aciclovir, famciclovir
			Change antiretroviral drug
			Change drug
				For neuropathic pain
				• NSAIDS[a]
				• Opioids
				• Adjuvants
				  ◦ Tricyclic antidepressants (amitriptyline, imipramine)
				  ◦ Benzodiazepines (clonazepam)
				  ◦ Anticonvulsants (gabapentin, carbamazepine)
				• Corticosteroids
				• Acupuncture

Type	Symptoms	Possible causes	Disease-specific treatment	Symptom-specific treatment
Gastrointestinal	Nausea/vomiting	Esophageal candidiasis CMV HAART	Fluconazole, amphotericin B, Ganciclovir, foscarnet Change antiretroviral regimen	Dopamine antagonists (haloperidol, prochlorperazine) Prokinetic agents (metoclopromide) Antihistamines (promethazine, diphenhydramine, hydroxyzine) Anticholinergics (hyoscine, scopolamine) H_2 receptor antagonists (cimetidine) Proton pump inhibitors (omeprazole) Serotonin antagonists (ondansetron, granisetron) Benzodiazepines (lorazepam) Corticosteroids
	Diarrhoea	MAI Cryptosporidiosis CMV Microsporidiosis Other intestinal parasites Bacterial gastroenteritis, malabsorption	Azithromycin, ethambutol Paromomycin Ganciclovir, foscarnet Albendazole Other antiparasitic agents Other antibiotics	Bismuth, methylcellulose, kaolin Diphenoxylate + atropine Loperamide Tincture of opium (paregoric)
	Constipation	Dehydration Malignancy Anticholinergics, opioids	Hydration Radiation/chemotherapy Medication adjustment	Activity/diet Prophylaxis on opioids Softening agents • surfactant laxatives (docusate) • bulk-forming agents (bran, methylcellulose) • osmotic laxatives (lactulose, macrogol, sorbitol) • saline laxatives (magnesium hydroxide) Peristalsis-stimulating agents • anthracenes (senna) • polyphenolics (bisacodyl)

Type	Symptoms	Possible causes	Disease-specific treatment	Symptom-specific treatment
Respiratory	Dyspnoea	PCP Bacterial pneumonia Anaemia Pleural effusion/mass/ obstruction, decreased respiratory muscle function	Trimethoprim/sulfamethoxazole, pentamidine, atovaquone etc. Other antibiotics Erythropoietin, transfusion Drainage/radiation/ surgery	Use of fan, open windows, oxygen Opioids Bronchodilators Methyl xanthines Benzodiazepines (lorazepam)
	Cough	PCP, bacterial pneumonia TB	Anti-infective treatment (as above) Antituberculosis chemotherapy	Cough suppressants (dextromethorphan, codeine, other opioids) Decongestants, expectorants (various)
	Increased secretions ("death rattle")	Fluid shifts, ineffective cough, sepsis, pneumonia	Antibiotics as indicated	Atropine, hyoscine, transdermal or subcutaneous scopolamine, glycopyrrolate, fluid restriction Discontinuation of intravenous fluids
Dermatologic	Dry skin	Dehydration End-stage renal disease End-stage liver disease malnutrition	Hydration Dialysis Nutritional support	Emollients with or without salicylates Lubricating ointments
	Pruritus	Fungal infection End-stage renal disease End-stage liver disease dehydration Eosinophilic folliculitis	Antifungals Dialysis Hydration Steroids, antifungals	Topical agents (menthol, phenol, calamine, capsaicin) Antihistamines (hydroxyzine, cetirizine, diphenhydramine) Corticosteroids Antidepressants Anxiolytics
	Decubiti/pressure sores	Poor nutrition Decreased mobility, prolonged bed rest	Improve nutrition Increase mobility	Prevention (nutrition, mobility, skin integrity) Wound protection (semi-permeable film/hydrocolloid dressing) Debridement (normal saline, enzymatic agents, alginates)

Type	Symptoms	Possible causes	Disease-specific treatment	Symptom-specific treatment
Neuropsychiatric	Delirium/agitation	Electrolyte imbalances, dehydration Toxoplasmosis, cryptococcal meningitis Sepsis	Correct imbalances, hydration Sulfadiazine/pyrimethamine antifungals Antibiotics	Neuroleptics (haloperidol, risperidone, chlorpromazine) Benzodiazepines (lorazepam, midazolam)
	Dementia	AIDS-related dementia	HAART	Psychostimulants (methylphenidate, dextroamphetamine) Low dose neuroleptics (haloperidol)
	Depression	Chronic illness, reactive depression, major depression	Antidepressants (tricyclics, SSRIs, monoamine oxidase (MAO) inhibitors, other)	Psychostimulants (methylphenidate, dextroamphetamine) Corticosteroids (prednisone, dexamethasone)

[a] NSAIDS: non-steroidal anti-inflammatory drugs.
Note: not all medications will be available in all settings.
Source: Selwyn & Forstein, 2003 *(34)*.

3. Management of weight loss

Table 7. Management of weight loss

Condition	Treatment and dosages (for adults)	Suggestions for home care
General weight loss	Encourage the patient to eat, but do not force as vomiting may result. Offer more frequent smaller meals of the patient's preferred foods.	Consider possible reasons for weight loss (tumours, *Candida* oesophagitis, TB, atypical mycobacteria, CMV colitis, cryptosporidiosis). Avoid cooking close to the patient. Let the patient choose the foods he/she wants to eat from what is available. Accept that intake will decrease as the patient becomes more ill. Seek help from trained health worker in case of rapid weight loss, consistent refusal to eat or inability to swallow.
Anorexia and severe fatigue	**Prednisolone** 5–15 mg daily for up to 6 weeks	Try to stimulate appetite.
Nausea and vomiting	Provide antiemetics (see Table 9).	Offer more frequent smaller meals of the patient's preferred foods; do not force the person to eat.
Thrush or mouth ulcer	See Table 10.	—
Diarrhoea	See Table 13.	—

4. Management of fever

Fever may be a side-effect of antiretroviral (ARV) regimens; if suspected, see Protocol 1, *Patient evaluation and antiretroviral treatment for adults and adolescents*, Table 11.

Table 8. Management of fever

Condition	Treatment and dosages (for adults)	Suggestions for home care
General fever	Assess and treat cause. Give **paracetamol** or **acetylsalicylic acid** every 4 hrs (no more than 8 tablets paracetamol in 24 hrs). Make sure the patient remains hydrated.	Encourage the patient to drink water, diluted tea or fruit juice frequently. Use physical methods like wet compresses or ice packs.

5. Management of nausea and vomiting

Nausea and abdominal discomfort may be side-effects of ARV regimens or due treatment of opportunistic infections; if suspected, see Protocol 1, *Patient evaluation and antiretroviral treatment for adults and adolescents*, Table 11, and Protocol 2, *Management of opportunistic infections and general symptoms of HIV/AIDS*, section on Gastrointestinal infections.

Table 9. Management of nausea and vomiting

Condition	Treatment and dosages (for adults)	Suggestions for home care
Nausea and vomiting	**Metoclopromide** 10 mg every 4–8 hours **Haloperidol** 1–2 mg once daily (OD) or BID **Chlorpromazine** 25–50 mg every 6–12 hours **Cyclizine** 50 mg up to four times daily **Clemastine** 1 mg BID **Cetirizine** 10 mg OD **Hydroxyzine** 25–50 mg three or four times daily **Ondansetron** 8 mg OD or BID	Seek foods the patient likes that cause less nausea. Offer smaller meals and have the patient drink frequently and slowly. Seek help from trained health worker for: • vomiting more than once a day • dry tongue • passing little urine • abdominal pain.

6. Management of mouth ulcers or pain on swallowing

Be aware that mouth ulcers or painful swallowing may be caused by CMV ulcers of the mouth or oesophagus, herpes infection or candida oesophagitis.

Table 10. Management of mouth ulcers or pain on swallowing

Condition	Treatment and dosages (for adults)	Suggestions for home care
General	—	Use soft toothbrush to gently scrub teeth, tongue, palate and gums. Rinse mouth with diluted salt water (a pinch of salt in a glass of water) after eating and at bedtime (usually 3–4 times daily). Topical anaesthetics can provide some relief. Dissolve 2 aspirin in water and rinse the mouth with it up to four times a day. Pain relief may be required (see Table 1). Remove food leftovers with gauze/cloth soaked in salt water. Soft foods may decrease discomfort. Textured foods and fluids may be swallowed more easily. Avoid very hot, cold or spicy foods.
Candida (oral thrush)	**Miconazole** buccal tablets 1 tablet OD for 7 days If severe and/or no response: **Fluconazole** initial loading dose: 200 mg (1 day); maintenance: 100 mg daily for 10–14 days or until symptoms resolve	
Aphthous ulcers	**Prednisolone** applied as crushed grains **Dexamethasone** solution as mouthwash **Kenalog** cream applied to sores	
Herpes simplex	**Aciclovir** 400 mg PO 5 times a day	
Foul-smelling mouth due to oral cancer or other lesions	**Metronidazole** mouthwash: crush 2 tablets in water and rinse mouth.	

7. Management of dry mouth

Table 11. Management of dry mouth

Condition	Treatment	Suggestions for home care
Dry mouth	Review medications; condition could be a side-effect.	Give frequent sips of drinks. Moisten mouth regularly with water. Let the person suck on fruits such as oranges (citrus fruits should be avoided in cases of sores).
Significant lack of saliva	Refer to dentist.	—

8. Management of hiccups

Table 12. Management of hiccups

Condition	Treatment and dosages (for adults)	Suggestions for home care
General, or with oral thrush	**Fluconazole** 100 mg/d, if severe start with 200 mg followed by 100 mg per day until symptoms resolve)	First try manoeuvres to control hiccuping. Have the patient stimulate the throat by: • quickly eating 2 heaped teaspoons sugar; • drinking cold water; • eating crushed ice; or • rubbing the upper palate with a clean cloth (towards the back where it is soft). Or have the patient interrupt normal breathing by: • holding breath or breathing into paper bag, stopping if discomfort occurs; or • pulling the knees to the chest and leaning forward (compressing the chest).
Advanced cancer with distended stomach	**Simethicone** (up to 100 mg TID (reduces flatulence)	
If no response to simethicone or recurrence of condition	**Metoclopromide** (10 mg tablet, 1–2 tablets 3–4 times daily) **Haloperidol** (5 mg tablet: from ¼ to 1 tablet 1–3 times daily)	
Brain tumour	Anti-epileptic medication	

9. Management of diarrhoea

Diarrhoea may be a side-effect of ARV regimens (see Protocol 1, *Patient evaluation and antiretroviral treatment for adults and adolescents*, Table 11); other causes include CMV colitis, cryptosporidiosis, microsporidiosis, giardiasis, Kaposi sarcoma, other infective agents, etc.

TABLE 13. MANAGEMENT OF DIARRHOEA

Condition	Treatment and dosages (for adults)	Suggestions for home care
General	Increase fluid intake, to prevent dehydration. Use oral rehydration solution (ORS) if large volume of diarrhoea. Suggest a supportive diet. Give constipating drugs, unless there is blood in stool or fever, or if patient is younger than 5 or elderly. **Loperamide** 4 mg to start, then 2 mg after each loose stool (maximum 12 mg/day, though some patients need more) Or (if approved): • **codeine** 10 mg TID (up to 60 mg every 4 hours); or • **oral morphine** 2.5–5.0 mg every 4 hours (if severe)	Encourage the patient to drink plenty of fluids to replace lost water (given in small amounts, frequently). Increase frequency of small amounts of food intake, such as rice soup, porridge, ORS, bananas, other soups. Be careful with milk and chocolate. Special care for rectal area: • after the person has passed stool, clean with toilet paper or soft tissue paper; • wash the anal area three times a day with soap and water; and • if the patient feels pain when passing a stool, apply petroleum jelly around the anal area. Seek help of a trained health worker for any of the following: • vomiting with fever • blood in stools • diarrhoea for more than 5 days • increasing weakness • broken skin around the rectal area • perianal ulcers.
Rectal tenderness	Local anaesthetic ointment or petroleum jelly	
Incontinence	Petroleum jelly to protect perianal skin	

10. Assessment of dehydration in adults

An assessment of the state of hydration is essential in the management of persons with chronic diarrhoea.

TABLE 14. ASSESSMENT OF DEHYDRATION IN ADULTS

Clinical features	Dehydration		
	Mild	**Moderate**	**Severe**
General condition	Weak	Weak	Restless, irritable, cold, sweaty, peripheral cyanosis
Pulse	Normal	Slight tachycardia	Rapid, feeble
Respiration	Normal	Normal	Deep and rapid
Skin elasticity	Normal	Pinch retracts slowly	Pinch retracts very slowly
Eyes	Normal	Sunken	Deeply sunken
Mucous membranes	Slightly dry	Dry	Very dry
Urine flow	Normal amount; urine dark	Reduced amount; dark amber in colour	No urine; bladder is empty

11. Management of constipation of more than two days

Table 15. Management of constipation of more than two days

Condition	Treatment and dosages (for adults)	Suggestions for home care
Impacted	Perform rectal exam and remove manually.	Offer drinks often. Encourage consumption of fruit (including dried fruit), vegetables, linseed porridge, soft foods. Give a tablespoon of vegetable oil before breakfast. Have the patient gently put petroleum jelly or soapy solution into the rectum, or do it yourself if the patient cannot. For this procedure, as for any contact with potentially infective matter, use protective gloves.
Other constipation	Give stool softener/bulk agents, varying the dose for the individual: • a bulk-enhancing agent the first time, e.g. bran 4 tablets/day or **psyllium** 2–3 tablespoons in water/juice up to TID; • **macrogol**, 13.125 g/dose, 1–2/day; • **lactulose**, 10–20 ml T/D; • **bisocodyl** 5–15 mg at night; or • **senna** 2 tablets to start (7.5–8.6 mg each) TID, up to 2 tablets every 4 hours). **Remember:** always provide a bowel regimen with stool softener, with or without a stimulant, to patients being treated with opioids such as morphine or codeine.	

12. Management of incontinence

Table 16. Management of incontinence

Condition	Treatment and dosages (for adults)	Suggestions for home care
Incontinence of urine or faeces	• Assess for possible neurological reasons (cerebral toxoplasmosis or other opportunistic infections (OI)). • For males: use urine bottle, condom or catheter. • For females: consider catheterization. • In general consider diapers, regardless of patient sex. • Keep stools firm with **loperamide** (see Table 13).	• Change pads or diapers regularly. • Keep skin clean and dry; apply protective ointments as needed.

13. Management of itching

Skin rashes, both mild and severe, can be a side-effect of ARV regimens; if suspected, see Protocol 1, *Patient evaluation and antiretroviral treatment for adults and adolescents*, Table 11.

TABLE 17. MANAGEMENT OF ITCHING

Condition	Treatment and dosages (for adults)	Suggestions for home care

Scabies, prurigo, eczema, ringworm, dry itchy skin, psoriasis, icterus	Assess whether condition is a side-effect of medication.
	
	General care
	• Local steroid creams may be useful if inflammation is present in absence of infection (bacterial, fungal or viral).
	• Antihistamines:
	  ◦ **chlorpheniramine** 4–5 mg BID, **cetirizine** 10 mg OD, hydroxyzine 25–50 mg TID;
	  ◦ **diphenhydramine** 25–50 mg at bedtime or up to TID, possibly useful for severe itching.
	• For skin infections, use 0.05% chlorhexidine rinse after bathing.
	• For itching from obstructive jaundice, try **prednisolone** (20 mg OD) or **haloperidol** (2 x 1 mg OD).
	• For eczema, gently wash with warm water and dry skin. Do not use soap. Topical steroids may be used for the short term (but not on face).
	• For ringworm, use compound benzoic and salicylic acid ointment **(Whitfield ointment)** or other antifungal cream. If extensive, use **fluconazole** (start with 200 mg on first day, followed by 100 mg OD).
	• Consider treatment for scabies even if there are no typical lesions **(ivermectine** 200μg x 1 dose; see Protocol 2, *Management of opportunistic infections and general symptoms of HIV/AIDS*, section on General symptoms, scabies.)
	• For psoriasis, use coal tar ointment 5% in 2% salicylic acid and expose to sunlight 30–60 minutes per day.
		Try any of the following:
		
		• applying petroleum jelly to the itchy area;
		• putting one spoon of vegetable oil in 5 litres of water to wash the patient;
		• diluting one teaspoon of **chlorhexidine** in a litre of water and applying after bathing; or
		• using warm water for bathing.
		
		Seek help from a trained heath worker for painful blisters or extensive skin infection.

14. Management of bedsores

Table 18. Management of bedsores

Condition	Treatment and dosages (for adults)	Suggestions for home care
Signs of infection	All patients need skin care to avoid pressure sores. • Ensure infection is not from another source. • If redness, tenderness, warmth, pus or crusts present, assess for fever; if systemically unwell, or if infection extends to muscle, refer to hospital, start IV/IM antibiotics (or oral **cephalexin** or **dicloxacillin**). • Start **cephalexin** or **dicloxacillin** 500/1000 mg four times daily (QID) if any of the following present: ◦ lesion greater than 4 cm ◦ red streaks ◦ tender nodes ◦ more than 6 abscesses. • Drain pus if fluctuant, elevate limb and follow up next day. • If sores are only red, tender and warm, clean them with antiseptic, drain pus if fluctuant and follow up in two days. • For ill-smelling tumours or ulcers use crushed **metronidazole** to cover the affected area.	*Soothing the pain of bedsores and hastening their healing* • For small sores, clean gently with salty water and allow to dry. • For bedsores that are not deep, leave the wound open to the air. • If painful, give painkillers such as paracetamol or aspirin regularly. • For deep or large sores, gently clean and cover with clean light dressing daily to encourage healing. • Seek help from a trained health worker for any discoloured skin, or if bedsores worsen. *Preventing bedsores in bedridden PLWHA* • Help the patient to sit up in a chair from time to time if possible. • Lift patient up in the bed – do not drag patient, as it can break the skin. • Change the patient's position on the bed often, if possible every 1–2 hrs – use pillows or cushions to maintain position. • After bathing, dry skin gently with a soft towel. • Oil the skin with cream, body oil, lanolin or vegetable oil. • Massage back, hips, elbows and ankles with petroleum jelly. • If there is leakage of urine or stools, protect the skin with petroleum jelly applied around the genital area, back, hips, ankles and elbows. • When passing urine or stool in bed, the patient should be supported over the receptacle so as to avoid injury and soiling of linen. *Bedding suggestions* • Keep bedding clean and dry. • Put extra soft material, such as a soft cotton towel, under the patient. • For incontinent PLWHA, use plastic sheets under the bed sheets to keep the mattress dry.

15. Management of mental health problems

For individuals living with HIV, attention to and care of mental health is of particular significance. For example, studies suggest that people living with HIV who suffer from depression have lower levels of adherence to HIV medication. On the other hand, antidepressant treatment improves adherence to antiretroviral treatment among depressed PLWHA *(35)*.

Mental health issues in PLWHA may arise independently of HIV as part of an associated illness (organic cause), or as a reaction to the HIV diagnosis or related stressors and social issues, such as stigmatization and health uncertainty.

Anxiety disorders cover a broad spectrum. Anxiety can be non-pathological, or it can present as part of another illness, such as depression or thyrotoxicosis. In other cases, it presents as an independent entity, ranging from anxiety that is pervasive and persistent (generalized anxiety disorder, or GAD) to anxiety in specific situations, either with an identifiable source (a traumatic event or phobic entity) or without, as in panic attacks. For each type, severity may also vary from mild to severe.

TABLE 19. MANAGEMENT OF ANXIETY

Condition	Treatment and dosages (for adults)	Suggestions for home care
GAD	Counsel on managing anxiety in accordance with the specific situation, teach relaxation techniques, listen carefully and provide emotional support. Self-help based on **cognitive behavioural therapy** (CBT) principles should be encouraged, or a CBT referral made if available. CBT involves a short course of sessions with a psychologist or psychiatrist to explore the origins and warning signs of depression and learn skills to manage it. A **selective serotonin reuptake inhibitor** (SSRI) is an appropriate first-line pharmacological treatment, e.g. **citalopram** 10 mg OD for the first week, increasing to 20 mg or higher (max. 60 mg/day) for several weeks. A **benzodiazepine** can provide rapid symptomatic relief from anxiety but because of tolerance and dependence should not be used beyond 2–4 weeks. It may be useful at the start of SSRI treatment to prevent an initial worsening of	*Helping with anxieties* • Take time to listen to the patient. • Discuss the problem in confidence. • Soft music or massage may help the patient to relax. • Connect the patient with appropriate support groups. • In case of increasing anxiety or depression, refer to a health care provider.
Panic disorder	An **SSRI** should be used as a first-line treatment. • If the SSRI is contraindicated or ineffective, **clomipramine** can be used (25 mg OD to start, increased over 2 weeks to daily dose 100–150 mg) Self-help based on CBT principles should be encouraged, with referral for	
Phobic disorders	An **SSRI** may be begun. CBT is particularly important, for example, using	

16. Management of sleeping problems

Insomnias are disorders in initiating or maintaining sleep. They may be divided into initial insomnia, middle insomnia and early-morning wakening. In many cases the insomnia is a symptom of another mental or physical disorder, such as:

- unmanaged pain
- anxiety
- depression
- drug withdrawal (e.g. from alcohol, diazepam or heroin).

Insomnia, nightmares and somnolence can all be side-effects of certain ARV regimens, especially those with efavirenz; if suspected, see Protocol 1, *Patient evaluation and antiretroviral treatment for adults and adolescents*, Table 11.

TABLE 20. MANAGEMENT OF INSOMNIA

Condition	Treatment and dosages (for adults)	Suggestions for home care
Insomnia	Ascertain whether the underlying cause of insomnia has been addressed, e.g. depression, anxiety, mania, pain or substance withdrawal. In the absence of such causes, better sleep hygiene should be considered. • Exercise in the daytime, use relaxation techniques such as meditation or listening to calming music, and observe a routine of retiring and rising at the same time each day. • Daytime napping and using the bed for daytime activities should be discouraged and caffeine and alcohol intake reduced, especially at nighttime. For initial insomnia, getting up after 20 minutes and engaging in a relaxing activity before returning to bed may be recommended. In some individuals, short term use of a benzodiazepine (e.g. **temazepam** 5–10 mg at night) or another hypnotic (such as 3.75–7.5 mg **zopiclone**) can be taken at least one hour before retiring. Either one can be continued for a maximum of 3–4 weeks, to avoid tolerance and dependence. Longer term treatment may be beneficial in a small number of cases, but may cause rebound insomnia; hypnotics should be tapered slowly.	Listen to the fears that may be keeping the patient wake, and respond to these fears in a reassuring manner. Reduce noise where possible. Do not give the patient strong tea or coffee late in the evening. Treat pain if present.

17. Management of affective disorders

17.1. Depression

Symptoms of depression include:

- low moods, reduced energy, decreased activity and diminished capacity for enjoyment;
- reduced interests and concentration, and marked tiredness after even minimum effort;
- disturbed sleep and diminished appetite; and
- reduced sense of self-esteem and self-confidence (even in mild depression), often with some feelings of guilt or worthlessness.

The lowered mood varies little from day to day, is unresponsive to circumstances and may be accompanied by so-called "somatic" symptoms, such as early-morning awakening, marked psychomotor retardation, agitation, loss of appetite, weight loss and loss of libido.

Table 21. Management of depression

Condition	Treatment and dosages (for adults)	Suggestions for home care
Depression (general)	Assess and classify as to suicide risk, major or minor depression, complications from loss or other difficult life events. • Consult with a psychiatrist for treatment • Consider whether the condition may be due to effects of medication, e.g. efavirenz; see Protocol 1, *Patient evaluation and antiretroviral treatment for adults and adolescents*, Table 11.	Provide support and counselling. Mobilize family and friends for support, and refer patient to PLWHA support groups or religious support groups. Do not leave alone if suicide risk: • counsel; • help patient find a solution if sleep-disturbed; and • follow up.
Mild depressive episode Symptoms from two or three of the symptom groups listed in the text are usually present. The patient is usually distressed by them but is probably able to continue with most activities.	Antidepressants are not recommended, as monitoring, problem-solving and exercise are more important.	—
Moderate depressive episode Symptoms from all four groups listed in the text are usually present, and the patient is likely to have great difficulty in continuing with ordinary activities.	For a single moderate episode of depression, it is advised that treatment be continued for 4–6 months; longer for multiple episodes. *First-line treatment* should be an SSRI, e.g. **citalopram** 10–20 mg/d, increasing with monitoring over several weeks to a maximum of 60 mg/d. The lowest possible therapeutic dose should always be used. In the early stages of SSRI use, the patient should be closely monitored for restlessness, agitation and suicidal tendencies. Many PLWHA find the potential side-effect of reduced libido unacceptable.	—
	Second-line therapy should be considered if SSRI is poorly tolerated or ineffective after 6–8 weeks. An antidepressant from another class (usually a tricylic or an MAO inhibitor, e.g. **amitryptyline** initially 25 mg TID) can then be used, with reference to a standard text for guidelines on withdrawing or substituting. However, it must be borne in mind that tricylics are very toxic in overdose, so they should not be considered if there is a risk of self-harm. An alternative SSRI could also be tried, e.g. **sertraline** commencing at 50 mg daily.	
	Caution: The herbal antidepressant **St John's wort** interacts with PIs and NNRTIs, leading to low levels of these drugs in the blood and risking the development of drug-resistant HIV. It is thus not recommended for patients taking PIs or NNRTIs.	

Condition	Treatment and dosages (for adults)	Suggestions for home care
Severe depressive episode without psychotic symptoms Several of the above symptoms are marked and distressing, typically loss of self-esteem and feelings of worthlessness or guilt. Suicidal thoughts and acts are common, and several "somatic" symptoms are usually present.	For severe or resistant depression, a combination of antidepressants and CBT is recommended. Depending on the severity of the depression and the risk to the patient, a mental health specialist may consider **lithium** (enough to achieve a plasma level of 0.4–1.0 mmol/litre), electroconvulsive therapy or **venlafaxine** (starting dose 75 mg/day), with appropriate advice to the patient, including baseline tests: a minimum of electrocardiogram (ECG), thyroid and renal function for lithium, and ECG and blood pressure for venlafaxine.	Educate patient and family about medication. Refer for counselling. Ensure follow-up.
Severe depressive episode with psychotic symptoms A severe episode of depression with hallucinations, delusions, psychomotor retardation or stupor.	Psychotic symptoms may require commencement of an antipsychotic, following review by a mental health specialist.	—
Suicidal thoughts	Assess if the person has a plan and the means to carry out suicide. If so, consider patient to be high risk and refer for hospitalization.	Do not leave alone. Remove harmful objects. Mobilize family and friends.

17.2. Mania and bipolar affective disorder (BPAD)

- Individuals with HIV may suffer comorbidly from BPAD, which is characterized by two or more episodes of mood disturbance, including one that is manic or hypomanic.
- Mania has been documented as occasionally presenting in individuals with no personal or family history of BPAD, but with advanced HIV or very low CD4 counts.

Typical signs of mania and BPAD:

- Mood is elevated out of keeping with the patient's circumstances and may vary from carefree joviality to almost uncontrollable excitement.
- Elation is accompanied by increased energy, resulting in overactivity, pressure of speech and a decreased need for sleep. There is often marked distractibility. Self-esteem is often inflated with grandiose ideas and overconfidence.
- Loss of normal social inhibitions may result in behaviour that is out of character as well as reckless or inappropriate.
- In addition, delusions (often grandiose) or hallucinations may be present.

TABLE 22. MANAGEMENT OF MANIA AND BPAD

Condition	Treatment and dosages (for adults)	Suggestions for home care
Mania and BPAD	Mood stabilizers – including lithium (plasma level 0.4–1.0 mmol/litre), **valproate semisodium, lamotrigine** and **gabapentin** – can be used with caution. **Valproate semisodium** is an enzyme inhibitor, so that as with most psychotropics to varying degrees, its potential effect on ARV levels should be considered when starting or stopping valproate semisodium. *Caution:* **carbamazepine** should generally not be used because of interactions with ARVs and risk of agranulocytosis. CBT can also play an important role in helping provide the patient with the skills to recognize the warning signs and triggers of mood swings. Psychotic symptoms may require commencement of an antipsychotic, following review by a mental health specialist.	Caregivers can help with medication compliance and identification of early warning signs of mood disorders.

18. Management of dementia

Dementia is a syndrome due to brain disease, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. It should be noted with dementia that:

- consciousness is not clouded; and
- impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour (e.g. disinhibition) or motivation.

Individuals with HIV may also present with cognitive impairment or apparent dementia for other reasons.

- Depression and anxiety can present with forgetfulness and concentration difficulties, so should be excluded from a diagnosis of dementia.
- Acute infection may also present with confusion (delirium), and should also be excluded.
- In addition, some people with advanced HIV and very low CD4 counts may present with cognitive impairment that is thought to be due to the effects of HIV on the CNS, or possibly to the immune response to the virus.

TABLE 23. MANAGEMENT OF DEMENTIA

Condition	Treatment and dosages (for adults)	Suggestions for home care
Dementia	• Assess for alternative explanations, such as depression and delirium. • Assess for reversible causes of dementia, such as normal pressure hydrocephalus, operable tumours, hypothyroidism, neurosyphilis and vitamin B12 and folate deficiencies. Treat accordingly. • Consider pain or fear as possible causes, and treat accordingly. • The mainstay of treatment for HIV-associated dementia is HAART.	As far as possible, keep patient in a familiar environment. • Keep things in the same place, easy to reach and see. • Keep a familiar pattern to the day's activities. • Remove dangerous objects. • Speak in simple sentences, one person at a time. • Keep noise down. • Make sure somebody is always present to look after the patient.
Dementia with behavioural changes such as aggression or restlessness	Non-pharmacological strategies are preferable, such as attempts to communicate patiently. Medication may also be considered, e.g. low dose **quetiapine** (12.5 mg daily), if the patient is distressed. When the patient is being cared for at home, carer support, including relief for the caregiver, should be offered where resources allow. Reducing restlessness may also be more critical in the home environment, since the family may be adversely affected by this behaviour over time.	
Paranoia, severe agitation or distress at night Distress, particularly if patient is experiencing paranoid delusions or other psychotic symptoms	Again, non-pharmacological strategies are preferable, such as attempts to communicate patiently. Medication may be considered, e.g. low dose **quetiapine** (12.5 mg daily), if the patient is distressed, following careful psychiatric assessment of the nature of the patient's symptoms and experiences. Due attention should be given to the increased risk of falls if medication is given.	

19. Management of cough or difficulty breathing

Cough or difficulty breathing may be due to common opportunistic infections seen in HIV/AIDS or to immune reconstitution syndrome, which is usually seen within two to three months of starting ART. If the latter is suspected, see Protocol 1, *Patient evaluation and antiretroviral treatment for adults and adolescents*, section on Immune reconstitution syndrome.

TABLE 24. MANAGEMENT OF COUGH OR DIFFICULTY BREATHING

Condition	Treatment and dosages (for adults)	Suggestions for home care
Dyspnoea with bronchospasm	Give oxygen via mask if possible. *Asthma protocols* • Give bronchodilators by metered-dose inhaler with spacer/mask or nebulizer. Continue until patient is not able to use them or has very shallow or laboured breathing. • Give **prednisolone** 1 mg/kg per day (usually 60 mg in one dose in the morning); wait one week to assess response, than slowly reduce by 10 mg over a week.	*For simple cough* • Use local soothing remedies, such as honey, lemon or steam (plain or with eucalyptus). • If patient has a new productive cough for more than two weeks, it may be tuberculosis. Arrange with health worker to send three sputum samples for examination for TB. In addition to treatment given by a health worker • Help the patient into the best position to ease breathing – usually sitting up. • Leaning slightly forward and resting arms on a table may help. • Use extra pillows or some back support. • Open windows to allow in fresh air. • Fan with a newspaper or clean cloth. • Give patient water frequently to loosen sputum. *For safe handling and disposal of sputum* • Handle with care to avoid spreading infection. • Use a tin for spitting and cover it. • Empty the container in the toilet and wash the tin with a detergent or clean with boiled water. *For easing use of remaining lung function* • Plan activities to accommodate breathlessness. • Avoid crowding, cooking and smoking in the patient's room.
Heart failure or excess fluid	**Furosemide** 40–160 mg/day in a single or divided dose until symptoms improve (monitor for overdiuresis)	
Cough with thick sputum	• Administer nebulized **saline**. • If more than 30 ml/day, try expiratory technique ("huffing") with postural drainage. • Avoid tracheal suction, which is very distressing to the patient.	
Excessive thin sputum	**Hyoscine** (make use of its anticholinergic side-effect) 10 mg every 8 hours	
Pleural effusion (due to Kaposi sarcoma, pneumonia, etc.)	Aspirate pleural fluid if possible (see also Protocol 2, *Management of opportunistic infections and general symptoms of HIV/AIDS).*	
Dry cough	**Codeine** 5–10 mg QID or, if no response, oral **morphine** (2.5–5 mg) as long as needed (try to reduce after one week)	
New productive cough more than 2 weeks **TB**	• Send three sputum samples for acid-fast bacilli (AFB) testing. • See Protocol 4, *Management of tuberculosis and HIV coinfection.* • Continue treatment to prevent transmission.	
Dyspnoea in terminal patients	• Oral **morphine/tramadol** in small dose. • For patients not already on oral morphine for pain, give 2.5 mg every 6 hours; if no relief increase dose progressively by clinical measures; treat pain and anxiety. • For patients already on oral morphine, increase dose progressively by 25%.	

20. Prevention of contractures and stiffness

Table 25. Prevention of contractures and stiffness

Condition	Treatment and dosages (for adults)	Suggestions for home care
Stiffness and contractures **Muscle spasms**	**Diazepam** 5–10 mg 2–3 times daily **Tetrazepam** 50 mg/day, up to 200 mg/day in 2 doses **Baclofen** starting 5 mg TID, increasing every 3 days up to 25 mg TID	Do not confine – encourage mobility. Do the following simple range-of-motion exercises if patient is immobile. • Exercise limbs and joints at least twice daily. • Protect joints by holding the limb above and below and support it as much as possible. • Bend, straighten and move joints as far as they normally go. Be gentle and move slowly without causing pain. • Stretch joints by holding as before but with firm steady pressure. • Bring the arms above the head and lift the legs to 90 degrees – let the patient do it as far as possible and help the rest of the way. Massage the patient.

21. Management of vaginal discharge from cervical cancer

Table 26. Management of vaginal discharge from cervical cancer

Condition	Treatment and dosages (for adults)	Suggestions for home care
Vaginal discharge from cervical cancer	**Metronidazole** 100 mg tablets as pessary OD	Provide daily hygiene. Patient can sit in basin of water with pinch of salt, twice daily if possible.

22. Drug interaction considerations

There are a few instances in which medications used in palliative care are not recommended for use with antiretroviral agents such as the more potent PIs (e.g. ritonavir and indinavir) or NNRTIs (e.g. nevirapine and efavirenz), due to drug interactions mediated through the cytochrome P450 enzyme system involved in hepatic metabolism. These substances to avoid include triazolam, midazolam, terfenadine, astemizole and St John's wort *(36–40)*. In most other cases, such as longer-acting benzodiazepines, anticonvulsants and tricyclic antidepressants, it is recommended rather that clinicians monitor patients closely for evidence of under- or overmedication, and that therapeutic drug level monitoring be used in instances where it is available and may provide useful additional information.

V. Special advice for terminal care

It is very helpful in the care of dying patients for family members to understand and anticipate some of the medical, emotional and spiritual changes that can occur as part of the normal process of dying in the last months of life. The health care team can play an important role in educating family members and other caregivers about end-of-life issues, including what to expect over the final course of the illness. At the end of this section, Table 27 presents a general prognostic timeframe for approaching the end of life, describing typical patient features and interventions that may be helpful in the last months, weeks, days and hours of life. General recommendations for working with patients' families in end-of-life care are presented immediately below.

1. Preparing for death

- Encourage communication within the family. A family meeting may be useful to identify the fears and worries and of the patient and of the family.
- Talking with the patient to establish the patient's understanding and prognosis of the disease is important.
- Discuss worrisome issues such as custody of children, family support, future school fees, old quarrels and funeral costs.
- Let the patient know he/she will be loved and remembered.
- Talk about death if the person so wishes. Find out if the patient has ever seen anyone die and his or her own fears about death. Such fears may have a basis in physical and/or psychological ones.
- Make sure the patient gets help in addressing any feelings of guilt or regret.
- Respond to spiritual needs as the patient requests, providing connections with spiritual counsellors or religious institutions of the patient's choice.

2. Presence

- Be present with compassion.
- Visit regularly, hold hands, listen and talk.

3. Caring

Provide comfort measures, such as:

- moistening lips, mouth and eyes
- keeping patient clean and dry
- treating fever and pain (around the clock if necessary)
- controlling other symptoms and relieving suffering with medical treatment as needed
- providing liquids and small amounts of food as needed
- providing physical contact.

4. Bereavement

After the death of the patient, it is important to acknowledge and attend to the bereavement needs of survivors. Particular issues for families affected by HIV include:

- the relatively young age at which most patients die, which can be a more difficult loss for families than the death of an older family member;
- the immediate and longer term risk of financial and social losses;
- the stigmatized nature of the disease, which may complicate the grieving process; and
- the possibility that other family members have already have died from HIV/AIDS, or that survivors may be HIV-infected and at risk for dying from it.

All of these issues make it necessary for HIV/AIDS care providers to be sensitive and responsive to the needs of survivors and orphans to help them deal with the grief and multiple losses which HIV/AIDS often inflicts on families.

TABLE 27. COMMON MANIFESTATIONS IN PLWHA APPROACHING THE END OF LIFE, AND SUGGESTIONS FOR FAMILY AND CAREGIVER SUPPORT

Type of manifestation	Last months	Last weeks	Last days	Last 24–28 hours
PLWHA end-of-life manifestations				
Physical	• Increased fatigue • Increased sleep • Decreased interest in eating • Increase in pain or other symptoms	• More time in bed • Insomnia • Less interest in food and drink • Decreased energy • Difficulty walking	• Incontinence • Sleep pattern reversal • Sweats • Confusion • Cognitive failure • Changes in skin (pallor) • Respiratory changes	• Somnolence • Restlessness • Agitation • Gradual or sudden loss of consciousness • Further changes in skin colour • Periodic breathing • Gurgling • Moaning • Delirium
Emotional	• Increased need for closeness, talking, physical contact • Social withdrawal • Increased sadness, crying • Seeking closure, expressing feelings of love	• Desire to talk about funeral arrangements • Periods of intense emotional expression • Bargaining • Life review, discussion of past events • Desire to reassure family • Fear of sleep	• Greater peacefulness, quiet • Increased communication • Signs of closure/saying goodbye • Increased anxiety	• May be unresponsive or minimally responsive • Confusion, delirium, inability to express emotions clearly
Spiritual	• Increased interest in spiritual matters • Prayer • Desire for contact with religious/spiritual leader • Questioning of faith	• Dreams or visions of deceased loved ones • Increased faith in God • Periods of quiet reflection	• Increased clarity in thinking and emotions • Increased sense of peace and transcendence	• Perception of other dimensions of experience • Increased sense of peace • Deep peaceful sleep

Type of manifestation	Last months	Last weeks	Last days	Last 24–28 hours
Suggestions for family/caregiver support				
All	• Allow patient to dictate food preferences. • Offer and encourage food/fluids (never pressure or force). • Offer assistance with walking. • Help create a comfortable, safe environment. • Work closely with treatment team and report any new or worsening symptoms or problems. • Provide emotional support; listen. • Try not to deny patient's acceptance of illness by saying everything will be okay. • Allow patient to cry and vent emotions. • Do not minimize sad feelings. • Pray with patient if possible. • Assist patient in contacting spiritual leader.	• Support patient's choice to rest as needed. • Continue to report any increase in pain or symptoms to the treatment team. • Monitor any changes in sleep patterns, eating, etc. • Support discussion of end- of-life wishes. • Moderate visiting so patient can rest. • Allow for life review discussion, reminiscing. • Provide physical contact, e.g. back rubs, foot massages. • Communicate feelings of love, acceptance. • Leave bedroom light on if patient is fearful of the dark. • Reassure patient frequently that loved ones will be present whenever possible. • Participate in discussion of spiritual issues.	• Keep patient clean and dry. • Reposition patient frequently if unable to move. • Offer but don't force foods and fluids. • Be aware of level of consciousness, ability to swallow prior to feeding. • Provide physical contact. • Moisten lips with ice chips, swabs. • Continue verbal communication, play favourite or soothing music. • Allow family and friends to keep bedside vigil. • As a caregiver, remember to rest and eat whenever possible. • Pray with patient.	• Provide warm/cool compresses as needed if cold/sweating. • Talk to patient (even if unresponsive). • Report changes in breathing to treatment team (and be reassured about abnormal breathing changes at end of life). • Notify team if patient appears uncomfortable (frowning, furrowed brow). • Provide medications as needed/directed. • Talk with patient and express emotions. • Provide verbal and nonverbal support through words and actions. • Say goodbye and give permission to go. • Reassure patient. • Express love and acceptance. • Participate in supportive rituals.

Note: The symptoms and signs listed in this table are meant to be typical rather than universal. Patients do not necessarily exhibit all of them, and the final course of illness differs significantly among PLWHA. The timeframe for individual manifestations will also vary substantially in individual cases from what is shown.
Source: Selwyn & Rivard, 2003 *(41)*.

VI. Suggested minimum data to be collected at the clinical level

The suggested minimum data to be collected is important in the development of key indicators on access to palliative care and its success. Such indicators assist managers in decision making on ways to strengthen and expand these services to all PLWHA who need them.

The following data should be collected on a regular basis (e.g. monthly, quarterly or semi-annually):

- number of HIV/AIDS patients requiring palliative care[3]
- number of HIV/AIDS patients receiving palliative care
- number of HIV/AIDS patients receiving any pain management
- number of HIV/AIDS patients receiving opioid pain management

[3] Defined as the PLWHA who exhibit the signs and symptoms described in this protocol.

Annex 1. Equianalgesic dose equivalents for opioids

TABLE 28. EQUIANALGESIC DOSE EQUIVALENTS FOR OPIOIDS

Opioid agonist	Approximate equianalgesic dose	
	Oral	Parenteral
Morphine	30 mg every 3–4 h	10 mg every 3–4 h
Hydromorphone	7.5 mg every 3–4 h	1.5 mg every 3–4 h
Methadone	15 mg every 6–8 h	10 mg every 6–8 h
Fentanyl	25 mcg (transdermal)[a] every 72 h	0.01 mg
Hydrocodone[b]	30 mg every 3–4 h	—
Oxycodone[b]	30 mg every 3–4 h	—
Codeine[b]	180–200 mg every 3–4 h	130 mg every 3–4 h

[a] Not for use in opioid-naive patients.
[b] May be available in fixed-dose tablet combination with paracetamol or aspirin.
Source: Jacox et al., 1994 *(32)*.

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