Part II – Neurological Disorders

CHAPTER 20
CARE IN NEUROLOGY

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2012

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BRIC 2012 

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NEUROLOGY IN AFRICA

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Cover: Tor Vegard Tobiassen

Layout: Christian Bakke, Division of Communication, University of Bergen

Printed by Bodoni, Bergen, Norway 

ISBN 978-82-7453-085-0

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CHAPTER 20

CARE IN NEUROLOGY

The burden of neurological disease in Africa is already evident from earlier chapters where they account for >5% of all deaths and >14% of all disabilities. Neurological disorders account for 10-20% of adult medical admissions to hospitals in Africa, 20-30% of whom die in hospital and >30% of whom are disabled at discharge. The leading neurological causes of death in hospitals are stroke, HIV disease, infections and head injury, and the leading causes of disability are stroke, paraplegia, trauma, and epilepsy. Most medical practice is concerned with the control of symptoms and this is particularly true when caring for patients with neurological disorders. The common symptoms and worries encountered in advanced neurological disorders are outlined below in Table 20.1. Neurological care invariably involves elements of palliative care. Palliative care is about caring for a patient when the disease no longer responds to curative treatment. This involves special attention to symptoms such as pain, and psychological, social and spiritual well-being. Palliative care regards dying as a normal process and offers practical support to help the patient and family. It is an integral part of patient care in hospital and is best delivered by a team approach. This includes family, nurses, doctors, physiotherapists, occupational therapists and spiritual advisors. The aim of this chapter is to present an overview of care and symptom control in patients with neurological disorders with an emphasis on palliative care. The student should aim to be familiar with this and in particular the relief of pain.

Table 20.1 Common symptoms and worries in patients with advanced neurological disorders

Physical	Psychological	Social	Spiritual
pain confusion/delirium loss of communication dysphagia seizures nausea/vomiting spasticity dyspnoea immobility constipation	depression fear anxiety stigma/guilt	loss of income fear for children spouse & dependants	religious non religious why me?

MAIN SYMPTOMS

Pain

Pain is defined as *a subjective unpleasant sensory* and *emotional experience* associated with *actual* or *potential tissue damage*. Pain is a common disorder and WHO estimates that 5-30% of the world's population experience persistent pain depending on where they live. The most commonly affected sites worldwide are head, neck, knees and lower back. Pain is influenced by the patient's mood, morale and the underlying reason for the pain. Chronic pain may persist long after the tissue damage has been done and is defined as pain lasting for >3/12.

Total pain is an interaction of the physical, emotional, psychological and spiritual components. The consequences of pain include immobility, depression, poor sleep and nutrition and overdependence on family and carers. Longer term consequences affect employment, family, and social life. Chronic pain as a result of neurological disorders is a major and neglected cause of disability in Africa. The management of pain involves **non pharmacological measures, drug treatments, psychological** and s**piritual support**. The aim of drug treatment is to provide an effective and regular treatment which completely stops pain and prevents its recurrence. The commonly used drugs in pain control (Table 20.4) and the WHO steps in their use (Table 20.5) are outlined below.

Pathophysiology

Pain is broadly classified into two types: **nociceptive** and **neuropathic (**Table 20.2). The difference between nociceptive and neuropathic is not always clear-cut clinically and any one individual may suffer from one or both types of pain.

Nociceptive pain is caused by activation of primary pain receptors in tissues and is transmitted to the brain through slow non myelinated peripheral C fibres and faster conducting larger myelinated (A) fibres. It can be either somatic arising from skin, musculoskeletal (muscle spasticity, joint deformities) or visceral arising from internal organs (malignancy, stone) or bone (fracture). The type of pain depends on the site, origin and cause of pain. It ranges from the familiar pricking and burning pain in skin conditions to a dull, continuous, diffuse, aching as described in internal malignancy or the intermittent, sharp and colicky pain which occurs in gastrointestinal or ureteric colic.

Neuropathic pain by contrast is mostly neurological in origin arising from damaged neural tissue either in the peripheral or the central nervous system. The main sites of origin are peripheral nerves (HIV, diabetes), nerve roots (herniated disc, herpes zoster), spinal cord (paraplegia) and the brain (post stroke). The sensations that characterize neuropathic pain are variable and often multiple and are described as burning, gnawing, aching or lancinating (knife-like) or shooting in character. There is frequently numbness or dysaesthesia (altered unpleasant sensation) or allodynia (when a non painful stimulus is perceived as pain) in a superficial sensory distribution coupled with local autonomic dysfunction. Neuropathic pain can be either intermittent, lasting seconds or continuous, lasting hours, and can persist even without the stimulus. It generally responds poorly to treatment. Pain without identifiable tissue or nerve damage is termed idiopathic. The N-methyl–D aspartate (NMDA) channel receptor complex, substance P, bradykinin and serotonin are all involved in the pathophysiology of pain. These are found predominantly in the spinal cord and peripheral nervous system.

Table 20.2 Neurological types of pain

Classification	Main causes
Neuropathic	
peripheral	neuropathies: HIV, diabetes, neuralgia, injury, causalgia, complex regional pain syndromes (local limb injury)
central	thalamic stroke, paraplegia, spinal cord injury, disc disease, HIV, syphilis
Nociceptive	
spasticity & rigidity	strokes, quadriplegia/paraplegia, dystonia, tetanus, stiff person syndrome
others	headache, arthritis

Measurement

All types of pain should be described fully in terms of quality, severity, location, mode of onset, provoking and relieving factors, and time course. Pain is subjective but can be measured. The simplest measurement uses self reported severity in terms of mild, moderate, severe and very severe which can be recorded and graded on a corresponding scale of 1-4. In clinical practice however, there is widespread use of the verbal or written analogue scale. This is a scale of 1-10, where 1 is the least and 10 is the worst pain imaginable. The patient is asked *"where on this scale of 1-10 do you put your pain?"* The value of the pain scale is that it is independent of language, easy to understand and use and can be recorded and repeated at each patient visit and response to therapy monitored.

Major causes of neurological pain in Africa

- spinal cord injuries
- neuropathies
- myelopathies
- malignancies
- stroke
- chronic neurological disorders

MANAGEMENT OF PAIN

Relief of pain should be the responsibility of all health care workers. The main aim is to diagnose, treat and stop the pain. In chronic neurological disorders this frequently involves providing maximal pain relief, as complete alleviation is not always possible. The range of clinical treatments includes non pharmacological and pharmacological measures. The non pharmacological approach is summarised in Table 20.3. The drug treatment of pain of neurological origin is based on the distinction between the pain of nociceptive and neuropathic origin and is summarised in Table 20.4 In practice, although these may be difficult to distinguish, the pain of nociceptive origin responds better to non-opioid analgesics such as **paracetamol, aspirin** and **non steroidal anti-inflammatory drugs** whereas pain of neuropathic origin responds best to **tricyclic antidepressants** e.g. **amitriptyline** and the **anticonvulsants** e.g. **gabapentin** and **carbamazepine.** Opioids can be used in both types and their role in the management of pain is summarized below in Table 20.4. Pain due to local compression of peripheral nerves or nerve roots may be relieved by appropriate surgery. Nerve root blocks and epidural spinals provide temporary relief. Patients with chronic pain benefit from a multidisciplinary approach involving cognitive behaviour therapy, physiotherapy and occupational therapy.

Table 20.3 General and local measures used in pain management

Intervention	Indication	Comments
Non Pharmacological		
Explanation, relaxation, positioning	any pain	non invasive
Complementary therapies aromatherapy, massage	chronic pain	may improve pain relief *(no evidence for use in severe pain)*
Transcutaneous electrical nerve stimulation (TENS)	musculoskeletal, soft tissue	patient is in control
Acupuncture	chronic myofacial pain, migraine	pain relief *(no evidence for use in severe pain)*
Radiotherapy (palliative)	bony metastases particularly spinal	excellent pain relief
Local		
Invasive anaesthesia *spinal, regional blocks*	spinal & localised root/plexus lesions	very effective but needs skilled operator
Topical agents *heat/cold*	any pain	
capsaicin cream		burning, redness, cough. *(takes 2-6 weeks to work)*
lignocaine patch		few side effects, expensive

DRUG TREATMENT OF PAIN

Non-opioids

These include non steroidal anti-inflammatory drugs (NSAIDs) and paracetamol. The most commonly used NSAIDs are **aspirin, ibuprofen,** and **diclofenac**. Their doses, routes of administration and side effects are outlined in Table 20.4. These are the main first line treatment for most pain regardless of whether it is of nociceptive or neuropathic origin and are used at all 3 steps in the WHO analgesic ladder (Table 20.5). NSAIDs should be used cautiously in patients with renal impairment as they may further impair function and may provoke renal failure. In patients with a history of dyspepsia the concurrent prescription of **proton pump inhibitors** or **histamine-2 receptor blockers** help to reduce the symptomatic upper GIT side effects.

Opioids

Opioids include all drugs that act at opioid receptors. These receptors are scattered throughout the body though mainly in the central and peripheral nervous system. Opiates are either derived from the opium poppy **(morphine** and **codeine)** or synthesised in the laboratory

(pethidine). Opioids are indicated for pain at steps two and three of the WHO ladder (Table 20.5). This includes pain in patients with advanced disease and their short-term use to relieve breakthrough or severe acute pain of any origin.

The use of opioids for non-malignant chronic pain is controversial. In general, opioids on their own should be avoided for intractable chronic neurological pain (usually neuropathic) to reduce the risk of dependence. However their use in advanced or terminal disease should not be restricted as they are necessary and there is no risk of dependence in this setting. The biggest barriers to their use are availability and the stigma from both the doctor and the patient surrounding their use. Once these can be overcome they provide excellent pain relief. Whenever opioids are used, they should be given at regular intervals, e.g. morphine every 4 hours (**oxycodone** can be given 6 hourly), preferably via the oral route or when necessary via the parenteral route. The dose and frequency should be according to the needs of the patient and be reduced in renal or hepatic failure and in the elderly. Constipation is usually not a major issue in clinical practice.

It is important to realise that opioids are controlled drugs with strict regulations concerning their availability, prescription and use anywhere in the world. A major limitation to their use in many low income countries are the stringent national control policies regarding the accessibility and use of opioids for pain. However some countries in Africa have recently prioritized their use in pain control and opioids are available for medical use.

Adjuvants

These mainly include the antidepressants **amitriptyline** and the anticonvulsants **carbamazepine** and **gabapentin** or **pregabalin**. These are used in all three steps in the WHO analgesic ladder for the management of neuropathic pain. They are most commonly used as adjuvants in combination with opioids or non opioids depending on the severity of the pain. In some patients with chronic pain of neuropathic origin they are used on their own without analgesics. Examples of neurological disorders benefitting from their use include neuropathies (HIV & DM) and post herpetic and trigeminal neuralgias.

Their dose, route, frequency and side effects are outlined in Table 20.4. The main limitations are their side effects and frequency of administration which may limit patient compliance. It is always wise to start at the lowest dose and increase it slowly. In general antidepressants are taken once daily, often at night whereas anticonvulsants are prescribed twice or three times daily. The main side effects of tricyclics are anticholinergic and include sedation, dry mouth, postural hypotension and constipation among others. Side effects of the anticonvulsants include drowsiness (which often clears with regular usage), confusion and ataxia. Both antidepressants and anticonvulsants may be used together as they have different mechanisms of action in the nervous system.

Table 20.4 Drugs used in pain management

Indication	Drug/dose/route/frequency	Side effects
Minor pain *(non opioids)*	aspirin 300-500 mg tab, 1-2 po/6 hourly ibuprofen 400 mg tab, 1-2 po/pr/8-12 hourly diclofenac 50-75 mg, po/pr/im/12 hourly paracetamol 500 mg tab,1-2 po/pr/6 hourly	gastric irritation, peptic ulceration, GIT bleeding, nausea, renal dysfunction liver damage in over dosage
Intermediate pain *(opioids mild)*	codeine/dihydrocodeine 30-60 mg, po/pr/im/6 hourly tramadol 50-100 mg/po/pr/im/6 hourly	constipation
Major pain *(opioids strong)*	* pethidine 50-100 mg/po/im/4-6 hourly morphine 2.5, 5,10-20 mg/po/im/sc/4-6 hourly	constipation sedation, nausea, vomiting, respiratory depression (rare)
Chronic neurological pain *(adjuvant)*	amitriptyline 10-100 mg/po/nocte, starting dose is 10-25 mg increasing as tolerated carbamazepine 2-300 mg/po/8-12 hourly *(main use is in trigeminal neuralgia)* gabapentin 100 mg/po/8 hourly or 300 mg nocte increasing by 300 mg every 1-2 days to max of 2.4-3.6 gm daily as tolerated *or* pregabalin 75 mg/po/12 hourly increase to max of 600 mg daily as tolerated	sedation, dry mouth, constipation, hypotension, blurred vision, confusion sedation, dizziness, ataxia, blood dyscrasias sedation (transient) unsteadiness, oedema, headache

**duration of action of pethidine is too short for use in chronic pain relief*

Table 20.5 WHO analgesic ladder

Step 1	non-opioid **± adjuvant**
Step 2	mild opioid for mild-moderate pain ± non-opioid **± adjuvant**
Step 3	strong opioid for severe pain ± non opioid **± adjuvant**

Key points

- adequate pain control is very important in patient care
- controlling pain, if done properly does not shorten & may allow normal life
- opioids are used for pain not responding to simple analgesics & NSAIDs
- opioids are indicated for pain control in advanced neurological disease
- neuropathic pain frequently responds to combinations of antidepressants & analgesics

OTHER MAIN SYMPTOMS

Impaired communication

Impaired communication occurs in many neurological disorders. It ranges from aphasia in stroke to dysarthria in motor neurone disease and the inability to understand or comprehend in dementia. In virtually all situations, communication with the patient switches from speech to a non verbal form. This may take the form of "fixed expressions", gestures, signs or written commands. The family should be encouraged to try anything they feel is acceptable as a way of communicating to the patient. A simple communication board with images or illustrations

indicating a person's daily needs can be very helpful at this stage. It is also wise to advise health care workers, family members and carers to behave at the bedside as if the patient hears and understands what is being said. Impaired communication may be improved in certain circumstances. Measures include making certain the patient is comfortable and pain free, that the environment is conducive to communication, without outside noise or interference and with appropriate face to face seating. The help of a person trained in speech and language therapy should be sought where ever possible.

Key points

- make sure patient is pain free & comfortable
- encourage family to try to communicate
- communicate in a conducive environment without noise or interference
- sit in front so the patient can clearly see your face
- obtain help from a person experienced in speech and language therapy

Confusion/delirium

Neurological disorders have high rates of confusion and behavioural disturbances. The main causes include infections, stroke, anaemia/anoxia, metabolic disorders, neurodegenerative disorders e.g. dementia, extrapyramidal disorders, SOL, drugs and psychiatric disorders. The main causes of confusion/coma have already been outlined in chapter 9. Management depends on the clinical situation and the overall aim. In the early stages, it is important to retain a high index of suspicion for a reversible cause and the aim should be to screen for any underlying disorder. Simple bedside screening tests, include measuring oxygen saturation, glucose, malaria parasite and an HIV test. The patient should ideally be nursed in a quiet, dimly lit area or room away from other patients and surrounded by family. The health care worker should aim to be supportive and reassuring to the patient and family. If these measures do not succeed then drug treatment should be started with neuroleptics.

Drug treatment

Haloperidol is the drug of first choice starting with low dose 0.5-1.0 mg/po/im/bd increasing as required. In patients with acute delirium, it may be necessary to use higher starting doses, 1.5-3 mg stat po/im or sc and to repeat after the first 1-2 hours if necessary. The total 24 hour dosage of haloperidol ranges from 5-30 mg. **Chlorpromazine** 25-50 mg (or 50-100 mg if necessary) po/im/8 hourly is an alternative. In the later stages of an advanced or terminal disease treatment should start directly with neuroleptics.

If there is a major anxiety component, then an anxiolytic may be used in addition to neuroleptics. **Diazepam** 5-10 mg/po/im 8 hourly is usually the drug of first choice. If the cause is raised intracranial pressure, then steroids, usually **dexamethasone** 8 mg/po/iv is given twice or three times daily (steroids can be given once daily as a single dose) until symptoms are controlled and then it is reduced after 3-5 days to 4 mg twice or once daily or twice weekly as is necessary. The second dose should ideally not be later than early afternoon as steroids can sometimes cause insomnia. The drugs most commonly used to treat confusional states are outlined below in Table 20.6.

Table 20.6 Drugs commonly used for confusion/delirium

Class	Drug/dose/route/duration	Indication	Side effects
Neuroleptics	haloperidol 0.5-3 mg/po/sc/12 hourly increasing to 5-10 mg 12 hourly if necessary	delirium/ insomnia	drowsiness, dry mouth, parkinsonism
	chlorpromazine 25-50 mg/po/im/ or 100 mg/po/8 hourly	psychosis	dyskinesia, parkinsonism
	thioridazine 10-75 mg/po/nocte	confusion/ insomnia	arrhythmias, parkinsonism
Anxiolytics	diazepam 10-20 mg/po/rectally/8 hourly	anxiety	drowsiness
	lorazepam 0.5-2 mg/po/im/iv/od	anxiety	drowsiness
	midazolam 5-10 mg/sc/im/or rectally /8 hourly	anxiety	drowsiness
	oxazepam/temazepam 10-15 mg/po/nocte	insomnia	drowsiness

Key points

- neurological disorders have high rates of confusion & delirium
- it is important to exclude a treatable cause
- main antipsychotic drugs used are haloperidol & chlorpromazine
- it is important to treat with an adequate dose
- main anxiolytics are the benzodiazepines

Seizures

Epileptic seizures are a common complication in terminal neurological disorders and are usually self limiting. Acute management is directed at protecting the patient from immediate injury and aspiration and the emergency drug treatment and prevention of recurrences. **Benzodiazepines** followed by **phenytoin** or **phenobarbitone** are the drugs of first choice for active or prolonged tonic clonic seizures. The choice of drug, dosage and frequency may have to be adjusted according to the age of the patient and the underlying disorder and these have already been outlined in chapter 4.

Dysphagia

This is a frequent and very disabling symptom in patients with neurological disease. The main causes include all causes of coma, stroke, motor neurone disease, myasthenia gravis and acute neuropathies. The main presenting complaints are inability or difficulty eating, drinking or swallowing safely. Quite apart from the practical difficulties is the loss of enjoyment of eating and drinking. The main aim is to support safe oral feeding for as long as possible while avoiding aspiration, dehydration, malnutrition and patient exhaustion. Good nursing/ family care is needed as these patients are more difficult to feed and usually take longer. Some practical measures to deal with dysphagia include upright positioning whilst feeding, physical therapy with chewing and swallowing exercises, a high calorie diet with food/liquids thickened and regular oral hygiene every 2-4 hourly. Nasogastric tube feeding is a useful temporary or short term measure but should be avoided where death is inevitable as occurs in dementia. A percutaneous endoscopic gastrostomy (PEG) feeding tube may be used in patients with long term disorders presenting with intractable dysphagia. Measures used to treat dysphagia in neurological disorders are summarised in Table 20.7

Table 20.7 Measures used to treat dysphagia in neurological disorders

Indication	Intervention	limitations
Partial dysphagia	physical therapy with chewing and swallowing exercises, head & neck position, increased frequency of swallowing	aspiration pneumonia
Dehydration	fluids >2-3 litres/daily	aspiration pneumonia
Malnutrition	diet: food/liquids thickened, high calorie diet	dehydration/aspiration
Excess saliva/ drooling	oral hygiene 2-4 hourly anticholinergics: amitriptyline 10-25 mg/day/po, scopolamine 0.4 mg/sc/patches prn	mouth too dry and saliva more difficult to swallow
Dysphagia	nasogastric tube feeding (NGT) percutaneous endoscopic gastrostomy (PEG)	aspiration pneumonia, (usually a short term intervention but can save lives) perforation, infection, (used in long term dysphagia)

Nausea and vomiting

This is a common symptom complicating intracranial disorders. The main aim in treatment is to maintain adequate fluid and calorie intake and good oral hygiene. The antiemetics **metoclopramide** and **domperidone** are useful for nausea of gastrointestinal origin. **Ondansetron** is helpful for chemotherapy and drug induced nausea and **cyclizine** in combination with dexamethasone for vomiting in patients with raised intracranial pressure. The commonly used drugs to treat nausea and vomiting are presented in Table 20.8.

Table 20.8 Drugs commonly used for nausea and vomiting

Indication	Drugs/dose/route/duration	Side effects
Nausea vomiting	metoclopramide10 mg/po/iv/8 hourly prochloperazine 5 mg/po/im/8 hourly domperidone10-20 mg/po/pr/8 hourly	dystonic reactions, parkinsonism, drowsiness
	cyclizine 25-50 mg/iv/im/6 hourly	drowsiness, dystonic reactions, parkinsonism
	ondansetron 8-16 mg/po/pr/iv 12 hourly	constipation, headache
Raised intracranial pressure	dexamethasone 4-16 mg/po/iv/bid	indigestion, insomnia, mood disturbance, hyperglycaemia, (perforation increased with NSAIDs), bone necrosis

Spasticity

Spasticity is a common and complex problem in neurological care particularly in patients with stroke and paraplegia. The aim of treatment is to increase mobility and avoid pain, contractures and bedsores. The management of spasticity mainly involves physiotherapy, occupational therapy and drug treatment (Chapter 10). Physiotherapy involves passive stretching exercises and local measures including joint supporting and splinting. The antispasmodics most widely available in Africa are **diazepam** and **baclofen**. The starting dose of diazepam is 2-5 mg three times daily increasing gradually over weeks to a maximum of 20 mg three times daily. **Clonazepam** once daily is an alternative to diazepam. The starting dose of baclofen is 5 mg

twice daily orally increasing slowly over weeks to 20-30 mg twice daily as required. These can be used either as monotherapy or in combination if monotherapy fails. Both drugs are started at a low dose titrating slowly upwards against response. The limiting adverse effects of both are drowsiness and fatigue.

Other oral drugs used for spasticity include **dantrolene** and **tizanidine**. These are mainly second line antispasmodics but are often used in conjunction with first line drugs. Baclofen can be administered intrathecally by injection or pump for intractable spasticity and **botulinum toxin** is used by local injections for intractable spasticity, but both of these measures are only available at specialised centres. Pain resulting from spasticity or spasms can be very severe and is sometimes opioid refractory and needs high doses of muscle relaxants. The main drugs used to treat spasticity are outlined in Table 20.9.

Table 20.9 Drugs used for spasticity

Indication	Drugs/dose/route/duration	Side effects
Spasticity	diazepam 2.5-5 mg/po/8 hourly increasing to 10-20 mg/8 hourly	drowsiness, fatigue
	baclofen 5-10 mg/po/12 hourly increasing to 20-30 mg/12 hourly	muscle weakness, drowsiness, headache, nausea, insomnia
	dantrolene 25 mg/po/daily increasing slowly to 50-100 mg/6 hourly	drowsiness, fatigue, hepatocellular damage
	tizanadine 2 mg/po/6-8 hourly increasing slowly to 6 mg/6-8-hourly	drowsiness, GIT symptoms, allergy, hepatocellular damage

Immobility

Immobility occurs in most patients with advanced or terminal neurological disorders. The main aim of management of the immobile patient is to prevent pain, bed sores and contractures and to make the patient comfortable. To help achieve this aim it is necessary to keep the skin dry and clean. This may involve urinary catheterization when there is a non-functioning bladder or the patient is unable to mobilise to the toilet. Care of paralysed or immobile limbs involves frequent passive movements and ensuring the patient's position is regularly changed. This task is best done initially by a physiotherapist with the aid of antispasmodics and analgesics and the methods later taught to a family carer.

Dyspnoea

Breathlessness and cough are common and distressing symptoms in patients with neurological disorders. The main causes include stroke, infections, neuromuscular disorders and neurodegenerative disorders such as motor neurone disease. It is important to exclude acute reversible causes of respiratory failure such as myasthenia gravis, Guillain-Barre syndrome, medications or infection. Non pharmacological management includes the use of oxygen and relaxation techniques. Ventilatory support is usually not a realistic option unless there is a reversible component.

Management therefore in advanced neurological disorders involves the use of **morphine** initially 2.5-5 mg orally 6 hourly increasing the dose and frequency as required to relieve patient distress. The route of administration may be changed to parenteral depending on the

patient's overall condition. Increasing dyspnoea in neurological disorders is frequently a sign of underlying pneumonia.

Constipation

Constipation is a frequent complication of neurological disorders, in particular those with spinal cord dysfunction, paralysis and immobility. Early intervention is important to prevent this. Measures include ensuring a satisfactory fluid intake, adequate high bulk and roughage diet and the careful use of laxatives. This includes the combined use of stool softeners (liquid paraffin), osmotic laxatives e.g. **magnesium salts** and **lactulose** and/or **colonic stimulants including senna** and **bisacodyl**. Rectal stimulants include **glycerine** and/or **bisacodyl** suppositories or enemas with **phosphate** or **soap** and water. Suppositories and enemas may be the best method of dealing with chronic neurological constipation and manual evacuation may be necessary in cases of faecal impaction.

PALLIATIVE CARE

Palliative care can be involved at any stage of a life-threatening condition, including at the time of diagnosis even if the survival prognosis is fairly long. A large part of palliative care is the provision of adequate relief of pain and other distressing symptoms. The most common problem identified in persons with advanced and terminal neurological disease in Africa is a lack of pain relief. Economic loss caused by lack of earnings, spiritual loss caused by a feeling of loss of God's help, emotional loss caused by a loss of hope and the social stigma of the disease and of feeling isolated in the community have all been identified as problems. Difficulties identified for care givers in Africa are lack of finance, loss of time from work and other activities and the practical aspects of caring for an often bedbound patient. Their main activities include the provision of food, drugs, and consolation needed for the day to day care of the patient. Palliative care aims to provide practical measures to support both patient and family. These include provision of food, drugs, consolation and assisting with the day to day care for the patient.

General care and support

Care in Africa is done mostly by the patient's family and they should always be involved in all major decisions concerning the patient. Both patient and family need understanding of their difficult situation. The health care worker should aim to be informed, gentle, honest, and to be aware of the range of emotions that may be encountered including fear, denial, grief, sadness, worry and finally acceptance. Carers should also be sensitive to and respect the cultural and spiritual needs of the patient. These may involve traditional healers, alternative medicines and religious support depending on the patient's wishes, needs and beliefs. It is important to ask the patient directly concerning the need for spiritual support.

Needs of patients

Palliative care emphasises the importance of alleviation of symptoms particularly in the final stages of disease process. In the last days, weeks and months of life the patient's main needs are symptom relief including pain, anxiety, secretions and nausea. Most people at this stage benefit from combinations of **morphine/antiemetic/anxiolytic ± antimuscarinic**. These can delivered either orally or parenterally by injection. A syringe pump driver is the preferred method of delivery in very ill people. A good death occurs when the patient is cared for where

he wishes to die which is usually at home and is free from pain, worry and other distressing symptoms. Palliative care aims to help patients and their carers achieve this (Table 20.10).

Table 20.10 Aims & possible interventions with palliative care

Main Aim	Intervention
Relieve pain & other symptoms	provide analgesics and medications that are accessible, affordable & available (AAA)
Provide resources necessary to care	financial support
Provide an infrastructure to deliver care	teach, train health care workers & involve family members
Include palliative care as part of the continuum of health care and living	make palliative care a right for everyone

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