

Palliative Care in
Mesothelioma
Handbook for Nurses





Applying palliative medicine in mesothelioma	1
Symptoms in mesothelioma	2
3 steps of symptom management	3
Dyspnea in mesothelioma	4
Pain in mesothelioma	9
Other common symptoms in mesothelioma	16
For successful palliative care in mesothelioma	17
For good communication	18

Contents are based on the lecture 'Palliative care of Pleural mesothelioma' conducted on November 2012, 'Communication skill in care of people with mesothelioma' conducted in 2014. Also some contents were referred to Ahmedzai S.H., Clayson H(2006). Supportive and Palliative Care in mesothelioma. In: O' Byrne K., Rush V, eds. Malignant Pleural Mesothelioma : Oxford University Press, 2006; 403-433, Nagamatsu Y, Horiuchi S, Natori Y (2012). The stages and difficulties of patients with malignant pleural mesothelioma. J Human Care Study, 12, 69-81.

1. Applying palliative medicine in mesothelioma

Mesothelioma is a devastating disease for patients and their families as it causes great suffering. For this reason, and because of the short median survival time of fewer than 12 months from diagnosis, it is important to introduce a palliative approach to patient management from an early stage, preferably from the time of diagnosis.

Palliative medicine aims to provide holistic care of people whose illness is acknowledged to be incurable. This approach combines three intentions:

- the best possible treatment of physical symptoms
- attention to and management of psychological and socio-emotional problems
- support of the patient' s family during the illness and in bereavement

2. Symptom in mesothelioma

Mesothelioma creates a particularly high symptom burden. It produces as much breathlessness as and significantly more pain than lung cancer, as well as many other symptoms:

Breathlessness	96%	Social	16%
Pain	91%	Nausea	14%
Cough	41%	Fatigue	13%
Weight loss	41%	Dysphagia	11%
Anxiety	31%	Psychiatric	10%
Anorexia	25%	Constipation	8%
Depression	19%	Ascites	8%
Sweating	18%	Vomiting	5%
Emotional	16%	Painful metastasis	5%

Table 1: Symptoms in malignant pleural mesothelioma

Clayson H (2007): The Experience of Mesothelioma in Northern England

It is not appropriate to apply lung cancer care into mesothelioma because mesothelioma causes more dyspnea and pain than lung cancer.

3. 3 steps to manage symptoms

Step 1 :

Understand the meaning of symptoms for individual patients



Step 2 :

Correct the correctable physical causes of symptoms



Step 3:

Do all possible to reduce the perception of symptoms by using evidence-based treatments alongside attention to psychosocial factors

4. Breathlessness in mesothelioma

Breathlessness is a very common symptom in Mesothelioma. Prevalence in mesothelioma is 96%, hence 21–90% in cancer.

The **Causes** are:

- Pleural effusion
- Reduction in lung volume
- Fixed lung
- Pericardial effusion
- Anaemia
- Co-morbidities
- Anxiety

Breathlessness can be terrifying to experience as shown by these quotes from patients:

‘Fighting for breath’ , ‘gasping for air’ , ‘drowning in fluid’ , ‘suffocating to death’ . ‘out of control’

Breathlessness is a bio-psychosocial phenomenon. Although they are hugely anxious, patients and relatives do not know when to call for help and often wait until they are desperate. Crises cause fear of imminent death. Breathlessness is visible, stigmatising and causes social isolation due to lack of mobility, loss of agency and embarrassment.

Note:

- Breathlessness in mesothelioma has multiple aetiologies - not all physical
- There is **NO** correlation between patients’ degrees of perception of breathlessness and blood gas levels or respiratory rate
- There is **NO** correlation between relief of breathlessness and physiological measurements

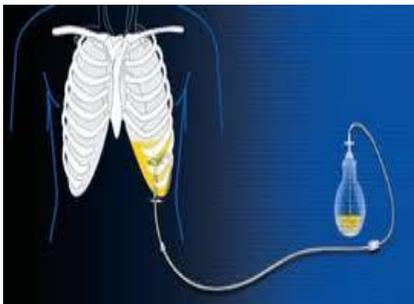
Therefore the **only** reliable measurement is self-report

4-1. Management of Breathlessness

1. **Treat all correctable causes**, for example:

- Aspirate pleural effusion and consider pleurodesis for recurrent cases*
- Surgery may release a 'trapped lung'
- Surgical aspiration of pericardial effusion
- Correct anaemia
- Control heart failure
- Antibiotic for infection
- Explore and manage anxiety

***An indwelling pleural catheter** is effective in refractory cases in which pleurodesis has failed. The indwelling drain can be managed by the patient's family and may create pleurodesis with time. This has been found to reduce the number of hospital admissions for recurrent effusions (see diagrams below)



Diagrams 1 and 2: Indwelling pleural drain

2. Everyone should have a hand-held fan

This is a simple low-cost, low-tech intervention that should be offered to every patient who has difficulty breathing; it will do no harm. The patient should direct the fan so that the cold air blows onto the lower part of the face.

NB: Hand-held fans are preferred to static fans possibly because they promote a sense of mastery

The movement of cool air with a fan has been observed to reduce dyspnoea in patients. It is thought that stimulation of mechanoreceptors or temperature receptors mediated via the trigeminal nerve may alter afferent feedback to the brain and modify the perception of dyspnoea.

3. Use low-dose morphine

Suggested starting dose is 2.5mg oral morphine solution every 4 hours if needed to relieve breathlessness. If this fails to improve the patient's breathlessness the dose should be increased gradually in line with the normal prescribing guidance for morphine.

Note:

The highest density of opioid receptors is found in alveoli, bronchi and trachea. Morphine reduces minute ventilation by slowing respiratory rate and tidal volume. There is no evidence of respiratory depression when used in line with standard prescribing guidance for morphine.

4. **Use complementary therapies** such as relaxation, pacing activities, visualization to encourage the patient to gain some control
5. **Use rehabilitation or physiotherapy specialists** to teach the patient about Breathing Control
6. **Educate carers** so that they can assist the patient
7. **Use a multi-dimensional approach**, considering all possible interventions as shown in the following diagram:



Diagram 3: Multidimensional interventions for breathlessness

4-2. End of life terminal dyspnoea

This is extremely distressing for the patient and his family. At end of life the following medications should be used to relieve distress:

IV morphine is choice: 2 – 5 mg IV Q5–10 minutes until relief

In rare cases, where relief is not obtained, it is ethical and compassionate to provide sedation by using barbiturates or benzodiazepines e.g. midazolam to relieve patient of symptoms

In summary, after correcting all treatable conditions, improve mastery before breathlessness becomes refractory:

- Explore patient' s understanding, hopes, fears & expectations
- Always provide a hand-held fan
- Use low-dose morphine
- Consider complementary and creative therapies
- Involve family/carers
- Involve rehabilitation if appropriate

5. Pain in mesothelioma

Pain is also very common symptom in Mesothelioma.

Pain score of mesothelioma is higher than the one of lung cancer²⁾.

2) Nowak A, Stockler MR, Byrne MJ. Assessing quality of life during chemotherapy for pleural mesothelioma: feasibility, validity, and results of using the European Organization for Research and Treatment of Cancer Core Quality of Life Questionnaire and Lund Cancer Module. *Journal of Clinical Oncology* 2004;22:3172–80.

Quote from patient with mesothelioma:

'... the pain' s always there but I can control it with the medication, up to a point. It varies day by day; sometimes it' ll pull in my back, other times it' ll pull in my front, other times it' ll pull where I had my biopsy – it' s real

The Cause of Pain

Pain in mesothelioma is complex due to the various pain-sensitive structures that might be involved: the pleura, intercostal nerves, pericardium, diaphragm, ribs and vertebrae, spinal cord and nerve roots plus nerve plexuses e.g. brachial plexus. Thus the pain can be of inflammatory, neuropathic or bony origin.

A combination of these types of pain frequently occurs and any perception of pain is greatly moderated by psychosocial factors. Fear and anticipation of pain are common to all cancers but the severe psychological burden in mesothelioma, and its impact on pain perception, requires particular understanding. This means that efforts to achieve pain control need to address these various factors; this requires a

multidimensional approach as in the diagram below:

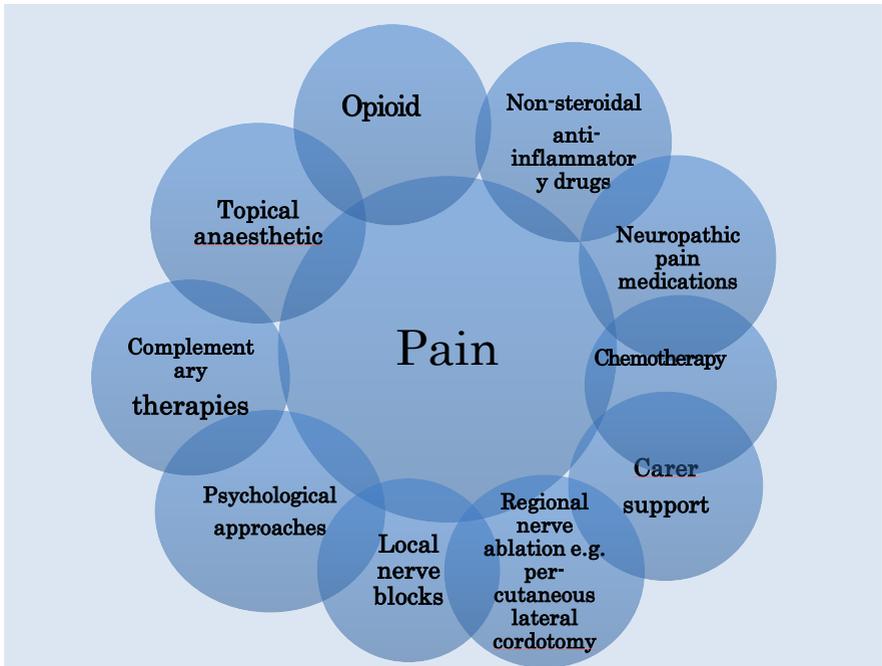


Diagram 4: Multi-dimensional interventions for pain

5-1. Management of Pain in mesothelioma

Inflammatory pain: Tumour cells and possibly asbestos fibres invade soft tissues and interact with host macrophages release of cytokines, prostaglandins and other vasoactive substances which create the inflammatory response.

Treatment

This may respond to simple non-steroidal anti-inflammatory drugs, or occasionally to corticosteroids (these may also increase appetite and general well-being but due to their side-effects are not recommended for long-term use). Regular paracetamol, 1gm qds or a mild opioid analgesic such as codeine may be added with benefit. Morphine is not very effective for this type of pain but more specialized drugs such as methadone and ketamine have anti-inflammatory actions.

Neuropathic pain: This arises when there is damage to either peripheral nerves or to nerve structures in the CNS. It can be self-perpetuating. Typical sensations that patients describe are burning or coldness, raw, 'electric shocks', numbness, itching and tingling. Hypersensitivity to stimuli (allodynia) and altered sensations (dysaesthesia) are common. Patients typically rub or tightly hold the affected area.

Treatment

Antidepressants e.g. amitriptyline, commencing at 25mg at night

Anticonvulsants e.g. gabapentin

NMDA antagonists e.g. methadone (opioid) or ketamine

Topical lidocaine 5% patches for localized pain e.g. a small area on the chest wall or a track metastasis

Bone Pain: Local advanced tumour or metastatic hurt nerves in bone. Also cytokines and koninis released by tumour cause long-term sensitisation as in neuropathic pain. This happens when rib and vertebral bodies are invaded by mesothelioma.

Treatment

Bone pain may have nociceptive, inflammatory and neuropathic elements so any of the above medications may be useful. However, in addition, radiotherapy to a localised area of bone pain is highly effective.

Complications: rarely, paralysis of ipsilateral diaphragm, and 11% experience mild motor loss or dysaesthesia.

Break through pain: This is pain that occurs between doses of a regular opioid and is not due to inadequate dosing.

Treatment

All patients who are prescribed sustained release morphine should have a supply of liquid oral morphine equivalent to 1/6th of the 24-hour dose to use if breakthrough pain occurs.

Example: A patient who is taking s/r morphine 60mg twice a day i.e. 120mg per 24 hours, should also have a supply of liquid oral morphine and take 20mg if breakthrough pain occurs. If more than 2 doses are required in 24 hours then the regular long-acting dose of morphine should be increased to at least the sum of all doses required in the previous 24-hour period.

5-2. Pain control in mesothelioma - a suggested model:

Step 1 : Non-opioid +/- non-steroidal anti-inflammatory drug

For localized chest wall pain consider topical local anaesthetic or, if bone pain, use radiotherapy



Step 2 : Start opioid

Use short-acting oral morphine solution initially and start at low dose e.g. 2.5mg 4-hourly as required. Once pain control has been achieved, usually within a few days, convert the effective total 24-hour dose into regular doses of a long-acting morphine - to be taken regularly. A laxative should ALWAYS be prescribed with morphine as intractable constipation is a very distressing side-effect.

Sometimes patients cannot tolerate the side effects of morphine in which case an alternative opioid such as oxycodone may be used.



Step 3: Add a neuropathic pain agent

If any clinical features suggest neuropathic pain and there has been no improvement on morphine then stop morphine and commence a neuropathic pain agent (see above).

If morphine has helped but there are still features of neuropathic pain then **add a neuropathic pain agent** as above.

In some cases two neuropathic pain agents with different modes of action may be more effective than one





Step 4: Refer for Specialised interventions

If distressing pain persists refer quickly for specialised interventions:

Ketamine and methadone: These 2 analgesic medications can be highly effective in refractory pain but both require specialist management due to their complex actions and the possibility of major side effects.

Percutaneous cervical cordotomy: This technique involves ablation of the contra-lateral lateral spinothalamic tract and is used for unilateral severe pain below the clavicle. It can be very useful in pleural mesothelioma. The patient must be able to lie still for 1 hour and be conscious and cooperative – 47% achieve prolonged benefit (Jackson et al, 1999). This is only available in specialised centres.

5-3. Pain assessment

The rule is that *'pain is what the patient says it is'* - therefore self-assessment is the only reliable method of pain evaluation. Pain score charts or visual analogue scales can be extremely useful in determining whether or not treatments are effective when used by individual patients as a self-comparison method.

5-4. How to use Morphine

Start low dose every 4 hours, using liquid oral morphine
Increase quickly - every 3 days initially - until pain is controlled
Then switch to a sustained release preparation

If side effects occur consider:

1. Is the dose too high?
2. Would an alternative opioid be better or
3. Ask 'Is this neuropathic pain?' If so, change to medication for neuropathic pain

Other Opioid: Oxycodone, fentanyl, methadone, Ketamine

6. Suggestions for managing other common symptoms

Cough - establish cause; consider dexamethasone if an inflammatory cause, gabapentin if muscle spasm, antibiotic if infection

Rarely, after radical extra-pleural pneumonectomy (EPP), consider post-surgical bronchial fistula

Sweating - consider cimetidine, use cotton clothing and a fan

Fatigue - may benefit from rehabilitation if well enough or pacing of activities or corticosteroid (short-term)

Nausea - metoclopramide or haloperidol initially but may need corticosteroid +/- levomepromazine. Two thirds of patients need more than one anti-emetic in combination

Anxiety - honest but compassionate information and assurance of continuing support for the patient and family. If the patient is also depressed mirtazapine is particularly useful due to its side effect of increasing appetite as well as lifting mood. Complementary therapies may help e.g. visualization, relaxation etc.

Patients who are still well enough can benefit greatly from attending an asbestos victim support group

In some cases formal psychiatric assessment may be necessary

Consider involvement of faith leaders if appropriate.

7. Summary: For successful palliative care in mesothelioma:

1 Address all symptoms that cause suffering

Pain in mesothelioma is complex and severe, breathlessness is terrifying, multiple other symptoms occur, and psychological issues worsen the experience of symptoms. Multiple medications are often required.

2 Act quickly

British Thoracic Society guidelines suggest palliative care by specialists should be introduced in early stages of mesothelioma. However even in UK around half the mesothelioma patients do not receive palliative care. Be aware that severe symptoms arise quickly in mesothelioma, and tend to get worse as the disease progresses (unlike in most cancers where they tend to plateau). Be prepared to act quickly and refer rapidly for appropriate treatment by a palliative or pain management specialist working within a multi-disciplinary team

3 Address psychosocial issues

Mesothelioma causes much distress and the psychosocial issues exacerbate physical problems. Try to understand what is causing distress to individual patients, always treat them with respect and compassion, and reassure them that you will support them and their families throughout the illness.

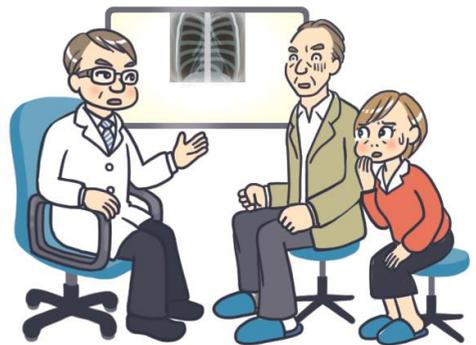
8. For good communication with people with mesothelioma

A **trusting relationship** between the patient and his or her medical professionals to good palliative care and this relationship must be based on honesty. Also being polite to patients is essential because no one want to be treated as a child or incompetent one at the end of life. Now he/she is weak and unable to take care of himself, but he/she used to have a wonderful life. Also speak kindly with soft voice because patients are full of pain psychologically as well as physically. Medical staffs must respect them when my patient refuses the offer. All staffs must simply behave like the way one want to be treated when he/she die.

Patients have a right to know

Patients have a right to information about their condition and you should not withhold information necessary for their decision-making (unless you judge it would cause the patient serious harm that is more than simply cause upset). If families are told the disease is fatal but the patient is not told the truth a great deal of tension is created between them that add to the emotional problems of all concerned.

In the UK, the patient' s family is informed about the illness only if the patient first gives consent for this to happen. Families and doctors cannot and should not make decisions for conscious patients who have full mental capacity because assumptions about others' wishes are frequently incorrect - the only way of knowing what someone wants is to ask. Of course, **patients need to be fully informed** in order to express preferences and make appropriate decisions.



How to inform bad news

The first issue in mesothelioma is that the doctor must tell the patient and his or her family that, regardless of whatever treatments might be chosen, there is no cure for this illness. This communication must be done with **great compassion and sensitivity**, checking the patient's understanding while allowing him to absorb the bad news at his own pace.

The information will come as a dreadful shock to the patient and might well need to be repeated because the patient will often have difficulty believing that there is no cure. As patients come to understand that message,



it is essential to tell them that a lot can be done to ease the symptoms and also that you, the doctor, will be available to provide support throughout the illness. Rather than saying 'There is no cure, nothing can be done' – remarks that leave patients extremely shocked and traumatized – it is better to say something like 'I am sorry that we cannot cure your condition but we will do all we can to delay its progress and help you deal with it and we will support you and your family at all times'. Communication skills training at undergraduate and postgraduate levels will help doctors with this difficult task.

It is known that **being honest about prognosis** helps both patient and doctor: *The patient*, knowing that his time is limited, is able to regain control and plan ahead, make choices about his end-of-life care and make his wishes known to his family

The doctor is not then engaged in keeping up pretense and colluding with the patient and his family about the illness. This allows the doctor to concentrate on relieving the patient's symptoms and other problems.

Coping narrative

Patients (and relatives) were determined to assure medical staffs that they were coping. The '*coping narrative*' is an important strategy in mesothelioma and restores a sense of control, bolsters self-esteem and inhibits enquiry & disclosure around emotionally-distressing areas - *BUT* it also inhibits asking for help and compromises family carers and health care professionals

It is important role of nurses to assess the real needs.

Mesothelioma progress quickly. The problems and symptoms happen one after another take away the time and ability to solve each problem. It is distressing to get a new problem just before solving previous one. This is what a mesothelioma patient's experience. One loose ability to do something when attacked by multiple difficulties. Sometimes a patient cannot face the



problem or waste time by stick to one matter. Medical staffs are feel 'I wish he/ she did ...' however that may be all that patient can do because he/ she had too much burden. Probably he/she suffer most. Medical staffs should not to blame patient's attitude or decision but support all the time.

Palliative Care in Mesothelioma Handbook for Nurses

(Not for sale)

Written by

Sarah Y Nagamatsu

Helen Clayson

Yukiko Nakayama

©2015. All rights reserved.

Published by

Mesothelioma Nursing Japan

Sarah Nagamatsu

