



Managing Advanced
Cancer Pain Together

Managing Advanced Cancer Pain Together (MACPT)

An expert guidance

www.macpt.eu

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Contents

1.0	Introduction	1
1.1	Purpose of the guidance	1
1.2	Prevalence of advanced cancer pain	1
1.3	Under-treatment of advanced cancer pain	2
1.4	Taking a holistic approach	2
1.5	Communication is essential	2
2.0	Assessment of advanced cancer pain	4
2.1	When to assess pain	4
2.2	Classification of pain	5
2.3	Pain assessment tools	5
2.4	Taking a history	6
2.5	Pain assessment for people with cognitive impairment	7
2.6	Using the assessment	7
2.7	Using the MACPT conversation tool	7
3.0	Managing advanced cancer pain	8
3.1	Prevention	8
3.2	Person-focused pain management plans	8
3.3	Non-pharmacological approaches	9
3.3.1	Physical exercise	9
3.3.2	Other therapeutic approaches	9
3.3.3	Emotional support	9
3.3.4	Psychological therapy	9
3.4	Pharmacological approaches	9
3.5	Oncological approaches	11
3.6	Bone metastases	11
3.7	Refractory (intractable) pain	11
4.0	Developing a treatment plan	12
5.0	Conclusion	13
5.1	Key learnings	13
	References	14
	Acknowledgements	14
	Notes	15
	Appendix 1: The MACPT conversation tool	17

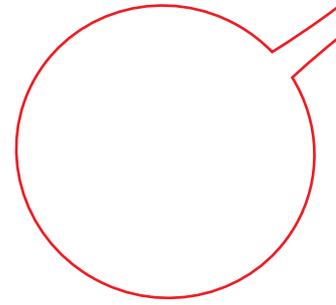
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1.0 Introduction



Most people with advanced cancer will experience some form of pain, but the reality is that some of this pain can go undetected or unnoticed and be under-reported. Even when pain is reported, it is frequently inadequately or under-treated, contributing to reduced quality of life (QoL) for people with advanced cancer.

Many people with advanced cancer pain may never need to see a pain specialist and their pain can be well managed in the hospital or community setting. This guidance aims to provide every member of the multi-professional care team with the necessary knowledge to assess and manage advanced cancer pain in day-to-day clinical practice. The key to best practice is to adopt a holistic, person-focused care approach, beginning with a detailed discussion that explores all dimensions of pain.

The Managing Advanced Cancer Pain Together (**MACPT**) group is a multi-professional group of cancer pain management specialists who have drawn on their expertise and current best practice guidelines to offer guidance on the management of pain in the advanced cancer setting.

Despite advances in cancer treatments, people living longer, and the greater availability of supportive care, pain management remains a challenge. Pain is still misunderstood, under-reported and often under-treated, causing unnecessary distress.

Many guidelines exist for managing pain in general^{1,2} and in the cancer setting specifically.³⁻⁷ However, little is published that addresses pain in advanced cancer that is both clinically applicable and takes a truly holistic person-focused approach. Managing pain in advanced cancer may be more challenging than single-site cancer, due to the spread of the disease in addition to the psychological impact of living with advanced disease and what this means for the individual.

This guidance takes a person-focused approach in its consideration of the assessment, prevention and treatment of advanced cancer pain. It will look at all facets of pain management including physical, social, emotional and spiritual elements. The use of existing validated tools is suggested where appropriate.

This guidance and accompanying MACPT conversation tool are also freely available at www.macpt.eu, as well as links to useful resources for healthcare professionals interested in the management of cancer pain.

1.1 Purpose of the guidance

The guidance is intended to be used as a training material for clinical staff new to managing pain in advanced cancer. It also serves as a convenient quick-reference resource for all healthcare professionals (HCPs) that is highly practical and useful in day-to-day clinical practice. The guidance is aimed at community and hospital staff including doctors, nurses and other members of the multi-professional care team, but people living with cancer and their carers may also benefit from reviewing the principles laid out in this guidance.

1.2 Prevalence of advanced cancer pain

It is estimated that 62–86% of people with advanced cancer experience physical pain,⁸ although this figure could be under-reported, and when one considers other aspects of pain the figure is likely to be much higher.

In the advanced cancer setting, a worsening of pain may be considered by some patients as a sign of disease progression, which could lead to unspoken fears, depression with an associated reduction in quality of life (QoL), a belief that their medication has failed prompting non-adherence,⁵ or a perceived deterioration in prognosis.^{9,10}

Pain and discomfort can be caused by locally advanced cancer and/or metastases to any organ, including the liver, lungs and brain. This is as a result of the tumour pressing on a nerve or causing other complications. It is important to note that not all pain in advanced cancer necessarily relates to advanced cancer or metastases and may be attributed to another disease.

Bone metastases are common in people with solid tumours including prostate, breast and lung cancer, and can significantly impact QoL.¹¹ Around one-half of people living with bone metastases may experience associated moderate-to-severe pain, which is not treated adequately in the majority of cases.¹²

1.3 Under-treatment of advanced cancer pain

Under-treatment of cancer pain is common^{11–13} with evidence to suggest that people receiving support in community-based and non-specialist settings experience greater pain intensity than those in specialist care.¹⁴

The first step to addressing under-treatment is to encourage the person with cancer to discuss openly and honestly every aspect of how the cancer and treatment is affecting them, including their pain. This may require direct questioning about any fears and barriers to treatment they might have. The person should be told that help and support are available to manage their pain and other symptoms.

In the majority of cases, by applying the World Health Organization (WHO) pain ladder¹⁵ (discussed later in this guidance) combined with appropriate dosage guidelines, it should be possible to provide pain relief for the vast majority of patients.⁸ The reasons for under-treatment are numerous and complex, and can arise from the person with cancer, their family and carers, HCPs, societal influences, or a combination of these factors. Some examples can be found in Table 1.

Table 1: Reasons for under-treatment of pain

- Lack of knowledge (HCPs and person with cancer)
- Acceptance of sub-optimal pain control
- Fear of drugs, including side effects
- Reluctance to admit pain
- Failing to understand the impact of pain on the person with cancer
- Reluctance of HCPs to ask about pain or offer treatments
- HCP fear of over prescribing
- Looking at pain in isolation from other symptoms/factors

1.4 Taking a holistic approach

Pain is often given descriptions that relate to its source, duration, frequency and intensity. However, none of these labels describe the human dimension of experiencing pain and how it can affect the person, including their relationship with others, themselves and their world.¹⁶ Pain control may never be fully achieved or maintained if only the physical aspect of pain is assessed.¹⁶ Figure 1 illustrates that emotional, social and spiritual aspects must also be considered and this guidance considers how best to do this.^{5,16}



Figure 1: Many of the more challenging aspects of a person's pain, including the social, emotional and spiritual elements, exist below the surface, hidden from the view of others.

1.5 Communication is essential

Effective communication from the person with cancer helps their care team understand the meaning of their pain to them and the impact on their life. This enables the care team to accurately complete the pain assessment, decide if additional education is required, and ultimately ensure the best pain management strategies are co-created between both parties. If the person is incapacitated or cognitively impaired, they may find it difficult to adequately express their pain and communication with their families or carers becomes essential.

Effective communication from HCPs helps educate people with advanced cancer about pain management, including expectations from their treatment. It will also increase adherence to treatment,⁵ provide the person with the vocabulary to talk about their pain,¹⁷ and promote patient empowerment and self-management.¹⁸ Conversely, poor communication is likely to be a major contributor in the under-treatment of cancer-related pain.^{14,17} Communication strategies are suggested throughout this guidance.

Best practice in the management of pain starts with a comprehensive pain assessment, which is considered in the following section.

Communication tips

- Create time and privacy to have the conversation
- Create a safe environment
- Speak clearly
- Rephrase your questions if the person does not understand
- Avoid medical jargon
- Make sure you are 'open' with your body language
- Listen without interruption
- Empathise
- Ask questions to clarify unclear information
- Paraphrase what you have heard back to the person to show you have understood their concerns
- Include family members/carers in discussions with the person's permission
- Encourage use of the 'MACPT conversation tool' (Appendix 1)

The following case studies are based on patient situations and may help in critically applying the guidance. At various points throughout the guidance, questions relating to the case studies will be posed to help you reflect on what you have read and consider how you might assess and manage advanced cancer pain.

Case study 1

Jim is a 65-year-old retired gardener, married with no children, who was very active before his diagnosis. Jim was initially diagnosed with locally advanced prostate cancer and treated with anti-hormone therapy and radiotherapy. Unfortunately, his disease continues to spread despite chemotherapy and targeted therapy. Jim is now feeling very tired, has increasing bone pain, and he is very concerned about his disabled wife.

Case study 2

Emma is 42 and married with two children (aged 15 and 17). Emma works as a bank manager. Diagnostic investigations initially showed a large lung tumour with mediastinum lymph node involvement and bone metastases at L3 and L5. Six months after completing chemotherapy, Emma goes to the emergency department because of acute back pain. She is worried about what this pain means for her and her children who are at school.



Both Jim and Emma are reporting pain, what other issues would you wish to evaluate when meeting Jim and Emma?

How might their pain impact on these other concerns?

2.0 Assessment of advanced cancer pain

Pain assessment requires looking beyond obvious symptoms and taking into consideration the whole person and what the experience of pain means to that individual.¹⁶ It is important to remember that two people with the same physical symptoms might experience their pain in very different ways. Table 2 defines the different dimensions of pain that should be considered during an assessment and how they may relate to the person with cancer. The different dimensions rarely happen in isolation and are generally interrelated.

Table 2: The human dimension of pain

Physical pain

A disturbance or disruption in the relationship between the person and their body

Social pain

A disturbance or disruption in the relationship between the person and their world including their family, work and society

Emotional pain

A disturbance or a disruption in the relationship between the person and their emotions, or how they see themselves

Spiritual pain

A disturbance or disruption in the relationship between the person and their beliefs and values

A successful pain assessment involves both clinical and interpersonal skills, and requires a degree of sensitivity and humility. A thorough pain assessment cannot be rushed; however, even with time constraints, it is possible to perform a good pain assessment by really paying attention, hearing the person's story and seeing them beyond their symptoms.¹⁶ The entire care team has a role in contributing to the ongoing assessment of a person's pain.

The art of assessing pain¹⁶

- Create time
- Pay attention
- Avoid distractions
- Think beyond the physical symptoms
- Undertake a clinical history, physical assessment and required investigations/tests
- Work as a team
- Apply an intervention and review it regularly

Case study question



How do you plan to further assess, investigate and evaluate all aspects of Jim and Emma's pain?

2.1 When to assess pain

It is important to assess a person's pain before the start of their treatment to establish a baseline. It is then possible to determine how effective a pain management intervention has been by conducting further assessments as often as needed and comparing the person's current experience of pain with that at baseline. Re-assessments could be triggered by a change in the person's symptoms, a change in their ability to carry out daily activities, or a review of treatment interventions.

Pain rarely occurs in isolation from other symptoms and other life events. It is frequently accompanied by fatigue, sleep disturbance, loss of appetite, anxiety and depression, as well as a sense of being isolated and alone. All of these can have an impact on the experience of pain.¹⁶

Tip

Set aside enough time for a proper baseline pain assessment. Perhaps ask the person to prepare in advance by thinking about their recent experience with cancer and pain, show them you have time to listen, remove distractions, and ensure privacy. Good care occurs when we give someone our full attention.

2.2 Classification of pain

Table 3 details the common classifications used to describe different types of pain associated with advanced cancer. Identifying the underlying pathophysiology, duration and onset of a person's pain is important because it helps to form the management plan. These classifications are used in conjunction with measures of how intense the pain is, as assessed by various tools discussed in section 2.3.

Case study questions



How might you categorise Jim and Emma's pain?

Is their pain acute, chronic or a combination of both?

Table 3: Pain classifications^{7,16}

Pathophysiology

Nociceptive

Pain resulting from tissue damage, often described as sharp, an ache or a throbbing sensation

Neuropathic

Pain resulting from nerve damage or a tumour putting pressure on a nerve, often described as burning, a heavy sensation or numbness

Duration

Acute

Sudden onset, may last for days, hours, minutes, e.g. post-operative

Chronic

More than 3 months' duration, e.g. bone metastases

Onset

Refractory and intractable

Cannot be adequately controlled despite interventions (not always physical in nature)

Breakthrough

Exacerbation of pain despite adequately controlled baseline pain

Incident

Pain that arises as a result of activity

2.3 Pain assessment tools

The use of validated, standardised pain management tools is recommended as part of a comprehensive pain assessment³ and supports interaction between the person with cancer and their care team. Many different tools exist, ranging from simple scales that give an indication of pain intensity alone to detailed questionnaires that assess all dimensions of pain. Other facets of well-being, including functional ability and QoL, can also be assessed (see Table 4). Some have been developed specifically for people with cancer, while others were developed for other therapy areas and have later been found to be useful in the cancer setting.

Neurological and psychological assessments may also be required, including mental status and motor function. The choice of tool is determined by the clinical setting, e.g. inpatient, outpatient or community, whether cognitive impairment is present, and often the time available to conduct the assessment. However, a comprehensive assessment is desirable, particularly before treatment starts.

Table 4: Commonly used assessment tools

Pain intensity assessment

- Numeric rating scale
- Visual analogue scale
- Verbal rating scale
- Face pain scale^{19,20} – for adults with cognitive impairment

Detailed pain assessment

- Brief Pain Inventory (short form)²¹
- McGill Pain Questionnaire (short form)²²
- German Pain Assessment: Core Documentation and Quality Assurance (KEDOQ-DSF)²³
- Neuropathic Pain 4 (DN4)²⁴

Specific pain assessment

- Neuropathic Pain Symptom Inventory²⁵
- European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire (QLQ)-BM22²⁶ (specific for bone metastases)

Quality of life assessment (including impact of pain)

- EORTC QLQ-C30²⁷
- Functional Assessment of Cancer Therapy-Bone Pain (FACT-BP)²⁸
- Comprehensive Geriatric Assessment^{29,30}

Self-assessment

- MACPT conversation tool (Appendix 1)

Although there are many recognised and validated assessment tools, these alone will not result in a comprehensive assessment. HCPs need to engage with the hidden aspects of pain and how this impacts on the person. The accompanying MACPT conversation tool in Appendix 1 is designed to help people talk about all dimensions of their pain experience and enable HCPs to gain a deeper understanding of the person's pain and its impact. The MACPT conversation tool was developed following a review of currently available tools and the literature, and after identifying that there was a gap for a tool that was simple to use, patient-led, and which incorporated a holistic approach. Early versions were shared with a number of clinical staff, carers and patients, and adaptations made according to the feedback received.

Case study questions



Which of these tools might you use to further assess Jim and Emma's pain and concerns?

What reasons might Jim or Emma have for not disclosing the extent of their pain to you and the team?

2.4 Taking a history

Asking questions like those in Table 5 in conjunction with assessment tools will support a detailed pain history. Remember to be vigilant for unspoken, visual cues that could indicate the person in pain might be holding information back and re-ask or rephrase questions when necessary.

Tip

Critically plan what assessment tool you might use in advance of meeting a person with advanced cancer and make sure you know how to use it. Consider forwarding the tool to the person in advance of the assessment.

Table 5: Some question prompts you may wish to use³¹

Character and site of pain

- When did your pain start? What was happening at the time?
- Where do you feel the pain?
- Does it spread to any other places?
- What pain sensation do you experience?
- How strong is your pain now/at rest/when you move/during the last week?

Associated factors

- What makes your pain feel better or worse?
- What other symptoms does your pain cause?
- How does your pain affect your sleep?
- How does your pain affect your work/daily activity?
- How does your pain affect your social/recreational activities?
- How does your pain influence how you think about things? Your mood?

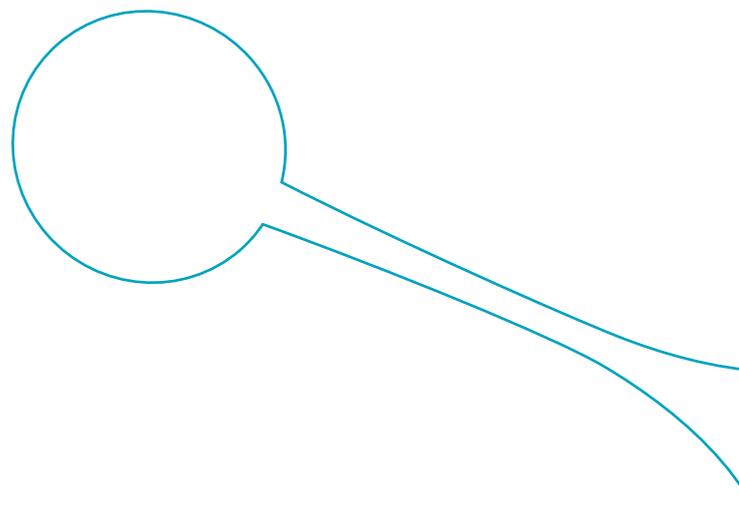
Expectations

- What are you hoping for from your pain treatment?
- What do you think the causes of your pain are?
- What does your family understand about your pain?
- How much better would your pain need to get for you to resume activities that are important to you?
- How do you normally cope with pain?
- Tell me what options you are aware of for managing pain. What thoughts do you have as to what might work best for you?

Case study question



Which of the questions in Table 5 might be useful to ask Jim and Emma?



2.5 Pain assessment for people with cognitive impairment

The presence of cognitive impairment makes assessment more difficult. For many people, including those with dementia, brain metastases or learning disabilities, it may be possible to use a verbal rating scale, horizontal or vertical visual scale, or the face pain scale along with clinical observation.⁵ If the person's impairment is too severe for them to self-report their pain, then a behavioural observation-based assessment is required.

A review of behavioural pain assessment for elderly people with severe dementia concluded that the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC) and DOLOPLUS2 may be the most appropriate to use with this group.³²

When assessing pain in someone with cognitive impairment is important to think about the questions used and to involve the person's family or carer.

2.6 Using the assessment

Thorough and detailed formal documentation of pain assessment findings is essential to promote continuity of care and to monitor the effectiveness of pain management strategies. Information should be shared clearly and accurately between all those caring for the person with cancer in both the hospital and community settings, as well as the person themselves.

Tip

Ask yourself:

Do you have a sense of how Jim and Emma are affected by their pain?

Do you know what is most important to them?

Have you completed a thorough assessment, including other symptoms that are troubling Jim and Emma?

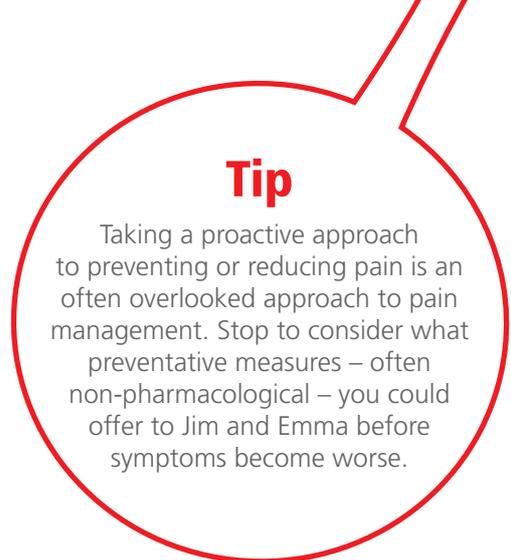
2.7 Using the MACPT conversation tool

An ideal discussion about pain is one that is led by the person experiencing the pain. The MACPT conversation tool found in Appendix 1 and other tools can be used to help the person to reflect on the different dimensions of their pain.

3.0 Managing advanced cancer pain

Following a comprehensive baseline assessment including results of investigations/tests, the person with advanced cancer pain and the care team can co-create a tailored management plan.

Every person with advanced cancer should be given information about pain prevention and treatment options, and be encouraged to take an active role in their pain management. This approach may help in reducing and managing pain. Pain is not an isolated symptom and management plans should take a holistic perspective. It is important to stress that pain is not always inevitable if a proactive approach is taken by the multi-professional care team and the person with cancer. A number of evidence-based pain management guidelines are currently in use and helped to form this guidance.³⁻⁷



Tip

Taking a proactive approach to preventing or reducing pain is an often overlooked approach to pain management. Stop to consider what preventative measures – often non-pharmacological – you could offer to Jim and Emma before symptoms become worse.

3.1 Prevention

In many situations cancer-related pain may be postponed, prevented or reduced before it becomes intense enough to cause further distress. Focusing on the whole person, prevention strategies in most cases will require a combination of both pharmacological and non-pharmacological approaches. Table 6 details possible preventative measures.

Table 6: Preventative measures

Physical pain

- Coping strategies
- Attention-diversion strategies
- Physical therapies
- Complementary therapies
- Pharmacological intervention
- Cancer treatments

Social pain

- Addressing a possible need for increased family/social support
- Support to engage with family and social groups and to continue working, if that is important
- Provide guidance on family and/or peer support

Emotional pain

- Support to continue things the person enjoys doing
- Provide guidance on supporting self-esteem and self-worth
- Encouragement to share their thoughts and feelings
- Keeping a diary about feelings and emotions

Spiritual pain

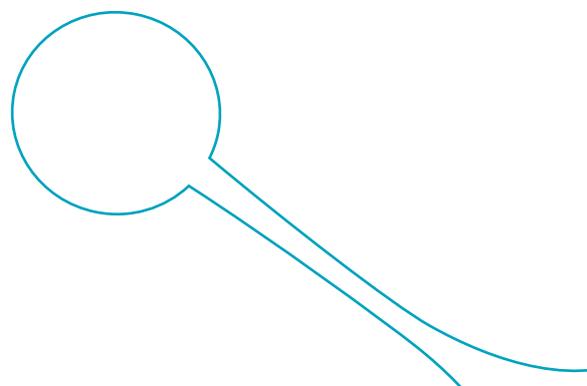
- Acknowledging the person's values and beliefs
- Seeking religious or non-religious pastoral support
- Talking to a trusted friend or a member of the oncology team
- Talking with a psychologist, counsellor or a member of the pastoral care team

3.2 Person-focused pain management plans

Open and honest discussion between the person with advanced cancer pain and the care team is important to establish expectations from treatment and to agree on therapy goals. The person can be encouraged to take co-responsibility for decision making and to proactively take action to help effectively manage their pain. HCPs should provide patients with verbal and written information on pain and its management, including the points illustrated in Table 7.

Table 7: Pain management plan discussion points³³

- Causes of pain
- Common experiences of cancer pain
- Effective treatment options (e.g. medicines and non-pharmacological management strategies)
- Guidance on taking medication, managing side effects, addressing concerns (e.g. mixing with alcohol, drowsiness, disturbed sleep, driving, impact on QoL)
- Working as a team to address under-reporting
- When to seek specialist help



3.3 Non-pharmacological approaches

3.3.1 Physical exercise

People living with advanced cancer have traditionally been encouraged to rest³⁴ due to concerns about bone fragility or perceived lack of benefit of exercise. However recent studies show the effectiveness of prescribed exercise in the cancer pain setting, with improvements in QoL and physical function reported.^{34–37} There is currently no agreement on optimal exercise parameters and only limited evidence regarding the safety of exercise for this population, so HCPs should use their clinical judgement to determine what level of activity is appropriate.

Calculating a person's Mirel's Score³⁸ to predict the likelihood of a bone fracture may be helpful when considering an activity programme. The American Cancer Society recommends people with bone metastases exercise on even surfaces to minimise the risk of falls, and avoid any weight-bearing exercises that can cause a loss of balance.³⁹ Heavy weightlifting and high-impact activities that put a lot of stress or weight on bones should also be avoided.³⁹ Non-weight-bearing exercise like swimming may be a good option for those with bone metastases.

3.3.2 Other therapeutic approaches

Many supportive therapies are reported as helpful by people experiencing cancer pain, including massage, relaxation techniques, imagery, counselling, heat and cold therapy, postural re-education, and trans-cutaneous electrical nerve stimulation (TENS).¹⁴ Complementary therapies including acupuncture, reflexology, reiki, complementary oils, and hypnotherapy may assist.⁵ The benefits from these therapies vary from person to person but can help people with advanced cancer manage their pain and should be critically considered.

People with advanced cancer should be encouraged to consider these supportive therapies unless the multi-professional care team believe potential harm could result.

3.3.3 Emotional support

People dealing with advanced cancer pain may find comfort and support talking through their concerns with trusted friends, a family member, one of the healthcare team, or with leaders of their faith communities, for example a priest, imam, minister or rabbi. Patient support groups can also provide a valuable forum for discussing concerns, often connecting people going through similar experiences. For the person living with advanced cancer pain 'being heard' is a critical component of addressing their pain.

3.3.4 Psychological therapy

Research on psychological factors related to cancer pain has focused on dealing with psychological distress and coping strategies. Approaches include coping skills training and attention-diversion strategies.⁴⁰ There is also evidence that cognitive behavioural techniques that address and promote self-management can lead to improved pain management.⁴⁰

3.4 Pharmacological approaches

The WHO proposed a three-step treatment approach for managing cancer pain, and this approach remains the foundation of management strategies today.¹⁵ The WHO guidelines categorise pain as mild, mild-to-moderate or moderate-to-severe, and recommend the use of non-opioid analgesics, weak opioids and strong opioids corresponding to each pain 'step'. Adjuvant therapies, both pharmacological and non-pharmacological, are often used to complement opiate-based therapy and should be added as appropriate. Examples of commonly used pharmacological therapies for pain are shown in Table 8 overleaf.

Tip

Muscle work is possible lying in bed with isometric exercise. Contract the muscle (e.g. the thigh), slowly count to 6, and release the muscle again. Repeat this exercise 5–10 times in the morning and in the evening.

Table 8: Pharmacological treatments for pain

	Medication	Examples
Nociceptive pain		
Mild pain (WHO step 1; numerical rating scale [NRS] 1–3)	Non-opioids e.g. paracetamol, non-steroidal anti-inflammatory drugs, COX-2 inhibitors ± adjuvant therapy	Paracetamol, ibuprofen, diclofenac, metamizol
Mild-to-moderate pain (WHO step 2; NRS 4–6)	Weak opioids ± non-opioid analgesic ± adjuvant therapy	Codeine, tramadol, dihydrocodeine
Moderate-to-severe pain (WHO step 3; NRS 7–10)	Strong opioids ± non-opioid analgesic ± adjuvant therapy	Morphine, methadone, oxycodone, hydromorphone, fentanyl, alfentanil, buprenorphine, levorphanol, oxymorphone, tapentadol
Neuropathic pain		
	Anticonvulsants	Pregabalin, gabapentin
Adjuvant therapy		
	Corticosteroids (for swelling/inflammation)	Dexamethasone
	Antidepressants	Amitriptyline Clomipramine
	Benzodiazepines	Diazepam

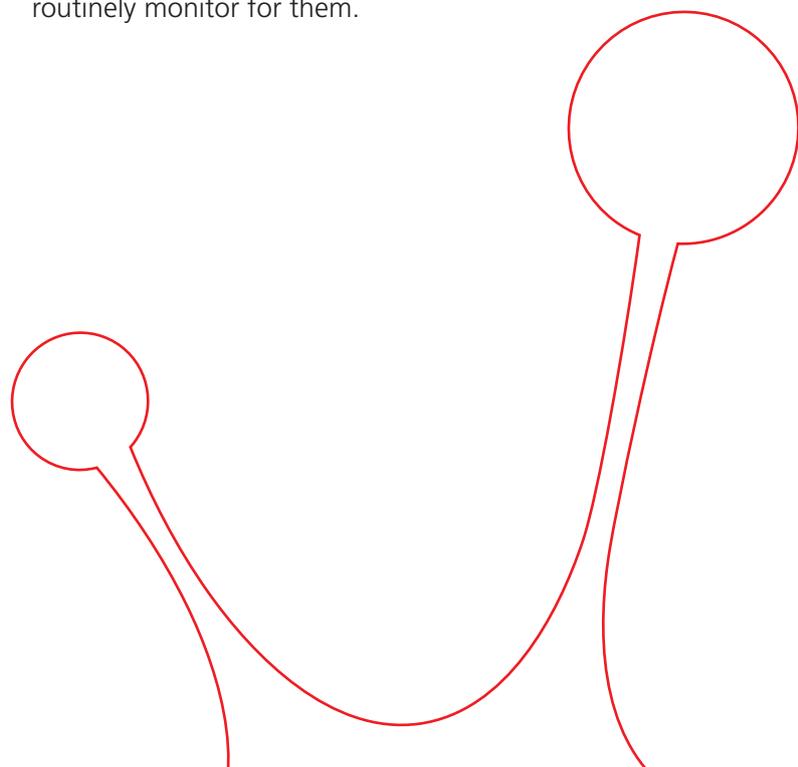
The care team should critically consider the best route and timing of administration of pain medication for the person and the care setting including oral, sublingual, buccal, intranasal, skin patches, subcutaneous and intravenous. Table 8 details commonly used treatment approaches. A combination of slow-release drugs for acute and chronic pain with immediate-release drugs for breakthrough and incident pain are generally required. Immediate-release opioids, including oral, subcutaneous and intravenous opioids, are recommended for predictable and non-predictable breakthrough pain, and buccal, sublingual or intranasal fentanyl offer faster analgesia for spontaneous pain.^{3,6} The WHO pain ladder is part of an overall pain management strategy.

Pharmacological therapy may also play an important role in the treatment of depression and anxiety, which affect many people with advanced cancer and can strongly influence their experience of pain, including their ability to cope with pain.

It is important to be aware of the possible side effects of any medication given to manage pain and to routinely monitor for them.

Reporting of side effects

All medicines can cause side effects. If you get any side effects, talk to your doctor, pharmacist or nurse. By reporting side effects, you can help provide more information on the safety of medicines.



Consider the best route and timing of administration of pain medication for the person and the care setting¹⁵

By mouth

- Use the oral route whenever possible,⁵ even for opioids

By the clock

- For chronic pain, provide analgesia at regular intervals (by the clock⁵) rather than simply as *pro re nata* (PRN)

By the WHO pain ladder¹⁵

Step 1

- For mild pain start with a non-opioid and increase the dose, if necessary, to the maximum recommended dose
- Use an adjuvant therapy such as an antidepressant or anticonvulsant, if indicated
- If the individual presents with moderate or severe pain skip Step 1

Step 2

- If or when non-opioids do not adequately relieve pain, add a weak opioid intended for mild-to-moderate pain
- Add or continue adjuvant therapy, if appropriate

Step 3

- If or when the non-opioid or weak opioid no longer adequately relieves the pain, switch to an opioid that is effective for moderate-to-severe pain
- Add or continue adjuvant therapy, if appropriate

For the individual

- Individualise the treatment plan according to the person's goals

3.5 Oncological approaches

Overall oncological management of the disease is a vital component of preventing pain or providing significant relief if pain is already present. Treatment options vary depending on the underlying disease, site, type and cause of pain. External beam radiotherapy, endocrine treatments, chemotherapy, targeted therapies, radioisotopes and surgery may be used to treat and palliate cancers⁴⁰ and have a role in preventative pain management. It should be noted that oncological treatments may cause side effects which need to be monitored and addressed.

3.6 Bone metastases

Bone metastases can be responsible for severe pain, fractures, nerve compression and hypercalcaemia. In many cases skeletal morbidity in people with advanced cancer may be slowed down or reduced by early intervention by the clinical team and taking a more proactive approach.

Bone-targeted agents (denosumab and bisphosphonates) have a role in the prevention of skeletal-related events and are effective in reducing skeletal morbidity from bone metastases.³ The European Society for Medical Oncology (ESMO) guidelines on management of cancer pain recommend that bone-targeted therapy should be considered as part of the therapeutic regimen in patients with metastatic bone disease, whether they are experiencing pain or not.³

3.7 Refractory (intractable) pain

Refractory (or intractable) pain is pain that cannot be adequately controlled despite interventions. In such a case, the person with advanced cancer should be referred to a pain specialist. It is essential to consider the holistic assessment and the impact of emotional and spiritual distress, which is often present.

4.0 Developing a treatment plan

Each treatment plan should be co-created between the person with advanced cancer pain and the team caring for them. Having clearly assessed and discussed the person's concerns, the results of the investigations and the cause of pain, and having a better understanding of what the pain means to the person, a treatment plan is discussed and developed. The treatment plan should include looking beyond the obvious physical symptoms to encompass the more hidden social, emotional and spiritual aspects of pain.

Treatment plans will normally have elements of pharmacological and non-pharmacological interventions. Key to developing a good treatment plan is ensuring the person understands the plan, and that the team has listened to and addressed any concerns the person has about aspects of the proposed treatment plan. The treatment plan is a further opportunity to provide assurance that the team is available to help the person

and their family, and to give them information on where further support is available and how the team can be contacted. Once the treatment plan is explained and agreed, a clear review date needs to be agreed. Giving the person a copy of the MACPT conversation tool and asking them to reflect on it prior to the next meeting may help towards achieving a more person-focused clinical encounter.

Case studies

Jim

Examination and investigations indicate that Jim's pain is coming from extensive bone metastases in his lower back (L2–L4). He describes a dull ache spreading across his back.

Emma

Examination and investigations show that Emma has further deterioration at L3 due to tumour progression, but has no evidence of spinal cord compression. Emma describes a feeling of numbness and pain radiating into her leg.



What treatment/s might you suggest for Jim and Emma?
Think of both pharmacological and non-pharmacological options

Consider any obstacles that might prevent Jim or Emma from taking certain medications

How might Jim and Emma be impacted by a good pain management plan?

Jim

Having discussed his pain and concerns with the team, Jim recognises that his tiredness is made worse by his uncontrolled pain. With the team he decides that he would like to increase his opiate therapy so that he has a slow-release opiate twice a day and a fast-acting opiate as needed, and that he will continue with his bone-targeted therapy. He has agreed to the offer of some further support for himself and his disabled wife.

Emma

Having co-created a management plan with Emma, the decision is made to offer her a mild opiate and gabapentin. Emma would also like to talk to a specialist nurse about how to tell her two children about her advancing disease.

Having developed a plan together, the team assure Jim and Emma of their support and plan a day and time to review the interventions.

5.0 Conclusion

Managing all aspects of pain is the responsibility of each member of the team supporting the person with advanced cancer. The majority of people with advanced cancer will experience some form of pain and while some will not have access to or require a pain specialist, the MACPT guidance can support the team to consider a person-centred pain management plan. While medicine has sometimes tended to focus on the more tangible and treatable forms of pain, there are less tangible forms of pain that needs addressing. If the care team aims to address the reality of pain and the personal distress it can cause, this can help to lessen the sense of isolation and helplessness in the person living with advanced cancer.

5.1 Key learnings

- Pain is frequently under-reported and under-treated in people with advanced cancer
- All members of the clinical team have an important role to play in assessing and addressing advanced cancer pain
- The physical, social, emotional and spiritual dimensions of the person need to be considered
- Open, honest and sensitive communication is essential
- A comprehensive pain assessment should be conducted at baseline and repeated at regular intervals
- The use of assessment tools including the MACPT conversation tool can help
- Prevention is an often overlooked component of pain management and should be considered
- A person-centred pain management plan should be co-created with the person with advanced cancer pain

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Appendix 1: The MACPT conversation tool

Using the conversation tool

An ideal pain assessment is when the person with pain leads the discussion and describes what troubles them most. By asking them to select three words from the conversation prompt that most closely match their experience of pain and then asking them to explain their choices provides a strong introduction to a holistic assessment.

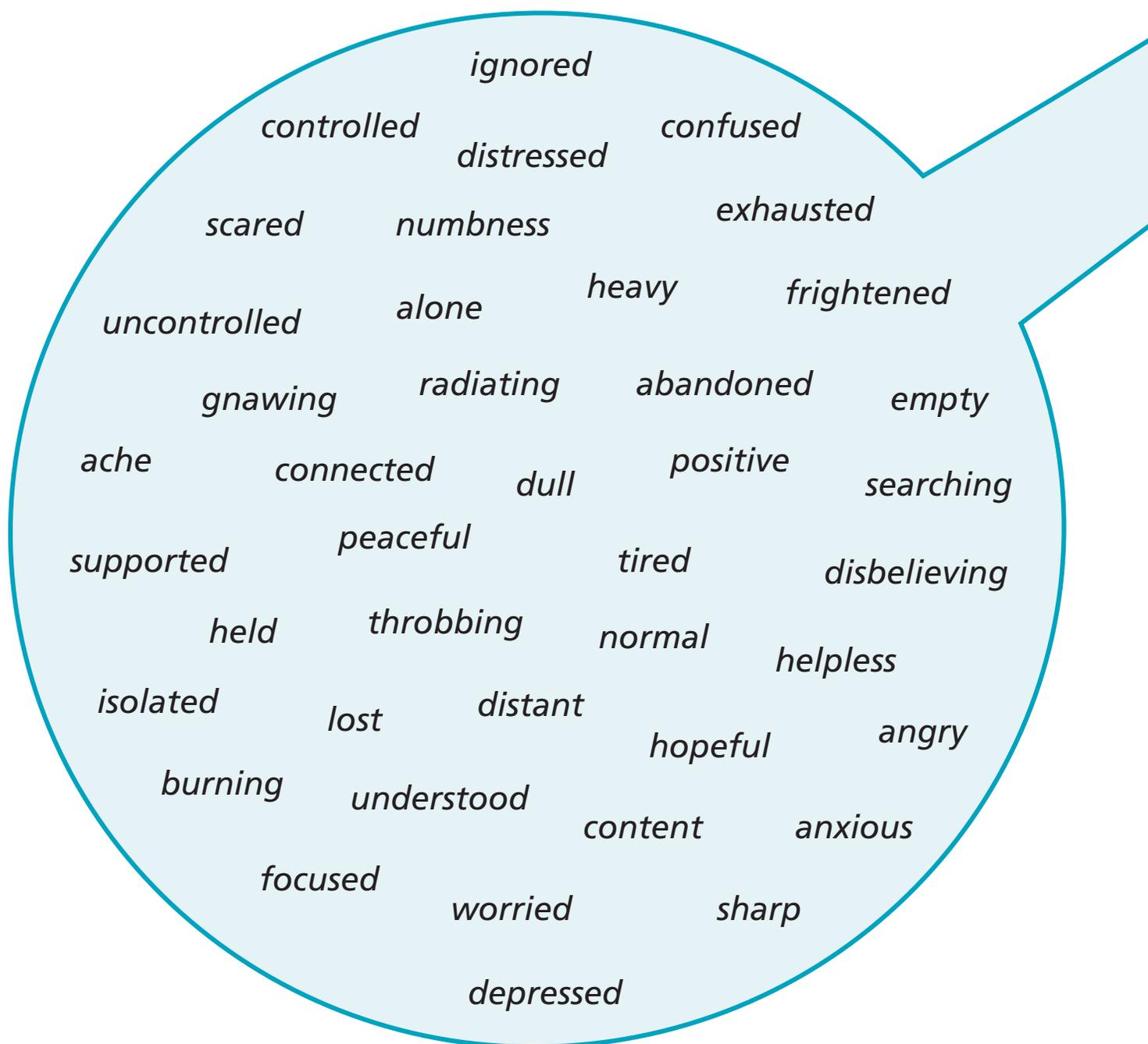
- Ask the person being assessed to circle three words from the conversation prompt overleaf that most closely match their experience of pain; give them time to think about their selection
- Ask the person to explain their choices, starting with the word that they feel most strongly represents their recent experience
- Listen carefully to what the person has to say, only prompting when necessary
- When the person has finished explaining their choice in their own words, ask questions to gain a deeper understanding of their experience of pain
- Use what you have learned to inform further assessments and the person's pain management plan



Managing Advanced Cancer Pain Together conversation tool

Everyone experiences pain differently. You might find it has an impact on your body, your sense of well-being and how you feel about yourself, or your relationships with others and the world around you.

Please circle three words that best describe your recent experience of pain



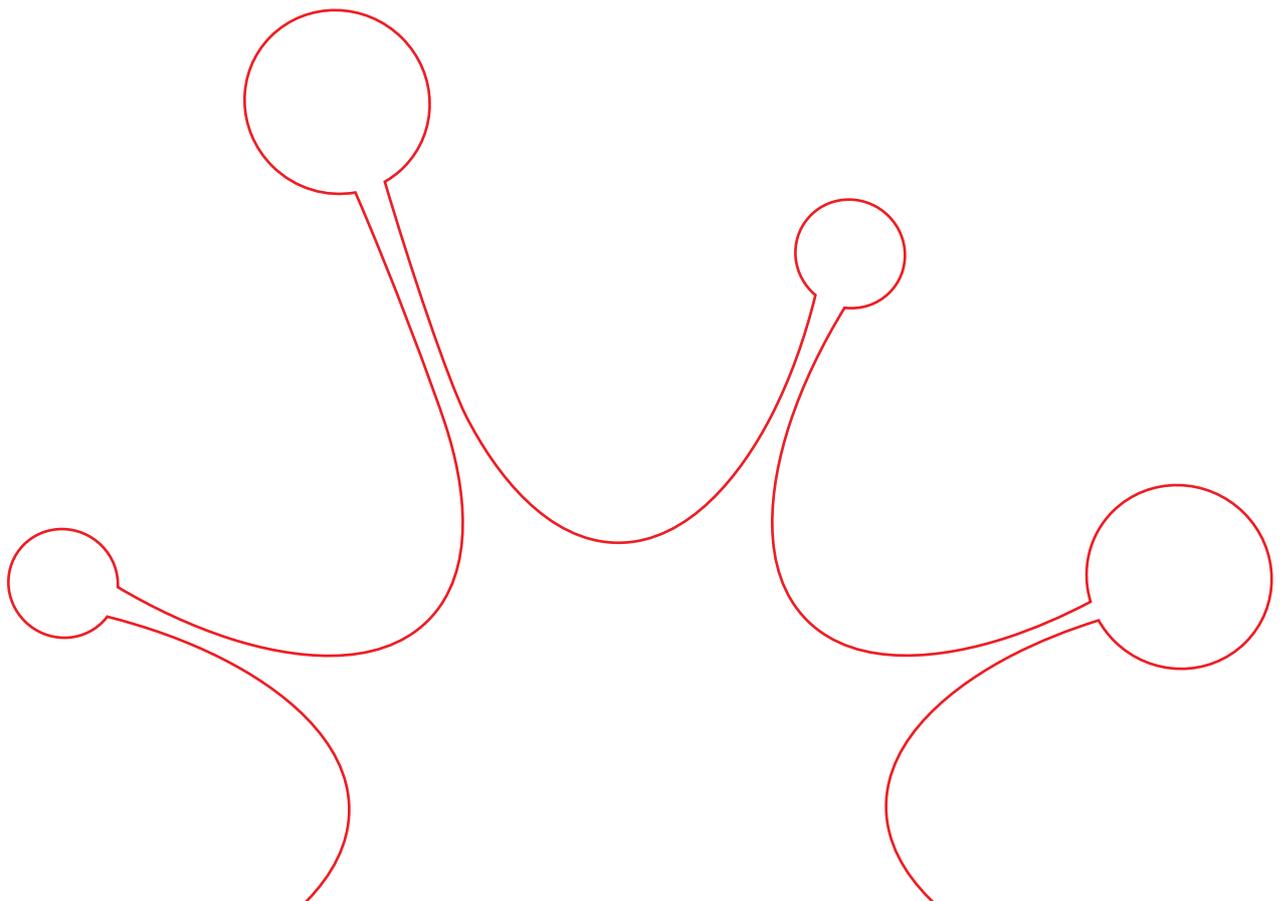
MACPT conversation tool © MACPT 2016.
May be reproduced for use in clinical practice.

The MACPT group would like to acknowledge sponsorship from Amgen (Europe) GmbH who provided an educational grant to allow the group to meet and develop the guidance. Amgen had no editorial input into the content of the guidance.

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