

# 17 Palliative care in melanoma

Palliative care as defined by the World Health Organization (WHO) is ‘an approach that improves the quality of life of patients and their families facing the problem[s] associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual’<sup>1</sup> (see also Appendix 6 *New Zealand palliative care definition*).

So defined, palliative care is applicable throughout the whole cancer illness.<sup>2</sup> The skills of palliative care specialists may be utilised by patients, their families and other clinicians, to assist in managing symptoms while patients are undergoing disease-modifying treatments. As the disease progresses, palliative care teams may provide continuing support aimed at maintaining or improving quality of life. Finally, palliative care teams may provide support for patients and their families at the end of life.

Any or all of these roles are highly applicable to patients with recurrent or metastatic melanoma, as these patients, many of whom are young, may have complex physical and emotional needs.<sup>3-5</sup> Stage IV melanoma has a propensity to metastasise widely so that affected people are particularly at risk for pain and fatigue.<sup>6,7</sup> As with other cancers, these and other symptoms tend to worsen as the individual’s condition deteriorates. Not only have people with melanoma been identified as being at risk of physical symptoms, but also of psychological concerns, particularly anxiety and mood disturbances.<sup>8</sup> Melanoma patients, in their last year of life, have been identified as a group who are at risk of deteriorating psychological functioning to a level where their ability to maintain their physical function is impaired.<sup>9</sup>

Palliative care is provided in a number of ways, with the majority of care coordinated by general practitioners and other members of the melanoma team. However, for patients and their families with more complex needs, more specialised care is needed.<sup>10</sup>

Integration of specialist palliative care into the melanoma multidisciplinary team allows partnerships between other health providers and specialists in palliative care (nurses, doctors, allied health) to be established and the individual needs of each patient to be considered. This allows specialist palliative care input to contribute to multidisciplinary care in a number of very positive ways and already evidence exists that the involvement of palliative care in the lives of cancer patients is beneficial. These benefits include improved symptom control and satisfaction with care, reduction of patient and family anxiety, reduction of time in hospital, and assistance in clarifying the goals of care.<sup>10-15</sup>

Evidence summary	Level	Reference
There are strong recommendations for the inclusion of palliative care specialists in the multidisciplinary care of skin cancer and melanoma patients in the UK and Scottish guidelines	I	4, 5
Palliative care services may assist advanced cancer patients and their families in improving symptom control, reducing anxiety and clarifying goals of care	I	12–14
Although this evidence relates to cancer in general, it is regarded as relevant and applicable	II	11

### Recommendation

	Grade
1. Palliative care specialists be included in the multidisciplinary melanoma treatment team to: <ul style="list-style-type: none"> <li>• provide assistance with symptom control</li> <li>• support melanoma patients and their families</li> <li>• when necessary, coordinate care of melanoma patients between settings</li> <li>• assist in clarifying goals of care</li> </ul>	<b>A</b>

## 17.1 Timing of referral for palliative care

Palliative care has often been linked to the very late stages of a terminal illness, with referrals for specialist palliative care advice occurring late in the disease trajectory,<sup>16–18</sup> but even at a late stage patients have gained benefit from palliative recommendations.<sup>19</sup> The WHO definition of palliative care indicates that palliative care referrals are appropriate at any stage of illness, even from diagnosis.

Although studies to address the timing of referral to palliative care specialists are limited, there is evidence that involvement of a palliative care team can improve symptom control, including pain, dyspnoea, anxiety, and spiritual wellbeing.<sup>11–14,19–22</sup> The timing of referral to a palliative care specialist should be dependent on the need for intervention for physical or psychological symptoms, not the stage of the illness.<sup>5,21,23</sup>

Evidence summary	Level	Reference
Referral for palliative care has often occurred in the very late stages of a terminal illness	III–3 IV	16 17, 18
Even with short involvement, patients gained benefit from palliative recommendations	IV	19
Timing of referral should be dependent on the need for intervention for physical or psychological symptoms	IV	23

Recommendation	
2. Referral for palliative care be based on the needs of the patient and family, not just the stage of the disease	C

## 17.2 Patients and families who benefit from referral to specialist palliative care

Palliative Care Australia has described a population-based model for palliative care delivery ranging from primary palliative care to an interdisciplinary specialist palliative care team.<sup>10</sup> The New Zealand definitions of palliative care also recognise generalist and specialist palliative care. Generalist palliative care is provided as an integral part of standard clinical practice by health care professionals who are not specialist in palliative care (see also Appendix 6 *New Zealand palliative care definition*).

To define which patients and their families require specialist palliative care it is necessary to consider for each patient:

- the wishes and needs (current and future) of this patient
- the needs (current and future) of this family, including bereavement
- the needs and capabilities of the generalist palliative care providers.

Many advanced cancer patients are at risk of burdens from physical symptoms, particularly pain, respiratory problems, nausea and vomiting.<sup>24</sup> Cutaneous metastases in melanoma may present particular burdens including pain, bleeding and disfigurement. Regardless of the stage of illness, any patient with poorly controlled symptoms is appropriate to be referred for specialist palliative care.

Specialist palliative care teams in in-patient, out-patient or community settings can assist other medical teams in achieving better symptom management. Patients with cancer often express fear of progressive symptoms, and it is important to take these concerns seriously and to offer reassurance that every effort will be made to address these problems should they arise.<sup>11,14,20–22</sup>

The burden of psychological symptoms in patients with progressive disease may be high as well and should also prompt referral for palliative care. After referral, individuals are less likely to describe anxiety and they express greater levels of satisfaction with care.<sup>12,13,25</sup>

The WHO also asserts that the needs of the family must be considered. Families and other informal caregivers may need support to sustain their ability to offer care. Palliative care specialists may assist families in understanding the goals of care, reducing their anxiety and improving their satisfaction with caring.<sup>26,27</sup>

Many patients with cancer wish to remain home for as long as possible and the majority of patients would prefer to die there.<sup>28</sup> Patients and families who receive input from specialist palliative care teams show better outcomes in terms of the amount of time spent at home and an increased likelihood of dying where they wished.<sup>15,22,29</sup> This may be achieved with a reduction in overall costs compared with the costs of conventional care.<sup>13</sup>

Finally, referral to palliative care may assist in improving bereavement outcomes for the family. The support of palliative care services to allow an open awareness of impending death as the disease progresses is associated with increased satisfaction for families. This has been suggested as one way of assisting families in the time following the person's death.<sup>30</sup>

In conclusion, not all patients with melanoma will need specialist palliative care during their illness, but providers of generalist/primary palliative care should be able to recognise when specialist palliative care is required for more complex needs, and specialist palliative care support should be readily available to patients, families and generalist/primary providers.

Evidence summary	Level	Reference
Specialist palliative care can improve symptom control for patients	I	12, 13, 14, 22, 25
Specialist palliative care can assist families to provide care in the place of choice	I	22, 29

### Recommendation

	Grade
3. Patients and their families with complex needs including physical, psychosocial and spiritual domains be referred to a specialist palliative care team at any stage during the illness	<b>A</b>

### References

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