

Optimal care pathway for people with basal cell carcinoma or squamous cell carcinoma



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Foreword

The pathway for cancer patients undergoing diagnosis and treatment for cancer is complex and poorly comprehended by those involved. It usually involves multiple healthcare providers and covers a range of institutions, both public and private. The optimal care pathways map this journey for specific tumour types, aiming to foster an understanding of the whole pathway and its distinct components to promote quality cancer care and patient experiences. These pathways act as a reminder that the patient is the constant in this journey and that the health system has a responsibility to deliver the care experience in an appropriate and coordinated manner.

The optimal care pathways are based on a revision of the original patient management frameworks (Department of Health 2007a) which had, for the first time, attempted to map the cancer pathway in an easily understandable form.

The purpose of this work is to improve patient outcomes by facilitating consistent cancer care based on a standardised pathway of care. The pathways are applicable to care whether it is provided in a public or private service. The principles and the expected standards of good cancer care are not expected to differ, even though treatment regimens may vary from patient to patient for a whole variety of reasons.

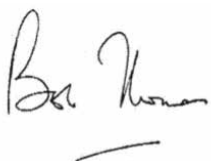
Victoria has undertaken this program of work as part of a national work plan aimed at improving cancer care. This national work plan was developed by the National Cancer Expert Reference Group (NCERG). The NCERG is a panel of experts and jurisdictional and consumer representatives that was established by the Council of Australian Governments (COAG) in 2010. In developing a national work plan for improving cancer care in Australia, the NCERG identified the value of a national approach to delivering consistent and optimal cancer care.

The NCERG has subsequently endorsed these new optimal care pathways, which they agree are relevant across all jurisdictions. Each jurisdiction has been invited to adopt and co-badge these for local use.

A wide range of clinicians, peak health organisations, consumers and carers were consulted and/or participated in their development and I want to thank all concerned for their generous contributions.

I am sure that those providing cancer care will find the specific pathways useful in deciding how best to organise service delivery to achieve the best outcomes for those we care for.

Importantly, readers should note that these care pathways are not detailed clinical practice guidelines. They are not intended to constitute medical advice or replace clinical judgement.



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Summary

Please note not all patients will follow every step of this pathway. The majority with BCC/SCC will not proceed beyond step 2.

Support: Assess supportive care needs at every step of the pathway and refer to appropriate health professionals or organisations.

Step 1

Prevention and early detection

Prevention: Solar radiation is the major environmental cause of all skin cancers. People should be encouraged to use a combination of sun protection measures.

A randomised control trial suggests that prophylaxis with daily nicotinamide (vitamin B3) may help to reduce BCC/SCC by 26 per cent.

Risk factors include:

- outdoor occupations
- immunosuppression
- previous radiotherapy
- solarium use
- fair or red hair colour
- skin that burns and does not tan

- tendency to freckle
- a history of blistering sunburn
- a previous BCC/SCC
- family history
- increasing age
- past exposure to arsenic
- multiple solar keratoses.

Intensive ultraviolet (UV) exposure in childhood and adolescence is a causative factor for developing BCC, whereas SCC is caused by chronic UV exposure incurred over decades.

For a proportion of SCC, human papilloma virus (HPV) may act in concert with sun exposure.

Early detection:

Opportunistic identification of high-risk patients, with subsequent total body cutaneous examination.

Management of increased risk should include:

- education (self-examination, sun protection)
- a total skin check every six to 12 months.

Step 2

Presentation, initial investigations and referral

Signs and symptoms:

SCC: The majority arise from solar keratoses. Induration, thickening or tenderness in the erythematous base of a scaling lesion.

BCC: A dome-shaped skin growth, pink scaly patch or pearly hard skin-coloured growth, a sore that will not heal or with visible blood vessels.

The following should be assessed by a primary care practitioner:

- any changing skin lesions, including new lesions or lesions that do not respond to treatment
- a rapidly growing skin lesion that remains unresolved after one month.

General/primary practitioner investigations:

Some lesions will be confidently diagnosed on clinical examination and history and others, particularly early lesions will require biopsy.

The following lesions should fall within the scope of a general practitioner with experience and confidence in surgical procedures. Well-defined primary lesions of:

- the trunk and extremities up to 15 mm; between 15 and 20 mm is a grey zone and they need referral depending on circumstances
- the face, forehead or scalp up to 10 mm.

Complete excision is the best approach for most within four weeks of the decision that it is necessary.

Dermoscopy by people who are adequately trained is useful in enhancing diagnosis of BCC.

Referral: Most BCCs/SCCs do not require referral.

For complicated BCC, consider referral for:

- incompletely excised lesions where surgical expertise is required for appropriate margins
- lesions involving the central face, ears, genitalia, digits, palm of hand or lower leg
- poorly defined lesions
- lesions fixed to underlying structures
- lesions lying adjacent to significant nerves
- trunk and extremities lesions > 20 mm
- cheek, forehead and scalp lesions > 10 mm.

For complicated SCC, consider referral for:

- SCC of the central face, scalp, lip and ear
- chronically immunosuppressed patients with multiple aggressive SCC
- locally recurrent and/or persistent SCC.

Healthcare providers should provide clear routes of rapid access to specialist evaluation.

Referral should incorporate appropriate documentation sent with the patient.

Communication – lead clinician to:¹

- remind the patient about primary prevention measures for minimising their risk
- explain to the patient/carer who they are being referred to and why
- support the patient and carer while waiting for specialist appointments.

¹ Lead clinician – the clinician who is responsible for managing patient care.

The lead clinician may change over time depending on the stage of the care pathway and where care is being provided.

Step 3

Diagnosis, staging and treatment planning

Diagnosis: Management may include: complete excision or re-excision with recommended margins; imaging (in some circumstances); a complete skin check.

Staging: Usually a biopsy is sufficient to diagnose a BCC/SCC.

In cases of SCC, clinically suspected lymph node metastases should be confirmed by fine needle aspiration cytology (under radiological or ultrasound guidance if required) if possible. Open surgical biopsy should be avoided.

Sentinel lymph node biopsy may be offered to patients as prognostic information and to assess the presence of lymph node metastasis +/- complete regional lymphadenectomy.

Treatment planning: Selected patients with advanced stage primary BCC/SCC, lymph node involvement and BCC/SCC in unusual sites are best managed by multidisciplinary teams in a specialist facility.

Research and clinical trials: Consider enrolment where available and appropriate.

Communication – lead clinician to:

- discuss a timeframe for diagnosis and treatment with the patient/carer
- explain the role of the multidisciplinary team in treatment planning and ongoing care
- provide appropriate information or refer to support services as required.

Step 4

Treatment:

Establish intent of treatment:

- curative
- a good cosmetic and functional result

Surgery involves excision with an adequate margin of skin and subcutaneous fat. Margin-control surgery may be considered for some patients.

Radiation treatment should be reserved for the small minority of primary BCCs and SCCs that present particular problems for conventional surgery and for cases of persistent, recurrent or advanced BCC and SCC to improve control rates.

Other therapies for early-stage BCC/SCC when surgery is not suitable may include: curettage and electrocautery; acitretin; cryotherapy; photodynamic therapy; or imiquimod cream.

Communication – lead clinician to:

- discuss treatment options with the patient/carer including the intent of treatment as well as risks and benefits
- discuss advance care planning with the patient/carer where appropriate
- discuss the treatment plan with the patient's general practitioner.

For detailed information see <<http://www.cancer.org.au/content/pdf/HealthProfessionals/ClinicalGuidelines>>.

Step 5

Care after initial treatment and recovery

All patients with a previous skin cancer are advised to undergo an annual skin examination for life.

Patients should be provided with information about preventing other cancers and educated on healthy lifestyle choices to improve general health and secondary prevention.

Communication – lead clinician to:

- explain the follow-up care plan to the patient/carer
- inform the patient/carer about secondary prevention and healthy living
- provide information about the signs and symptoms of recurrence.

Step 6

Managing recurrent or metastatic disease

Detection: Patients should be advised to be alert for any new or changing skin lesion, cutaneous lump or persistent new symptom.

Treatment: Where possible, refer the patient to the original multidisciplinary team. Treatment will depend on the location and extent of disease, previous management and the patient's preferences.

Palliative care: Early referral can improve quality of life and, in some cases, survival. Referral should be based on need, not prognosis.

Communication – lead clinician to:

- explain the treatment intent, likely outcomes and side effects to the patient/carer.

Step 7

End-of-life care

Palliative care: Consider referral to palliative care if not already involved. Ensure that an advance care plan is in place.

Communication – lead clinician to:

- be open about the prognosis and discuss palliative care options with the patient/carer
- establish transition plans to ensure the patient's needs and goals are addressed in the appropriate environment.

Optimal care pathway for basal cell carcinoma and squamous cell carcinoma

The optimal care pathway outlines seven steps in the patient journey. The pathway describes the optimal cancer care that should be provided at each step.

While the seven steps appear in a linear model, in practice, patient care does not always occur in this way but depends on the particular situation (such as the type of cancer, when and how the cancer is diagnosed, prognosis, management and patient decisions, and physiological response to treatment).

This optimal care pathway covers cutaneous basal cell carcinoma (BCC) and squamous cell carcinoma (SCC).

The **incidence** of treated BCC and SCC is more than five times the incidence of all other cancers combined in Australia. Because cancer registries do not routinely report skin cancers apart from invasive melanoma, exact incidence rates are not known.

The **costs** of screening and treating these usually non-fatal cancers cause a disproportionately high burden on the Australian health system, while cosmetic ill-effects such as facial disfigurement negatively affect quality of life. In 2012, the estimated total treatment cost for non-melanoma skin cancers in 2015 (diagnosis, treatment and pathology) was \$703 million (Fransen et al. 2012).

The majority of BCC/SCC are screened and treated in the primary care setting:

- by general practitioners (GPs)
- at skin cancer clinics (which may be run by GPs, dermatologists or nurses)
- other practitioners (for example, dermatologists).

Unlike most other types of cancer, there is a much lower risk that BCC/SCC will metastasize.

- It is estimated that BCC will spread to other parts of the body in less than 0.5 per cent of cases.
- The risk is slightly higher in cases of SCC, which spreads to other parts of the body in about 4 per cent of cases.

The majority of patients with BCC/SCC will not proceed beyond step 2 as the vast majority of patients can be successfully treated in the primary care setting and will not require further management.

Where the optimal care pathway pertains to this small minority of cases, this is indicated.

Intent of the optimal care pathway

The optimal care pathway is intended to guide the delivery of consistent, safe, high-quality and evidencebased care for people with cancer.

The pathway aligns with key service improvement priorities, including providing access to coordinated multidisciplinary care and supportive care and reducing unwanted variation in practice.

The optimal care pathway can be used by health services and professionals as a tool to identify gaps in current cancer services and inform quality improvement initiatives across all aspects of the care pathway. The pathway can also be used by clinicians as an information resource and tool to promote discussion and collaboration between health professionals and people affected by cancer.

The following key principles of care underpin the optimal care pathway and are applicable for all patients with BCC/SCC.

Patient-centred care

Patient- or consumer-centred care is healthcare that is respectful of, and responsive to, the preferences, needs and values of patients and consumers. Patient- or consumer-centred care is increasingly being recognised as a dimension of high-quality healthcare in its own right, and there is strong evidence that a patient-centred focus can lead to improvements in healthcare quality and outcomes by increasing safety and cost-effectiveness as well as patient, family and staff satisfaction (ACSQHC 2013).

Safe and quality care

This is provided by appropriately trained and credentialed clinicians, hospitals and clinics that have the equipment and staffing capacity to support safe and high-quality care. It incorporates collecting and evaluating treatment and outcome data to improve the patient experience of care as well as mechanisms for ongoing service evaluation and development to ensure practice remains current and informed by evidence. Services should routinely be collecting relevant minimum datasets to support benchmarking, quality care and service improvement.

Communication

It is the responsibility of the healthcare system and all people within its employ to ensure the communication needs of patients, their families and carers are met. Every person with cancer will have different communication needs, including cultural and language differences. Communication with patients should be:

- individualised
- truthful and transparent
- consistent
- in plain language (avoiding complex medical terms and jargon)
- culturally sensitive
- active, interactive and proactive
- ongoing
- delivered in an appropriate setting and context
- inclusive of patients and their families.

In communicating with patients, healthcare providers should:

- listen to patients and act on the information provided by them
- encourage expression of individual concerns, needs and emotional states
- tailor information to meet the needs of the patient, their carer and family
- use professionally trained interpreters when communicating with people from culturally and linguistically diverse backgrounds
- ensure the patient and/or their carer and family have the opportunity to ask questions
- ensure the patient is not the conduit of information between areas of care (it is the providers' and healthcare system's responsibility to transfer information between areas of care)
- take responsibility for communication with the patient
- respond to questions in a way the patient understands
- enable all communication to be two-way.

Research and clinical trials

Where practical, patients should be offered the opportunity to participate in research and/or clinical trials at any stage of the care pathway. Research and clinical trials play an important role in establishing efficacy and safety for a range of interventions in treatment of cancer, as well as establishing the role of psychological, supportive care and palliative care interventions (Sjoquist & Zalcberg 2013).

While individual patients may or may not receive a personal benefit from the intervention, there is evidence that outcomes for participants in research and clinical trials are generally improved, perhaps due to the rigour of the process required by the trial. Leading cancer agencies often recommend participation in research and clinical trials as an important part of patient care. Even in the absence of measurable benefit to patients, participation in research and clinical trials will contribute to care of cancer patients in the future (Peppercorn et al. 2004).

The following key principles of care are applicable to select cases of BCC and SCC, particularly those cases where patients require referral to specialist management and/or have complex care needs. The vast majority of patients will not require the level of care described.

Multidisciplinary care

This is an integrated team approach to healthcare in which medical and allied health professionals consider all relevant treatment options and collaboratively develop an individual treatment and care plan for each patient. There is increasing evidence that multidisciplinary care improves patient outcomes.

The benefits of adopting a multidisciplinary approach include:

- improving patient care through developing an agreed treatment plan
- providing best practice through adopting evidence-based guidelines
- improving patient satisfaction with treatment
- improving the mental wellbeing of patients
- improving access to possible clinical trials of new therapies
- increasing the timeliness of appropriate consultations and surgery and a shorter timeframe from diagnosis to treatment
- increasing the access to timely supportive and palliative care
- streamlining pathways
- reducing duplication of services (Department of Health 2007b).

Supportive care

Supportive care is an umbrella term used to refer to services, both generalist and specialist, that may be required by those affected by cancer. Supportive care addresses a wide range of needs across the continuum of care and is increasingly seen as a core component of evidence-based clinical care. Palliative care can be part of supportive care processes. Supportive care in cancer refers to the following five domains:

- physical needs
- psychological needs
- social needs
- information needs
- spiritual needs.

All members of the multidisciplinary team (MDT) have a role in providing supportive care. In addition, support from family, friends, support groups, volunteers and other community-based organisations make an important contribution to supportive care.

An important step in providing supportive care is to identify, by routine and systematic screening (using a validated screening tool) of the patient and family, views on issues they require help with for optimal health and quality-of-life outcomes. This should occur at key points along the care pathway, particularly at times of increased vulnerability including:

- initial presentation or diagnosis (first three months)
- the beginning of treatment or a new phase of treatment
- change in treatment
- change in prognosis
- end of treatment
- survivorship
- recurrence
- change in or development of new symptoms
- palliative care
- end-of-life care.

Following each assessment, potential interventions need to be discussed with the patient and carer, with a mutually agreed approach to multidisciplinary care and supportive care formulated (NICE 2004).

See the **appendix** for more information on supportive care and the specific needs of people with BCC/SCC.

Care coordination

Care coordination is a comprehensive approach to achieving continuity of care for patients. This approach seeks to ensure that care is delivered in a logical, connected and timely manner so the medical and personal needs of the patient are met.

In the context of cancer, care coordination encompasses multiple aspects of care delivery including multidisciplinary meetings, supportive care screening and assessment, referral practices, data collection, development of common protocols, information provision and individual clinical treatment.

Improving care coordination is the responsibility of all health professionals involved in the care of individual patients and should therefore be considered in their practice. Enhancing continuity of care across the health sector requires a whole-of-system response – that is, initiatives to address continuity of care occur at the health system, service, team and individual levels (Department of Health 2007b).

Optimal care pathway

Step 1: Prevention and early detection

This step outlines recommendations for the prevention and early detection of BCC/SCC.

1.1 Prevention

Solar radiation is the major environmental cause of all skin cancers. Sunburning, particularly to the point of skin peeling, and use of solariums should be avoided. Sensible sun protection does not put people at risk of vitamin D deficiency. For information on balancing the need for maintaining vitamin D levels and avoiding increased risk of skin cancers by excessive sun exposure refer to <http://www.cancer.org.au/preventing-cancer/sun-protection>.

Protecting children from sunburn and long-term overexposure to the sun reduces their risk of developing skin cancer later in life.

Effective prevention strategies (to be used when the ultraviolet index (UVI) is 3 or greater) include using long-sleeved clothing, broad-brimmed hats, broad-spectrum sunscreens with a sun protection factor (SPF) of 30 or higher, shade and sunglasses. People should be encouraged to use a combination of sun protection measures during the sun protection times to avoid reliance on one form of sun protection alone as an adjunct to sun avoidance and other sun protective measures. Local information about the current UVI is available through the SunSmart app available at www.sunsmart.com.au/tools/interactive-tools/free-sunsmart-app.

In addition, SCC has been shown to be associated with smoking in several studies (CCA & ACN 2008).

A randomised controlled trial in patients with previous skin cancers suggest that treatment with daily nicotinamide (the amide form of vitamin B3) may help to reduce BCC/SCC incidence in this population by 23 per cent (Martin et al. 2015).

1.2 Risk factors

People with the following are at higher risk of developing BCC/SCC:

- outdoor occupations
- immunosuppression (for example, post transplantation, chronic lymphomas and leukaemias)
- previous radiotherapy
- solarium use
- fair or red hair colour
- skin that burns and does not tan
- tendency to freckle
- a history of blistering sunburn
- a previous BCC/SCC (up to 60 per cent grow another within three years)
- a family history of skin cancer
- increasing age
- smoking (SCC)
- past exposure to arsenic
- multiple solar keratoses.

Intensive UV exposure in childhood and adolescence is a stronger causative factor for developing BCC than for SCC, whereas the latter is associated with chronic UV exposure incurred over decades (Leiter & Garbe 2008). Sun exposure in adulthood however is an important risk factor for both SCC and BCC (Iannacone et al. 2012).

The occurrence of BCC at earlier ages than SCC, its relatively common occurrence on the trunk as well as the face, and its probable origin in epidermal stem cells suggests that BCC requires a lower threshold of total solar radiation before malignant transformation than is required for SCC.

For a proportion of SCC, human papilloma virus (HPV) may act in concert with sun exposure.

1.3 Early detection

1.3.1 Screening

In the absence of any substantial evidence as to the effectiveness of skin screening in reducing mortality from BCC/SCC, general population-based screening cannot be recommended (CCA & ACN 2008).

Opportunistic identification of high-risk patients, with subsequent total body cutaneous examination on these patients, should be practised (CCA & ACN 2008). It is important for practising clinicians to be aware of high-risk groups in the population and that those in such groups also be aware of their status; regular total skin examination should be practised.

Management of increased risk should include:

- education about skin self-awareness and encouragement of regular self-examination
- education about sun protection advice for the person at risk and their family
- a total skin check every six to 12 months by a healthcare professional.

Training, experience and treatment centre characteristics

Adequate training and experience and agreed scope of practice in SCC/BCC is required of practitioners undertaking screening or treatment of these cancers.

Skin cancer clinics are not regulated in Australia, so it is important that patients check practitioner credentials when seeking screening or treatment in this setting. This might include establishing whether the practitioner is medically qualified, and then the extent of their postgraduate qualifications in general practice, skin cancer medicine, surgery or dermatology.

Step 2: Presentation, initial investigations and referral

This step outlines the process for establishing a diagnosis and appropriate referral. The types of investigation undertaken by the general or primary practitioner depend on many factors, including access to diagnostic tests and medical specialists and patient preferences.

2.1 Signs and symptoms

The majority of SCCs are thought to arise from solar keratoses. However, only a small percentage of solar keratoses evolve into an invasive SCC. Induration, thickening or tenderness in the erythematous base of a scaling lesion is very suggestive of early SCC.

A dome-shaped skin growth, pink or red scaly patch or waxy or pearly hard skin-coloured growth, a sore that will not heal or with visible blood vessels, are suggestive of BCC (Carucci & Leffell 2008).

The following should be assessed by a primary care practitioner:

- any changing skin lesions, including new lesions or lesions that do not respond to treatment
- a rapidly growing skin lesion that remains unresolved after one month.

See the NICE (2015) guidelines on suspected cancer recognition and referral at <<http://www.nice.org.uk/guidance/NG12/chapter/1-recommendations#skin-cancers>>.

2.2 Assessments by the general or primary medical practitioner

General/primary medical practitioners provide the majority of care for patients with BCC/SCC.

Some lesions will be confidently diagnosed on clinical examination and history and others, particularly early lesions with subtle clinical features, will require biopsy.

The following lesions should fall within the scope of a GP with experience and confidence in surgical procedures:

- well-defined primary lesions of the trunk and extremities up to 15 mm; between 15 and 20 mm is a grey zone and they need referral depending on circumstances
- well-defined primary lesions of the face, forehead or scalp up to 10 mm.

Complete excision of the lesion is the best approach for most lesions. Uncomplicated small tumours are best removed by an elliptical excision with a 3–4 mm margin (RACGP 2012). If complete excision is not considered appropriate, small representative samples, such as by one or more punch biopsies, shave biopsy or curettage, can be useful, especially taking into account the size and depth of the lesion under consideration.

The majority of BCCs that are clinically favourable – that is, small, nodular or superficial types not located in the central face – can be satisfactorily excised under local anaesthetic with direct primary closure in an ambulatory care setting. Dermoscopy by people who are adequately trained is useful in enhancing diagnosis of BCC.

Biopsy-proven superficial BCCs that are not suitable for excision (for example, cosmetically sensitive sites or lower legs with risk factors for poor healing) may be considered for non-surgical therapies such as topical imiquimod or photodynamic therapy. Patients receiving these treatments must be made aware of the need for follow-up of the treated site(s) to check for tumour recurrence.

Solar keratoses that persist following cryotherapy, enlarge or become tender should be biopsied to explore for the presence of SCC.

Training, experience and treatment centre characteristics

Adequate training and experience and agreed scope of practice in SCCs/BCCs is required of practitioners undertaking screening or treatment of these cancers.

Skin cancer clinics are not regulated in Australia, so it is important that patients check practitioner credentials when seeking screening or treatment in this setting.

Timeframe for completing investigations

Timeframes for undertaking a biopsy and receiving results should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress.

The following recommended timeframes are based on the expert opinion of the BCC/SCC Working Group:¹

- Excisional biopsy should be performed as soon as practicable, ideally within four weeks of the decision that it is necessary.

2.3 Referral

Unlike other cancers, the majority of tests to confirm a BCC/SCC diagnosis occur in the primary care setting before specialist referral. Most BCCs/SCCs do not require referral.

For complicated BCC, consider referral for the following lesions:

- incompletely excised lesions where surgical expertise is required for appropriate margins (particularly if the BCC is shown to be of aggressive type on biopsy (infiltrative or morphoeic))
- lesions involving the central face, ears, genitalia, digits, palm of hand or lower leg
- poorly defined lesions
- lesions fixed to underlying structures
- lesions involving or lying adjacent to significant nerves – for example, a facial or accessory nerve
- trunk and extremities lesions greater than 20 mm
- BCC subtypes that are at higher risk of recurrence and incomplete excision (such as infiltrating and morphoeic BCCs)
- cheek, forehead and scalp lesions greater than 10 mm (CCA & ACN 2008).

For complicated SCC, consider referral for the following lesions:

- SCC of the central face, scalp, lip and ear, which should be considered for referral for specialist care in view of the higher risk of local recurrence and the possible need for specialist reconstruction techniques to optimise both cosmesis and function
- chronically immunosuppressed patients with multiple aggressive SCCs
- head and neck SCC that are histologically aggressive on biopsy (poorly differentiated)
- locally recurrent and/or persistent SCC and or inadequately treated SCC (CCA & ACN 2008).

¹ The multidisciplinary experts group who participated in a clinical workshop to develop content for the BCC/SCC optimal care pathway are listed in the acknowledgements list.

A multidisciplinary approach may be important, and interdisciplinary referral may be needed.

Healthcare providers should provide clear routes of rapid access to specialist evaluation.

Referral should incorporate appropriate documentation sent with the patient including:

- photo/diagram/clear description or documentation of site
- pathology reports (a timely report back to the original referrer is expected)
- a letter that includes important psychosocial history and relevant medical history, family history, current medications and allergies where pertinent
- the results of current clinical investigations
- the results of all prior relevant investigations
- notification if an interpreter service is required.

Timeframe for referral to a specialist

Referral timeframes should be informed by evidence-based guidelines (where they exist) while recognising that shorter timelines for appropriate consultations and treatment can reduce patient distress.

The following recommended timeframes are based on the expert opinion of the BCC/SCC Working Group:

- Once the diagnosis is confirmed, referral should be as soon as practicable according to clinical concern.
- If the patient is not seen within an appropriate timeframe, the referring practitioner needs to follow up.
- The supportive and liaison role of the primary care practitioner and practice team in this process is critical.

2.4 Support and communication

2.4.1 Supportive care

An individualised clinical assessment is required to meet the identified needs of an individual, their carer and family; referral should be as required. Appropriate information for people from culturally and linguistically diverse backgrounds is important.

2.4.2 Communication with the patient, carer and family

Effective communication is essential at every step of the care pathway. Effective communication with the patient and carer is particularly important given the prevalence of low health literacy in Australia (estimated at 60 per cent of Australian adults) (ACSQHC 2013).

The general or primary practitioner should:

- remind the patient about primary prevention measures for minimising their risk (for example, sun protection measures)
- remind high-risk patients of the need for ongoing regular follow-up and skin self-surveillance
- reassure the patient about the timing of referral and treatment, if the lesion has not been removed
- provide the patient with information that clearly describes who they are being referred to, the reason for referral and the expected timeframe for appointments
- support the patient while waiting for the specialist appointment if required – and follow up if the appointment doesn't occur or is delayed.

Step 3: Diagnosis, staging and treatment planning

Step 3 outlines the process for confirming the diagnosis and stage of cancer, and planning subsequent treatment. The guiding principle is that interaction between appropriate MDT members should determine the treatment plan.

3.1 Diagnostic workup

Unlike other cancers, the majority of tests to confirm a BCC/SCC diagnosis occur in the primary care setting before specialist referral. Most BCC/SCC do not require referral.

In the diagnostic workup, management may include:

- complete excision (in instances where a punch, shave or incisional biopsy was performed pre-referral) or re-excision with recommended margins
- imaging (in some circumstances)
- all patients having a complete skin check.

3.2 Staging

Usually a biopsy is sufficient to diagnose a BCC/SCC. The majority do not require further investigation, particularly BCC.

Node-negative BCC/SCC does not require imaging staging investigations.

In cases of SCC, the lymph nodes should be examined to see if the cancer has spread. Clinically suspected lymph node metastases should be confirmed by fine needle aspiration cytology (under radiological or ultrasound guidance if required) if possible. Open surgical biopsy should be avoided (CCA & ACN 2008).

Although SCC is the obvious primary for regional lymph node metastases, this is not always the case, especially in the head and neck, which is the most common site of regional metastases. Patients may have had numerous previous skin cancers of the head and neck and may also be at increased risk for upper aerodigestive tract mucosal primary SCCs as the source of the SCC nodal metastasis. A thorough examination of the upper aerodigestive tract by an experienced clinician is necessary if any doubt as to the site of the primary lesion exists.

Sentinel lymph node biopsy (SLNB) may be offered to elected high-risk patients as prognostic information and to assess the presence of lymph node metastasis (Matthey-Giè et al. 2013). If metastatic SCC is detected, a complete regional lymphadenectomy may be performed in a second procedure after SLNB.

All staging should be undertaken using the American Joint Committee on Cancer TNM guidelines.

3.3 Treatment planning

Selected patients with advanced stage primary BCC/SCC, lymph node involvement and BCC/SCC in unusual sites are best managed by MDTs in a specialist facility.

3.3.1 Responsibilities of the multidisciplinary team

The responsibilities of the MDT are to:

- nominate a team member to be the lead clinician (the lead clinician may change over time depending on the stage of the care pathway and where care is being provided)
- nominate a team member to coordinate patient care
- develop and document an agreed treatment plan at the multidisciplinary meeting
- circulate the agreed treatment plan to relevant team members, including the patient's GP.

3.3.2 Responsibilities of individual team members

The general or primary medical practitioner **who made the referral** is responsible for the patient until care is passed to another practitioner.

The general or primary medical practitioner may play a number of roles in all stages of the cancer pathway including diagnosis, referral, treatment, coordination and continuity of care, as well as providing information and support to the patient and their family.

The care coordinator is responsible for ensuring there is continuity throughout the care process and coordination of all necessary care for a particular phase. The care coordinator may change over the course of the pathway.

The lead clinician is responsible for overseeing the activity of the team.

3.3.3 Members of the multidisciplinary team

The MDT should comprise the core disciplines integral to providing good care. Team membership will vary according to cancer type but should reflect both clinical and psychosocial aspects of care. Additional expertise or specialist services may be required for some patients (Department of Health 2007b).

Team members may include a:

- care coordinator (as determined by MDT members)*
- dermatologist*
- nurse (with appropriate expertise in wound management)*
- pathologist*
- radiation oncologist*
- radiologist/imaging specialists*
- surgeon*
- clinical trials coordinator
- dietitian
- GP
- medical oncologist
- nuclear medicine physician
- occupational therapist
- palliative care specialist
- pharmacist
- physiotherapist
- psychiatrist
- psychologist
- social worker.

* Core members of the MDT are expected to attend most multidisciplinary meetings either in person or remotely.

3.3.4 The optimal timing for a multidisciplinary team planning

Where appropriate, multidisciplinary discussion should be conducted before implementing treatment.

Results of all relevant tests and imaging should be available for the MDT discussion. The care coordinator or treating clinician should present information about the patient's concerns, preferences and social circumstances at the meeting (Department of Health 2007b).

3.4 Research and clinical trials

Participation in research and/or clinical trials should be encouraged where available and appropriate.

Australian Cancer Trials is a national clinical trials database. It provides information on the latest clinical trials in cancer care, including trials that are recruiting new participants. For more information visit <www.australiancancertrials.gov.au>.

3.5 Support and communication

3.5.1 Supportive care

Screening with a validated screening tool (such as the National Comprehensive Cancer Network Distress Thermometer and Problem Checklist), assessment and referral to appropriate health professionals or organisations is required to meet the identified needs of an individual, their carer and family.

An individualised clinical assessment is required to meet the identified needs of an individual, their carer and family; referral should be as required and include:

- reminding the patient about primary prevention measures for minimising their risk (sun protection measures)
- appropriate information for people from culturally and linguistically diverse backgrounds.

3.5.2 Communication with the patient

The lead clinician should:

- establish if the patient has a regular or preferred GP
- discuss a timeframe for diagnosis and treatment with the patient and carer
- discuss the benefits of multidisciplinary care and make the patient aware their health information will be available to the team for the discussion at the MDT meeting
- offer individualised BCC/SCC information that meets the needs of the patient and carer (this may involve advice from health professionals as well as written and visual resources)
- offer advice on how to access information and support from websites, and community and national cancer services and support groups
- use a professionally trained interpreter to communicate with people from culturally and linguistically diverse backgrounds
- if the patient is a smoker, provide information about smoking cessation.

3.5.3 Communication with the general practitioner

The lead clinician should:

- ensure timely (within a week) communication with the GP regarding the treatment plan and recommendations from multidisciplinary meetings and notify the GP if the patient does not attend appointments
- gather information from the GP, including their perspective on the patient (psychological issues, social issues and comorbidities) and locally available support services
- contribute to developing a chronic disease and mental healthcare plan as required
- discuss management of shared care
- invite the GP to participate in multidisciplinary meetings (consider using video or teleconferencing).

Step 4: Treatment for early, residual and locally advanced disease

Step 4 outlines the treatment options for BCC and SCC. For detailed information on treatment options refer to Cancer Council Australia and Australian Cancer Network clinical guidelines: *Basal cell carcinoma, squamous cell carcinoma (and related lesions) a guide to clinical management in Australia* available at <<http://www.cancer.org.au/health-professionals/clinical-guidelines/skin-cancer.html>>.

4.1 Treatment intent

The intent of treatment can be defined as:

- curative (the great majority of patients with BCC/SCC will be cured with simple excision)
- a good cosmetic and functional result.

4.2 Treatment options

The advantages and disadvantages of each treatment and associated potential side effects should be discussed with the patient.

4.2.1 Full skin examination

Full skin assessment should be undertaken to assess the risk of further skin cancers, surveillance planning and for detecting synchronous primaries. There is a role for digital photography in documenting multiple lesions and monitoring patients at high risk.

4.2.2 Surgery

The definitive treatment of a primary BCC/SCC involves excision of the tumour with an adequate margin of skin and subcutaneous fat. Margin-control surgery for BCCs/SCCs with a high risk of recurrence or metastasising or to preserve as much skin as possible (for example, nose or eye area) may be considered for some patients.

The majority of clinically favourable BCCs can be excised with a margin of 2–3 mm, with a very high chance of achieving complete excision and long-term control. An adequate microscopic margin for well-defined BCCs is 0.5 mm. If an aggressive form of BCC is suspected either clinically or on biopsy then a margin of 3–4 mm is appropriate (CCA & ACN 2008).

The recommended surgical margin of excision for SCC varies from 2 to 10 mm. For very large lesions, even wider margins may be necessary (CCA & ACN 2008).

4.2.3 Radiation therapy

Radiation therapy should be reserved for the small minority of primary BCCs and SCCs that present particular problems for conventional surgery and for cases of persistent, recurrent or advanced BCC and SCC where surgery can be complemented by radiation therapy to improve control rates (CCA & ACN 2008).

For BCCs, definitive radiotherapy should be considered when favoured by patient factors (for example, elderly patients not tolerant of surgery) and tumour factors (for example, scalp or nasal BCC).

Immediate re-excision or radiation therapy for incompletely excised primary BCC reduces the recurrence rate to less than 9 per cent (CCA & ACN 2008). Radiation therapy gives comparable control rates to re-excision for incompletely excised BCC and is an alternative to re-excision if further treatment is deemed advisable and re-excision is disadvantageous or not feasible (CCA & ACN 2008).

A radiation oncology opinion should be considered for late-stage primary, persistent and recurrent BCC. Adjuvant radiation therapy following surgery for recurrent BCC should be considered in patients with a poorer prognosis (for example, multiple recurrences, perineural invasion (PNI) and node-positive BCCs (CCA & ACN 2008).

If the excision specimen shows evidence of PNI in more than one nerve or nerves larger than 0.2 mm or evidence of PNI extending away from the main tumour mass, the patient should be referred for an opinion about postoperative radiotherapy as these patients are at higher risk of local recurrence.

For SCC, radiation therapy is an efficacious primary treatment for early primary SCC in a minority of patients:

- when surgery is not feasible – for example, if the patient is unfit for surgery or where there are anticoagulation issues
- when surgery will cause cosmetic or functional morbidity unacceptable to the patient – for example, loss of function of the lips or eyelids, large tissue deficits or multiple lesions
- symptom palliation.

4.2.4 Other therapies

The following treatments may be used for SCC in situ (Bowen's disease) and early-stage BCC/SCC when surgery is not suitable. The following treatments should be compared with surgery when discussing the likelihood of cure with the patient:

- curettage (with collection of a sample for histopathology) and electrocautery for small well-defined, superficial or nodular tumours primary BCCs and for select low-risk SCCs where excision is not feasible
- cryotherapy for early-stage biopsy-proven superficial BCCs
- oral acitretin as chemoprophylaxis for post solid organ patients and with previous SCC
- photodynamic therapy in select cases of biopsy-proven superficial BCC
- 5-fluorouracil (for multiple solar keratosis and localised biopsy-proven Bowen's disease)
- imiquimod cream for biopsy-proven superficial BCCs with a diameter of less than 2 cm.

For detailed information on these treatment options refer to the Cancer Council Australia and Australian Cancer Network clinical guidelines.

4.3 Research and clinical trials

Participation in research and/or clinical trials should be encouraged where available and appropriate.

For more information visit <www.australiancancertrials.gov.au>.

4.4 Complementary or alternative therapies

The lead clinician should discuss the patient's use (or intended use) of complementary or alternative therapies not prescribed by the MDT to discuss safety and efficacy and to identify any potential toxicity or drug interactions.

The lead clinician should seek a comprehensive list of all complementary and alternative medicines being taken and explore the patient's reason for using these therapies and the evidence base.

Many alternative therapies and some complementary therapies have not been assessed for efficacy or safety. Some have been studied and found to be harmful or ineffective.

Some complementary therapies may assist in some cases, and the treating team should be open to discussing the potential benefits for the individual.

If the patient expresses an interest in using complementary therapies, the lead clinician should consider referring them to health professionals within the MDT who have knowledge of complementary and alternative therapies (such as a clinical pharmacist, dietitian or psychologist) to help them reach an informed decision.

The lead clinician should assure patients who use complementary or alternative therapies that they can still access multidisciplinary team reviews (NBCC & NCCI 2003) and encourage full disclosure about therapies being used (Cancer Australia 2010).

Further information

- See Cancer Australia's position statement on complementary and alternative therapies at <<http://canceraustralia.gov.au/publications-and-resources/position-statements/complementary-and-alternative-therapies>>.
- See the Clinical Oncology Society of Australia's position statement available at <www.cosa.org.au/publications/position-statements.aspx>.

4.5 Support and communication

4.5.1 Supportive care

Screening with a validated screening tool, assessment and referral to appropriate health professionals and/or organisations is required to meet the needs of individual patients, their families and carers.

In addition to the common issues outlined in the **appendix**, specific issues that may arise include:

- reminding the patient about primary prevention measures for minimising their risk (e.g. sun protection measures)
- disfigurement and scarring from appearance-altering treatment (and possible need for a prosthetic), which may require referral to a specialist psychologist, psychiatrist or social worker
- possible wound infections following grafts require a wound swab and appropriate care by the patient's primary care practitioner or the surgeon who performed the graft; further review by a wound specialist may be required
- upper and lower limb lymphoedema, which may require referral to a trained lymphoedema practitioner.

4.5.2 Communication with the patient, carer and family

The lead clinician should discuss the treatment plan with the patient and carer (including the intent of treatment and expected outcomes) and provide the patient and carer with information on possible side effects of treatment, self-management strategies and emergency contacts.

Step 5: Care after initial treatment and recovery

Step 5 is concerned with the transition from active treatment to post-treatment care for patients with early BCC/SCC.

5.1 Survivorship

BCCs/SCCs rarely spread elsewhere in the body and are much less likely than other cancers to be fatal.

All patients with a previous skin cancer are advised to undergo an annual skin examination for life, as part of routine health checks by their healthcare provider, to look for the development of new lesions.

Evidence suggests that people diagnosed with BCCs/SCCs, particularly at a younger age, are at a greater risk of developing other cancers including breast, colon and lung cancers (Song et al. 2013). Patients should be provided with information about preventing other cancers and educated on healthy lifestyle choices to improve general health and secondary prevention.

Patients should be made aware that self-examination is essential.

5.2 Post-treatment care planning

5.2.1 Follow-up care

Surveillance after curative treatment for BCC/SCC is as follows:

- For patients with histological clearance and low-risk tumours (for example, BCCs and well-differentiated SCCs), no specific follow-up scheme is recommended other than regular surveillance for new skin cancers.
- For patients following non-surgical treatments, where there is no histological evidence of clearance, follow-up should be initially at three months. Examination includes a full skin check for new lesions as well as inspection of the site of the original lesion.
- For moderately to poorly differentiated SCC or SCC of the lip or ear, and in immunosuppressed patients with poor-prognosis SCC, follow-up should be initially at three months and then every six months and always include examination of the draining lymph node basin.
- In addition advice should be given regarding standard sun protection strategies (CCA & ACN 2008).

5.3 Research and clinical trials

Participation in research and/or clinical trials should be encouraged where available and appropriate.

For more information visit <www.australiancancertrials.gov.au>.

5.4 Support and communication

5.4.1 Supportive care

Screening using a validated screening tool, assessment and referral to appropriate health professionals and community-based support services is required to meet the needs of individual patients, their family and carers, including:

- reminding the patient about primary prevention measures for minimising their risk (sun protection measures)
- appropriate information for people from culturally and linguistically diverse backgrounds.

5.4.2 Rehabilitation and recovery

Rehabilitation may be required at any point of the care pathway from preparing for treatment through to disease-free survival and palliative care. Issues that may need to be addressed include managing cancer-related fatigue, cognitive changes, improving physical endurance, achieving independence in daily tasks, returning to work and ongoing adjustment to disease and its sequelae.

5.4.3 Communication with the patient, carer and family

The lead clinician should:

- explain the follow-up care plan
- provide information about the signs and symptoms of recurrent disease
- provide information about secondary prevention and healthy living.

Step 6: Managing recurrent or metastatic disease

Step 6 is concerned with managing recurrent or metastatic disease.

Unlike most other types of cancer, there is a much lower risk that BCC/SCC will metastasise.

- It is estimated that BCC will spread to other parts of the body in less than 0.5 per cent of cases (but recurs commonly in the mid-face (H-zone)).
- The risk is slightly higher in cases of SCC, which spreads to other parts of the body in about 4 per cent of cases.

6.1 Signs and symptoms of recurrent or metastatic disease

Patients should be advised to be alert for any new or changing skin lesion, cutaneous lump or persistent new symptom. This should be a trigger for further medical assessment.

6.2 Multidisciplinary team

In people with recurrent or distant metastatic disease, there should be timely referral to the original MDT (where possible), with referral on to a specialist centre for recurrent disease as appropriate.

6.3 Treatment for recurrent disease

6.3.1 Locally recurrent BCC

BCCs can recur late and usually can be managed by surgical excision or radiotherapy.

For recurrent BCCs, excision of the lesion with the scar and any previously treated area is usually necessary.

6.3.2 Locally recurrent SCC

Patients with recurrent SCC have an increased risk of further local recurrence as well as regional and distant metastases and require more urgent management. Margin control surgery and adjuvant radiation therapy should be considered as a treatment option. Sentinel node biopsy may be considered.

6.3.3 Nodal recurrent SCC

The incidence of lymph node metastases from SCC occurring in sun-affected skin is very low (less than 1 per cent) but may be considerably higher in certain situations including:

- SCC occurring at sites of mucosal squamous cell junction, including the lip, anus and vulva
- immunosuppression
- previous radiotherapy
- SCC arising in chronically inflamed/irritated lesions.

Among patients developing regional recurrence, specific tumour factors related to the development of regional recurrence include the following:

- Tumour size: SCCs larger than 2 cm are twice as likely as smaller lesions to develop regional recurrence.
- Tumour site: Lesions located on the ear and lip have a higher rate of local recurrence than cutaneous SCC elsewhere.
- Tumour grade: Poorly differentiated SCCs have double the recurrence rate of well-differentiated lesions.
- Tumour thickness: SCCs greater than 4 mm in thickness recur three times more commonly than thinner lesions.
- Peri-neural invasion is the most serious predictor of regional recurrence, with up to 50 per cent developing regional recurrence (CCA & ACN 2008).

Management may include sentinel node biopsy followed by prompt surgical treatment with clear margins, with or without adjuvant therapy.

6.4 Treatment for distant metastatic disease

In advanced disease the intent of treatment may be:

- locoregional control
- anti-cancer therapy to improve quality of life and/or longevity without expectation of cure
- symptom palliation.

In advanced disease, the morbidity and risks of treatment need to be balanced against the potential benefits.

The lead clinician should discuss treatment intent and prognosis with the patient and carer prior to beginning treatment.

If appropriate, advance care planning should be initiated with patients at this stage. Advance care planning can have multiple benefits such as ensuring a person's preferences are known and respected after the loss of decision-making capacity (AHMAC 2011).

6.4.1 Surgery

For SCC, the treatment of metastatic disease to lymph nodes is primarily surgical with or without postoperative radiation therapy.

6.4.2 Radiation therapy

Radiation therapy is important in managing metastatic SCC. Adjuvant radiation therapy following surgery for incompletely excised (persistent) SCC should be considered in patients with high-risk disease following a complete excision (for example, rapidly growing tumours, recurrent disease, close margins (< 5 mm), perineural or lymphovascular invasion, in-transit metastases, and regional nodal involvement) (CCA & ACN 2008).

6.4.3 Chemotherapy or drug therapy

Chemotherapy can be associated with high response rates in metastatic SCC as part of multimodal therapy or as a stand-alone treatment.

Systemic chemotherapy may be used in metastatic BCC or for locally advanced disease but may be used for symptom palliation.

Training, experience and treatment centre characteristics

The following training and experience is required of the appropriate specialist(s):

- Medical oncologists (FRACP or equivalent) must have adequate training and experience with institutional credentialling and agreed scope of practice within this area (ACSQHC 2004).
- Nurses must have adequate training in chemotherapy administration and handling and disposal of cytotoxic waste.
- Chemotherapy should be prepared by a pharmacist with adequate training in chemotherapy medication, including dosing calculations according to protocols, formulations and/or preparation.
- In a setting where no medical oncologist is locally available, some components of less complex therapies may be delivered by a medical practitioner and/or nurse with training and experience with credentialling and agreed scope of practice within this area under the guidance of a medical oncologist. This should be in accordance with a detailed treatment plan or agreed protocol, and with communication as agreed with the medical oncologist or as clinically required.

Hospital or treatment unit characteristics for providing safe and quality care include:

- a clearly defined path to emergency care and advice after hours
- access to basic haematology and biochemistry testing
- cytotoxic drugs prepared in a pharmacy with appropriate facilities
- occupational health and safety guidelines regarding handling of cytotoxic drugs, including safe prescribing, preparation, dispensing, supplying, administering, storing, manufacturing, compounding and monitoring the effects of medicines (ACSQHC 2011)
- guidelines and protocols for delivering treatment safely (including dealing with extravasation of drugs)
- appropriate molecular pathology access
- mechanisms for coordinating combined therapy (chemotherapy and radiation therapy), especially where facilities are not collocated.

6.5 Palliative care

Patients with advanced incurable disease should be referred for palliative care.

Evidence suggests that early referral to palliative care is associated with better outcomes in terms of quality of life, survival and aggressiveness of care at the end of life (Haines 2011; Temel et al. 2010; Zimmermann et al. 2014).

The lead clinician should ensure timely and appropriate referral to palliative care services. Referral to palliative care services should be based on need, not prognosis.

Patients should be encouraged to develop an advance care plan (AHMAC 2011).

Ensure carers and families receive information, support and guidance regarding their role according to their needs and wishes (Palliative Care Australia 2005).

Begin discussions with the patient and carer about preferred place of death.

For more information refer patients and carers to Palliative Care Australia at <www.palliativecare.org.au>.

6.6 Research and clinical trials

Participation in research and/or clinical trials should be encouraged where available and appropriate.

For more information visit <www.australiancancertrials.gov.au>.

6.7 Support and communication

After completing their treatment, patients should be provided with a treatment summary and follow-up care plan including a comprehensive list of issues identified by all members of the MDT. Transition from acute to primary or community care will vary depending on the type and stage of cancer; it needs to be planned. In some cases, people will require ongoing, hospital-based care.

6.7.1 Supportive care

Screening with a validated screening tool (such as the National Comprehensive Cancer Network Distress Thermometer and Problem Checklist), assessment and referral to appropriate health professionals or organisations is required to meet the identified needs of an individual, their carer and family.

In addition to the common issues outlined in the **appendix**, specific issues that may arise include:

- reminding the patient about primary prevention measures for minimising their risk (sun protection measures)
- disfigurement and scarring from appearance-altering treatment (and possible need for a prosthetic), which may require referral to a specialist psychologist, psychiatrist or social worker
- possible wound infections following grafts requiring a wound swab and appropriate care by the patient's primary care practitioner or the surgeon who performed the graft; further review by a wound specialist may be required
- upper and lower limb lymphoedema, which may require referral to a trained lymphoedema practitioner
- emotional and psychological distress resulting from fear of death, existential concerns, anticipatory grief, communicating wishes to loved ones, interpersonal problems and sexuality concerns
- financial issues as a result of disease recurrence (such as early access to superannuation and insurance)
- legal issues (including advance care planning, appointing a power of attorney and completing a will)
- treatment for physical symptoms such as pain and fatigue, loss of appetite or weight loss
- cognitive changes as a result of treatment (such as altered memory, attention and concentration)
- decline in mobility and/or functional status as a result of recurrent disease and treatments
- increased practical and emotional support needs for families and carers, including help with family communication, teamwork and care coordination where these prove difficult for families
- the need for appropriate information for people from culturally and linguistically diverse backgrounds.

6.7.2 Rehabilitation

Rehabilitation may be required at any point of the care pathway from preparing for treatment through to disease-free survival and palliative care. Issues that may need to be addressed include managing cancer-related fatigue, cognitive changes, improving physical endurance, achieving independence in daily tasks, returning to work and ongoing adjustment to disease and its sequelae.

6.7.3 Communication with the general practitioner

The lead clinician should:

- discuss with the patient's GP their role in symptom management, psychosocial care and referral to local services
- ensure regular and timely two-way communication regarding:
 - the treatment plan, including intent and potential side effects
 - supportive and palliative care requirements
 - the patient's prognosis and their understanding of this
 - enrolment in research and/or clinical trials
 - changes in treatment or medications
 - recommendations from the MDT.

6.7.4 Communication with the patient, carer and family

The lead clinician should ensure there is adequate discussion with the patient and carer about the diagnosis and recommended treatment, including the intent of treatment and possible outcomes, likely adverse effects and supportive care options available.

Step 7: End-of-life care

End-of-life care is appropriate when the patient's symptoms are increasing and their functional status is declining. Step 7 is concerned with maintaining the patient's quality of life and addressing their health and supportive care needs as they approach the end of life, as well as the needs of their family or carer. Consideration of appropriate venues of care is essential. The principles of a palliative approach to care need to be shared by the team when making decisions with the patient and their family.

7.1 Multidisciplinary palliative care

If not already involved, referral to palliative care should be considered at this stage (including nursing, pastoral care, palliative medicine specialist backup, inpatient palliative bed access as required, social work and bereavement counselling) with GP engagement.

If not already in place, the patient and carer should be encouraged to develop an advance care plan (AHMAC 2011).

The GP and palliative care team are essential in the management of the patient. The team may consider seeking additional expertise from a:

- pain specialist
- pastoral carer or spiritual advisor
- bereavement/grief counsellor
- therapist (for example, music or art).

There might also be a recommendation for accessing:

- home- and community-based care
- specialist community palliative care workers
- community nursing.

Consideration of the appropriate place of care and the patient's preferred place of death is essential.

Ensure carers and families receive information, support and guidance regarding their role according to their needs and wishes (Palliative Care Australia 2005).

For more information refer patients and carers to Palliative Care Australia at <www.palliativecare.org.au>.

7.2 Research and clinical trials

Participation in research and clinical trials should be encouraged where available and appropriate.

For more information visit <www.australiancancertrials.gov.au>.

7.3 Support and communication

7.3.1 Supportive care

Screening with a validated screening tool (such as the National Comprehensive Cancer Network Distress Thermometer and Problem Checklist), assessment and referral to appropriate health professionals or organisations is required to meet the identified needs of an individual, their carer and family.

In addition to the common issues identified in the **appendix**, specific issues that may arise at this time include:

- legal issues relevant to people with advanced disease such as accessing superannuation early, powers of attorney and completing a will
- information for patients and families about arranging a funeral
- specific spiritual needs that may benefit from the involvement of pastoral care
- bereavement support for family and friends
- specific support for families where a parent is dying and will leave behind bereaved children or adolescents, creating special family needs
- possible wound infections following grafts requiring a wound swab and appropriate care by the patient's primary care practitioner or the surgeon who performed the graft; further review by a wound specialist may be required
- symptoms including pain, fatigue, nausea, vomiting, anorexia, breathlessness and confusion
- decline in mobility and/or functional status impacting on discharge destination
- emotional and psychological distress from anticipatory grief, fear of death, anxiety/depression, interpersonal problems and anticipatory bereavement support for the patient as well as their carer and family
- practical, financial and emotional impacts on carers and family members resulting from the increased care needs of the patient.

7.3.2 Communication with the patient, carer and family

The lead clinician should:

- be open to and encourage discussion about the expected disease course, with due consideration to personal and cultural beliefs and expectations
- discuss palliative care options including inpatient and community-based services as well as dying at home and subsequent arrangements
- provide the patient and carer with the contact details of a palliative care service.

7.3.3 Communication with the general practitioner

The lead clinician should discuss end-of-life care planning and transition planning to ensure the patient's needs and goals are addressed in the appropriate environment. The patient's GP should be kept fully informed and involved in major developments in the patient's illness trajectory.

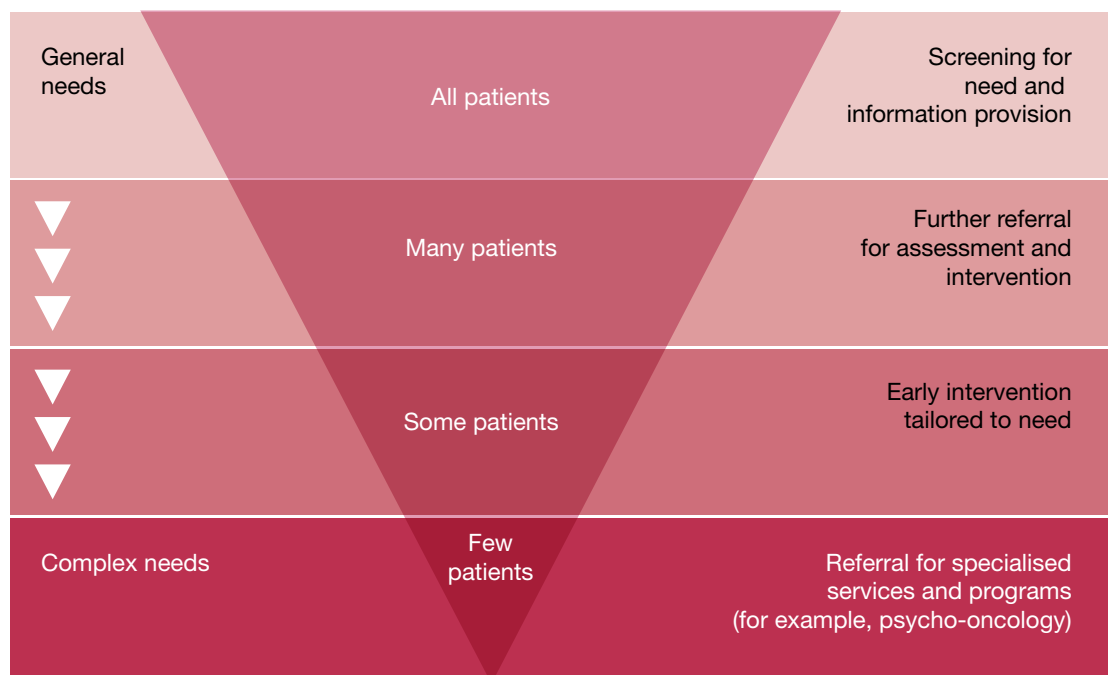
Appendix: Supportive care

Supportive care in cancer refers to the following five domains:

- physical domain, which includes a wide range of physical symptoms that may be acute, relatively short-lived or ongoing, requiring continuing interventions or rehabilitation (NBCC & NCCI 2003)
- psychological domain, which includes a range of issues related to the person's mental health and personal relationships (NBCC & NCCI 2003)
- social domain, which includes a range of social and practical issues that will impact on the individual and their family such as the need for emotional support, maintaining social networks and financial concerns (NICE 2004)
- information domain, which includes access to information about cancer and its treatment, support services and the health system overall (NBCC & NCCI 2003)
- spiritual domain, which focuses on the person's changing sense of self and challenges to their underlying beliefs and existential concerns (NICE 2004).

Fitch's (2000) model of supportive care (Figure 1) recognises the variety and level of intervention required at each critical point as well as the need to be specific to the individual. The model targets the type and level of intervention required to meet patients' supportive care needs.

Figure 1: The tiered approach



While all patients require general information, only a small minority will require specialised intervention. Indicators in patients with metastatic BCC/SCC who may require referral to appropriate health professionals and/or organisations include the following.

Physical needs

- Disfigurement and scarring from appearance-altering treatment (and possible need for a prosthetic) may require referral to a specialist psychologist, psychiatrist or social worker.
- Possible wound infections following grafts require a wound swab and appropriate care by the patient's primary care practitioner or the surgeon who performed the graft. Further review by a wound specialist may be required.
- Upper and lower limb lymphoedema may occur and referral to a trained lymphoedema practitioner may be needed.
- Cachexia/anorexia can occur as a result of disease or treatment. Validated malnutrition screening tools should be used at the key points in the care pathway to identify patients at risk of cachexia/anorexia and referral to a dietician for nutrition intervention.
- Alteration of cognitive functioning in patients treated with chemotherapy and radiation therapy require strategies such as maintaining written notes or a diary and repetition of information.
- Referral to a pharmacist may be useful for people managing multiple medications.

Psychological needs

- For some populations (culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islanders, and lesbian, gay, bisexual, transgender and intersex (LGBTI) communities) a cancer diagnosis can come with additional psychosocial complexities. Access to expert health professionals who possess knowledge specific to the psychosocial needs of these groups may be required.
- Fear of cancer recurrence is reported to be extremely common in the post-treatment phase. Some people may have disabling symptoms and may benefit from referral to psychology services.
- Distress can occur, particularly for patients with deeply indented scars, such as those that occur with skin grafting and/or with disfigurement, particularly of the face, head and neck. Providing patients with tailored and accurate information prior to treatment, facilitating patient decision making about appearance-altering treatment, and meeting others with similar personal experience may assist some people. Support and counselling from a specialist psychologist, psychiatrist or social worker may also be required.
- Distress and depression can be just as common in carers and family members including children.
- Consider a referral to a psychologist, psychiatrist or social worker if the patient is:
 - displaying emotional cues such as tearfulness, distress, avoidance or withdrawal
 - preoccupied with or dwelling on thoughts about cancer and death
 - displaying fears about the treatment process and/or the changed goals of their treatment
 - worried about loss associated with their daily function, dependence on others and loss of dignity
 - becoming isolated from family and friends and withdrawing from company and activities that they previously enjoyed
 - feeling hopeless and helpless about the impact that BCC/SCC is having on their life and the disruption to their life plans
 - struggling with communicating to family and loved ones about the implications of their cancer diagnosis and treatment
 - experiencing changes in sexual intimacy, libido or function
 - struggling with the diagnosis of metastatic or advanced disease
 - having difficulties with quitting smoking or other drug and alcohol use
 - having difficulties transitioning to palliative care.

Social/practical needs

- A diagnosis of metastatic BCC/SCC can have significant financial, social and practical impacts on patients, carers and families as outlined above. The additional costs of prosthetic, camouflage or lymphoedema services and wound/skin dressings may have a significant financial impact. A referral to a social worker should be considered for further assessment and identification of financial and practical support available.
- Significant restrictions to social activities may require referral to a social worker, occupational therapist, psychologist or psychiatrist.

Spiritual needs

- Patients with cancer and their families should have access to spiritual support appropriate to their needs throughout the cancer journey.
- Multidisciplinary teams should have access to suitably qualified, authorised and appointed spiritual caregivers who can act as a resource for patients, carers and staff. They should also have up-to-date awareness of local community resources for spiritual care.

Populations with special needs

Elderly people with cancer (70 years or older)

Planning and delivering appropriate cancer care for elderly people presents a number of challenges. Improved communication between the fields of oncology and geriatrics is required to facilitate the delivery of best practice care, which takes into account physiological age, complex comorbidities, risk of adverse events and drug interactions, as well as implications of cognitive impairment on suitability of treatment and consent (Steer et al. 2009).

A national interdisciplinary workshop convened by the Clinical Oncology Society of Australia (COSA) recommended that people over the age of 70 undergo some form of geriatric assessment, in line with international guidelines (COSA 2013). Assessment can be used to determine life expectancy and treatment tolerance as well as identifying conditions that might interfere with treatment including:

- function
- comorbidity
- presence of geriatric syndromes
- nutrition
- polypharmacy
- cognition
- emotional status
- social supports.

Adolescents and young adults

Recent years have seen the emergence of adolescent and young adult (AYA) oncology as a distinct field due to lack of progress in survival and quality-of-life outcomes (Ferrari et al. 2010; NCI & USDHHS 2006; Smith et al. 2013). The significant developmental change that occurs during this life stage complicates a diagnosis of cancer during the AYA years, often leading to unique physical, social and emotional impacts (often as a result of disfigurement and scarring from appearance-altering treatment) for young people at the time of diagnosis and throughout the cancer journey (Smith et al. 2012).

In caring for young people with cancer, careful attention to the promotion of normal development is required (COSA 2011). This requires personalised assessments and management involving a multidisciplinary, disease-specific, developmentally targeted approach informed by:

- understanding the developmental stages of adolescence and supporting normal adolescent health and development alongside cancer management
- understanding and supporting the rights of young people
- communication skills and information delivery that are appropriate to the young person
- addressing the needs of all involved, including the young person, their family and/or carer(s)
- working with educational institutions and workplaces
- addressing survivorship and palliative care needs.

An oncology team caring for a young person with cancer must:

- ensure access to expert AYA health professionals who possess knowledge specific to the biomedical and psychosocial needs of the population
- understand the biology and current management of the disease in the AYA age group
- consider clinical trials accessibility and recruitment for each patient
- engage in proactive discussion about fertility preservation and the late effects of treatment and consider the patient's psychosocial needs
- provide treatment in an AYA-friendly environment.

Aboriginal and Torres Strait Islander communities

The burden of cancer is higher in the Australian Indigenous population (AIHW 2014). Survival also significantly decreases as remoteness increases, unlike the survival rates of non-Indigenous Australians. Aboriginal and Torres Strait Islander people in Australia have high rates of certain lifestyle risk factors including tobacco smoking, higher alcohol consumption, poor diet and low levels of physical activity (Cancer Australia 2013). The high prevalence of these risk factors is believed to be a significant contributing factor to the patterns of cancer incidence and mortality rates in this population group (Robotin et al. 2008).

Nonetheless, skin cancers are exceedingly rare in Aboriginal and Torres Strait Islander people.

In caring for Aboriginal and Torres Strait Islander people diagnosed with cancer, the current gap in survivorship is a significant issue. The following approaches are recommended to improve survivorship outcomes (Cancer Australia 2013):

- Raise awareness of risk factors and deliver key cancer messages.
- Develop evidence-based information and resources for the community and health professionals.
- Provide training for Aboriginal and Torres Strait Islander health workers and develop training resources.
- Increase the understanding of barriers to care and support.
- Encourage and fund research.
- Improve knowledge within the community to act on cancer risk and symptoms.
- Improve the capacity of Aboriginal and Torres Strait Islander health workers to provide cancer care and support to their communities.
- Improve system responsiveness to cultural needs.
- Improve our understanding of care gaps through data monitoring and targeted priority research.

Culturally and linguistically diverse communities

For people from culturally and linguistically diverse backgrounds in Australia, a cancer diagnosis can come with additional complexities, particularly when English proficiency is poor. In some languages there is not a direct translation of the word 'cancer', which can make communicating vital information difficult. Perceptions of cancer and related issues can differ greatly in those from culturally diverse backgrounds and can impact on the understanding and decision making that follows a cancer diagnosis. In addition to different cultural beliefs, when English language skills are limited there is potential for miscommunication of important information and advice, which can lead to increased stress and anxiety for patients. A professionally trained interpreter (not a family member or friend) should be made available when communicating with people with limited English proficiency. Navigation of the Australian healthcare system can pose problems for those born overseas, and particular attention should be paid to supporting these patients.

Resources

For patients, families and carers

Australian Cancer Survivorship Centre

General and tumour-specific information, primarily focused on the post-treatment survivorship phase

- Telephone: (03) 9656 5207
- <www.petermac.org/cancersurvivorship>

beyondblue

Information on depression, anxiety and related disorders, available treatment and support services

- Telephone: 1300 22 4636
- <www.beyondblue.org.au>

Cancer Australia

Information on cancer prevention, screening, diagnosis, treatment and supportive care for Australians affected by cancer, and their families and carers

- Telephone: 1800 624 973
- <www.canceraustralia.gov.au>

Cancer Council (operated by Cancer Council Victoria)

A confidential telephone support service for people affected by cancer that provides information on treatment, cancer support groups and other community resources

- Telephone: 13 11 20
(Monday to Friday, 8.30 am – 5.30 pm)
- <www.cancervic.org.au>

Care Search: Palliative Care Knowledge Network

Information for patients and carers on living with illness, practical advice on how to care, and finding services

- Telephone: (08) 7221 8233
- <www.caresearch.com.au>

SCAN

A skin cancer risk assessment questionnaire to assist people to assess their skin cancer risk

- <<http://scanyourskin.org/skin-cancer-risk-checklist/>>

Skin & Cancer Foundation Australia

Information about BCC/SCC and patient support

- <www.skincancer.asn.au>

For health professionals

Australasian Lymphology Association

Professional organisation promoting best practice in lymphedema management, research and education

- Telephone: (03) 9895 4486
- <www.lymphoedema.org.au>

Australian Cancer Trials

Information on the latest clinical trials in cancer care, including trials that are recruiting new participants

- <www.australiancancertrials.gov.au>

Australian Wound Management Association

Member organisation for developing and improving wound management through education, research, communication and networks

- <www.awma.com.au>

Cancer Australia

Information for health professionals including guidelines, cancer guides, reports, fact sheets, DVDs, posters and pamphlets

- <www.canceraustralia.gov.au>

Cancer Council Australia

Information on prevention, research, treatment and support provided by Australia's peak independent cancer authority

- <www.cancer.org.au>

EviQ

Clinical information resource providing health professionals with current evidence-based, peer-maintained, best practice cancer treatment protocols and information relevant to the Australian clinical environment

- <www.eviq.org.au>

National Health and Medical Research Council

Information on clinical practice guidelines, cancer prevention and treatment

- <www.nhmrc.gov.au>

Skin Cancer College Australasia

Peak body representing and supporting skin cancer practitioners in Australia and New Zealand.

- <www.skincancercollege.org>

Glossary

Advance care planning – a process of discussing future medical treatment and care based on an individual's preferences, goals, beliefs and values, which can guide future decisions should the person become unable to communicate.

Alternative therapies – treatments that are used in place of conventional medical treatment, often in the hope they will provide a cure.

Care coordinator – the health professional nominated by the multidisciplinary team to coordinate patient care. The care coordinator may change over time depending on the patient's stage in the care pathway and where care is primarily located.

Complementary therapies – supportive treatment used in conjunction with conventional medical treatment. These treatments may improve wellbeing and quality of life, and help people deal with the side effects of cancer.

End-of-life care – a distinct phase of palliative care, appropriate when a patient's symptoms are increasing and functional status is declining despite anti-cancer therapy.

General/primary medical practitioner – the practitioner to whom the patient first presents with symptoms. This may be the general practitioner, a skin clinic clinician or a medical professional providing cancer screening services.

Lead clinician – the clinician who is responsible for managing patient care. The lead clinician may change over time depending on the stage of the care pathway and where care is being provided.

Multidisciplinary care – an integrated team approach to healthcare in which medical and allied health professionals consider all relevant treatment options and develop an individual treatment plan collaboratively for each patient (Department of Health 2007c).

Multidisciplinary team – comprises the core disciplines integral to providing good care. The team is flexible in approach, reflects the patient's clinical and psychosocial needs and has processes to facilitate good communication.

Optimal care pathway – the key principles and practices required at each stage of the care pathway to guide the delivery of consistent, safe, high-quality and evidence-based care.

Palliative care – any form of medical care or treatment that concentrates on reducing the severity of disease symptoms.

Patient management framework – tumour stream models adopted in Victoria in 2003 to reduce variation in cancer care. The optimal care pathways are updated versions of these models.

Prehabilitation – one or more interventions performed in a newly diagnosed cancer patient that are designed to improve physical and mental health outcomes as the patient undergoes treatment and beyond.

Primary specialist – the person who makes the referral to the multidisciplinary team (for example, specialist physician, surgeon, oncologist, palliative care specialist). This person will also make referrals for treatment and will be responsible for overseeing follow-up care.

Rehabilitation – comprises multidisciplinary efforts to allow the patient to achieve optimal physical, social, physiological and vocational functioning within the limits imposed by the disease and its treatment.

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Medical colleges and peak organisations

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Australian Association of Nuclear Medicine Specialists
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Australian College of Nursing
Australian Institute of Radiography
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