Patient management framework

Haematological tumour stream: acute myeloid leukaemia

Victoria
The Place To Be

Patient management framework

Haematological tumour stream: acute myeloid leukaemia

Acknowledgements

The Ministerial Taskforce for Cancer gratefully acknowledges the commitment of all the health professionals and consumers who gave their time and expertise to the development of the patient management frameworks

Published by Metropolitan Health and Aged Care Services Division,
Victorian Government Department of Human Services,
Melbourne Victoria Australia

May 2006

© Copyright State of Victoria, Department of Human Services, 2006.

This publication is copyright. No part may be reproduced by any process except in accordance with the provisions of the *Copyright Act 1968*.

Also published on www.health.vic.gov.au/cancer

Authorised by the Victorian Government,
50 Lonsdale Street, Melbourne.

Printed by GT Graphics Pty Ltd, 34 Stanley Street, Collingwood.

Contents

1. Introduction 1

2. Patient management frameworks 2

3. Credentialling and scope of practice 5

4. Multidisciplinary care 6

5. Supportive care 7

6. Steps in the care of patients with acute myeloid leukaemia 9

7. Specific supportive care needs to consider for patients with acute myeloid leukaemia 17

8. Resource list 18

9. Abbreviations 19

10. References 20

1. Introduction

Cancer is the leading cause of death in Victoria, representing 28.9 per cent of all deaths in 2002[22]. Population ageing will significantly increase the number of new cases of cancer over the next ten years, with an estimated 10,000 more cases per annum in Victoria by 2016. In 2003, 637 Victorians were diagnosed with leukaemia and in 2002, 383 deaths in Victoria were due to leukaemia[22].

Cancer is a complex disease to diagnose and treat, and represents a significant burden to patients and their families, the health system, and the community at large. Victoria's strategic and planned approach to cancer reform includes the establishment of a Ministerial Taskforce for Cancer, and implementation of the *Fighting cancer* policy[2] and *A cancer services framework for Victoria*[23]. Two significant directions of the Cancer Services Framework are the establishment of integrated cancer services in metropolitan and regional Victoria, and the development of service delivery and improvement through a tumour streams model.

Since 2004, eight integrated cancer services have been established in metropolitan and regional Victoria, based on specified geographic populations. The philosophy of an integrated cancer service is that hospitals and primary and community health services develop integrated care and defined referral pathways for the populations they serve. This requires effective collaboration between hospitals and community-based services, including general practitioners. This will promote more effective local coordination of care for cancer patients, and a more rational, evidence-based approach to cancer service planning and delivery. The Cancer Services Framework also recommended that organ or system-specific tumour streams be adopted to support the delivery and improvement of care. The reasoning behind the tumour streams is that a consistent approach to clinical management based on evidence-based practice will reduce unacceptable variations in care across the state.

2. Patient management frameworks

The Cancer Services Framework suggested some areas for improvement in the quality of care for cancer patients in Victoria. These included:

- under-treatment of patients with colorectal, lung and prostate cancer[8,20,21]
- inadequate follow-up surveillance of patients with testicular cancer[24]
- a high proportion of cancer patients undergoing surgery with surgeons who performed relatively few operations for colorectal cancer[10,21]
- a high proportion of surgery for ovarian cancer having been undertaken by generalists rather than specialist surgical oncologists[9].

As a consequence, the Cancer Services Framework recommended that tumour streams be developed to reduce unwanted variation in practice. In response, the Ministerial Taskforce for Cancer recommended that patient management frameworks be developed to provide a consistent statewide approach to care management in each tumour stream. The patient management frameworks are a clear description of the care pathway, identifying the critical points along that pathway and the optimal model of care required. It is important that all patients are assessed and managed appropriately throughout each stage of their journey; however, it should be noted that not all patients will progress through each step of the relevant patient management framework. This is a consequence of many factors, including disease outcomes, management decisions, and patient decisions.

2.1 Purpose of the patient management frameworks

The patient management frameworks are **a guide** to the **optimal care management** of patients in each tumour stream. They are intended to improve patient outcomes by facilitating consistent care based on evidence and best practice across the state. They set out the key requirements for the provision of optimal care which need to be considered at each step of the care pathway. In contrast to clinical practice guidelines that guide appropriate practice and decision making, the patient management frameworks provide a guide to the patient journey to ensure patients with cancer and their families receive optimal care and support.

As a guide, the patient management frameworks are to be followed subject to the health professional's independent medical judgment and the patient's preference in each individual case. They are designed to provide information to assist in decision making and organisation of service delivery.

The patient management frameworks **are not rules** and **do not carry a sense of prescription**. The patient management frameworks represent the 'what', rather than seeking to prescribe the 'how'. Recognising that services should be responsive to the needs of different patients at different phases, the patient management frameworks draw on best practice and encourage local solutions. For example, while multidisciplinary care is an essential part of treatment planning, how it is organised depends on the local situation.

In their current format, the patient management frameworks are not designed for accreditation purposes, but may be used to facilitate local benchmarking, service mapping and service development.

The patient management frameworks have been developed in collaboration with a wide range of practitioners, consumers and carers. Wherever possible, the patient management frameworks are based on current best practice, including clinical guidelines, care pathways, standards and research that exist to support optimal care at the critical points. In many cases, however, they are a statement of consensus regarding currently accepted approaches to treatment.

2.2 Structure of the patient management frameworks

The patient management frameworks set out seven critical steps of the patient journey. The seven steps provide a consistent structure across the ten tumour streams. While the seven steps appear as a linear model, it is clear that in practice patient care does not always occur in this way but rather depends on the particular cancer, when and how the cancer is diagnosed, prognosis, management decisions, and patient decisions.

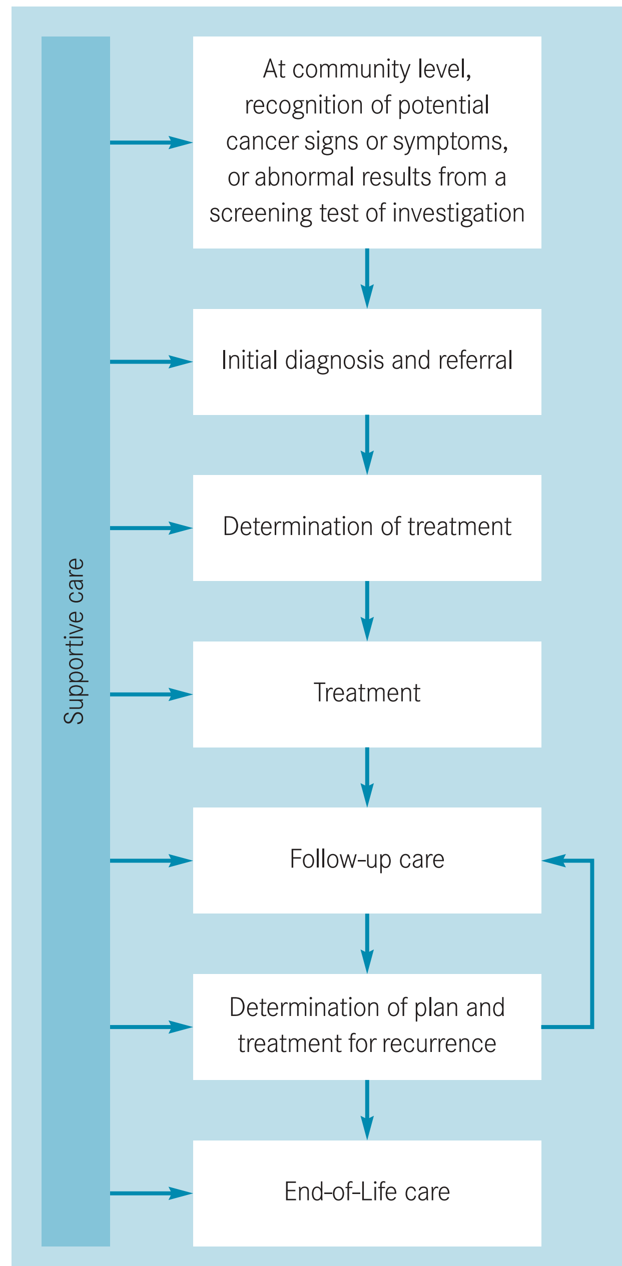
Underpinning the patient management frameworks are key principles that support all seven steps. These are:

1. patient-centred care. Patients should be involved as active participants in care planning and decision making, and wherever appropriate so should their partners, families and carers. Ultimately, any treatment decision rests with the patient or designated person. This requires information and discussion in their preferred language and sensitive to their culture

2. safe and high quality care. Cancer care is complex, involving a range of clinicians with different expertise. To ensure safe and high quality cancer care, it is important that clinicians have the technical skills and experience to carry out those aspects of cancer care they undertake and that there is institutional capacity to support such care, such as equipment, staffing and skill mix. Further detail is provided in section 3

3. multidisciplinary care. The cornerstone of best practice in cancer care is multidisciplinary treatment planning and multidisciplinary care. An effective multidisciplinary approach can result in survival benefit[12], increased recruitment into clinical trials[13,14], detection of emotional needs of patients[4], reduction in service duplication and improved coordination of services[3]. Further detail is provided in section 4

Figure 1: Steps of the patient journey



4. supportive care. People with cancer have psychological and social needs that are frequently undetected and unmet[15]. This has the potential to result in long term distress. In the context of cancer, supportive care describes all services that may be required to support people with cancer and their carers to meet their physical, psychological, social, information and spiritual needs. Further detail is provided in section 5

5. care coordination. The cancer journey is complex and challenging, and it is not uncommon for patients to be seen by many health professionals within and across multiple health services and across different sectors. A variety of strategies are successful in improving the coordination of care. Some of these include strategies directed at the team, such as multidisciplinary team meetings, clinical protocols and case conferencing; strategies directed at the patient, such as personal patient records, appropriate information provision or case managers; and strategies directed at the health care system, such as electronic medical records, standards, performance indicators and funding models. To ensure patients experience care that is coordinated and integrated over time and settings, services need to consider the range of strategies required to facilitate care coordination.

2.3 Development of the patient management frameworks

The patient management frameworks have been developed over a 15-month period in consultation with more than 500 clinicians and consumers through workshops and written submissions. Further information on the development process can be obtained at http://www.health.vic.gov.au/cancer/tumourstreams.htm.

Fourteen patient management frameworks have been developed, addressing the following tumour streams and tumour categories:

- breast
- central nervous system (cerebral metastases)
- central nervous system (malignant glioma)
- colorectal (colon and rectal)
- genitourinary (prostate)
- genitourinary (testis)
- gynaecological (ovarian)
- haematological (acute myeloid leukaemia)
- haematological (intermediate grade non-hodgkin's lymphoma)
- head and neck (larynx, pharynx and oral)
- lung (non-small cell)
- skin (melanoma)
- upper gastrointestinal (oesophagogastric)
- upper gastrointestinal (pancreatic).

2.4 Future review and development of the patient management frameworks

The 14 patient management frameworks that have been developed will be reviewed in December 2007. Further development of patient management frameworks relevant to the ten major tumour streams will commence in January 2007.

3. Credentialling and scope of practice

In 2004, the *National standard for credentialling and defining the scope of clinical practice*[1] was endorsed by the Australian Health Ministers. Developed by the Australian Council for Safety and Quality in Health Care, the standard provides a credentialling framework for all medical practitioners. Credentialling is a formal process for verifying qualifications, competence and performance of individual clinicians as well as defining their scope of practice within a specific health service. The process takes into account the skills and ability of the clinician as well as the capacity of the institution to support the clinician's practice.

This has particular relevance to clinicians working in the area of cancer care. Cancer care is complex for a number of reasons. These include:

- the large number and type of cancers that vary greatly in their pathology and management
- the range of clinicians with different professional expertise (medicine, nursing, allied health) that are involved in care
- the range of specialities for specific treatment modalities, such as breast or colorectal surgeons, radiation and medical oncologists, breast care nurses
- the life-threatening nature of many cancers and the serious complications and side-effects of some treatments
- the advances in technology and research that are changing best practice care at a rapid pace[7].

In Victoria, the complexity of cancer care poses specific challenges for health professionals working in the area of cancer. The large distances between health services and the relatively low numbers of complex cancers that will be seen at individual health services or by individual health professionals require that innovative approaches to care be developed. These include developing links between health professionals and multidisciplinary teams and initiatives such as the expansion of telemedicine, specific mentoring and upskilling programs.

For patients to have access to safe and high quality services, it is important that professionals working in the area of cancer care ensure:

- they have the necessary skills to carry out those aspects of cancer care they undertake and there is institutional capacity to support such care (for example, equipment, staffing and skill mix)
- they have clear links with a range of specialties or multidisciplinary care team required for cancer care, for the purpose of clinical advice, referral and continuing education
- they follow evidence-based practice or treatment recommendations of a multidisciplinary care team
- they undertake regular review of their performance and contribute to regular audit of their cancer care
- they are actively involved in continuing professional development
- their patients can make an informed choice about their care, including the options of referral to other professionals or specialised centres[7].

4. Multidisciplinary care

4.1 Achieving multidisciplinary care

Multidisciplinary care is an approach that includes both treatment planning and ongoing care. The 'gold standard' for multidisciplinary care is a team who meets regularly (whether in person or via teleconferencing) to prospectively plan care and treatment for all patients within a tumour group; however, it is expected that different components of multidisciplinary care will be implemented depending on the setting, the location of the team and the number and type of cancer patients being treated. While it may not always be possible to hold a multidisciplinary team meeting prior to surgery, for instance, it would be expected that some other form of multidisciplinary discussion around treatment planning take place. It is likely that regional multidisciplinary care will look different from metropolitan, while being guided by the principle that interaction between multidisciplinary team members is critical in the determination and effective implementation of the treatment plan. It is also acknowledged that patients move between the private and public sector and multidisciplinary care needs to take this into account.

4.2 Principles of multidisciplinary care[16]

The team

- There is an established multidisciplinary team comprising all core disciplines, including allied health and psychosocial health practitioners.
- The patient's general practitioner is regarded as a team member and processes to ensure effective communication with general practitioners are implemented.
- Effective communication and referral linkages are made to all core and non-core team members.

Communication

- All core disciplines where appropriate and relevant regularly attend multidisciplinary meetings to provide input to diagnostic, treatment, supportive and palliative care planning.
- In instances where not all patients within a tumour group or groups are discussed, team protocols are developed to outline those patients who will be presented at meetings.
- Processes for communicating treatment and care plans for team members who are absent are developed and implemented.

Full therapeutic range

- All patients regardless of where they reside will have information about and access to relevant treatments and services.
- Clinical trial involvement is considered for all eligible patients who will be undergoing cancer treatment.

Quality

- Decisions, protocols and care pathways are in line with current best practice, including standards, guidelines, research and where these are not available, currently accepted approaches to treatment.
- All relevant diagnostic results, reports and pathology and radiology images are available for multidisciplinary meetings.
- Collaborative links will be formed with smaller and larger referring centres and practitioners. The result will be a network of multidisciplinary teams and practitioners across and between integrated cancer services.
- Professional development activities are supported and held for all team members.

Involvement of patient

- Patients are informed of the multidisciplinary team process.
- Patients are informed of the recommendations of the multidisciplinary discussion, provided with information about all aspects of their treatment and participate in the decision making process.
- Patients are routinely given information about and access to supportive care services.

5. Supportive care

'Supportive care is an 'umbrella' term for all services, both generalist and specialist, that may be required to support people with cancer and their carers'[19]. It includes self-help and support, information, psychological support, symptom control, social support, rehabilitation, spiritual support, palliative care and bereavement care[19]. Supportive care is required throughout the diagnostic, treatment and follow-up phases of care[5].

In the context of cancer, supportive care needs include:

- physical needs (for example, pain, fatigue)
- psychological needs (for example, anxiety, distress)
- social needs (for example, practical supports, carer needs)
- information needs (for example, regarding diagnosis, prognosis, types of treatment)
- spiritual needs (for example, addressing hopelessness, despair).

5.1 Providers of supportive care

Supportive care is provided by generalist and specialist health services as well as community services. All members of the multidisciplinary team, including general practitioner, surgeon, radiation oncologist, medical oncologist, nurse, social worker and other allied health staff, have a role in the provision of supportive care. In addition, community capacity to support people with cancer makes an important contribution to supportive care. This includes support from family, friends, support groups, volunteers and other community-based organisations.

As a specialist service, palliative care may provide many of the elements of supportive care; however, palliative care also includes specific areas of expertise that may be required, such as unresolved symptoms, and complex psychosocial, end-of-life and bereavement issues[19].

5.2 Achieving supportive care

An important step in the provision of supportive care services is to identify, by routine and systematic questioning of the patient and family, views on issues they require help with for optimal health and quality of life outcomes[6]. Reassessment of their needs is not a 'once only' incident because a person's needs change along the disease trajectory[11].

A routine and systematic approach to identifying supportive care needs will help to identify people who are at higher risk of psychological or social distress. This identification provides the opportunity for further referral for assessment that is specific to their needs and recognises the individual factors that may place them at increased risk of psychological morbidity. Such factors include characteristics of the individual, such as age and marital status, and characteristics of the disease, such as time of diagnosis or recurrence, stage of disease and prognosis[15].

A detailed assessment will help to identify those patients who require more specific one-to-one intervention and follow-up.

5.3 Establishing a supportive care model

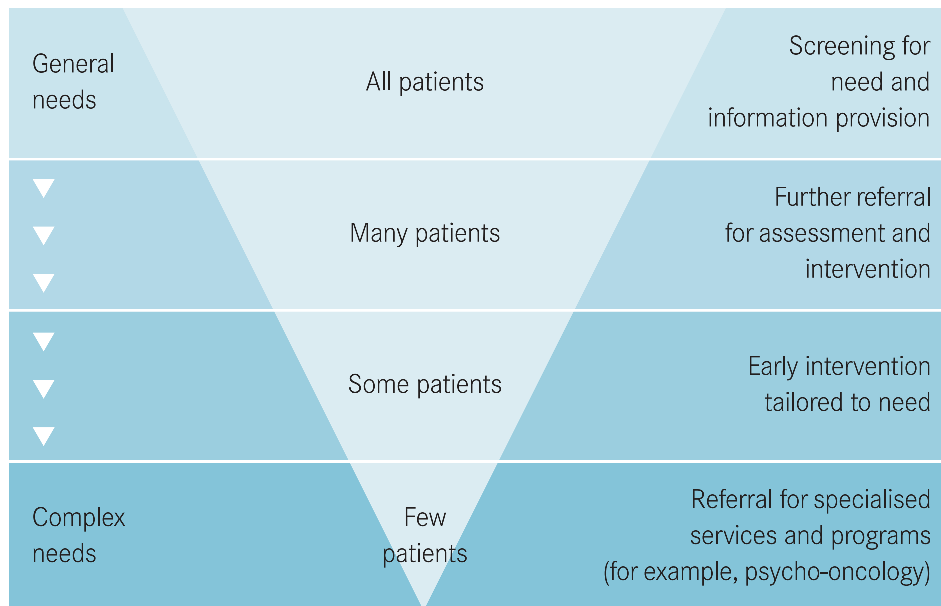
A supportive care model should recognise the variety and the level of intervention required at each phase and be specific to the individual. Such a model (see Figure 2) targets the type and level of intervention required to meet patients' supportive care needs. While there needs to be provision of general information to all patients, only a few patients will require specialised intervention.

As supportive care is provided by a range of services, it is important the following are considered in ensuring cancer patients have access to supportive care:

- processes that assist the identification of patient, family and carer supportive care needs
- clear referral pathways to specialised supportive care services
- adequate staff training in identifying and responding to supportive care needs
- promotion of supportive care as an important element of cancer service delivery.

Figure 2: Supportive care model

(Adapted from Fitch[5]. Reproduced with kind permission of Peter MacCallum Cancer Centre).



6. Steps in the care of patients with acute myeloid leukaemia

This section sets out the steps along the treatment pathway and the optimal care required. Not all patients will follow every step of the pathway. This will depend on the stage of the cancer at diagnosis and the patient's decisions about his or her care.

Step 1:
At community level, recognition of potential cancer signs or symptoms, or abnormal results from a screening test

This step identifies screening programs, the types of people who may be at higher than average risk of developing cancer, and the types of symptoms that require further investigation by the general practitioner.

1.1 Screening

- There are no screening programs for acute myeloid leukaemia.

1.2 Those at higher risk

- Risk factors include:
  - prior chemotherapy and/or radiation therapy
  - known previous haematologic disorder with a risk of leukaemic transformation: myelodysplastic syndromes, myeloproliferative diseases
  - known predisposing genetic disorders with a risk of leukaemic presentation.

1.3 Signs and symptoms that should lead to general practitioner consultation

- Symptoms at presentation are usually non-specific, particularly related to anaemia. They may include:
  - fatigue or other symptoms of anaemia
  - unexplained or persistent irritability in paediatric patients
  - pallor
  - unresolving infection or fevers
  - abnormal bleeding/bruising
  - persistent sore gums/mouth ulceration
  - unexplained bone pain
  - unexplained weight loss.
- Symptoms and signs related to a low white cell count (sepsis) and a low platelet count or abnormal coagulation (bleeding) are both more specific and mandate immediate assessment
- Note: While the majority of patients are over the age of 60 years, leukaemia can present in any age group and age cannot be used as a discriminator.

1.4 Timeframe for general practitioner consultation

- Patients with multiple presenting symptoms, particularly abnormal bleeding or sepsis, require consultation as a medical emergency.

Step 2:
Initial diagnosis and referral

This step details the process for establishing the diagnosis and appropriate referral. The types of investigations undertaken require discussion and agreement between general practitioner, specialist and the patient. Early, rapid diagnosis may have a major impact on survival.

2.1 General practitioner

- Patients with clinical features of abnormal bleeding should be referred to an appropriate facility without necessarily waiting for results of laboratory tests.
- Full blood examination should be done immediately. Results should be actively followed-up and acted on in the same working day. Pathology laboratories should directly contact the referring doctor if leukaemia is suspected.
- Patients with a laboratory diagnosis of possible acute leukaemia should be referred for immediate admission to an appropriate facility.

2.2 Referral

- A new diagnosis of acute myeloid leukaemia (confirmed or suspected) requires immediate discussion directly with a clinical haematologist or haematology registrar with adequate experience in the management of acute leukaemia (see step 4) and an adequately experienced multidisciplinary team in order to facilitate rapid assessment.
- Patients with severe symptoms or major laboratory abnormalities should be regarded as a medical emergency and be referred immediately. Others should be seen within two days.
- Appropriate documentation, including the results of all prior relevant investigations and imaging, relevant past history, and current medication/allergies, should be sent with the patient.
- Patients identified with acute myeloid leukaemia who present to emergency departments should be triaged as a medical emergency.
- The specialist should provide timely communication to the general practitioner about the assessment, and should notify the general practitioner if the patient does not attend.

2.3 Staging

- There is no accepted staging system for acute myeloid leukaemia, although patients can be categorised into prognostic groups based on cytogenetics and other features.

Step 3: Determination of treatment

This step identifies the members of the multidisciplinary team who need to be involved in initial treatment planning for this type of cancer. An experienced team, including a clinical haematologist with expertise in the management of leukaemia, should determine the recommended treatment path.

3.1 Multidisciplinary team

- The multidisciplinary team comprises (in alphabetical order):
  - clinical haematologist (adequate experience in the management of acute leukaemia—see step 4)
  - general practitioner
  - nurse
  - pharmacist
  - social worker,

  with access to:
  - a clinical haematologist expert in stem cell transplantation, to be consulted to enable early consideration and planning for allogeneic transplantation (including unrelated donor transplantation), if appropriate
  - infectious diseases physician, immediately the diagnosis is established
  - allied health services where appropriate (physiotherapist, occupational therapist, dietitian)
  - oral medicine specialist (for example, dentist for some patients)
  - palliative care services or pain management specialists where appropriate
  - psycho-oncology services where appropriate (psychologist/psychiatrist).
- A designated clinical haematologist should take the lead role for each patient.
- Participation in multicentre trials should be encouraged.

3.2 Multidisciplinary planning

- The multidisciplinary treatment plan should commence as soon as possible after the diagnosis is confirmed. Such planning must be reviewed and documented at a team meeting.
- Paediatric patients are usually managed by paediatric oncologists in highly specialised centres.
- The primary specialist who makes the referral to the multidisciplinary team is responsible for the patient until care is passed to another practitioner.

3.3 Next steps in starting treatment

- Immediate treatment is often required before a full meeting ratifies details of the management plan.
- Every patient being considered for active therapy should have samples taken for cytogenetics, flow cytometry and molecular diagnostics prior to the initiation of therapy.
- The lead clinician should ensure there is adequate discussion with the patient (and family) of the diagnosis and recommended treatment, including rationale and aim, likely effects, possible outcomes, other treatment options (including no active treatment), and psychosocial supports for patient and family.
- There should be timely communication to the general practitioner about the agreed treatment plan.
- Progression of care within the multidisciplinary team should be coordinated, ensuring the patient, general practitioner and multidisciplinary team members are clear on their responsibilities for coordination of care.

Step 4: Treatment

This step is concerned with the scope of clinical practice to deliver quality and safe practice. Scope of practice reflects both the expertise and experience of the individual as well as the organisational capability for the provision of safe, high quality cancer services[1]. A major component of therapy should, where appropriate, be participation in a clinical trial.

4A: Surgery

4A.1 Patients who may benefit from surgery

- Some patients may be offered surgical consultation during the treatment course for supportive care.
- Vascular access devices should only be inserted by proceduralists experienced in such procedures.

4A.2 Training and experience of surgeon

- Surgeon (FRACS or equivalent) with adequate training and experience that enables institutional credentialling and agreed scope of practice in the management of surgical complications that may arise in the treatment of acute myeloid leukaemia[1].

4A.3 Hospital or treatment unit characteristics

Staff

- Staffing includes:
  - accessible specialty staff, including intensive care and infectious diseases
  - clinical haematologists/medical oncologists and hospital medical officers who are readily available
  - nurses with appropriate qualifications and experience
  - surgeon as specified in 4A.2
  - anaesthetic services.

Facilities

- The following are available:
  - appropriate inpatient and ambulatory care facilities for managing these patients, including any complications. Immediate blood product support is essential
  - access to an emergency department with written protocols for the management of complications, such as neutropenic fever.

4B: Radiotherapy

4B.1 Patients who may benefit from radiotherapy

Occasionally, patients will be offered palliation with radiation.

Occasionally, patients will be offered radiation for treatment of the disease.

Total body irradiation may be indicated as part of conditioning for allogeneic stem cell transplantation and should only be given in centres with appropriately qualified and experienced staff and equipment.

4B.2 Training and experience of radiation oncologist

- Radiation oncologist (FRANZCR or equivalent) with adequate training and experience that enables institutional credentialling and agreed scope of practice in the treatment of patients with haematological malignancies[1].

4B.3 Hospital or treatment unit characteristics

Staff

- Staffing includes:
  - nurses
  - radiation oncologist as specified in 4B.2
  - radiation oncology medical physicist
  - radiation therapist.
- Staff need to be familiar with specific radiation techniques applicable to patients with acute myeloid leukaemia.

Facilities

- The following are available:
  - dual modality LINACS
  - CT planning for sophisticated radiation planning
  - treatment planning system.

4C: Drug therapy

4C.1 Patients who may benefit from drug therapy

- Prognostic stratification by clinical and laboratory features allows separation into groups with variable active treatment benefits.

4C.2 Training and experience of clinical haematologist

- Clinical haematologist (FRACP or equivalent) with adequate training and experience that enables institutional credentialling and agreed scope of practice in the treatment of patients with leukaemia[1].

4C.3 Hospital or treatment unit characteristics

Staff

- Staffing includes:
  - clinical haematologists and hospital medical officers—always available
  - medical oncologist as specified in 4C.2
  - nurses with adequate training in chemotherapy administration, handling and disposal of cytotoxic waste
  - If chemotherapy is prepared on site, then a pharmacist with adequate training in chemotherapy medications, including dosing calculations according to protocols, formulations and/or preparation is required
  - Some components of less complex therapies may be delivered in a setting where no medical oncologist is locally available, by another medical practitioner with training and experience that enables credentialling and agreed scope of practice within this area. 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
  - specialty staff, including intensive care and infectious diseases.

Facilities

- The facility has a clearly defined path to emergency care and advice after hours.
- The facility is able to care for neutropenic patients.

- There is access to haematology testing and immediate blood product support.
- Medical imaging is available.
- There is access to total parenteral nutrition.
- Emergency apheresis is accessible for the management of hyperleukocytosis.
- Cytotoxic drugs are prepared in a pharmacy with appropriate facilities.
- Occupational health and safety guidelines are followed in relation to handling of cytotoxic drugs, including preparation, waste procedures and spill kits[25].
- Guidelines and protocols, in the case of extravasation of drugs are available and understood.

Step 5:
Follow-up care

The focus of this step is to monitor the status of the disease and late adverse effects of therapy and to manage symptoms that arise following the initial treatment. It is important that a clear plan of follow-up is established to avoid excessive follow-up by multiple specialists. Follow-up may vary depending on the individual circumstances of the patient, the intrinsic risk of relapse of their disease, the treatment intention if relapse were to occur, and the long term risks associated with the initial therapy delivered.

5.1 Plan for follow-up

- For follow-up immediately post-therapy, the frequency of consultations will be determined by the patient's needs, and may range between weekly and six-weekly. The primary treating clinical haematologist should coordinate these, with input from the full spectrum of allied health professionals.
- For longer term follow-up and surveillance for recurrent/progressive disease, the timing and intensity of the surveillance will depend on the intended approach should recurrent disease be detected.
- A reasonable surveillance schedule is:
  - for the first two to three years after treatment: full blood examination (FBE) every one to three months, and clinical assessment with a careful history and physical examination every three months
  - to five years post-treatment: FBE and clinical review every three to six months
  - then annual FBE and clinical review indefinitely.

  Bone marrow biopsies for the above molecular studies may be added in the relevant cases for the first five years, dependent on the therapeutic plan for management of molecular relapse.
- Specific screening and monitoring may be required for some potential late effects of therapy, depending on the primary treatment used. These late effects may include endocrine effects (gonadal), cardiac effects, osteoporosis, transfusional iron overload, and secondary myelodysplasia.

5.2 Persons involved in follow-up care

- Not all disciplines need to be involved in longer term follow-up.
- The primary treating clinician is best placed to supervise and guide the follow-up of the patient, with input from the general practitioner, other specialists and allied health practitioners as required.
- Responsibility for follow-up investigations needs to be agreed between the primary treating clinician, the general practitioner and the patient, with an agreed plan documented, including notification to the general practitioner or multidisciplinary team member if the patient does not attend.
- The general practitioner has a key role in coordination of follow-up.

Step 6:
Determination of plan and treatment for recurrence

The focus of this step initially is treatment for recurrence where the intent may be either curative or disease control, acknowledging that in many situations the intent will be palliative. Clinical evaluation and patient decision making will determine the focus of the treatment. A major component of therapy for recurrence should, where appropriate, be participation in a clinical trial.

6.1 Investigative tests

- If recurrence is identified, there should be:
  - full blood count with blood film examination
  - bone marrow aspirate and trephine, including flow cytometry and cytogenetic analysis
  - HLA typing of patient and first degree relatives if appropriate (age less than 55–60 years, duration of complete remission > six months) after consultation with a centre performing allogeneic stem cell transplantation and if not previously done.

6.2 Multidisciplinary team

- The patient should be referred immediately to a clinical haematologist experienced in the management of acute leukaemia, preferably the physician who was responsible for the patient's primary treatment.
- Management recommendations at the time of relapse will in general be made by the patient's primary clinical haematologist, often following discussion with other members of the multidisciplinary team (as listed in 3.1).
- General practitioner and palliative care service participation are essential at this stage.
- On occasion, referral to another centre may be appropriate when considering stem cell transplantation, access to clinical trials or novel agents.

6.3 Treatments that a patient is most likely to have for recurrence

Treatment will depend on the location and extent of the recurrence, and on previous management.
Treatment may include:

- **surgery.** Patients may require insertion of a vascular access device to facilitate treatment and supportive care. Surgical excision of lesions may rarely be necessary for histopathology to confirm extramedullary disease
- **radiotherapy.** Irradiation of infiltrative/mass lesions (solitary chloromas) and craniospinal irradiation in the event of CNS disease may be appropriate. Total body irradiation (TBI) may be required in selected patients undergoing allogeneic transplantation. Note: TBI-based preparative regimens should be delivered only in centres with experience using TBI conditioning and autologous/allogeneic transplantation (minimum ten to 15 procedures per year)
- **drug therapy.** Consideration should be given to salvage chemotherapy in patients aged less than 70 years relapsing after durable first remission (> six to 12 months); allogeneic transplantation for patients aged less than 55–60 years if a compatible donor is identified; and/or use of novel agents (within or outside the setting of a clinical trial) in selected patients (Mylotarg, farnesyltransferase inhibitors etc.). Oral cytoreductive treatment with agents such as hydroxyurea is indicated for palliation of proliferative aspects of the disease (leucostasis, tissue infiltration). Note: If treatment is given with ultimate curative intent, the facilities need to be of the same level as for the initial therapy. Palliative chemotherapy may be deliverable in a less intense environment. Allogeneic stem cell transplantation must be delivered only in specialised units with appropriate human and physical resources

- **adjunctive therapies.** Regular transfusional support with red cells and platelets should be given when appropriate[16]; antimicrobials for the treatment and prevention of infections; analgesia for pain; and antifibrinolytics for thrombocytopenic bleeding and corticosteroids for suppression of disease-associated symptoms (bone pain, fever, sweats). Note: Patients receiving intensive salvage therapy (chemotherapy +/- transplantation) are at high risk of treatment-related complications. Centres must be capable of managing severe mucositis (total parenteral nutrition, analgesia, mouth care), opportunistic infections (invasive fungal disease, cytomegalovirus infection), graft-versus-host disease, organ toxicity (interstitial pneumonitis, veno-occlusive disease) and the consequences of prolonged intense immunosuppression. Centres should have access to a dental service familiar with mouth care issues in haematology patients.

Step 7: End-of-life care

The focus of this step is quality of life for the patient and their families through addressing physical, psychological, emotional and spiritual issues. For the family and carer, this may include bereavement support. Palliation is often complex in these patients, requiring multidisciplinary care, including important roles for palliative chemotherapy, blood support (and rarely radiotherapy) to optimise quality of life.

7.1 Multidisciplinary team

- The multidisciplinary team should include (in alphabetical order):
  - allied health staff as appropriate
  - general practitioner
  - medical oncologist/clinical haematologist
  - nurses with working knowledge of haematologic malignancies
  - palliative care service—relevant team members
  - pastoral care services—relevant team members
  - radiation oncologist.
- Close liaison is essential between the palliative care team, the general practitioner and the clinical haematologist.

7.2 Services that may be required

- An inpatient facility with a well resourced and integrated community/domiciliary program as close to the patients home as possible
- Palliative care service: community-based and inpatient
- Home and community care
- Allied health: dietitian, occupational therapy, pastoral care, physiotherapy
- Symptom control requires expedient medical review.
- Transfusion support can have a useful role but decisions can be complex, requiring specialised clinical transfusion knowledge.

7. Specific supportive care needs to consider for patients with acute myeloid leukaemia

The supportive care needs of patients with acute myeloid leukaemia will vary in severity and complexity along the disease trajectory. Identifying and assessing the supportive care needs of people with acute myeloid leukaemia involves a general assessment of the physical, psychological, social, information and spiritual needs as detailed in section 5. In addition to these general needs, all members of the multidisciplinary team should be aware of the particular needs related to acute myeloid leukaemia detailed below which may require intervention from specific members of the multidisciplinary team.

Physical needs

- Lengthy treatments require patients to remain in hospital for long periods of time[18]. Monitoring and maintaining nutritional status is important during this time and referral to a dietitian may be required.
- Close monitoring for early infection onset is required, as a consequence of high dose chemotherapy[18].
- Chronic graft-versus-host disease can cause persistent malaise[18]. Review by the medical specialist, and referral to a social worker, physiotherapist and occupational therapist to arrange extra supports and equipment is often required.
- Issues regarding chemically induced menopause, such as atrophic vaginitis and dyspareunia, and changes in androgens that may alter libido require sensitive discussion[15]. Open discussion about concerns and referral to social worker, psychologist or pscyhiatrist with skills in this area may be appropriate.

Psychological needs

Sexuality

- Sexual function may be slow to recover or libido may be low following high dose chemotherapy[18]. Issues regarding sexuality should be raised with all patients and possible referral to counsellor with expertise in the area may be required.

Infertility

- Infertility as a result of treatment can be an issue[18]. Sensitive discussion and possible referral to a social worker, psychologist or psychiatrist may be appropriate. Sperm, ovarian tissue or egg banking may be suggested.

Depression

- High dose chemotherapy is both physically and emotionally stressful and people who go through it continue to feel exhausted and depressed for a long period[18]. Regular screening and ongoing monitoring for depression by clinicians as part of the long term follow-up and referral to psychologist or psychiatrist may be required.

Information needs

- Information about follow-up is required because long term problems are common after high dose treatment and allogeneic bone marrow transplant[18].
- For people adapting to life after receiving bone marrow transplant there is a BMDI Bone Marrow Transplant Support Group (telephone 9342 7965; www.bmdi.org.au).
- The Leukaemia Foundation provides practical support, transport and accommodation for people and their families with leukaemia and related blood disorders (telephone 1800 555 021; www.leukaemia.com).

8. Resource list

For patients, families and carers

1. The Cancer Council Victoria

1 Rathdowne Street
Carlton 3053

Telephone:	03 9635 5000
Facsimile:	03 9635 5270
Email:	enquiries@cancervic.org.au
Web site:	http://www.cancervic.org.au/

For information on cancer, its treatment and side effects, support services, medical terminology, and research

2. Cancer Helpline (operated by The Cancer Council Victoria)

Telephone:	13 11 20
Hours:	Monday to Friday, 8.30 am–5.30 pm

For telephone peer support from people who have had cancer experiences or for information on more than 120 cancer support groups across Victoria

3. The Cancer Council Australia

http://www.cancer.org.au

Fact sheets:

Lifestyle:	www.cancer.org.au/lifestyle
Early detection:	www.cancer.org.au/earlydetection
Post diagnosis:	www.cancer.org.au/diagnosis

For health professionals

4. National Health and Medical Research Council

http://www.nhmrc.gov.au/publications/subjects/cancer.htm

For downloading clinical practice guidelines for cancer prevention and treatment

5. The Cancer Council Australia

Fact sheets for health professionals providing advice to patients:
http://www.cancer.org.au/factsheets

One-page fact sheets to help general practitioners and other health professionals advise their patients about cancer prevention, screening and diagnosis. These can also be downloaded from the patient education browser in the latest version (2.86) of the general practice software package, Medical Director.

Cancer resources for primary health care professionals:
www.cancer.org.au/primarycare

Directory of cancer resources to support general practitioners and other health professionals. Developed by the General Practice Committee of The Cancer Council Australia, the directory provides a single point of access to state, territory and national cancer resources.

6. Clinical trials

A national, online register of clinical trials being undertaken in Australia, the Australian Clinical Trials Registry, is available at http://www.actr.org.au. The Australian Clinical Trials Registry includes trials from the full spectrum of therapeutic areas, trials of pharmaceuticals, surgical procedures, preventive measures, lifestyle, devices, treatment and rehabilitation strategies and complementary therapies.

9. Abbreviations

CT	computed tomography
FRACP	Fellow of Royal Australasian College of Physicians
FRACS	Fellow of Royal Australasian College of Surgeons
FRANZCR	Fellow of Royal Australian and New Zealand College of Radiologists
LINACS	linear accelerators

10. References

1. Australian Council for Safety and Quality in Health Care, 2004, *Standard for credentialling and defining the scope of clinical practice,* ACSQHC, viewed 3 February 2006, http://www.safetyandquality.org/credentl.pdf.
2. Australian Labor Party, 2002, 'Fighting Cancer', *Australian Labor Party,* viewed 3 February 2006, http://www.vic.alp.org.au/dl/fighting_cancer.pdf.
3. Barr, O 1997, 'Interdisciplinary teamwork: consideration of the challenges', *British Journal of Nursing,* Volume 6, no. 17, pp. 1005–1010.
4. Butow, PN, Brown, RF, Cogar, S, Tattersall, MHN & Dunn, S, 2002, 'Oncologists reactions to cancer patients verbal cues', *Psycho-oncology,* Volume 11, pp. 47–58.
5. Fitch, M, 2000, 'Supportive care for cancer patients', *Hospital Quarterly,* Volume 3, no. 4, pp. 39–46.
6. Foot, G & Sanson-Fisher, R, 1995, 'Measuring the unmet needs of people living with cancer', *Cancer Forum,* Volume 19, no. 2, pp. 131–135.
7. Frommer, M, Heinke, M & Barton, M, 2005, The credentialing of cancer clinicians in Australia, *The Cancer Council Australia and the Australian Cancer Network,* Sydney, NSW, Australia.
8. Frydenberg, M, Giles, GG, Mameghan, H, Thursfield, VJ, Millar, J, Wheelahan, JB, Bolton DM, & Syme, RR, 2000, 'Prostate cancer in Victoria in 1993: patterns of reported management', *Medical Journal of Australia,* Volume 172, pp. 270–274.
9. Grossi, M, Quinn, MA, Thursfield, VJ, Francis, PA, Rome, RM, Planner, RS & Giles, GG, 2002, 'Ovarian cancer: patterns of care in Victoria during 1993–1995', *Medical Journal of Australia,* Volume 177, pp. 11–16.
10. Hill, DJ, Jamrozik, K, White, V, Collins, J, Boyages, J, Shugg, D, Pruden, M, Giles, GG & Byrne, MJ, 2000, 'Surgical management of breast cancer in Victoria in 1995', *Anti-Cancer Council of Victoria,* Melbourne.
11. Holland, J, 2002, 'History of psycho-oncology: overcoming attitudinal and conceptual barriers', *Psychosomatic Medicine,* Volume 64, no. 2, pp. 206–221.
12. Junor, EJ, Hole, DJ & Gillis, CR, 1994, 'Management of ovarian cancer: referral to a multidisciplinary team matters', *British Journal of Cancer,* Volume 70, pp. 363–370.
13. Magee, LR, Laroche, CM & Gilligan, D, 2001, 'Clinical trials in lung cancer: evidence that a programmed investigation unit and a multidisciplinary clinic may improve recruitment', Letter, *Clinical Oncology (Royal College of Radiologists),* Volume 13, no. 4, pp. 310–311.
14. McVie, JG, 1996, 'Current areas of treatment'. *Seminars in Oncology,* Volume 23, (Supplement 1), pp. 1–3.
15. National Breast Cancer Centre and National Cancer Control Initiative, 2003, 'Clinical practice for the psychosocial care of adults with cancer', *National Breast Cancer Centre,* Camperdown, NSW, Australia.
16. National Breast Cancer Centre, 2005, 'Multidisciplinary meetings for cancer care: a guide for health providers', *National Breast Cancer Centre,* Camperdown, NSW, Australia.
17. National Health and Medical Research Council, 2001, *Clinical practice guidelines on the use of blood components (red blood cells, platelets, fresh frozen plasma, cryoprecipitate),* NHMRC, viewed 14 April 2006, http://www.nhmrc.gov.au/publications/_files/cp78.pdf.
18. National Institute for Clinical Excellence, 2003, 'Guidance on Cancer Services: Improving Outcomes in Haematological Cancers', *NICE,* London, United Kingdom.
19. National Institute for Clinical Excellence, 2004. *Guidance on cancer services—improving supportive and palliative care for adults with cancer. The Manual,* National Health Service, London, United Kingdom.
20. Richardson, GE, Thursfield, VJ & Giles, GG, for the Anti-Cancer Council of Victoria Lung Cancer Study Group, 2000, 'Reported management of lung cancer in Victoria in 1993: comparison with best practice.'', *Medical Journal of Australia,* Volume 172, pp. 321–324.
21. Spigelman, AD & McGrath, DR 2002, *The National Colorectal Cancer Care Survey. Australian Clinical Practice in 2000,* National Cancer Control Initiative, Melbourne.
22. The Cancer Council Victoria, 2004, 'Canstat no. 41', *The Cancer Council of Victoria,* viewed 14 April 2006, http://www.cancervic.org.au/cancer1/facts/pdfs/canstats/canstat_41_cancer_vic_2003.pdf.
23. The Collaboration for Cancer Outcomes Research and Evaluation, 2003, 'A Cancer Services Framework for Victoria', *CCORE,* Melbourne.
24. Toner, GC, Neerhut, GJ, Schwarz, MA, Thursfield, VJ, Sandeman, TF, Giles, GG & Snow RM, for the Urology Study Committee of the Victorian Co-operative Oncology Group, 2001, 'The management of testicular cancer in Victoria, 1988–1993', *Medical Journal of Australia,* Volume 174, pp. 328–331.
25. Worksafe Victoria., 2003., *Handling cytotoxic drugs in the workplace.,* Melbourne: Victorian Workcover Authority, Melbourne.

State Government
Victoria

Department of
Human Services