

Module One– The cancer experience

Overview

The aim of this module is to develop the ability of the beginning specialist cancer nurse to apply fundamental concepts of cancer care across all domains of nursing practice.

Key concepts

The key concepts associated with the cancer experience include:

- The impact of cancer on all **domains of health** throughout the continuum of care.
- Unique needs and associated nursing care considerations of various populations with cancer, including children, Adolescents and Young Adults (AYA) and older people.
- Stigma and social perception of cancer.
- Components of cancer care delivery systems.
- Principles of multidisciplinary cancer care.
- The National Professional Development Framework for Cancer Nursing in cancer control.
- Scope of Practice of the Beginning Specialist Cancer Nurse.
- Principles of continuing professional development in accordance with professional and regulatory standards.

It is recommended that you complete the sections and their related activities in order. This is because each section and each activity contains information that you need in order to complete the sections and activities that follow.

Learning activities

At times, you will have learning activities to complete. The questions will relate to the content you've just read or the video you've just watched.

Resource Links

Resource links may be included throughout the module. These links lead to interesting resources, articles or websites, and are designed to encourage you to explore other available information.

Videos

You will be prompted to access EdCaN videos throughout this module.

Estimated time to complete

24 hours

Learning objectives

On completion of this module, you should be able to:

1. Describe the experiences and common concerns of people affected by cancer across the cancer journey.
2. Outline unique needs and nursing care considerations for individuals affected by cancer at specific developmental stages.
3. Appraise common personal and community beliefs regarding cancer and its management.
4. Describe the core nursing functions which contribute to improved experiences and outcomes for people affected by cancer.
5. Describe principles for delivering effective cancer services and their application in local service models.
6. Actively participate in continuing professional development activities relevant to development of nursing practice at a beginning specialist cancer nurse level.

Cancer control

Cancer control is the broad term used to encompass all efforts to meet the needs of people affected by cancer. Cancer control refers to all actions that aim to reduce the burden of cancer on individuals and the community, including research, prevention, early detection/screening, treatment, education and support for people with cancer and their families and monitoring of cancer outcomes.¹ National approaches to cancer control are also underpinned by the [National Service Improvement Framework for Cancer](#) ('the Framework').¹

The Framework¹ is intended to outline what all Australians with or at risk of cancer should expect to receive through the Australian health care system. Systematic implementation of the principles within the Framework informs local models of cancer care. In summary, these principles broadly include:

- strategies throughout the care continuum
- service planning and development based on the needs of people affected by cancer
- development of service delivery models to ensure equitable and best practice cancer care
- development of special programs to ensure accessibility and meet the needs of people from diverse backgrounds
- building on existing international and national plans
- recognition of the contribution of primary health care in continuing care.

The Framework¹ identified the following five main phases of the cancer control continuum at which health professionals and service providers can meet the needs of people affected by cancer. Seamless linkages between each phase are essential for coordinated and effective care.¹

1. Reducing the risk of developing cancer;
2. Finding cancer as early as possible, if early treatment is effective;
3. Having the best treatment and support during active treatment;
4. Having the best treatment and support after and between periods of active treatment;
5. Having the best care at the end of life if the cancer is not cured.

Learning activities

Completed

Activities

1. Access the [National Professional Development Framework for Cancer Nursing](#)² and discuss the strengths and limitations of the definitions of the following terms:
 - People affected by cancer
 - Cancer control
 - Domains of health

The cancer experience: nurses working in cancer control

A range of health and support services from community, primary, secondary and tertiary care agencies are required to address the needs of the person with cancer. Nurses are an essential component of service provision across all stages of the cancer experience.² The contribution of nurses in cancer control in Australia is guided by the [National professional development framework for cancer nursing](#) (The EdCaN Framework).²

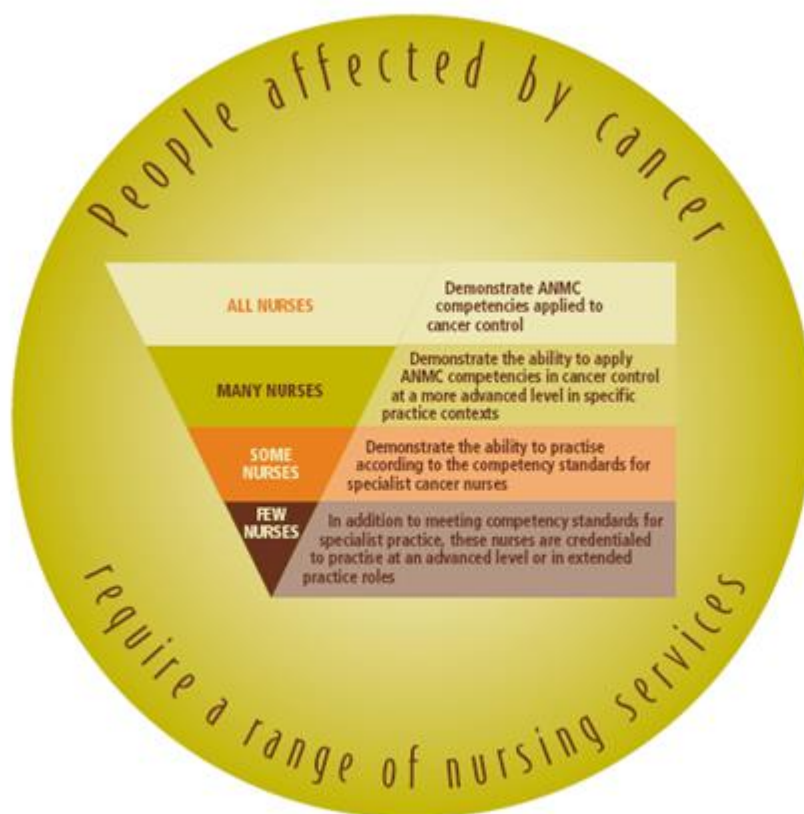
The EdCaN Framework builds on the [National Service Improvement Framework for Cancer](#)¹, and establishes expectations of all nurses working in cancer control.

The EdCaN Framework:²

- promotes a person-centred approach which is population based
- recognises that people affected by cancer have many, and often complex, needs requiring a multidisciplinary approach to which nurses can make important contributions
- is in line with the values, guidelines and principles set out by regulatory and professional bodies
- takes into account current evidence, population health needs and Australian government priorities in cancer control
- recommends that nurses be responsive to new practice areas and capabilities as they evolve
- recognises the importance of practice, education and research informing improvements to care.

The model presented below describes nurses' varying contributions at all phases of the cancer continuum, outlining the capabilities required of nurses working in different roles, in different settings and at different points along this continuum.

Figure: Professional development model for nursing in cancer control²



The competency standards for Specialist Cancer Nurses (SCNs) are intended for those nurses who choose to become specialists in cancer control. The standards are designed for nurses who work in dedicated cancer services and who are - primarily responsible for the care of people at a specific phase of their journey (for example, radiotherapy); across all phases of the cancer journey (for example, specialist breast care nurses³); or who work in a broader context but provide a specialist resource in cancer control to a range of generalist providers (for example, a cancer nurse coordinator). The competency standards are intended to represent the minimum standard required for specialist practice in cancer nursing. As their specialist practice advances, SCNs will demonstrate more effective integration of theory, practice and experience along with increasing degrees of autonomy in terms of judgments and interventions for people affected by cancer.⁴

The Beginning Specialist Cancer Nurse performance indicators have been developed to outline the expectations of a registered nurse upon completion of a program of professional development and professional experience. They have been adapted from the SCN competency standards. The learning resources developed within this program aim to help nurses acquire these capabilities.

Learning activities

Completed

Activities

- 1. Access the [EdCaN Framework²](#) , and read the principles underpinning the development of this document. For each principle, provide one practical example of how you can apply the principle in your practice.
- 2. Access the [EdCaN Framework²](#) and then:
 - summarise the four broad groups of nurses in cancer control
 - identify examples of individuals or groups of nurses from each group within the model in your local area.
- 3. Access the Beginning Specialist Cancer Nurse performance indicators (Integrated Clinical Assessment Tool – ICAT; Appendix One), and in collaboration with your resource person, develop a professional development plan for the next 12 months based on these criteria.

The cancer experience: the person diagnosed with cancer

A diagnosis of cancer has a profound effect on an individual and their family members' health and wellbeing. Cancer is a multisystem disease and its treatments can also have multiple systemic effects. As a potentially life-threatening disease, it is also a condition that is associated with significant fear. As a result, people affected by cancer can experience consequences across various physical, social, emotional, psychological, information, spiritual and practical aspects. These are likely to change over time.

Every individual's journey throughout the cancer experience is unique and affected by factors including developmental stage, socioeconomic status, psychosocial supports and culture. Nursing responses require astute assessment of individual needs and targeted interventions. In the later sections of this module, you will also consider the implications of development stage and culture as key influences on how an individual experiences cancer.

Common responses to cancer include:⁵

Psychological issues:

- Body image
- Sexuality
- Interpersonal problems
- New relationships post diagnosis
- Stress and adjustment reactions/Severe emotional distress
- Anxiety, depression, post-traumatic stress disorder (PTSD)

Practical issues:

- Costs
- Reconstructive surgery
- Travel and accommodation
- Other support needs
- Loss of income
- Difficulties with business dealings
- Legal issues related to advanced disease

Physical issues

- Nausea and vomiting
- Pain
- Fatigue
- Fertility
- Lymphoedema
- Disfigurement
- Odour
- Incontinence
- Bowel dysfunction

- Cognitive problems
- Communication difficulties
- Malnutrition
- Respiratory symptoms
- End of life concerns

Learning activities

Completed

Activities

1. From your experience describe:

- what a diagnosis of cancer means to you.
- common perceptions that individuals in our community have about cancer.

2. Access the [iheard website](#)⁶:

- Review some of the common questions and misconceptions that are raised by community members about cancer.
- Outline possible implications of common misconceptions regarding cancer in the wider community.

3. Watch [Jane's story: meet Jane](#) and complete the following learning activity:

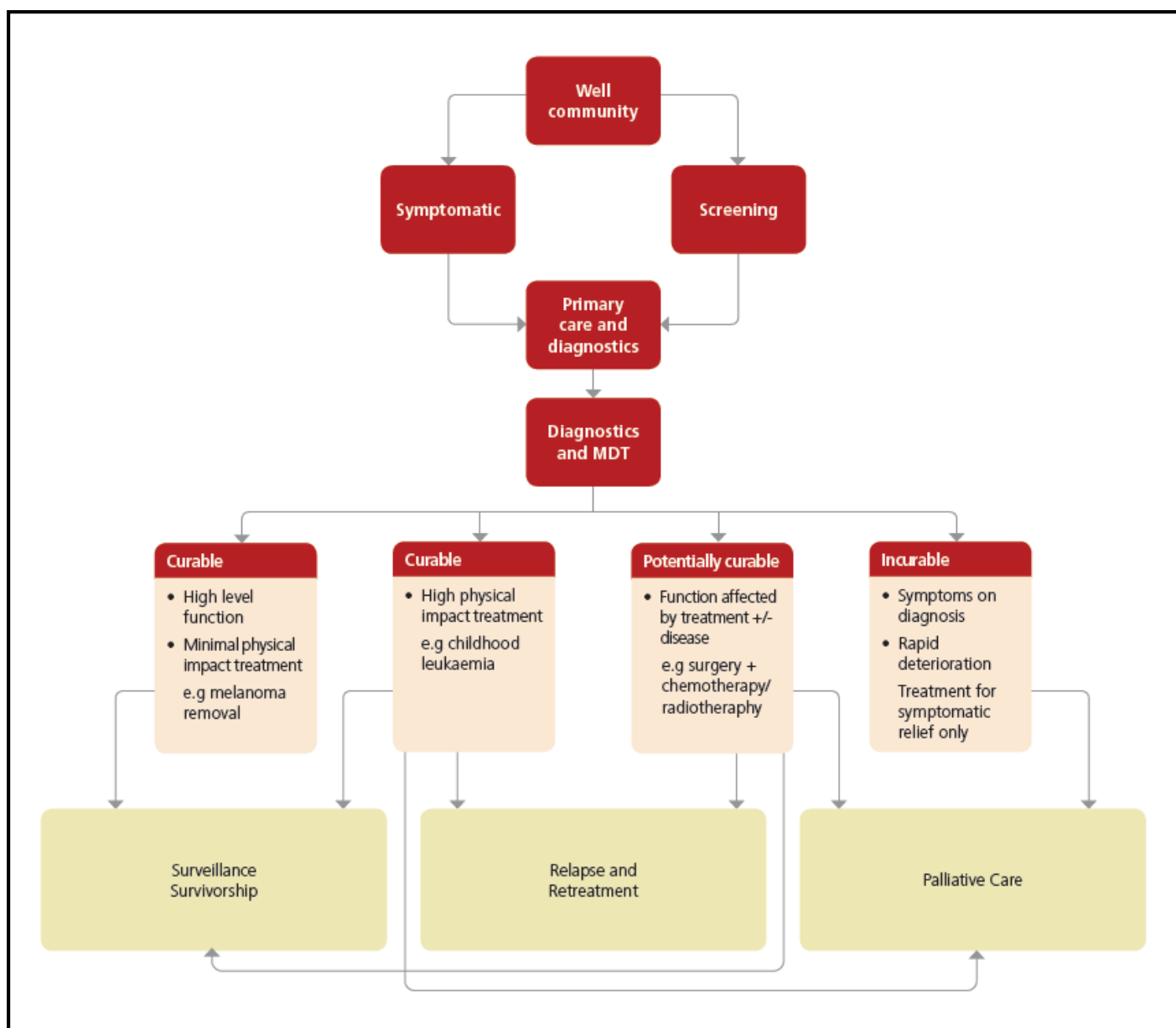


- Describe Jane's key health and support needs at this time.

The cancer experience over time

The clinical pathway for individuals diagnosed with cancer varies depending on a range of disease and treatment related factors that will be reviewed in Module Two. A summary of typical clinical pathways for a person diagnosed with cancer is presented in Figure 1. For example, a person whose cancer is diagnosed early, whose disease characteristics are not aggressive and for which there are effective treatment options, is likely to have potentially curable disease. In contrast, a person who has more extensive disease on diagnosis and whose treatment options are less certain may not have a curable disease. There are also many differences within each of these pathways. For example, there are multiple treatment options delivered over varying time frames for each individual on any of these pathways. Nursing care is based on an understanding that the needs and levels of support required by individuals or their families can vary at different points across the cancer experience.

Figure 1: Potential cancer pathways (Adapted from Department of Health, Western Australia. Model of Care for Cancer).⁷



Learning activities

Completed

Activities

- 1. Discuss similarities and differences in support needs for individuals at diagnosis, during treatment and in surveillance.
- 2. Discuss differences in support needs for individuals who are being treated for a potentially curable cancer compared to those whose disease may not be curable.
- 3. Watch [Jane's story: meet Jane](#) again and complete the following learning activity:



- How are Jane's key health and support needs likely to change in the future?

- 4. Review an individual's health record in your unit or an [EdCaN case study](#).
 - Chart their cancer journey on a pathway as in Figure 1.
 - Identify the health care professionals involved in their care at each phase.

Other factors affecting the cancer experience

Cancer in children

In 2007 the incidence of all cancers in children aged zero to 14 was 15.8 per 100,000 males and 13.7 per 100,000 females, with the highest rate of incidence in the zero to four age group (22.4 per 100,000 children).⁸

The most common cancers affecting children in 2006 were leukaemia (which accounts for one third of all childhood cancers) and tumours of the central nervous system (23%).⁹

Despite being relatively uncommon in children, cancer was the second leading cause of death (17% of all deaths) in children aged one to 14 years in 2009.¹⁰

The outlook for children diagnosed with cancer has improved, with five-year relative survival for children aged zero to 14 years diagnosed with leukaemia demonstrating significant improvement from 64% in 1982-86 to 83% in 1998 – 2004.¹⁰

The family's needs for support are substantial at the time of diagnosis, as they attempt to cope with a serious physical illness and the fear that their child will not be cured.¹¹

At diagnosis, parents must adjust to the emotional realisation that their child is living with a life-threatening disease, while simultaneously receiving a large amount of information on how to manage and care for their child during treatment. Parents are very vulnerable during this time, and have an intense need for support from partners, families, friends, employers, hospital staff, and other parents.¹²

How parents respond to their child's diagnosis can also have a profound effect on how the child develops and responds to his/her illness. Factors which may influence how parents react include:¹¹

- reactions to previous crises
- reactions of the child
- child rearing practices and attitudes
- available support systems
- perception of the illness
- previous knowledge or experience with cancer
- cultural and religious beliefs
- beliefs about the cause of the disease
- effects of the disease on the family
- concurrent stresses in the family.

Characteristics which affect children's responses include:¹¹

- age (most vulnerable - six months to four years)
- development level
- temperament
- social skills and self-concept
- pre-existing conditions and previous experiences
- intelligence level
- type of disease
- reactions of significant others.

Primary caregivers, who are important to the well-being of the child during treatment, need to understand the nature of the disease, treatment options and prognosis in order to participate in treatment decisions and to take on the care roles expected of them.^{13, 14} Nurses working with children who have cancer have a significant supportive role in:^{11, 14}

- providing information and supportive care
- helping the family understand the various therapies
- preventing or managing side effects or toxicities
- observing for early and late effects of treatment.

Learning activities

Completed

Activities [copy activities to your notebook]

1. Watch [Ellie's story: experience of diagnosis](#) and complete the following learning activity:



- Outline the key social and emotional issues Ellie's family may face over the next three months related to Ellie's diagnosis with ALL.

2. Access the following resources:

[Guidance on cancer services: improving outcomes in children and young people with cancer](#)¹⁴

[Clinical practice guidelines for the psychosocial care of adults with cancer](#)⁵

- Summarise key principles in providing supportive care for people affected by childhood cancer during the diagnostic phase.

Cancer in adolescents and young adults (AYA)

As a group, young people aged 15-24 accounted for 14% of the population in Australia in 2006. The incidence of cancer in this group was 32 per 100,000 people in 2004.¹⁵

The most common cancers affecting this group in 2006 were melanomas of the skin, Hodgkin Lymphoma and cancer of the testes (7.7, 3.9 and 3.5 per 100,000 young people respectively). These cancers accounted for 47% of cancers diagnosed among this age group.¹⁵

Although cancer is generally more common among older age groups, and five-year cancer survival is highest in the 20-29 year age group for both males (86%) and females (89%)¹⁶, cancer remains one of the leading causes of death among young Australians.¹⁵

Notable trends for cancers diagnosed in AYA in Australia include:

- Increasing incidence of cancer in AYA (25% increase from 1982 to 2004, with the incidence being almost twice that observed in 5-15 year olds).¹⁷
- Minimal detectable increase in AYA survival from cancer. Evidence from the surveillance, epidemiology and end results (SEER) program in the USA indicates that major improvements are occurring in survival rates in every age group except the AYA cohort.¹⁸
- Worse outcomes for AYA compared with children with cancer. While the overall five-year survival rate is similar for AYA and children, there are substantial survival differences between these two age groups dependent on cancer type. Australian data (1983-2005) demonstrated a survival advantage at five years for children (68%) compared with AYA (58%) affected by osteosarcoma.¹⁸

Adolescence is a time of dramatic change in physical growth, awareness of body image, and concepts of personal and social self.¹⁹ AYA affected by cancer have numerous additional challenges and require specific psychological and social support throughout their cancer journey.

The uncertainty, self-consciousness, emotional reactivity and still developing cognitive abilities of AYA, combined with their increased exposure to risky situations, makes diagnosis particularly difficult during this life stage.

AYAs need individualised care plans that recognise individual diagnoses, circumstances, and developmental stages.¹⁸ Working with AYA affected by cancer necessitates focusing on how normal life can be maintained while minimising psychological distress.²⁰

Reactions to diagnosis of cancer in AYA are complex and affected by family relationships, culture, chronological and psychological development. Any care provided must be multi-dimensional and incorporate the needs of the family. While there is limited research about the needs of AYA families specifically, there is some evidence that cancer affects the whole family and that family members can experience significant distress.²¹

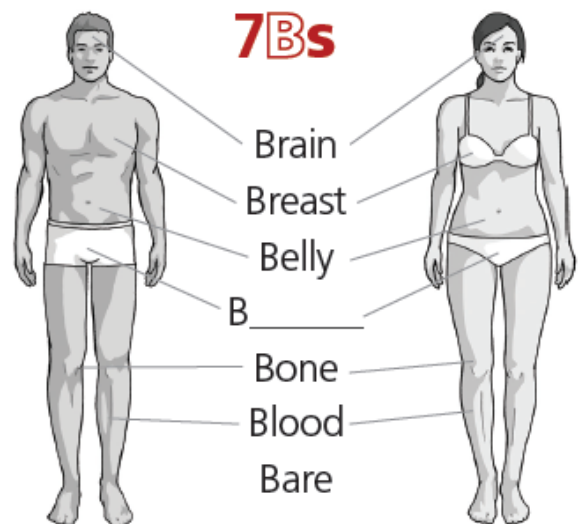
The increased demands on family associated with the high care needs of a person with cancer can result in restricted social relationships, work and other responsibilities and practical problems related to disease management and finances.²¹

Generally, there is a lack of awareness in the AYA population and primary health care providers of signs and symptoms for early diagnosis of cancer in this group. Developmental, psychological and social factors may place AYA at higher risk of a delay in diagnosis.²²

7 SYMPTOMS OF CANCER

- C** Change in mole or new one
- A** Abnormal discharge from orifice
- U** Unilateral knee/ shoulder pain/ swelling
- T** Tumor/ bulge/ bump/ lump anywhere
- I** Increasing lymph gland
- O** Obstinate fatigue, lethargy
- N** Neurologic deficit or symptom of ICP

SIGNS OF CANCER AYAs



The '7 symptoms' increase awareness of early clues to cancer diagnosis in AYA.²³ (Permission to reproduce images provided by author).

Learning activities

Completed

Activities [copy activities to your notebook]

1. Watch [*Justin's story: dealing with diagnosis*](#) as he describes his reaction to a diagnosis of osteosarcoma then complete the following learning activity:



- Describe Justin's key health and support needs now and into the future.

2. Identify local health resources available to support AYA and their families to meet their unique health needs, and consider how these resources are made accessible to AYA.

Cancer in the older person

Psychosocial changes associated with ageing and multiple co-morbidities in older people can influence the type of treatment and support required.²⁴ The unique treatment and care needs of older people with cancer have been described as a new specialty termed 'geriatric oncology'.²⁴

Studies suggest that changes associated with ageing can sometimes lead to older people receiving suboptimal treatment, or treatment that is not consistent with their personal preferences.^{24, 25} Some studies report that older people with aggressive lymphoma are less likely to be treated for cure than younger people with the same disease and are less likely to survive for five years due to limited access to clinical trials.²⁶

Beneficent ageism refers to a neglect of an older person's wishes. The older person's social role is distorted and health professionals assume an ability to represent the older person's best interests without endorsement from them.²⁷

Additional complications can arise in the older person due to co-morbidity factors. Comprehensive geriatric assessments may help to support decision making in relation to treatment plans for older people²⁸. The following factors should be taken into account when assessing the older person with cancer:²⁹⁻³¹

- functional status
- co-morbidity
- cognition
- social support
- psychological state
- concomitant medications
- nutrition
- continence
- carer support.

Learning activities

Completed

Activities [copy activities to your notebook]

1. Watch [Arthur's story: meet Arthur](#) and complete the following learning activity:



- Describe the issues Arthur may experience across all domains of health related to a diagnosis of cancer.

2. Access the article [Tools for assessing elderly cancer patients](#)²⁹ and [NCCN clinical practice guidelines for oncology - senior adult oncology](#)³¹ (a free resource, but you must register and then click 'Remember me' to bypass the login page in future), and:
 - use a specific geriatric assessment tool on an individual in your unit who is over 75 years of age.
 - discuss benefits or limitations associated with using a geriatric assessment tool in an oncology setting.

The cancer experience in culturally and linguistically diverse (CALD) groups

Access to and effective engagement with health services by CALD individuals and communities may be impeded by their lack of familiarity with the complex Australian health system, and lack of consideration of the health and spiritual beliefs of different cultures.³²

Cultural safety extends beyond cultural awareness and cultural sensitivity and has at its core the experience of the person receiving care.³³ Cultural safety principles aim to ensure:

- individuals receive care that meets their cultural needs and promotes feelings of being safe^{33, 34}
- individuals are not afforded less favourable outcomes because they hold a different cultural outlook³⁴
- care provided is respectful towards culture³⁴
- there is no assault, challenge or denial of an individual's identity, of who they are and what they need.³⁵

A culturally safe approach to care requires health professionals to:

- be aware and mindful of their personal attitudes and values towards gender, race, religion and sexuality
- be self-aware and reflect on their practice
- understand post-colonisation
- apply the principles of effective communication and be aware of different styles of communication
- be inclusive
- act respectfully to empower individuals³⁴
- promote shared respect, meaning, knowledge and experiences.³⁵

Unsafe cultural practice occurs when actions diminish, demean or disempower the cultural identity of an individual.³⁴

The PCC4U project is acknowledged as the author of the above content. PCC4U is funded by the Australian Government Department of Health and Aging.

Three steps towards cultural safety

Developing culturally safe practice requires the capacity to make adjustments to services that accommodate culturally different needs. The process of developing culturally safe practices requires the participation of individuals and organisations in three broad steps:³⁶

Step 1: Cultural consciousness or awareness of the constructs of one's own culture and recognition of unique and similar qualities of other cultural groups. Engagement with minority cultural groups is imperative to the process of cultural consciousness and building collaborative cancer control programs.

Step 2: Cultural appraisal or assessment to identify cultural domains of difference that need to be considered in the plan of person-family centred cancer care.

Step 3: Cultural safety skill development of appropriate behaviours, attitudes, and communication strategies that reduce the gap of inequities in cancer outcomes.

Learning activities

Completed

Activities [copy activities to your notebook]



1. Describe strategies you can use to avoid stereotypes and ensure that you apply the principles of cultural safety to every individual in your care.



2. Watch [Mrs Li's story: symptoms](#) and complete the following learning activities:



- Reflect on the family relationships and cultural background within the case study, and explain how you would develop an understanding the implications of Mrs Li's beliefs, values and customs in planning her care.
- If Mrs Li was admitted to your health facility, describe how you would ensure access to an appropriate interpreter service.

The following recommended readings will assist your responses:

Kwok C, Sullivan G. Chinese-Australian women's beliefs about cancer: implications for health promotion. *Cancer Nursing* 2006; 29(5):E14-21³⁷

Chui YY, Donoghue J, Chenoweth L. Responses to advanced cancer: Chinese-Australians. *Journal of Advanced Nursing* 2005; 52(5):498-507³⁸



3. Access the EdCaN learning resource page, [‘Indigenous people’s views of cancer’](#). Summarise some of the cultural meanings of cancer that may be held by Indigenous peoples.

4. Access the Indigenous health workers webpage on the [Australian Indigenous HealthInfoNet website](#)³⁹, and:

- review the summary information about Indigenous health workers
- identify Indigenous health workers in your local area
- identify and outline the role of resources, networks and/or other health professionals in your local area which may be accessed to support Indigenous people affected by cancer.

Multidisciplinary approaches in cancer control

Given the multiple complex needs of individuals affected by cancer, a multidisciplinary approach is recommended throughout the cancer journey. Multidisciplinary care has been described as 'an integrated team approach to health care in which medical and allied health care professionals consider all relevant treatment options and develop collaboratively an individual treatment plan for the person affected by cancer'.⁴⁰

Learning activities

Completed

Activities

1. Access Burt's [Health History](#) and watch the [Burt's story: treatment decisions](#), as he discusses his treatment options.



- Identify the issues Burt may experience throughout his cancer journey.
- List the health professionals who might be involved in Burt's care to meet his needs.

2. Identify members of the multidisciplinary team in your practice area.

3. Describe the key contributions that each health professional within the MDT would make to an individual's cancer journey.

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