Osteosarcoma case based learning resource

Overview of the osteosarcoma case based learning resource: Justin's story

This case study recounts the experience of Justin, a 16-year-old male diagnosed with osteosarcoma.

The case study contains four sections:

1. Find the condition early.
2. Have the best treatment and support during active treatment.
3. Have the best treatment and support between and after active treatment.
4. Have the best care at the end of life.

It is recommended that you complete the sections and their related activities in order. This is because each section and each activity includes information that will help you complete the sections and activities that follow.

Learning activities

At times, you will have learning activities to complete. Click on the learning activities button and a list of questions will pop up. The questions will relate to the content you've just read or the video you've just watched.

Videos

There is a video component to this case study that is presented in seven parts. You can watch the video clips when prompted throughout this case study, or at any time by clicking on the video icon in the right-side menu. Learning activities throughout the case study will discuss the video and ask questions about it.

Resource links

Resource links are included throughout the case study. These links lead to interesting articles or websites, and are designed to encourage you to explore other available resources.

PDF of osteosarcoma module
You can download a PDF version of the osteosarcoma module.

Suggested citation:

Cancer Australia. (2018) EdCaN module: Osteosarcoma case based learning resource, version 2.2.

Aim of the osteosarcoma case study

This case study aims to facilitate the development of competencies that reflect the role of the Specialist Cancer Nurse (SCN) in delivery of supportive care, including provision of information and education for people affected by osteosarcoma in adolescents and young adults (AYA).

Rationale

Adolescents and young adults (AYA) are a discrete population with unique biological, emotional and social characteristics. A cancer diagnosis is a significant disruption to the major developmental changes that occur across these ages. Peak incidence of osteosarcoma occurs in the AYA group.(Hinshaw & Fink, 2007) The median age at diagnosis with osteosarcoma is 20 years.(National Comprehensive Cancer Network, 2014)

There are many points along the cancer journey when the SCN can improve outcomes for AYA affected by osteosarcoma. These include:

Section 1: Find the condition early

Symptoms of osteosarcoma may be confused with growing pains.(National Comprehensive Cancer Network, 2014) Treatment delays of six months or more have been reported among AYA due to late presentation to health services and initial failure to recognise symptoms as indicative of cancer.(Martin et al., 2007)

Increasing the awareness of clues to early cancer diagnosis, in the context of normal AYA development within the health care community, may lead to further investigation and earlier referrals to specialist cancer services.(Early detection of cancer in AYAs Working Group, 2014)

Section 2: Have the best treatment and support during active treatment

AYA with cancer face unique issues associated with privacy, information sharing, sexuality, fertility, education, employment, peer and family relationships and body image.(Decker, 2006; Psychosocial management of AYA cancer patients Working Group, 2014; Wu, Chin, Haase, & Chen, 2009)

Age-appropriate clinical management strategies should be used to support AYA. Key aspects of care which should be addressed include:(Psychosocial management of AYA cancer patients Working Group, 2014)

- maintaining continuity of care
- managing adherence issues
- use of complementary and alternative therapies
- ensuring appropriate boundaries between health professionals and AYA.

Supportive measures for family and significant others are critical to minimise emotional impact and ensure a supportive environment for the AYA with cancer.

Therapeutic relationships with the SCN can facilitate AYA engagement in decision making and treatment.

Section 3: Have the best treatment and support between and after active treatment

AYA who have received treatment for cancer can experience a range of late effects.

AYA may face a transition between paediatric and adolescent services to mainstream adult services in the follow up phases of their cancer journey that can lead to gaps in care. It is important to maintain contact with the young person into survivorship.(Psychosocial management of AYA cancer patients Working Group, 2014)

Section 4: Have the best care at the end of life

The transition for the AYA from curative to palliative care can be challenging for all involved.

Provision of age-appropriate palliative care services must focus on the needs and wishes of the young person, support for family and friends and support of health professionals caring for this group.

Early introduction of services is important so young people have the time to build a trusting relationship with palliative care teams, both hospital and community based.(Psychosocial management of AYA cancer patients Working Group, 2014) The SCN can facilitate open and honest exploration of issues, such as spirituality, meaning and personal goals, while providing optimal symptom control.

Section 1: Find the condition early

Objectives

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

1. Interpret key national and international epidemiological trends in AYA specific to cancer incidence, mortality and survival.
2. Discuss the unique characteristics of AYA and the impact of cancer on this population group.
3. Identify barriers to early detection of AYA cancers.
4. Explain strategies the SCN may use to promote early detection of osteosarcoma in AYA.
5. Implement strategies to provide information, education and support to people undergoing investigation of symptoms of osteosarcoma in the AYA population.

Cancer in AYA in Australia

Cancer in AYAs (adolescents and young adults aged 15-24) accounted for 0.8% of all cancer cases diagnosed in Australia in the period 2010-2014.[63]

The most common cancers affecting AYA in the period from 2010-2014 were melanoma (14.6% of all cancers), gonadal germ cell cancers (13.8%), and Hodgkin lymphoma (13.6%).[63]

In the period 2010 – 2014, five-year relative survival for AYA diagnosed with cancer was 89%, which was significantly increased from 80% in 1983 – 1989.[63]

In the period 2011 – 2015 there were 499 cancer deaths in AYA, comprising 8.8% of all deaths in this age group the leading causes of cancer death were brain cancer, bone cancer, acute lymphoblastic leukaemia, other soft tissue cancers, and acute myeloid leukaemia.[63]

Learning activities		
Completed	Activities	
☐	1	Review Table 2.2: The most commonly diagnosed cancers, 15-24 years, by sex 2010-2014 in Cancer in adolescents and young adults in Australia(PDF, 926KB). AIHW (2018)[63] Summarise the differences in distribution of cancer type related to sex in AYA.
☐	2	Identify your state/territory cancer plans and programs specific to meeting the needs of AYA with cancer.

Impact of cancer in AYA

Adolescence is a time of dramatic change in physical growth, awareness of body image, and concepts of personal and social self.(Ramini, Brown, & Buckner, 2008) AYA affected by cancer have numerous additional challenges and require specific psychological and social support throughout their cancer journey.(Australian Institute of Health and Welfare (AIHW), 2011)

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 stage.(Australian Institute of Health and Welfare (AIHW), 2011; Palmer, Thompson, & Thomas, 2008) Working with AYA affected by cancer necessitates focusing on how normal developmental tasks can be attained while minimising psychological distress.(Eiser, Hill, & Vance, 2000)

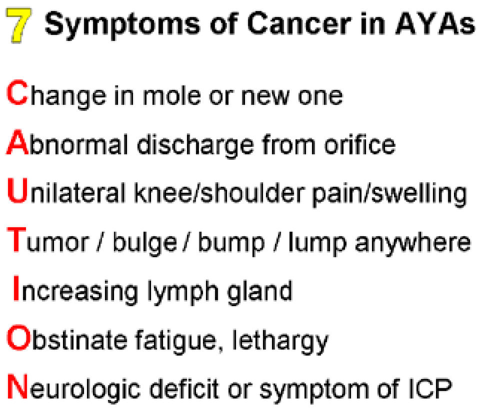
Reactions to a diagnosis of cancer in AYA are complex and affected by family relationships and culture, as well as chronological and psychological development. Any care provided must be multi-dimensional and incorporate the needs of the family. While there is limited research about the needs of AYA families specifically, there is evidence that cancer affects the whole family and that family members can experience significant distress.(Rossi-Ferrario, Zotti, Massara, & Nuvolone, 2003)

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.(Rossi-Ferrario et al., 2003)

Learning activities		
Completed	Activities	
☐	1	Access the Practice framework for working with 15-25 year old cancer patients.(Palmer et al., 2008) Review section 5, page 22. Outline how the factors in AYA development may impact on their cancer journey.
☐	2	Identify local resources available to support AYA and their families to assist with early diagnosis, and consider how these resources are made accessible to AYA.

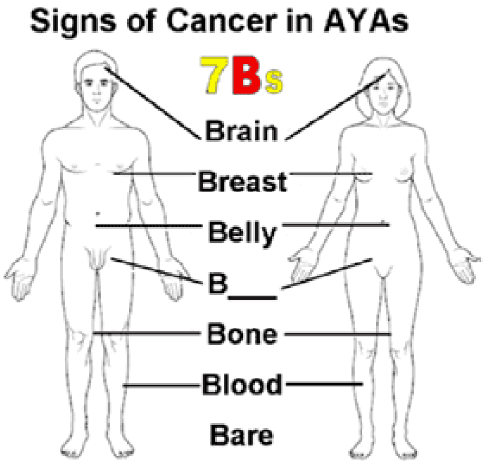
Early detection of osteosarcoma

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.(Early detection of cancer in AYAs Working Group, 2014) The following images highlight key signs and symptoms to be alert for in AYA.



7 Symptoms of Cancer in AYAs

Change in mole or new one
Abnormal discharge from orifice
Unilateral knee/shoulder pain/swelling
Tumor / bulge / bump / lump anywhere
Increasing lymph gland
Obstinate fatigue, lethargy
Neurologic deficit or symptom of ICP



The '7 symptoms' increase awareness of early clues to cancer diagnosis in AYA(A. Bleyer, 2007). (Permission to reproduce images provided by author).

Resource link

Early detection of cancer in AYAs: guidance for general practitioners and primary health care providers. Early detection of cancer in AYAs Working Group (2014)(Early detection of cancer in AYAs Working Group, 2014)

The clinical presentation of osteosarcoma commonly includes localised bone pain over several weeks or months, and a palpable tender soft tissue mass. Pain is often intermittent and symptoms may be confused with growing pains, which may delay thorough investigation.(Klein & Siegal, 2006; National Comprehensive Cancer Network, 2014) There may also be a limp, loss of function, or even decreased range of motion.(Klein & Siegal, 2006)

Osteosarcomas tend to form in areas of rapid bone growth or turnover, such as in the long bones of a developing adolescent.(Klein & Siegal, 2006; Skubitz & D'Adamo, 2007) The most common sites of disease are the femur, tibia and humerus.(Skubitz & D'Adamo, 2007) Incidence of osteosarcoma is higher in males than in females (2.7:1).(Australian Institute of Health and Welfare (AIHW), 2011)

Elevated alkaline phosphate or lactate dehydrogenase may be present and may correlate with poorer prognosis.(National Comprehensive Cancer Network, 2014) Common metastatic sites are the lungs and other bones and overt metastases are present in 10%-20% of individuals at diagnosis.(National Comprehensive Cancer Network, 2014; Skubitz & D'Adamo, 2007)

Several risk factors and other conditions have been associated with increased risk of osteosarcomas, these include:(Skubitz & D'Adamo, 2007)

- prior radiation therapy
- prior antineoplastic agents, particularly with alkylating agents or anthracyclines
- Paget's disease
- chronic osteomyelitis
- Osteochondroma
- Enchondroma
- Fibrous dysplasia.

Diagnostic and staging investigations for osteosarcoma include:(National Comprehensive Cancer Network, 2014; The ESMO / European Sarcoma Network Working Group, 2012)

- X-rays of the involved bone
- magnetic resonance imaging and/or computed tomography of the whole compartment with adjacent joints to evaluate the extent of disease
- bone scan to determine if other lesions are present
- core needle or open biopsy of suspected primary malignant bone tumour to confirm diagnosis prior to any surgical procedure.

Learning activities

Completed	Activities	
☐	1	Review the signs and symptoms which may indicate osteosarcoma, and explain why there may be a delay in diagnosis of this condition in AYA populations.
☐	2	Identify how the developmental achievements across all domains of health that occur in adolescence may be influenced by a diagnosis of osteosarcoma. Use the following resources: • onTrac at PeterMac.(Peter MacCallum Cancer Centre, 2008) Victorian adolescent and young adult cancer service • Strongbonds website: adolescent development section(Strongbonds, 2009)

Case study: meet Justin

Case study: meet Justin

Justin is a 16-year-old male who was recently diagnosed with osteosarcoma.
Watch Justin's first video and work through the accompanying learning activities.

Justin’s story 1: diagnosis

Learning activities

Completed	Activities	
☐	1	Critically discuss the missed opportunities for diagnosis for Justin, and the reasons for these.
☐	2	Discuss the role an SCN may have in addressing these missed opportunities in Justin's case.
☐	3	Identify the symptoms Justin described that might indicate the need for further investigation.

Section 2: Have the best treatment and support during active treatment

Objectives

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

1. Discuss the implications of staging of osteosarcoma for a person's cancer journey.
2. Discuss the key supportive care needs for people diagnosed with and undergoing treatment for osteosarcoma.
3. Discuss current treatment approaches for osteosarcoma.
4. Use evidence-based approaches to facilitate the ability of the person affected by osteosarcoma to participate in decisions about their treatment and care, according to their preferences.
5. Identify the implications of these treatment approaches for the functioning of AYA across all domains of health during the treatment phase and in the longer term.
6. Implement evidence-based interventions to respond to the supportive care needs of people affected by osteosarcoma.
7. Tailor supportive care interventions to an individual's personal, developmental and social circumstances.
8. Discuss options for fertility preservation for AYA affected by cancer.
9. Discuss advantages and disadvantages of specialist treatment facilities for AYA.

Types and staging of osteosarcoma

Osteosarcoma is characterised by the production of osteoid or immature bone by malignant cells.(Skubitz & D'Adamo, 2007) In practice, tumours are typically classified according to stage (localised versus metastatic) and grade (low or high grade). Osteosarcoma is broadly classified into three histologic subtypes (intermedullary (central), surface, and extraskeletal).(National Comprehensive Cancer Network, 2014)

The following osteosarcoma types have been identified:(Klein & Siegal, 2006)

Central

High-grade:

- Conventional
- Telangiectatic
- Small cell
- Epithelioid
- Osteoblastoma-like
- Chondroblastoma-like
- Fibrohistiocytic
- Giant cell-rich.

Low-grade:

- Low-grade central:
    - Fibrous dysplasia-like
    - Desmoplastic fibroma-like.

Surface

Low-grade:

- Parosteal.

Intermediate-grade:

- Periosteal.

High-grade:

- Dedifferentiated parosteal
- High-grade surface.

Intracortical

Gnathic

Extraskeletal

High-grade

Low-grade.

The most common pathologic subtype is high-grade intramedullary osteosarcoma which is the classic or conventional form comprising nearly 80% of osteosarcoma.(National Comprehensive Cancer Network, 2014)

For practical purposes, individuals are divided between those who present without clinically detectable metastatic disease (localised osteosarcoma), and those who present with clinically detectable metastatic disease (metastatic osteosarcoma).(National Cancer Institute (NCI), 2009) Bone metastases are associated with significantly worse survival outcomes compared with metastatic disease confined to the lungs.(Skubitz & D'Adamo, 2007)

The American Joint Committee on Cancer (AJCC) TNM staging classification system is based on assessment of histological grade, tumour size, presence of regional and/or distant metastases.(National Comprehensive Cancer Network, 2014) An outline of the TNM staging system for bone cancer is accessible in the NCCN Guidelines Version 1.2015 Bone Cancer.(National Comprehensive Cancer Network, 2014)

Individuals with suspected osteosarcoma should undergo complete staging prior to biopsy. Principles of management related to biopsy for bone cancer include:(National Comprehensive Cancer Network, 2014)

- biopsy diagnosis is necessary prior to any surgical procedure or fixation of the primary site
- biopsy is optimally performed at a center that will do definitive management
- placement of the biopsy is critical
- biopsy should be core needle or surgical biopsy
- appropriate communication between the surgeon, musculoskeletal radiologist, and bone pathologist is critical
- fresh tissue may be needed for molecular studies and tissue banking
- final pathological evaluation should include assessment of surgical margins and size/dimensions of tumour.

Learning activities		
Completed	Activities	
☐	1	Compare the likely prognosis for people diagnosed with localised osteosarcoma and metastatic osteosarcoma.
☐	2	Compare the physical symptoms and psychological needs that may be common among people newly diagnosed with: • localised osteosarcoma • metastatic osteosarcoma.
☐	3	Develop an education plan to prepare AYA for a bone biopsy procedure.

Health history

Patients name: Justin

Sex: M ☑ F ☐

Age: 16

History: Plain x-rays revealed an active lesion with poorly defined margins and mild periosteal reaction. Soft tissue mass was present.

A diagnostic workup of MRI and bone scan revealed unilateral pulmonary metastases with no distant spread identified.

Full blood picture, ESR (erythrocyte sedimentation rate), Electrolytes, liver function tests, showed no abnormalities. However, alkaline phosphatise and Lactate dehydrogenase (LDH) were elevated.

Biopsy revealed conventional osteosarcoma of the proximal humerus, osteoblastic histological variant - grade 3.

Met with Justin and his parents. Justin presented as a relatively mature young man.

Provided an explanation that he had a type of bone cancer and would need to have some treatment - chemotherapy in hospital for about 10 weeks and then a biopsy to assess response to treatment before going on for surgery and more chemotherapy.

Discussed the option of a multi-centre international clinical trial being conducted through the Children’s Oncology Group (COG) that might be suitable for him. Indicated he would probably receive some high dose methotrexate with leucovorin rescue, doxorubicin and ifosfamide or similar combination.

Side effects of the chemotherapy discussed - alopecia, increased risk of infection, and infertility. Sperm banking discussed. Urgent referral made to the reproductive unit.

Brief surgical discussion covered high probability of limb sparing surgery with wide excision of tumour in humerus. Wedge resection of lung for pulmonary metastases also required. Will discuss in more detail following response to cytotoxic therapy is apparent.

Richard Johns
Oncologist

Learning activities	
Completed	Activities
☐	3 Outline the prognostic and treatment implications of the following findings from Justin's diagnostic testing: • poorly defined margins • mild periosteal reaction with soft tissue mass • unilateral pulmonary metastases • elevated LDH and ALP • conventional osteosarcoma of the proximal humerus • osteoblastic histological variant - grade 3.
☐	4 At 16 years of age, Justin's parents would be involved in the decision making process for treatment of his disease. Outline the legal rights of a 16-year-old in relation to treatment consent and decision making.
☐	5 Discuss how the multidisciplinary team (MDT) could assess Justin's preferences for information and involvement in decision making.

Experience of diagnosis

Establishment of therapeutic relationships with AYA right from the start is critical to establish trust, and to engage AYA and relevant family members in decision making and participation in treatment.

The complex decisions around treatment may place additional stress on the AYA and their family. The SCN can play an important role in enhancing the clinical information provided, in correcting misunderstandings and in helping the AYA and their family to source further information if needed to assist their treatment decision.

Effective communication and information provision for the AYA and family is vital. Points to remember when communicating with children and adolescents about their cancer include:(Ranmal, Prictor, & Scott, 2008)

- communicating about cancer with children and adolescents may help them understand the disease and its treatment and enable them to cope better with their cancer
- children and adolescents face many issues and may benefit from greater opportunities to talk to health professionals
- concerns about their illness and its treatment can result in psychological, behavioural and developmental problems for AYA
- educational programs may benefit adolescents with cancer when individual factors such as age, level of understanding and medical condition have been considered.

AYA have unique medical and psychosocial needs. Improved health outcomes may be achieved through an understanding of the impact of cancer and its treatment on AYA development, including social and emotional wellbeing.

Regular psychosocial assessment and screening have been recommended as methods to identify preventable at risk behaviours and mental health concerns. Interventions such as referral to provide preventative counselling and anticipatory guidance can then be initiated to improve psychosocial outcomes.(Yeo & Sawyer, 2009)

Learning activities

Completed	Activities
☐	1 Access the Psychosocial management of AYAs diagnosed with cancer: Guidance for health professionals,(Psychosocial management of AYA cancer patients Working Group, 2014) and: • Summarise strategies to improve communication with AYA diagnosed with cancer. • Discuss how the SCN can implement these points in clinical practice.
☐	2 Access examples of AYA assessment tools in the following documents: Practice framework for working with 15-25 year old cancer patients(Palmer et al., 2008) Psychosocial assessment for adolescents and young adults with cancer(Yeo & Sawyer, 2009)

	• Discuss the extent to which the tools adequately assess the specific needs of a person diagnosed with and receiving treatment for osteosarcoma. • Compare the extent to which current assessment tools in your workplace adequately assess the supportive care needs of AYA affected by cancer.

Case study

Justin's story 2: dealing with diagnosis

Learning activities

Completed	Activities
☐	6 Consider the immediate practical and emotional needs of Justin's family: • If Justin lived outside the metropolitan region, outline the accommodation and support services available for him and his family. • Identify potential social and financial impacts on the family. • Outline possible responses to meet the family's spiritual needs. • Discuss specific issues that might be experienced by Justin's 10-year-old sibling. Outline support available for siblings.
☐	7 Justin has expressed concerns about what to tell his mates and girlfriend about his cancer. How would you respond to his concerns? The 'relationships' section of the 2beMe website(The Personal Care Products Council Foundation, 2010) may be helpful in formulating a response.
☐	8 Discuss the supportive care options available to Justin at this time. Consider your health care facility resources and external groups and networks which an SCN may refer Justin to.

Fertility preservation for AYA

Cancer treatments can leave individuals at risk of gonadal failure and infertility. Loss of fertility is associated with distress and lowered self-esteem and quality of life in cancer survivors.(Yap & Davies, 2007)

Predicting who will become infertile as a result of specific therapies is difficult due to individual variability in fertility outcomes.(Bashore, 2007) Infertility incidence varies by regimen and may differ between males and females.(Palmer et al., 2008) The extent of dysfunction depends on the agent, dose, length of exposure and age of the individual.

Gonadotoxic antineoplastic agents include:(Bashore, 2007)

- Alkylating agents:
    - Busulfan.
    - Cyclophosphamide.
    - Ifosfamide.
    - Melphalan.
- Nitrosoureas:
    - Carmustine.
    - Lomustine.
- Platinum agents:
    - Cisplatin
- Other:
    - Procarbazine

The impact of ionising radiation on infertility also depends on age at exposure, site and extent and type of radiotherapy.(Yap & Davies, 2007) Radiation doses as low as 1.2 Gy may result in impaired spermatogenesis, and radiation more than 4 Gy will result in complete sterility.(Bashore, 2007) Total body irradiation and high dose pelvic radiotherapy are associated with the greatest risk to fertility.

AYA should receive fertility information early in the diagnostic phase of cancer treatment so they have time to review materials, ask questions, and make a decision.(Bashore, 2007; Palmer et al., 2008) The most effective and established means of preserving fertility in young people with cancer includes:(AYA cancer fertility preservation guidance working group, 2014)

- oocyte and embryo cryopreservation where appropriate for females
- sperm cryopreservation for males before cancer treatment starts.

Inclusion of health professionals with reproductive fertility expertise in multidisciplinary teams has been suggested to promote access to fertility preservation.(Palmer et al., 2008)

Private conversations with AYA are recommended to allow adolescents to ask questions they might be uncomfortable asking in their parents' presence.(Bashore, 2007)

Barriers which prevent fertility preservation at time of diagnosis include:(Bashore, 2007)

- lack of time
- health professionals' failure to discuss risks to fertility
- cost of preservation
- significant parental anxiety at diagnosis.

Resource link

Fertility preservation for AYAs diagnosed with cancer: guidance for health professionals.(AYA cancer fertility preservation guidance working group, 2014) AYA cancer fertility preservation guidance working group (2014)

Livestrong fertility. Livestrong Foundation

Long Term Side Effects of Cancer Treatment – Information. Canteen

For males

Antineoplastic agents affect testicular function by damaging somatic and germ cells, resulting in reduced sperm production. Permanent sterility has been reported in men receiving more than 7.5 g/m2 BSA total dose of cyclophosphamide for sarcomas.(Longhi, Macchiagodena, Vitali, & Gaetano, 2003)

Radiation doses as low as 1.2 Gy may result in impaired spermatogenesis, and radiation more than 4 Gy will result in complete sterility.(Bashore, 2007)

Some men may change from azoospermic to oligospermic or normospermic after several years, but this is unpredictable and not reliable.(Longhi et al., 2003)

Sperm donation is a highly effective method of preserving fertility.(Yap & Davies, 2007) Most commonly collected through masturbation, the semen is processed and cryopreserved. Semen preservation success rates of between 42% and 64.5% have been reported.(Bashore, 2007) More invasive methods of semen collection include epididymal sperm aspiration, penile vibration and electroejaculation.(Bashore, 2007)

Resource link

Fertility preservation for adolescent and young adult males.(Andrology Australia, 2013) Andrology Australia (2013)

For females

Antineoplastic agents and radiotherapy speed up the loss of follicles, and bring forward the onset of menopause in females. Ovarian atrophy and a marked loss of the primordial follicle pool are seen on histological examination.(Yap & Davies, 2007)

Pelvic and abdominal irradiation poses the greatest threat to the ovaries. Irradiation at 6 Gy may cause irreversible ovarian failure, and doses at 2 Gy may halve the oocyte population. Radiotherapy damage, such as impaired uterine growth and blood flow, may also lead to later obstetric complications such as early pregnancy loss, low birth weight, and premature labour.(Yap & Davies, 2007)

Gonadotoxicity in females may be acute and cumulative and the potential of ovarian recovery is unpredictable. It is known that advancing age is a major disadvantage, and is related to ovarian reserve.(Yap & Davies, 2007)

Currently, there are no proven methods of protecting ovarian function from the effects of antineoplastic agents or radiotherapy, other than to surgically remove the ovaries from the irradiated field.(Stern, Toledo, Gook, & Seymour, 2006)

There is some evidence that gonadotropin-releasing hormone (GnRH) agonists may play a role in protecting ovarian function from antineoplastic agents, but this is yet to be established.(Bashore, 2007; Palmer et al., 2008)

Embryo cryopreservation is a viable technique but is only available for women in a stable relationship or for those who consider sperm donation. Due to the need for ovarian hyperstimulation for egg recovery, this method is contraindicated in the case of cancers which are hormone-sensitive.

Oocyte cryopreservation also requires ovarian hyperstimulation but offers a chance for AYA without partners to preserve fertility. Ovarian harvest and autologous transplantation has shown resumption of ovarian endocrine function and follicular development. More research is needed in this area.(Bashore, 2007)

Learning activities		
Completed	Activities	
☐	1	Using the following headings, outline how the following factors would be considered in determining eligibility for fertility preservation. • Age. • Tanner stage. • Disease. • Prognosis. • Treatment modality.
☐	2	Access Fertility preservation for AYAs diagnosed with cancer: guidance for health professionals.(AYA cancer fertility preservation guidance working group, 2014) • Discuss options that would be available for fertility preservation for Justin prior to treatment for osteosarcoma. • Describe the role of a fertility counsellor and their function within the MDT.

Treatment approaches for osteosarcoma

Initial treatment of osteosarcoma aims to achieve a good clinical response, as evidenced by reduction of pain and discomfort, restoration of function, return of temperature of overlying skin to normal, and reduction in the soft tissue component of the tumour.(Rytting et al., 2000)

The choice of surgical management and adjuvant antineoplastic agent regimen are most critically influenced by histologic response to neo-adjuvant therapy.

Histologic response is defined as the proportion of tumour cell kill determined on biopsy or resection. A good histologic response is reported as greater than 90% necrosis in the specimen collected and combined with a clinical response lends to a favourable outcome in terms of long-term prognosis and the possibility of limb-sparing surgery.**(Hinshaw & Fink, 2007)**

Principles of surgical management of bone cancer include:(National Comprehensive Cancer Network, 2014; The ESMO / European Sarcoma Network Working Group, 2012)

- safe removal of tumour
- preservation of as much function as possible
- adequate surgical margins to reduce risk of local recurrence.

Local tumour control may be achieved by either limb-sparing resection or limb amputation. Benefits of limb-sparing surgery (LSS) include the advantage of retention of function and less body mutilation than with primary amputation. However, these benefits are balanced against the potential for longer hospitalisation due to infection, repeated prosthesis lengthening for young individuals, and increased risk of local recurrence if the LSS results in poorer cancer control locally.

Evidence is mixed about whether LSS results in improved quality of life over amputation. However, body image and everyday functional competence were better in individuals following LSS.(Eiser, Darlington, Stride, & Grimer, 2001) Amputation is generally reserved for individuals with tumours in unfavourable anatomic locations precluding limb-sparing surgery.

Metastatic disease confined to the lung may also be considered for surgical management. Complete surgical resection of lung metastases offers possibility of cure in up to one-third of individuals.(Skubitz & D'Adamo, 2007) Individuals who are not surgical candidates may be offered palliative chemotherapy.(Skubitz & D'Adamo, 2007)

Irrespective of surgical management, poor prognostic factors include metastasis at presentation and poor histologic response to preoperative chemotherapy.

Other factors that may contribute to poor prognosis include large tumour volume, older age, axial tumour location, presence of pathologic fracture and local recurrence after surgery.(Kim, Cho, Song, Lee, & Jeon, 2007)

Disease-free survival rates at five years are 10-30% for individuals who present with metastatic disease only in the lungs, and who achieve a complete response to antineoplastic agents in addition to total resection of tumour. Survival rates increase to 50-70% when current multi-agent chemotherapy regimens are used.(Skubitz & D'Adamo, 2007)

Osteosarcomas are considered relatively radiation resistant,(Skubitz & D'Adamo, 2007) though radiotherapy may play a part in palliative or supportive care.(National Comprehensive Cancer Network, 2014; The ESMO / European Sarcoma Network Working Group, 2012)

Learning activities	
Completed	Activities
☐	1 Summarise the impact across all domains of health of limb amputation in AYA.
☐	2 Access the NCCN Guidelines Version 1.2015 Bone Cancer.(National Comprehensive Cancer Network, 2014) (Free resource, but you must register and then click 'Remember me' to bypass the login page in future). • Identify the indications for neoadjuvant antineoplastic agents for osteosarcoma.
☐	3 For each of the following drugs commonly used in protocols to treat osteosarcoma: • Methotrexate (high dose). • Doxorubicin. • Cisplatin. • Ifosfamide. a. Identify the classification of the drug. b. Discuss potential short and long term toxicities associated with the drug. c. Explain the nursing interventions to prevent, detect early and manage these toxicities. d. Identify other nursing considerations associated with administering these drugs.

Cancer clinical trials and AYA

Advances in cancer treatment in relatively rare AYA cancers rely on global collaboration and research consortiums. Organisations such as the Children's Oncology Group (COG) and institutional partnerships are critical in the global effort to learn more about AYA cancer, to disseminate best evidence in clinical management, and to facilitate and coordinate clinical trials.

Internationally, participation in clinical trials has been identified as important to improved outcomes, particularly for AYA affected by sarcoma, yet AYA are included much less in clinical trials than younger children.(Australian Institute of Health and Welfare (AIHW), 2011; Bleyer, 2006; Pentheroudakis & Pavlidis, 2005)

It has been reported that AYA affected by bone and soft tissue sarcomas in Victoria were significantly less likely to be included in clinical trials than children. Participation in clinical trials for 15-20 year olds was 4% (survival rate 52%) and for 10-15 year olds 33% (with 80% survival).(Mitchell et al., 2004)

Learning activities

Completed	Activities	
☐	1	Identify why few AYA participate in clinical trials. Discuss how this situation can be improved.
☐	2	Access the following sites to identify possible trial opportunities for Justin: • Australian New Zealand Clinical Trials Registry • Clinical trials section of the U.S. National Cancer Institute website

Supportive care needs

Due to AYA developmental stage and the impact of a diagnosis of cancer and its management, AYA have distinct supportive care needs across all domains of health which require access to multidisciplinary supportive care expertise throughout the cancer journey. The following list highlights some of these needs and responses:(Palmer et al., 2008)

- A designated AYA key worker is an integral member of the MDT providing consistency, advocacy, advice and support to navigate health services. They can promote a holistic approach and are identified as central to the coordination of care.
- A preventive approach to psychosocial support, involving regular assessments, rather than crisis intervention is promoted. Lack of psychosocial support during and after treatment has been identified as a potential factor in the lower levels of treatment adherence among AYA compared with other age groups.
- Age-appropriate assessment tools should be used to improve understanding of AYA oncology, psycho-oncology and supportive care needs.
- Assessment of the AYA and people affected by AYA cancer is necessary to identify their information, practical, support, financial, educational or employment needs. Screening assessment should occur regularly at significant points of the cancer journey.
- Families have a key role in the care of AYA. The involvement of family and parents in the care of AYA must be negotiated and reviewed during all stages of care.
- Knowledge of normal behaviours and responses that accompany the AYA developmental stage are crucial when evaluating the impact of the illness on the young person, the appropriateness of their responses and the need for additional supportive care.
- Addressing schooling, education and training needs can assist the AYA to maintain normality, provide a focus for the future, reduces the workload on completion of treatment and maintains links with peers.
- Diagnosis and treatment may have a negative impact on some peer relationships. AYA may require support to manage these important relationships.
- Age-appropriate mental health interventions are required.
- Boundaries around expected behaviour in hospital should be set as early as possible.
- Maintenance of a reasonable quality of life may be achieved through promoting normality. AYA need to continue to achieve developmental tasks, and to participate in milestones. Showing flexibility and an understanding of the importance of these parts of the young person's life helps to support adherence and encourages trust.
- AYA have spiritual and existential needs due to their developmental stage and as a response to a cancer diagnosis.
- The provision of nutritional advice can assist in recovery, improve general quality of life and wellbeing, and reduce the likelihood of ongoing nutritional problems.

Resource links

Psychosocial management of AYAs diagnosed with cancer: Guidance for health professionals.(Psychosocial management of AYA cancer patients Working Group, 2014) Psychosocial management of AYA cancer patients Working Group (2014)
Redkite
Canteen

Learning activities	
Completed	Activities
☐	1 Access Improving outcomes with children and young people with cancer(National Collaborating Centre for Cancer, 2005) and: • List the roles of the 'key worker'. • Outline an example of each of these roles of the 'key worker' in practice.
☐	2 Summarise current evidence about supportive care strategies to respond to the following issues faced by AYA due to treatment- related effects of osteosarcoma: • body image • sexuality • peer and family relationships.

Challenges in the management of AYA affected by cancer

Adherence

Non-compliance, refusal and abandonment of treatment are commonly reported challenges to the management of care for AYA.(A. Bleyer, 2007) Rates of non-adherence in AYA with chronic medical conditions are estimated between 7% and 60%.(Butow et al., 2010) It is suggested that the following factors may be associated with adherence in AYA populations:(Kennard et al., 2004)

- Developmental task of gaining independence from the family may impact the ability of the adolescent to accept the control from authority figures.
- Parent-child agreement on issues around medication has been correlated with better adherence in the oncology population.
- Self-esteem, denial, social maladaptation, emotional problems and psychiatric illness influence adherence.
- Depression and depressive symptoms associated with non-adherence.
- Mood may influence adherence even in subclinical ranges.
- Higher self-esteem associated with higher adherence.
- Parent-child conflict associated with disruption to adherence.
- Strong family organisation and supportiveness, such as coordination in planning and achieving regimen goals, promotes adherence.

Key practice points for managing adherence issues with AYA include:(Psychosocial management of AYA cancer patients Working Group, 2014)

- roactively identify potential non-adherence with treatment regimens
- identify the main issues for the individual and work together to address them.

An overview of evidence related to the management of adherence can be accessed in the Psychosocial management of AYAs diagnosed with cancer: Guidance for health professionals.(Psychosocial management of AYA cancer patients Working Group, 2014)

AYA and experimentation

The use of recreational drugs presents an important and under-recognised issue in AYA cancer care. Young people between 20 and 29 years consistently record the highest use across a number of illicit drugs in the community and those between 14 and 19 closely follow.(Ross, 2007)

In addition to illicit drug use, young people are at a high risk of alcohol abuse (in the form of binge drinking) and of cigarette smoking. Problems associated with drug withdrawal may occur for AYA receiving cancer treatment. Drug use may reduce adherence to treatment or it may directly increase sensitivity to medications.(Palmer et al., 2008)

An overview of evidence related to the management of alcohol and drug use during treatment can be accessed in the Psychosocial management of AYAs diagnosed with cancer: Guidance for health professionals.(Psychosocial management of AYA cancer patients Working Group, 2014)

Learning activities		
Completed	Activities	
☐	1	Discuss how you would assess the needs or preferences of an AYA in relation to drug and alcohol use or other taboo or illicit activities.
☐	2	Describe factors which may contribute to non-adherence to the treatment regimen.
☐	3	Formulate interventions that can be implemented to encourage AYA adherence to recommended treatment regimen.

Care delivery models

Considerable controversy exists about whether to manage AYA with cancer at paediatric or adult facilities. AYA have unique needs that require tailored services which are currently inadequately met in adult and paediatric oncology settings.(Pentheroudakis & Pavlidis, 2005)

Evidence suggests that cancers most common in the AYA group are more like childhood cancers in terms of their biological reactions and responses to treatment.(A. Bleyer, 2007) However, when considering the most appropriate treatment facility for an individual, consideration must be given to the ability of the unit to provide appropriate psychological and social support to the AYA.(Palmer et al., 2008; Pentheroudakis & Pavlidis, 2005)

It has been suggested that AYA oncology units offer an ideal environment for treatment, multidisciplinary interaction, skilled nursing care, individualised psychosocial support, and coordinated clinical research.(Pentheroudakis & Pavlidis, 2005)

Improved outcomes in AYA cancer have been associated with care provided in facilities with a high volume of similar caseloads annually.(Pentheroudakis & Pavlidis, 2005)

Improved survival rates have been demonstrated in health facilities with specialty caseloads in the AYA groups being treated for germ cell tumours, Hodgkin's lymphoma, sarcomas, and for bone marrow transplantation.(Hillner, Smith, & Desch, 2000) The effect is particularly clear for surgical expertise where the impact of caseload on short-term outcomes is large.(Hillner et al., 2000) The reasons for this relationship are complex and multifactorial.

Key resources

South Australian Adolescent and Young Adult Cancer Care Pathway. Department of Health, Government of South Australia (2009)(Adolescent and Young Adult Working Party of the Statewide Cancer Clinical Network, 2010)
National Service Delivery Framework for Adolescents and Young Adults with Cancer. Cancer Australia & Canteen (2008)(Cancer Australia & CanTeen, 2008)

Learning activity	
Completed	Activity
☐	1 Access the following resources and discuss key features that have been identified in care delivery models to optimise outcomes for AYA. • National Service Delivery Framework for Adolescents and Young Adults with Cancer. Cancer Australia & Canteen (2008)(Cancer Australia & CanTeen, 2008) • Steps forward: towards a service delivery improvement framework for adolescents and young adults with cancer. Cancer Forum (2009)(Hanson, Hunt, & Merz, 2009)

Section 3: Have the best treatment and support between and after active treatment

Objectives

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

1. Examine the supportive care needs of people affected by osteosarcoma in AYA between and after active treatment.
2. Implement evidence-based clinical and supportive care nursing interventions for people affected by AYA cancer between and after active treatment for osteosarcoma.
3. Collaborate with other care providers to ensure a coordinated, planned and documented approach to meeting supportive care needs for people affected by AYA cancer.

Following treatment

Long-term follow up is essential to ensure adherence to health promotion activities, timely diagnosis of relapse, and prevention of related or unrelated comorbidities. (National Comprehensive Cancer Network, 2014)

Current NCCN guidelines recommend that surveillance following treatment for osteosarcoma should occur every three months for two years, then every four months for year three, and then every six months for years four and five.(National Comprehensive Cancer Network, 2014) Yearly assessments follow.(National Comprehensive Cancer Network, 2014) The NCCN guidelines recommend that a personalised 'survivorship prescription' is given to those finishing treatment, to schedule comprehensive follow up with a multidisciplinary team.(National Comprehensive Cancer Network, 2014) Follow up includes physical examination, functional assessment, chest imaging and plain film of the extremity affected by osteosarcoma.(National Comprehensive Cancer Network, 2014)

One of the major issues for AYA on completion of treatment is a loss of continuity, as their medical care changes from active treatment to surveillance.

The following recommendations have been made for the provision of effective survivorship care for AYA:(Palmer et al., 2008)

- encourage a continuing relationship with the primary oncologist
- provide monitoring of survivors for late effects
- develop written survivorship care plans
- provide supportive care options
- conduct regular assessments
- provide AYA with a complete treatment summary
- help the young person to reintegrate
- prepare AYA for returning to school
- provide opportunities for young survivors to meet each other.

Due to the limited research in the AYA population, information on survival issues is based primarily on research with children who survive cancer. The substantial long-term impacts of cancer on AYA survivors include employment and vocational training, relationships, and late effects of treatment.(Palmer et al., 2008; Pentheroudakis & Pavlidis, 2005)

Long-term effects following treatment in AYA include impairment of endocrine function (including for some people infertility, abnormal growth and development or bone mineral accretion), cardiac and neurological impairment, cognitive decline (for example, following treatment for tumours of the CNS), psychological effects, and increased risk of developing a second cancer.(National Institute of Health and Clinical Excellence (NICE), 2005) The incidence of second cancers in AYA treated for sarcomas has been reported at just under 20%. The most common second cancer in childhood osteosarcoma survivors was breast cancer (in females), skin cancers, gastrointestinal cancers, and thyroid cancer.(Nagarajan et al., 2011)

Learning activities	
Completed	Activities
☐	1 Access Practice framework for working with 15-25 year old cancer patients(Palmer et al., 2008). Review section 12, on page 61. • Discuss how the recommendations could be implemented within your health facility.

☐	2	Summarise the implications of the sense of uncertainty experienced by AYA affected by cancer.

Justin's blog

Hi again!! Not much to do sitting around at home. I'd be lost without my computer. At least I can surf the net, even if I can't surf the waves ;-) It's a really good place to get things off my chest and to hear that I'm not alone. Sometimes it's hard to relate to my mates who are getting on with things while I'm stuck here.

A lot's happened in the last six months, since the chemo. I was in and out of hospital so many times. Just before the op (managed to keep the arm and they took a chunk of lung (wedge resection for the purists out there!)) I went on a new members camp with CanTeen.

I wasn't sure what to expect at first, maybe a bunch of kids sitting around moaning, but I was heaps wrong!! There was some of that you know, sitting around and talking, but the others on camp, they understood, they've been through it too and really understand what it's like. I made heaps of new friends, and the activities were really sick, like canoeing and swimming and games. Wish Soph could have been there.

I haven't heard from my buds Liam and Brett in a while. They're busy with stuff I suppose. Don't think they really understand; when they came over to my house last time they didn't seem to know what to say, just heaps of stupid stuff that doesn't seem to matter much anymore. So much has changed, I've changed. Going through cancer treatment is like nothing they would know about or want to know about.

I'm still pretty tired, tired of feeling sick, tired of being cooped up and guess what...the doc says I can't play sport anymore or lift anything heavy with my left arm. Sport's my life, it can't be true!!

Between that and Mum and Dad - ahhhhh! They mean well but what about what I want, it's my life isn't it? Things haven't been so bad between them lately. The social worker and them sat down and sorted some stuff out with them. FINALLY...

And school, I've missed so much school between being in hospital and low counts after the chemo. I did go back for a few days, but some jerk made a comment about me being bald and how he reckons you can 'catch' cancer so he didn't want to come near me. I don't think he was alone though 'cause no-one really came near me. Makes you think about who ya real friends are. Even after all that, I actually miss school, a little, how am I going to catch up? There was an auto repair TAFE subject I'd been thinking about before I got sick. Now I don't know what I'll do.

Hey, you know it's all happening for Soph, she's got an apprenticeship as a hairdresser. It's awesome!! She's been so supportive, the whole time I've been sick - she's moving in soon. Well she's been around here so much lately, it makes sense.

Don't know what's going to happen in the future - I worry about whether the cancer will come back? Does anyone else think like that?

Learning activities		
Completed	Activities	
☐	1	Describe supportive care responses which could be implemented to meet Justin's needs related to his uncertain future.
☐	2	Discuss the benefits of AYA keeping a diary, such as Justin's blog, during their cancer journey.

Section 4: Have the best care at the end of life

Objectives

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

1. Analyse the SCN's role in facilitating the transition to palliative care for people affected by AYA cancer.
2. Analyse the supportive care needs of people with advanced and progressing osteosarcoma and their family and carers across all domains of health.
3. Liaise with all members of the MDT to promote the exchange of appropriate information to ensure that the needs of AYA and their families are addressed.
4. Provide people affected by AYA cancer with age appropriate information to enable them to understand treatment options and make informed decisions about interventions for their end of life care.
5. Discuss the impact an AYA's death would have on family and friends and suggest appropriate supportive interventions.

Transition to palliative care

It is estimated that:(Decker, Haase, & Bell, 2007; Short, Vassey, & Moran, 2008)

- in developed nations, 10 out of every 10,000 children aged 0-19 will require palliative care
- approximately 5300 Australian 0-19-year-olds face life-limiting illnesses, with up to half of these people requiring a pro-active approach to palliative care.

A specialised approach is required for the care of AYA at the end of life.

The transition from curative to palliative care for all people requires support and understanding. Life-threatening illness, with its effect on body image, mobility, independence, decision-making and peer interactions, impacts significantly on adolescence.(Hynson, Gillis, Collins, Irving, & Trethewie, 2003)

AYA dying of cancer will present those caring for them with a unique set of challenges that revolve around managing an individual's symptoms; supporting families that are often burdened with care of other children and changes to work and finances; along with the significant challenges associated with communicating in a developmentally sensitive way.

Everyone involved in the care of the AYA who is dying will be affected by it. The involvement of a specialist paediatric/AYA palliative care team is crucial.(Hynson et al., 2003)

"The challenge of palliative care for young adults is to recognise and support the child with little experience of life as an adult, yet at the same time facilitate their transition to an adulthood that may never be achieved."(George & Craig, 2009)

Practice points identified in clinical practice guidelines include:(Psychosocial management of AYA cancer patients Working Group, 2014)

- Focus on the needs and wishes of the young person
    - Involve the young person in decision-making and where possible support them to die in their place of choice.
    - Maintain continuity of care and ensure continuing availability of psychosocial support.
    - Ensure optimal clinical symptom management including existential symptoms and anticipatory grief.
- Support family and friends
    - Provide information about what to expect and sources of psychosocial support to the young person’s family members, partner and friends.
    - Ensure a knowledgeable health care professional provides information on signs and symptoms of the dying process.
    - Provide and recommend grief support prior to, as well as at the time of, the young person’s death.
    - Develop a bereavement plan for family members for 1 to 2 years following the young person’s death.
    - Encourage continuing peer interaction and support.
- Support health professionals
    - Ensure appropriate support and supervision is available for staff caring for AYA patients.

Resource link

Journeys: palliative care for children and teenagers.(Palliative Care Australia, 2010) This resource is designed for parents and carers of children and teenagers with a life-limiting illness.

Adolescents and Young Adults (AYA) webpage. CareSearch. 2014

Learning activities

Completed	Activities
☐	1 Examine factors that would facilitate or hinder the transition to palliative care for a person with metastatic osteosarcoma.
☐	2 Discuss barriers to referral to palliative care in AYA.
☐	3 Access Journeys: palliative care for children and teenagers(Palliative Care Australia, 2010) • Outline practical information that could be used to support and provide information for AYA and their families.

Health history

Patients name: Justin

Sex: M ☑ F ☐

Age: 17

History: Six months after the completion of adjuvant therapy and 15 months after diagnosis, 17-year-old Justin visited his general practitioner.

He had been experiencing intermittent pain in his chest and back, breathlessness after a short amount of physical activity, and was generally tired.

Investigations revealed lesions in both lungs and thoracic spine, which biopsy confirmed as recurrent osteosarcoma.

Case study

In this video, Justin's disease has progressed. He's angry and fearful of what's to come.

Justin's story 3: disease progression

Justin's story 4: treatment

In this video, Justin talks about the treatment, his feelings about Sophie, and his parents.

Learning activities

Completed	Activities
☐	1 Referring to literature on grief responses, identify the common responses of Justin and his family and friends to his disease progression.
☐	2 Discuss strategies the SCN could use to assess and support the grief responses experienced by Justin's family and friends.
☐	3 Discuss the SCN's role in assisting Justin to define and achieve goals at the end of his life.

Case study

In this video, Justin expresses his wish to leave hospital and return home.

Justin's story 5: end of life

Learning activities

Completed	Activities
☐	1 Access Family meetings in palliative care: multidisciplinary clinical practice guidelines(Hudson, Quinn, O'Hanlon, & Aranda, 2008) • Develop a plan for a family meeting with Justin and his family to discuss his discharge home. Identify: • the issues you will discuss • the needs of Justin's family and friends • which clinicians would need to be involved.
☐	2 In planning Justin's discharge home, discuss: • which services he'd need to be referred to • who'd need to be notified • what specific plans would need to put into place.

Health history

Patients name:	Justin
Sex:	M ☑ F ☐
Age:	17
Notes:	Justin's care has been managed at his father's house for the last three weeks. A roster was developed so there was an adult carer at home with Justin at all times. Justin's pain has increased and his dyspnoea is worsening. The community nurse and general practitioner, in collaboration with the palliative care team, started a syringe driver which is titrated to manage Justin's symptoms. Justin was restless and appeared distressed to his family as he started to lose consciousness. Justin's mother and Sophie were extremely upset, and the family felt that they could no longer manage his care at home. An ambulance was called to transfer Justin back to hospital.

Case study

In this video, specialist cancer nurse Anne talks about the impacts of Justin's cancer.

Justin's story 6: impact on family

Learning activities

Completed	Activities	
☐	1	Consider how Justin and his family may have been more effectively supported and prepared to manage Justin's death at home.
☐	2	Review the literature to outline the common concerns and needs experienced by siblings such as Cameron when death is imminent. How can the SCN respond to the needs of siblings at this time?

Self-care and the specialist cancer nurse

Healthcare workers participating in cancer control efforts face an increased risk of stress or compassion fatigue.(Barnard, Street, & Love, 2006; Barrett & Yates, 2002; Girgis & Hansen, 2007)

Causes of stress may include: (Barnard et al., 2006; Girgis & Hansen, 2007)

- complex healthcare states and comorbidities
- the high level and intensity of interpersonal relationships
- increasing acuity
- individuals' expectations of care
- technological advances requiring increasingly sophisticated nursing skills
- decreased length of hospital admission
- the necessity of dealing with the dying process.

In palliative care, unique factors may magnify the risk of compassion fatigue. These include:(CareSearch, 2011)

- accumulated losses
- emotionally charged care
- sustained and exclusive focus on terminal illnesses and terminal care
- mortality issues of the clinician (existential, spiritual, or personal).

The clinical importance of compassion fatigue has been highlighted through its impact on outcomes such as:

- increased medical errors(West et al., 2006)
- increased turnover and absenteeism(Williams et al., 2001)
- decreased quality of care(Shanafelt, Bradley, Wipf, & Back, 2002)
- decreased satisfaction expressed by recipients of care(Vahey, Aiken, Sloane, Clarke, & Vargas, 2004)
- significant impact which burnout has on the professional and personal lives of affected personnel.

Protective practices for health care professionals are recommended to:(CareSearch, 2011)

- help compartmentalise work from the rest of life - identify ways to leave the job behind
- clarify and support staff in establishing professional boundaries
- promote emotional and physical health
- include regular self-care techniques for managing stress.

Resource link

Subjective Experiences of Coping Among Caregivers in Palliative Care. OJIN: The Online Journal of Issues in Nursing, 2013(Uren & Graham, 2013)

Reflecting on the Concept of Compassion Fatigue. OJIN: The Online Journal of Issues in Nursing, 2011(Sabo, 2011)

Case study

In this video, Anne describes Justin's condition at the end of his life.

Justin’s story 7: end of life

Learning activities

Completed	Activities
☐	1 Reflect on a situation where a person has asked if medication administered to their loved one will hasten death. • How did you respond? • Discuss evidence-based communication strategies you might use in this situation.
☐	2 Access self-care resources in the following link: • CareSearch(CareSearch, 2011) Discuss strategies nurses could implement to protect themselves from workplace stress and burnout.
☐	3 Outline the role of a bereavement care plan to support relatives and friends of the deceased.
☐	4 Describe strategies that may be implemented within a bereavement plan.

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