THE UNIVERSITY OF QUEENSLAND
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Teaching Palliative Care to Occupational Therapy Students:

Development of Learning Resources

Final Report

Report to the Palliative Care for Undergraduates Project Team

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Acronyms used in this report and their full form

Acronym	Full title
ANZCOTE	Australian and New Zealand Council for Occupational Therapy Education
BSSERC	Behavioural & Social Sciences Ethical Review Committee
CIT	Institute of Technology
DOHA	Australian Government Department of Health and Ageing
DVD	Digital Versatile Disc
FTE	Full Time Equivalent
GP	General Practitioner
MREC	Medical Research Ethics Committee
OT	Occupational Therapy
PC	Palliative Care
PC4OTS	Palliative Care for Occupational Therapy Students
PCC4U	Palliative Care Curriculum for Undergraduates
PDF	Portable Document Format
SPSS	Statistical Package for Social Sciences
UK	United Kingdom

Executive Summary

This report has been prepared for the Australian Government Department of Health and Ageing, the Palliative Care Curriculum for Undergraduates (PCC4U) Project team, and for those health professionals interested in the teaching of palliative care to undergraduate occupational therapy (OT) students. It details the process and outcomes of a project entitled:

"Teaching Palliative Care to Occupational Therapy Students: Development of Learning Resources".

This project commenced when a team within the Division of Occupational Therapy at The University of Queensland, Australia, received funding from the Australian Government Department of Health and Ageing (DOHA) through the Palliative Care for Undergraduates (PCC4U) Project, to develop teaching resources to support the education of occupational therapy students in the field of palliative care. The fundamental aim of the project was to develop resources to facilitate teaching of occupational therapy-specific knowledge and skills to undergraduate students in the field of palliative care.

The project sought to develop a problem-based learning resource incorporating case studies and a powerpoint presentation. It was envisaged that this resource could then be employed in a range of teaching situations including didactic teaching and problem-based learning approaches (e.g., asking students to develop a comprehensive OT care plan in palliative care; team problem solving). The opportunity to provide an inter-professional education component where students are required to consider the roles of multiple professionals in the field was also recognised. The portability of resources to ensure use of the information by occupational therapy schools regardless of geographic location was a fundamental consideration.

The following broad project goals were developed:

- Form a Project Research Team with overarching responsibility for the direction and monitoring of the project and meet on a regular basis to ensure the progress of the project;
- Explore and develop a broad understanding of the occupational therapy role in palliative care;

- Develop teaching materials for training in palliative care, including PowerPoint presentations, with detailed instructions of session content and activities, case materials for problem-based learning, self-exploration stimuli, and resources for further reading.

In line with these goals, it was anticipated that materials emerging from this project would include:

- A document summarising resources utilised by Australian occupational therapy schools to teach palliative care and indicating preferences for additional resources
- Powerpoint resources to facilitate teaching of palliative care to occupational therapy students
- **Two** comprehensive case studies – one paediatric and one adult – provided in hard and soft copies
- Photographs for inclusion in powerpoint presentations
- Sound and/or video recordings of interviews with key people in the field of palliative care
- Information from occupational therapists presently employed in the field of palliative care.

General Project Outcomes

Resources developed in association with this project include:

- A DVD portraying a range of interview vignettes with clinicians in the field for use in training;
- A collection of photographs for use in training;
- A powerpoint sequence for use in training;
- A bibliography of literature specific to occupational therapy in palliative care, and
- **Five** clinical case studies representing a range of aspects common to work as an occupational therapist in palliative care.

Future Development of this Initiative

At the conclusion of this project the team has developed several recommendations that will support the future development of this initiative. These include:

1. Provision of the package to occupational therapy education programs in state-wide, interstate and international locations.
2. Encouraging use of the materials in the undergraduate and postgraduate training of occupational therapists.
3. Ensuring that occupational therapists new to services where palliative care is provided are aware of the training package and are able to access the package.
4. Obtaining evidence of positive outcomes of implementation of the training package.
5. Dissemination of outcomes of the surveys conducted, in terms of published papers in professional journals.
6. Dissemination of outcomes of later evaluation of the provision of training using this package, in terms of conference presentations.

Introduction

Background to the Project

In the past, palliative care has represented a small part of the teaching curriculum in occupational therapy undergraduate programs. More recently, teaching staff at the University of Queensland have acknowledged the importance of educating students in the field of palliative care, and content input in this program has increased since 2006. This increase has been greatly supported by the availability of "Palliative Care: A learning resource of health care students" developed by the National Palliative Care Program team.

While the availability of this program has assisted students in developing a basic understanding of the general field of palliative care, elaborating on this learning has been hindered by the lack of occupational therapy-specific resources and case studies.

Project Description

The "Teaching Palliative Care to Occupational Therapy Students Project" sought to develop a set of tailored resources aimed at supporting occupational therapy students to understand the occupation therapy-specific role in palliative care. It was proposed that funding be applied to the development of a problem-based learning resource which could incorporate at least two detailed case studies, and might then be employed in a range of teaching situations, including didactic teaching and problem-based learning approaches (e.g., asking students to develop a comprehensive OT care plan in palliative care; team problem solving). The opportunity to provide an inter-professional education component where students are required to consider the roles of multiple professionals in the field, or to work in a multidisciplinary student team to determine a comprehensive care plan, was also recognised.

It was proposed that the person engaged to undertake this project liaise with other occupational therapy schools in Australia to identify and collate the resources utilised to teach palliative care, and to obtain suggestions about new teaching material that might be valuable to them. The opportunity to find out about the perceived training needs of occupational therapists working within this field was also identified.

Project Aim

To develop an accessible training program, with accompanying set of resources, which encourage an understanding of the occupational therapy-specific role, as well as the opportunity to gain a greater understanding of the roles of the interdisciplinary team, involved in care of those with serious and life limiting health conditions.

In achieving this aim the project aimed to develop:

- A document summarising resources utilised by Australian occupational therapy schools to teach palliative care and indicating preferences for additional resources
- Powerpoint resources to facilitate teaching of palliative care to occupational therapy students
- Two comprehensive case studies – one paediatric and one adult – provided in hard and soft copies
- Photographs for inclusion in powerpoint presentations
- Sound and/or video recordings of interviews with key people in the field of palliative care
- A document summarising the present roles, recommendations and training needs of occupational therapists presently employed in the field of palliative care

Project Objectives

To develop a training program that will:

- Build the knowledge and confidence of occupational therapy students to enhance the care offered in palliative care;
- Be useful to university programs teaching occupational therapy courses;
- Be available to occupational therapy schools irrespective of geographic location.

Research Team

This project drew on the combined skills and expertise of occupational therapists and post-graduate students of occupational therapy with different levels of clinical, academic, and teaching experiences. All but one of the PC4OTS team were employed within the Division of Occupational Therapy, at The University of Queensland, Australia, which is a world-recognized tertiary training institution. The research team included:

- Dr Pamela Meredith – Lecturer, School of Health and Rehabilitation Sciences (Division of Occupational Therapy)
- Mrs Judy Desha – Research Assistant, School of Health and Rehabilitation Sciences (Division of Occupational Therapy)
- Mr Kieran Broome – Research Assistant and PhD candidate, School of Health and Rehabilitation Sciences (Division of Occupational Therapy)
- Ms Fiona Jones – Research Assistant and PhD candidate, School of Health and Rehabilitation Sciences (Division of Occupational Therapy)
- Professor Lorna Rosenwax – Head, School of Occupational Therapy, Curtin University of Technology

Defining Palliative Care

According to Terry, Olsen, Wilss and Boulton-Lewis (2006, p. 338), "the goal of palliative care is to relieve the suffering and to improve the quality of life of dying patients". In 2004, the World Health Organisation defined palliative care as:

> *an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.*

Occupational Therapy in Palliative Care

The roles, challenges and benefits of occupational therapy with people with terminal illnesses have long been discussed in the literature (Dawson, 1982; Gammage, McMahon, & Shanahan, 1976; Lloyd, 1989; Rahman, 2008; Tigges & Sherman, 1983; vanderPloeg, 2001), and evidence of the role of occupational therapy in palliative care is beginning to accumulate (vanderPloeg, 2001). The training of occupational therapists to engage in this role, however, has received little attention. In 1995, Dawson and Barker published an exploratory paper describing the roles and training needs of occupational therapists working in the field of palliative care in Australia. At the time, these authors noted that the information had "…important implications for curriculum development and training programmes at undergraduate and postgraduate levels" (Dawson & Barker, 1995, p. 120). According to their review, undergraduate occupational therapy programmes in Australia incorporated training in grief and loss, death and bereavement, and counselling skills; however, the training did not cover these areas in depth, nor mention a hospice or palliative care role specifically. Based on their findings, Dawson and Barker called for improvements to the undergraduate training of

occupational therapists to incorporate palliative care. In the fifteen years (1993 to 2008) since this study was undertaken, there has been little consideration of these issues in the occupational therapy literature.

The underlying concepts and philosophy of palliative care vary considerably from those of more traditional settings in which occupational therapists might be employed (Pizzi & Chromiak, 2001). The goal of occupational therapy in this field is to facilitate continued participation in life, in spite if impending death (Marcil, 2006). There is a focus on physical, social, emotional and spiritual comfort of the client, rather than medical cure, and occupational therapy has been described as "compensatory" in nature, as opposed to being "rehabilitative" (Pearson, Todd, & Futcher, 2007). Prochnau and Boman (2003) identified five unique themes which are experienced more intensely by occupational therapists working in this field, relative to those working in other areas of occupational therapy practice. These included: high levels of satisfaction, unique hardships and difficulties, a need and opportunity to develop coping strategies, an awakening of spirituality, and ongoing personal growth. A range of additional issues arise due to the time-limited nature of working with end of life issues, including time pressure and frequent changes in therapeutic goals. In this field, perhaps more than any other, the psychological and physical elements of occupational therapy are united.

Rationale

Because the field of palliative care varies from more traditional occupational therapy approaches, palliative care warrants specific attention during occupational therapy training programs. In 1995, Dawson and Barker highlighted this need, with evidence that 64% of palliative care occupational therapists in their 1993 study reported having received no undergraduate training in palliative care. Among those who had received training, most felt inadequately prepared for their current work role. Dawson and Barker (1995) recommended that undergraduate training "specifically mention hospice and palliative care" (p. 125), and that it offers opportunities for students to apply their skills in clinical reasoning to this field, experience more clinical placements, have more dedicated lectures and tutorials, and more case studies. The extent to which these recommendations have been adopted by the occupational therapy schools in Australia and New Zealand remains unknown. In the United Kingdom, however, Kealey and McIntyre (2005, p. 232) have observed that there is still a need to "…increase education and resources [for occupational therapists]…" in palliative care.

Obtaining Ethical Clearance

Ethical clearance for the project was sought and obtained from the Medical Research Ethics Committee (MREC) Behavioural & Social Sciences Ethical Review Committee (BSSERC), The University of Queensland. This ethical clearance involved several aspects, including: information sheets and consent forms for survey participants, information sheets and consent forms for individuals being interviewed and videoed for the development of the multimedia training DVD's, and a release form for those who were videoed or photographed for the purposes of the training package. Consent for participation in the survey component of the project was assumed by return of survey forms. Information sheets and consent forms are included in Appendix 3, and ethical approval documentation is provided in Appendix 4.

The Present Study

Based on the uniqueness of the field palliative care, and the lack of attention to this topic in the occupational therapy literature in the past, there is a need to obtain current information about: (a) the roles, training needs, and recommendations of occupational therapists employed in this field, and (b) the approaches to delivery of palliative care training in Australian and New Zealand Occupational Therapy Schools. As noted earlier, this exploratory information is intended to guide development of an occupational therapy-specific undergraduate training package in palliative care, as advocated by Dawson and Barker fifteen years ago.

Methods

Participants

Participants were sought from two stake holder groups: 1) occupational therapy clinicians presently employed in the field of palliative care in Australia and New Zealand (*Clinicians*), and 2) Australian and New Zealand occupational therapy education programs (*Schools*).

Clinicians: A total of 24 clinicians completed survey forms. As can be seen from Table 1, clinicians were predominantly Australian and employed in hospital settings, and all worked with adults. Clinician participants were represented from 13 different university courses, including Australian, New Zealand, British and South African universities, although the majority were from The University of Queensland. Less than half of the clinician participants (45.8%) reported having received undergraduate training in palliative care, and 75% reported that they had felt unprepared to work in this field. No one indicated that they were "totally

prepared" to work with people in the palliative stages of their lives. As indicated in Table 2, half of respondents graduated this century, and half in the last. The majority did not work full-time in palliative care roles, and the mean percentage of full time equivalent hours (FTE) devoted to palliative was 32 percent.

Schools: There are 15 occupational therapy schools in Australia and New Zealand and, of these, six responded to the survey (response rate of 40%). Due to the confidential nature of the surveys, no other information about these schools is available.

Table 1. Demographic Details and Categorical Survey Data for the Clinician Survey Participants

Demographic Variable N = 24		**n (%)**
Country of Practice	Australia	17 (70.8)
	New Zealand	7 (29.2)
Employment setting	Community (adult)	5 (20.8)
	Hospital (adult)	9 (37.5)
	Both Hospital and Community (adult)	4 (16.7)
	Missing	6 (25.0)
Training in Palliative care at University	Yes	11 (45.8)
	No	13 (54.2)
How prepared did you feel to work in palliative care?	Totally unprepared (1)	7 (29.2)
	Generally unprepared (2)	10 (41.7)
	In between (2.5)	1 (4.2)
	Neutral (3)	4 (16.7)
	Generally prepared (4)	2 (8.3)
	Totally prepared (5)	0 (0)

Demographic Variable	**N = 24**	**n (%)**
University attended	The University of Queensland	9 (37.5)
	La Trobe University	1 (4.2)
	Cumberland	2 (8.3)
	CIT Wellington	2 (8.3)
	Charles Sturt University	1 (4.2)
	James Cook University	1 (4.2)
	UK University	1 (4.2)
	Canterbury Christ Church Univ, UK	1 (4.2)
	Auckland University of Technology	1 (4.2)
	University of Sydney	1 (4.2)
	Otago Polytechnic	2 (8.3)
	Lincoln Institute of Health Sciences, Melbourne	1 (4.2)
	University of the Witwatersrand, South Africa	1 (4.2)
Year Graduated	Before 1980	1 (4.2)
	Before 1990	4 (16.7)
	Before 2000	7 (29.2)
	After 2000	12 (50)

Measures

Two separate survey forms were developed for the purpose of this project, targeting Clinicians and Schools respectively. These surveys were developed by the primary investigator, following discussions with occupational therapists that have worked in the field of palliative care and ageing, and can be found in Appendix 5. These measures required participants to write detailed answers to specific questions, consistent with the first stage of the Delphi survey technique (see Dawson & Barker, 1995). Questions used were open ended,

in order to encourage the participants to generate their own thoughts and needs based on their own experiences.

Procedure

As previously noted, ethical approval for both components (Clinician and School) of this project was obtained from The University of Queensland. A copy of this document is available in Appendix 2. Procedures varied slightly for the two participant groups:

Clinicians: Information sheets (Appendix 3) and survey forms (Appendix 5) were distributed widely, targeting occupational therapy groups including: Aged Care Special Interest Group (Queensland), OT Australia, and the New Zealand Occupational Therapy Association. An additional twenty-six emails were sent to occupational therapists who attended a Professional Issues Forum at the 2006 World Federation of Occupational Therapy Congress. Four of these emails were returned as undeliverable. A further nine surveys were posted to occupational therapists known by the researchers to be working in the field of palliative care in Queensland.

Schools: There are 15 schools of occupational therapy in Australia and New Zealand, and contact details for these were obtained from the Australian and New Zealand Committee for Occupational Therapy Education (ANZCOTE) contact list. School survey forms were forwarded by mail with a covering letter and information sheet to all Heads of Schools Australia wide (13) and New Zealand (2). An introductory email was also sent in advance of the package, providing information and signalling the arrival of the survey package. Because of the wide distribution of surveys, and the short time line of the research project, no attempt was made to follow-up with clinicians or schools to prompt participation.

Results

Statistical Analyses

Qualitative data arising from each of the survey questions were explored by the chief investigator for themes, and these themes are presented in tables summarising content and frequency of comments. The small amount of quantitative data was analyzed using SPSS Version 15.0. Participants with missing data were excluded, resulting in smaller numbers in some analyses. No outliers were detected. Descriptive data for continuous demographic and survey data are provided in Table 2.

Table 2. Descriptive Data for Demographic and Survey data for the Clinician Survey Participants

Variable	N	Mean	Standard Deviation	Min	Max
Period of time employed in years	24	4.64	5.09	0.16	20.0
Number of years since graduation	24	11.5	8.5	1.0	34.0
Percentage of FTE devoted to palliative care	23	32.09	32.61	1	100
Training in palliative care at University (1 = yes, 2 = no)	24	1.54	.51	1	2
Readiness to work in palliative care (1 = totally un-prepared, to 5 = totally prepared)	24	2.06	0.91	1	4

Correlational Analyses

A Spearman's rho correlational analysis was conducted between the continuous and ranked ordinal data survey questions, in order to identify any relationships among the variables. The five variables included in these analyses were: time employed in palliative care, percentage of time dedicated to palliative care, number of years since graduation, education in palliative care, and how prepared occupational therapists felt to work in palliative care. Two significant relationships emerged: (1) the number of years since graduation was significantly and positively related to the period of time employed in palliative care ($r = .75$, $p < .001$), and (2) how prepared therapists felt to assume a role in the field of palliative care was significantly negatively related to whether or not they had received training at university ($r = -.45$, $p = .03$). Thus, those who have worked for longer have spent more years employed in palliative care, and those who received training reported that they were more prepared to work in this field.

The Perceived Effect of Training in Palliative Care

In order to further explore associations between undergraduate training in palliative care and other variables, a series of independent samples t-tests were conducted with training in palliative care as the grouping variable and three independent variables: time employed in palliative care, percentage of time devoted to palliative care, and number of years since graduation. Two significant findings were obtained: (1) those who had received training in palliative care had been working in the field of palliative care for a shorter period of time (M = 3.6 years) compared with those who had received no training (M = 5.6 years, $t = 4.44$, $p = .05$), and (2) those who had received training in palliative care had been working as an occupational therapist for a shorter period of time (M = 8 years) compared with those who had received no training (M = 14.5 years, t = 4.44, $p = .05$). This suggests that undergraduate training in palliative care has increased in more recent years.

A Mann Whitney U test was undertaken to examine the relationship between participation in undergraduate training and preparedness to work in palliative care. This result was significant: U = 36.5, $N_1 = 11$, $N_2 = 13$, p = .04, two tailed, suggesting that those who had received training in palliative care (M = 2.5, mean rank = 15.7) felt more prepared to work in this field compared to those who had not (M = 1.7, mean rank = 9.8). Despite this significant difference, however, it should be noted that the mean scores for both groups (1.7 and 2.5) fall below the neutral range on the five-point scale of preparedness to work in this field.

Report of Qualitative Feedback from Clinicians

A number of open-ended questions were posed to survey participants to provide insight into participants' perceptions about the skills that are important in the field of palliative care. Although some survey questions appear repetitive, this strategy was employed in order to evoke a broad range of responses.

Please describe any elements of your undergraduate occupational therapy training that you recall to have been related to palliative care:

Although 11 participants indicated that they had received training in palliative care at university level, 13 responded to this question. The most frequently cited topic was Kubler-Ross' five stages of grief, mentioned by three of the participants; a further two noted input on concepts related to death, and one recalled learning about bereavement. Three clinicians cited education on communication skills or generic counselling skills under this heading. Only one

participant recalled learning about OT theory and philosophy in palliative care, while another specified that they had received NO training on the OT role. Other content included: generic manual handling/hoists, pathology/neuroanatomy, energy conservation/fatigue management, and equipment prescription, each reported by separate participants. In addition to specifying content of the OT programs, one participant mentioned that they had completed a palliative care/oncology elective in 4th year of university, while another recalled attending weekly tutorials for one semester. Two participants reported the use of case studies, while one recalled a lecture from an OT in the field, largely focussing on relaxation.

Please describe any knowledge or skills (if any) you wish you had gained (but did not) prior to commencing employment in palliative care:

A summary of the information obtained in response to this question is provided in Table 3. The most frequently cited concerns involved communication and meeting psychosocial needs. In addition, one participant shared the view that, even with the best of instruction and resources, employment in this field is likely to be challenging.

Table 3. Summary of knowledge or skills participants wished they had gained (but did not) prior to commencing employment in palliative care

Content **N = 21**	**Frequency** **n (%)**
Communication skills specific to palliative care (e.g., discussing death, talking about disease progression, discussing changing functional need, breaking bad news, empathy, sensitivity, how to acknowledge impending death and maintain hope). Includes communicating with families and with clients.	9 (42.8)
Psychosocial aspects of palliative care (e.g., the grief process, death, loss, bereavement, spirituality, psychological adjustment)	6 (26.6)
The terminal phase of life (e.g., the transition from living to dead, disease progression, functional decline, physiological changes, expected presentation of symptoms at the very end stage – degeneration)	6 (26.6)

Content **N = 21**	**Frequency** **n (%)**
OT role in palliative care (e.g., occupational performance, OT domains just as in inpatient care for other conditions, short term nature of goals)	5 (23.8)
Diagnoses relevant to palliative care (e.g., cancer, respiratory/cardiac failure, organ cancer, brain tumour)	5 (23.8)
Treatments, including chemotherapy, XRT, and medications, and the functional impact of these (e.g., impact of timing of pain relief and ADLs)	4 (19)
Self care/coping as a clinician working with palliative patients (e.g., coping with the death of a patient, coping with carer's grief, building resilience, coping with stress, access to counselling and support services for self)	4 (19)
Principles of palliative care (e.g., basic palliative care concepts)	3 (14.3)
Energy management (including fatigue management, activity prioritising	2 (9.5)
Pain management	2 (9.5)
Self awareness – reflecting on own experiences of life and death in life and work, including own cultural beliefs, and how these can impact on our practice	2 (9.5)
Cultural beliefs on death and dying	2 (9.5)
Community services and disciplines relevant to palliative care (e.g., hospice services)	2 (9.5)
Need to reinforce *positive* experience that can be had in this field – no need to be anxious, the thought can be scarier than the reality	2 (9.5)
The *individual* nature of palliative care (e.g., the meaning of equipment can be positive if it is seen as enabling a person to remain at home for longer, or negative if it is viewed as a final sign of giving up)	2 (9.5)

Content **N = 21**	**Frequency** **n (%)**
Promotion of OT in palliative care	1 (4.8)
Expectations and outcomes in terms of function and quality of life	1 (4.8)
Clinical case studies and practical stories	1 (4.8)
Fieldwork placement specific to palliative care	1 (4.8)
Pressure care	1 (4.8)
Nutrition	1 (4.8)
Manual handling training and practical experience	1 (4.8)
Meaningful stimulation in the home environment	1 (4.8)
Dealing with *the "system*"/working within the confines of different systems (e.g., funding criteria that restricts modifications)	1 (4.8)
Other *symptom management* (e.g., shortness of breath)	1 (4.8)

What, if anything, would you recommend that schools of occupational therapy incorporate into their undergraduate teaching curriculum to support practice in palliative care?

Many of the responses to this question (see Table 4) were replicas of the previous answers. However, there was a little more focus on the preparation of students for this field, as evidenced in comments on the need for students to reflect personally on the concepts of death and dying, to focus education on the rewards of working in this field, the unique ethical circumstances that can emerge in this field, and to inform students of the likelihood of meeting people in palliative stages of care even when not choosing to work specifically in this field.

Table 4. Recommendations for inclusion into occupational therapy undergraduate teaching curricula

Content **N = 22**	**Frequency** **n (%)**
Communication skills specific to palliative care (e.g., counselling skills, providing emotional support, discussing death, talking about disease progression, discussing changing functional need, breaking bad news, dealing with grief, empathy vs sympathy, end stage of life issues). Includes communicating with families and with clients.	10 (45.5)
Wide range of *diagnoses* (illnesses and diseases) seen in palliative care, and progression/stages	4 (18.2)
Ppsychosocial aspects of palliative care (e.g., the grief process, death and dying, loss, bereavement, spirituality, psychological adjustment)	4 (18.2)
Self care/coping as a clinician working with palliative patients (e.g., coping with the death of a patient, coping with carer's grief, building resilience, coping with stress, access to counselling and support services for self)	4 (18.2)
Emphasise *client focus* rather than rehabilitation or therapist driven goals	3 (13.6)
Difference in *focus* of service delivery between palliative field and other fields of employment (e.g., intervention supporting decline in function rather than improving function, shift focus to recognise that achievements can be made within the context of palliation/dying, adaptation focus)	3 (13.6)
Opportunity for students to *reflect* on their own mortality and beliefs about death and dying	3 (13.6)
The impact of *cultural* beliefs on death and dying	3 (13.6)
OT role in palliative care (general) – across various settings e.g., paediatrics	3 (13.6)

Content **N = 22**	**Frequency** **n (%)**
Pressure care, positioning	3 (13.6)
Basic information about palliative care (e.g., definitions, basic palliative care concepts)	3 (13.6)
Provision of equipment (contrast with option of home modifications)	2 (9.1)
Greater understanding of *treatments*, including chemotherapy, XRT, and medications, and the functional impact of these (e.g., impact of timing of pain relief and ADLs)	2 (9.1)
Oedema management/awareness	2 (9.1)
Stress management/relaxation strategies (functional and cognitive)	2 (9.1)
Fatigue management	2 (9.1)
Working in the field offers a positive, rewarding and fulfilling experience (under the right circumstances)	2 (9.1)
Knowledge and understanding of *community services* and disciplines relevant to palliative care (e.g., hospice services)	2 (9.1)
Understanding of the *terminal phase* of life (e.g., the transition from living to dead, disease progression, functional decline, physiological changes, expected presentation of symptoms at the very end stage – degeneration)	2 (9.1)
OT role in bereavement, end of life care e.g., description, importance of it	2 (9.1)
Energy management (including fatigue management, activity prioritising	1 (4.5)
Coping strategies for client and family	1 (4.5)

Content **N = 22**	**Frequency** **n (%)**
Decreasing challenging personal and environmental situations	1 (4.5)
Know that community OTs are commonly asked to see palliative care patients as part of their job description	1 (4.5)
Transfers (bed, chair, toilet, shower)	1 (4.5)
Pain relief	1 (4.5)
Appropriate *goal setting*	1 (4.5)
Appropriate *expectations* and outcomes in terms of function and quality of life	1 (4.5)
Clinical *case studies* and practical stories	1 (4.5)
Fieldwork placements	1 (4.5)
Ethics around palliative decision making	1 (4.5)
Multidisciplinary *team* roles (e.g., hospice/cancer nurse, GP)	1 (4.5)
Clinical reasoning (e.g., be aware that equipment prescription is not a formula but is part of a comprehensive assessment)	1 (4.5)

Please describe your present occupational therapy role in palliative care

The roles engaged in by the occupational therapy respondents are presented in Table 5. Most of these responses can be summarised into the following broad areas: equipment, energy conservation, counselling and psychosocial interventions, home modifications, education,

positioning, and liaison; however, there are a number of additional roles mentioned by one or two of the participants.

Table 5. Summary of present tasks of the occupational therapy role in palliative care

Content N = 24	Frequency n (%)
Equipment assessment/prescription/provision (including cost effective decision making) e.g., wheelchairs, seating	20 (83.3)
Energy conservation/fatigue management/work simplification	14 (58.3)
Counselling and support to client and family – need for rapport	14 (58.3)
Discharge planning	11 (45.8)
Home modifications/home environment set-up	10 (41.7)
Education (e.g., on manual handling, care options, community services, use and care of equipment)	10 (41.7)
Positioning/pressure care, skin integrity	9 (37.5)
Managing functional decline, facilitating function (including assessment), ADL, safety	9 (37.5)
Cognitive/perceptual assessments	8 (33.3)
Oedema management including splinting and pressure garments	7 (29.2)
Quality of life – support to maintain roles, leisure, meaning	7 (29.2)
Assessment of physical/environmental barriers (not specifically home), and adaptations	6 (25)

Content **N = 24**	**Frequency** **n (%)**
Screening and assessment of other skills (e.g., motor, sensory, psychosocial, volition/motivation, occupational performance)	5 (20.8)
Referral to other support agencies	5 (20.8)
Stress management/relaxation	5 (20.8)
End of life care planning, end of life goals – client focussed	5 (20.8)
Life stories (video, drawing, diaries/journals, memory projects, letter writing)	4 (16.7)
Liaise with team members, hospice and community services	4 (16.7)
Pain management	3 (12.5)
Assessing social environment e.g., review social supports	3 (12.5)
Sleep hygiene	2 (8.3)
Symptom management e.g., breathlessness	2 (8.3)
Other positioning e.g. respiratory patients not able to lie flat	1 (4.2)
Carer groups	1 (4.2)
Living well program	1 (4.2)
Management (of OT services) – including supervision of others	1 (4.2)
Upper limb management	1 (4.2)
Nutrition	1 (4.2)

Content N = 24	Frequency n (%)
Patient advocate	1 (4.2)
Accessing funding options	1 (4.2)
Negotiate and schedule daily routines to facilitate care at home	1 (4.2)
Manage expectations	1 (4.2)

Please describe your needs for further development as a professional in the field of palliative care

Perceptions of the forms of training that would be valued by clinicians in this field was sought in order to support the present training package, and to inform further educational development (see Table 6). Interestingly, the main perceived needs were in the area of providing psychosocial support. Several of the needs alluded to establish the OT role more clearly in this field, with benchmarking and a more OT-relevant theory base.

Table 6. Summary of further occupational therapy professional development needs in palliative care

Content N = 22	Frequency n (%)
Psychosocial care of palliative patients (client and family emotions, spirituality, understanding grief/death/loss). Further developing the psychosocial OT role.	7 (31.8)
Training in *communication* – high level counselling skills	6 (27.3)

Content **N = 22**	**Frequency** **n (%)**
Understanding the medical perspective (e.g., diagnosis, medication, symptoms, currency), including impact on function	6 (27.3)
Development of resources (e.g., flowchart for referral process, equipment), programs, strategies, assessments, and outcome measures	2 (9.1)
Education about analgesia, input regarding pain management	2 (9.1)
Input on *relaxation*	2 (9.1)
Post-grad course in palliative care (with a distance learning option)	2 (9.1)
Need recognition and support for working in this specialised field	2 (9.1)
Oedema/lymphodoema management	2 (9.1)
Input on energy management	1 (4.6)
Learning opportunities for experienced OTs	1 (4.6)
Support to develop OT research in palliative care	1 (4.6)
Information about OT treatment in different stages of palliative care	1 (4.6)
Development of OT-specific theories in the field of palliative care.	1 (4.6)
Skills in managing end of life issues, including bereavement	1 (4.6)
Prioritising client needs	1 (4.6)
Self care	1 (4.6)

Content N = 22	Frequency n (%)
More benchmarking among OTs in palliative care	1 (4.6)
Improved multidisciplinary communication and management	1 (4.6)
More opportunities to network and share information	1 (4.6)
Spend more time in hospice environment	1 (4.6)
Further develop the profession in the community	1 (4.6)

Please make any further comments that you consider might assist in the development of palliative care teaching resources for students

The opportunity to provide further comments was provided, and responses are summarised in Table 7. Thirteen of the 24 participants added comments in this section, and while some related to the positive experience of working in this field, others emphasised the challenged for a student or new graduate.

Table 7. Summary of further comments from clinicians working in palliative care

Content N = 13
"People often think that palliative care/oncology is a really miserable caseload, but I don't necessarily agree and so would like to see that reinforced to students. People really appreciate the role OT has when they are in the most difficult point in their life."

Content **N = 13**
"I think it's great to include this in OT undergraduate program. Good luck!"
"Professional/emotional toll of working with progressive illnesses, death and dying and coping strategies for the therapist"
"Lots of skills for palliative care are generic OT skills, but the focus changes and need to adapt skills to meet clients' needs and expectations."
• Funding arrangement for palliative care in Queensland • Equipment provision processes
• "Links from University to staff working clinically • Links between University and the Centre for Palliative Research and Education."
"Include OTs working in these areas at tertiary hospitals to provide case studies and overviews of key roles of OT in this area."
"A certain level of maturity and awareness of own mortality is required for OT work in palliative care. We have had students on placement who are not ready to undertake this type of work. I don't think a huge focus should be placed on this area in the undergraduate curriculum, but it is the sort of thing that would be ideally tackled in a postgraduate context, when people have had a chance to work out what sort of therapist they are/want to be. There needs to be practical and informational elements, particularly in the area of grief and loss. Role plays with actors are a great way to learn/practice communication skills."
"Students need to see and not just read a book or article. Some of the most useful clinical skills I learnt at Uni were taught "hands on" (for example, hoisting skills, range of motion, and manual muscle testing, practice counselling skills, worksite visits, etc)."

Content N = 13
"Like psychiatry, it is not something to be afraid of, but can be very enjoyable, with a few laughs, and one is making a big difference to someone, or their carer's, life, so it is rewarding."
"I think students should be strongly encouraged to debrief palliative care experiences in supervision as this work is emotionally very draining. Clinical placements in palliative care may be useful; however, not all students would necessarily function well in this environment."
Review of the Allied Health Professional Services for cancer related palliative care: An assessment of need. The Allied Health Professions Palliative Care Project Team, April, 2004 (email provided)
• "Practical application manual handling (this can be transferrable to other aspects of patient care also) • Exploring death, grief and loss, and communication with patients and families • Learning in greater depth, the total scope of OT role in palliative care."

Report of Qualitative Feedback from Schools

All of the six occupational therapy schools that responded to the survey reported that they include training in palliative care in their curriculum. A number of open-ended questions were posed to School participants to provide insight into the nature of palliative care training presently offered, and guidance regarding what resources might be valuable aids to support the teaching of palliative care. Responses to these questions are summarised in Table 8. Of interest, three of the six university courses responding to the survey utilised the PCC4U Resource Kit in some manner.

Table 8. Summary of palliative care (PC) instruction in occupational therapy schools in Australia and New Zealand

School	Year(s) included	Overall hours allocated to PC	Summary of content	Resources used	Resources desired
1	One topic 3rd year first semester; one topic 4th year second semester	Approx 4	General issues in palliative care Client considerations Client stories OT role and issues in palliative care	"The Human Body" video – Herbie's story. Lecturer designed powerpoint. Palliative Care Curriculum for Undergraduates (PCC4U) Resource Kit	Handouts for student resources. OT-specific video/DVD footage
2	Throughout the curriculum	10 + extra hours within other topics e.g., ethics, cancer care	Principles and underpinning values of PC; conditions leading to PC; impact on occupation, participation, health and wellbeing; role of OTs and other professionals; roles of family, other relatives and carers; ethical issues around PC and end of life care (ELC)	Television shows, documentaries, clients' interviews, family members, etc – demonstrating person-, occupation- or ethical-based perspectives. Powerpoint presentations. Guest lecturers/speakers use case studies from own experience. PCC4U Resource Kit	Establishing partnerships with OTs with expertise in this field. Having guest speakers share their lived experience of palliative care or working in this environment.

School	Year(s) included	Overall hours allocated to PC	Summary of content	Resources used	Resources desired
3	Case studies throughout the curriculum. 4th year first semester	3-4 hours	Death & stages of dying; contextual influences on adaptations to dying; culture and religion; definitions; overview of OT in PC – change in focus/assessment/ discharge planning; important considerations; outcome measures in PC; group discussion re case studies, readings.	Powerpoint. Case studies.	
4	2nd year, 2nd semester	2	Death and dying – stages of grief; supporting the family; sustaining hope; energy conservation; equipment to maintain skin integrity and independence; knowledge of hospice care.	Powerpoint developed by lecturer	Case studies including or considering the role of an OT. A video of an OT who works in this area – discussing what the role is, why she likes this area of work. Also, discussion from family/clients who receive OT intervention.

School	Year(s) included	Overall hours allocated to PC	Summary of content	Resources used	Resources desired
5	2nd year, 2nd semester (presently developing a post-graduate OT course)	3-4 hours	Principles of palliative care; application of these to scenarios in workshop.	Lecture from specialist in the area (medical or CNC) with powerpoint. Case studies from experienced clinicians	OT specific resources – role of OT in general multidisciplinary approach
6	1st year, 1st and 2nd semesters; 4th year 1st semester	8.5 + extra content in other courses	Spirituality and religion; death and bereavement; defining PC; illness progression; individual differences/client centered; meaning in life, life review; OT role; advanced health directives; suicide, euthanasia; a "good death".	Video: Palliative Care – More than just pain control. DVD: Advanced Health Directives. Lecturer developed powerpoint. Aspects of the PCC4U Resource Kit	OT-specific case studies, video footage and photos.

Discussion

The aim of this exploratory study was to obtain information about the present methods of teaching palliative care to undergraduate occupational therapy students, and the perceptions of occupational therapists in this field regarding: the training they obtained as an undergraduate student, their perceived training needs, and training needs and issues for undergraduate students. Based on this aim, some valuable information has been identified. These findings are summarised below.

1. All of the six responding undergraduate occupational therapy teaching programs reported including palliative care in their curriculum. Hours devoted to palliative care

material ranged from two to ten. The main resources requested by these programs included:

- Student handouts
- OT-specific video footage – OT role and discussion with family/clients
- Guest speakers – with a lived experience of receiving palliative services, or of working in the field
- Case studies including the role of an OT

2. Of the 24 clinician participants responding to the survey, 54.2 % reported having received no training in palliative care as undergraduate students. This is slightly fewer than the 64% identified by Dawson and Barker in 1995. Of note, participants varied considerably in their period of time since graduation (1974 to 2007), and it is possible that the more recently graduated students are those more likely to have received undergraduate training.

3. This was supported by findings that those who had been working in palliative care (indeed, worked generally) for a shorter period of time had received more training. This seems to indicate that the extent of training in palliative care has increased in more recent years, and is consistent with practice at The University of Queensland, for example.

4. The question of whether training in the field generalises to improved confidence to practice is of particular interest. In this study, 75% of participants reported that they felt totally or generally unprepared to work in this field. Only 8% (2 students) reported feeling generally prepared to work in palliative care, and none felt totally prepared. This finding is consistent with the findings by Dawson and Barker (1995) that their respondents did not "…feel adequately prepared for their current work" (p. 122), suggesting that there has been only a little change in this issue in the last fifteen years. Of note, one of the two students in the present study who indicated that they felt "*generally prepared*" to work in this field noted on the survey that this was directly due to having completed a specialist elective in fourth year, while the other completed a semester program of weekly tutorials with a "heavy focus on HIV and oncology".

5. This trend for training in palliative care to improve confidence to practice was evidenced statistically, with those participants who reported having received training feeling more prepared to work in the field compared to those who had not.

6. It was interesting to see the aspects of undergraduate training in palliative care that was most frequently recalled by clinicians. The work of Kubler-Ross was most often cited, followed by generic communication and counselling skills. Indeed, much of the content was general occupational therapy course content that would be expected to have been included in most curriculums. Only six participants mentioned specific palliative care content.

7. One other significant finding was that people who graduated earlier were more likely to have worked in the field of palliative care for longer (up to 20 years). On the face of it, this finding is not surprising. While it might be tempting to conclude that palliative care is a field that supports staff retention, however, it should be noted that this study sought the opinion only of people who are presently employed in the field, and did not seek opinions from occupational therapists who may have worked in palliative care and then left to work elsewhere.

8. It was interesting to note that few of the respondents are employed in palliative care-specific positions. As observed by one interview participant, it can be adaptive to have an alternative case load to distract from the intensity of end of life issues.

The qualitative responses to the clinician surveys were quite consistent across questions, and serve to confirm findings from earlier research regarding the main roles of occupational therapist in palliative care. Dawson and Barker (1995) identified four categories of roles from their study, listed here in order of importance: (1) Problem-solver, (2) Teacher/educator, (3) Networker/communicator, and (4) Facilitator of creativity or creative activities. Of note, the value of these roles varied with clinical settings (e.g., hospital, hospice). These roles were further discussed by vanderPloeg (2001). The themes emerging from the present study may be categorised under several headings:

1. <u>Desirable knowledge, skills and attributes</u> – Beyond requiring basic information about palliative care (e.g., definitions, basic concepts) participants emphasised the importance of developing strong communication and counselling skills, an understanding of the range of psychosocial aspects relevant to palliative care, and knowledge of factors impacting in the terminal phase of life, was highlighted. The

need to understand the circumstances from the perspective of the identified client as well as their family members was also emphasised. It was recommended that occupational therapists employed in this field obtain palliative care-specific knowledge regarding: (1) medical factors (e.g., diagnoses, treatments/medications), (2) occupational therapy-specific factors (e.g., impact on function and roles), (3) psychosocial factors (e.g., death, bereavement, spirituality, impact of culture, self-awareness, self-care), (4) services and multi-disciplinary team members in the field (e.g., hospice services, the "system"), and (5) ethical issues.

2. The occupational therapy role in palliative care – Participants emphasised the importance of understanding the specialist and unique nature of the occupational therapy role in this field. This included the need to emphasise the client's goals above all others, and understanding the vagaries of the field (e.g., intervention supporting decline in function rather than improvement). One respondent noted the importance of considering the paediatric field as a further speciality. Education, assessment and interventions in the following main areas were detailed:

    - Provision of equipment
    - Symptom management: pain, fatigue, breathlessness, oedema, positioning, nutrition, sleep
    - Counselling – supportive, decision making, goal setting, bereavement
    - Home modification
    - Manual handling/transfers
    - Quality of life - meaningful stimulation, leisure, social roles
    - Stress management and relaxation
    - Placement/residency management – care options, discharge management
    - Cognition/perception
    - Life stories
    - Running support groups

3. Recommendations for the future of occupational therapy in palliative care – Several suggestions emerged from the survey findings to support the growth and development of the OT role in this field. These include the need:

    - to promote the role of occupational therapy in palliative care
    - for more tailored assessments and outcome measures
    - for clinicians in this field to obtain appropriate support, including postgraduate training and distance learning packages
    - for research specific to the occupational therapy role in this field
    - to advance occupational therapy theory in this field
    - to engage in benchmarking among occupational therapists in palliative care
    - to provide more opportunities to network and share information
    - to increase the links between universities and staff working clinically (interestingly, both clinicians and university programs requested this)

4. Recommendations specifically for the undergraduate course – These included:

    - Use clinical case studies and practical stories
    - Consider fieldwork experiences in the field
    - Provide the opportunity for students to reflect on their own beliefs about death and dying, and their own mortality
    - Ensure applied learning, rather than formula approach – use clinical reasoning, role plays, observation
    - Invite guest OT speakers working in this field in tertiary settings

5. Tips for students – These can be summarised as follows:

    - Palliative care skills are similar overall to those required in other fields of occupational therapy

- You may see palliative patients even in setting where you might not expect to
- Take the responsibility to debrief following experiences in this field
- The thought can be scarier than the reality – it can be a positive and rewarding experience
- Remember: not everyone is ready to work in this field

While the information obtained in this study is diverse and consistent with previous evidence in the field, it should be remembered that both of the samples were relatively small, and that it is not possible to establish how representative the samples are of the populations from which they were drawn. In addition, a range of selection, response and researcher biases may have been introduced. It should also be noted that only the first of the three stages of the Delphi survey technique was applied with the clinician group, and more robust findings would be obtained by proceeding with further rounds of questionnaires. Further, while the diverse nature of the respondents (e.g., educational centre, time since graduation) can improve external validity, it can also serve to dilute conclusions. Thus, investigating similar questions with more homogenous groups may prove advantageous. As a result of these factors, findings should be interpreted with some caution.

Further Research

Several issues from this project give rise to suggestions for further research. The first is the opportunity to proceed with the next round of Delphi questionnaires in which clinicians in this field are afforded the opportunity to comment on the findings of the present research, and to prioritise the identified items. It is possible, for example that, because of the open nature of the survey questions, some respondents may simply have forgotten to include elements of their role.

In order to address the issue of homogeneity, it would be of interest to investigate the attitudes of new graduate occupational therapy students from within individual occupational therapy programs on their preparedness to work in the field of palliative care, and to relate this to the amount of palliative care training provided in the program. It would also be of interest to evaluate the confidence and knowledge of students in this field before and after participation in their undergraduate training.

Research Project Conclusion

Based on this study, it would appear that the extent of training for undergraduate occupational therapy students in the area of palliative care has increased in recent years, and that this is impacting on the slightly improved confidence of these therapists to work in this specialist field. Nevertheless, this confidence continues to be low, supporting earlier calls to further improve the training provided to occupational therapy students and to provide continuing education for occupational therapists already employed in this field (Dawson & Barker, 1995). The surveys conducted with the schools of occupational therapy and with occupational therapists in the field of palliative care have also yielded a wealth of valuable information upon which to base the proposed undergraduate training package, with potential application beyond this initial goal.

Development of the Resource Package

Incorporating the information from both groups of participants, and with additional input from the PC4OTS project team, components of the resource package were developed. These include:

1. The interview DVD and vignettes
2. Case studies
3. Teaching content and powerpoint

Development of interview DVD and vignettes

It was considered important to develop a range of teaching tools and resources which could be used in a variety of ways. One consideration was the importance of 'real world' experiences of occupational therapists who work in palliative care. Interviews were held with six palliative care occupational therapists, who were asked about their understanding, experiences, and roles in the provision of occupational therapy in palliative care. Three of these interviews were videotaped. These videoed interviews were edited to form a thirty minute DVD, and 11 vignettes were produced which cover a range of issues related to the occupational therapy role in palliative care. Topics covered include:

- How would you describe the OT role in palliative care?

- How does palliative care differ from other areas of OT practice?
- Common interventions
- The most important skill…Listening
- Talking about death and dying
- Self care
- Who do you work with
- Challenges
- A rewarding area of practice
- Tips for undergraduates, and
- Working in palliative care.

Development of case-studies

A fundamental part of the learning experience is the opportunity to participate in problem-based learning where, with the guidance of case study material and question prompts, students have the opportunity to apply their clinical reasoning skills to cases which reflect "real world" material. To this end, two occupational therapists were engaged to develop case studies specific to paediatric and adult palliative care. Each case study is accompanied by a set of objectives, and a "Cheat Sheet" providing suggestions and answers to the questions posed during the case study. The content of these case studies was discussed and honed during a series of project team meetings, and objectives were designed to target issues raised by clinicians in the field. These are formatted to reflect the sort of information and tasks that might be found in palliative care settings. Case studies are available in Appendix 3.

As a teaching resource, content found in both the powerpoint and vignettes will support students to answer questions posed in the case studies. In addition, extra readings and internt searches are recommended.

Development of the Teaching Content and Powerpoint Resource

The teaching content was progressively developed during this project through several steps:

- a reflective process involving several project team brainstorming activities,
- consideration of past lecturing resources,
- suggestions and recommendations emerging from interviews with individual occupational therapists expert in the field of palliative care,
- suggestions and recommendations emerging from surveys returned from occupational therapists employed in the field of palliative care,
- suggestions and recommendations emerging from surveys returned from schools of occupational therapy from within Australia and New Zealand,
- a literature review, and
- photographs courtesy of Zoe's Place, and other photographs taken for the purposes of this package.

The powerpoint package has been designed to be overly inclusive, in order that desired aspects can be selected and tailored by teaching staff. Case study activities and vignettes can be inserted as required. The package can potentially be used in three ways:

1. by lecturers teaching didactically to students
2. as a self-directed learning package by students
3. as a self-directed learning package by occupational therapists new to the field.

In addition to the general powerpoint package, a powerpoint of possible tutorial activities has been developed.

Summary and Conclusion

The overall aim of the "Teaching Palliative Care to Occupational Therapy Students: Development of Learning Resources" (PC4OTS) project was to develop training resources that would be useful within schools of occupational therapy in Australia and New Zealand in improving the confidence and ability of occupational therapy students to provide services in a palliative care setting. In support of this overall aim, survey forms from 24 occupational therapy clinicians working in palliative care were analysed, six clinicians were interviewed, and survey forms from six occupational therapy schools were analysed. The literature

relevant to occupational therapy in palliative care was reviewed, and progressive project team meetings were held to discuss content and format of the package. Interviews were also conducted with the family of two children with a life-limiting genetic disorder. As a result of this collection of information, the following resources have been developed:

- A report summarising resources utilised by Australian occupational therapy schools to teach palliative care and indicating preferences for additional resources;
- A report summarising information about roles and training needs from occupational therapists presently employed in the field of palliative care;
- A comprehensive powerpoint package with photographs, and an opportunity to embed video footage, to facilitate teaching of palliative care to occupational therapy students;
- A series of vignettes of interviews with two occupational therapists employed in the field of palliative care to facilitate teaching of palliative care to occupational therapy students;
- A bibliography of published literature relevant to the role of occupational therapy in palliative care;
- Five case studies – two paediatric and three adult – provided in hard and soft copies.

Future Directions

It is suggested that, on the basis of the experience of the research team and the project to this point, future development of this initiative includes:

- Expansion of the program by providing seminars designated as "train the trainer" seminars to state-wide, interstate and New Zealand occupational therapy schools.
- Encouraging use of the materials in the undergraduate and postgraduate training of occupational therapists.
- Obtaining evidence of positive outcomes of the training package when it is provided to students.
- Dissemination of outcomes of the evaluation of the project in terms of published papers in professional journals.
- Ensuring that occupational therapists new to services where palliative care is provided are aware of the training package and are able to access the package.
- Obtaining evidence of positive outcomes of implementation of the training package.

- Dissemination of outcomes of the project in terms of conference papers at occupational therapy and palliative care conferences.
- Dissemination of outcomes of the surveys conducted, in terms of published papers in professional journals.
- Consideration of the value of consolidating the content of the workshops into a book.

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Appendices

APPENDIX 1

Bibliography of Occupational Therapy-Specific References

Bibliography of Occupational Therapy-Specific References

(NB. This is designed to be a comprehensive but not exhaustive list of available resources in this field)

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APPENDIX 2

Paediatric Palliative Care Resources

Paediatric Palliative Care Resources

Paediatric Palliative Care listserve:

http://lists.act.org.uk/mailman/listinfo/paedpalcare

International Children's Palliative Care Network

The ICPCN is the only international network of organisations and individuals working within all children's palliative care services across the world. ICPCN advocates and raises awareness of the needs of life-limited children and their families. We are lobbying for the global development of dedicated children's palliative care services.

Includes a directory of organisations internationally.

http://www.icpcn.org.uk/

Annual Evidence Update Palliative Care in Children

The Palliative & Supportive Care and Child Health Specialist Libraries has brought together the latest collection of evidence and supporting information in the National Knowledge Week for Palliative Care in Children. Links will be provided to relevant guidance and systematic reviews, together with information on developments and organisations working in this area.

http://www.library.nhs.uk/childhealth/ViewResource.aspx?resID=270331

The Children's Trust

St. Margaret's School at The Children's Trust, Tadworth, KT20 5RU.

www.thechildrenstrust.org.uk

Palliative Care Organisation of Australia

http://www.pallcare.org.au/Default.aspx?tabid=1121

PAEDIATRIC PALLIATIVE CARE ORGANISATIONS

Zoe's Place (QLD)

www.zoesplace.com.au

Paradise Kids (Gold Coast)

www.paradisekids.org.au

Bear Cottage (NSW)

http://www.bearcottage.chw.edu.au/

APPENDIX 3

Information Sheet and Consent forms

OT School Survey

Participant Information Sheet

(Please retain this sheet for your information)

Title: P**alliative care training for occupational therapy students.**

Investigator: **Dr Pamela Meredith** PhD BOccThy BSc BAHons (Division of Occupational Therapy, School of Health and Rehabilitation Sciences, The University of Queensland); Ph: (07) 3365 2084; p.meredith@uq.edu.au

The inclusion of dedicated training in palliative care in Australia is relatively new in occupational therapy programs. Indeed, the extent to which this field is covered in occupational therapy training is likely to vary considerably between university programs.

More recently, the inclusion of palliative care in some occupational therapy curricula has been supported by the recent availability of "Palliative Care: A learning resource of health care students" developed by the National Palliative Care Program team. While the availability of this program has assisted students in developing a basic understanding of the general field of palliative care, elaborating on this learning has been somewhat hindered by the lack of OT-specific resources and case studies.

Funding has now been made available to develop additional OT-tailored resources to support this training. However, in order that the resources developed be of maximum benefit to the occupational therapy schools in Australia and New Zealand, it is important to first gain an understanding of the needs of these various schools.

Thus, your assistance is sought to provide some information upon which to base this project. Participation involves simply completing the attached survey form, and should take no more than 15 minutes. Surveys will contain questions about the inclusion of palliative care training in your curriculum, and the resources that are used in this training. Information obtained in these surveys may also be used to develop a paper on the provision of training in palliative care for occupational therapy students in Australia.

All information you reveal in these questionnaires will remain strictly confidential, and will be used solely for the purposes of this study. To ensure confidentiality there are no identifying questions on the survey. All completed surveys will be stored in a locked filing cabinet.

/2…

Your participation in this project is voluntary. You are entitled to withdraw from this project at any time, and to have any or all of the information you provide withdrawn from consideration in the project upon your request. Feedback on general findings of this study will be made available to you upon its completion through a written report; however, you are free to discuss the study with the researcher at any time.

This study has been cleared by one of the human ethics committees of The University of Queensland in accordance with the National Health and Medical Research Council's Guidelines. You are of course, free to discuss your participation in this study with Dr Pamela Meredith (contactable on 07 3365 2084). If you would like to speak to an officer of the University not involved in the study, you may contact the Ethics Officer on 3365 3924.

If you are agreeable to participating in this research, please complete the attached survey form and return it in the enclosed envelope. Return of this survey will confirm your consent to participation in this project.

Thank you for your interest in this research project.

Yours faithfully,

Dr Pamela Meredith

Lecturer

Division of Occupational Therapy.

Occupational Therapists in Palliative Care Survey

Participant Information Sheet

(Please retain this sheet for your information)

Title: P**alliative care training for occupational therapy students.**

Investigator: **Dr Pamela Meredith** PhD BOccThy BSc BAHons (Division of Occupational Therapy, School of Health and Rehabilitation Sciences, The University of Queensland); Ph: (07) 3365 2084; p.meredith@uq.edu.au

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Funding has now been made available to develop additional OT-tailored resources to support this training. However, in order that the resources developed be of maximum benefit to the occupational therapy schools in Australia and New Zealand, it is important to first gain an understanding of the perceived training needs of occupational therapists that work in this field.

Thus, your assistance is sought to provide some information upon which to base this project. Participation involves simply completing the attached survey form, and should take no more than 15 minutes. Surveys will contain questions about your experience of palliative care training in your original university training, your present role in palliative care, and your recommendations for further training. Information obtained in these surveys may also be used to develop a paper on the provision of training in palliative care for occupational therapy students in Australia.

All information you reveal in these questionnaires will remain strictly confidential, and will be used solely for the purposes of this study. To ensure confidentiality there are no identifying questions on the survey. All completed surveys will be stored in a locked filing cabinet. /2…

Your participation in this project is voluntary. You are entitled to withdraw from this project at any time, and to have any or all of the information you provide withdrawn from consideration in the project upon your request. Feedback on general findings of this study will be made available to you upon its completion through a written report; however, you are free to discuss the study with the researcher at any time.

This study has been cleared by one of the human ethics committees of The University of Queensland in accordance with the National Health and Medical Research Council's Guidelines. You are of course, free to discuss your participation in this study with Dr Pamela Meredith (contactable on 07 3365 2084). If you would like to speak to an officer of the University not involved in the study, you may contact the Ethics Officer on 3365 3924.

If you are agreeable to participating in this research, please complete the attached survey form and return it in the enclosed envelope. Return of this survey will confirm your consent to participation in this project.

Thank you for your interest in this research project.

Yours faithfully,

Dr Pamela Meredith

Lecturer

Division of Occupational Therapy.

Interview Participant Information Sheet

(Please retain this sheet for your information)

Title: **Developing training resources for teaching palliative care to occupational therapy students.**

Investigator: **Dr Pamela Meredith** PhD BOccThy BSc BAHons (Division of Occupational Therapy, School of Health and Rehabilitation Sciences, The University of Queensland); Ph: (07) 3365 2084; p.meredith@uq.edu.au

This project has been designed to support the education of occupational therapy students in the field of palliative care. Participation in this project entails an individual interview with a qualified occupational therapist, which may be recorded with a still camera, or audio or video recorded. Any footage of you which is recorded during this process may include your face and features as well as your comments. The footage will be edited and developed into a presentation for use in training occupational therapy students to work in the field of palliative care. This presentation will be available free of charge to those interested in this field. The aim of the presentation is to improve the knowledge, skills and satisfaction of those employed in the palliative care field, and thereby to improve the quality of care for those receiving palliative care.

Participation should take approximately 30 minutes. You have the right to remain anonymous should you prefer, and will have the opportunity to approve or reject the content of the footage before it is finalised as a presentation.

Your participation in this project is voluntary. You are entitled to withdraw from this project at any time, and to have any or all of your interview withdrawn from consideration upon your request.

This study has been cleared by one of the human ethics committees of The University of Queensland in accordance with the National Health and Medical Research Council's Guidelines. You are of course, free to discuss your participation in this study with Dr Pamela Meredith (contactable on 3365 2084). If you would like to speak to an officer of the University not involved in the study, you may contact the Ethics Officer on 3365 3924.

If you are agreeable to participating in this project, please complete the attached permission letter and return it. You may also use this form to indicate your intent *not* to participate. Thank you for your interest in this project.

Yours faithfully,

Dr Pamela Meredith

Lecturer, Division of Occupational Therapy.

Interview Consent Form

Title: **Palliative care training for occupational therapy students.**

Investigator: **Dr Pamela Meredith** PhD BOccThy BSc BAHons (Division of Occupational Therapy, School of Health and Rehabilitation Sciences, The University of Queensland), Ph: (07) 3365 2084; p.meredith@uq.edu.au

I, _____ (please print full name), hereby

(tick whichever applies)

- ☐ consent
- ☐ do not consent

to take part in the project entitled **Developing training resources for teaching palliative care to occupational therapy students.**

I acknowledge that I have read the information sheet provided, and that the project, so far as it affects me, has been fully explained to my satisfaction by the investigators. I freely consent to my participation in the project.

I understand that I will be given the opportunity to view footage, and to approve the footage involving me before it is developed into a presentation. I am aware that, although my face will be displayed in the presentation, my identity will not be revealed unless I specifically indicate my desire that this occur.

I understand that I am free to withdraw from this project at any stage without affecting my care.

Signed:_____Date:_____

I am aware that I have a right to withdraw this permission at any time. I have viewed the contents of the footage of myself taken in relation to this project, and I therefore (please tick one):

- ☐ grant permission
- ☐ do not grant permission

for this footage to be edited and used in accordance with requirements of the project for the purposes of developing the training video for training on spiritual care in palliative care.

I would prefer that:

- ☐ I maintain my confidentiality in this presentation
- ☐ My name is known in this presentation

Signed:_____Date:_____

APPENDIX 4

Ethical Approval

APPENDIX 5

Surveys:

- **Clinician, and**
- **Occupational therapy school**

Survey

For Occupational Therapists in Palliative Care

Palliative Care Training for Occupational Therapy Students Project

1. How long have you been employed in palliative care?: _____years _____months

2. How much of your FTE (working hours) is devoted to delivering palliative care services? (please use percentage)

_____

3. In what area of palliative care do you work? (e.g., adult, paediatrics, community, oncology, etc):

_____

4. When did you graduate as an occupational therapist?:

_____

5. From which University did you graduate?:

_____

6. Did you receive training in palliative care as part of your undergraduate occupational therapy program? (circle one) Yes No

7. If **yes**, please describe any elements of your undergraduate occupational therapy training that you recall to have been related to palliative care:

_____

_____

_____

_____

8. Based on your undergraduate experiences, how prepared did you feel to assume a role in the field of palliative care? (circle one):

1	2	3	4	5
Totally unprepared	Generally unprepared	Neutral	Generally prepared	Totally prepared

Please proceed to the next page

9. Please describe any knowledge or skills (if any) you *wish* you had gained (but did not) prior to commencing employment in palliative care:

10. What (if anything) would you recommend that schools of occupational therapy incorporate into their undergraduate teaching curriculum to support practice in palliative care?:

11. Please describe your present occupational therapy role in palliative care (include aspects that you consider to be occupational therapy specific as well as those that are more generic):

Please proceed to the next page

12. Please describe your needs for further development as a professional in the field of palliative care:

13. Please make any further comments that you consider might assist in the development of palliative care teaching resources for students:

Thank you for your participation in this project.

Please return the completed survey form to:

Dr Pamela Meredith

Division of Occupational Therapy

The University of Queensland, St Lucia QLD 4072

p.meredith@uq.edu.au

Developing training resources for teaching palliative care to occupational therapy students

Occupational Therapy School Survey

1. Is palliative care included in your OT School curriculum?

□ Yes (go to **item 2**)

□ No (go to **item 3**)

2. **If YES:**

When in the occupational therapy program is it included? (please include: curriculum unit(s), year(s), semester(s), etc.):

_____

_____

_____

_____

How many hours are allocated overall to the teaching of palliative care?

_____

Please briefly summarise the palliative care topics covered:

_____

_____

_____

_____

Please indicate and briefly describe any resources that are used in the teaching of palliative care in your program?

□ Video / DVD

_____

_____

_____

_____

Please continue over

□ Power Point

_____

_____

□ On line package or program

_____

_____

□ Power point (commercial or locally produced)

_____

_____

□ Case studies

_____

_____

Please list any additional resources that you use that are not covered above:

_____

_____

_____

_____

Please indicate any resources that you would *like* to be able to use/would like to see developed:

_____

_____

_____

_____

3. **If NO:**

How likely is it that you will be introducing palliative care into the curriculum in the next two years?	1 Highly unlikely	2 unlikely	3 Unsure	4 Likely	5 Highly likely

Please continue over

Please indicate and briefly describe any resources that may be useful in the teaching of palliative care to occupational therapy students?

□ Video / DVD

_____

_____

□ Power Point

_____

_____

□ On line package or program

_____

_____

□ Power point (commercial or locally produced)

_____

_____

□ Case studies

_____

_____

□ Other:

_____

_____

Please indicate any resources that you would like to be able to use/would like to see developed:

_____

_____

Thank you for taking the time to complete this questionnaire.

Please return completed questionnaires to:

Dr Pamela Meredith, Division of Occupational Therapy,

The University of Queensland, St Lucia, Queensland, 4072.

p.meredith@uq.edu.au

APPENDIX 6

Case Studies –

1. Paediatric:

James and Tom Smith

Lauren Ambrose

2. Adult:

Bessie Tucker

Lillian Whiteman

Shane Dervell

Walter Cuthbert

Palliative Care Paediatric Case Study

Tom and James Smith

Part 1 – Initial Contact - 1996

You are an occupational therapist working in a paediatric palliative care respite and hospice service. The following progress note was written from an initial interview with Mrs Smith, the mother of two boys with a life threatening condition.

Clinical Notes		Name: *James Smith* DOB: *15/03/1989*
20/05/1996	***Occupational Therapy – Initial Interview*** *– Mrs Smith (mother) attended an initial interview at the hospice centre.*	
	She reported she did not want to be a burden (no previous requests for assistance); however, she felt she was "no	
	longer able to cope". Mrs Smith has two sons (James, 12 years and Tom, 5 years) who have both been diagnosed	
	with a rare, progressive mitochondrial condition known to be life threatening. They had a fairly typical birth and	
	medical history until 7 years (James) and 5 months (Tom). Mrs Smith reports the following information:	
	<u>James</u> – James has a significant intellectual impairment associated with his condition. He attends school for 2 hours	
	per day. He is able to feed himself with supervision and is able to transfer and mobilise independently. He requires	
	assistance for all other self care tasks. James enjoys watching DVDs and listening to music. James is starting to	
	question his progressive loss of functioning. ———————————————————————————	
	<u>Tom</u> – Tom presents with regular grand mal seizures and reduced kidney function (currently receiving dialysis).	
	He is verbal with a mild intellectual impairment. He is able to eat smooth foods, which are supplemented with	

	gastrostomy feeds. In the past two years Tom has had 6 surgeries, including an iliostomy and surgery for spinal
	curvature. He is most alert during the night, can demonstrate aggressive behaviour towards his mother and others
	around him, and will often 'escape' over the high fence surrounding their garden.----------
	Mrs Smith reports she has recently divorced from her husband, who no longer wishes to be involved in the
	children's care. She has no other family in Australia, and is unable to work due to the care demands for her two
	boys. Mrs Smith receives limited funding to care for her children. There have been respite carers involved in the
	past; however, these carers have not maintained contact past the first visit due to the high needs of the boys.
	Both boys have short sleep-wake cycles (sleep in approximately 2 hour blocks during the night), and Mrs Smith
	attends to their care needs approximately 4 times per night. ----------
	Action -
	Plan -
	A Jones, Occupational Therapist----------

Question 1. *What would be your next steps? Following the SOAP approach to writing progress notes, complete the action (A) and plan (P) sections of this progress note.*

Action – What will you do in the session?

Question 2. *Who is the client?*

Question 3. *What else do you need to find out?*

Question 4. *Who else do you think needs to be on the healthcare team? What information will you provide to the professionals you refer to? How will you do this?*

Palliative Care Paediatric Case Study

Tom and James Smith

Part 2 – Transition from paediatric to adult palliative care services - 2003

Mrs Smith's GP contacts you to discuss his concerns regarding her health. He reports that Mrs Smith has been diagnosed with the adult strain of the mitochondrial condition, which is leading to deterioration of her jaw and chewing patterns. He is concerned about her significant weight loss and her mental state.

You contact Mrs Smith and find that James' health has deteriorated. Mrs Smith has placed Tom in a children's hospice facility for two weeks in order to stay at the hospital with James. James has been moved to an adult hospital facility as he is now 19 years of age; however, Mrs Smith reports he 'does not fit'. James wandered off the ward yesterday and was found two hours later in the cardiac ward. He has "a cognitive age of 7 years" and Mrs Smith feels he is not adequately stimulated in the adult hospital setting. Mrs Smith feels the changeover of staff (from paediatrician to adult specialists) means she needs to be available to explain his comprehensive medical history and provide the one-on-one support James requires.

Write the progress notes from this information.

Clinical Notes	Name: *James Smith* DOB: *15/03/1989*
12/07/2003	*Occupational Therapy –*

	Action -
	Plan -
	A Jones, Occupational Therapist----------

Question 5. *What are the issues around the transition from paediatric to adult palliative care services?*

Question 6. *What are the considerations you need to make when involved with an adult with restricted cognitive and functioning capacities?*

What are the ethical considerations?

Question 7. How could you ease the transition from paediatric to adult care services?

Palliative Care Paediatric Case Study

Tom and James Smith

Part 3 – Bereavement - 2008

James is now 24 years of age, and Tom is 17 years of age. The medical team feels that both boys have a prognosis of approximately 12 to 16 months.

James has become withdrawn and spends large periods of time sitting alone in his room. When speaking to others, the topic of death (of himself and others) appears to be the primary theme.

Question 8. *How will you support James? Describe some ways in which you might discuss death, dying and grief with James.*

Tom is no longer able to breathe, mobilise, verbalise or eat independently. He appears agitated and anxious.

Question 9. *How could you support Tom? What will you do?*

Mrs Smith would like to cease all medical intervention. She asks for your advice.

Question 10. *How do you respond? What will your intervention focus on at this stage?*

Question 11. *When and how will you end the therapeutic relationship?*

Question 12. *Where else might Mrs Smith access support during this period?*

Question 13. *Describe the changing roles of Mrs Smith across this final stage through bereavement.*

Palliative Care Paediatric Case Study

Tom and James Smith

Cheat Sheet

Answers to Questions

Question 1

The following suggestions for Action and Plans may be incorporated; however, this list is by no means exhaustive:

- Collaborate with Mrs Smith to identify at least one goal particularly important to her, such as assisting her boys to regulate their sleep/wake cycle more consistently
- Goal setting measures such as the COPM may be utilised
- Investigate and organise alternative respite and funding where possible
- Alternative ways for Tom to release his frustrations and high energy levels

Question 2

The clients are:

- Tom
- James
- Mrs Smith

Question 3

Find out more about:

- How Mrs Smith would prefer to communicate?
    - Some families prefer to initiate contact at all times, email only or discuss their children after hours only so they are not ‘reminded’ at work, etc.
- Possible reasons for Tom’s aggression

- Reasons why James is attending school for 2 hours per day only, and how this time could be extended

Question 4

The team:

- GP
- Paediatrician
- Occupational Therapist
- Social worker
- Mother – possibly James and Tom
- Physiotherapist
- School staff
- Speech pathologist
- Clinical specialists
- Others?

The sort of information provided to these team members should stimulate an interesting discussion on ethical issues surrounding confidentiality, release of information forms, discussing the relevance of information with the family before it is released.

Question 5

For a summary of the issues surrounding the transition from paediatric to adult palliative care services see powerpoint notes.

Question 6

A group discussion regarding the different considerations to be made may reveal some of the following:

- Individual choice and preference
- Legal requirements
- Issues of privacy and confidentiality
- Possibly competing rights and requirements of the mother/child/service
- Provision of information

- Meeting the needs of all parties involved in the most practicable way

Question 7

- Organise case conferences between the paediatric and adult staff prior to the transition
- Help prepare a summary of their needs, such as amount of supervision required.
- Present information in an easy to read way e.g., life story book
- Assist Mrs Smith to develop a pack to take to hospital of toys/books/favourite pillow/calming music/etc

Question 8

As a group activity, brainstorm engaging ways to support James, such as:

- Play/art/music based discussion of death and dying
- Being available to listen
- Use of videos or stories
- Assist him to develop memory books or videos, etc.
- Engaging a music therapist or similar

Other considerations:

- The presence of spirituality contributes to the resilience of children through qualities such as hope, trust and faith.
- Connecting children to their dream, desires, others, nature and meaningful cultural experiences contributes to their sense of purpose and meaning.
- Occupational therapists identify the importance of spirituality and cultural beliefs in influencing the well-being of the child and incorporate this into their therapeutic encounter.
- Occupational therapists can assist a child to make these connections and provide them with meaning in the community, society and world in which they live.

Question 9

Group discussion of support options for Tom including:

- Relaxation strategies
- Supporting Tom to engage in activities important to him that he can still manage
- Working with the team to find effective ways of enabling Tom to communicate (e.g., switches, etc)

Question 10

Group discussion regarding appropriate responses to ceasing medication:

- It is the choice of the family – listen to their thoughts
- Assistance to obtain information regarding impact of ceasing medication
- Discuss with family the need to involve the doctor (and others?) in the decision
- Assistance developing an advanced health directive, if necessary
- Discussion with the team

Question 11

Group discussion regarding appropriate ways to terminate the relationship

- Consider the ideal circumstance vs the likely reality
- Need to have discussed this with the family prior to the death of the child
- Therapeutic relationship typically extends past bereavement, depending on the relationship with the family and context of the service
- Gradually refer to alternative agencies e.g., adult counselling

Question 12

- Parent support groups
- Friends
- Family – at a distance
- Adult community mental health
- Counselling through private or NGO agencies e.g., Lifeline
- Focus on re-engagement in roles and occupations meaningful to Mrs Smith

Question 13

- Mrs James has lost wife role – now ex-wife. With death of her children she will lose the practical roles of: mother, care-giver, nurse, physiotherapy assistant, occupational therapy assistant, etc. These roles will have formed much of her identity. Consider impact of these issues on bereavement. Eventually, can assist her to re-focus on re-engagement in roles and occupations meaningful to Mrs Smith – self-care, leisure, social, worker role.

Palliative Care Paediatric Case Study

Lauren Ambrose

DOB: 20/06/2006

Lauren is two years old, and enjoys watching Hi-5, playing with her fairy dolls, and spending time with her family. She has an older brother named Sam who has just started school. Lauren was diagnosed with aggressive acute myolitic leukaemia at 18 months, with a 7 month prognosis. Lauren fatigues quickly. Her parents have decided to remove her from the hospital to spend her remaining time at home. Lauren's grandparents have moved in to help with her care, and they are receiving twice daily assistance from a community nursing agency for her self care needs.

You are the occupational therapist employed in the nearest community health service. The occupational therapist at the children's hospital has asked you to take on the case in order to support Lauren's return home and maintenance in this setting.

Question 1. *Who is the client?*

Sam's teacher reported he has become aggressive in the playground, and his academic performance is deteriorating. His parents have noticed that he has become more boisterous at home and takes a long time to go to sleep each night.

Question 2. *How could you support Sam?*

As Lauren's condition deteriorates and she begins to have seizures, her parents become distressed and anxious, as they feel they cannot manage this end stage alone and do not want to watch her experience these seizures in their home. They ask for your advice.

Question 3. *What would you say? How could you support the family during this time?*

Question 4. *When and how would you end the therapeutic relationship?*

Palliative Care Paediatric Case Study

Lauren Ambrose

Cheat Sheet

Answers to Questions

Question 1

- Lauren
- Sam
- Parents
- Grandparents

Question 2

- Play or art-based therapy to discuss fears about death and dying
- Determining the main triggers for Sam, such as:
    - Loss of time spent with parents
    - Fear of death and dying
    - Need for control given instability in home environment
    - Need for additional support for homework and schoolwork
    - Concerns Lauren may be dying because of him (cognitive stage, i.e., because he did not let her share his toys last week)
    - Fear of becoming close to friends in case he loses them also
    - Fears he or parents may die – if Lauren can die so san anyone.
- School based support e.g., teacher education, academic based occupational therapy, etc.
- Helping Sam develop a way of explaining to the class why he is sad sometimes
- Engaging Sam in activities that are meaningful to him
- Assisting Sam and his family to develop ways in which to spend time together in meaningful activities regularly.

Question 3

Group discussion regarding appropriate responses. You may wish to consider:

- Supporting the family to access hospice or inpatient care, depending upon their wishes, or organising increased community support
- Assisting the family to identify positive aspects in their relationship with their daughter at this stage.
- Assisting the family to identify and implement meaningful roles, such as reading to Lauren, selecting favourite photos to put beside her bed, etc.

Question 4

Group discussion related to how you might end the therapeutic relationship.

- The therapeutic relationship in paediatric palliative care typically extends through bereavement.
- Follow up contact
- While continuing to provide support, slowly commence referral to alternative services, including adult and child counselling, support groups, etc.

Palliative Care Case Study – Bessie Tucker

DOB: 18th September 1959

Part 1 – Before the First Visit

You are a community OT working in the community rehabilitation department of Grovely Hospital, visiting palliative clients in the community. Under palliative care funding guidelines, you are only eligible to see people with a prognosis of 12 weeks or less. Your most recent referral is from the palliative care doctor, Dr Stevens, who has been seeing Bessie Tucker in the palliative care outpatient clinic. Bessie has end-stage respiratory disease. Dr Stevens has concerns about Bessie's current and future ability to live at home, given a recent deterioration in condition. Dr Stevens has also sensed some relationship issues between Bessie and her sister / carer, Lara.

Question 1. *End-stage respiratory disease is one condition seen in palliative care. With your knowledge of respiratory conditions and occupation, what occupations and activities may be difficult for a client with an end-stage respiratory condition?*

You phone Bessie and organise to visit her in two days time. On the day of your visit, the palliative care car that is usually set aside for you is in use. The palliative care car contains your usual trial equipment. You have organised to borrow a community nursing car.

Question 2. *What trial equipment would you choose to load into the car to possibly use with Bessie?*

Palliative Care Case Study – Bessie Tucker

DOB: 18th September 1959

Part 2 – The First Home Visit

Entering the house, you can smell cigarettes. Bessie's sister Lara invites you into the living room, where Bessie is sitting. Lara heads to the kitchen to continue her work. Bessie appears underweight and depressed. Bessie has yellow stains on her index and middle fingers of her right hand.

You complete the initial assessment with Bessie (see the completed form below), identifying her needs and concerns. Halfway through your interview, she lights up a cigarette with a shaking hand. When her sister is out of the room, she mentions that she's "not really getting along with her right now".

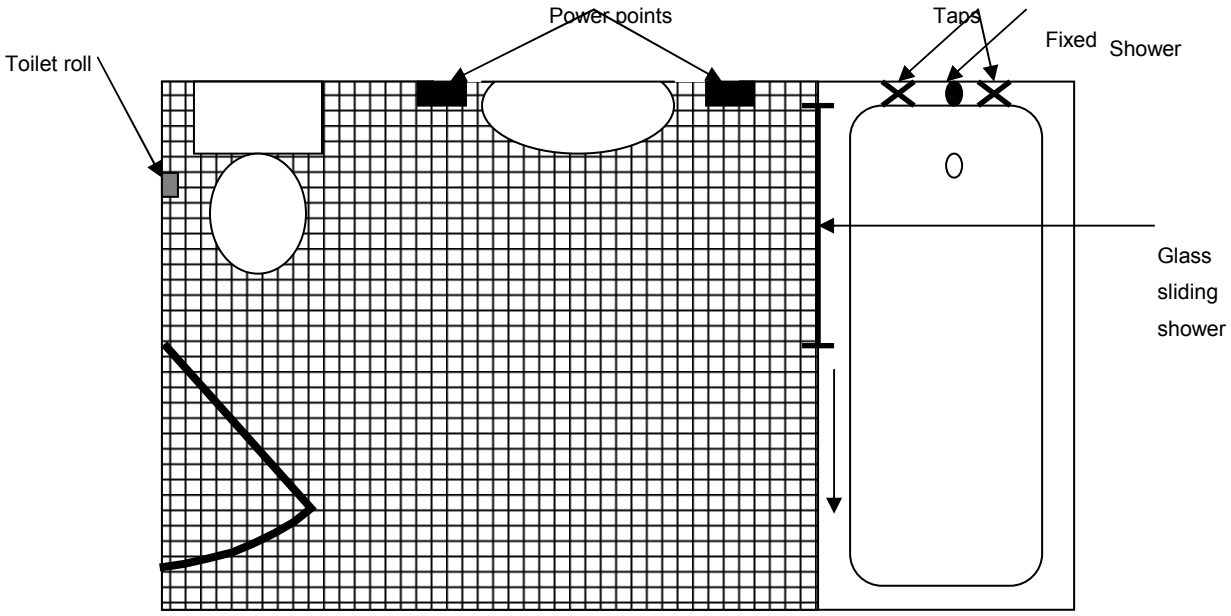
Activity 1 – *Group Discussion*

How does your knowledge that Bessie is continuing to smoke influence your attitude to providing therapy to help Bessie cope with respiratory disease?

Would you advise her to stop smoking? Why or why not?

You get to the end of the assessment form and Bessie shows you around her house to assess her living environment. You sketch the following diagram for future reference.

To see beyond the disease



Bathroom layout – overhead view

Activity 2. *Refer to the initial assessment form and the diagram above. What modifications or equipment would you use in the bathroom to assist Bessie?*

GROVELY HOSPITAL

OCCUPATIONAL THERAPY

PALLIATIVE CARE

Affix Client ID Here

Name: Bessie Tucker

DOB: 18 / 09 / 1959

Address: 17 Gorman Cct, Everton Downs

Phone: 3872 9384

Medical Conditions: end stage pulmonary disease, COPD. Hypertension. Hx asthma.

Prognosis: Approximately 2-4 months

Medications: See chart for details. Uses oxygen therapy as required.

Alert / Precautions: Sister owns large dog. Phone before visiting for dog to be restrained.

Current Issues: Fatigue impacting on ADLs. Breathlessness. Condition deteriorating.

Chart Review Notes:

Key Stakeholders

- ❒ Wife / Husband / Partner: N/A
- ☑ Carer: Sister
- ☑ Family: Sister - Lara

  2 children, live in Adelaide (unable to visit at this time)

  No current partner
- ☑ Doctor: Dr Stevens
- ☑ Nurse: Gabriella (pall care CN)

	❒ Other HP: _____

Life Roles (including pre-morbid) *Previously worked at Woolworths. Enjoys catching up with friends and going to movies.*

ADL Status:	**Indep.**	**Assist.**	**Diff.**	**N/A**	**Comments**
Mobility	❒	❒	☑	❒	} *Fatigue*
Stairs	❒	❒	☑	❒	
Transfers	☑	❒	❒	❒	
Continence	☑	❒	❒	❒	
Toileting	☑	❒	❒	❒	
Showering	❒	❒	☑	❒	*Fatigue while standing, also reports breathlessness due to steam (door closed)*
Grooming	☑	❒	❒	❒	
Dressing	☑	❒	❒	❒	
Mealtimes	☑	❒	❒	❒	
Meal preparation	❒	☑	❒	❒	*Sister, although Bessie (A) with light prep*
Cleaning	❒	☑	❒	❒	*Sister, although Bessie helps with cleaning dishes*
Home maintenance	❒	☑	❒	❒	*Sister*
Education	❒	❒	❒	☑	
Work	❒	❒	❒	☑	*Finished work approx 2 months ago*

Leisure	❒	❒	☑	❒	Fatigue
Socialising	❒	❒	☑	❒	Fatigue while mobilising
Money management	☑	❒	❒	❒	
Healthcare	☑	❒	❒	❒	
Medication management	☑	❒	❒	❒	
Religion & spirituality	❒	❒	❒	☑	
Sleep	❒	❒	☑	❒	Props self up on pillows. Breathlessness & discomfort on pillows (no support)
Transport	❒	❒	☑	❒	Can't drive anymore. Uses taxis, but c/o expensive.

Social Situation: (e.g. family, friends, visitors) Strained relationship with sister (carer). Sister co-owns house (inherited from parents).

Environmental Assessment (attach diagrams as necessary):

Entry: 3 steps at front, rail on (L) ascending. 4 steps at back. Rails bilat.

Internal access: Mix lino, carpet, tiles.

Outdoor access: Large flat front, back, side gardens. Grass. Narrow concrete driveway.

Toilet: In bathroom. ° rails, ° equipment. 410m seat height.

Shower: Shower over bath (shallow) 260mm height. Glass sliding shower screen (2 door). Fixed shower rose.

Bathroom: Tiled. Basin with two power points. Heater available.

Kitchen: Small. Lino floors. Standard bench heights. Breakfast bar.

Dining / lounge: Chairs 420mm high. Small table. States usually eats in lounge room watching TV (uses "stable tables")

Bedroom: Double bed, 350mm high. On castors. Good access.

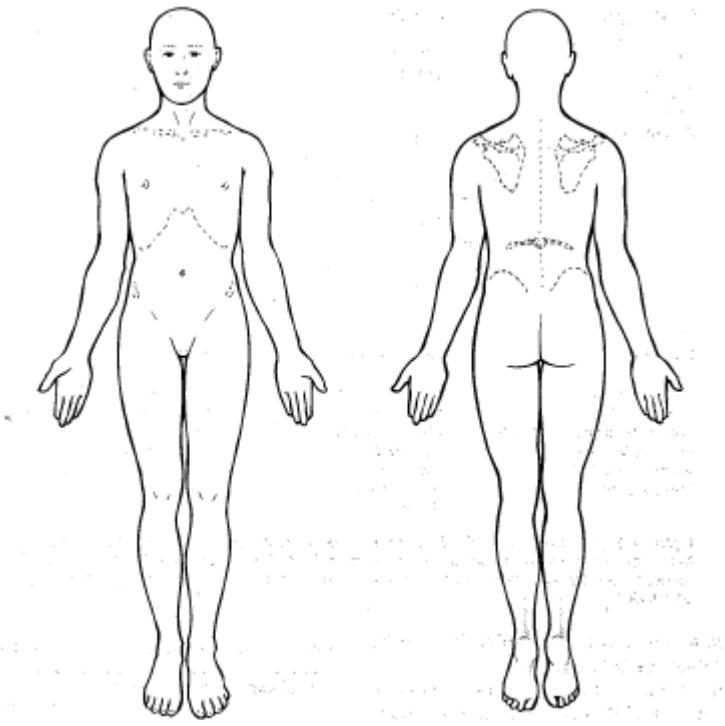
Work Environment: Position _____

Environmental considerations _____

_____

Pain: Please describe your pain: *discomfort while breathing* Score *1* / 10

_____



Perpetuating Factors: _____

_____

_____

_____

Relieving Factors: _____

_____

_____

_____

Yellow Flags

❒ Physical activity makes pain worse

Fatigue: *Fatigues easily. Can only do very light activity.*

_____

Breathing: *Breathless on exertion. Also breathless in shower (feels steam makes it difficult) and while lying down flat. Cannot tolerate lying flat.*

Psychological Status

Affect *Reports feels stressed at times.*

Mood _____

Psychomotor _____

Hallucinations _____

Delusions _____

Other disorders of thought _____

Motivation *Keen to manage symptoms* _____

Sensory

Hearing: (R) _____ (L) _____

Auditory procession: _____

Vision : (R) _____ (L) _____

Visual perception: _____

Visual & oculomotor reflexes: Nystagmus Convergence Constriction / Dilation

Smell: _____

Taste: _____

Light touch: _____ 2pt discrimination _____

Deep touch: _____

Temperature: _____ Hot / cold discrimination _____

Pain discrimination: _____

Balance: _____

Balance dominance: ❒ Visual ❒ Vestibular ❒ Proprioceptive

Balance reactions: _____

Sensory behaviours: ❒ Sensory avoidance ❒ Sensory seeking ❒ Low registration

Proprioception: _____

Kinaesthesia: _____

Stereognosis: _____

Physical Assessment

Positioning & Posture:

Rest in bed: _____ Time _____ (hrs/day)

Seated: *Spends most of day sitting in armchair as easiest place to breathe* _____ Time _____ (hrs/day)

Standing: _____ Time _____ (hrs/day)

Dynamic: _____ Time _____ (hrs/day)

ROM / End feel: UL _____

LL _____

Trunk / head / neck _____

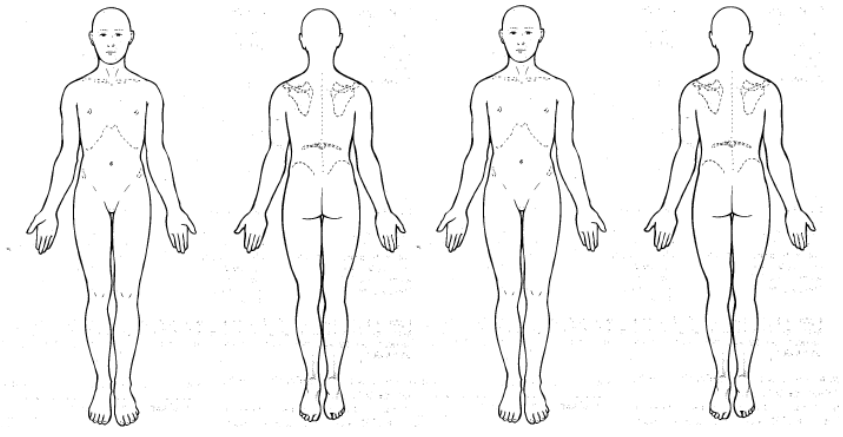
MMT: UL _____

LL _____

Trunk / head / neck _____

Coordination _____

Endurance *approx. 20m walking to fatigue* _____



Soft Tissue Assessment: _____

Slight build

Neurological signs & symptoms: _____

Oedema: Position _____

Measurements _____

Feel _____

Perpetuating factors _____

Relieving factors _____

Skin integrity: Ulcers / wounds / scars / trophic changes / other _____

Pressure area risk: _____

Existing pressure areas: _____

Waterlow score: _____

Cognition

Orientation (date / time / place) _____ Memory (instant / delayed) _____

Naming _____ Instruction following _____

Subtraction and mental handling _____ Copying _____

MMSE _____

MoCA _____

ACL _____

Cognitive observations *NAD* _____

Communication *NAD*

Expressive language _____

Receptive language _____

Articulation _____

Pragmatics & Social skills _____

Nutrition

Yesterday interview _____

Fluid intake _____

Top 3 Goals Set By Client **/5** **/5**

1. *Easier showering* Performance ❒ Satisfaction ❒
2. *More comfortable position in bed* Performance ❒ Satisfaction ❒
3. *Better relationships with family* Performance ❒ Satisfaction ❒

Other goals: _____

Current Issues

ADLs: _____

Pain: _____

Safety: _____

Other: _____

Impression

_____

Plan: _____

_____

_____

_____

_____

_____

Referral to:

- ❒ CN
- ❒ VMO
- ❒ PT
- ❒ Podiatry
- ❒ Dietician
- ❒ SP
- ❒ Psychologist
- ❒ Social worker
- ❒ Bereavement counsellor
- ❒ Other: _____

Review

- ❒ Nil further follow up required

- ❒ Client / family to contact OT if concerns / questions / need arise
- ❒ Review in 1/7
- ❒ Review in 1/52
- ☑ Review in 2/52
- ❒ Other review _____

Occupational Therapist (print name) *Ashley Taylor*_____

Signature _____ Date: ____/____/____

Palliative Care Case Study – Bessie Tucker

DOB: 18th September 1959

Part 3 – Follow-up Visits

When you get back to the office, you organise for the equipment to be supplied and the modifications to be commenced. You then document the home visit in the chart notes.

Chart Notes	Name: *Bessie Tucker* DOB: *18 / 9 / 1959* URN: *613902*
21/9/06	*Nursing cont... and referred to for OT Ax as per Dr Steven's recommendation. R/V in 3 / 7. ——————*
	———————————————————————— Gabriella Leggatt (CN)
22/9/06	*Occupational Therapy Home visit conducted this pm. See initial assessment for further details. Primary concerns*
1550hrs	*include 1) fatigue and breathlessness while showering, 2) breathlessness while resting in bed, poor support from*
	pillows 3) social issues with sister / carer. ———————————————————
	Rx – Contacted Cancer Fund to supply 4WW, attendant propelled W/C and OTF. ——————————
	- Bath transfer bench for showering and adjustable bed back rest organised through palliative care funding.
	- Bed raiser 150mm placed in situ. Loan from OT.

	- Advised to shower with door open, advised to cover / disconnect power points due to electrical hazard. ----
	- Replacement of fixed shower rose with flexible hose referred to Home Assist Secure. ----------
	- D/W Bessie Re: future planning for equipment needs ----------
	- Educated Re: energy conservation and work simplification techniques ----------
	- Information given Re: community transport services ----------
	Plan: R/V in 2/7 to install equipment. ---------- Ashley Taylor (Occupational Therapist)

In two days time you visit Bessie again to help set up the equipment. Home Assist Secure has not yet visited to change the shower outlet, although they are booked to visit the next day.

You take the opportunity to chat with Bessie during the visit. Bessie starts to talk about her children in Adelaide.

> **Bessie (B):** “My children are coming up in a week. Yeah, uh, I’m pretty stubborn like that, I plan to stick around.”
>
> **Therapist (T):** [looks concerned and interested]
>
> **B:** “Yeah, I wish they could be up sooner. You know, grandchildren and school.”
>
> **T:** “So they’re finding it hard to get up here with life commitments?”
>
> **B:** “Yeah. I know I’ll get to see them. But there’s so much to talk to them about. You never know how long you’ve got.”
>
> **T:** “Have you been able to talk to your family about your prognosis? How do you think they’re feeling about it?”

B: “It’s hard to talk over the phone. And, uh, yeah, my sister’s been looking after me well, but it’s a bit weird between us. Yeah, you know she owns half the house. I think she wants it, but I need to leave something to my kids too. And you know with all that life support thing. You see, I’ve had a good life. I’m ready to go when it’s my time. I don’t want to be there with all those tubes and drips. I’ve told my doctor I don’t want those things, but I’m not sure what my family would say in that situation…if they’d try to stop it. Lara’s never been good at that sort of thing.”

T: “Is that something you would like me to help you work on?”

B: “Yeah, I think that would be good. You know, you’re actually pretty good to talk to. A lot of my friends don’t know what to say. It’s pretty obvious I’m dying, but they don’t seem to want to talk about it.”

Question 3. *What could you do to assist/support Bessie at this stage?*

At the end of the visit, you let Bessie know to contact you if she has any further concerns or needs arise. A week and a half later you haven’t heard from her. You check her chart and see a note that she has passed away. You call her house and organise with her family a time to pick up the bed raisers.

At this visit, you meet her son, Mason, and daughter, Liz. They tell you that the funeral was very appropriate. Liz sheds a few tears while talking to you. They thank you for helping their Mum out at this time.

Question 4. *How do you respond?*

Palliative Care Case Study – Bessie Tucker

DOB: 18th September 1959

Cheat Sheet

Answers to Questions

Question 1

Respiratory disease can impact on breathing, and thus endurance and fatigue. Postural changes (e.g. lying) may also impact on breathlessness. Oxygen therapy may impact on occupational performance due to physical restrictions and transporting of oxygen.

Possible areas of occupation and activities that you may consider are:

- ADL: walking, transfers, showering, dressing, stairs
- IADL: shopping, travel (walking), catching the bus, air travel, meal preparation, cleaning, taking out garbage, exercise, mowing the lawn
- Work: activities with high endurance demands
- Leisure: activities with high endurance demands
- Play: activities with high endurance demands
- Rest and sleep: sleeping (lying down)
- Education: activities with high endurance demands
- Social participation: travel to others, talking

Anxiety and depression are common secondary conditions that can present in end-stage respiratory disease. The impact of anxiety and depression on occupation is wide-ranging.

Question 2

Possible items of equipment include;

- Over toilet frame
- Shower chair / stool
- Perching stool
- Carer call system
- Wheelchair (with attendant propelled function)
- 4-wheeled walker with seat
- Information pack on energy conservation, work simplification and labour saving devices (e.g. towel robe for drying self)

- Chair / bed raiser
- Bed back rest or bolster

Question 3

Possible considerations include:

- Education regarding Advanced Health Directives ("Living will") and wills
- Suggest ways for Bessie to record her life for her children and grandchildren, e.g. My Journey project.
- Education on other supports available e.g., social workers, bereavement counsellor for children.

Question 4

Encourage students to brainstorm responses and phrases that they might use.

Encourage discussion on the appropriateness of physical touch (e.g., placing a hand on their shoulder), the appropriateness of therapists expressing emotion and their reactions to different phrases (e.g. empathetic vs. patronising).

Activities

Activity 1

Facilitate group discussion around emotional, moral, practical and ethical issues. Some possible considerations include:

- Client freedom of choice
- Client control issues near end of life
- Advice the client may already have received; what client knows
- Supports available for quitting smoking
- Motivational interviewing
- Public health system burden
- Smoking cessation commonly reduces symptoms in all stages of the disease
- Wait list eligibility criteria

Activity 2

There are three main considerations in the bathroom for Bessie including:

- Fatigue while standing in shower
- Breathlessness in shower with door closed
- Future planning for deteriorating condition

In this case, the therapist, Ashley, recommends that:

- Bessie shower with the shower door open to reduce breathlessness.
- The power points near the shower are covered up with a waterproof dressing to avoid water from the shower creating a hazard.
- Due to the low height of the bath, the use of a bath transfer with two legs outside the bath. She also considered the use of a raised bath board
- The fixed shower rose be replaced with flexible flower hose (or purchase shower hose for bath faucet).
- Bessie receive an over toilet frame to prepare for a possible future deterioration in condition that may impact on transfers. Bessie can also use the over toilet frame as a tall stool to rest on while drying.
- Education regarding future labour saving devices be provided to Bessie.

Palliative Care Case Study – Lillian Whiteman

DOB: 23rd February 1932

Part 1 – Before the First Visit

You go on your afternoon round in the palliative care inpatient unit at Grovely Hospital. The nurses ask you to see Lillian, whose condition has recently deteriorated.

Looking through Lillian's medical chart you find out that her diagnosis is most likely breast cancer with spinal and cerebral metastases. Lillian was recently admitted to the palliative care unit (four days ago) when her diagnosis was confirmed. Although Lillian has recently experienced deterioration in function and her condition has been deemed by the specialist as incurable, the prognosis is uncertain and she may live for two weeks up to six weeks.

Before seeing Lillian you talk to the nurse on duty. The nurse says that Lillian has recently lost the ability to speak, which is making it very difficult to provide care, especially pain management. Lillian has been refusing pain medication and the nurses have observed that she seems distressed and in pain. She reported pain prior to losing her communication abilities. A referral has been made to the Speech Pathology Department, and Lillian is on their waitlist. The palliative care unit has no dedicated speech pathologist. Lillian has also had a lot of difficulty transferring and walking, and her legs often "give out". The nurses are currently using a hoist to transfer her, although Lillian often makes her family help her to walk and transfer into / out of a chair when they visit. Her son and daughter visit regularly and the nurses report that they are distressed and upset about the situation.

Question 1. *As Lillian has not yet been assessed by the speech pathologist, you need to gain more information about her communication difficulties? What communication skills do you wish to informally assess during your initial visit, and how do you go about doing this? What strategies will you use to assist your communication with Lillian? How will you build rapport with Lillian?*

Question 2. *How would you approach Lillian's pain management situation?*

Palliative Care Case Study – Lillian Whiteman

DOB: 23rd February 1932

Part 2 – The Initial Assessment

You visit Lillian on the ward and introduce yourself as the Occupational Therapist. You sit close to her and begin to try to understand her communication abilities. She appears to be able to hear and understand you, but she seems unable to form words and can only make exasperated sounds. She is able to nod and gesture appropriately. She points to her name on the chart and then gestures with her index and thumb parallel and vertical, about a centimetre apart.

Therapist (T): Your name?

Lillian (L): [Gestures again with fingers]

T: Shorter?

L: [nods]

T: You want to be called a shorter name. Do you want me to call you Lily?

L: [smiles and nods three times]

You conduct the initial assessment, using a lot of yes / no questions and negotiating signs and gestures for other things such as “Can you give me a thumbs up if you’re doing OK with these activities, like eating? …Good, Now, a thumbs down if it’s a problem … OK … and a thumb to the side if the nurses are helping you out with it”.

When you talk about her children and her prognosis, Lily starts crying. With further questioning, you find out that Lily is concerned about not being able to communicate with her children, expressing her feelings and emotions towards them and passing on her life memories.

Question 3. *Palliative care services often offer a "My Journey" program or resource where clients are guided on how to reminisce and put together memoirs, memories and messages for loved ones. How could you modify this process for Lily?*

The interview and assessment continues for an hour and a half with breaks.

Activity 1. *Refer to the initial assessment form (below) that has been partially completed by Ashley. Complete the final sections (plan, referral and signature) based on the results of the initial assessment and your knowledge of palliative care interventions.*

You talk to Lily about seeing her again when her family are visiting the next morning.

GROVELY HOSPITAL

OCCUPATIONAL THERAPY

PALLIATIVE CARE

Affix Client ID Here

Name: *Lillian Whiteman A.K.A. "Lily"*

DOB: *23 / 02 / 1932*

Address: *283 New Menzies Rd, Appleby, 4029*

Phone: *3385 4728*

Medical Conditions: *Ca breast with spinal and cerebral mets. Previous (L) TKR. Hypertension. Wears glasses.*

Prognosis: *Approximately 2-6 weeks*

Medications: *See chart for details.*

Alert / Precautions: *Expressive communication difficulties*

Current Issues: *Nurse states refusing pain management (although appears in pain), difficulty walking – legs "give out" and currently using hoist, but has family assist with walking. Family stressed, especially Re: care planning.*

Chart Review Notes:

Key Stakeholders

- ❒ Wife / Husband / Partner: *Deceased*
- ❒ Carer: ____
- ☑ Family: *Son - Michael*
  Daughter - Fiona
  2 grandchildren
- ☑ Doctor: *Dr Freeman*
- ☑ Nurse: *Inpatient ward*
- ☑ Other HP: *Referred to SP*

Life Roles (including pre-morbid) *Chart states was retired homemaker. Husband deceased 3 years ago. Friends visit regularly. Enjoyed gardening and has a cottage garden. Misses garden. Has been learning French at the U3A.*

ADL Status:	Indep.	Assist.	Diff.	N/A	Comments
Mobility	❒	❒	☑	❒	o/e - able to walk 30m with assistance for safety.
Stairs	❒	❒	☑	❒	
Transfers	❒	☑	☑	❒	o/e - sit to stand. 1* heavy (A). (R) sided weakness. Other transfers (I)
Continence	☑	❒	❒	❒	
Toileting	❒	❒	☑	❒	Difficulty with transfers only
Showering	❒	☑	❒	❒	Nurses report unsafe standing, currently using mobile shower commode
Grooming	❒	❒	☑	❒	o/e difficulty reaching with (R) hand to brush hair, nurses currently (A)
Dressing	☑	☑	❒	❒	Mostly (I). Nurses (A) with bra
Mealtimes	☑	❒	❒	❒	
Meal preparation	❒	❒	❒	☑	Sister, although Bessie (A) with light prep
Cleaning	❒	❒	❒	☑	Sister, although Bessie helps with cleaning dishes
Home maintenance	❒	❒	❒	☑	Sister
Education	❒	❒	☑	❒	Wants to say goodbye to friends at U3A. French book beside bed.
Work	❒	❒	❒	☑	
Leisure	❒	❒	☑	❒	Gardening. Wants to see garden again.
Socialising	❒	❒	☑	❒	Difficulty communicating.
Money management	❒	❒	❒	☑	
Healthcare	❒	❒	❒	☑	

Medication management	❒	❒	❒	☑	
Religion & spirituality	❒	❒	❒	☑	
Sleep	☑	❒	❒	❒	*Mild restlessness due to pain.*
Transport	❒	❒	❒	☑	*Has not yet tried.*

Social Situation: (e.g. family, friends, visitors) *Nurses report son and daughter stressed, visit regularly. Friends visit regularly.*

Environmental Assessment (attach diagrams as necessary):

Entry: _____

Internal access: _____

Outdoor access: _____

Toilet: _____

Shower: _____

Bathroom: _____

Kitchen: _____

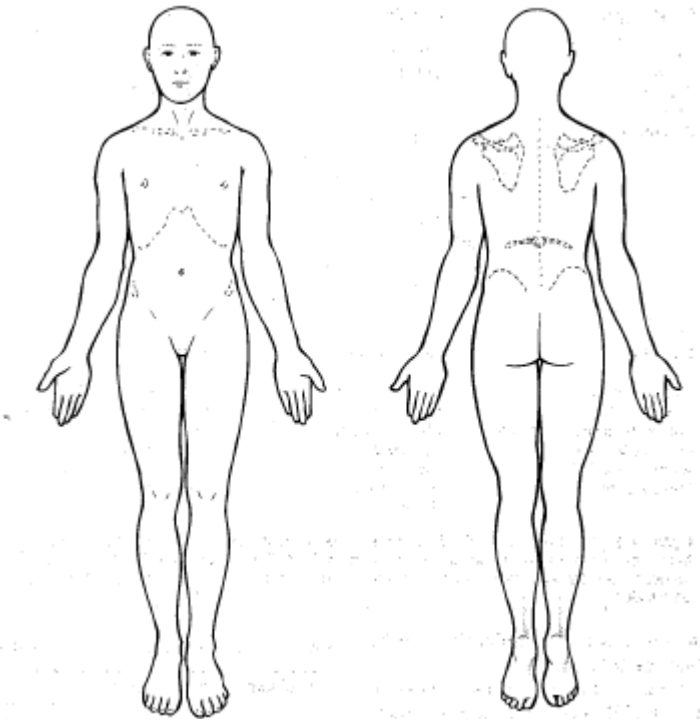
Dining / lounge: _____

Bedroom: _____

Work Environment: Position _____

Environmental considerations _____

Pain: Please describe your pain: *all over* Score *6* / 10



Perpetuating Factors: Constant, 24/7

Relieving Factors: Nil

Doesn't want to take drugs as made it difficult to think straight

Yellow Flags

❒ Physical activity makes pain worse

Fatigue: Fatigues easily. Also, becomes frustrated with communication difficulties.

Breathing: NAD

Psychological Status

Affect

Mood

Psychomotor

Hallucinations

Delusions

Other disorders of thought

Motivation

Sensory

Hearing: (R) (L)

Auditory procession:

Vision : (R) _____ (L) _____

Visual perception: _____

Visual & oculomotor reflexes: Nystagmus Convergence Constriction / Dilation

Smell: _____

Taste: _____

Light touch: _____ 2pt discrimination _____

Deep touch: _____

Temperature: _____ Hot / cold discrimination _____

Pain discrimination: _____

Balance: _____

Balance dominance: ❒ Visual ❒ Vestibular ❒ Proprioceptive

Balance reactions: _____

Sensory behaviours: ❒ Sensory avoidance ❒ Sensory seeking ❒ Low registration

Proprioception: _____

Kinaesthesia: _____

Stereognosis: _____

Physical Assessment

Positioning & Posture:

Rest in bed: _____ Time _____ (hrs/day)

Seated: _____ Time _____ (hrs/day)

Standing: _____ Time _____ (hrs/day)

Dynamic: _____ Time _____ (hrs/day)

ROM / End feel: UL *(R) reduced ROM flexion and abduction due to right-sided weakness*

_____

LL _____

_____

Trunk / head / neck _____

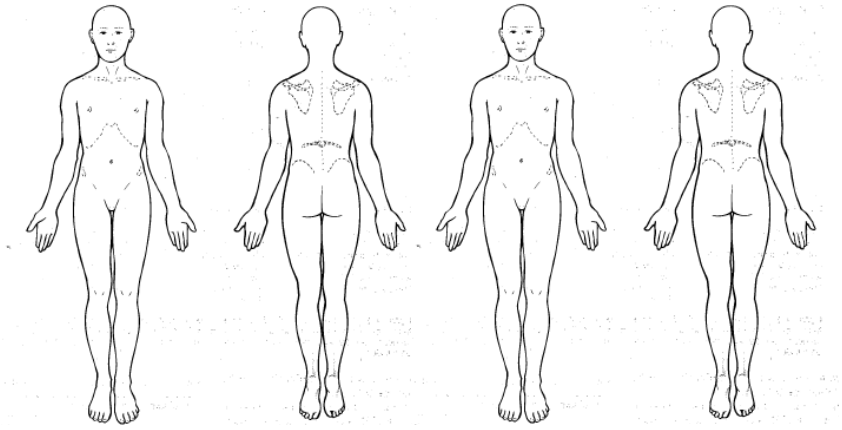
MMT: UL *Mild (R) side weakness*

LL *Moderate (R) side weakness*

Trunk / head / neck

Coordination

Endurance *approx. 30m walking to fatigue*



Soft Tissue Assessment:

Neurological signs & symptoms:

Oedema: Position

Measurements

Feel

Perpetuating factors

Relieving factors

Skin integrity: Ulcers / wounds / scars / trophic changes / other

Pressure area risk:

Existing pressure areas:

Waterlow score:

Cognition

Orientation (date / time / place) _____ Memory (instant / delayed) _____

Naming _____ Instruction following _____

Subtraction and mental handling _____ Copying _____

MMSE _____

MoCA _____

ACL _____

Cognitive observations *NAD* _____

Communication

Expressive language *Difficulties with verbal expression. Uses gestures and signs. Can write, but slow and fatigues easily.* _____

Receptive language *NAD* _____

Articulation *Unknown.* _____

Pragmatics & Social skills *NAD* _____

Nutrition

Yesterday interview _____

Fluid intake _____

Top 3 Goals Set By Client		**/5**		**/5**
1. *Be in garden again*	Performance	❒	Satisfaction	❒
2. *Walking*	Performance	❒	Satisfaction	❒
3. *Communicating with son and daughter*	Performance	❒	Satisfaction	❒

Other goals: _____

Current Issues

ADLs: _____

Pain: _____

Safety: _____

Other: _____

Impression

Plan:

Referral to:

- ❒ CN
- ❒ VMO
- ❒ PT
- ❒ Podiatry
- ❒ Dietician
- ❒ SP
- ❒ Psychologist
- ❒ Social worker
- ❒ Bereavement counsellor
- ❒ Other: _____

Review

- ❒ Nil further follow up required
- ❒ Client / family to contact OT if concerns / questions / need arise
- ☑ Review in 1/7 *with family present*
- ❒ Review in 1/52
- ❒ Review in 2/52
- ❒ Other review _____

Occupational Therapist (print name) *Ashley Taylor*

Signature _____ Date: ____/____/____

Palliative Care Case Study – Lillian Whiteman

DOB: 23rd February 1932

Part 3 – The Family Visit

You visit Lily on the unit the next morning when her son and daughter are visiting. You introduce yourself and talk about what you've discussed with Lily already. You encourage Lily to provide input and be involved wherever possible and model communication strategies, such as asking yes / no questions and pausing for a reply.

Lily's children are finding it difficult to cope with her prognosis and possible care. They reveal that there is no Advanced Health Directive or Enduring Power of Attorney (EPoA) completed. Lily echoes their concerns regarding the EPoA, especially in light of her previous experience with medication side-effects affecting her cognition. They are also confused about where Lily should be residing: whether Lillian should stay in the palliative care unit, whether they should take her home, or if they should book her into a nursing home near to where they live.

When you discuss the possibility of returning home for a visit in the near future, Lily's son Michael is interested in assisting. He has a Ford Falcon station wagon which would fit equipment and has a wide passenger door. Lily lives in a low-set house, with one step in at the front door.

Question 4. *What other information would you want to know? What questions might you ask? What considerations would you make to enable a home visit?*

Question 5. *How would you facilitate future care planning for Lily? What are your impressions at this stage?*

After the appointment you talk to the doctor and social worker about organising an EPoA. Dr Freeman asks that you do a cognitive screen on Lily before she'll even consider following up with an EPoA.

Question 6. *What is Enduring Power of Attorney? How could you determine Lillian's mental capacity for decision making?*

The next time you meet with Lily after the weekend, she is sitting in the unit garden of the hospital. She indicates that she really enjoyed the visit home. She appears a lot more contented. As you are going on holiday for the next two weeks, you tell Lily about the OT who will be covering while you are away.

When you return from holiday, Lily has deteriorated and is in her final days. You visit her while her family are with her to offer your support. Lily passes away the next day.

Palliative Care Case Study – Lillian Whiteman

DOB: 23rd February 1932

Cheat Sheet

Answers to Questions

Question 1

Communication impairments may impact on your ability to interview and build rapport with Lillian. Possible considerations are:

- The type of communication impairment – this will impact on how you compensate (e.g., expressive aphasia [verbal, sign, written, gesture], apraxia, dysarthria, concurrent receptive aphasia)
- Use observations and questions to narrow down the areas of impairment (e.g., "Can you nod if you understand what I'm saying")
- Use yes/no questions, or multi choice questions
- Try written and verbal
- Be prepared with pen, paper
- Dedicate more time for the initial and follow-up appointments
- Organise to see Lillian with the speech pathologist to develop strategies for communication
- Prepare the area (e.g., reduce background noise and distractions)
- Pay extra attention to non-verbal communication
- Use short sentences and questions, and use closed yes / no question where appropriate
- Offer alternative forms of communication, such as pointing to a communication board or writing responses
- Let Lillian know if you have not fully understood what she is saying, repeat what you did understand so that she does not have to repeat the whole sentence / idea
- Allow break times if Lillian becomes frustrated
- Impact of medication on communication
- Impact of fatigue – time of day of your visit
- Acknowledge her competence

Question 2

Some things to consider may be:

- Lillian's sense of control of her situation
- Lillian's beliefs and ideas regarding pharmacological pain management or pain more generally (possibly consult with family as to pre-morbid attitudes)

- Establish why Lillian might be refusing pain management e.g., if it is in tablet form and she has swallowing dysphagia
- Lillian's beliefs, ideas and openness to non-pharmacological pain management strategies (e.g. distraction, occupation, aromatherapy, relaxation, CBT)
- What communication strategies are the nurses using?
- What methods are being used to assess pain (e.g., face chart, observations)
- Has Lillian experienced side-effects from the medication (e.g., drowsiness)?
- What are Lillian's primary goals for her palliative care (i.e., is pain management a priority)?
- Communication
- Cognition

Question 3

Possible considerations include:

- Supply with educational material on the "My Journey" process.
- Seek to involve speech pathologist
- Teach family and friends communication strategies or organise for a speech pathologist to talk to the friends and family. Friends or family may assist in compilation of memoirs.
- Offer alternative ways of communicating memories (e.g., bring in magazines to cut out, photographs, magnetic words) and provide a template.
- Enable, prepare, and organise the family to take Lily on a visit home to collect items.

Question 4

Other questions and considerations may include:

- Accessibility of garden (slopes, widths, surface)
- Space and ability to place a temporary ramp at the front door
- Internal accessibility (hobs, internal steps, width of doorways, toilet accessibility if Lily requires toilet during visit)
- Emergency procedures as required
- Manual handling training
- Provision of, and education regarding, assistive devices for mobility and transferring (e.g., handy-bar or transfer strap for car door, attendant wheelchair for mobilising around home and garden)
- Emergency communication card/ communicating in emergency
- Education for family/friends regarding her communication

Question 5

Possible considerations include:

- Incorporating and advocating for a client-centred approach with Lily choosing her care.
- Assessing both Lily and her family's perception of Lily's functional abilities.
- Assessing the family's capacity for care and home set-up if she was to return home.
- Assessing and supporting the family's feelings towards Lily's prognosis and their emotional coping strategies.
- Investigating carer support options available (e.g., respite carers)

At this stage Ashley's impression is that staying in the palliative care unit with day visits to home may be the best option.

Question 6

A Google search will point to relevant information and legislation in your state or territory. Enduring Power of Attorney allows for another designated person to make decisions on your behalf as if you had made them yourself in the event of an accident or illness. Limitation can be put upon decision making. Common distinctions are powers regarding medical treatment or finances or both.

Cognitive assessments may include a combination of:

- MMSE (Mini-Mental State Examination)
- BRISC (Barry Rehabilitation Inpatient Screening of Cognition)
- MoCA (Montreal Cognitive Assessment)
- Assessments of executive functioning
- Observations
- Informal assessment

The assessment protocols will need to be modified for Lily to take into account her communication difficulties.

Activities

Activity 1

From the initial assessment, Ashley's plan includes:

- Discussions with nursing staff / doctor regarding Lillian's concerns about drugs impacting on cognition and initial communication findings / strategies

- Trial modified transfers and mobility with a rollator with therapist supervision
- Discuss with family details about home environment and transport options, and explore possibility of visit to home (see garden and collect memorabilia) with / without therapist present
- Provide “My Journeys” kit and template
- Educate family re: communication strategies
- Discuss family needs
- Trial long-handled comb and sponge to enable independence
- Conduct follow-up visits in unit garden when available and encourage nursing staff to take Lily to unit garden as able
- Discussion with speech pathologist re: initial findings and times when family may be visiting
- Ashley makes no additional referrals at this stage

Palliative Care Case Study – Shane Dervell

DOB: 7th January 1963

Part 1 – Before the First Visit

You are a community generalist OT working in Ashton. Ashton is a regional suburban area with no major tertiary hospital. You work in the multidisciplinary community health service, servicing Home and Community Care and general rehabilitation clients. One of the referrals from the community nurses is for: "HIV / AIDS – palliative care. Please assess for equipment". The community nurse, Gabriella, phones you to follow up and mentions that she has also made a referral to the regional palliative care nurse, Millie.

You don't usually see palliative care clients and have no assessments forms or resources.

Question 1. *List 3 web resources, journals or books that you may use to up-skill yourself in palliative care?*

You would like to contact other OTs working in palliative care to get an initial assessment form. List one contact number / email for a palliative care service or palliative care OT in your state.

Question 2. *What is HIV / AIDS? What are some considerations that you may have to make when providing services for a person with HIV / AIDS?*

You phone Shane and organise for a visit the next day.

Palliative Care Case Study - Shane Dervell

DOB: 7th January 1963

Part 2 – The First Home Visit

You arrive at Shane's house and head up the front stairs with your home visit pack. You hear the radio station that you were listening to in the car playing inside. Shane's partner, Aaron, meets you at the door and invites you in. He invites you to sit on the lounge while he goes to get Shane out of bed. You say, "Do you mind if I give you a hand?" so that you have the opportunity to see how Shane is transferring and how Aaron assists.

Activity 1. *Refer to the initial assessment form that has been partially completed by the Occupational Therapist, Linsday. Complete the referral section based on your reading of this form. Discuss your referral choices as a group.*

Question 3. *The initial assessment form lists four interventions. What reasoning might have lead the therapist to choose these interventions?*

Are there any alternative interventions that you can suggest?

1. pain relief strategies for his heel:

2. assistive devices :

3. psychological pain management strategies :

4. manual handling training for the carer:

You complete the initial assessment with Shane and Aaron and negotiate the intervention plan. When you go to get the trial OTF from the car for education, Shane says “No, I won’t be using that.”

Question 4. *How do you respond?*

You return to your office at the Ashton Community Health Centre and complete your paperwork, referrals and equipment ordering. You call Aaron in two days time to check that the equipment has arrived. Aaron says, “Thanks for doing all this. It’s a lot easier now that we’ve got everything in place.” You remind Aaron that he or Shane can phone you any time that a need arises. You don’t hear from him again, but find out from Millie five weeks later that Shane has passed away and that the equipment was picked up. Millie tells you that it was a very moving funeral and that Aaron is coping well, given the situation.

ASHTON COMMUNITY
HEALTH SERVICE
OCCUPATIONAL THERAPY

Affix Client ID Here

Name: Shane Dervell

DOB: 7 / 1 / 63

Address: 87 Old Bligh Rd, Tully Ck

Phone: 4872 0478

Medical Conditions: HIV / AIDS, asthma, previous # (L) scaphoid 1996

Prognosis: Approximately 2 months

Medications: See chart for details

Alert / Precautions: HIV with possible skin tears (blood spots and fragile skin)

Current Issues: Referral from CN for OT Ax Re: equipment and pain Mx

Chart Review Notes:

Key Stakeholders

- ☑ Wife / Husband / Partner: Aaron
- ☑ Carer: A/A
- ❒ Family:
- ☑ Doctor: Dr Steinberg
- ☑ Nurse: Millie (pall care CN)
- ☑ Other HP: St John's respite carer 4hrs, 2days / wk

Life Roles (including pre-morbid) Previously worked as a truck driver. Close social circle.

ADL Status:	Indep.	Assist.	Diff.	N/A	Comments
Mobility	❒	❒	☑	❒	*Leans on carer, max approx. 50m walking. Pain in heels.*
Stairs	❒	❒	☑	❒	*Poor endurance.*
Transfers	❒	☑	☑	❒	*1 x (A) carer sit → stand, poor technique in limited toilet space*
Continence	☑	❒	❒	❒	
Toileting	☑	❒	☑	❒	*Diff. with transfers. Otherwise (I)*
Showering	❒	❒	☑	❒	*Stands → fatigue*
Grooming	☑	❒	❒	❒	
Dressing	☑	❒	❒	❒	*Slow*
Mealtimes	❒	❒	☑	❒	*Nausea, pain in mouth, decreased intake*
Meal preparation	❒	☑	❒	❒	
Cleaning	❒	☑	❒	❒	
Home maintenance	❒	☑	❒	❒	
Education	❒	❒	❒	☑	
Work	❒	❒	❒	☑	
Leisure	❒	❒	☑	❒	*Fatigue*
Socialising	❒	❒	☑	❒	*A/A*
Money management	☑	❒	❒	❒	
Healthcare	❒	☑	❒	❒	*Carer takes to appointments*

Medication management	❒	☑	❒	❒	Carer (A)
Religion & spirituality	❒	❒	❒	❒	
Sleep	❒	❒	☑	❒	Pain in legs.
Transport	❒	☑	❒	❒	Driven by carer

Social Situation: (e.g. family, friends, visitors) Estranged from family (nil contact with mother, father deceased). No siblings. Supportive partner as carer, carer experiencing fatigue but respite in situ recently. Friends visit frequently.

Environmental Assessment (attach diagrams as necessary): High-set house

Entry: 13 steps at front, 8 at back. Rails bilat.

Internal access: Carpeted. Nil steps. Tiles in kitchen and bathroom.

Outdoor access: Sloping block. Flat at front and driveway. Paved access to car.

Toilet: Seperate room. ° rails, ° equipment. 400m seat height.

Shower: 110mm hob, Glass hinged door. ° rails, ° equipment. Standard taps.

Bathroom: Large

Kitchen: Large. Lever taps.

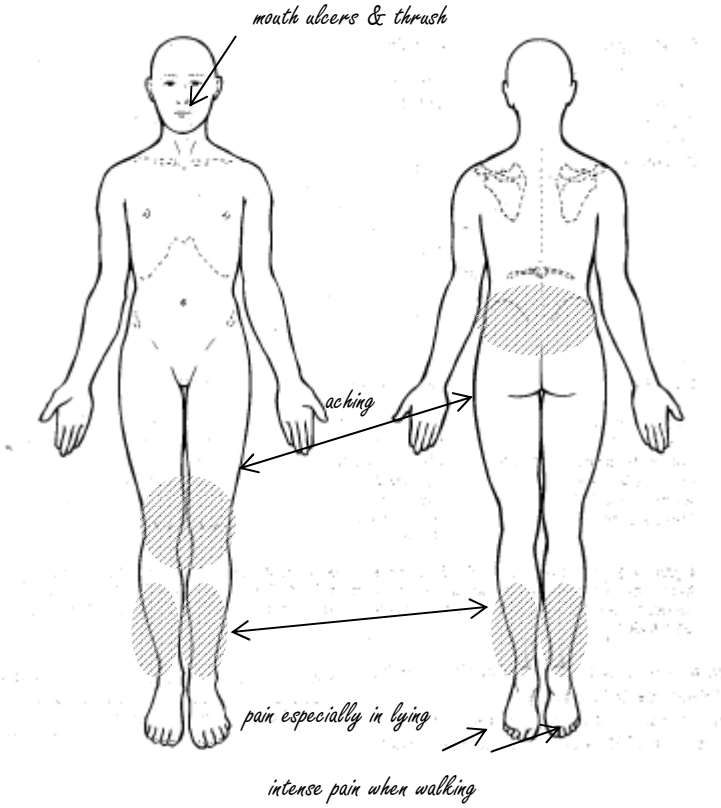
Dining / lounge: Chairs 440mm high, no arms. Solid table.

Bedroom: Queen bed, 450mm high.

Work Environment: Position _____

Environmental considerations _____

Pain: Please describe your pain: aching, shooting, stabbing Score 4 / 10



Perpetuating Factors: _____

Relieving Factors: *Medication*

Some relief from hot shower

Yellow Flags

❒ Physical activity makes pain worse

Fatigue: *Fatigues easily, esp. in afternoon / night.*

Breathing: *NAD*

Psychological Status

Affect *Mild dysthymia.*

Mood _____

Psychomotor *NAD*

Hallucinations *NAD*

Delusions *NAD*

Other disorders of thought *NAD*

Motivation _____

Sensory

Hearing: (R) _____ (L) _____

Auditory procession: _____

Vision : (R) _____ (L) _____

Visual perception: _____

Visual & oculomotor reflexes: Nystagmus Convergence Constriction / Dilation

Smell: _____

Taste: _____

Light touch: _____ 2pt discrimination _____

Deep touch: _____

Temperature: _____ Hot / cold discrimination _____

Pain discrimination: _____

Balance: *leans on carer for support* _____

Balance dominance: ❒ Visual ❒ Vestibular ❒ Proprioceptive

Balance reactions: _____

Sensory behaviours: ❒ Sensory avoidance ❒ Sensory seeking ❒ Low registration

Proprioception: _____

Kinaesthesia: _____

Stereognosis: _____

Physical Assessment

Positioning & Posture:

Rest in bed: _____ Time *approx 12* (hrs/day)

Seated: _____ Time _____ (hrs/day)

Standing: _____ Time *approx 0.4* (hrs/day)

Dynamic: _____ Time *approx 0.5* (hrs/day)

ROM / End feel: UL _____

_____

LL _____

_____

Trunk / head / neck _____

_____

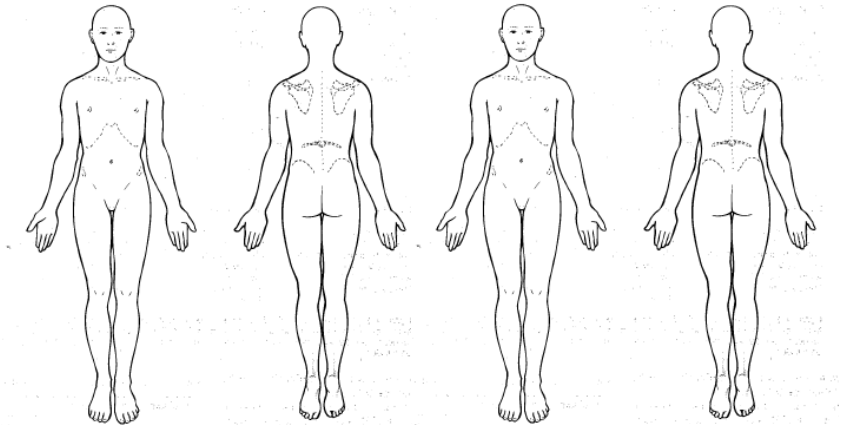
MMT: UL

LL *poor strength, fatigues easily, occasionally legs "give way"*

Trunk / head / neck

Coordination

Endurance *approx. 50m walking to fatigue*



Soft Tissue Assessment:

inflammation lips 2° to mouth ulcers

Underweight ++

Neurological signs & symptoms:

Oedema: Position *Nil.*

Measurements

Feel

Perpetuating factors

Relieving factors

Skin integrity: Ulcers / wounds / scars / trophic changes / other *blood spots*

Pressure area risk: *changes position regularly → low risk, but underweight.*

Existing pressure areas:

Waterlow score:

Cognition

Orientation (date / time / place) *NAD* Memory (instant / delayed) *NAD*

Naming _____ Instruction following _____

Subtraction and mental handling _____ Copying _____

MMSE _____

MoCA _____

ACL _____

Cognitive observations *NAD*

Communication *NAD*

Expressive language _____

Receptive language _____

Articulation _____

Pragmatics & Social skills _____

Nutrition

Yesterday interview *crackers, biscuits, can only handle small meals lunch and dinner*

Fluid intake *approx. 800ml tea, approx 500ml water.*

Top 3 Goals Set By Client	**/5**	**/5**
1. *Reduce pain and instability while walking*	Performance ❒	Satisfaction ❒
2. *Reduce pain while swallowing*	Performance ❒	Satisfaction ❒
3. _____	Performance ❒	Satisfaction ❒

Other goals: _____

Current Issues

ADLs: _____

Pain: _____

Safety: _____

Other: _____

Impression

Plan: *advised to trial gel heel inserts in shoes for outdoors, sheepskin slippers, indoors (supplier info supplied)
*wheeled walker, OTF and shower chair from Cancer Foundation. Educated Re: same
*educated Re: psych pain Mx strategies
*transfer training with carer (manual handling)

Referral to:

- ❒ CN
- ❒ VMO
- ❒ PT
- ❒ Podiatry
- ❒ Dietician
- ❒ SP
- ❒ Psychologist
- ❒ Social worker
- ❒ Bereavement counsellor
- ❒ Other: _____

Review

- ❒ Nil further follow up required
- ❒ Client / family to contact OT if concerns / questions / need arise
- ❒ Review in 1/7
- ☑ Review in 1/52
- ❒ Review in 2/52
- ❒ Other review _____

Occupational Therapist (print name) Lindsay Brown

Signature _____ Date: ____/____/____

Palliative Care Case Study – Shane Dervell

DOB: 7th January 1963

Cheat Sheet

Answers to Questions

Question 1

Direct the students to access informational resources and identify potential people to phone regarding assistance.

Possible sources may include:

- Care search: http://www.caresearch.com.au/
- Palliative Care Australia: http://www.palliativecare.org.au/
- Palliative Care For Undergraduates: http://www.caresearch.com.au/Caresearch/Default.aspx?alias=www.caresearch.com.au/Caresearch/pcc4u
- OT AUSTRALIA Who's Working Where directory
- Your state health service website (e.g. http://www.health.qld.gov.au)
- Cooper, J. (2006). Occupational therapy in oncology and palliative care. England: John Wiley & Sons Ltd.
- Boog, K., & Tester, C. (2007). Palliative care: a practical guide for the health professional: finding meaning and purpose in life and death. Churchill Livingstone.

Question 2

Helpful websites for finding out more about HIV / AIDS include:

- http://www.thewellproject.org/en_US/HIV_The_Basics/What_is_HIV.jsp
- http://www.health.vic.gov.au/ideas/diseases/sti_hiv_questions
- http://www.afao.org.au/view_articles.asp?pxa=ve&pxs=84&pxsc=&pxsgc=&id=405

Hold a group discussion to elicit special considerations for working with people with HIV. Examples of issues arising may include:

- Disclosure and stigma
- Attitudes of health care providers (what is your own attitude towards people with HIV / AIDS?)
- Opportunistic infection (importance of hygiene between houses for community OTs and between patients in hospitals). Community OTs should consider

carrying water-free hand-cleansers in their car (e.g., alcohol-based, micropore).
- Infection risk for health care providers and carers (exposure to blood, containment and disposal of bodily fluids, washing protocols)
- Partners or friends with HIV / AIDS (feelings of guilt / resentment, grief and loss for partner / friends)
- Polypharmacy and side-effects such as nausea and confusion (e.g., antiretrovirals, medications to manage opportunistic infections, medications to manage symptoms of opportunistic infections)

Question 3

1) P*ain relief strategies for his heel:* advised to trial gel heel inserts in shoes for outdoors, sheepskin slippers for indoors (supplier info supplied)

Neuropathic pain with identified trigger (i.e., impact of heel on ground). Pressure relief devices used to compensate for pain. Compensation / symptom management is used more often than remediation in the palliative approach. Gel heel inserts for outdoors to be more aesthetically in line with normal roles and habituation.

Other interventions may include, for example, use of a wheelchair or crutches (although crutches may exacerbate pain in upper back) to reduce impact through heels, or referral to CN / physician for pharmaceutical symptom management (e.g., anticonvulsants / antidepressants for neuropathic pain).

2) *Assistive devices :* wheeled walker, OTF and shower chair from Cancer Foundation. Educated re: same

Wheeled walker – increases stability while walking, partial transfer of weight through arms rather than feet, seat allows for frequent rest breaks, retains independence.

Over toilet frame – reduces the distance needed to transfer, no known issues with bowel movements, increases ease and stability of transfer.

Shower chair – increases stability and safety in shower, reduces fatigue by allowing client to be seated.

Other interventions may include, for example, wheelchair, crutches or four-point stick for mobility, grab rails or toilet seat raiser for toilet transfers, and shower stool, grab rail, shorter showers or no-wash cleanser for showering.

3) *Psychological pain management strategies:* educated re: psych pain management strategies

Difficulty remediating causes of neuropathic and palliative pain. Multiple sites of pain. Cognition intact. Strategies may include, for example, relaxation, CBT, counselling, distraction, engagement in meaningful occupations, or complementary therapies such as music therapy or aromatherapy.

4) *Manual handling training for the carer:* transfer training with carer (manual handling)

Allows partner to continue to be involved in caring, but remain safe. May have generalisability e.g., bed / chair / toilet / car transfers. Reduces reliance on equipment and is useful when equipment is not available (i.e., when not at home).

Question 4

Options may include:

- Find out why he does not want to use it (e.g., aesthetics, fears relating to equipment stability, denial of difficulty) and allay if possible
- Offer as an option in the future, e.g., “It sounds like you don’t need it at the moment. I can understand that. Do you mind if I quickly measure it up now just in case anything changes in the future. In that case, you can give me a call and we can organise it if and when you might need it.”
- Offer other options (explaining the pros and cons) such as:
    - a toilet seat raiser with / without grab rails,
    - reversing in to the bathroom with wheeled walker to provide surface to push on / stabilise when transfer, or
    - using biomechanical strategies (e.g., tuck one foot back before standing, lean forward prior to standing, use one hand pushing down on the toilet seat to help with standing)
- Combination of the above

Activities

Activity 1

Referral Choices: Facilitate group discussion around formation of a multidisciplinary team.

Possible referrals might include:

- Referral to speech pathologist for strategies related to eating and swallowing (due to client's experience of pain associated with thrush and ulcers in his mouth)
- Referral to a dietician for nutritional supplements (as client is underweight)
- Referral to bereavement counsellor for partner to prepare for death (no other family support identified)
- Referral to CN / physician for review of medications to manage pain (e.g., while swallowing, while lying in bed)

Referrals may be influenced by: preference of client and partner, availability of services in the area, skill base of therapist (especially in areas of role overlap), therapist's knowledge of the roles of other health practitioners.

Inform the group:

In this case study, the therapist referred to the speech pathologist (good interdisciplinary relationship with community speech pathologist who conducted a consultation over the phone with the client and partner) and discussed the issues and outcomes of the initial visit with the community nurse Millie.

Palliative Care Case Study - Walter Cuthbert

DOB: 7th October 1949

Part 1 – Initial Contact

You receive a referral from the palliative care nurses for "OT Assessment". You catch up with Walter's current nurse, Leanne, in the office. She tells you that Walter can be a "bit of a handful" and may be angry or aggressive. Leanne is the second palliative care nurse to be assigned to Walter.

Question 1. *What information do you want to find out prior to the visit and what sources of information would you use?*

Information:

Sources:

You phone up to book a home visit with Walter. At the time of the phone call, Walter is asleep, so you negotiate a time with his wife, Winnie. When you turn up on the day, Winnie meets you at the door with a slightly uncomfortable look and takes you in to see Walter. Walter is sitting in a lounge chair in the front sun room. You take a seat across from Walter.

Therapist (T): "Hi Walter, I'm [insert own name], one of the occupational therapists with the palliative care team at the Grovely Hospital."

Walter (W): "What the hell do you want?"

T: "I'm here to see if there's anything we can do to help you out with your everyday activities. Sometimes when people have cancer and get tired, it can

become difficult to do everyday things like showering or getting out to the doctors or shops."

W: "OK, ask your questions then. That's all you people fucking do. You just ask questions and write things down on your piece of paper and waste tax payers money."

T: "Hmmm… it sounds as if you haven't had any help so far that's been of much use.."

W: "No. Just wasting time."

T: "OK, can you tell me what the biggest issue is for you at the moment".

W: "Well have a look at my legs. That's not how they're meant to be".

Question 2. *How would you react to this situation? How would you build rapport with Walter?*

React:

Rapport:

Palliative Care Case Study - Walter Cuthbert

DOB: 7th October 1949

Part 2 – The Initial Interview

After starting with oedema massage to reduce the swelling in Walter's legs (with positive outcomes), you conduct the initial interview with Walter and his wife, Winnie. Walter's brother-in-law, Daeng, is in the kitchen during the interview, but comes out to offer you a drink.

Activity 1. *Refer to the initial assessment form that has been partially completed by the previous occupational therapist, Ashley. Complete the final sections (plan, referral, review and signature) based on the results of the initial assessment and your knowledge of palliative care interventions.*

You return back to your office at Grovely Hospital after seeing two other clients. You photocopy the assessment form for your records and file the original in Walter's chart.

Activity 2. *Complete the progress note in the space below.*

Chart Notes	Name: *Walter Cuthbert* DOB: *7 / 10 / 1949* URN: *615029*
17/8/06	*Nursing. Client seen at home this am. c/o – nil complaints. Reviewed medication regime. No change required at this*
1105hrs	*time. Referral made for OT Ax. Leanne Higgs (CN) ———————————————————————*
18/8/06	*Occupational Therapy*
1320hrs	

GROVELY HOSPITAL
OCCUPATIONAL THERAPY

PALLIATIVE CARE

Affix Client ID Here

Name: Walter Cuthbert

DOB: 7 / 10 / 49

Address: 20 Edgerton Drive, The Gap

Phone: 3926 8973

Medical Conditions: Ca – malignant pancreatic adenocarcinoma, hypertension

Prognosis: Approximately 1 month

Medications: Pain medications (injected – syringe driver). Webster pack for medication management

Alert / Precautions:

Current Issues: Referral from CN for OT Ax

Chart Review Notes:

Key Stakeholders

☑ Wife / Husband / Partner: Winnie

☑ Carer: A/A

☑ Family: Brother in law staying to assist

☑ Doctor: Dr Freeman

☑ Nurse: Leanne Higgs

❒ Other HP:

Life Roles (including pre-morbid) Previously worked in the army as an officer. Worked in sales past 6 yrs since retiring from army. Enjoys fishing.

ADL Status:	Indep.	Assist.	Diff.	N/A	Comments
Mobility	❒	❒	☑	❒	Fatigues after approx 10m walking
Stairs	❒	❒	❒	☑	No stairs in house. 1 step at entry, able to negotiate.
Transfers	❒	❒	☑	❒	Diff with lounge chair and bed transfers sit-stand
Continence	❒	❒	☑	❒	Incont at night due to diff mobilising & occasional "leaking" during day
Toileting	☑	❒	❒	❒	OTF in situ
Showering	❒	☑	❒	❒	Fatigue while standing, wife assists with washing
Grooming	☑	❒	❒	❒	
Dressing	☑	❒	❒	❒	
Mealtimes	☑	❒	❒	❒	
Meal preparation	❒	❒	❒	☑	
Cleaning	❒	❒	❒	☑	
Home maintenance	❒	❒	❒	☑	
Education	❒	❒	❒	☑	
Work	❒	❒	❒	☑	
Leisure	❒	❒	❒	☑	Not interested in fishing at this time.
Socialising	☑	❒	❒	❒	
Money management	☑	❒	❒	❒	
Healthcare	❒	❒	❒	☑	

Medication management	❒	☑	❒	❒	Wife assists with medications and injections.
Religion & spirituality	❒	❒	❒	☑	
Sleep	☑	❒	❒	❒	
Transport	❒	☑	❒	❒	Wife assists with car transfers

Social Situation: (e.g. family, friends, visitors) Friends visit regularly, although uncomfortable about dying. Winnie reports enjoying role as carer as she feels it is something tangible that she can do to help. Winnie reports that she is worried that Walter often gets frustrated and angry at his condition and care and has not been accepting much help from visiting nursing staff.

Environmental Assessment (attach diagrams as necessary):

Entry: 1 step at entry

Internal access: Flat access, carpeted. Lino in kitchen. Wide hallway.

Outdoor access: Steep driveway, but flat before garage.

Toilet: 400mm. OTF in situ. Separate to bathroom.

Shower: 120mm hob, Glass hinged door. Fixed shower rose.

Bathroom:

Kitchen:

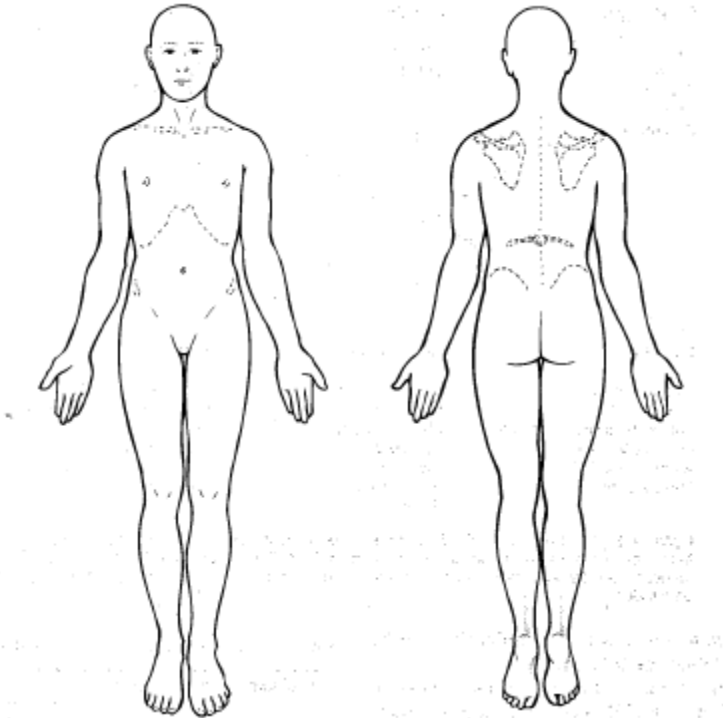
Dining / lounge: Armchair seat height 420mm, rocking and fixed positions. On legs.

Bedroom: 440mm queen bed on castors.

Work Environment: Position

Environmental considerations

Pain: Please describe your pain: Aching pain in legs 2° oedema. Generalised pain. Unable to rate pain as states pain medication "very strong" Score / 10



Perpetuating Factors: _____

_____

_____

_____

Relieving Factors: _____

_____

_____

_____

Yellow Flags

❒ Physical activity makes pain worse

Fatigue: *Fatigues easily after approx 10-m walking. Reports minimal disruption to sleep.*

Breathing: *NAD*

Psychological Status

Affect *Appears angry.*

Mood _____

Psychomotor _____

Hallucinations _____

Delusions _____

Other disorders of thought _____

Motivation _____

Sensory

Hearing: (R) _____ (L) _____

Auditory procession: _____

Vision : (R) _____ (L) _____

Visual perception: _____

Visual & oculomotor reflexes: Nystagmus Convergence Constriction / Dilation

Smell: _____

Taste: _____

Light touch: _____ 2pt discrimination _____

Deep touch: _____

Temperature: _____ Hot / cold discrimination _____

Pain discrimination: _____

Balance: _____

Balance dominance: ❒ Visual ❒ Vestibular ❒ Proprioceptive

Balance reactions: _____

Sensory behaviours: ❒ Sensory avoidance ❒ Sensory seeking ❒ Low registration

Proprioception: _____

Kinaesthesia: _____

Stereognosis: _____

Physical Assessment

Positioning & Posture:

Rest in bed: _____ Time 13 (hrs/day)

Seated: _____ Time 10 (hrs/day)

Standing: _____ Time _____ (hrs/day)

Dynamic: _____ Time _____ (hrs/day)

ROM / End feel: UL _____

_____

LL _____

_____

Trunk / head / neck _____

_____

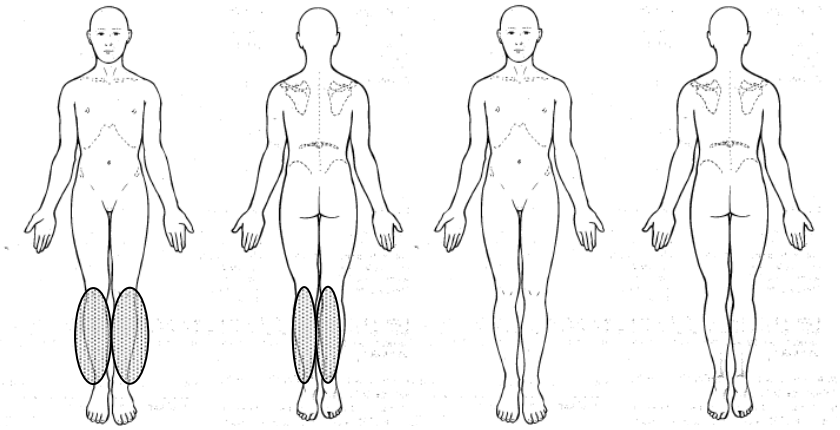
MMT: UL

LL

Trunk / head / neck

Coordination

Endurance



Soft Tissue Assessment:

Neurological signs & symptoms:

Oedema: Position *Moderate pitting oedema below knee bilaterally.*

Measurements

Feel *Pitting. Moves easily with oedema massage.*

Perpetuating factors

Relieving factors

Skin integrity: Ulcers / wounds / scars / trophic changes / other

Pressure area risk: *Low – weight shift and pressure relieves independently regularly.*

Existing pressure areas:

Waterlow score:

Cognition

Orientation (date / time / place) _____ Memory (instant / delayed) _____

Naming _____ Instruction following _____

Subtraction and mental handling _____ Copying _____

MMSE _____

MoCA _____

ACL _____

Cognitive observations _____

Communication

Expressive language _____

Receptive language _____

Articulation _____

Pragmatics & Social skills _____

Nutrition

Yesterday interview _____

Fluid intake _____

Top 3 Goals Set By Client		**/5**		**/5**
1. *Reduce oedema in legs*	Performance	❒	Satisfaction	❒
2. *Easier chair and bed transfers*	Performance	❒	Satisfaction	❒
3. *Stop "making a mess everywhere" (continence)*	Performance	❒	Satisfaction	❒

Other goals: _____

Current Issues

ADLs: _____

Pain: _____

Safety: *? Safety of transfers in / out car (not observed on initial Ax)* _____

Other: _____

Impression

_____

Plan: _____

_____

_____

_____

_____

Referral to:

- ❒ CN
- ❒ VMO
- ❒ PT
- ❒ Podiatry
- ❒ Dietician
- ❒ SP
- ❒ Psychologist
- ❒ Social worker
- ❒ Bereavement counsellor
- ❒ Other: _____

Review

- ❒ Nil further follow up required
- ❒ Client / family to contact OT if concerns / questions / need arise
- ❒ Review in 1/7
- ❒ Review in 1/52
- ❒ Review in 2/52
- ❒ Other review _____

Occupational Therapist (print name) *Ashley Taylor*

Signature _____ Date: ____/____/____

Palliative Care Case Study - Walter Cuthbert

DOB: 7th October 1949

Part 3 – Follow-up

You organise for equipment to be delivered to Walter including chair and bed raisers, a shower stool and wheelchair. Leanne, the palliative care nurse, has followed up with continence aids. You have spoken to the doctor who has approved oedema bandaging, and to your line manager about accessing short-stretch compression bandages. Your line manager informs you that they can't access oedema bandages through palliative care funding at this stage, but she will look in to it.

On your next visit, you assess Walter and Winnie's use of the equipment, which was found to be successful. While undertaking an oedema massage session alone with Walter, he spontaneously says;

> **W:** "You know, I don't think I'm that worried about it. I don't know about Winnie though."

From the tone of Walter's voice, you realise that by "it" he is referring to dying. Walter has not talked about dying up to this point.

Question 3. *How do you respond to Walter? What words would you use as your initial response?*

After working with Winnie and Daeng on manual handling, you decide that it would be appropriate to teach them basic oedema massage to undertake between OT visits. Daeng has expressed interest in doing this, as he would like to help out more.

Activity 3. *In pairs, practise basic oedema massage and identify key points / terminology that you would use when teaching this to family members.*

On your third visit to conduct oedema massage, Walter's skin has become a bright yellowy-orange colour.

Question 4. *What would you do in response to Walter's change in skin colour? How does this affect your therapeutic intervention?*

No one is home on your sixth visit. After talking the Leanne, you find out that Walter has been admitted to the hospital palliative care ward in a critical condition and is likely to pass away within the next few days.

Question 5. *How would you proceed from this point? How would you enact closure of the therapeutic relationship?*

Palliative Care Case Study - Walter Cuthbert

DOB: 7th October 1949

Cheat Sheet

Answers to Questions

Question 1

Information (e.g.):

- Contact details and social situation
- Diagnosis
- Prognosis
- Possible reasons for anger / aggression (medical, social)
- More detail on OT services required / reason for referral (e.g., equipment, carer support)
- What services / interventions have been/are already being provided

Information Sources (e.g.):

- Chart review
- Leanne, palliative care nurse
- Palliative care doctor
- Client or partner / family during initial phone call

Question 2

In this case study, the therapist, Ashley, decided to start by immediately working on oedema management (trialling oedema massage) prior to completing the initial assessment. This approach was useful in building therapeutic rapport with Walter, and Walter subsequently commented that it was the most useful thing that any other the team members had done.

Other options that Ashley could have undertaken include a goal setting exercise (e.g., informal, COPM) or a collaborative interview involving Walter's wife, Winnie.

Question 3

Hold group discussion re: appropriate responses. Considerations may include use of reflective listening: e.g., “You’re not that worried about dying?”, or “You’re concerned about how Winnie will cope?”

Question 4

Change in skin colour: Ensure that you inform the nurse and doctor of the change in medical status. This change should have no impact on your therapeutic interventions thus far, as it does not affect ADL status. You may like to consider the cosmetic impact of skin colour change and provide counselling, strategies or equipment re: same.

Question 5

Depending on your level of rapport with Walter and his family you may consider:

- Contacting the family to offer your condolences and support
- Offering referral as required to a bereavement counsellor or social worker
- Attending Walter's funeral
- Debriefing with your supervisor or other health professionals involved in Walter's care
- Undertaking a private ritual or cognitive reframing to mark Walter's passing

Activities

Activity 1

Possibilities for intervention include, but are not limited to:

- Oedema massage (therapist or train wife / brother-in-law)
- Oedema bandaging (seek clearance from doctor)
- Elevation of legs (e.g., with footstool, with pillows in bed)
- Referral to / inform CN for continence management or organise continence pads if trained
- Bedside commode for use at night
- Bed stick for transfers
- Bed / chair raisers
- Over bed / chair table or “stable (lap) table” if Walter would like to sit in bed / lounge chair for meal-time
- Train partner / brother-in-law in manual handling (e.g., car transfers)

- Wheelchair for long-distance mobilising (may require temporary ramp at front steps if condition deteriorates)
- Shower chair / stool
- Install grab rail or temporary grab rail (vertical or horizontal) for safe transfers into shower

Activity 2

Progress notes:

- Ensure that technical aspects of progress notes are adhered to.
- Ensure that oedema massage is documented.
- Ensure that initial assessment form is referred to.
- Ensure that plan is clear and easy for others to understand.
- Reference to initial discussion (e.g., verbally aggressive) must be appropriate and professional.

Activity 3

Practise oedema massage in pairs. Hold a group discussion afterwards on key points (e.g., strokes toward the heart, avoid use of jargon, use written instructions as a reminder).

APPENDIX 7

Powerpoint presentation