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Appendix 1

Literature Searches 2005

Search Words	Database	Results	Refines search	Results	Retrieved References
Dementia, Alzheimer's and Palliat*	Cinhal	364			81
Palliat* and dementia	Pubmed	295	1995-2005	295	30
Dementia special care units and Palliat*	Cinhal	8			2
Dementia units	Cinhal	22			8
Special care units and dementia	Cinhal Proquest	248 75			27 5
Dementia and stag* and prognosis	Cinhal	45			3
Dementia and stag* and Alzheimer*	Cinhal	691	Last 5 years	395	17
FAST and dementia	Cinhal	67			2
Palliative approach and residential care or nursing home	APAIS Medline	121			6
Palliat* program or pathway and long term	Proquest	3			1
Palliative and aged and nursing home	Proquest	10			1
Practice development and nursing	Pubmed	6836	Combine and palliate* and dementia search	2	2

Appendix 2

ATTENTION STAFF

NEXT STAFF MEETING TO BE HELD <insert date>

IT WOULD BE GREATLY APPRECIATED IF ALL INTERESTED STAFF MEMBERS COULD ATTEND

SHARON ANDREWS RN (BN HONS) - A PhD STUDENT WITH THE UNIVERSITY OF TASMANIA WILL BE ATTENDING THE STAFF MEETING TO INFORM STAFF ABOUT RESEARCH WHICH SHE WISHES TO UNDERTAKE IN THE UNIT. SHARON WILL BE DISTRIBUTING INFORMATION ABOUT HER RESEARCH PROJECT TITLED:

"*DEVELOPING A PALLIATIVE APPROACH FOR PEOPLE WITH DEMENTIA IN A RESIDENTIALSPECIAL CARE UNIT*"

SHARON IS SEEKING ASSISTANCE FROM STAFF MEMBERS ON THE UNIT TO PARTICIPATE IN THE RESEARCH.

Appendix 3

Study Title: *Developing a palliative approach for people with dementia in a residential special care unit.*

Chief Investigator:
Dr Andrew Robinson, Senior Lecturer, School of Nursing and Midwifery, University of Tasmania.

Associate Investigators:
Dr Camillus Parkinson, School of Nursing and Midwifery, University of Tasmania.

Dr Chris Toye, School of Nursing Midwifery and Postgraduate Medicine, Edith Cowan University.

Sharon Andrews, PhD candidate, School of Nursing and Midwifery, University of Tasmania.

Purpose of the Study:
This study is designed to explore how care is currently organised for people with dementia in the special care unit through the formation an action research group. This group will consist of interested nursing and care staff from the dementia special care unit who will work together to explore issues within practice and develop their practice consistent with a palliative approach. If you choose to participate in the study, you would be involved in collaboratively planning, implementing and evaluating strategies to address areas of concern and improve the delivery of resident care.
The ultimate aim of this study is to develop nursing practice around a palliative approach to improve the provision of care for residents and their families, with dementia in a special care unit.

This study is being undertaken to fulfil the requirements of the degree of Doctor of Philosophy in Nursing, by Sharon Andrews.

Participant Benefit:
Your involvement in the study will enable you an opportunity to engage in professional development with other staff and contribute to the improvement of quality care for people with dementia and their family members.

Inclusion Criteria of the Study:
You are invited to participate in this study, which will involve registered nurses/enrolled nurses, and extended care assistants who work on the dementia special care unit. To be

included within the research you will need to have at least 12 months experience in your current position and be a permanent staff member.

Study Procedures:
If you choose to participate in the study, you will be invited to take part in a series of group meetings with the research student. It is anticipated that these meetings will occur fortnightly from late February 2006 to October 2006 and then monthly from November 2006 to March 2007 and will be of approximately one hour in duration. During these meetings you will be invited to discuss the issues surrounding the provision of palliative care for people with dementia in the special care unit.

Prior to the commencement of the project you will be invited to attend a seminar conducted by the researcher, which will provide an overview of what participating in an action research project will involve.
Each meeting will be audiotaped and later transcribed into case notes. These notes will include an initial analysis by the research student of what was said in the meeting, with the inclusion of direct comments offered by the group members. The notes will be returned to you prior to the subsequent meeting and will reflect the content of what had been discussed during the session. You will be given the opportunity to modify the notes if they contain any inaccuracies. These notes will form part of the theoretical basis for the development, implementation and evaluation of strategies to improve the provision of care for people with dementia and their families. During the meetings you need only provide information which you feel comfortable to share. The meetings will organised to occur within work hours, however occasionally they may occur when you are not on shift at the facility and it will be your decision if you choose to attend to meeting.

Possible Risks or Discomfort:
Because this study will investigate the provision of palliative care for people with dementia and their families, discussions about end-of-life care and death may emerge at times during the meetings. While it can be considered a therapeutic experience to talk about such issues with other colleagues, it is possible that some participants may find this a sensitive topic. If you experience distress or anxiety/discomfort during any meeting it will be paused and you will be given the opportunity to continue or terminate your involvement at that time. You will be offered referral and support from a trained counsellor, if you so desire.

Anonymity and Confidentiality:
All information which you share in the context of the meetings will be regarded as confidential by the student researcher. Only the student researcher and chief investigator will have access to the meeting transcripts or case notes. Members of the action research group will be assigned a code which will appear on all transcriptions and case notes. The code will be randomly chosen and assigned to you. It will consist of a letter and number. Only the student researcher and chief investigator will have access to the codes – to ensure that your identity is protected. Any information presented to others, in the PhD thesis or any other publication will be de-identified to readers through the use of these codes, so that your identity will not be revealed. Information provided by you in the

meetings will be reported in published material as either individual comments, or grouped with other comments of action research group members. Throughout the research process you will be aware of your own code that you are able to check the accuracy of the case notes which are returned to you. You may also be aware of the codes of other members in the group. Therefore, as a participant you will be asked to ensure you maintain the confidentiality of information provided by other members of the group and not disclose the content of the meetings outside the group. Your will also be asked to maintain the anonymity of others in the group.
The facility where you work will not be identifiable in any of the information presented either in the PhD thesis or any other publication.

All research data (audiotapes, transcripts) produced from the meetings will be stored in a locked cupboard in the School of Nursing and Midwifery, University of Tasmania. It shall be stored for 5 years from the completion of the study and then destroyed.

Voluntary Participation:
Your participation in the research is entirely voluntary and you may withdraw from the study at any time without prejudice. You may also withdraw any data that you have provided during the study, should you so desire. Your consent to participation in this study is evidenced by signing a consent form.

This project has received ethical approval from the Human Research Ethics Committee (Tasmania) Network which is constituted under the National Health & Medical Research Council.

Thank you for your consideration of this information. Your participation in this study would be greatly appreciated.

If you wish to participate in the study or if you have any questions you would like to ask before you make a decision, please contact and make an appointment with:
Sharon Andrews RN BN (Hons)
PhD Candidate
Ph: (03) 62[xxxxxx] or [number]
Email: sharon.andrews@utas.edu.au

Contact Persons
If you have any further questions relating to the study please contact:

Dr Andrew Robinson
Tasmanian School of Nursing and Midwifery
Locked Bag 121, Hobart
Email: andrew.robinson@utas.edu.au
OR
Dr Camillus Parkinson
Locked Bag 121, Hobart

Email: camillus.parkinson@utas.edu.au

If you have any concerns in relation to the ethical nature or complaints to the manner in which the study has been conducted please contact:
Executive Officer of the Human Research Ethics Committee (Tasmania)
Ms Amanda McAully
Tel: 62[xxxxxx]

Results of the Study:

At the completion of the study, participants will be invited to a seminar which will discuss the outcomes.

Please note that you will be given copies of the information sheet keep for your own records.

Appendix 4

Questions action area one – Education Session for SCU staff

Why is this intervention important/ how is it going to make a difference?

- Improve relative's understandings of dementia, special care unit and special care unit.
- May assist to allay some of the family member's anxiety around the time of admission.
- Booklet may also be a source of information for staff and may be a useful tool which they could direct family members to have a look at when they require more information.
- Improve family members' understandings of how staff interact and engage with residents – i.e. such interactions which outside the unit may appear inappropriate (such as validation techniques, Doll therapy).
- Open up channels of communication between staff and family members.

What do you think will be the outcome of the intervention?

- Assist family to cope with their relative's dementia and the environment when they come to visit their relative.
- May assist family member to feel more at ease when visiting their relative – which may improve relative experiences of visiting their relative on the unit.
- May assist to help family members better understand the working environment of the unit, in the sense that staff enter "the resident's world".
- May assist to improve relationships between staff and family members

What could go wrong/ what are the risks?

- Family not wanting to read or reluctant to read information provided.
- Family members may not provide feedback about the information – i.e. may not return the feedback forms; or may not wish to talk about the information.
- Family members of residents often decrease contact with residents as dementia progresses - may inhibit feedback if some family members are withdrawing.
- Staff may not have time to follow-up with family members who have not returned the feedback forms.

How will you report what happens as a result of the intervention?

- Staff will make a follow-up courtesy call to those family members who have not returned to feedback form within two weeks to seek verbal feedback.
- Staff will keep field work notes in relation to family member feedback or feedback from other staff members on the unit.

Who's responsible?

- Members of the action research group will each distribute information booklets to family members of residents on the unit.

- An allocation form will indicate the family members that each ARG member is responsible for.
- The sheet will be kept in the front of the information folder.
- On the sheet there will be space to document when the information booklet was given to the family member, whether the feedback has been returned, if a follow-up call had been made and whether the family member provided a response.

There will also be blank spaces for other staff to indicate if they have distributed a booklet to a family member of a newly admitted resident. This information will then allow the members of the ARG to follow-up with the family member if needed.

<u>Question action area two – Information packages for family caregivers:</u>

Why is this intervention important/ how is it going to make a difference?

- Enables family to be given a greater choice about their wishes for their relatives care.
- Enable wishes of family members to be documented before the end of life phase

What do you think will be the outcome of the intervention?

- Facilitate increased family involvement in the care planning process
- Create dialogue among family members about advance care planning issues
- Improve quality of care provided to residents as their condition deteriorates as the POT document will assist to guide RACF staff, GPs and family in the decision making process.

What could go wrong/ what are the risks?

- May be difficult to organise a meeting with a family member (workload issues for staff, availability of family member)
- Staff members may not understand the new form – which would inhibit them filling it out.
- Family not comfortable to talk about issues associated with POT document.

How will you report what happens as a result of the intervention?

[Person 1] and [Person 2] - they will also seek feedback from other staff who may have filled out the POT for newly admitted residents.

<u>Questions action area three – Pain assessment and management strategy:</u>

Why is this intervention important/ how is it going to make a difference?

- Improve communication between all staff re: pain assessment and management.
- Improved resident comfort as a result of improved monitoring and improved continuity towards pain management.
- Greater involvement of care staff in the formal assessment of pain – will improve the documentation of assessment.
- Improved documentation of action/intervention by trained staff.

- The form will be easily accessible to other staff such as GPs for purposes of review and will enable easier reference to the resident's ongoing pain management.
- Will reduce double documentation – no longer need to document in the daily notes if assessment and intervention are documented on the assessment form.

What could go wrong/ what are the risks?

- Form not filled out, or only filled out by some staff
- Staff not understanding how to fill out the form
- Staff continue to document in the daily notes rather than on the pain assessment and management form
-

How will you report what happens as a result of the intervention?

- Members of the ARG will keep field notes
- An audit of the completed pain forms will be undertaken at a one month and three month period. The audit after the first month will enable the group to determine wether the forms are being used and used correctly.
- Members of the ARG (Marilyn and Helen) will photocopy de-identified pain assessment forms and return them to the researcher who will conduct the audit.

How will we educate ECAs about how to use the pain assessment scale?

- [Person 3] will provide education from the Cert 3 program and explain how to use the new pain assessment form.

<u>Questions action area four – Palliative care planning case conferencing:</u>

Why is this intervention important/ how is it going to make a difference?

- Enables family to be given a greater choice about their wishes for their relatives care.
- Enable wishes of family members to be documented before the end of life phase

What do you think will be the outcome of the intervention?

- Facilitate increased family involvement in the care planning process
- Create dialogue among family members about advance care planning issues
- Improve quality of care provided to residents as their condition deteriorates as the POT document will assist to guide RACF staff, GPs and family in the decision making process.

What could go wrong/ what are the risks?

- May be difficult to organise a meeting with a family member (workload issues for staff, availability of family member)
- Staff members may not understand the new form – which would inhibit them filling it out.
- Family not comfortable to talk about issues associated with POT document.

How will you report what happens as a result of the intervention?

Appendix 4

[Person 1] and [Person 2] - they will also seek feedback from other staff who may have filled out the POT for newly admitted residents

Appendix 5

Questionnaire Development

Two tools looking at knowledge and attitudes regarding palliative care and dementia were located within the literature. With modification these tools were deemed appropriate to meet the needs of the study:

- Community attitudes to palliative care (ADoHA 2003)
- Knowledge of Alzheimer's Test (Mass & Swanson 2000)

Tool development occurred across three stages, discussed below.

1) Clarifying the conceptual domain and modification/generation.

Initial qualitative work to ensure the appropriateness of the questionnaires for the research context and participants in this study was undertaken. The "Knowledge of Alzheimer's Test" (Mass & Swanson 2000) had undergone an extensive process of development in the US as part a large scale project. For the most part, the original instrument met the needs of this project. Therefore, no changes were made to the tool during this stage of the development process.

The "Community Attitudes to Palliative Care" (ADoHA 2003) instrument was extracted from a larger information gathering tool used in research that investigated community awareness of palliative care across three states of Australia. This questionnaire provided an initial template from which a modified questionnaire suitable to the aged care environment and the specific principles of a palliative approach (ADoHA 2006) could be developed.

An essential component to a reliable instrument is its validity. Building validity begins in the earliest phases of instrument development or modification (Lynn 1986; Nunnally & Bernstein 1994). A first and essential step in modifying the "Community Attitudes to Palliative Care" (ADoHA 2003) instrument was to identify the conceptual domain. According to Carmines and Zeller (1979) this is the domain of content around which the instrument will test. The principles central to a palliative approach, as evident in the literature (ADoHA 2006) comprised the conceptual domain of the instrument. Members of my PhD supervisory team, who had expert

knowledge in palliative care and gerontology were consulted when developing the conceptual domain upon which the instrument was based. Mastaglia, Toye & Kristjanson (2003, p. 282) have supported the use of a mixed method approach to identify the domain of interest and suggest that this method contributes to development of an instrument that is both meaningful in relation to the conceptual domain and understandable in its overall intent.

Content validity of an instrument relates to how well the items of the instrument adequately reflect the domain of content to be measured (Carmines & Zeller 1979; Grant & Davis 1997; Waltz, Strickland & Lenz 1991). Modifications were made to existing items in the "community attitudes to palliative care" instrument (ADoHA 2003), and new items were generated to ensure that the central principles of a palliative approach were covered. For example, changes included:

- Addition of items relating to the multi-disciplinary nature of a palliative approach.
- Addition of an item that related specifically to dementia, in order to address staffs' knowledge around the appropriateness of a palliative approach for people with life limiting conditions other than cancer.

These changes were made in consultation with experts from the research team and experienced clinicians from the aged care environment.

During the process of item modification and generation, how items were constructed was also given careful consideration to ensure that each item measured a particular element directly relating to the conceptual domain. Mastaglia, Toye and Kristjanson (2003, p. 11) refer to this as "apparent internal consistency". Items that were considered as ambiguous by experts in the supervision team were deleted. Language within the instrument was modified to ensure its appropriateness to the aged care environment. For example, "palliative care" was replaced with "palliative approach" and "patient" was replaced with "individual". Additionally, the clarity of each item was also explored. Clarity refers to the meaning of each item being clear and understandable (Mastagalia, Toye & Kristjanson 2003). Considering that the SCU staff who would respond to the survey would have varying levels of education and literacy, "plain English" was used and jargon was avoided as a strategy to enhance clarity. Following these modifications the title of the instrument was also changed to

better reflect the intent of the tool. It was renamed the "Palliative Approach Questionnaire" and henceforth will be referred to as this or as the PAQ. The "Knowledge of Alzheimer's Test" and the "Palliative Approach Questionnaire" were subsequently reviewed by a panel of experts.

In the PAQ response options were on a 5-point Likert scale, ranging from 'strongly agree' to 'strongly disagree', with 'not sure' as an option. The response format was chosen as it would allow examination of changes in staff knowledge over time should an educational intervention be required.

2) Review of tools by an expert panel

The use of an expert panel has been supported by numerous authors as a useful means to review instruments under development (Gable & Wolf 1993; Grant & Davis 1997; Imle & Atwood 1988; Mastagalia, Toye & Kristjanson 2003). While there are varying opinions on the adequate amount of reviewers (Tilden, Nelson & May 1990; Waltz, Strickland & Lenz 1991), Lynn (1986) and Mastagalia, Toye and Kristjanson (2003) recommend between five and six reviewers in total. Other authors have indicated that the size of the panel is contingent upon desired expertise for the content review (Grant & Davis 1997). Five panel members were approached, based on their expertise across palliative care, aged care and dementia care; with three of these members also having previous experience in instrument development. It was anticipated that a panel of this size would provide sufficient feedback for the purposes of the review.

The reviewers were contacted initially via email and following their acceptance, they were sent a "Letter of Introduction to the project" (see below), "Review Instructions" (see below) on how to undertake the review and a "Reviewer Template" (see below) on which they could document their response to each item. For the "Palliative Approach Questionnaire", feedback from the panel was requested in relation to content validity, clarity and apparent internal consistency. The template for instrument development published by Mastagalia, Toye & Kristjanson (2003) was used to guide panel members. The merits of the review template were that it was easy

to adapt for the project, it contained clear instructions for reviewers and enabled reviewers the opportunity to provide qualitative feedback.

A slightly different approach was adopted for the panel review of the "Knowledge of Alzheimer's Test" (Mass & Swanson 2000). Given that the tool had already undergone extensive development and psychometric testing in the US setting, the panel of reviewers were asked to consider the appropriateness of the language used in the tool, as it related to the Australian context and to provide alternatives to language that they considered unsuitable. It was noted in the reviewers' instructions that the terms "Alzheimer's" and "Alzheimer's disease" would be replaced with "dementia", in recognition that dementia encompassed a range of causes for cognitive impairment in older people. The panel was also informed that the tool would be administered to staff with varying educational backgrounds and were asked to comment on whether the questions were appropriate for different levels of staff (e.g. RNs, ENs, PCAs, service staff). Finally, the reviewers were encouraged to comment on any other issues as they saw necessary with respect to this tool

I compiled the "Results of the panel review" (see below) review and evaluated with the assistance of one of my research supervisors who had expertise in instrument development. The "Knowledge of Alzheimer's Test" was renamed as the "Knowledge of Dementia Quiz" (KDQ). It was considered that replacing the word "test" with "quiz" would make the title of the instrument less confronting to staff members who may have previously had little experience of undertaking surveys. During the above development activities I also designed a demographic questionnaire in consultation with the ARG members, to elicit information from respondents about their previous education with respect to dementia and palliative care.

3) Piloting of questionnaires and final modifications.

The final step in the process of tool modification was piloting. The demographic questionnaire, PAQ and KDQ were piloted with 17 staff members from another RACF not involved with the research, who volunteered to participate. The group of staff members comprised: two ENs; four RNs, seven PCAs; two catering staff; and two lifestyle and leisure officers. When the questionnaires were administered to these

staff I was present so that they could discuss any issues or problems they encountered when completing the questionnaires. Staff members were instructed to consider if each item on the questionnaires was clear and understandable. They were asked to comment on the layout of the questionnaires, the ease of completion and any unclear items, or items that they considered contain jargon. The staff members were also asked to indicate whether they felt that any of the questions were inappropriate for their level of knowledge/ understanding. Only minor problems were reported in the pilot and these could be easily addressed (see below "Piloting Results"). The final versions of the demographic questionnaire, PAQ and KDQ are provided in Appendix 6.

References

ADoHA 2003, *Community attitudes to palliative care issues*, Canberra, ADoHA, Rural Health and Palliative Care Branch.

ADoHA 2006, *Guidelines for a palliative approach in residential aged care, enhanced version*, Canberra, Rural Health and Palliative Care Branch, Government Department of Health and Ageing.

Brazil, K. & Vohra, J.U. 2005, Identifying educational needs in end-of-life care for staff and families of residents in care facilities, *International Journal of Palliative Nursing*, vol. 11, 475-480.

Carmines, E.G. & Zeller, R.A. 1979, *Reliability and validity assessment*, Beverly Hills, Sage.

Gable, R & Wolf, M 1993, *Instrument development in the affective domain*, 2nd edn, Kluwer Academic Publishers, Norwell.

Grant, J. & Davis, L. 1997, Selection and use of content experts for instrument development, *Research in Nursing and Health*, vol. 20, 269-274.

Imle, M. & Atwood, J. 1988, Retaining qualitative validity while gaining quantitative reliability and validity: development of the transition to parenthood concerns scale, *Advanced in Nursing Science*, vol. 11, 61-75.

Lynn, M. 1986, Determination and quantification of content validity, *Nursing Research*, vol. 35, 382-385.

Mass, M. & Swanson, E. 2000, *Nursing interventions for Alzheimer's family role trials: final report to the National Institute of Nursing Research*, Iowa, University of Iowa.

Mastagalia, B., Toye, C. & Kristjanson, L. 2003, Ensuring content validity in instrument development: challenges and innovative approaches, *Contemporary Nurse*, vol. 14, 281-291.

Nunnally, J. & Bernstein, .I 1994, *Psychometric Theory*, California, McGraw-Hill Inc.

Parker, D. & De Bellis, A. 1999, A profile of dying residents in South Australian nursing homes, *International Journal of Palliative Nursing*, vol. 5, 162-170.

Tilden, V, Nelson, C & May, B 1990, 'Use of qualitative methods to enhance content validity', *Nursing Research*, vol. 39, 172-175.

Waltz, C., Strickland, O. & Lenz, O. 1991, *Measurement in nursing research*, Philadelphia, F.A. Davis.

Appendix 5

LETTER OF INTRODUCTION TO THE PROJECT

Dear [insert name],

Thank you for agreeing to assist me in the refinement of the Palliative Approach Questionnaire and the Knowledge of Alzheimer's Test. Both of these questionnaires will be used within my doctoral study, which is concerned with the development of nursing practice around a palliative approach for people with dementia in a residential special care unit.

Firstly, the Palliative Approach Questionnaire is intended to measure the knowledge of residential aged care staff about a palliative approach. I intend to administer the questionnaire during the initial and final phases of my doctoral study to various staff within the aged care facility (Registered Nurses, Enrolled Nurses, Extended Care Assistants, Diversional Therapists, Domestic and Catering Staff). The questionnaire is a modified version of an instrument developed for use by the Department of Health and Ageing to assess community attitudes to palliative care issues.[1] There was no psychometric testing undertaken on the original instrument and I am currently undertaking work to establish the reliability and validity of the modified version. Your comments are a necessary first step towards refining the instrument. The items will be scored on a 5-point Likert type Scale (strongly agree – strongly disagree and not sure). I would appreciate any comments you may have regarding the use of this type of scale; otherwise my requests for your input are listed on the enclosed sheet entitled Attachment 1.

---

[1] Department of Health and Ageing 2003, *Community Attitudes to Palliative Care Issues*, Rural Health and Palliative Care Branch, Australian Department of Health and Ageing, Canberra.

The Knowledge of Alzheimer's Test was developed at the University of Iowa, United States[2]. It has undergone Psychometric testing in the U.S. setting; however it will require some adaptation for use in the Australian setting in relation to the language used in the questionnaire. Attachment 2 contains a copy of the instrument and my requests for your comments. It is estimated that reviewing both of the instruments will take about one hour of your time.

Please feel free to ring me with any queries on [number] or [number]. I have been working with my co-supervisor to develop the instruments, Dr Chris Toye of Edith Cowen University, telephone number [number], she will also be happy to talk to you. Thank you for being so generous with your time and expertise in helping me to further refine these tools. If convenient please email you comments to me at sharon.andrews@utas.edu.au. Your input is greatly appreciated.

Yours sincerely,

Sharon Andrews RN BN (Hons)

University of Tasmania
School of Nursing and Midwifery
Private Bag 121
Hobart, Tasmania 7011
Email: sharon.andrews@utas.edu.au

[2] Mass. M & Buckwalter K 1990, *Evaluation of the Special Alzheimer's Care Unit: Phase 1*, Report of Baseline Data.

REVIEW INSTRUCTIONS

1. Clarity.

Please read each statement and indicate in Column A whether the statement is Clear (C) or Unclear (U). If it is unclear, please note the suggested changes below the statement.

2. Content Validity.

This questionnaire is intended to measure knowledge of a palliative approach among staff who are caring for older people with dementia. Please re-read each statement and indicate in Column B, by writing "Y" or "N", whether or not the statement "fits" with this intent and with the definition of a palliative approach. In Column C please write "Y" or "N" to indicate whether or not the item is redundant. If "Y" is written, please write the number of the corresponding item beside that letter.

3. Apparent Internal Consistency.

Please review the items of the questionnaire in general, and indicate, in Column D, whether or not the statements appear to measure the same thing, by writing "Y" or "N". Please also comment as you see fit.

Thank you for donating your time and using your experience to assist me in this way.

Definition: A palliative approach aims to improve the quality of life for individuals with a life-limiting illness and their families, by reducing their suffering through early identification, assessment and treatment of pain, physical, cultural, psychological, social and spiritual needs. The provision of active treatment for the person's condition may still be important and provided concurrently with a palliative approach. It aims to promote the principles of palliative care philosophy to all people whatever their illness, stage or context of the care setting.[3]

Please note that items 6,7,9,11 and 12 of the questionnaire are reversed scored.

		A	B	C	D
				REDUNDANCY. NO.	
1	A palliative approach is for older people.				
2	With an ageing population, the need for a palliative approach is going to increase.				
3	A palliative approach allows the person receiving care to choose how they live the remainder of their life.				
4	It is the doctor's obligation to inform all individuals with a life limiting illness about the option of a palliative approach.				
5	A palliative approach provides support for both the individual and their family.				

[3] Australian Department of Health and Ageing 2004, *Guidelines For A Palliative Approach In Residential Aged Care*, Rural Health and Palliative Care Branch, Australian Government Department of Health and Ageing, Canberra.

		A	B	C	D
				REDUNDANCY. NO.	
6	A palliative approach is only for people who have cancer.				
7	A palliative approach requires referral from a doctor or hospital before it can be implemented.				
8	A palliative approach helps people die with dignity.				
9	A palliative approach is another name for terminal care.				
10	A palliative approach can be appropriate for people with dementia.				
11	A palliative approach can only be provided in a specialised palliative care unit or hospice.				
12	A palliative approach can only be delivered by staff with qualifications in palliative care.				
13	A palliative approach addresses relief from physical symptoms.				
14	A palliative approach addresses psychological and spiritual distress as well as the medical side of care.				

		A	B	C	D
				REDUNDANCY. NO.	
15	A palliative approach includes bereavement support for the family.				
16	A palliative approach involves a team comprising all health care staff, the family, and where possible the individual receiving care.				

Other general comments:

_____

_____

_____

_____

Directions: Review of the Knowledge of Alzheimer's Test.

Please read each item of the questionnaire and if you do not believe that the language used is appropriate for the Australian context please suggest what you would consider to be an acceptable alternative.

Please indicate if there are any items in the questionnaire that clearly wouldn't be appropriate to the Australian context.

This questionnaire will be administered to various aged care facility staff (Registered Nurses, Enrolled Nurses, Extended Care Assistants, Diversional therapy staff, Domestic and Catering staff). Please provide any other general comments.

Please note that the terms 'Alzheimer's and Alzheimer's disease' will be replaced with 'dementia'.

The subscales for the questionnaire have been included at the end of this document.

KNOWLEDGE OF ALZHEIMER'S TEST (KAT)

(NB. correct answer in bold and underlined)

Directions: Circle T if the statement is true or F if the statement is false.

PLEASE PROVIDE COMMENT

1. Memory loss is part of the normal ageing process.	T	**F**	
2. Alzheimer's is a disease which progresses at an individual rate.	**T**	F	
3. Low stimulation is important to the individual with advanced Alzheimer's disease.	**T**	F	
4. The only loss produced by Alzheimer's disease is a progressive decline in memory.	T	**F**	
5. In the care setting, restraints are the best way to manage a demented patient who wanders.	T	**F**	
6. When a person with Alzheimer's disease shows signs of increasing confusion or stress, isolation is sometimes an appropriate management	**T**	F	

technique.			
7. Repeatedly asking questions is a symptom of the memory loss of Alzheimer's disease.	**T**	F	
8. The family with an Alzheimer's disease victim is often in a state of chronic grief.	**T**	F	
9. The T. V. is a good distracter for the patient with Alzheimer's disease.	T	**F**	
10. When a patient with Alzheimer's disease becomes accusatory, it is best to deny the accusation and remind the person of his disease process.	T	**F**	
11. Non-verbal cues are not important to the Alzheimer's disease patients because they depend more on communication content to assist function.	T	**F**	
12. Environmental control is a prime intervention with persons with Alzheimer's disease.	**T**	F	
13. Individuals with Alzheimer's disease have a tendency to become more dependent on significant others.	**T**	F	
14. Maintaining a routine is important to the person with Alzheimer's disease.	**T**	F	
15. The family is an important source of information regarding pre-admission behaviours of the patient with Alzheimer's disease.	**T**	F	
16. Making the care setting more meaningful with family pictures is helpful to the victim of Alzheimer's disease.	**T**	F	
17. Physical exercise should be			

avoided by the person with Alzheimer's disease because it increases the person's stress level.	T	**F**	
18. Rest periods should not be planned for the patient with Alzheimer's disease in order to assure sleeping throughout the night.	T	**F**	
19. Generally, the cause for disruptive behaviours in the patient with Alzheimer's disease is the loss of ability to cope with stress.	**T**	F	
20. The patient with advanced Alzheimer's disease has insight into their behaviours.	T	**F**	
21. The cerebral cortex is the area of the brain where pathological changes are most often found with Alzheimer's disease.	**T**	F	
22. Alzheimer's disease is easily diagnosed with laboratory tests and X-ray.	T	**F**	
23. There is research evidence that large amounts of Lecithin or other Choline sources used early in the disease process are beneficial in treating Alzheimer's patients.	T	**F**	
24. Radios and TVs are usually good ways to keep Alzheimer's patients in touch with the world.	T	**F**	
25. Alzheimer's patients should stay in bed all night so that they can get their sleep.	T	**F**	
26. Alzheimer's patients are often not able to learn anymore because of their brain damage.	**T**	F	
27. Nutritional requirements for Alzheimer's patients are the	**T**	F	

same as for others of the same age and amount of activity.			
28. A possible explanation for Alzheimer's patients repetitive requests for food may be impairment in the normal appetite control centre.	**T**	F	
29. Alzheimer's patients who step high over cracks or lines in the floor have a muscle control disturbance.	T	**F**	
30. There is always a continual decrease in sex drive from the early to the last stage of Alzheimer's disease.	T	**F**	
31. The loss of ability to recognize urge to defecate and/or urinate can be a reason for Alzheimer's patients' incontinence.	**T**	F	
32. Most drugs used to treat persons with Alzheimer's disease are used to increase the patient's comfort rather than to cure the disease.	**T**	F	
33. Chemical abnormalities in Alzheimer's disease are comparable in some ways to those in Parkinson's disease.	**T**	F	

Other comments:

_____

_____

_____

_____

_____

Subscales of the Knowledge of Alzheimer's Test:

Nb. No definitions were developed for these subscales, by the investigators at the University of Iowa.

Subscale	Items
Signs and symptoms of Alzheimer's	1,2,4,7,8,13,20,30,31
Treatment or care of Alzheimer's Disease patients	3,5,6,9,10,11,12,14,15,16,17,18,23,24,25, 27,32
Etiologic pathology	19,21,22,26,28,29,33

Scoring of KAT: count the number of correct answers.

RESULTS OF PANEL REVIEW

Palliative Approach Questionnaire

Findings of the panel review highlighted a number of issues with items in the palliative approach questionnaire. As a result 2 items were deleted; 4 items were reworded and another two items were broken up into additional items.
The criterion for deleting items was set at disagreement of two reviewers. Items were retained if only one reviewer disagreed and the remaining reviewers offered no comment or other negative feedback.

Item	Problem	Action
1	• Needs re-wording: unclear (R1) • Unclear – does not fit with definition, age should not be included for ethical reasons (R2)	Reworded - A palliative approach is suitable for all aged groups
2	• The item measures need for palliative approach – is not consistent with definition (R3) • Unclear - does not fit with definition, age should not be included for ethical reasons (R2)	Delete item
4	• Does not fit with intent of definition (R3). • Does not fit with definition and is too controversial (R2)	Delete Item
11	• Question may be too easy (R2)	Item remained but was slightly reworded
12	• Question may be too easy (R2)	Item remained but was slightly reworded
13	• Question may be too easy (R2)	Item remained but was slightly reworded
14	• Redundant with item 13 (R1) • Double barrelled questions (R1) Question may be too easy (R2)	Item broken up into three separate items.
16	• Question may be too easy (R2) • Double barrelled questions (R1)	Item remained but was broken up into 3 separate items.

Additional Comments:

Questions 11-16 were identified by R1 as perhaps being too easy and for this reason respondents may be able to could work out the answers. The reviewer was concerned that this could impact on identifying a difference between pre-test and post-test responses. None of the other reviewers indicated a similar concern, so the decision was made to keep the items in the instrument.

RESULTS OF PANEL REVIEW

Knowledge of Alzheimer's Test

Findings of the panel review highlighted a number of issues with items in the Knowledge of dementia test. As a result 9 items were deleted, 8 items were reworded to improve clarity of the questions and all items were modified so that "Alzheimer's disease" was replaced with "dementia", and terms such as "Alzheimer's sufferer" or Alzheimer's Victim" were replaced with "a person with dementia".

Item	Problem	Action
2.	➢ Rephrase: dementia (R3, R4)	Rephrase: dementia progresses at an individual rate.
3.	➢ Rephrase : person with dementia (R3, R4,R5) ➢ Perhaps provide an explanation of low stimulation (R1) ➢ Reword (R2)	Reworded - A calm environment if important to the individual with advanced dementia.
5.	Rephrase : person with dementia (R3, R4,R5)	Rephrased
6.	Rephrase : person with dementia (R3,R4) The emphasis on isolation as low stimulation can be seen as a negative and redundant with item 3. (R1)	Deleted
8.	Rephrase : person with dementia (R3,R4,R5)	Rephrased
9.	Rephrase : person with dementia (R3,R4,R5) Replace: distracter with distraction (R3)	Rephrased
10.	Rephrase : person with dementia (R3,R4,R5) Item may not be appropriate for staff below EN level (R4) Intent of the question is not clear.	Deleted
11.	Rephrase : person with dementia (R3,R4,R5) Item may not be appropriate for staff below EN level (R4)	Reworded: People with dementia depend more on what is said than upon non-verbal cues (e.g. body language, signs).
12.	Rephrase : person with dementia (R3,R4) Replace the word "control" with design (R2) Item may not be appropriate for staff below EN level (R4)	Reworded: The design of the environment is an important part of providing care for people with dementia.
13.	Rephrase : person with dementia (R3,R4,R5) Replace: significant others with family/carer (R3)	Reword: People with dementia tend to become more dependent on family

		friends
14.	Rephrase : person with dementia (R4)	Rephrased
15.	Rephrase : person with dementia (R3,R4)	Rephrased
16.	Rephrase : person with dementia (R2,R3,R4, R5)	Rephrased
17.	Rephrase : person with dementia (R3,R4) Item may not be appropriate for staff below EN level (R4)	Rephrased
18.	Rephrase : person with dementia (R2,R3,R4,R5) Item may not be appropriate for staff below EN level (R4)	Reworded: Rest during the day should be avoided for a person with dementia to ensure that they get a good night's sleep.
19.	Rephrase : person with dementia (R2,R3,R4,R5) Item may not be appropriate for staff below EN level (R4,R2) Double barrelled question	Deleted
20.	➢ Rephrase : person with dementia (R2,R3,R4) ➢ Item may not be appropriate for staff below EN level (R4)	Reworded: A person with advanced dementia understands why they behave the way that they do
21.	➢ Item may not be appropriate for staff below EN level (R4)	Deleted
22.	➢ Item may not be appropriate for staff below EN level (R4)	Deleted
23.	➢ Rephrase : person with dementia (R3,R4) ➢ Item may not be appropriate for staff below EN level (R4) ➢ Is this knowledge up to date? (R4) ➢ Not necessary and is redundant (R2)	Deleted
24.	➢ Rephrase : person with dementia (R2,R3,R4) ➢ Not a good question, a bit black and white, some people with AD might like the radio or TV (R2).	Rephrased
25.	➢ Rephrase : person with dementia (R2,R3,R4)	Rephrased
26.	➢ Rephrase : person with dementia (R2,R3,R4) Double barrelled question	Deleted
27.	➢ Rephrase : person with dementia (R3,R4)	Deleted

28.	• Is this the case for all dementias??? (R4)	Deleted
29.	• Rephrase : person with dementia (R3,R4)	Rephrased
30.	• Rephrase: Alzheimer's to dementia (R3,R4) • Item may not be appropriate for staff below EN level(R4)	There is always a continual decrease in sex drive from the early to the last stage of dementia.
31.	Rephrase : person with dementia (R3,R4) • Item may not be appropriate for staff below EN level (R4)	Reworded: The loss of ability to know when there is a need to go to the toilet can be a reason for incontinence in people with dementia.
32.	Rephrase : person with dementia (R3,R4) • Item may not be appropriate for staff below EN level (R4) • This item may not be appropriate now with the use of cholinesterase inhibitors…this item is perhaps not needed (R2)	Reworded: Medications used for people with dementia are used to treat the symptoms of dementia rather than as a cure.
33.	• Item may not be appropriate for staff below EN level (R4) • Is this true for all dementia types?? (R4)	Deleted

Appendix 5

PILOTING RESULTS

Palliative Approach Questionnaire:
Comments from respondents:

- Include grid lines on the questionnaire to improve ease and accuracy of completion.

No problems or comments about the items on the palliative approach questionnaire – all were considered clear and understandable

Knowledge of Dementia Quiz:
Comments from respondents:

- Majority of respondents wanted an "unsure/not sure" response category, rather than just true/false.
-

Item	Problem	Action
9	Unclear – clarify what is meant by "non-verbal cues" x....	Reworded: People with dementia depend more on what is said than upon non-verbal cues (e.g. body language, signs).
11	Add "staff" or other people to the item x....	Reworded: People with dementia tend to become more dependent on family and other people.

Appendix 6

Aged Care Staff Demographic Questionnaire

1. Please circle which member of staff you are:

a) Registered Nurse b) Enrolled Nurse c) Extended Care Assistant

d) Diversional therapist e) Catering team member f) Cleaning team member

f) Other, Please specify: _____

2. Please indicate your age:

a) Under 25 years b) 26-35 years c) 36-45 years

d) 46 years and older

3. Please show approximately how long you have worked in your current position within this organisation:

Years	Months

4. How long (overall) have you worked in aged care?

e.g.

2 years	3 months	Enrolled Nurse

5. Do you have any qualifications not already mentioned?

a) Yes b) No c) Not applicable

If Yes, please specify, (e.g.. Graduate certificate/Diploma, Certificate 3)

_____

6. Have you learned about palliative care in the past?

a) Yes b) No

If Yes please specify when and how. (e.g. 3 years ago, attendance at an education seminar; 2 years ago caring for family members who required palliative care.)

_____

_____

7. Have you learned about dementia in the past?
a) Yes b) No

If Yes please specify when and how. (e.g. 3 years ago, attendance at an education seminar; 2 years ago, caring for a family member with dementia.)

_____

_____

8. Have you worked elsewhere in palliative care?
a) Yes b) No

If Yes, please specify:

(a) what kind of setting (e.g., hospice, home)_____

(b) approximately when _____

(c) for how long _____

(d) in what position (e.g. EN)_____

PALLIATIVE APPROACH QUESTIONNAIRE

Please indicate your response by ticking the appropriate box to the following statements:

A palliative approach:

		Strongly Agree	Agree	Disagree	Strongly Disagree	Not sure
1	is suitable for all age groups.	☐	☐	☐	☐	☐
2	allows the person receiving care to choose how they live out their life.	☐	☐	☐	☐	☐
3	provides support for the person who has the illness or disease.	☐	☐	☐	☐	☐
4	provides support for the family.	☐	☐	☐	☐	☐
5	is only for people who have cancer.	☐	☐	☐	☐	☐
6	needs a referral from a doctor before it can be implemented	☐	☐	☐	☐	☐
7	needs a referral from a hospital before it can be implemented.	☐	☐	☐	☐	☐
8	helps people die with dignity.	☐	☐	☐	☐	☐
9	is another name for terminal/end of life care.	☐	☐	☐	☐	☐
10	can be suitable for people with dementia.	☐	☐	☐	☐	☐
11	needs to be provided in a specialised palliative care unit.	☐	☐	☐	☐	☐
12	needs to be provided in a specialised hospice.	☐	☐	☐	☐	☐

		Strongly Agree	Agree	Disagree	Strongly Disagree	Not sure
13	needs to be delivered by staff with qualifications in palliative care.	☐	☐	☐	☐	☐
14	aims to relieve physical symptoms.	☐	☐	☐	☐	☐
15	aims to relieve psychological distress.	☐	☐	☐	☐	☐
16	aims to relieve spiritual distress.	☐	☐	☐	☐	☐
17	includes bereavement support for the family.	☐	☐	☐	☐	☐
18	may be needed when a person is still receiving some active treatment.	☐	☐	☐	☐	☐
19	involves a team approach, the team including:					
	health care staff	☐	☐	☐	☐	☐
	the family	☐	☐	☐	☐	☐
	where possible the person receiving care.	☐	☐	☐	☐	☐

Appendix 6

	TRUE	FALSE	UNSURE
Memory loss is part of the normal ageing process.			
Dementia progresses at an individual rate.			
A calm environment is important to the individual with advanced dementia.			
The only loss produced by dementia is a progressive decline in memory.			
In the care setting, restraints are the best way to manage a person with dementia who wanders.			
Repeatedly asking questions is a symptom of the memory loss associated with dementia.			
The family of a person with dementia is often in a state of chronic grief.			
The TV is a good distraction for a person with dementia.			
People with dementia depend more on what is said than upon non-verbal cues (e.g. body language, signs).			
The design of the environment is an important part of providing care for people with dementia.			

Appendix 6

People with dementia tend to become more dependent on family and other people.

Maintaining a routine is important to the person with dementia.

The family is an important source of information about pre-admission behaviours of the person with dementia.

Making the care setting more meaningful with family pictures is helpful to a person with dementia.

Physical exercise should be avoided by the person with dementia because it increases the person's stress level.

Rest during the day should be avoided for a person with dementia to ensure that they get a good nights sleep.

A person with advanced dementia understands why they behave the way that they do.

Radios and TVs are usually good ways to keep people with dementia in touch with the world.

A person with dementia should stay in bed all night so that they can get their sleep.

A person with dementia who steps high over cracks or lines in the floor has a muscle control disturbance.

There is always a continual decrease in sex drive from the early to the last stage of dementia.

The loss of ability to know when there is a need to go to the toilet can be a reason for incontinenc
e in people with dementia.

Medications used for people with dementia are used to treat the symptoms of dementia rather than as a cure.

Thankyou for your participation.

Appendix 7

Audit tool development process

The development of the audit tool was initially guided by the "Principles for best practice in clinical audit" developed by National Institute for Clinical Excellence (NICE 2002). While the audit was not strictly a clinical audit, these principles were useful in directing initial development activities. The development of the audit tool involved the three stages.

1) Identify conceptual domain and generate audit domains and audit criteria

The conceptual domain for the audit tool was based on the key principles of a palliative approach to care (ADoHA 2006). Audit domains and specific audit criteria were generated. According to the NICE (2002, p.1) an effective and "systematic method" to developing the audit criteria is to derive them from existing "good quality guidelines or review of the evidence". Therefore, eight audit domains and 42 corresponding audit criteria were based largely on information from the *Guidelines* (ADoHA 2006) and other available evidence (NICE-SCIE 2007). The eight audit domains were:

1. Advance care planning
2. Symptom Assessment and Management
3. Psychological Support
4. Family Support
5. Spiritual Support for residents
6. Recognition of the dying phase (end-of-life care)
7. Review of care for the dying phase
8. Bereavement support

2) Identify sources documentation for audit

As part of the development process key sources of documentation central in directing care were identified. This was necessary as different sources of documentation would contain different types of information. Documentation sources identified included:

- Resident Health and Lifestyle Assessment (HLA): used to collect information about the resident across numerous domains outlined in Figure 2 (below). Nursing staff complete the resident HLA across a 28 day period after admission and is reviewed every four months.
- RCS documentation: completed by nursing and care staff for a 28 day period after admission (post a seven day settling time) and is redone on an annual basis over a 14-day period; unless there is an indication for review earlier (e.g. change in a resident's condition).
- Resident care plan: describes care processes according to the following headings: "Problems identified"; "Problem evidenced by"; "desired outcomes" and "interventions", across 16 care related areas (see Appendix 9 for an example). The care plan is informed by resident HLA and RCS documentation and written by senior nursing staff. The care plan is reviewed every three months.
- Resident daily care notes and medical notes: These notes are completed via exception reporting – therefore, entries are made when there is an exception to normal care processes or change in circumstances of the resident

The staff responsible for certain documentation could be recorded (e.g. RN, EN, PCA, other) in a column on audit tool.

Figure 2- The resident HLA documentation

Medical history	Personal hygiene
Pain assessment	Swallow assessment checklist
Physical assessment	Initial swallowing assessment
Communication assessment	Toileting assessment
Mobility	Sleep assessment
Falls risk assessment	Behaviour management
Physiotherapy assessment	Health maintenance /treatment
Eating, drinking nutrition tool	Skin integrity risk assessment
Skin integrity care assessment	religious needs assessment
Technical and complex nursing	Therapy needs assessment
Palliative care planning	Preliminary depression assessment
Preferred activities assessment	Geriatric depression assessment/ Cornell Assessment of independence

3) Panel review and piloting

The audit tool underwent an expert panel review for clarity and content validity. The same panel members who reviewed the questionnaire also participated in reviewing the audit tool. A summary of the reviewers' feedback and actions taken to amend the audit tool are outlined below. After having made the amendments the researcher conducted a pilot of the audit tool utilising notes from five residents. During this activity, it became evident that attempting to record the category of staff members who were responsible for certain documentation was extremely time-consuming and cumbersome, as not all entries clearly indicated the author. At this point a pragmatic decision was made to not record this information as it did not add significantly to the quality of the data being collected. The final version of the audit tool is provided in Appendix 8.

References:

ADoHA 2006, *Guidelines for a palliative approach in residential aged care, enhanced version*, Canberra, Rural Health and Palliative Care Branch, Government Department of Health and Ageing.

NICE-SCIE 2007, *A NICE–SCIE Guideline on supporting people with dementia and their carers in health and social care: National Clinical Practice Guideline number 42*, National Collaborating Centre for Mental Health, Royal College of Psychiatrists' Research and Training Unit, Leicester.

NICE 2002, *Principles for best practice in clinical audit*, Oxford, Radcliffe Medical Press Ltd.

Appendix 7

Key Areas	Criteria		Action
(1) Advance Care Planning	**1.1**	Usually called **Advance care planning** document. (R1)	Reword: Advance care planning document
	1.2	Is advanced care plan the same as advanced care directive the same as advanced care plan document? [R3] [R1] [R2] Need to know if there is enduring guardianship documentation. [R5]	Replace 1.2: with enduring guardian documentation. Keep the terms wishes and note if there is documentation that indicates that the person responsible "has no opinion".
	1.3	Suggest adding: Notify family of deterioration [R2]. Why just "wishes"? What if they have no opinion, but get transferred because of the RACFs staff choice? [R1] Collapse 1.2 and 1.3 into a criteria which refers to wishes of the person responsible re: resident deterioration , rather than having separate sections for chronic vs. acute deterioration as most changes with be acute on chronic [R5]	Collapse 1.2 and 1.3 into a single criteria: Documented wishes of the person responsible in relation to course of care (e.g. treatment options) with reference to resident deterioration (also indicating if the PR has no wishes).
	1.5	Although different between some states, usually referred to as enduring power of attorney for medical decision [R2] Enduring guardianship already mentioned above. So collapse these criteria into one re: presence of a person responsible	Collapse 1.4 and 1.5 to read: Indication of person responsible for decision making.
	1.7	3 monthly would be too often and not be done. Changes in chronic illness are due to slow deterioration	Change time frame to 6-12 months.

		that is not always clearly perceptible. 6-12mths or more often as indicated [R2]	
(2) Symptom Assessment	**2.1**	Usually refer to as comprehensive assessment [R2]	Remove: global.
	2.2	Suggest: 12 months or earlier if indicated [R2] This could be redundant with 2.1, suggest that this read that symptom assessment be reviewed in last 12 months [R5]	Reword criteria: Evidence of review of comprehensive symptom assessment within the last 12 months or earlier if indicated.
	2.3	Suggest that you reconsider criteria 2.3-2.5 to look at how symptoms are assessed and managed on an ongoing basis. [R5] These criteria appear to relate to management of incidental or breakthrough symptoms.	Reconsider this criteria on piloting.
(3) Symptom Management	**3.3**	See comment criteria 2.3-2.5 this also applies here [R5]	Reconsider this criteria on piloting.
	3.5	Perhaps use offer small regular meals, or size of meals documented. [R5] Dysphagia assessment already covered in 2.1 and 2.2 [R5] Also, perhaps add something about offering regular fluids here [R4] Persistent oral feeding and issues: re fluid will be covered by the last point in relation to future consideration. Including size of meal might be important from symptom assessment perspective. [R5]	Remove comment re: persistent oral feeding. Reword criteria to read: Nutritional Management: Food choices documented Size of meal documented Separate out criteria re: future considerations – this will cover issues related to enteral feeding, offering regular fluids etc. Criteria to read: Future wishes of resident or family documented about nutrition and hydration in event of deterioration in the resident's condition.

		This may not be appropriate in some cases (re: persistent oral feeding) [R1]	
	3.6	What about oral mucosa as part of skin integrity? [R4] Air flow mattress is included under pressure relieving device, no need for it to be separate. [R2] Perhaps just include a section about the presence of interventions to manage skin integrity and this would include what you have stated. [R5]	Include: oral mucosa. Reword: Skin Integrity Assessment (including oral mucosa) Interventions for pressure area care documented (e.g. Pressure relieving devices, position changes, mouth care activities).
(4) Psychological Support	**4.2**	(Suggest to add: if necessary) according to resident's behaviour/symptom management needs – (Not all residents with dementia will need this and some facilities have the expertise on staff) [JR]	Add "if necessary"
(5) Family Support	**5.1**	Suggest to add: cultural concerns [R3] See 1.6, again not quite the same but may be too close to sustain a separate audit line. [R1]	Add cultural concerns. Keep this criteria as it has a different focus to 1.6.
	5.2	Perhaps need to roll together with 5.1. [R1]	Integrate with 5.1
	5.3	Include whether supportive interventions are documented for family member based on the assessment of need [R5]	Add a criteria identifying if supportive interventions have been documented.
(6) Spiritual Support	**6.1**	Suggest spiritual or religious orientation [R4]	Reword

	6.2	Distinction between pastoral care and spiritual seems unclear. The 2 points seem similar. [R4] Redundant with 1.6, wouldn't this happen with family reviews etc? [R1]	Reword to indicate spiritual or religious.
(8) Review of Care Plan for Dying phase	**8.1**	Pain medications should be regular not PRN [R4]	
	8.4	Suggest add: Use of appropriate pressure relieving devices. [JR]	Add

Appendix 8

Final audit tool

Aim of the audit:
To record documentation that indicates the use of a palliative approach in the residential aged care setting. The following definition of a palliative approach has been adopted:

A palliative approach aims to improve the quality of life for individuals with a life-limiting illness and their families, by reducing their suffering through early identification, assessment and treatment of pain, physical, cultural, psychological, social and spiritual needs. The provision of active treatment for the person's condition may still be important and provided concurrently with a palliative approach. It aims to promote the principles of palliative care philosophy to all people whatever their illness, stage or context of the care setting[4].

Development of the Audit tool:

- The audit tool has been developed to capture key features of a palliative approach to care. The Guidelines for a Palliative Approach in Residential Aged Care (ADoHA, 2004) have been used as a guide to identity the key audit areas, these being:
  - Advance care planning
  - Symptom Assessment
  - Symptom Management
  - Psychological Support
  - Family Support
  - Spiritual Support
  - Recognition of the dying phase (end of life care)
  - Bereavement support

Audit criteria are listed under each of these headings.

Documentation to be audited:

- Resident care plan; daily nursing notes; medical notes; admission documentation; RCS (resident classification scale) documentation.

Time Frame for the audit:

- Daily nursing notes and medical notes will be audited retrospectively across a time frame of 12 months, from the audit date. This time frame of 12 months was chosen on expert opinion, with the intention of providing a long enough time frame to capture a spread of documentation of events or practices relevant to a palliative approach in the long term care setting.

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[4] Australian Department of Health and Ageing 2004, *Guidelines For A Palliative Approach In Residential Aged Care*, Rural Health and Palliative Care Branch, Australian Government Department of Health and Ageing, Canberra.

- The resident's current care plan, admission documentation and most recent RCS assessment will also be spot audited.

Resident notes to be audited:

- The notes of 15 residents will be audited, these residents being randomly selected from the total of 36 who are currently in the dementia special care unit in the aged care facility involved in the study.
- In addition to this, notes from at least five residents who have died in the previous 12 months will also be audited to establish the extent to which the last two key audit areas were addressed (timely recognition of the dying phase and bereavement support).

Abbreviations contained in the audit tool:

Where the information was documented:
CP: Care plan
Notes: nursing notes (NN) or medical notes (MN)
Ad: Admission documentation
RCS: RCS documentation
Other: behaviour charts, diversional therapy care plan

Key Areas	Criteria	Where information was documented					Additional Information
		CP	Notes	Ad	RCS	other	
(1) Advance Care Planning	**(1.1)** Advanced care plan document						
	(1.2) Documented future wishes in relation to: **Deterioration in chronic condition:** ➢ Course of action (supportive care, active measures) ➢ Wishes re: transfer to another facility (acute) ➢ Notify family of deterioration						

	(1.3) Documented Nominated person for decision making/guardian **(1.4)** Enduring power of attorney (medical decisions)						
	(1.5) Documented meetings between family and health care team (and resident if appropriate) re: future/advanced care planning.						
	(1.6) Evidence of regular review of advance planning documentation in consultation with family (e.g. 6-12 months or more often as indicated)						
(2) Symptom Assessment	**(2.1)** Evidence of comprehensive assessments on admission						**Specify**:
	(2.2) Evidence of formal symptom assessment in the last 12 months or earlier if indicated						**Specify:**
	(2.3) Documentation of asking resident re: symptoms – “do you have pain/discomfort/an ache”, “are you short of breath”						
	(2.4) Documentation of resident verbalising a symptom.						
	(2.5) Documentation of staff observation - non-verbal descriptors or cues observed for symptoms:						

	e.g. pain, dysphagia, dyspnoea refer to Attachment 1 for examples						
(3) Symptom Management	**(3.1)** Non-pharmacological interventions for symptom management						
	(3.2) Documented effect/follow-up of interventions: ➢ E.g. behaviour indicates reduced pain and increased comfort ➢ E.g. reduced coughing when swallowing E.g. Decreased breathlessness following intervention						
	(3.3) Evidence of multi-disciplinary input to assist symptom management if required by the resident: E.g.: ➢ Physiotherapy ➢ Chronic pain team ➢ Dietician ➢ Speech pathology ➢ Palliative care specialist ➢ Dementia support unit						
	(3.4) Nutritional Management: ➢ Resident						

	preferences for food documented ➢ Documented: offer small regular meals ➢ Small amounts of fluid regularly if appropriate ➢ Dysphagia assessment ➢ Documentation re: considerations relating to enteral feeding, with family and resident if possible – where appropriate ➢ Oral health assessment.						
	(3.5) Skin integrity: ➢ Documentation related to use of pressure reliving devises – eggshell mattress, spenco mattress, air flow mattress						
	(3.6) Evidence of regular review of symptom management E.g.. Care plan review 3 monthly or as indicated by change in condition (i.e. is management strategy working?)						
(4) Psychological Support	**(4.1)** Use of screening tools: ➢ Depression (Corneal scale for						

	depression in dementia) ➢ Delirium screening tool						
	(4.2) Evidence of input/consultation from specialists service input if necessary according to residents needs – ➢ psycho geriatric ➢ Dementia support unit ➢ Specialist Palliative Care services						
	(4.3) Non-pharmacological interventions to assist with psychological support: ➢ Therapeutic touch unless otherwise documented ➢ Pastoral care input						
(5) Family Support	**(5.1)** Documented discussion(s) with family : ➢ resident's condition, ➢ course of illness ➢ prognosis ➢ care/treatment options – involvement in decision making ➢ family concerns ➢ Cultural concerns						
	(5.2) Evidence of discussion with family about a palliative approach or palliative care (did this occur separately						

	from 5.1? or was is implicit within earlier discussions documented)						
	(5.3) Documentation of ➢ assessment of family needs for support and what support is already available ➢ Genogram or family tree/information to document relationships with family members. ➢ Level of involvement family wishes to have in residents care						
	(5.4) Pastoral care involvement Spiritual care						
(6) Spiritual Support	**(6.1)** Documentation of spiritual orientation and needs.						
	(6.2) Evidence of review of spiritual needs in consultation with resident (if possible) and family.						
	(6.3) Evidence of spiritual support: ➢ Pastoral care or Chaplin involvement ➢ Evidence of involvement from other spiritual person						

	➢ NB check that 6.2 and 6.3 have not doubled up on the same information!						
(7) Recognition of the Dying Phase	**(7.1)** Documented discussion with family re: ➢ deteriorating condition ➢ clarification of care options						
	(7.2) Evidence of discussion re: ➢ changes that family can expect i.e. breathing, LOC, appearance						
	(7.3) Evidence discussion: ➢ Family preferences for visiting (may or may not wish to be present at time of death) ➢						
	(7.4) Documentation of signs indicating movement into end-of-life phase: ➢ peripheral shutdown ➢ changes in respiratory patterns and secretions ➢ change in LOC ➢ restlessness						
(8) Review of Care Plan for Dying phase	**(8.1)** Medication review – necessary medications only, mode of delivery						

	➢ PRN medications ordered for pain, respiratory secretions, restlessness						
	(8.2) Alternate methods of medication administration: ➢ Use of syringe driver						
	(8.3) Documented decisions regrading hydration; taking into account wishes of residents/family and best practice evidence. ➢ e.g. Frequent mouth care						
	(8.4) Skin Care : ➢ Position change only minimal if does not cause distress; pressure relieving devices						
	(8.5) Evidence of Pain assessment or documentation related to resident discomfort.						
	(8.6) Use of end-of-life assessment tools for pain and discomfort (e.g.. Assessment of discomfort in dementia – ADD; Discomfort scale for dementia of Alzheimer's type – DS-DAT)						
(9) Bereavement Support	**(9.1)** Identification of bereavement support interventions for family						

(family)	**(9.2)** Evidence of follow-up bereavement support: ➢ Information, ➢ Referral to services ➢ phone call(s) by staff member						
	(9.3) Card or letter sent to family following death of resident						
	(9.4) Evidence of Pastoral care follow-up						

Appendix 9

INTERVIEW QUESTIONS

How long has your family member been on the SCU?

What did you know about dementia before or at the time of your relatives' admission to the SCU?

What did you know about the SCU at the time of your relatives' admission?

Where did you get your information from (re: dementia and the unit)?

What was it like when they were first admitted to the SCU? How did you feel?

How did the staff on the unit find out information about your relative when he/she was first admitted?

Can you tell me your experience of having a family member with dementia?
What are the difficulties of having a family member with dementia?

Can you tell me what is done well in the care of your relative and what is not done so well?

Can you tell me what palliative care means to you?

Do you consider dementia as a palliative or terminal condition?
How do you think palliative care relates to your relative?
Do you think that your family member would benefit from palliative care/a palliative approach to care?

Has anyone at the facility ever discussed with you issues around end of life care for your relative?

Has anyone asked you about what your relative's wishes if they became unwell? Has there been any planning put in place? Have you ever had any joint discussions with the GP and the facility staff?

Do you think it would be useful to have information on the unit about dementia and care practices on the unit?

Appendix 10

Information Sheet – Family Caregivers

Preamble for family members as interview participants (Read by Pastoral Carer):
[Greeting to family member]……"Good morning/Good afternoon Mr/Mrs……."
"I am approaching you on behalf of Sharon Andrews, who is a research student with the School of Nursing and Midwifery at the University of Tasmania. She is currently undertaking research on [The SCU] to develop nursing practice and improve the provision of care for people with dementia on [The SCU] and their families. As part of her study she is interested in family members' experiences of care received by yourself and your relative on the unit. She is particularly interested in your experiences or knowledge about palliative care on the unit and how nursing practice may be improved in this area. Sharon is inviting family members to take part in a one to one interview to discuss these issues. Taking part is totally voluntary and there is no pressure on you to participate. If you are not interested in participating, then it won't be held against you in any way. If you are interested in being part of this research, please let me know in the next few days if possible, and I can make an appointment for you with Sharon so that she can provide you with an information sheet and answer any questions you may have.

Information Sheet:

Study Title: *Developing a palliative approach for people with dementia in a residential special care unit.*

Chief Investigator:
Dr Andrew Robinson, Senior Lecturer, School of Nursing and Midwifery, University of Tasmania.
Associate Investigators:
Dr Camillus Parkinson, School of Nursing and Midwifery, University of Tasmania.
Dr Chris Toye, School of Nursing Midwifery and Postgraduate Medicine, Edith Cowan University.
Sharon Andrews, PhD candidate, School of Nursing and Midwifery, University of Tasmania.
Purpose of the Study:
The aim of this study is to develop nursing practice around a palliative approach to improve the provision of care for people with dementia in a special care unit and their families.

This study is being undertaken to fulfil the requirements of the degree of Doctor of Philosophy in Nursing, by Sharon Andrews.

Participant Benefit:
Your involvement in the study may contribute to the improvement of quality care for people with dementia and their family members.

Inclusion Criteria of the Study:
You are invited to participate in this study which will involve family members and a range of other stakeholders (Nursing and care staff, medical staff, allied health, management staff) who work with residents from the dementia special care unit. To be included within the research your family member will need to have been a permanent resident on the special care unit for a minimum of three months.

Study Procedures:
If you choose to participate in the study, you will be invited to take part in a single one hour interview with the research student, at a convenient time for you during August and October 2006. The interview may occur at a location of your choice or alternately in the meeting room of Southern Cross Care Training Centre. During this interview you will be invited to share your experiences as a family member regarding the care that you and you your relative receive and how this care may be improved through the provision of a palliative approach.

Each meeting will be audiotaped and later transcribed (typed out). The transcript will form part of the theoretical basis for the development, implementation and evaluation of strategies to improve the provision of care for people with dementia and their families. During the meetings you need only provide which you feel comfortable to share. You will be shown the interview transcript at a later date if you wish and have the opportunity to make changes before the data is analysed.

Possible Risks or Discomfort:
Considering that the purpose of this study is to investigate the provision of care with respect to palliation for people with dementia, discussions surrounding end-of-life care and death may emerge at times during the meetings. While it can be considered a therapeutic experience to talk about such issues, it is possible that some you may find this a sensitive topic. If you experience distress or anxiety/discomfort during any interview it will be paused and you will be given the opportunity to continue or terminate the interview. You will be offered referral and support from a trained counsellor, if you so desire.

Anonymity and Confidentiality:
All information, which you share in the context of the interview, will be regarded as confidential by the student researcher. Only the student researcher and chief investigator will have access to the interview transcripts. You will be assigned a code, which will appear in all transcriptions. The code will be randomly chosen and assigned. It will consist of a letter and number. Only the student researcher and chief investigator will have access to the codes – to ensure that your identity is protected. Any information presented to others, in the PhD thesis or any other publication will be de-identified through the use of these codes so that your identity will not be revealed. Information you provide will be reported within published material as either individual comments or grouped with comments of other interviewees. The facility at which the research is occurring will not be identifiable in any of the information

presented either in the PhD thesis or any other publication. All research data (audiotapes, transcripts) produced from the meetings will be stored in a locked cupboard in the School of Nursing and Midwifery, University of Tasmania after the completion of the study. It will be stored for 5 years from completion and then destroyed.

Voluntary Participation:
Your participation in the research is entirely voluntary and you may withdraw from the study at any time without fear of prejudice towards yourself or your relative. You may also withdraw any data which you have provided during the study, should you so desire. Your consent to participation in this study is evidenced by signing a consent form.

This project has received ethical approval from the Human Research Ethics Committee (Tasmania) Network which is instituted under the National Health & Medical Research Council

Thank you for your consideration of this information. Your participation in this study would be greatly appreciated.

If you wish to participate in the study or if you have any questions you would like to ask before you make a decision, please contact and make an appointment with:
Sharon Andrews RN BN (Hons)
PhD Candidate
Ph: (03) 62[xxxxxx] or [number]
Email: sharon.andrews@utas.edu.au

Contact Persons
If you have any further questions relating to the study please contact:
Dr Andrew Robinson
Tasmanian School of Nursing and Midwifery
Locked Bag 121, Hobart
Email: andrew.robinson@utas.edu.au
OR
Dr Camillus Parkinson
Locked Bag 121, Hobart
Email: camillus.parkinson@utas.edu.au

If you have any concerns in relation to the ethical nature or complaints to the manner in which the study has been conducted please contact:
Executive Officer of the Human Research Ethics Committee (Tasmania)
Ms Amanda McAully
Tel: 62[xxxxxx]

Results of the Study: At the completion of the study, participants will be invited to a seminar which will discuss the outcomes. Please note that you will be given copies of the information sheet to keep for your own records.

Consent Form – family caregiver interview

Title of Project: *Developing a palliative approach for people with dementia in a residential special care unit.*

---

1. I have read and understood the 'Information Sheet' for this study.
2. The nature and possible effects of the study have been explained to me.
3. I understand that the study involves the participation in a single 1 hour interview, where I will be asked to discuss my experiences as a family member regarding the care that I and my relative receive and how this care may be improved through the provision of a palliative approach. I understand that the interview will be audiotaped and transcribed by the research student.

   I also **agree / do not agree (please circle)** to the research student accessing my relative's nursing/medical notes and care plan for the purpose of undertaking an audit related to their care.
4. I understand that I may feel anxious or distressed as I discuss my experiences and if this occurs the interview can be terminated and I will be given the opportunity to see a trained counsellor.
5. I understand that all research data will be securely stored on the University of Tasmania premises for five years after completion of the study and will then be destroyed.
6. Any questions that I have asked have been answered to my satisfaction.
7. I agree that research data gathered from me for the study may be published provided that I cannot be identified as a participant.
8. I understand that my identity will be kept confidential and that any information I supply to the researcher(s) will be used only for the purposes of the research.
9. I agree to participate in this investigation and understand that I may withdraw at any time without any effect, and if I so wish, may request that any data I have supplied to date be withdrawn from the research.

Name of Participant: _____

Signature: Date:

Statement by Investigator

☐ I have explained this project and the implications of participation in it to this volunteer and I believe that the consent is informed and that he/she understands the implications of participation

If the Investigator has not had an opportunity to talk to participants prior to them participating, the following must be ticked.

☐ The participant has received the Information Sheet in which my details have been provided so that participants have had opportunity to contact me prior to them consenting to participate in this project.

Name of Investigator _____

Signature of Investigator _____

Appendix 11

Research Newsletter

To the staff members,

The first phase of the research project entitled: *"Developing a palliative approach for people with dementia in a residential special care unit"*, is almost complete. As part of this first phase of data collection staff were asked to complete a number of questionnaires. Thank you to those staff who participated. The response rate to the questionnaires was excellent! Out of the 42 questionnaires which were distributed to staff 37 (88%) were completed and returned. This data will make a highly valuable contribution to the research project.

Additionally, the results of the questionnaires were also very positive. Two questionnaires were given to all staff members. The *Palliative Approach Quiz*, investigated staff member's knowledge in relation to palliative approaches to care within the aged care environment. The *Knowledge of Dementia Quiz* also investigated the understandings of staff members in relation to the signs and symptoms of dementia and some care practices.

Responses to the *Palliative Approach Quiz* demonstrated that staff members had an good understanding of the principles of palliative care. The results revealed that 20 of the 21 questions were answered correctly by the majority of staff members:

- 15 questions were answered correctly by at least 90% of staff members who completed the questionnaire.
- 3 questions were answered correctly by 80-89% of staff.
- 1 question was answered correctly by 70-79% of the staff, and
- 1 question was answered by 56% of staff correctly.

There was only one question where the majority of staff did not provide a correct response.

Responses to the *Knowledge of Dementia Quiz* also demonstrated a good knowledge base of staff. The results showed that 22 of the 23 questions were answered correctly by the majority of staff.

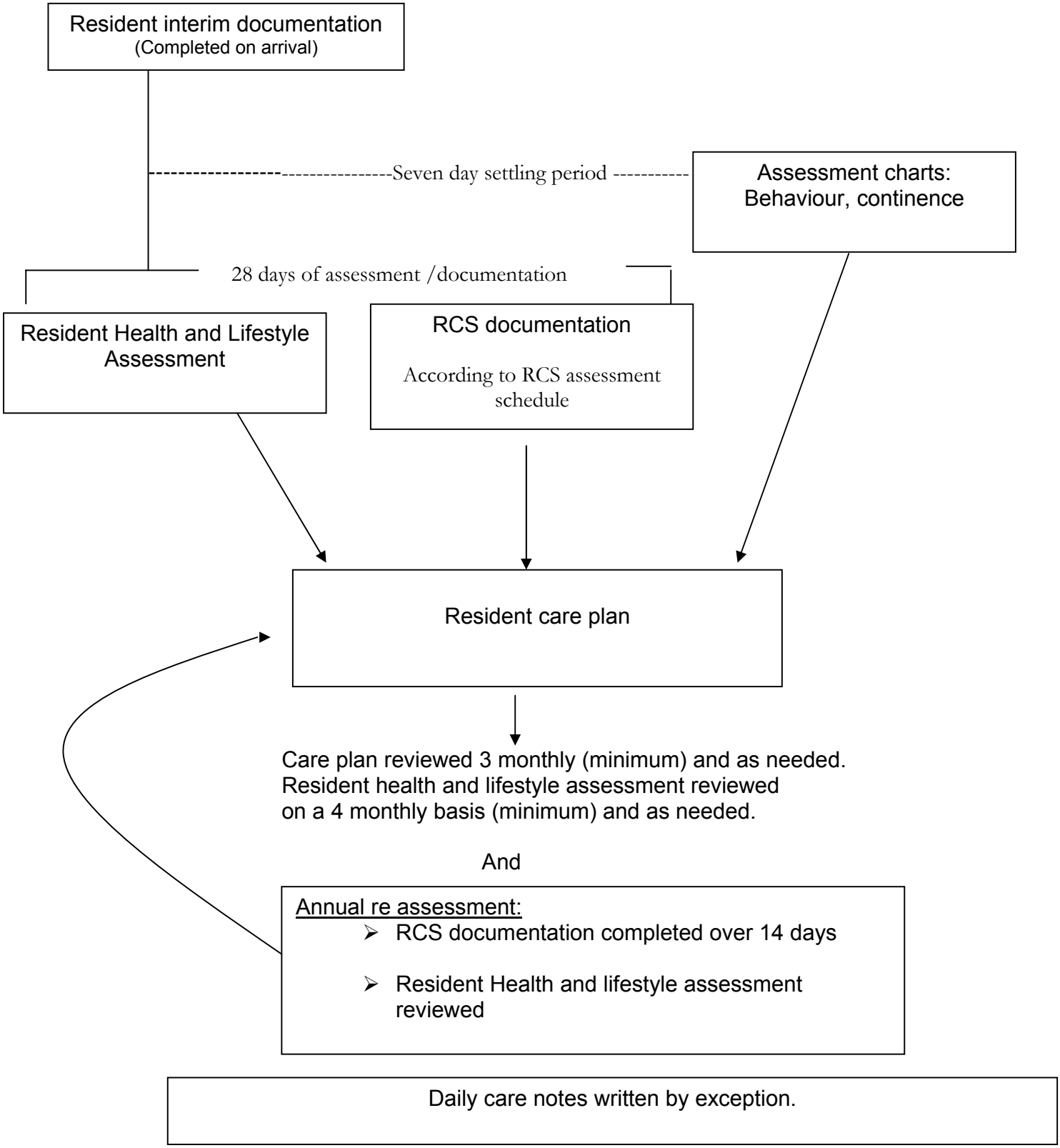
- 6 questions were answered correctly by at least 90% of staff. (n. b. 2 questions were answered correctly by 100% of staff).
- **6 questions were answered correctly by 80-89% of staff**
- 7 questions were answered correctly by 70-79% of staff, and
- 3 questions were answered correctly by 50-70% of staff.

There was only 1 question which was not answered correctly by the majority of staff.

Congratulations to those staff members who completed the questionnaires as these results are very positive. Additional newsletters will be distributed in the future to keep you informed about the project. If you have any further questions about the research please feel free to contact Sharon at or (03) 62[xxxxxx].

Appendix 12

Resident documentation processes at the facility



Appendix 13

Assessment and Management of Incidental Symptoms

Symptom Category	Episodes in 12 month period	Assessment tools used	Pharmacological interventions		Non-pharmacological Interventions	Review of symptom management strategies
			Type of intervention	Outcome		
Agitation	162 **(40% of total symptom episodes recorded)**	nil	Documented in 133 entries **(82%):** Analgesia **16%** Anxyolitic **-49%** Anxyolitic & analgesia **2%** Anti-psychotic - **14%** Anti-psychotic and analgesia **1%**	Of 133 entries: **56%**– stated medication had either 'some effect', 'little effect', 'with effect', 'with desired effect', 'good effect', 'settled effect' **44%** – no documented follow up.	9 entries – distraction, reassurance, one-to-one time 7 entries - physical restraint	2 entries – GP review of medication
Pain	222 **(53% Add % of total symptom episodes recorded)**	**2**- Formal pain assessments (RCS doc'n) Of the 222 episodes of pain staff documented: **54%**- site of the pain **17%**- analgesia given for 'general discomfort' . **15%**- analgesia given 'to promote comfort' . **14%**- 'PRN analgesia given' >**1%** - non-verbal cue of pain	212 entries - related to analgesic administration **(95%)**	Of 212 entries: **24%**– 'with effect' >**2%** - 'some/little effect' **18%**– 'good effect' (8 entries stated improvement in settled behaviour and falls; 1 entry stated content and relaxed) **57%**- no effect or outcome documented in relation to medication administration	2 entries – hot packs	3 -entries GP review 1 entry - GP referred resident to physio-therapist

Review of Drug Charts:

Analgesia **2 (out of 15)** residents ordered simple analgesia, regularly, three or four times per day

1 (out of 15) residents ordered simple analgesia once per day with an additional "as necessary" (PRN) order

1 (out of 15) residents ordered simple analgesia twice per day with an additional "as necessary" (PRN) order

7 (out of 15) residents ordered simple analgesia as necessary" (PRN) order, no regular order

4 (out of 15) residents had no analgesia ordered.

Appendix 14

Palliative care planning form

Appendix15

ARG Analysis Matrix

Thematic Concern	Identified problem	Supporting Concerns	Data Source
Addressing Knowledge and information needs of key stakeholders	Insufficient staff knowledge of a palliative approach and the Guidelines	ARG unaware of knowledge levels of SCU staff about a palliative approach	• Reconnaissance: ARG discussions
		Knowledge deficits in relation to some aspects of a palliative approach to care	• Action Cycle 1; Action Plan 1: Findings of PAQ
		Absence of open discussion amongst staff about issues associated with palliative care death and dying.	• Reconnaissance: ARG discussions • Action Cycle 1; Action Plan 4: • Narrative accounts from critical conversation with staff
		No previous education for SCU staff focusing on a palliative approach to care in the aged care context or on the Guidelines	Action Cycle 1; ARG Collaborative Analysis: ARG narratives
	Unmet information and knowledge related needs of family caregivers	Concerns that family caregivers' have poor understandings about the dementia trajectory, the special care environment and specialized dementia care practices.	• Reconnaissance: ARG discussions
		Knowledge deficits of family caregivers in relation to biomedical aspects of dementia, dementia trajectory, how to access information	• Action Cycle 1; Action Plan 3: Narrative accounts of family caregivers
	Pain assessment and	Concerns about pain assessments not being conducted when casual staff are on shift. Concerns that residents' pain is not adequately managed by casual nursing staff.	• Reconnaissance: ARG discussions
		Limited use of formal pain assessment tools to assess	• Action Cycle 1; Action Plan 2: Audit findings

Reconfiguring care practices to support evidence based standards	management processes not consistent with best practice standards	episodes of pain. Informal strategies of assessment and information transfer	[criteria 2.4]. • Action Cycle 1; ARG Collaborative analysis: ARG narratives
		Limited documentation relating to the outcome of interventions to manage pain	• Action Cycle 1; Action Plan 2: Audit findings [criteria 2.4].
		Problems in collaboration between PCAs and Nursing staff in facilitating pain management	• Action Cycle 1; ARG Collaborative analysis: ARG narratives
	Current processes for palliative care planning not consistent with best practice standards	Decision making around care issues associated with the deterioration of a resident's condition and end of life care not proactively discussed with family caregivers or the 'person responsible'.	• Reconnaissance: ARG discussions • Action Cycle 1; Action Plan 3: Narrative accounts of family caregivers • Action Cycle 1; Action Plan 4: Narrative accounts from critical conversation with staff • Action Cycle 1; ARG Collaborative analysis: ARG narratives
		No evidence indicating planned communication processes or meetings between health care team and family caregivers in relation to end of life care considerations	• Action Cycle 1; Action Plan 2: Audit findings [criteria 1.6]
		Current facility documentation for end of life planning inadequate	• Action Cycle 1; ARG Collaborative analysis: ARG narratives
		Confusion between GPs and nursing staff as to whose role it is to initiate palliative care planning conversations.	• Action Cycle 1; Action Plan 4: Narrative accounts from critical conversation with staff • Action Cycle 1; ARG Collaborative analysis: ARG narratives

Appendix 16

Palliative Approach Education Session

Guidelines for a Palliative Approach in Residential Aged Care

Rationale for introducing a palliative approach in aged care

- Industry driven
- Development of Guidelines
- Valuable tool
  - to achieve the demands of consumers
  - enhance staff skill base
  - ensure a consistent approach
- The unique needs of residents

How were the *Guidelines* developed?

- APRAC project team
- Consultation with Key Stakeholders
- Funded by the Australian Government Department of Health and Ageing through the National Palliative Care Program
- **You can find a copy in the nurses station of St Cecilia!!**

Summary of Topics Covered In Guidelines

- Palliative Approach
- Dignity and quality of life
- Advance care planning
- Advanced dementia
- Physical symptoms
- Nutrition and hydration
- Cachexia
- Dysphagia
- Mouth care, skin integrity, bowel care
- Complementary therapies
- Psychological support
- Family support
- Social support, intimacy & sexuality
- Cultural issues
- Spiritual support
- Volunteer support
- End of life (terminal care)
- Bereavement support
- Management's role in implementing a palliative approach

Palliative Approach and Accreditation : relevant Standards

- Standard 1: Management systems
  1.1-1.9 staffing and organisational developments
- Standard 2: Health and personal care
  2.4 appropriate clinical care
  2.5 specialised nursing needs
  2.6 referral to other services
  2.7 pain management
  2.9 palliative care
- Standard 3: Resident lifestyle
  3.4. emotional support
  3.6 privacy and dignity
  3.8 cultural and spiritual life
  3.9 choice and decision-making
  3.10 security of tenure

What is palliative care?

" An approach that improves the quality of life of individuals and their families facing the problems associated with a 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, psychological and spiritual"

(World Health Organisation Definition of Palliative Care 2002)

'How people die remains in the memories of those who live on' (Dame Cicely Saunders)

Three forms of palliative care

- End-of-life care
- Specialist palliative care services
- A palliative approach

End-of-life care

- Final days or weeks of life
- Goals sharply focused on the resident's physical, emotional & spiritual comfort and support for family
- Difficulties arise with determining if a resident is moving into a terminal phase with co-morbidities - requires discussion about needs/wishes with the individual/family.

Symptoms that indicate terminal phase

- Being bed bound
- Loss of appetite
- Profound weakness
- Trouble swallowing
- Dry mouth
- Weight loss
- Changes in breathing
- Day by day deterioration

Specialist palliative care services

- Provide specialist input to patients with complex end-of-life care requirements and needs
- Provide consultation (information/advice) on complex issues in partnership with primary care service/practitioner
- Interdisciplinary team provides additional resources

A palliative approach

- Improve quality of life
- Physical, spiritual, cultural, psychological, social
- Open approach to death and dying
- Includes caring for the family
- Active treatment for a disease is still appropriate
- Implemented in advance to end of life phase
- Appropriate for wide range of life limiting illnesses (eg dementia, frailty/ageing)

A Palliative Approach

- This is considered best practice in providing care for residents of aged care facilities
- THIS IS THE APPROACH THAT WE AIM TO FOSTER ON the SCU
- Resource: Palliative Approach Guidelines.

When should a palliative approach be implemented?

- *Guideline* No 1
  Methods used to identify survival time have limitation in accuracy and precision, and are therefore not recommended. Rather, a combination of active treatment to manage difficult symptoms while continuing to follow a palliative approach is considered best practice.

Where should a palliative approach be implemented?

- *Guideline* No 2

  Implementing a palliative approach in RACFs can reduce the potential distress to residents and their families caused by a transfer to an acute setting.

- *Guideline* No 3

  A palliative approach can be provided in the resident's familiar surroundings if adequately skilled care is available.

Who should implement a palliative approach?

- *Guideline* No 4

  Providing information about a palliative approach may help residents and their families to consider a palliative approach as active care rather than withdrawal of treatment.

- *Guideline* No 5

  A multidisciplinary team that promotes goal setting in collaboration with the family is critical to the success of a palliative approach. This approach decreases discomfort for residents, saves valuable resources and improves satisfaction levels for the family when they recall the care provided.

Benefits of a palliative approach

- What are the potential benefits of a palliative approach for:
  - residents and their families
  - Staff

  - Share your ideas!

Palliative approach On St Cecilia

- Our resident's are undergoing a process of gradual decline.
- This approach to caring for people is offered according to their needs and is not based on the stage of their condition or diagnosis.
- We need to openly discuss with family members our approach to care so that they can voice their wishes.

The role of carers in a palliative approach.

- Carers are central as you provide day to day "hands on" care we rely on you to provide information about any changes or issues you observe.
- You are central in communicating about how family are coping with their relatives changing condition.
- You play an important role in assisting with symptom management.

<u>Conclusion</u>
Any questions????

Next:

- **Session focusing on pain assessment/ management**
- **Trial of new pain assessment tool on the SCU and how you can help!**

Appendix 17

Feedback form – staff education session

Education Session

This evaluation forms relates to the education session conducted on a Palliative Approach. Please fill read the below statements and circle the response option that best matches the way that you feel.

1	Agree
2	Disagree
3	Not Sure

EXAMPLE:
There are no "right" or "wrong" answers to these questions 1 2 3

1.	I found it helpful to learn about a palliative approach.	1	2	3
2.	Having a better understanding of a palliative approach will assist me in caring for people with dementia.	1	2	3
3.	The education session was easy for me to understand.	1	2	3
4.	I am aware that a set of guidelines exist for a palliative approach in residential aged care.	1	2	3
5.	I know how to access the guidelines for a palliative approach in aged care, on the unit where I work.	1	2	3
6.	The presenters were knowledgeable about a palliative approach.	1	2	3

7. Would you like to attend more education about a palliative approach?

(Please tick ✔ one)

□ Yes □ No

8a. If yes please comment below:

_____

_____

9. What was the most useful part of the education session?

_____

_____

10. What was the least useful part of the education session?

_____

_____

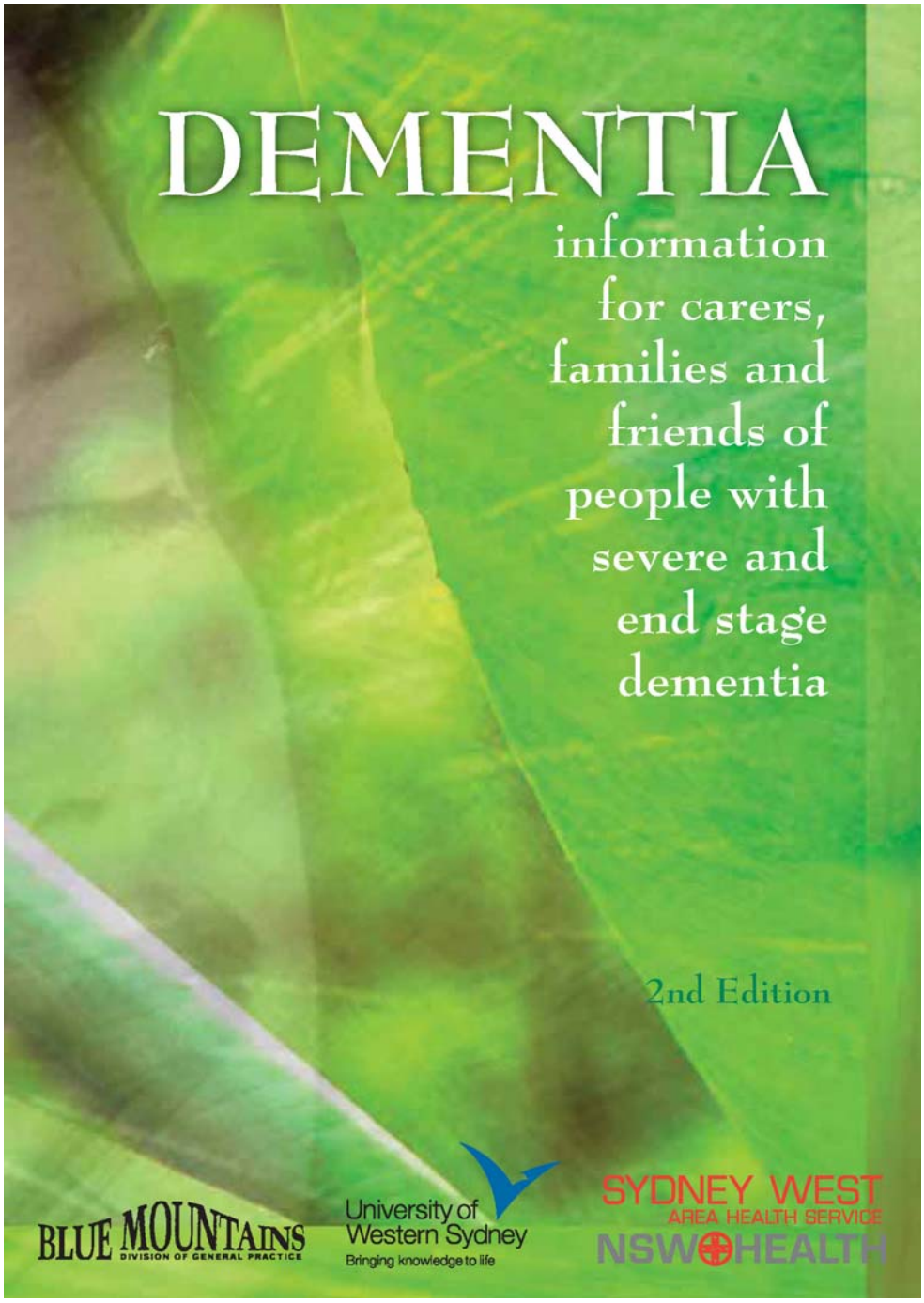
11. How would you improve the education session?

_____

_____

Appendix 18

Second edition may be found at:
http://www.uws.edu.au/__data/assets/pdf_file/0008/7100/INFORMATION_Dementia__Web_Ready.pdf which has since superseded edition one.



Appendix 19

THE SCU FACT SHEET

Characteristics of The SCU:

- Secure unit which contains 35 permanent beds and 1 respite bed.
- It has a concealed courtyard which residents have access too.
- 6 double rooms with a shared bathroom.
- 2 single rooms each with a bathroom.
- 18 single rooms with shared bathroom.

What To Expect When Visiting The SCU:

While visiting a resident is often an enjoyable experience for family members and friends, at times residents on The SCU may exhibit behaviours that you may find unusual or confronting. The information which is provided here and on the other attached fact sheets (Alzheimer's Australia) is designed to assist you in understanding that people with dementia may at times act in unexpected ways and that this is part of their disease process.

You will see and experience a variety of behaviours from residents when you visit The SCU. Below is a list of behaviours that may see or experience when you visit the SCU. Because The SCU is a unique environment and provides specialised care for people with advanced dementia, some behaviours (as outlined below) which would be considered as unusual if they occurred outside the unit, are often part of daily life for the staff and residents of The SCU.

Examples of Behaviour:

- Urinating in inappropriate places;
- Undressing in inappropriate places;
- Rummaging through belongings of others;
- Intrusiveness towards other residents and family members

The staff on the SCU, are very aware that these behaviours may be disturbing to family members, other residents and at times may compromise the dignity of a resident. Therefore, staff will do their best to act quickly in such circumstances to ensure that a resident displaying such behaviour is assisted to a more appropriate or private location. The staff on the SCU are very experienced in providing assistance to residents to ensure that their privacy and dignity is maintained.

Staff are also aware that it is important for you and your relative to spend quality time together, with minimal interruption. For this reason it is important that you inform a staff member if you feel that this is not occurring so that they may be able to redirect residents who may be interrupting you, or assist you and you family member to a more private location.

Other behaviours which you may see when visiting the SCU are:

- Residents wandering around the unit hand in hands with other residents;
- Residents wandering around the unit in small groups stating that they wish to leave or "go home";
- One or more residents standing around the entry point to the unit;
- Residents holding/nursing a doll

Residents on the SCU often form relationships with other residents which can be a positive and fulfilling experience for them. Some residents may become dependent on another resident or may not wish to separate from them. If you find that you are having difficulty in coping with this type of behaviour, please approach a staff member to discuss this.

You may also see some residents holding or nursing a doll. "Doll therapy" has long been used in the care of people with dementia. This type of intervention is only appropriate for some people with dementia. For those who do respond positively to this therapy, they can show a decrease in levels of agitation and restlessness and improved engagement with others around them. Staff monitor the use of dolls with residents very closely, if you have any questions in relation to this therapy please contact a staff member to discuss these.

Additionally, the safety of residents on the SCU is one of our central priorities, therefore it is important that you do not allow any person to leave the SCU if you do not know who they are. Always redirect the person to see a staff member if possible or find a staff member to assist you to the exit point on the unit.

The information provided within this fact sheet is a general guide as to some of the experiences you may have when visiting the SCU. We hope that this information will help you to better understand some of the unique aspects of providing care for people with dementia. If you have any further concerns or questions please approach a staff member from The SCU to discuss these.

An information booklet about dementia is also available from the SCU, free of charge for family members. The booklet provides information about:
1) The different types of dementia and common changes that occur; 2) what to expect as the dementia progresses; and 3) what sorts of issues family members/friends may need to consider in the future. If you would like a copy of this resource please ask one of the staff members from the SCU and they will be able to assist you.

Appendix 20

Family Caregiver recruitment algorithm

1. APPROACH FAMILY CAREGIVER

Approach the family member ('Person Responsible') and introduce the research intervention to them and provide them with an opportunity to participate in the intervention.

E.g. Hello Mary, can I speak with you again about the research that I am involved in? If you remember I have been part of research over the past 12 months with a nurse from the University of Tasmania. We are looking at how we can improve the car for residents on the unit and their family members. Thank you for participating in the first part of out research intervention, when we distributed the information booklets and fact sheet about [The SCU]. We have had an excellent response from family members and you have been provided with very useful information to improve our care practices. I am wondering if you would be interested in helping us with another part of our project? We want to involve family members in a process of advance care planning, where you are able to discuss your wishes for your relatives' future care and have these documented. As previously, your participation is completely voluntary, please feel free to say no if you do not want to participate.

↓

2. IS THE FAMILY CAREGIVER EXPRESSING AN INTEREST IN PARTICIPATING?

YES → ↓

NO → ↓

Thank you for your time -no further conversation needed

3. Give the family caregiver the research information sheet.

Explain:

- Take time to read the information sheet
- Draw attention to how the family caregiver can contact you.
- If the family caregiver has any questions encourage them to contact you and ask you.
- Ask the family caregiver to advise you within 2 weeks if they wish to participate.

↓

4. FAMILY MEMBER CONTACTS YOU TO PARTICIPATE

NO

YES ↓

5. **Ensure that the family caregiver has read and understood information sheet and signed consent form.**

- Staff member to sign the consent form.
- Distribute information package to family caregiver.
- **Write down family caregiver code on allocation form!**
- Remind family caregiver of the follow-up phone call (if they have agreed) in two weeks time if feedback form is not received.

Appendix 21

Evaluation form- information booklet

This set of questions relates to what you, think about the Information booklet

Thinking about **the booklet titled "Information for family and friends of people with severe and end stage dementia"**, please circle the option which best matches the way you feel about it. There are three possible answers to choose from for the first eight questions. For **each** question, **circle** the **one** number that is right for you.

1	Agree
2	Disagree
3	Not Sure

EXAMPLE:
There are no "right" or "wrong" answers to these questions 1 2 3

Please answer every question

1.	I found the booklet to be helpful.	1	2	3
2.	There were sections in the booklet that were useful to me.	1	2	3
3.	There were sections in the booklet that made me anxious.	1	2	3
4.	The booklet generally improved my understanding about dementia.	1	2	3
5.	The booklet helped me to understand some of the changes caused by dementia.	1	2	3
6.	I found it overwhelming to read the booklet.	1	2	3
7.	The booklet helped me to understand future decisions that I may need to make as my family member's dementia progresses.	1	2	3
8.	I think that the booklet will be useful to me in the future.	1	2	3
9.	The booklet was easy to understand.	1	2	3

10. I found the booklet too confronting. 1 2 3

_____

11. Do you think that the fact sheet will be useful for family members of residents who are newly admitted to the SCU? (**please tick ✔ one**)

☐ Yes ☐ No

Please comment

_____

_____

_____

12. Did you read the whole booklet? (**please tick ✔ one**)

☐ Yes ☐ No

12a. If no, which pages of the booklet did you read? (**please list**)

_____

_____

13. Were there any topics that you feel were **not covered** in the booklet that **should be included**? (**please tick ✔ one**)

☐ Yes ☐ No

13a. If yes, what topics would you like to see included:

_____

_____

14. Were there any topics included in the booklet that you think **should not have been included**? (**please tick ✔ one**)

☐ Yes ☐ No

14a. If yes please comment below:

_____

_____

15. Did the information provided in the booklet enable you to feel more comfortable to approach staff and discuss concerns which you may have had in relation to your relative?

□ Yes □ No

15a. If yes please comment below:

_____

_____

16. Did you contact any of the support services located on the back of the booklet?

□ Yes □ No

16a. If yes please comment below:

_____

_____

Appendix 22

Evaluation from: SCU fact sheet

This set of questions relates to what you think about the "SCU sheet".

Thinking about **the SCU Fact sheet** please circle the option which best matches the way you feel about it. There are three possible answers to choose from for the first eight questions. For **each** question, **circle** the **one** number that is right for you.

1	Agree
2	Disagree
3	Not Sure

EXAMPLE:
There are no "right" or "wrong" answers to these questions 1 (2) 3

1.	I found the fact sheet about the SCU to be helpful.	1	2	3
2.	The fact sheet assisted me to understand some of the things I might experience when visiting the SCU	1	2	3
3.	The fact sheet assisted me to feel less anxious about visiting the SCU.	1	2	3
4.	The fact sheet was easy to understand.	1	2	3
5.	I found it overwhelming to read the fact sheet	1	2	3
6.	The fact sheet discouraged me from visiting the SCU.	1	2	3

7. Do you think that the fact sheet will be useful for family members of residents who are newly admitted to the SCU? (**Please tick ✔ one**)

☐ Yes ☐ No

Please comment

_____

_____

_____

8. Were there any topics that you feel were **not covered** in the fact sheet that **should be included**? (**please tick ✔ one**)

□ Yes □ No

8a. If yes, what topics would you like to see included:

_____

_____

_____

9. Were there any topics included in the fact sheet that you think **should not have been included**? (**please tick ✔ one**)

□ Yes □ No

9a. If yes please comment below:

_____

_____

_____

10. Did the information provided in the fact sheet enable you to feel more comfortable to approach staff and discuss concerns, which you may have had in relation to your relative?

□ Yes □ No

10a. If yes please comment below:

_____

_____

_____

11. Approximately how long has you family member been a resident of the SCU?

_____

_____

Thankyou for you time.
Please enclose the evaluation in the self addressed stamped envelope to return.
If you do not have the self addressed envelope please return to: [inset address].

Appendix 23

Information Sheet

Study Title: *Developing a palliative approach for people with dementia in a residential special care unit.*

Chief Investigator:

Dr Andrew Robinson, Senior Lecturer, School of Nursing and Midwifery, University of Tasmania.

Associate Investigators:

Dr Camillus Parkinson, School of Nursing and Midwifery, University of Tasmania.

Dr Chris Toye, School of Nursing Midwifery and Postgraduate Medicine, Edith Cowan University.

Sharon Andrews, PhD candidate, School of Nursing and Midwifery, University of Tasmania.

Purpose of the Study:

The aim of this study is to develop nursing practice around a palliative approach to improve the provision of care for people with dementia in a special care unit and their families. This study is being undertaken to fulfil the requirements of the degree of Doctor of Philosophy in Nursing, by Sharon Andrews (referred to below as 'student researcher').

Who will be invited to be part of the study?

If you are a family caregiver or considered the person responsible for a resident on The SCU, you are invited to participate in the study.

What will be required of me in the study?

Family caregivers will be invited to take part in the study by a staff member who works on The SCU and is involved in the research project. Family caregivers taking part in the study will be asked to read two types of information. The first is an information booklet called *"Information for families and friends of people with severe and end stage dementia"* and the second is a fact sheet about The SCU which provides detailed information about the special care environment. It will take approximately 30-40 minutes to read this information package. You do not have to read it all at once; you may read the booklet in sections if this is easier. We ask that you read the information within a two week period and after you have done this, we would appreciate it if you could fill out two short questionnaires about the information. The questionnaires should take you no longer than 10 minutes to complete. You will be given a reply paid envelope to post your completed questionnaire back.

Because your feedback is very important to the study, the staff member who provides you with the information package will also ask for your permission to be contacted via phone

if we have not received your feedback forms after the two-week period. The phone call will provide you with an opportunity to give verbal feedback about the information package if you wish. If you do not want to be contacted via phone, **this does not** stop you from participating in the research.
In order for us to track who has been able to return the evaluation forms you will be assigned a number on the top of your questionnaire. This number will be kept confidential and only the staff member who gave you the information package and the student researcher will have access to these numbers and they will be destroyed at the completion of the research.
You are welcome to keep the information booklet and The SCU fact sheet.

What are the possible benefits of my participation?
Family caregivers of people with dementia have told us in earlier research that they had little knowledge about dementia and what happens to someone as their dementia progresses. They have also voiced concerns that they had little understanding of the special care environment. The benefit to you by participating in this study is that you will learn more about dementia and the changes that your relative may undergo as the disease progresses. The booklet also provides information that may assist you to make future health care decisions on behalf of your relative with dementia. The fact sheet about The SCU may also help you to better understand the special care environment. If you find the information helpful and are happy to return the evaluation forms to us, then we will be able to analyse all the responses and investigate possibilities for distributing this information to all family caregivers of residents who are admitted to The SCU in the future.

What are the possible risks or Discomfort associated with the study?
A possible discomfort associated with the study is the time taken to read the information and complete the evaluation forms. Also there is a possibility that you may feel upset if you have not heard or read information about the final stages of dementia previously. Should you feel upset by the information that you read and wish to discuss this further, please speak with the person who gave you the booklet and fact sheet, and they will be able to arrange further assistance for you. Alternatively if you do not feel comfortable to approach the staff member, please contact either the Chief investigator Dr Andrew Robinson (contact details below) or Sohn Andrews (contact details below). Furthermore, the information booklet also has a list of contact number of organisations on the back cover that will also be able to provide you with assistance.

Voluntary Participation
Your participation in the study is entirely voluntary. Your consent to participation in this study is evidenced by signing a consent form. This form will be given to you by the staff member who gave you this information sheet should you choose to be part of the study. You may withdraw at any time from the study without affecting your relationship with the health professionals caring for you relative on The SCU, nor will it affect the care of your relative in any way. Part of your participation also involves consenting to a follow-up phone call if you have not returned the evaluation forms after 2 weeks of receiving the information package. You are also free to withdraw your consent to this follow-up phone

call at any time by telephoning the person who gave you the information package or alternatively by contacting either Dr Andrew Robinson (contact details below) or Sharon Andrews (contact details below).

Confidentiality and Anonymity

All data obtained will be treated confidentiality by the research team. All data from the evaluation forms will be pooled together and analysed so you will not be able to be identified in any way. Any information presented to others, in the PhD thesis or any other publication will be published using group responses, not individual responses. The facility where your relative resides will not be identifiable in any of the information presented either in the PhD thesis or any other publication. All research data (including questionnaires) will be stored in a locked cupboard in the School of Nursing and Midwifery, University of Tasmania. It shall be stored for 5 years after the completion of the study and then destroyed.

This project has received ethical approval from the Human Research Ethics Committee (Tasmania) Network which is constituted under the National Health & Medical Research Council

If you wish to participate in the research:

Please contact the staff member who gave you this information within 2 weeks if you wish to participate Ph: (03) 62[xxxxxx].

Other Contact Persons

Dr Andrew Robinson
Tasmanian School of Nursing and Midwifery
Locked Bag 121, Hobart
Ph: (03) 62[xxxxxx]
Email: andrew.robinson@utas.edu.au

OR

Sharon Andrews
PO Box 815 Moonah 7009
Ph: [number]
Email: Sharon.andrews@utas.edu.au

If you have any concerns in relation to the ethical nature or complaints to the manner in which the study has been conducted please contact:

Executive Officer of the Human Research Ethics Committee (Tasmania)
Tel: 62[xxxxxx].

Appendix 24

CONSENT FORM

Title of Project: *Developing a palliative approach for people with dementia in a residential special care unit.*

---

1. I have read and understood the 'Information Sheet' for this study.
2. The nature and possible effects of the study have been explained to me.
3. I understand that the study involves me reading an information booklet and fact sheet and returning evaluation forms to the research team relating to these materials.

   I **DO / DO NOT** (circle response) provide consent for a member of the action research group to make a follow-up phone call to me if they have not received the evaluation forms from me after 2 weeks.
4. I understand that I may feel anxious or stressed by what read and if this occurs I am aware of who I can contact to arrange assistance/support for me.
5. I understand that all research data will be securely stored on the University of Tasmania premises for five years after the completion of the research and will then be destroyed.
6. Any questions that I have asked have been answered to my satisfaction.
7. I agree that research data gathered from the study may be published provided that I cannot be identified as a participant.
8. I understand that my identity will be kept confidential and that any information I supply to the researcher(s) will be used only for the purposes of the research.
9. I agree to participate in this investigation and understand I may choose not to return the evaluation forms and withdraw at any time without any effect, and if I so wish, may request that any data I have supplied to date be withdrawn from the research.

Name of Participant: _____

Signature: Date:

Statement by Co-Investigator

☐ I have explained this project and the implications of participation in it to this volunteer and I believe that the consent is informed and that he/she understands the implications of participation

If the Investigator has not had an opportunity to talk to participants prior to them participating, the following must be ticked.

☐ The participant has received the Information Sheet in which my details have been provided so that participants have had opportunity to contact me prior to them consenting to participate in this project.

Name of Investigator _____

Signature of Investigator _____

Appendix 25

PAIN ASSESSMENT AND MANAGEMENT FORM

AFFIX RESIDENT LABLE HERE

ECA/RN/EN may complete **columns 1 to 7**
RN/EN is required to document in **column 8** if assessment if undertaken by ECA

1. Date	2. Time	3. Location	4. Pain scale (0-10)	5. Abbey Pain Score	6. Other description (e.g.. Behavioural cues)	7. Signature of Assessor	8. Assessment confirmed by RN/EN (Y/N) and signature. If No – please state why.
20/3/07	1800	Central Abdo	Non verbal	7	Resident guarded, and holding abdo, agitated	P. Brown (ECA)	Yes

ABBEY SCALE: If resident is not able to verbalise their pain use the Abbey Pain scale. While observing the resident score the below 6 questions.

Q1: Vocalisation (e.g.. Whimpering, groaning, crying) *Absent 0 Mild 1 Moderate 2 Severe 3*
Q2: Facial expression (e.g. looking tense, frowning, grimacing, looking frightened) *Absent 0 Mild 1 Moderate 2 Severe 3*
Q3: Change in body language (e.g.. Fidgeting, rocking, guarding part of body, withdrawn) *Absent 0 Mild 1 Moderate 2 Severe 3*
Q4: Behavioural change (e.g.. Increased confusion, refusing to eat, alteration in usual patterns) *Absent 0 Mild 1 Moderate 2 Severe 3*
Q5: Physiological change (e.g. Temp, pulse, BP outside normal limits, perspiring, flushing or pallor) *Absent 0 Mild 1 Moderate 2 Severe 3*

ADD SCORES FOR Q1-6, TO GET A TOTAL PAIN SCORE ⇨

0-2	3-7	8-13	14+
No pain	Mild pain	Moderate pain	Severe pain

9. Date	10. Time	11. Interventions Analgesic and non-analges	12. Outcome 30-60mins after intervention		13. RN/EN follow-up if pain not resolved post intervention.	14. Signature
			Pain Score (Abbey score or Verbal)	Resolved (Y/N)		
20/03/07	1815	Paracetamol 1gm Hot pack x2	2	Yes		J. Bloggs (RN) P. Brown (ECA)

Note: (All sections of the form are to be competed if a section is not applicable indicate N/A)

ADD SCORES FOR Q1-6, TO GET A TOTAL PAIN SCORE ⇨

0-2	3-7	8-13	14+
No pain	Mild pain	Moderate pain	Severe pain

Appendix 26

PLAN OF TREATMENT

I _____ am the:

☐ Legally appointed guardian/enduring guardian of _____ (insert resident's name). I have attached a copy of the Guardianship order/Instrument Appointing enduring guardian. I understand that I am legally bound to follow _____(insert resident's name) specific directions and act in his/her best interests according to that document.

OR

☐ Person responsible for _____ (insert resident's name). As the person responsible, I have a right and a responsibility to understand that the proposed treatment is, what the risks and alternatives are, that I can say "yes" or "no" to a proposed treatment, and that I can seek a second opinion.

☐ I am aware that _____ (insert resident's name) has previously made a statement of wishes about their treatment. I have attached a copy of this statement.

As the "person responsible" I understand that any treatment I consent to must be in the best interests of the care recipient and must reflect any of their previously expressed wishes. Even though I may have indicated that I do not want the care recipient to have certain treatments or actions taken in their care, I understand that these may be necessary to keep the care recipient comfortable. I am aware that in order to maintain the care recipient's comfort treatment choices may need to be reviewed, especially during an end of life phase. I understand that the treatment options documented are an expression of wishes and may not necessarily be offered, if the treating doctor considers those treatments to be futile.

I request (insert name) _____ the following level of care/treatment to be provided to (insert resident's name) _____

LEVELS OF CARE/ TREATMENT	YES	NO	ADDITIONAL COMMENTS/SPECIAL REQUIREMENTS
Palliative 1 Aims to keep the person free from pain and discomfort. Any investigations or treatments will be to provide pain relief & ease discomfort, but not to prolong life. Cardiopulmonary resuscitation (CPR) will not be attempted.	☐	☐	If the resident's condition is deteriorating and death is a likely possibility, I request that the resident: (Tick any of the following if you feel they are applicable): Not be transferred to hospital unless absolutely necessary. - ☐**Yes** ☐ **No** Only be given interventions, (such as blood tests, x-rays, IV/SC fluids or antibiotics) if they are to improve comfort. - ☐**Yes** ☐ **No** Be provided with measures at the facility to enhance comfort (i.e. medication for pain/ breathlessness). - ☐**Yes** ☐ **No** Other wishes (Please specify):

	YES	NO	
Palliative 2/Limited May include palliative treatment in hospital, if necessary. May include some action to treat illness. No life support machines or intensive care measures. Does not include elective surgery except, for comfort or pain relief. Cardiopulmonary resuscitation (CPR) will not be attempted.	☐	☐	If the resident's condition is deteriorating and death is a likely possibility, I request that the resident: (Tick any of the following if you feel they are applicable) Be provided with interventions (i.e. x-rays, blood tests, transfusions intravenous/ subcutaneous fluids as deemed medically appropriate to improve comfort or the resident's condition. - ☐**Yes** ☐ **No** A trial of drugs be given if deemed medically appropriate to improve comfort or the resident's condition (e.g.. Antibiotics) - ☐**Yes** ☐ **No** Other wishes (please specify)
Active or Intensive Transfer to hospital for active treatment of the person's condition with the intent to prolong the person's life. May include surgery or other intensive/invasive life support measures (i.e. tube feeding, ventilation). In the event of deterioration transport to hospital will be arranged and following transfer all decisions will be made by the treating medical staff at the hospital.	☐	☐	If "Yes" please specify under what circumstances you would want life prolonging measures and what type of measure you would want initiated:

Please specify any other wishes regarding the resident's care (this may include other medical, nursing considerations; body or organ donation; religious and cultural considerations):

Signature (Person responsible): _____ **Date:**

Based on the work published by: the Central Coast Division of General Practice and developed in conjunction with Northern Sydney Central Coast Health; NSW advance care directive association; SESAHS Chronic and Complex care program.

Appendix 27

Advance Care Planning For a Person with Advanced Dementia In Residential Aged Care

The following information has been designed to assist you in understanding the process and importance of advance care planning for a resident with advanced dementia. This process enables aged care staff, the resident and their family to benefit from documentation that provides guidance on the preferred course of action, in the event of future health problems or deterioration of the resident. It enables decisions to be documented in advance so that the wishes of the resident (or 'person responsible') can be respected. The process for future or advanced care planning differs depending on the cognitive capacity of a person to make his or her own health and medical decisions.

Who Can Be Involved in Advance Care Planning For a Person with Advanced Dementia?

Discussions related to the future care should ideally involve the resident. However, in circumstances when they do not have the capacity to articulate their own wishes, in relation to their medical and personal care (for example people with advanced dementia), it is possible for a 'person responsible' to make these decisions on their behalf. The person responsible can state the wishes for the resident's health care based on what they believe is in the resident's best interest and consistent with what the resident would have wanted.

Advance Care Planning and Plan of Treatment

The process of advance care planning requires that you have an understanding of the person's heath status and what decisions might need to make related to their future care. Staff at the aged care facility and the person's GP will be able to assist you to understand this. You will also need to consider the wishes of the person with dementia and what they would have wanted for their future care.

A Plan of Treatment is part of the advance care planning process. It is a written document completed by the 'person responsible' that outlines their wishes and preferences for the resident's future care clinical and personal care, especially related to end of life care. This information helps to guide staff when providing care to the resident.

Who is the person responsible?

The 'person responsible' is not necessarily the person's next of kin (but in many cases they may be). The person responsible is a concept defined in law and it applies to adults who have a disability and who are incapable of consenting treatment/care options. For adults, the 'person responsible' is in the following priority order:

- A guardian (including an enduring guardian) who has the power to consent to health care, which includes the power to withdraw consent to treatment;
- A spouse, including de-facto spouse – with whom the patient has a close and continuing relationship;
- An unpaid carer who is now providing domestic services or support to the patient, or who provided these services and support before the patient entered the residential facility;

- A relative or friend who has both a close personal relationship and a personal interest in the patient's welfare.

(Note more information about the 'person responsible' can be obtained from the Guardianship and Administration Board).

As the 'person responsible', it is advisable that you take the Plan of Treatment form home and have time to read and consider it. You may wish to discuss the information with others who have a significant interest in the resident's care (i.e. family members; GP). It is important that you communicate your wishes for the resident's future care with the aged care staff so that they are aware of your wishes, can discuss these with you and answer any questions you may have. It is advisable that you meet with staff from the facility, who provide care for the resident to share your wishes and have them documented appropriately.

How Do I Change or Revoke The Plan of Treatment?

Plans of Treatment are reviewed regularly by staff at the facility in consultation with the person responsible. If the person responsible wishes to change or revoke the document, they will need to notify the medical staff either verbally or in writing. Changes to the document will also need to be signed by the person responsible.

If you have any further questions in relation to advance care planning please feel free to approach any of the following staff: [Person 1] ([The SCU]), [Person 2] ([The SCU]) or [Person 4] (Nurse Supervisor), PH: [number]

Appendix 28

Research Newsletter

To the staff members of the SCU,

The research project entitled *"Developing a palliative approach for people with dementia in a residential special care unit"* continue to be conducted on the SCU. The study is for a PhD project conducted by Sharon Andrews. The aim of the study is to investigate how care practices of staff may be developed around a palliative approach to improve the provision of care for residents on the unit and their family members.

Within this stage of the project the research team will be trialling a number of interventions on the SCU. One of these interventions will be the conduct of education sessions, which will cover aspects of a palliative approach and pain management for people with dementia. Other interventions, which will be undertaken on the unit, will also be discussed at the education sessions.

Staff are invited to attend one of the below scheduled sessions:

<Date > : < time> < Date> : < time>

Your attendance is voluntary. These sessions will be held in the meeting room at the facility. Dates and session times will also be displayed on the noticeboard on the SCU.

Your participation in one of the above sessions would be greatly appreciated and will make a valuable contribution to the research and the development of improved care practices on the SCU. The staff of the unit have been very supportive of this project in the past and we hope that this support will continue during this stage.

If you have any further questions about the research please feel free to contact Sharon at sharon.andrews@utas.edu.au or (03) 62[xxxxxx].

Appendix 29

Family caregiver – allocation form

NB. If you make a follow-up phone call to family member – document their responses to the information in your journal.

Resident Name	Staff member who distributed booklet	Booklet Given: Date and family caregiver name	Code on evaluation form	Feedback form returned (Yes/No)	Follow-up call (Yes/No)	Response to phone call (Yes/No)

Appendix 30

Pain Assessment and Management (PAM) Strategy

Staff participation criteria:

- Personal care assistants (PCAs), Registered Nurses (RNs) and Enrolled Nurses (ENs) that attended the education and information sessions associated with Palliative Approach Guidelines, will be able to participate in the trial of the PAM strategy.

PAM strategy:

- If a resident is considered to be experiencing pain or discomfort a PCA/RN/EN can undertake a pain assessment, in accordance with the Abbey pain scale (existing assessment tool used on the SCU).

- The PCA/RN/EN can document the findings of the assessment on the PAM form [columns 1 to 7 on the PAM form].

- An RN will be required to review and concur with any assessment undertaken and documented by a PCA or EN. The RN will retain responsibility for the assessment findings. If the RN disagrees with the assessment they will be required to document this and corresponding reasons why [columns 8 on PAM form].

- The choice of intervention will also remain the responsibility of the RN.

- If the intervention chosen is non-pharmacological and able to be administered by a PCA (e.g. hot drink, application of a hot/cold pack, position change, massage), the PCA can document the application of the intervention on the PAM form [columns 9 to 11].

- However, if the intervention cannot be administered by the PCA or is pharmacologically based, the RN/EN will be required to carry out the intervention as consistent with normal practice and document this on the PAM form [columns 9 to 11].

- The staff member who was responsible for the initial assessment should undertake a follow-up assessment of the resident's pain status following the chosen intervention [column 12]. If this is not possible (e.g. due to change of shift) an RN/EN may also undertake this follow-up assessment. If the resident's pain is not resolved 30-60 minutes after the intervention the RN/EN should document follow-up action taken to address this [column 13 and 14].

- The PAM forms will be stored in the nursing station of the SCU, in a specific folder which will be labelled and accessible to RNs/ENs, PCAs and GPs. An

example of a completed pain scale will be included within the folder to assist staff as will a set of guidelines for use of the form.

- The process of filling out the pain PAM form is entirely voluntary for any staff member on the unit who has undertaken the relevant education session.

Time Frame:

- The PAM strategy will be piloted over a three month period. It is also anticipated that a three month period will allow a sufficient amount of pain assessment and management forms to be trialled for the purposes of an evaluative audit.

- Considering that the PAM strategy is being trialled as part of a research project, staff have been informed at the education sessions that the PAM form does not replace their usual documentation which is required according to facility policy.

Appendix 31

Family caregiver: recruitment algorithm

2. APPROACH FAMILY MEMBER

Approach the family member ('Person Responsible') introduce the research intervention to them and provide them with an opportunity to participate in the intervention.

E.g. Hello Mary, can I speak with you again about the research that I am involved in? If you remember I have been part of research over the past 12 months with a nurse from the University of Tasmania. We are looking at how we can improve the care for residents on the unit and their family members. Thank you for participating in the first part of our research intervention, when we distributed the information booklets and fact sheet about [The SCU]. We have had an excellent response from family members and you have been provided with very useful information to improve our care practices. I am wondering if you would be interested in helping us with another part of our project? We want to involve family members in a process of advance care planning, where you are able to discuss your wishes for your relatives' future care and have these documented. As previously, your participation is completely voluntary, please feel free to say no if you do not want to participate.

2. IS THE FAMILY MEMBER EXPRESSING AN INTEREST IN PARTICIPATING?

YES

NO

Thank you for your time -no further conversation needed

3. Give the family member the research information sheet.

Explain:

- Take time to read the information sheet
- Draw attention to how the family member can contact you.
- If the family member has any questions encourage them to contact you and ask you.
- Ask the family member to advise you within 2 weeks if they wish to participate.

4. FAMILY MEMBER CONTACTS YOU TO PARTICIPATE

YES

NO

5. **Ensure that the family member has read and understood information sheet and signed consent form.**

- Staff member to sign the consent form.
- Distribute Plan of Treatment and advance care planning fact sheet.
- **Initiate discussion about advance care planning + aim of intervention + encourage family member to read pgs 22-29 in information booklet which they would have already received!**
- Organise a date for a follow-up meeting in 2 weeks.

Appendix 32

Information Sheet

Study Title: *Developing a palliative approach for people with dementia in a residential special care unit.*

Chief Investigator: Dr Andrew Robinson, School of Nursing and Midwifery, University of Tasmania.
Associate Investigators: Dr Camillus Parkinson, School of Nursing and Midwifery, University of Tasmania.
Dr Chris Toye, School of Nursing Midwifery and Postgraduate Medicine, Edith Cowan University.

Sharon Andrews, PhD candidate, School of Nursing and Midwifery, University of Tasmania.

Purpose of the Study:

The aim of this study is to develop nursing practice around a palliative approach to improve the provision of care for people with dementia in a special care unit and their families. This study is being undertaken to fulfil the requirements of the degree of Doctor of Philosophy in Nursing, by Sharon Andrews (referred to below as 'student researcher'). One of the interventions in this study involves trialling an advance care planning process for 5-10 residents on The SCU.

Who will be invited to be part of the study?
If you are a 'person responsible' for a resident on The SCU, you are invited to participate in the study. You will need to be the 'person responsible' for making medical and nursing decisions in relation to the residents care. A 'person responsible' is recognised as the person who can lawfully be a substitute decision maker on behalf of another person who has lost the capacity to make decisions for themselves.

What will be required of me in the study?
By taking part in the study you will be asked to participate in an advance care planning process on behalf of the resident you are responsible for on The SCU. Advance care planning for someone with dementia involves you thinking out and stating your wishes for the resident's health care based on what they believe is in the resident's best interest and consistent with what the resident would have wanted. These wishes relate to their future medical and nursing care in the event when the resident's health deteriorates. You may also include any other wishes related to the medical and nursing care of the resident which you feel are important or the resident would want upheld. A registered or enrolled nurse from The SCU and who is involved in the research project will have provided you with an opportunity to read this information sheet. If you wish to participate in the project please contact XXX or XXX (Contact details over page) within 2 weeks. If you agree to participate in the project you will be asked to attend at least two meetings.

The first meting will involve you reading and signing a consent form for the project. The registered or enrolled nurse will also further discuss with you the advance care planning process that you have elected to participate in. You will also be given 2 documents related to Advance Care Planning. When the registered or enrolled nurse gives you this information, they will organise a date for a second meeting with you, in approximately two weeks. A time will be made which is most convenient for you. During the two weeks prior to the planned meeting date you will be asked to take home the advance care planning documentation and read it carefully. You may discuss this documentation with any people who you think will be helpful or significant to your decision making process, this is however not a requirement.

At the next meeting, the registered or enrolled nurse and a member of the care staff, will discuss with you your wishes in relation to the future medical and nursing care of the resident. As part of this discussion your wishes may be documented on the Plan of Treatment form. If you are not ready to document your wishes and feel that you need further discussion, subsequent meetings can be organized with the staff members. The wishes that you express will act as a guide for health care professionals who are involved in providing care to the resident. The resident's General Practitioner will also be invited to this meeting so that you have an opportunity to discuss any concerns with them.

What are the possible benefits of my participation?

The advance care planning process is designed to improve the communication and documentation of wishes that the 'person responsible' has in relation to the future care of the resident on The SCU. This process will allow you to discuss with staff what you believe the resident would have wanted for their future care if their condition deteriorated. The benefits to you are that you may have a greater level of involvement in the planning of future care for the resident.

What are the possible risks or Discomfort associated with the study?

Even though you may have considered issues relating to the resident's health deteriorating in the future, and what your wishes for their care would be, there is a possibility that you may feel distressed by the sensitive nature of the information presented to you. If this occurs please contact the staff member who gave you the information and they can arrange further assistance. Alternatively if you do not feel comfortable to approach the staff member, please contact either the Chief investigator Dr Andrew Robinson (contact details below) or Sharon Andrews (contact details below). It is also possible that you may feel distressed during the meeting with the registered or enrolled nurse when you are actually filling out the Plan of Treatment form. Should this occur the staff member will ask if you wish to discontinue with meeting and a trained counsellor at the facility will be available to provide you with support. You will be given the opportunity to continue the meeting at a later date or to discontinue your participation all together.

Voluntary Participation

Your participation in the study is entirely voluntary. Your consent to participation in this study is evidenced by signing a consent form. This form will be given to you by the staff member who gave you this information sheet should you choose to be part of the study.

You may withdraw at any time from the study without affecting either your relationship with the health professionals on The SCU, nor will it affect the care of your relative/the resident in any way. You are free to withdraw your consent at any time by telephoning the person who gave you the information package or alternatively by contacting either Dr Andrew Robinson (contact details below) or Sharon Andrews (contact details below).

Confidentiality and Anonymity

All data obtained will be treated confidentiality by the research team. De-identified copies of the Plan of Treatment forms will be provided to the student researcher for analysis. The identity of the resident or yourself will not be available to the student researcher. All data from Plan of Treatment forms will be pooled together for analysis. Any information presented to others, in the PhD thesis or any other publication will not contain any information which could identify you or the resident. The facility where the resident lives will not be identifiable in any of the information presented either in the PhD thesis or any other publication. All research data ,will be stored in a de-identified format, in a locked cupboard in the School of Nursing and Midwifery, University of Tasmania. It shall be stored for 5 years after the completion of the study and then destroyed.

This project has received ethical approval from the Human Research Ethics Committee (Tasmania) Network which is constituted under the National Health & Medical Research Council

If you wish to participate in the research:

Please contact either staff members [Person 1] or [Person 2] on Ph: (03) 62[xxxxxx] on a Monday or Tuesday.

Other Contact Persons:

Dr Andrew Robinson	**OR**	
Tasmanian School of Nursing and Midwifery		Sharon Andrews
Locked Bag 121, Hobart		PO Box 815 Moonah 7009
Ph: (03) 62[xxxxxx]		Ph: [number]
Email: andrew.robinson@utas.edu.au		Email: Sharon.andrews@utas.edu.au

If you have any concerns in relation to the ethical nature or complaints to the manner in which the study has been conducted please contact: Executive Officer of the Human Research Ethics Committee (Tasmania) Tel: 62[xxxxxx].

Appendix 33

CONSENT FORM

Title of Project: *Developing a palliative approach for people with dementia in a residential special care unit.*

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1. I have read and understood the 'Information Sheet' for this study.
2. The nature and possible effects of the study have been explained to me.
3. I understand that the study involves me, as 'the responsible person', attending at least 2 meetings as part of an advance care planning process.
4. I understand that at the first meeting there will be some initial discussion about advance care planning and my role. I will be given information relating to advance care planning to take home and read. I understand that after receiving this information I have approximately two weeks to consider the information and speak to others about it if I wish.
5. I understand that in the second meeting with staff I will be asked to discuss my wishes for the future care of the resident for whom I am considered the 'person responsible'.
6. I understand that I may feel anxious or distressed by what read and if this occurs I am aware of who I can contact to arrange assistance/support for me.
7. I understand that if I become upset or distressed throughout any of the meetings I have with the registered or enrolled nurse that the meeting will be stopped and I will be given the option to discontinue the meeting and will be offered assistance/support.
8. I understand that all research data will be securely stored on the University of Tasmania premises for five years after the completion of the research and will then be destroyed.
9. Any questions that I have asked have been answered to my satisfaction.
10. I agree that research data gathered from the study may be published provided that I or the resident I am responsible for cannot be identified.
11. I understand that my identity will be kept confidential and that any information I supply to the researcher(s) will be used only for the purposes of the research.
12. I agree to participate in this investigation and may withdraw at any time without any effect, and if I so wish, may request that any data I have supplied to date be withdrawn from the research.

Name of Participant: _____

Signature: Date:

Statement by Co-Investigator

☐ I have explained this project and the implications of participation in it to this volunteer and I believe that the consent is informed and that he/she understands the implications of participation

If the Investigator has not had an opportunity to talk to participants prior to them participating, the following must be ticked.

☐ The participant has received the Information Sheet in which my details have been provided so that participants have had opportunity to contact me prior to them consenting to participate in this project.

Name of Investigator _____

Signature of Investigator _____

Appendix 34

Dear <insert GP name> ,

I would like to inform you about PhD research project being conducted on [The SCU] at [RACF] that may involve a resident(s) for whom you provide care. This project, supported by [RAC provider], has a focus on developing care practices around a palliative approach[5] for people with dementia. As part of the project, an advance care planning process will be trialled for 10-15 residents, over the next 3 months. The aim of this intervention is to improve facility documentation relating to the future care of residents with dementia. The project will principally involve the 'responsible person'[6] for the resident with dementia (in most cases this will be a family member).

Staff from [The SCU] will be providing information to those 'responsible persons' who wish to participate in the research, this information will include:

- an advance care planning fact sheet (Attachment 1) and
- a copy an advance care planning document (Plan of Treatment) (Attachment 2).

Advance care planning meetings will also be organised with the 'responsible person'. These meetings will be designed to:

- enable the 'person responsible' to discuss and outline their wishes for the resident's future care;
- clarify any questions/concerns with nursing/medical staff; and
- complete the Plan of Treatment document.

Prior to organising these meetings, one of the nursing staff from [The SCU] will contact you, if a meeting relates to a resident in your care. Your involvement in the advance care planning discussions would be highly valued. While there is no prescribed number of meetings as part of this process, it is anticipated that at least one meeting will be held to discuss issues relevant to the future care of the person with dementia. The meetings should take no longer than an hour and attempts will be made to schedule a convenient time to facilitate your attendance.

As Chair of the project steering committee, I sincerely hope that you will consider participating in this research. If you have any further questions in relation to the project, please contact Sharon Andrews on (03) 62[xxxxxx] or [number] or email Sharon.Andrews@utas.edu.au

Kind Regards

[Person 5]

Director of Nursing

[RACF]

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[5] Department of Health and Ageing (2006) Guidelines for a palliative approach in residential aged care, Department of Health and Ageing: Canberra.

[6] Responsible person as according to the Tasmanian Guardianship and Administration Act (1995).