End of Life Dementia Care

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Commonwealth Dept Health & Ageing
Advisory Committee: Prof Moyez Jiwa, A/Prof Chris Toye, Helen Dymond, Sandy Crowe, Catherine Zlantnik, Shannon Tassell, Nola Andrews
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Participating organisations
Catholic Homes Inc., Juniper Aged Care
Hall & Prior Aged Care, Southern Cross Inc.
Adventist Aged Care, Maurice Zeffert Home Inc.
Eldercare, Helping Hand, Southern Cross Care, Italian Benevolent Foundation, AASA

Alzheimer’s Australia 15th National Conference May 2013, Tasmania
Barbara Horner, Heather Freegard, Jan Akers, Curtin University
Project background

Commonwealth Govt. Palliative Care Round 5 funding for CoP-D1 Project (Community of Practice), 2010-11 involving AAWA, Curtin CHIRI, University Tasmania, Wicking DREC Menzies Institute, produced a suite of Resources www.caresearch.com.au

DoHA WADTSC’s - National Priority Area, ‘End of Life Care’

Project occurred during 2012-13

A ‘community of practice’ is a group of clinicians with a common concern, problems, or passion who commit to work together to achieve an agreed outcome.
Aims of the project

Provide a training program that could be used within an organisation independently of external support to improve end of life care of people with dementia living in residential care.

Program objectives:
1. Audit practice, identify area for improvement (gap or need)
2. Establish COP who will plan & lead the process of improvement (team committed to working together on common purpose)
3. Implement education to address the area for improvement
4. Record changes in practice
5. Manage enablers & barriers
6. Document the process of change
Project process

- Develop a training & development program (Toolkit) to build capacity of organisations to implement changes in practice
- Pilot with 5 organisations in WA – implement, evaluate, modify and improve
- Repeat with 2 new organisations in WA
- Implement through second DTSC - SA DTSC (data not included)
- Refine and improve
- Release training package through DTSC as resource, practice improvement initiative: improve practice in end of life care for PWD
Implement with 7 Organisations in WA

- Southern Cross Care Inc.
- Adventist Aged Care
- Catholic Homes Inc.
- Hall & Prior Rockingham facility
- Juniper – Annesley facility

Then

- Maurice Zeffert Home
- Juniper - Ella Williams
Implementation in SA

4 RAC providers from 7 who were approached

- Helping Hand
- ElderCare
- Southern Cross Care
- Italian Benevolent Foundation

12 X week program completed April 30th, compiling evaluation of program and Toolkit.
Project preparation - engagement

- Selection from a convenience sample of facilities; built on partners of COP project
- **Engagement** each organisation commit to participation ($2k scholarship), nominate 2 key people to participate in the program, provide time for activities, set up communication/facilitation
- The 2 key people needed to have the capability, desire, strength and knowledge to lead project and implement change, document process, report on project
Project process - development

1. Develop Facilitator Manual and Resource Kit
2. Engage, recruit and commit organisations (many conversations)
3. Workshop #1 x 1 day – introduction to program & materials,
4. Organisations commence – identify gap, form COP, start planning
5. Workshop #2 x 1 day – feedback and share progress; refine plans
6. Progress intervention within organisations
7. Workshop #3 x 1 day – reporting on project outcomes, evaluation, sustainability
Overview of program – cycle of improvement

Training Program that adopts a train-the-trainer approach
12 x weeks: assessment, education, evaluation, reflection
Supported by package of materials: Facilitator’s Manual, Resource Kit of materials, Evaluation process & tools

Stages:
1. Preparation: organisational audit with a focus on changes to practice
2. Education/development: series of modules on dementia care, palliative approach, COP, to bring about changes to practice
3. Evaluation: assessing effectiveness, consolidation, establishing future improvements
Facilitator Manual: Guide for practice improvement

Stage 1 – Preparation
Establish team leaders, identify ‘gap’ in practice (audit tool, SWOT tool)

Stage 2 – Intervention
Form COP, develop goals for intervention (COP tool, SMART tool), form action plan, implement action using resources & references

Stage 3 – Evaluation
Evaluate the process (journal notes) evaluate impact of change (instruments D-KAT2, PAQ)

Resource Kit – DVDs, booklets, articles

NB. Chang, E., Johnston, A. 2012, Challenges in Advanced Dementia, University of Western Sydney, Australia https://cdn.intechweb.org.pdfs27619.pdf

Training to care for people with dementia
Training to care for people with dementia

1. Area of Concern
   - EOL D

2. Specific Issue

3. Form a work team

4. Plan of Action

5. Implementation

6. Feedback

7. Evaluation:

Preparation

Workshop 1

Workshop 2

Follow up

Workshop 3

Change Map
Overview of participant feedback

‘great project with potential for unifying the whole team’
‘proud of the outcome’
‘information filtered out to others’
‘opportunity to influence others – ripple effect’
‘like being on a journey’
‘time to look back and reflect into the process’
‘daunting at first but the process was really quite easy’
‘success has empowered us to use the same process for further change’
Program evaluation summary

**Capacity:** AR process and tools were evaluated positively; COP some success although difficult to maintain group

**Awareness:** increased knowledge of good care, greater awareness of issues in practice, improved communication with residents & families

**Enablers:** timeline and logical steps, support from PO, resources & information impacted wide audience

**Barriers:** work and pressures got in the way, maintaining team when other issues got in the way, lack of sustained commitment of management

**Sustainability:** catalyst for organisations to develop own sustainability plans, positive if change influenced policy
Project evaluation (incomplete without SA experience)

Relationships: initiating and maintaining relationships across organisations was time consuming but achievable

Organisational commitment: had to fit with current practice

Content: maintaining currency always challenging, growing quantity of resources available

Training: little evidence to show that training alone changes practice; requires commitment, skill, leadership, staff empowerment to change culture and sustain improvement; climate of improvement - learning organisation

Sustainability: dependent upon organisational commitment to quality practice as well as staff development; outside circle of influence of external party
Issues for consideration

- Research on impact of training – DIRECT (valued but does not necessarily change practice)
- Practice improvement needs to part of business – TOrCCh (leadership, communication, empowerment, culture)
- Training approaches – flexible, sustainable, supported, ongoing, KPI not an extra
- Capacity – challenges of work, characteristics of workforce, needs of residents, operational realities
Thank you