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Australian Government Department of
Health and Ageing
National Palliative Care Program
Local Palliative Care Grant

**Communities of Practice in Palliative
Dementia Care**

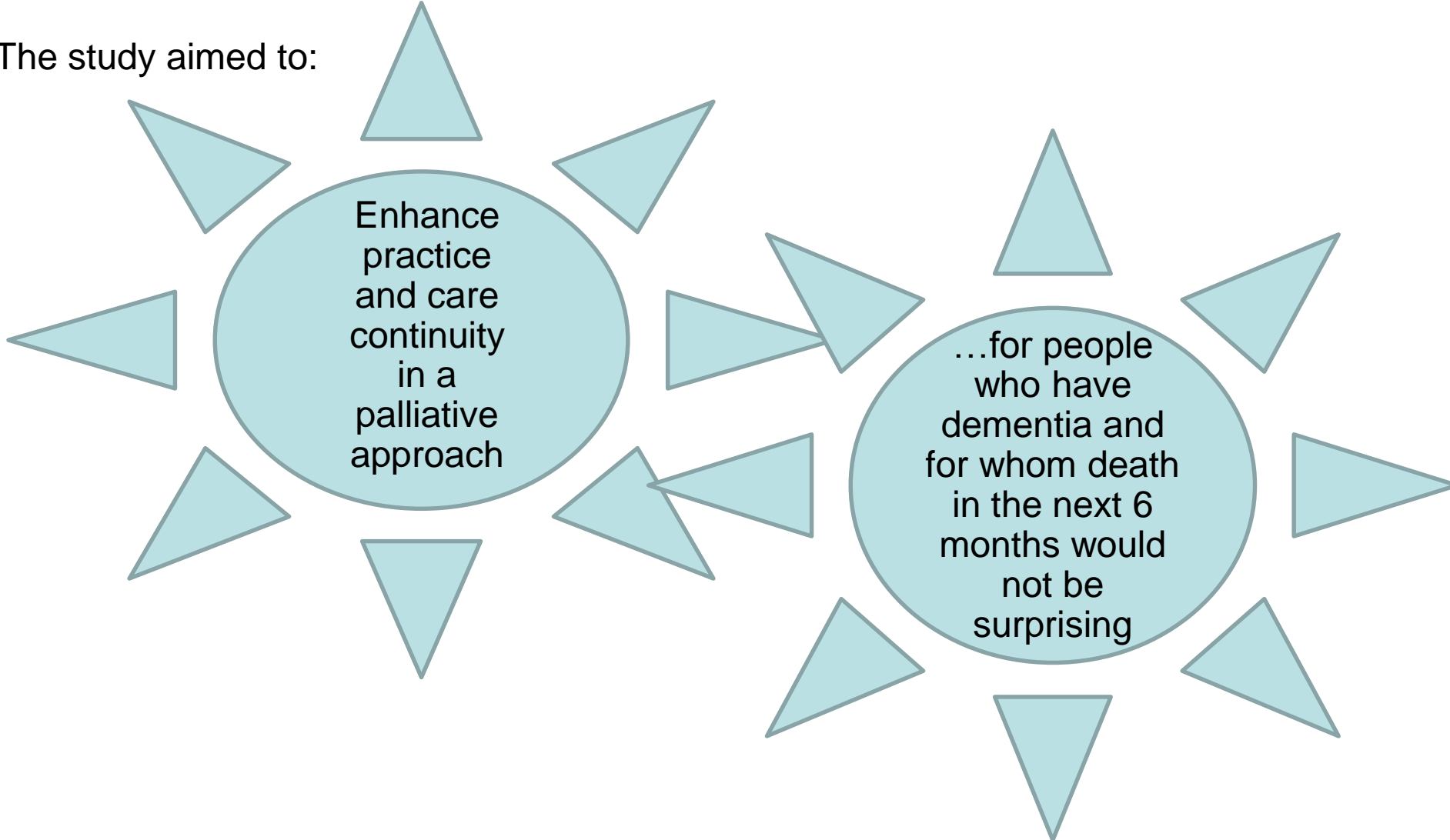
The COP-D1 Project



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The study aimed to:





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Why?





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Why a palliative approach?

- People live with dementia
- People also die with – and often because of - dementia
- A palliative approach is about quality of life and quality of death – wherever care is delivered



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- a planned, proactive approach
- in conditions that lead to death
- provides holistic care
- includes support of the family
- recognises the family carer as part of the (generalist) and multidisciplinary health care team
- may be supported by specialist palliative care



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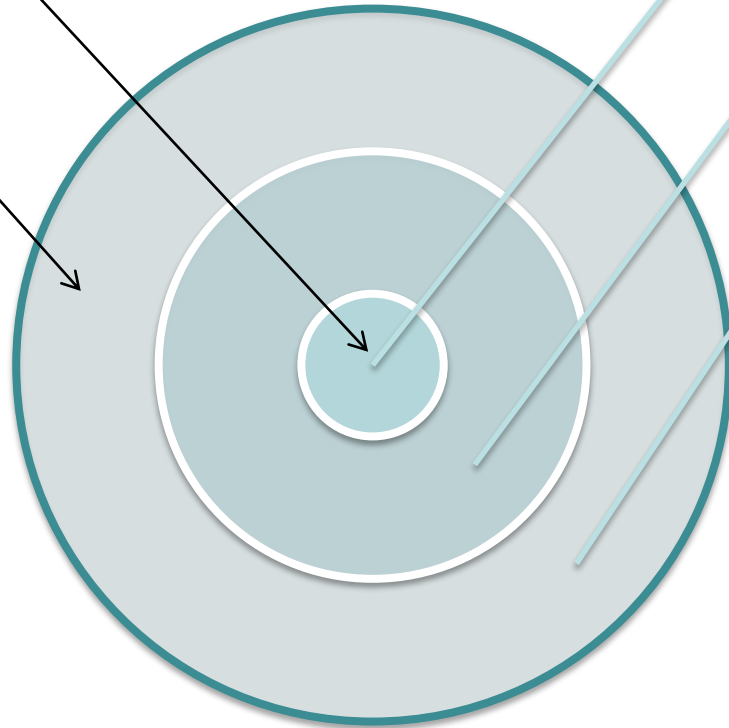


Specialist palliative care services

Person with dementia and their family

Care setting

Team providing palliative approach





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Why address care consistency close to the end of life?

- In the final months, there is a high potential for care transitions
- There is a particularly high potential for inconsistent and fragmented care



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Disempowered people + Distressed families
+ Different care providers =

Confusion

Hostility

Anxiety

Opportunities lost

Sorrow





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Alzheimer's Australia WA Ltd
Living with dementia



Curtin University



Menzies Research Institute
An Institute of the University of Western Australia



Alzheimer's Australia Tas
Living with dementia

How?





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The overview

A two-state, study that addressed:

- quality delivery of a palliative approach and care continuity
- via implementing a community of practice in each state.



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A community of practice?

A group of (mainly) practitioners:

- with shared passion for excellence in dementia care
- committed to drive enhanced practice



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Step One

Describe Current Practice

Staff surveys, key informant interviews, family interviews



Step Two

Implement Communities of Practice



Step Three

Describe and Compare Refined Practice

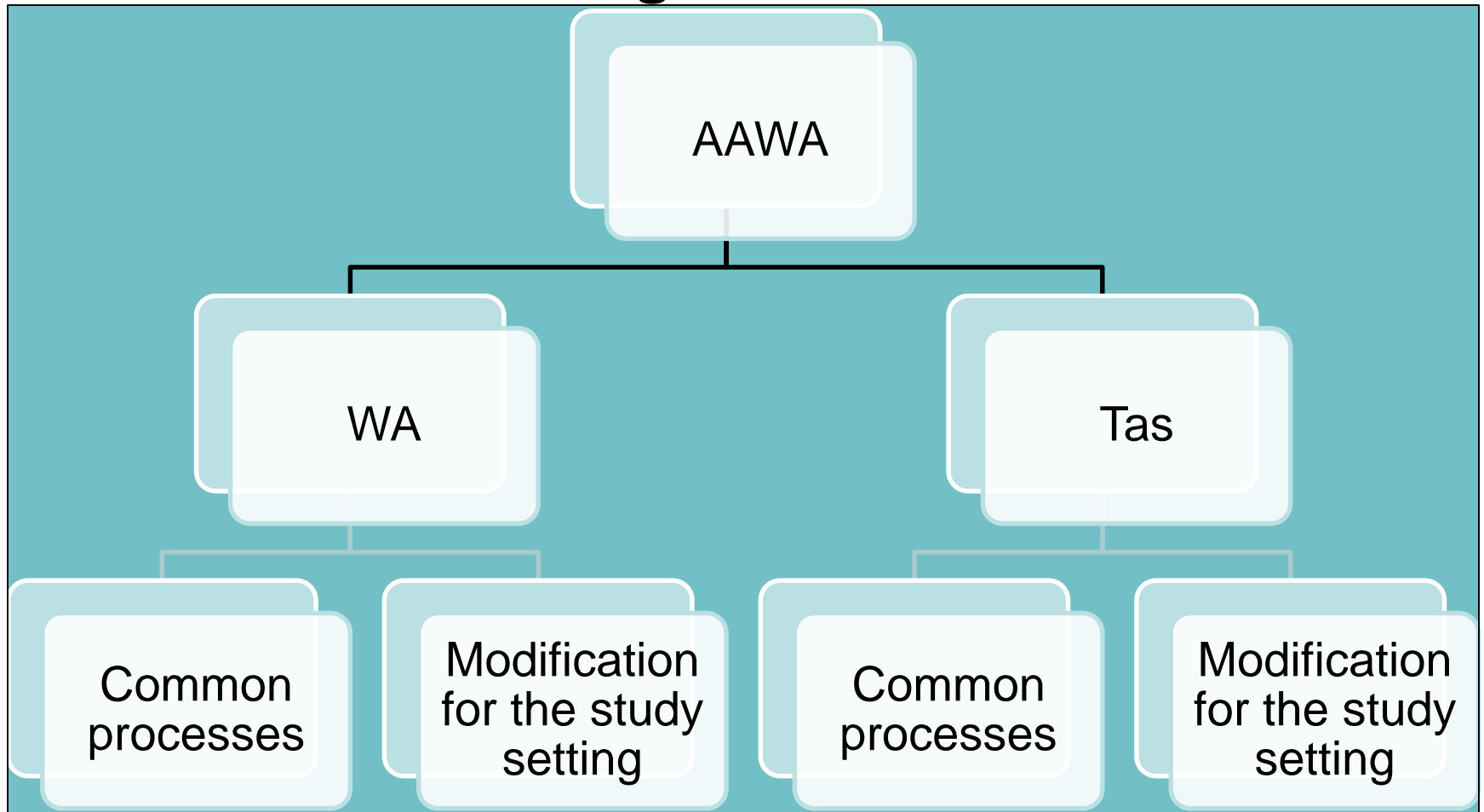
Staff surveys, key informant interviews, family surveys & interviews



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The Big Picture





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'Infrastructure' in Perth

- Coordination from AAWA (DG & SH)
- Academic leadership from Curtin Uni - CT, MJ, BH, KH
- Project Manager (JA)
- Resource Development Coordinator (CZ)
- Research Team (AP, KF, SG)
- Admin support (AC)



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Canning Division of General Practice

Bentley Hospital

Southern Cross
Community Aged
Care

Partners

AAWA in Home
Respite and Support

Annesley RACF and
Rowethorpe Medical
Centre



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Reference Group in WA

Experts

- Mrs Jean McLeod
- Dr Craig Berg
- Dr Scott Blackwell
- Prof Jeff Hughes
- Ms Helen Walker

Organisation representatives

- Ms Sam Howkins
- Ms Deb Patterson
- Dr Sean Maher
- Ms Anne Deck
- Ms Carolyn Green
- Ms Jessie Ho
- Dr Kim Walsh

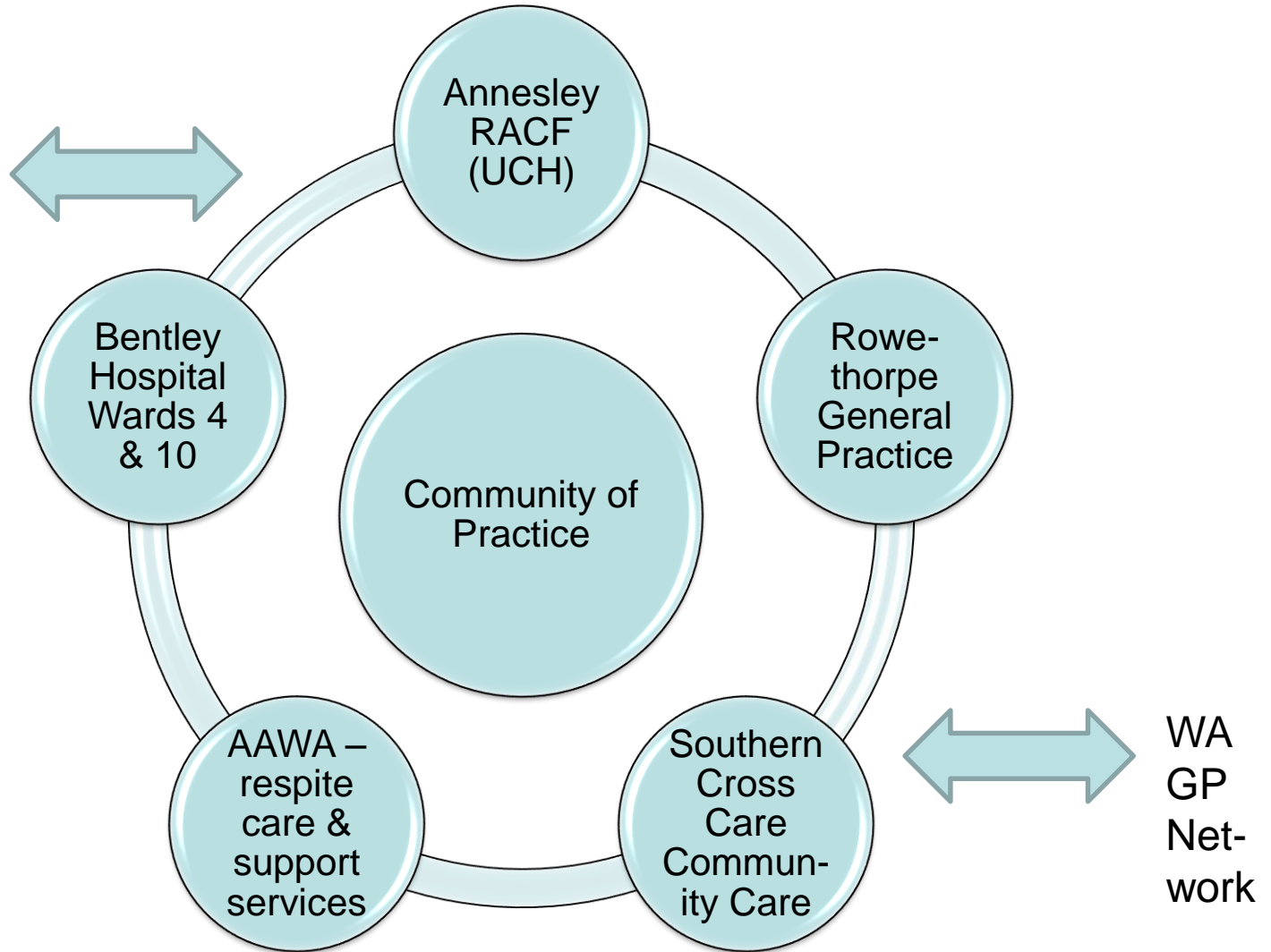




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Canning
Division of
General
Practice





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Scoping and reflecting

Developing action plans

Determining and meeting resource needs

Implementing actions

Evaluation and reflection



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Scoping and reflecting

Concerns raised were around:

- staff communication
- support for the family
- reassurance for the person with dementia



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Issues identified when reporting current practice and its outcomes included:

- Difficulty in communicating about end of life care
- Challenges for families - navigating a system in which the needs of the individual with dementia were not always recognised



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Developing action plans

1. To address staff communication – staff education & information delivering consistent messages about end of life care in dementia.
2. To provide family support – range of resources
3. To reassure the person with dementia – ensuring their background and preferences are known and agitation is managed appropriately



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Determining and meeting resource needs

Implementing actions

Evaluation



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Preparing the staff - education & information

Goals:

1. Consistent understanding of a palliative approach for people with dementia approaching death
2. Consistent understanding of best practice in this area
3. Consistency within and between organisations



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Process evaluation: how well was it implemented?

1. How many of the staff attended relevant sessions?
2. How many staff used information resources and how often?



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Outcome evaluation: were the goals met?

- how much had knowledge been improved?
- how consistently?
- how usefully?



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Staff:

1. Delivered education
2. Maintained records of staff education
3. Advised us of sessions so we could evaluate knowledge change and sessions themselves
4. Continued to cooperate with planned post intervention evaluations



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Family Support

Goals:

Provision of information and resources that family carers would find helpful



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Process evaluation: how well was it implemented?

How many of the eligible family carers received the resources and how?

Outcome evaluation: were the goals met?

How much did the resources help family carers and how?



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Staff:

1. Maintained records of eligible family carers
2. Logged material given to/used with these family carers
3. Helped offer family carers an opportunity to provide their feedback, if they wished



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Reassuring the person with dementia

Goals:

1. Implementation of initiatives to facilitate personalised care
2. Ensuring that any agitation was appropriately assessed and managed (assessed via staff education/information outcomes)



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Process evaluation: how well was it implemented?

For how many of the eligible clients were the initiatives implemented?

Outcome evaluation: were the goals met?

Did the background and preferences become more consistently understood/known



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Staff:

1. Maintained records of eligible people with dementia
2. Logged initiatives implemented for each person
3. Helped us to offer family carers an opportunity to provide their feedback, if they wished
4. Helped us to seek feedback from other providers.



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What did we find?





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Staff education

- Four modules delivered to between 50% and 71% of intended professionals
- Three modules delivered to 86% of eligible support workers
- Significant knowledge change in key areas
- Generally highly positive feedback



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- **Before the education, knowledge deficits were noted in:**

recognising dementia as life limiting;

recognising symptoms of late stage dementia;

issues related to pain assessment & delirium;

understanding a palliative approach.



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- **After the education, knowledge deficits generally decreased but:**
- hospital staff still tended to equate a palliative approach with terminal care
- misconceptions regarding the need for a referral persisted in these staff
- across most settings, issues related to pain assessment and delirium remained evident



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Family support

- Informational resources (about services and/or dementia progression) provided to 47% of the 64 eligible family carers
- 18 family carers also attended group information sessions about dementia progression

Feedback was extremely positive



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Before the change

I went to a meeting ... there were a number of carers there and I was surprised and in some respects shocked by the fact that some of them knew very little about the services and facilities and help that they could get ...at least half of them didn't know half the things that I knew. And that surprised me because ... many of them had been caring for quite a long time.



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After the change

[The information resource was shared with the rest of the family]...they don't really understand why dad doesn't talk any more it makes them realise ... why is he doing that, well that's just the way it is.



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Personalised care

- 33% of 64 eligible people with dementia had relevant resources completed
- 29% more had them initiated

Feedback was more mixed and time limited adequate testing related specifically to transfers.



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CoP and KI Interviews

- General positive feedback, less positive when change was constrained by timelines (some disappointment)
- *I felt fairly comfortable talking about [the] palliative level of care to people [before]. But I feel that we are much more resourced now... I feel more comfortable – [and] support workers are actually asking ‘can they be involved in this?’*
- *People feel more comfortable to raise their concerns, particularly to the doctors, about making an appropriate care plan*



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- *.. you just won't believe how beneficial it was." she said "It explained things." And ... I've had two families say "we just watched our loved one go through it - [it] was like they went through it step by step. And they found that they were relieved because they thought "no this is normal we don't have to rush them off to hospital".*



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Conclusion

- Communities of Practice can succeed in cross sector practice enhancement.
- Our findings indicate positive outcomes for families (and staff)
- outcomes for clients are likely to only become evident in the longer term.



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A big thank you to all the staff and families involved in the project