Shared Understandings: Improving Palliative Care for People with Dementia

Final Report

A project funded
Under the Caring Communities Program
By the Australian Government Department of Health & Ageing

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Project commenced May 2002
Project completed by May 2005
Fund Holder & service conducting project – Alzheimer's Australia ACT

What we did

- Identified a group of professionals from Palliative, Dementia and Aged Care drawing them together in a bi monthly meeting to develop a shared understanding of issues involved in Palliative Care for people with Dementia.
- Surveyed families of people with dementia that had died within the previous 12 months. Recording the family member's perspective on the quality of the Palliative care that was received within the Residential Aged Care Facility by the person with Dementia. Reviewed the relevant medical chart and offered counseling after interview.
- Surveyed Aged Care staff to measure attitudes, knowledge and skills in Palliative and Dementia care.
- Facilitated Palliative Care education to Aged Care staff.
- Facilitated Dementia education to Palliative and Aged Care staff

What has been learned

- Education of families and staff play a big role in supporting quality Dementia and Palliative Care.
- Both families and staff need support during and after the Palliative process (clinical and emotional)
- PWD in the early stages of the disease process need to be supported and encouraged to make future health decisions (EPA)
- Bereavement care during the disease process and after death of the PWD plays a large part in the emotional recovery of the family and staff (debriefing, memorial services, counseling)

What is useful to other projects / communities

- The short training session developed for Residential Aged Care Facility staff can be used as an introduction to Palliative Care
- Supportive materials available on Palliative Care and Dementia Care
- The organizational partnerships made between Dementia Care services and Palliative Care services. This connection has improved the capacity of the community by ensuring referral between services.

What are the benefits of disseminating information about your project

- Alzheimer's Australia ACT has and will raise awareness of the issues surrounding Palliative Care for people with dementia in articles in the association's newsletters, community and educational talks. This project has raised awareness within the ACT and surrounding region of the issues within Dementia and Palliative Care
- An awareness of the need for improvements in the palliation process within RACF for people with dementia
- Invitations to participate as a peak body in various palliative care forums

What needs to happen in order to sustain the key achievements of the project

- Continuation of the partnerships developed between Palliative Care services, Alzheimer's Australia ACT and RACF's in the ACT and outlying areas
- Funding to continue to support improvement in Palliative Care services for PWD and their families.

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Alzheimer's Australia ACT

Executive Summary

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Alzheimer's Australia ACT provides dementia support services for families and professionals who care for people with dementia as well as for people with dementia themselves. We provide education programs through seminars and courses promote community awareness and advocate for better services. Alzheimer's Australia ACT is committed to support the prevention of dementia, while valuing and supporting people with dementia.

The project was developed to ensure that people with dementia who require palliative care services are provided with those services by organizations whose staff have expertise in both dementia and palliative care. Due to the implementation of "ageing in place" within RACF's and the recognition that remaining in familiar surroundings is beneficial to people with dementia, the project was to assist in the development of new skills and awareness of the palliative care approach. The implementation of palliative and dementia education and collaborative partnerships between services will enable People with Dementia to stay within the same residential aged care facility and receive quality end of stage care lessening the likelihood of being admitted to the unfamiliar environment of acute care for the last days of their life.

Aims

1. To improve the quality of palliative care services offered to People with Dementia in the ACT and Greater Southern Area Health Service.
2. To produce an education resource for workers
3. To lay the foundation for an improved professional relationship between dementia care, other aged care workers and palliative care specialists. (Reference Group).

Methodology

- Identify key issues and areas of action by discussion within the professional reference group and use of Literature review developed by Professor Esther Chang under the Caring Communities project
- Identify Residential Aged Care Facilities prepared to participate by completing staff surveys and participating in palliative training
- Have RACF's participating nominate People with Dementia's family members to be interviewed on their perceived view of the quality of care delivered to the Person with Dementia. Review relevant deceased Person with Dementia's medical chart. Offer counseling after interview
- Using data collected and evaluated by the centre of Mental Health Research at the Australian National University from staff survey and the interview with family identify issues and implement training
- Develop an educational resource useful to aged and palliative care workers.

Results

- Increased interaction and understanding between Residential Ages care staff, Palliative Care staff and Alzheimer's Australia ACT. This is shown by increase in Dementia Helpline calls, over the counter enquiries and referral to the Hospice volunteer and education service. As well as requests for dementia and palliative care information by families of people with dementia, aged and palliative care staff as well as people with a recent diagnosis of dementia.
- Addition of Palliative Care and progression at the end stage of dementia to dementia network education and carer education worker training sessions.

- Education added to courses held for people with dementia who have recently received a diagnosis. This is to give the opportunity for future health and life care decisions to be made. Families have reported the person with dementia being given the opportunity to learn and express these important issues with the majority completing Enduring Power of Attorneys.
- Loss and grief workshop for families held twice a year due to gap show by family interview.
- Relationship formed with Palliative Care Education services and individual professional in the field. As shown by request to join forums on Palliative Care.
- Alzheimer's Australia purposing a position paper on People with Dementia and Palliative Care
- Educational resource available

Conclusions

This project has been the first step (pilot project) by Alzheimer's Australia ACT to bring the important issues of Palliative Care for people with Dementia to the forefront. The ACT and surrounding areas rapidly ageing population has and will continue to mean that more people with dementia will require end of life care within Residential Aged Care facilities.

Advance dementia is a progressive degenerative disease that follows no set course. It is a life limiting disease thus awareness was needed to emphaise it as a terminal illness. The project data collected supported the importance of family and aged care staff understanding dementia as a terminal illness that requires specialist palliative care.

Major achievements

- Ethics Approval
- Connections made between aged care facilities and the skilled palliative team members of the ACT Hospice. Ongoing training and support
- Education will continue to be delivered by dementia educator to palliative care staff
- Alzheimer's Australia is the peak body and has a voice in the future of palliative care services locally and nationally
- Resources and support available to aged care staff, families and PWD – help sheets, video books training presentation on palliative care and dementia
- Success in sourcing further funding for new palliative care projects.

The main factors behind the success of the major achievements have been the willingness of various professional within different disciplines willing to participate in this project.

The main issues behind why Residential Aged Care facilities failure to complete training after committing to the project were

- Staff shortages within ages care facilities leading to lack of time available to complete surveys and attend training
- Unwillingness by RACF to approach bereaved families to complete quality of care interview
- Other dementia project running at the same time competing for facilities time

- Quarantine of RACF due to infectious outbreak
- Lack of availability of specialist palliative care educators

The main objective and thus the most important to this pilot project were to improve palliative care for people with dementia. Future projects embarked on by Alzheimer's Australia ACT will build on this capacity and sustainability generated by this project.

The development and future implementation of the "Guidelines for a Palliative approach in Residential Aged Care" will see professionals from aged and palliative care working to develop numerous resources for this important area of health care. Alzheimer's Australia are dementia care specialists and is the peak body with expertise in this area. We will continue to work cooperatively with specialists in the palliative care sector to develop and implement better models of Palliative Care for people with dementia living in Residential Aged Care facilities and at home.

The projects original plan involved a time frame of three years and a larger amount of funding. The cut back in time and finances impacted on the projects ability to target wider participation using a part time project officer. A large proportion of this time was set aside for relationship building and approaching Residential Aged Care Facilities, palliative care staff and related professionals in the field. This added to the time involved in the evaluation process firstly within our own internal evaluation through the ANU, secondly by the Commonwealth evaluation and reporting and thirdly by the University of Wollongong evaluation process.

Our suggestion to overcome this issue would be to have a project officer for the duration of the project with an understanding of the community sector. The changes of key staff within the commonwealth assisted in poor communication and support between the project manager and commonwealth project officers.

Sustainability
The ongoing benefits of this project are the available resources and the continuation of partnerships developed over the projects life.

Alzheimer's Australia ACT actively supports our national body, Alzheimer's Australia in the publication of a national position paper on Palliative Care for People with Dementia.

Dissemination
The "Sundowner" Alzheimer's Australia ACT quarterly newsletter has been used to bring topics from within Palliative Care to our membership.

Information about the project has been shared via staff team meetings, support groups and community discussions also to wider Aged and Palliative Care community via the monthly Dementia Network meetings.

The opportunity to present the project to a wider audience at Adelaide to the Third International Conference of Ageing, Spirituality and Palliative Care September in 2004.

Alzheimer's Australia ACT will continue to share new ideas and the latest research through our education and support groups. This project has highlighted the

importance of being an active participant in the network of people across the aged, dementia and palliative care sector to help share and learn new information.