ANGLICARE NT

Groote Palliative Care Support Service

Final Report

A project funded

under

The Caring Communities Program

by the Australian Government Department of Health & Ageing

Author: Michael Sweeney
Project Managers: Libby Morgan, Sue Sellar & Kathy Massy
Evaluator: Internal evaluation
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Main Report

Acknowledgments:

We acknowledge the support and guidance of the Angurugu community leaders, the project committee members, project staff of Anglicare NT, and the project staff of the Australian Government Department of Health and aged.

We would also like to thank the many individuals from the Groote Eylandt Archipelago who gave freely of their time to assist with this sensitive and some times probing project.

I would also like to take this opportunity to commend the commitment shown by all support workers and project staff also their perseverance over the life of this project.

Senior community leaders
Murabuda Wurramarba
Gayangwa Lalara (Indigenous Cultural Consultant)

Project coordinated by:

Libby Morgan	August	2003 – 2004 February
Sue Sellar R.N.	February	2004 – December 2004
Kathy Massy	December	2004 – August 2005

Government P/O contacts over project.

Cate Lynch
Darryl Butter
Tina Blakemore
Peter Pierce
Carolyn Modra
Vanessa Harris
Maxine Clark

Executive Summary

Background

Anglicare NT secured the cooperation and support from the NT Palliative Care, Department of Heath & Community Services (Angurugu Health Centre), Angurugu Community Government Council, Commonwealth Department of Heath & Aging.

Agreement signed in August 2003 for a two-year period the project now known as the Groote Palliative Care Support Services the project delivered progression reports in October 03 April 04 October 04 and this final report July 05.

The project was coordinated by:

Libby Massy	August	2003 - February 2004
Sue Sellar R.N	February	2004 – December 2004
Kathy Massy	December	2004 – August 2005

All communication regarding this project should be addressed to

ceo@anglicare-nt.org.au

First identified by community leaders and explored further by Anglicare NT & the Angurugu Community government council, through its extensive work in the field of human services.

The findings clearly exposed a distinct lack of capacity to deliver suitable community based direct palliative care support, Within the Angurugu community, and the East Arnhem region as a whole.

It was recognised the intention and objectives of the Australian Government Department of Health & Ageing Caring Communities Program, could provide the opportunity to better target this under serviced area.

The processes and cultural ceremonies surrounding death are enormously important to the Angurugu community and integral to community function. In most circumstances, a death can supersede all other community activities, regardless of significance.

If someone were to die in their community inside their home, the relatives including direct family members may not re-occupy the home for an undetermined period. The Groote Eylandt community also employ a smoking ritual of relatives the house and other structures in which an individual has died, this is to purify and cleanse bad spirits. In addition the Age care facility would be closed for respect this in itself makes it difficult to function, It is necessary to demonstrate adherence to community beliefs and ceremonies.

Adhering to traditional ceremonies occupies and in many instances engulfs the community as a whole.

In a number of instances when an individual has passed away out of the community, and needs to be recovered from their place of death and returned home. This will often present, additional difficulties. Including: cultural, funding, and capacity i.e.

*- No access to the place of death to perform traditional ceremonies.

*- No funding available to return the individual to their home community.

*- limited capacity to send appropriate community delegated individuals to escort the late community member back home.

It was deemed imperative that the Angurugu community age care facility develop the capacity to limit the need for out of community palliative care, and or receive individuals back from current palliative care when appropriate.

This area is further compounded by a high incidence of a fatal neuro-degenerative disease known as Machado Joseph Disease (MJD) with several people with the disease in or entering into the very high care needs phase with a known progression to death of 3-5 years).

This project has identified a need to plan for the holistic support and care requirements of these individuals and families, including the anticipated new sufferers, also to build the skill base and capacity focusing on their specific requirements.

As an indication, the frequency of deaths in the community numbering 25 over the life of this project which is indicative, invoked a review of current palliative care options, for the local and wider communities.

Setting:

The people of the Groote Eylandt Archipelago and the East Arnhem region as a whole are not homogeneous; it has a lightly distributed multifaceted proud diverse population. Many of whom live and function in a less traditional way, providing professional western style services, while doing so, attempting to remain true to their traditional beliefs, to the most part skillfully balancing both indigenous traditions and western expectations.

Many others exist in a more traditional way maintaining time-honored roles and practices, securing the community heritage and legacy for future generations.

This project focused primarily on the Angurugu community and situated an office for operations within the Age care facility, the facility has established its self as a recognised focal point which lends its self well to the provision of information regarding palliative care, also the local indigenous support workers employed at the facility would be engaged in the development and support of individual referred for palliative care. The facility itself is also strategically positioned within the community and managed by Anglicare NT through the Angurugu community government council.

Other appropriate settings and venues were accessed though out the project in an effort to explore and discuss this sensitive area.

Project Objectives

The anglicare NT and Angurugu community council planed to further our commitment to the people of Angurugu byway of enhanced services, through developing and providing innovative and flexible options that address the requests for suitable community based palliative care support.

1. Provide a culturally appropriate system of integrated service delivery within the local community to deliver palliative care.
2. Use culturally appropriate carer teams to support specific palliative care needs in a remote community.
3. Coordinate and facilitate education in specific palliative care issues for support workers carers and families.

This was achieved by:

Working with people, their families, support networks, other service providers, the community, and all levels of government over the whole period of the project by:

- Lobby for the rights of the indigenous people of Groote Eylandt who in the final stages of life request the desire to return or remain at home or within the community to die when appropriate;
- Enhance their quality of life; and
- Providing viable options as an augment to current palliative care service delivery models.
- Ensuring that people and their families who present with specific requests, regarding end of life choice, are always afforded respect and dignity;

- Empowering individuals and families with an end of life choice, by informing, supporting and advocating;
- Supporting local communities and other organisations to work together when exploring and developing palliative care services;
- Developing a culture of inclusion, flexibility, and continuous improvement;
- Recognising, supporting, and developing the skills and expertise of our staff to work with individuals and families faced with an end of life palliative care choice; and
- Ensuring the preservation of dignity, choice, social, cultural, spiritual and emotional needs are met, and not to solely focus on the physical aspects of death and dying.

Methodology / Description

The project focused on the community of Angurugu and surrounding outstations and extended to Bikerton Island and Umbakumba on a referred needs bases, with direct care being provided for referred individuals with in the age car facility of Angurugu.

The project employed a project officer for 20 hours per week this officer implemented the project and setup the relevant committee's communication and training strategies, including information exchange and direct client care.

The project officer employed an indigenous cultural consultant for 26 hours per week to provide language and cultural interpretation to the project officer care professionals steering committee regarding structure and application including direct client care.

The project officer engaged a voluntary non-indigenous consultant who was an allied health professional, who provided support and supervision and was a member of the reference committee.

The project officer established communication networks with The Angurugu Health Centre which, as the primary health care provider in the community, provided information regarding the clinical care needs of clients, procure pharmaceutical needs and refer clients to other specialist services (eg allied health) as necessary.

Throughout the project day to day management was provided by senior anglicare executives.

Government supplied evaluation tools were utilised as required.

There were unintentional beneficial outcomes, including constant promotion an advocating for the project by the project coordinators and others, this help secure new supplemental ongoing funding from 2005, allowing us to better target this under resourced area, without this project to reference, it is believed this new funding would have been difficult to secure.

The community has a high incidence of a fatal neuro-degenerative disease known as Machado Joseph Disease (MJD) and several people with the disease are in or entering into the very high care needs phase (there is a known progression to death of 3-5 years).

This project has identified a need to plan for the holistic support and care requirements of these individuals and families, including the anticipated new sufferers, and to build a skill base and capacity focusing on their specific requirements.

Anglicare NT and the Angurugu Community Council have adopted and applied the principles of cultural safety concerning service delivery. In the delivery of overall services including palliative care, this approach extends beyond cultural awareness and cultural sensitivity.

The introduction maintenance of specific training utilising existing allied health practitioners and cultural advisors will continue subsequent to the termination of this project.

Establishing service capacity to deliver direct palliative care support with in the community when appropriate.

Development of Island specific service delivery protocols.

The opportunity to highlight and identify, to a wider audience the ongoing complexities associated with service delivery to extreme remote island based indigenous communities.

The network and communication channels established during this project have identified mutual benefits and appear to be strong.

Factors that influenced the effectives of the project included a tremendously driven team of people that believed in the overall community benefits that can be derived from a project of this nature.

Factors that had a negative effect on the success of the project included:

There have been twenty-five deaths in the community over the project period this has significantly influenced the capacity to meet the stated objectives due to traditional sorry days and imposed closures for respect. Anglicare NT operates on the island, using western management and methodologies and to the most part maintains a balance between traditional community cultural expectations and the demands of managing an NGO environment.

Disparities of language, education, training and culture. Gulfs in expectations of health and health care between providers of health care and the Aboriginal community members, and effective retention of competent staff.

In retrospect our acceptance of the amended agreement for a two year period rather than the original three has placed undue pressure on our team and community to meet the project objectives, given the cultural protocols, therefore more credence should be given to cultural advisors when clearly stated that it's "not practical or advisable to attempt this project under the imposed government project officers driven time frames.

Poorly developed project agreements NINE DRAFTS IN ALL poor project budget and line items.

Constantly changing government project officer, resignation of two pivotal project officers.

The extreme remote location and limited accommodation options.

The capacity to introduce a new project officer in the limit time available. This developed assimilation issues for community and project officer.

For the project to be sustained or built upon in the future it will be the community and our ongoing task to effectively address and develop protocols and procedures that build on our current understanding. It is expected that the support offered and processes established through this initiative will enable people to respectfully manage their loved ones terminal stages of life, and if requested remaining in their home communities whilst having access to suitable resources.

Main Message

- What we did
    - Provided in community direct palliative care to individuals.
    - Provided information sessions targeting palliative care issues.
    - Established ongoing long-term networks.
    - Identified the model of service delivery to be used when delivering palliative care within the community.
    - Established a steering committee and reference group.
    - Employed a project officer.
    - Employed a cultural advisor.
    - Engaged a voluntary non indigenous consultant.
    - Contributed to the regional M.J.D issue.
    - Encouraged the reference committee members to be active in dissemination of project.
    - Recruited, trained and supported key indigenous non indigenous age care facility staff, to provide home-based support for palliative care patients and their families.

- What has been learned
    - A clearer understanding of the capacity needs for the region.
    - Most activities within indigenous communities are protracted this subject is on the top of the list regarding decision making, feed back, involvement, action, consultation etc. more time was needed to suitably address this subject.
    - Accepting specific research of this nature without adherence to the community leader's direction and advice, not to do so is a recipe for program dysfunction at best. Therefore, government project officers should give credence with regard to community wishes generally and not pressurise organisations into accepting conditions.
    - An appreciation and recognition that indigenous volunteers are becoming over used with the constant assumption that their time and efforts will be forthcoming each time a request for their involvement is made. In short the assumption that if it is believed a particular project is good for the community then they are honour bound to provide support for no remuneration.
    - Established ongoing funding for palliative care services provision for the wider community. Including a mobile respite service with focused funding for individuals and family members that have become carers, referencing this project.

What is useful to other projects/communities

- We believe we have approached and conducted this program using a variety of tried and tested methods adapting when necessary, there are a myriad of resources around for this subject and the project officer could make themselves available to assist others to navigate this area.
- We have developed direct palliative care protocols, which can be adapted these are also accessible from the project officer.
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Resources developed and availability

- Developed palliative care service delivery protocols
- Developed Groote Eylandt community specific Anindilyakwa literature on palliative care.

What have been the benefits of disseminating information about this project.

- The opportunity to highlight and identify, to a wider audience the ongoing complexities associated with palliative care service delivery to extreme remote island based indigenous communities.