LIVING AND DYING IN STYLE

Final Report

A Project funded

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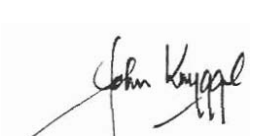
THE CARING COMMUNITIES PROGRAM

By the Australian Government Department of Health and Ageing

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Mr John Krygger, Chief Executive Officer

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Confidential Report to the Department

MAIN MESSAGE – LIVING & DYING IN STYLE PROJECT

What was done?

- Advance Care Planning (ACP) was introduced to Palliative Care Programs and Residential Aged Care Facilities throughout South West Victoria.
  200 nurses, counsellors, pastoral carers and 2 doctors representing 31 agencies completed one of 8 Respecting Patient Choices (RPC) training courses, each held over 2 days, to become Advance Care Planning Consultants.
- The project was extended to include practice nurses, community health staff and Community Aged Care Packages case managers so that the frail aged living in the community could be involved in ACP.

What has been learned?

- The framework of Advance Care Planning is a useful way of introducing discussions about end-of-life issues, and to assist in decision-making for patients and families.
- Enthusiastic executive support within each agency is essential for the system of Advance Care Planning to be implemented.
- Once implemented, the routine introduction of Advance Care Planning in day-to-day Palliative and Aged Care enhances preparations for, and the quality of, end-of-life care.
- The majority of people do not want the dying phase of their lives extended. Wishes discussed or documented are generally respected

What is useful to other projects/communities?

- The Respecting Choices Program at Austin Health, Melbourne has the licence and Government funding to promote Advance Care Planning throughout Australia.
  To make use of the necessary materials for ACP owned by Austin Health, each new agency must sign a Licence with them.
- General information and resources for ACP are also available from The Office of the Public Advocate and State Palliative Care organisations.

What have been the benefits of disseminating information about the project?

- Awareness of ACP amongst health professionals, health care agencies, the legal profession and the general community has been raised.
- Conversations about decision-making for end-of-life care are occurring outside the initial target population of the project.

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

- The Regional Palliative Care program will continue to promote ACP and provide training for new ACP consultants.
- Ideally a Project Manager whose responsibility is ACP should be funded to ensure the integrity of the system across the region.
- Executive support and a 'clinical champion' within each agency are also important.

What resources were developed?

- **The 'Living and Dying in Style'** booklet by Dr. Eric Fairbank is available from South West Healthcare, as are posters promoting ACP.
  Contact: Mabel Mitchell 55644179 mmitchell@swh.net.au or
  Dr. Eric Fairbank 55644180 efairbank@swh.net.au
- For training manuals, documents and other materials owned by the Respecting Patient Choices Program at Austin Health, and further information/links about ACP - view the RPC website: www.respectingpatientchoices.org

EXECUTIVE SUMMARY

Project Title: Living & Dying in Style

Time Period: April 2003 to March 2006-03-21
Lead Agency: South West Healthcare Warrnambool

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1. The Setting

'Living and Dying in Style' was a project with a theme of supporting people approaching the end of their lives by promoting Advance Care Planning (ACP) in Palliative and Residential Aged Care, throughout rural and remote communities in South West Victoria. The main centres in this part of the Barwon South Western Health Region are Warrnambool, Hamilton and Portland, each with its own district of smaller towns and rural communities. In the final analysis participating agencies included 10 hospitals, 19 Residential Aged Care Facilities, 6 General Medical Practices, 3 Aged Care communities services and the Regional Department of Veteran Affairs.

Why was this project needed?

Within the Warrnambool Palliative Care Program there was seen to be a need to introduce conversations about end-of-life issues as a routine. Previously these discussions were often postponed until the 'right' moment, and opportunities were either missed or not sought at all. There was also a concern that, without planning, unwanted medical interventions and treatments were being inappropriately used to unnecessarily prolong the dying phase of a terminal illness.

A common practice in Residential Aged Care Facilities was the completion of a 'Terminal Wishes" form. A member of the family often completed the form with no evidence of discussion with the resident (or other members of the family) rendering the form useless if the resident was transferred to an acute facility.

Much has been written about improving the planning for end of life care. Articles such as those by Lyn (2002) and Stienhauser (2001) summarise the essentials. Work on developing a model for Advance Care Planning had been done in USA such as the SUPPORT trial (1995) or that by Dr Hammes (1998) with the development of the Respecting Choices Program. Locally, Austin Health had begun a trial of the Respecting Patient Choices Program with assistance from Dr Hammes.

In Victoria we have been able to appoint a surrogate decision maker and refuse medical treatment for a current condition since 1988 but Nair et al (2000), Taylor (2203) and Cartwright (2004) all reported poor knowledge of this and lack of usage.

2. Project Objectives

The objective was to use the framework of ACP (as developed by the Respecting Patient Choices (RPC) Program at Austin Health) as a way of commencing conversations about preparations for dying. This was, firstly, to give people the opportunity to record their own choices in regard to future medical treatments. Then, in the course of these discussions, the idea was to move beyond treatments to psychosocial goals and values that might be important to people at this time.

In this way people could retain a sense of control and ease the burden of decision on their families. The potential for conflict and doubt would be lessened, communication improved and, in turn, personal relationships strengthened.

To achieve this it was planned to train staff from the palliative care programs and residential aged care facilities to enable them to initiate conversations and discuss end-of –life issues as well as document the choice of an Enduring Power of Attorney (Medical Treatment), an alternate agent, if desired, and the Advance Care Plan.

3. Methodology/Description

To achieve these aims the Respecting Patient Choices team was invited to train a group of thirty key South West staff (mostly nurses and social workers) to become the first Advance Care Planning Consultants. The project officer and the medical practitioner, having done additional training to become trainers themselves, were then able to conduct a series two-day training courses across the region, using RPC materials. A total of eight training courses resulted in 200 ACP Consultants.

Each agency to be involved was visited in advance to ensure that the system was understood, and that there was executive and other senior staff support. The project officer spent many subsequent hours travelling throughout the region to support and update newly trained ACP consultants, to ensure integrity of the system, to encourage those who were tardy for whatever reason and to evaluate progress.

Finally once documents for those without legal capacity to make their own decisions became available, selected ACP consultants did a further half-day training course. This was developed for this project with the help of South West Healthcare Counselling and Support staff.

The project was extended to include practice nurses, community health staff and Community Aged Care Packages case managers so that the frail aged living in the community could be involved in ACP.

4. Results

Results of the project were evaluated in various ways:

- Evaluation of the training provided to prepare staff to implement ACP, using an RCP tool, showed that the course met the objectives of content and quality.
- Similarly, the additional training program, (developed by the project staff and two trained social workers), for ACP with people who do not have the legal capacity to make medical decisions was rated highly.
- ACP consultants were surveyed to assess their level of activity, their feedback about ACP and the development and sustainability of ACP. The majority of ACP was being done by just over 50% of the consultants trained. Some had changed roles and some did not want to continue for personal reasons.
  Positive comments were received about improved communication and better preparation, while the main adverse comment related to the time taken to have conversations and complete the documentation.
- A survey of GPs showed varying understanding of the process of ACP and the Medical Treatment Act but importantly showed that nearly all would respect a patient's documented choices.
- Consumer feedback was generally positive. Mention was made of improved communication and "relief" with only occasional comments of ACP not being necessary or "interfering with God's plan".
- Outcomes varied between Warrnambool, Portland and Hamilton Palliative Care Programs with the highest percentage (66%) introduced to ACP in Warrnambool. Of those not introduced 20% were not competent and another 10% were in the terminal phase of their illness already.
- Implementation in RACFs was gathering momentum with many agencies concentrating on offering ACP to all new residents.

- There has been a significant amount of activity in areas outside the original target population in district nursing, community health, General Practices and acute hospital wards.
- A document audit of ACP showed some minor mistakes and that most choices were followed as originally requested, site of death being an exception for a small number of people.

5. Discussion Points

- The major achievement of this project was to show that when the framework of ACP is routinely used in day-to-day practice to introduce conversations about end-of-life care, then the preparations for dying, and the quality of care is enhanced.
- The success of this project commenced with the RPC Program from Austin Health agreeing to train key people in the South West in the process of Advance Care Planning.
- A written licence agreement to provide ongoing access to training manuals, documents and other materials owned by Austin Health has also been important.
- Awareness of the project was promoted by information visits to all agencies and General Practitioners, through various media outlets, public speaking to community groups, presentations at Palliative Care conferences, letters to legal practitioners and newsletters every 3 months.
- A negative effect on the success of the project was the turnover of executive and senior staff in several agencies that delayed or even stopped implementation in some cases. This was aggravated by the lack of formal agreements between the lead agency and the others, so there was no written commitment for them to continue in the project.
- Other problems related to time: the time to travel across the region to distant agencies (for which there is no real solution), the time to engage people in conversations (better now than at a time of crisis) and the time to complete the documentary process (demanding an efficient system).
- The sustainability of the project at this stage depends on the Regional Palliative Care Program (in which the project officer and the medical practitioner are employed.) Its future would be better ensured if funding were available to employ an ongoing Project Manager to maintain the integrity of the system. Executive support and a 'clinical champion' of ACP in each agency are also important.
- To be replicated by other organisations the support of the Respecting Patient Choices Program is necessary, a signed Memorandum of Understanding with them being essential for access to their ACP materials.
- This project espouses the core values for Palliative Care Standards, the Palliative Approach for Aged Care and the principles of the National Palliative Care Strategy.

6. Conclusions

The use of ACP as a framework helps to provide the kind of day-to-day Palliative and Aged Care that maintains dignity, provides autonomy and choice for all individuals and their families, while acting with respect and compassion as end-of-life plans are made.

The Respecting Patient Choices Program, Austin Health has established resources and an efficient system of Advance Care Planning.

Advance Care Planning takes time and successful implementation requires it to be given priority.

Knowledge of the Medical Treatment Act Victoria 1988 and Advance Care Planning is low and there is a need to continue to increase community awareness.