# Learn Now; Live Well: An Educational Program for Caregivers Living with a Life Threatening Illness

## Final Report

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***under***

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# Executive Summary

## BACKGROUND

**Program/project title:** Learn Now; Live Well: An Educational Program for Caregivers Living with a Life Threatening Illness

**Time period:** March 2003 to April 2006
**Organisation**: Hollywood Hospital and The University of Sydney

**Setting:** The LNLW Education Program was established at the Palliative Care Unit Hollywood Private Hospital (HPH).

**Background:**

A number of reviews and research studies of carers' needs have identified that carers of palliative care patients experience a significant range of unmet needs, experience physical and emotional exhaustion. While less is known of the longer term consequences of caring, it is now widely recognised that increased access to support is crucial for carers to be able to maintain this role. This project arose out of an increased awareness by clinical palliative care team that carers were experience difficulties in maintaining their caring role due to a lack of confidence in their ability and knowledge.

It is widely recognised that for many palliative care patients the desire to be cared for at home is very high. Family carers are critical in achieving this goal. For caregivers this can mean taking on responsibilities for physical care, emotional support, administration of medications; all areas they most commonly have limited, if any, experience. In addition to the patient's desire to be cared for at home, changes in healthcare have led to an increase in patients with high care needs being discharged home. Given the pivotal role of carers, there is an evident need to adequately prepare caregivers prior to for this role. In establishing this project no formal programs could be found that met the needs of carers of palliative care patients to prepare them for this role. As highlighted in a number of studies, lack of information can be the most problematic area for caregivers when taking on a primary care giving role (Sawicki & Graf, 2002). Furthermore, studies by Larson et al (1998) and Robinson and colleagues (1998) clearly indicate that provision of adequate caregiver education prior to discharge can significantly improve the caregivers ability to cope with the care giving experience. The lack of an education approach to discharge planning was identified as problematic by the clinical team. In exploring how to meet this need the lack of human resources, a structured program and formal evaluation of carer education was identified as barriers to providing this type of education of caregivers on a consistent basis. The project specifically aimed to address this need**.**

## PROJECT OBJECTIVES

The aim of the Learn Now; Live Well (LNLW) Programme was to provide education and support to informal caregivers of patients living with a life threatening illness. Specifically, this project aimed to:

- Provide caregivers with practical skills in caring for someone at home.
- Increase awareness of existing community resources for caregivers.
- Increase caregivers' confidence through knowledge and information.
- To promote the concepts of palliative care.

## *Methodology/Description*

**Target Population:** The target population for this project were carers of palliative care patients. Two hundred and five carers were recruited to participate in the study. Key health professionals

from institutional and community organisations involved in the project were interviewed as part of the process evaluation.

**Method:** The principle purpose of the evaluation was to determine the effectiveness, outcomes and acceptability of the LNLW Program. In line with the principles that underpin program evaluation, this evaluation used the systematic collection of data to identify if the aims were met, if the processes were effective in implementing the program, and to identify areas that may require further refining. A combined summative and formative evaluation process was used. Summative evaluation seeks to examine the effects or outcomes of the program. That is to the extent to which the program goals were met. Process evaluation explores the effectiveness of the strategies used in delivering the program.

The key outcomes for the program were identified as an increase in carer confidence and knowledge, and successful implementation of the program. To assess the effectiveness of the program data was collected at three time points:

- Time 1 - Immediately prior to education session
- Time 2 - Immediately post education session
- Time 3 - After four weeks from the education session.

Qualitative interviews were undertaken with a small randomly selected sample of carers.

**Data collection tools:** Two key tools were developed to undertake the evaluation after a review of the literature failed to identify any formal evaluation tools appropriate for this project. All the tools developed for this project were tested in the pilot phase. In addition, open-ended feedback was obtained.

***Carer Knowledge:*** For each of the six education modules had a questionnaire focusing on knowledge related to the content of that module. This was developed using a five-point response strongly agree to strongly disagree.
***Carer Confidence:*** Carer Confidence was evaluated using the prompt: *I feel confident in my abilities to perform the tasks of a carer'*.
**General Feedback:** A feedback form was administered to carers after each session. The feedback questionnaire consisted of ten questions with a 5 point scale ranging from strongly agree to strongly disagree. Qualitative answers were also elicited.

## *Results*

Key findings, and successful outcomes of *The Learn Now; Live Well Project* were:

- The *Learn Now; Live Well* education programs reduced carer isolation, and increased carer confidence and knowledge;
- The *Learn Now; Live Well* education programs increased access to support for carers
- The *Learn; Now Live Well* education program was successfully implemented in community and inpatient settings
- The *Learn Now; Live Well* education program improved carer outcomes across a range of community based carer groups.
- The significant collaboration and support from the host institution, community organisations and NGO that participated in the project was a factor that contributed to the success.
- Collaboration across sectors can reduce duplication of services and maximise use of limited resources in providing support for carers.

## *Discussion*

### *What are the major achievements of the project?*

- To have developed, implemented and evaluated an education program tailored for family caregivers that met the project objectives of increasing carer knowledge and confidence.

In addition, the evaluation highlighted that carers experienced increased support, and reduction in isolation.

- The development of a collaborative approach across disciplines and with community based organisations that prior to the project had not previously collaborated.
- The sharing of resources and reduction in duplication across sectors.
- The testing of the program in a diverse range of participant.

***What factors contributed to the success of the project and/or helped you meet the project's objectives?***

- Having a multidisciplinary knowledgeable working party that supported the coordinator through the project.
- The project coordinator's skills to do with group facilitation clearly had an impact on the success of this project.
- Working with organisations that have a significant standing in the community in relation to either health care or palliative care. The reputation of these organisations added credibility to the program.

***What factors had a negative effect on the success of the project and/or limited your ability to meet the project's objectives?***

- The finite amount of funding meant that the project could not meet all the needs identified in the Perth Community through adding on more courses. However, it also became important that the LNLW modules were evaluated thoroughly before conclusions could be made.
- Access to respite for carers would have increased access for carers to the program.

***Do you now consider any of the stated objectives unimportant? If so, which ones and why?***

No

***What other problems did the project face and how did you address them?***

- In undertaking the evaluation the timing of the follow up telephone evaluation raised concerns for the team. While no participants complained it was recognised we were potentially contacting carers that may be newly bereaved. A letter was written prior to making the third contact giving carers the option of withdrawing.

***What recommendations do you have for ways in which your project could have been improved?***

- The coordinator gained a better understanding on the importance of communication with all groups involved within the project. Approaches to maintaining communication need to be incorporated into future projects.

***What aspects of the project are going to be sustained and how?***

- We have applied for further funding through the Department of Health and Aging. LNLW will now be taught to HCP's in a variety of settings.

***What lessons can other regions/services/organisations learn from your project?***

- The importance of supportive education. Health education needs to have a large support component so that learners feel supported through their learning experience. If learners are supported they are more able to change behaviours and accept new information.
- The importance of promoting a project through a variety of media such as newspapers, radio interviews and conference presentations.

***Under what circumstances could the outcomes of your project be replicated elsewhere?***

- The program could be implemented in arrange of settings, using a train the trainer module of up skilling group facilitators to deliver the program.

***How did you disseminate information relating to your project?***

- The outcomes of this project have been presented at state and national conferences and publications in nursing journals. Full evaluation publications will be submitted to peer reviewed journals.

***How did the project link with The National Palliative Care Strategy?***

- This program contributed to the Palliative Care Strategy through providing increased support to carers of palliative care patients, and therefore potentially palliative care patients.

## *Conclusion*

Recommendations from this project are:

- Based on the successful outcomes of this project *The Learn Now Live Well Education Program* be recommended as a resource for health professionals caring for individuals in the palliative care phase of the illness.
- The Transferability *of The Learn Now Live Well Education Program* to other client groups be evaluated.
- Any further evaluation should explore how to link with bereavement services to facilitate access to bereavement support for carers.
- Approaches to provide short term Carer respite (i.e. couple of hours) need to be explored.
- In developing programs for carers collaboration across sectors and organisations should be encouraged to maximise the opportunities for sharing of resources and increasing the acceptability of resources developed. Collaboration and support from different areas contributed to the successful outcomes of this project.
- Future evaluations should explore the roles and skills of the facilitator in this type of program. The team are aware that the facilitator was extremely skilled and played a significant role in the success of the education groups.
- The model used in this project is one that could be adopted in other areas, such as end stage neurological conditions, paediatric settings, and potentially for carers of cancer patients early in their treatment. Future program development should explore these areas.
- Evaluation of future programs should maintain a qualitative component. For carers this provided a greater opportunity to provide detailed feedback .
- Community or institutional based education programs can be effective, but require skilled preparation of content and delivery of the program. Given the positive outcomes for this project funding of the facilitator role is crucial to developing and running this type program.
- Future projects if feasible should be extended to undertake a longer post education follow up evaluation.