EXECUTIVE SUMMARY

This project, *Educating and Supporting Carers in Palliative Care* set out to offer support and education to home palliative carers and educate their local service providers about specific carer needs. The primary aim was to improve carer capacity to cope with caring, and to adjust to their life after caring was over.

Feedback by carers from Carer Resource Centre and the National Carer Counselling Program (NCCP) combined with research from Maggie O'Shea and Annie Cantwell-Bard's *An Unrecognised Grief* indicate that this is an area that needs to be widely addressed.

Carers are unpaid family, friends or neighbours who provide all types of care for another person. Often their lives are completely disrupted by the time and energy this takes. Carers NSW (CNSW) is the peak body offering support, education and advocacy to all carers. It has been found that carers have similar needs for resources, information, emotional support and education regardless of their situation. In addition, carers providing palliative care need specific information in some areas.

This project took the view that by supporting palliative carers as individuals with specific needs, care given to the recipient would be given with more confidence and understanding thus improving the quality of care and the quality of life for carers. With the education of service providers, an increase in the understanding of carer needs has been addressed, as well as encouraging links between community services and palliative care units.

The report outlines some key findings about palliative carers in the home setting. These include:
Carers:

- Carers not knowing if the person they cared for was on palliative care or not
- Carers not asking for help
- Difficulties for carers in knowing what services to ask for, or who to ask
- The specific difficulties and fears carers face
- How home palliative caring situation could be improved
- Needs of the carer sometimes unspoken, misunderstood or unmet
- Receiving good support and help from a variety of service providers.

Service Providers:

- The need for better understanding of palliative carers' needs
- Requests for more training and education on loss and grief and palliative care
- A Western based culture of service delivery and values in a multicultural society
- Services needing to understand and link better with each other
- Respite service coordinators appear to be the most common link between services

Some participants in both groups:

- Lacked understanding about what palliative care is and is not
- Had no or little training on skills to recognise and cope with loss and grief
- Misunderstood the role of morphine and pain management

The project has raised community awareness of palliative carer needs and surrounding issues. Few people talk comfortably about loss, grief, death and dying. Those that do manage it skilfully.

With more people electing to live at home for as long as possible, there is an increased need for a society which understands palliative care and provides financial and emotional support to carers and the services they draw on. This enables the best and most appropriate services to be delivered to assist carers whilst caring, and afterwards adjusting to a new life.