MINISTER FOR HEALTH MS KATY GALLAGHER MLA SPEAKING AT THE LAUNCH OF THE ACT ABORIGINAL AND TORRES STRAIT ISLANDER PALLIATIVE CARE RESOURCES ON 18 OCTOBER 2006
PROJECT SUMMARY

ACT Health was given funding by the Australian Government Department of Health and Ageing to implement the Community Awareness Raising of Aboriginal and Torres Strait Islander Palliative Care Practice Principles in the ACT.

A scoping project was undertaken in the early stages of the project to assess the needs of the ACT Aboriginal and Torres Strait Islander community.

ACT resources were developed in line with the National Community Awareness Raising of Aboriginal and Torres Strait Islander Peoples Palliative Care Practice Principles. The ACT resources that were developed as part of this project were a poster, brochure and workbook.

These resources were developed to assist Aboriginal and Torres Strait Islander peoples in the ACT community to access culturally appropriate palliative care services and to raise the awareness of mainstream palliative care providers on how to provide culturally appropriate care.

As part of this project a steering committee was established to oversee the development of a two-day workshop for mainstream palliative care and Aboriginal health workers. The workshop was held on 17 and 18 October 2006 with 45 people participating on the first day and 38 people participating on the second day. The workshop’s aim was to provide participants with information on the need for providing culturally appropriate palliative care to Aboriginal and Torres Strait Islander peoples. This was achieved through the use of personal experiences, story telling, the ACT resources and case studies.

During the Workshop the ACT Minister for Health, Ms Katy Gallagher MLA and Ms Julie Tongs Chief Executive Officer of Winnunga Nimmityjah Aboriginal Health Service held a joint launch of the resources made possible through this project. The ACT Minister for Health launched the ACT resources, while Ms Tongs launched pamphlets on grief and loss developed by Winnunga through community consultation. The printing of these pamphlets was funded through the Community Awareness Raising of Aboriginal and Torres Strait Islander Palliative Care Practice Principles for the ACT project.

The consultant who ran the two-day workshop wrote a report for ACT Health and made the following recommendations:

1. The continuation of a Palliative Care Steering Committee to provide guidance for the development of;
   a) Cultural Protocols relating to Death, Dying and Grieving in the ACT Aboriginal and Torres Strait Islander Community;
   b) Key resources including an ACT specific CD ROMs and others; and
b) A capacity in the ACT to fund ‘return to country’ for people who want to die at home; and

2. The implementation of a continuing program of cultural activity including annual workshops and forums about palliative care approaches for Aboriginal and Torres Strait Islander people and aged care facility based cultural activities.

Some outcomes of the Aboriginal and Torres Strait Islander Palliative Care project in the ACT include:

- Improved cultural competencies within the palliative care sector.
- The identification of cultural advisors who can relate their personal, professional and sensitive issues to a mainstream audience.
- The enhancement of working relationships between institutions represented on the Steering Committee.
- The development of cultural resources for groups affected by death, dying and grieving issues in the Aboriginal and Torres Strait Islander community.
- The dissemination of relevant information and materials in resource folders for at least 50 agencies in the area.
- Cooperation between Aboriginal and Torres Strait Islander peoples who are employed in government and non-government agencies and mainstream services.
- Cross cultural awareness training was provided for many people in the sector by exposure to members of Aboriginal and Torres Strait Islander communities and participation in cultural events.

Cultural protocols on death and dying for the ACT Aboriginal and Torres Strait Islander community are currently being developed. The cultural protocols will address the role of mainstream services in creating cultural safety and also address grief, loss, death and dying in the Aboriginal and Torres Strait Islander community, cultural identity and diversity, communication and the role of family, extended family and community. Winnunga Nimmityjah Aboriginal Health Service will develop the cultural protocols in consultation with other important stakeholders in the ACT.

Instead of going ahead with the development of a CD, it was recommended that the development a book of stories written by Aboriginal and Torres Strait Islander peoples on their experiences with death, dying and grieving would be more accessible and more useful as a reference. This valuable resource will be developed though community consultation and will be an additional resource for mainstream palliative care workers to complement the resources that have been developed through this project.
Stage One:
The first stage of the project involved a literature search of all background and resource materials with the aim of identifying issues to be addressed with stakeholders.

The search included analysis of the "Indigenous Palliative Care Implementation – State and Territory Summary Report – August 2004" which highlighted the following pertinent issues:

- The majority of jurisdictions had established a two-tiered structure i.e. State Co-ordination and Regional Co-ordinator; and
- The lack of, and late, referrals from Aboriginal and Torres Strait Islander health organisations.

The literature review also highlighted the benefits of employing Aboriginal health workers in mainstream palliative care facilities.

Stage Two:
The second phase of the project involved one-to-one consultations with relevant members of the ACT Aboriginal and Torres Strait Islander community. At this stage it was identified that due to the population size in the ACT that one-to-one interviews would be more beneficial to participants than a workshop.

These consultations aimed to determine:
- Whether the palliative care needs of clients and their carers are being met;
- If so, how they are being met;
- Feedback on the national resources; and
- Gaps in the system.

Consultations were held with staff from Clare Holland House, the HACC/ACAP Officer at Ngunnawal Aboriginal Corporation, the Senior Aboriginal Liaison Officer at the Canberra Hospital, the Manager of the Aboriginal and Torres Strait Islander Health Unit at ACT Health, the Carer Liaison Officer and Marketing Officer at Winnunga Nimmityjah Aboriginal Health Service, a representative from the United Ngunnawal Elders Council and a representative from Tuggeranong Aged Day Care.

Development of Resources:
The consultations (listed above) were undertaken with a view to determining the current palliative care services being provided to, and accessed by, Aboriginal and Torres Strait Islander peoples in the ACT. The consultations provided ACT Health with significant information that could then be used for the development of the resources.

A draft poster and brochure was then developed to raise awareness of palliative care in the Aboriginal and Torres Strait Islander community. An ACT specific artwork was designed for use on all ACT resources developed under this project.

Two versions of a brochure and poster were drafted and were provided to Winnunga Nimmityjah Aboriginal Health Service for additional comment and further revisions were made.

A workbook for mainstream palliative care workers was also developed. The workbook is intended to provide guidance to health care workers when delivering palliative care.
services to Aboriginal and Torres Strait Islander clients and was developed in consultation with Winnunga Nimmityjah Aboriginal Health Service (please see Attachment A).
EDUCATION/TRAINING OPPORTUNITIES:
ACT Health negotiated for Ms Kerry Arabena of the Australian Institute of Aboriginal and Torres Strait Islander Studies to assist in the delivery of education and training under this project.

To assist ACT Health and Ms Arabena a steering committee was established to oversee the development of culturally appropriate education/training sessions.

The steering committee was chaired by Ms Kerry Arabena and included representatives from:
- Carers ACT
- ACT Palliative Care Society
- Winnunga Nimmityjah Aboriginal Health Service
- Ngunnawal Aboriginal Corporation
- Clare Holland House
- Greater Southern Area Health Service
- Aboriginal Liaison Officer Service, ACT Health
- Clinical Nurse Consultant Palliative Care, the Canberra Hospital and
- ACT Health

The steering committee asked a project officer from the Victorian Indigenous Palliative Care Project 2005 "The Journey: Coming Home, Caring Together" to come and meet with them to discuss the project. The steering committee liked what had been presented in Victoria and believed that this project could work in the ACT.

Several options were discussed before a two-day workshop was agreed upon. Other options investigated were holding several one-hour seminars, a one-day workshop and several half-day workshops.

A workshop dinner was also incorporated into the two-day workshop with the aim to enable participants to network in a more relaxed environment.

The workshop was open to Aboriginal and Torres Strait Islander health workers, palliative care workers, aged care workers, non-government organisations and mainstream health workers. The aim of the workshop was to give people the opportunity to understand more about each other's work and to make the links and relationships necessary to offer quality palliative care services, in a partnership, to Aboriginal and Torres Strait Islander people in the ACT and region.

The workshop invitation was sent out to over 100 stakeholders in the ACT and surrounding NSW.

WORKSHOP:
The workshop was held over two days on Tuesday 17 and Wednesday 18 of October 2006 at the Australian Institute of Aboriginal and Torres Strait Islander Studies in Acton. The title of the workshop was Death, Dying and Grieving in our Community a palliative approach for Aboriginal and Torres Strait Islander peoples (please see the invitation at Attachment B).
The workshop was officially opened by a Ngunnawal elder and had two themes. The first day was a cultural day that looked at cultural protocols, death, dying, rituals and beliefs for Aboriginal cultural and for Torres Strait Islander culture. The second day looked at mainstream services and programs available and asked what future activity participants wanted to see follow from this project.

To assist in the learning process workshop folders were provided for participants containing the presentations for the two days (please see Attachment C). The folders included information on the following organisations and issues:

- ACT Palliative Care Society
- Carers ACT
- Clare Holland House
- Aboriginal and Torres Strait Islander Liaison Service at the Canberra Hospital
- The Canberra Hospital Palliative Care Service
- Ngunnawal Aboriginal Corporation
- Winnunga Nimmityjah Aboriginal Health Service
- Sorry Business
- Mainstream Palliative Care Services Perspectives on Death and Dying
- Program of Experience in the Palliative Approach (PEPA)

Also included in the folders were copies of the resources launched by the ACT Health Minister Ms. Katy Gallagher MLA and Ms Julie Tongs Chief Executive Winnunga Nimmityjah Aboriginal Health Service:

- Best Practice Palliative Care a Workbook for Aboriginal and Torres Strait Islander People in the ACT;
- Relieving Your Grieving, palliative care and illness counseling brochure and poster; and
- Grieving in our Community pamphlet series by Winnunga Nimmityjah Aboriginal Health Service.

As part of the workshop participants were asked to move into three small groups to discuss two case studies (please see Attachment D). These case studies gave participants the opportunity to discuss options and provide culturally appropriate choices for the client and their family.

**DETAILED INFORMATION ON THE LAUNCH OF THE PRINCIPLES INCLUDING QUANTITATIVE INDICATION REGARDING THE NUMBER FOR ATTENDANCE AT THE LAUNCH AS WELL AS A LIST OF PEOPLE IN ATTENDANCE**

**LAUNCH OF ACT RESOURCES:**

The ACT Minister for Health, Ms Katy Gallagher MLA and Ms Julie Tongs, Chief Executive Winnunga Nimmityjah Aboriginal Health Service held a joint launch of ACT resources on 18 October at the Australian Institute of Aboriginal and Torres Strait Islander Studies in Acton.

The resources that were launched were the ACT palliative care brochure, poster and workbook along with Winnunga’s pamphlets “Grieving in our Community”.

The “Grieving in our Community” pamphlets were documents that had been developed through community consultation by Winnunga Nimmityjah Aboriginal Health Service.
These resources were developed for Aboriginal and Torres Strait Islander peoples to assist in dealing with grief and loss. There are four pamphlets titled:

- Sorry Business
- Telling our Stories
- What do we tell the Kids and
- How you might feel when someone you love dies – designed especially for children

The “How you might feel when someone you love dies” pamphlet was designed and written by a group of children aged between 5 and 12 years of age.

The steering committee gained full agreement that these resources would be extremely valuable for the community and through the funding made available to ACT Health, the department was able to print these resources on behalf of Winnunga Nimmityjah Aboriginal Health Service (please see Attachment E).

Please see section below for a list of participants who attended the launch and the workshop.

**FULL ACCOUNT OF OUTCOMES INCLUDING QUANTITATIVE INFORMATION ON PARTICIPATION AT THE WORKSHOP**

Participants who attended the workshop and the launch were from the following organisations:

- Department of Health and Ageing, Australian Government
- Carers ACT
- Lowana Young Women’s Service
- ACT Palliative Care Society
- Winnunga Nimmityjah Aboriginal Health Service
- Ngunnawal Aboriginal Corporation
- SIDS and Kids
- ACT Division of General Practice
- Amity Aged Care
- Clare Holland House
- Greater Southern Area Health Service
- Sydney South West Area Health Service
- A Medical Psychotherapist
- Burrangiri Centre
- Department of Families, Community Services and Indigenous Affairs, Australian Government and
- ACT Health.

The workshop numbers were actually very good with 45 people participating on the first day and 38 people participating on the second day.

Participant feedback forms were handed out to all participants to complete at the end of day two.
REPORT ON FEEDBACK REGARDING MATERIALS AND WORKSHOP

Feedback on the workshop and resource materials has been very positive. Some of the feedback received at the workshop:

“The workshop and the resources will be very useful in my role as an Aboriginal Health Worker”.

“I will use the information to educate fellow workers… it was good to network, and learn about the cultural information… the importance of communication with all cultures was important.”

“This will help me build relationships with people in the community.”

People on average rated between ‘very good’ and ‘excellent’ information being provided at the workshop especially the introduction to the services, the ACT resources, Torres Strait Islander issues, Aboriginal specific issues, the launch of the resources and the opportunity to interact with other participants.

Participants at the workshop agreed to provide feedback to their organisation through discussions with colleagues, taking resources back to their organisation and undertook to develop relationships with other agencies in the sector (For a copy of the Consultant’s Report please see Attachment F).

PRINTED MATERIAL AND DISTRIBUTION

The posters, brochures and workbooks are currently being distributed to health professionals and organisations in the following numbers:

- General Practices (430 posters, 2150 brochures + 430 work books)
- Clare Holland House (50 posters, 100 brochures + 200 work books)
- Winnunga Nimmityjah Aboriginal Health Service (25 posters and 200 brochures)
- Ngunnawal Aboriginal Corporation (10 posters + 50 brochures),
- Aboriginal and Torres Strait Islander Liaison Officer Service (50 posters + 100 brochures + 50 work books),
- Carers ACT (5 posters, 50 brochures + 50 work books)
- Calvary Health Care (20 posters, 50 brochures + 50 workbooks)
- Palliative Care Strategy Steering Committee
- Workshop (50 posters, 50 brochures + 50 workbooks)
- Queensland request (2 brochures, 1 poster + 5 workbooks)
- CATSIN (1 brochures, 1 poster + 1 workbook)

CULTURAL PROTOCOLS

The steering committee also identified the need to have cultural protocols on death and dying for the ACT Aboriginal and Torres Strait Islander community developed as a priority. The cultural protocols will address the following issues:

- Historical perspective and current impacts
- Overview of current health status
- Grief and loss in the Aboriginal and Torres Strait Islander community
- Cultural identity and diversity
- Cultural safety
- The death and dying in the community
- Communicating positively and respectively
- Role of family, extended family and community
- Working with Aboriginal and Torres Strait Islander patients and families
• Working in partnership with Aboriginal and Torres Strait Islander organisations
• Role of mainstream services in creating cultural safety

Winnunga Nimmityjah Aboriginal Health Service will undertake the project in consultation with Ngunnawal Aboriginal Corporation, the Canberra Hospital Aboriginal Liaison Officer Service and through community consultation. The document will be developed to ensure that the protocols best reflect the cultural practices and needs of a diverse Aboriginal and Torres Strait Islander community in the ACT.

**TIME LINE FOR THE CULTURAL PROTOCOLS**
Work has begun on the cultural protocols and money has been allocated. The protocols could not be completed prior to the workshop as the facilitator from Winnunga Nimmityjah Aboriginal Health Service wanted suggestions and ideas for inclusion into the cultural protocols from participants attending the workshop.

The time line for the project is:

**November/December 2006:**
- End November outline of proposal to Ngunnawal Aboriginal Corporation for their approval and or changes
- Early December community meetings to start to talk through the issues

**January/February 2007:**
- Draft for comment
- February - meetings with relevant organisations/groups/community for comment and or changes

**March 2007:**
- Cultural protocols final version

The protocols will be printed once they are completed. As part of this project, ACT Health will look into the possibility of having the protocols launched by the ACT Minister for Health, Ms Katy Gallagher MLA.

**BOOKLET OF STORIES BY ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLES**
Another project that is currently being undertaken is the development of a booklet of stories written by Aboriginal and Torres Strait Islander peoples on their experiences with death, dying and grieving.

The booklet will be an additional valuable resource for mainstream palliative care workers to complement the resources that have been developed through this project. The booklet will be developed through community consultation and it is anticipated that the project would be completed by the end of April 2007. The booklet will include the artwork that was developed as part of this project along with other pieces of artwork and photos that are special to the individual or family mentioned in the booklet. It is anticipated that through this medium, readers will gain a better appreciation of Aboriginal and Torres Strait Islander cultures and the importance of providing culturally appropriate palliative care.

The booklet will be printed once it has been completed. As part of this project, ACT Health will look into the possibility of having the booklet of stories launched by the ACT Minister for Health, Ms Katy Gallagher MLA.
CONCLUSION

The Providing Culturally Appropriate Palliative Care to Aboriginal and Torres Strait Islander peoples in the ACT project was a really positive experience. ACT Health has received very positive feedback from participants at the two-day workshop and from the steering committee members on the overall project.

The consultant listed the following recommendations from their report and the recommendations include the continuation of a Palliative Care Steering Committee to provide guidance for the development of:

1. The continuation of a Palliative Care Steering Committee to provide guidance for the development of;
   c) Cultural Protocols relating to Death, Dying and Grieving in the ACT Aboriginal and Torres Strait Islander Community;
   b) Key resources including an ACT specific CD ROMs and others; and
   d) A capacity in the ACT to fund ‘return to country’ for people who want to die at home; and

2. The implementation of a continuing program of cultural activity including annual workshops and forums about palliative care approaches for Aboriginal and Torres Strait Islander people and aged care facility based cultural activities.

Some outcomes of the Aboriginal and Torres Strait Islander Palliative Care project in the ACT include:

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- The development of cultural resources for groups affected by death, dying and grieving issues in the Aboriginal and Torres Strait Islander community.
- The dissemination of relevant information and materials in resource folders for at least 50 agencies in the area.
- Cooperation between Aboriginal and Torres Strait Islander peoples who are employed in government and non-government agencies and mainstream services.
- Cross cultural awareness training was provided for many people in the sector by exposure to members of Aboriginal and Torres Strait Islander communities and participation in cultural events.

The recommendations from the consultant’s report were tabled at the ACT Palliative Care Strategy Working Group and these recommendations were accepted and will be included in the ACT Palliative Care Strategy that ACT Health is currently developing.