

# NT Palliative Care Conference 21<sup>st</sup> May 2015

Alice Springs Convention Centre

Topic: "Sorrow Malpa"

Presentation by Andrea Mason, CEO, Ngaanyatjarra Pitjantjatjara Yankunytjatjara (NPY) Women's Council.

Thank you for this opportunity to speak to day.

## Introduction

I would like to acknowledge the traditional owners of Alice Springs, The Central Arrernte people it is on their country that I live and work. The Central Arrernte people are connected to the Ngaanyatjarra Pitjantjatjara Yankunytjatjara (NPY) nations through songlines and ceremony, and because of this, I have always felt welcomed in Alice Springs.

I would also like to give acknowledge and recognition to Kim McRae, Manager of the Tjungu Team in NPY Women's Council and a former staff member of NPY Women's Council and Tjungu team, Barb Lewis who was a sorrow malpa for many Anangu during her time at NPY Women's Council.

And finally Margaret Smith, a director of NPY Women's Council, who has been a malpa to me since 2008. In regards to this presentation, I would like to thank Kim, Barb and Margaret for their counsel and guidance.

For those of you here today who are not from central Australia, I would like to explain a couple of Pitjantjatjara words, one is malpa and the other is Anangu.

Malpa can mean friend, companion, colleague or mentor. Two malpas working together in our region are often an Anangu (Aboriginal) person and a non-Anangu person. The action of these two people working together is called malparara.

An Anangu is the name by which Aboriginal people from the Pitjantjatjara and Yankunytjatjara (Anangu) and Ngaanyatjarra (Yarnangu) language groups describe themselves.

In NPY Women's Council, the non-Anangu person often has formal qualifications in a particular work practice area. The Anangu person usually has high level cultural knowledge, an understanding of service delivery in the context of an Anangu community, is well informed of the political environment of communities and often speaks two sometimes three languages including English.

So from my experience and that of NPY Women's Council, this malparara combination of expertise and capacity creates relationships of synergy, and by this I mean one plus one equals three. So a person on their own, they have the potential to do much good, but together with a malpa, the potential is a possibility to multiply that good.

For a few minutes I would like to talk about sorrow malpas. I heard this phrase in a conversation by an NPY Women's Council member a couple of years ago. This member had just lost a sister who had been cared for in the Alice Springs Hospital's palliative care team. She and her family also received palliative support from NPY Women's Council's Tjungu Team.

When that particular Tjungu staff member retired some months later, the NPY Women's Council member who had lost her sister remarked during the farewell morning tea, that we were saying goodbye to someone special, a person who is our malpa during sorrow, a sorrow malpa.

### **Sorrow Malpa**

So a Sorrow Malpa is a person who has a role to support a dying patient receiving palliative care, as well as supporting the patient's family. A sorrow malpa may be a non-Anangu doctor, nurse, social worker, counsellor or specialist. They may also be workers in organisations who work with the dying such as NPY Women's Council. However, a doctor, nurse, social worker, counsellor or specialist may also not be a sorrow malpa because they only want to focus on their professional role, which is ok. So when this is the

situation, it is then absolutely critical that malpa workers from organisations like NPY Women's Council are employed to support the patient and their family.

We live in a world fast paced world, where everything is accessible and if it is not then someone is trying to find the means to take the world to that place. Social media is now a part of daily life from Facebook to the internet to 24 hour television.

If you work with Anangu and especially during a time of sorrow, it is important to not rush, but to slow things down. To explain this I would like to tell you of a story that a family member told me. He was driving on a road in remote WA when he saw an elderly Aboriginal man walking ahead on the road. He pulled up and asked the man if he wanted a lift. The gentleman initially resisted, then eventually he accepted the offer.

Some way down the road my Uncle could see that the old man was distressed, so my Uncle said to the old man " hey grandfather are you ok?" The man replied "No, I need to get out, my body is here but my spirit is back where you picked me up".

And in a sense this is what the period of palliative care, the period of sorrow is allowing. To slow down the pace at which a person has been living and to give him or her the opportunity to let their spirit catch up with the journey he or she is about to take.

And when an Anangu moves from receiving medical treatment to palliative care, that person starts a journey to a special place, they move from the secular to the sacred.

This is the cultural responsibility of all Anangu people from our region, they do this on a personal level and their family is also with them, their family joins them on this journey.

For Anangu to make this transition, to take this rite of passage to this sacred place, is very important.

And why is it sacred? It's because those on this journey are creating the dynamic that opens the way for their family members to continue their journey.

So what about the role of the family during a period of palliative care and what about the role of Sorrow Malpas? Quite simply each have different roles, but both are necessary to assist an Anangu to receive palliative care and to meet their cultural obligations to move through this important rite of passage.

For Anangu families the dynamic they contribute in this sacred place is love. They do this through remembering, recounting, through singing and reassuring the family member who is dying that they are loved and that they will be remembered.

For Sorrow Malpas the dynamic they contribute is equally as important. Sorrow Malpas are given the honour to help level the experience that a palliative care patient is going through close to and near death and that experience is the trauma of separation.

For Sorrow Malpas their role is to level out the journey, the highs and lows that the palliative care patient and their family will experience. They achieve this by doing their work with dignity and empathy. Sorrow Malpas facilitate the practical and relationship assistance this is needed during this time.

And so where the family are giving love, Sorrow Malpas are giving an Anangu who is palliative, control as they are dying. Sorrow Malpas are invaluable, they are listening attentively, they are ever watchful, they are aware that the hospital room, the ward, the hospital is a sacred place because a rite of passage is in motion.

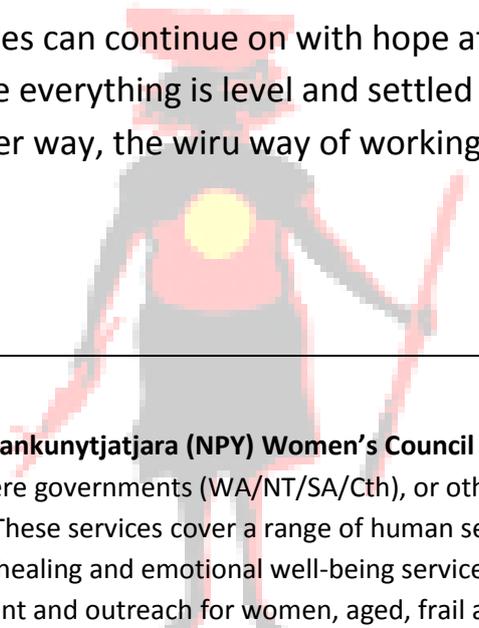
And these two dynamics combined - love and control, allows Anangu, with great **hope**, to fulfil their cultural obligations as they meet their responsibility of passing on to the next stage.

As I have reflected on these three relationships, of the one who is dying, their family and Sorrow Malpas, I have felt great comfort because what is being demonstrated is our health sector responding to Anangu law and practice.

I believe when this is done, it is demonstrating an authentic and proper Australian palliative care service, in which Anangu are respected, and where the practice of palliative care more generally is lifted to a higher standard.

And because this is occurring in central Australia, families are kept well (emotionally and spiritually).

More importantly families can continue on with hope after they have lost a family member, because everything is level and settled and in NPY Women's Council, this is the proper way, the wiru way of working.



**Ngaanyatjarra Pitjantjatjara Yankunytjatjara (NPY) Women's Council** supports Aboriginal women and their families in areas where governments (WA/NT/SA/Cth), or other sectors are not willing or unable to provide assistance. These services cover a range of human service areas: traditional healers (ngangkari) who offer healing and emotional well-being services, domestic and family violence crisis case management and outreach for women, aged, frail and disability case management, disability advocacy and carer respite, a child and family service for children where neglect or growth faltering is present and where families have involvement with the child protection system, programs for young people, emergency hardship assistance and a social enterprise created to enable women in the remote central and western deserts to earn their own income from fibre arts – the Tjanpi Desert Weavers.

To find out more go to [www.npywc.org.au](http://www.npywc.org.au)

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