



# Kapululangu

## Aboriginal Womens Law and Culture Centre

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**REVITALISING WOMEN'S CULTURE  
CARING FOR WOMEN & COMMUNITY**

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Committee Secretary  
Standing Committee on Family, Community, Housing and Youth  
PO Box 6021  
House of Representatives  
Parliament House  
CANBERRA ACT 2600  
AUSTRALIA

Submission No.1276

(Inq into better support for carers)

*AOC 2/9/08*

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

I write this submission from the perspective of a White (Irish-Australian) woman who:

- lives with a group of Aboriginal women elders in a remote desert community (Balgo, WA) on a traditional Aboriginal Women's Law Ground;
- manages and maintains a Women's Tjilimi (or Women's House) where six or more women elders live together;
- provides daily care and assistance to these women elders as part of my responsibilities as the coordinator of the local Kapululangu Aboriginal Women's Association (AC); and
- is the registered carer for an Aboriginal woman elder who had her leg amputated in November 2007 as a result of diabetes and since this time have supported her through her hospital experiences and later in her home community.

I am a White woman carer of Indigenous Australian women elders in a remote desert community. I am concerned about the experiences of carers, and the people they are caring for, in the Indigenous community of Balgo, 248 kilometres south of Halls Creek in the south-east Kimberley region.

The issues I wish to raise are:

1. Providing the Carer with Information as an Avenue for Informing the Aboriginal Patient:
2. Using the Carer as a Communicator When English is not the First Language
3. Carer Dealing with Medical Behaviours around Cultural Concepts of Disease.
4. Carer Dealing with Patient's Immense Loneliness Inherent in Isolating Remote Area Aboriginal Patients

5. Lack of Provision of Accommodation, Meals and Transport for Carers in Hospitals
6. Carer Assisting Medical Professionals with Appropriate Cultural Relations
7. Having to Deal with Nurses' Rudeness as a Carer
8. Carers Doing the Work of Nursing and Educator Staff
9. Carers Difficulties with Aboriginal Liaison Workers, Social Workers & Occupational Therapists
10. Lack of Counselling or Support for the Carer in Hospital Context
11. Carer Dealing with Lack of Disabled and Aged Facilities in the Community:

I will provide information regarding the experiences of both carers and those they care for – from the perspective of a non-Indigenous carer certainly but reflecting the experiences of Indigenous carers and their families in our community of Balgo in the south-east Kimberley.

My knowledge in this field responds to four locations of care:

- in family: issues facing carers in a remote Indigenous community
- the state of care for the Aged and Disabled in our community.
- catering for Indigenous patients and carers in the hospital/institutional context;
- carer support services to remote communities in relation to aged and disabled care.

These domains are not isolated and they are all influenced by the degree of support and services offered by government.

I note that both non-Indigenous service providers and Indigenous clients are responsible for the successes and the disappointments currently facing Indigenous carers and their relatives in need of care. But these incidences tend to always be, to various degrees, with the non-Indigenous service providers holding control.

Ultimately the responsibility of providing adequate and efficient services to carers and their relatives lies with the State/governments which design the policies and with the bureaucratic institutions charged with implementing those policies concerning aged care, care for people living with disabilities and for their carers. These policies and procedures are tied into the multi-tiered governmental relationship with Indigenous peoples both individually and collectively which percolates across the full spectrum of the Indigenous policy arena.

#### My Experience as a Non-Indigenous Carer in an Aboriginal Community:

My personal experience as a carer stems from my long-term friendship with one of the women elders with whom I live and work. For the purpose of this paper I will call this woman "MA".

On 26 November MA was flown out of Balgo community having collapsed in the Balgo clinic. While she was on the Flying Doctor Plane she stopped breathing. After she was transferred to the ambulance at Derby Hospital her heart stopped beating. She had septicaemia throughout her body as a result of a wound in her foot which had developed gangrene. Consequently she suffered multiple organ failure – kidney, heart and lungs. After being stabilised she was flown directly to Perth Royal Hospital where her right leg was amputated below the knee. She was in the Intensive Care Unit for five days, before being transferred to an isolation ward at Royal Perth Hospital because of carrying MRSA on her skin. Two weeks after her first amputation below the knee, her wound became infected and she was forced to

agree to second amputation, this time above the knee. She remained at Royal Perth until 23 December when she was transferred to an isolation ward at Shenton Park Rehabilitation Centre (Perth). At Shenton Park she underwent an intensive period of mobilisation training before being released to return home to her community on 25 January. At home for three months she spent an hour every day maintaining the exercises she was shown at Shenton Park. She returned to Shenton Park on 5 May for a further seven weeks training: this time in how to walk on a prosthetic leg. She returned to Balgo on 29 June and continues daily walking practice most mornings in the local clinic but has not become a proficient user of an artificial limb. She is thus confined to a wheelchair. MA cares for two young grandchildren, a 14 year old girl, and her aged mother. She also provides to a degree for her husband, a male elder, with whom she is in a mutually supportive relationship.

My caring role for MA began on 27 November 2007. Upon being informed by her family members on the night of the 26 November that MA had been sent to Perth for an amputation I organised to fly from Brisbane (where I temporarily was) to Perth on the morning of the 27 November. I normally live in Balgo community where I have lived and worked closely with MA for many years. I did not return to Brisbane for two months, staying in Perth to support MA through her ordeal. I also cared for MA after she left Royal Perth Hospital and moved to Shenton Park Rehabilitation Hospital to attend the physiotherapy gym to learn how to be mobile as an amputee. I accompanied MA back home, supported and encouraged her during the three months she was at home in her community. I returned to Perth with her on 5 May to attend Shenton Park and supported her on a daily basis while she learnt to use a prosthetic leg. During this seven week period I took two weeks to have and recover from a gall bladder operation (on 29 June). I organised for friends to support Margaret at the gym during this time, but continued to care and provide for her at our accommodation. I returned to Balgo with her on 29 June and continue to care for her. While her husband cares for her of a night, and at some times during the day, I remain her primary carer. Over a period of eight months (27 November to 27 July) I have had no completely carer-free time.

In addition to the experience of caring for MA I have, as the coordinator of the women's organisation and centre in Balgo, provided constant care for thirteen women elders between 1999 and 2001 while living together with them in a one room tin shed on the Balgo Women's Law Ground for two years. Between 2005 and 2007 I provided support services to six women elders. Between 29 January and 5 May 2008 and again since June 29 I have provided constant daily care for six women elders with whom I live at the Kapululangu Women's Centre. As a consequence of this history, I am more experienced than any other non-Indigenous person living in Balgo or indeed any person servicing the community from outside of the town about the concerns and issues confronting the women elders of the community.

#### 1. Providing the Carer with Information as an Avenue for Informing the Aboriginal Patient:

When I arrived at Royal Perth Hospital on 27 January in response to the news that my friend, or according to Aboriginal kinship relations my Pimiri (/aunty), the Aboriginal woman elder MA had been rushed down to Perth I was under the understanding that she had had part of her foot amputated. (I had accompanied MA to Derby Hospital in January 2000 in a successful attempt to save her foot.) There was a lot of confusion around what had happened to MA that had resulted in the amputation below her knee. The hospital staff was willing to allow me to be with MA from 8am to 8pm for the five days that she was in the Intensive Care Unit. That this was on the basis of my claim to have a relationship with MA through my position as the coordinator of the women's centre in her community indicated the willingness of nursing staff

to make allowances for Aboriginal patients. However, they were unwilling to provide me with very much information about MA's medical issues. I was grateful that, following her operation, MA had been kept sedated until someone she knew was present. Unfortunately, as she increasingly gained consciousness and started to question where she was I was unable to fully explain to her what had happened to her. As her carer I would have appreciated being able to inform her better.

## 2. Using the Carer as a Communicator When English is not the First Language

Because MA's first languages are Ngarti and Kukatja (Aboriginal languages) this is what she spoke and understood in the early stages of her recovery. She normally speaks passable English, which is her fourth language, but it took two weeks before she began to communicate more fluently in English. Even when she was speaking English the nurses had difficulty understanding her. She had similar difficulty understanding their English – especially as she was spoken to by busy nurses with a vast variety of accents. This made her feel inadequate and stupid. As her carer, with a less than fluent grasp of the Kukatja language, it was left to me to translate to and from Kukatja and, later, between Aboriginal English and English. Most nurses dealt with this problem by not communicating with her although there was the rare few who really showed that they cared by learning some Kukatja words. It was clear that most nursing staff required increased training in cross-cultural communication skills and in catering for Aboriginal patients from remote areas (which is vastly different from Aboriginal patients from urban areas).

For example, it was left to me to inform MA that she would need to have a second amputation. MA was only just coming to full realisation that she had had her leg amputated. I had decided against telling her about the amputation until she realised it herself in her own time thereby allowing her a period of natural adjustment. It was a full week before she realised that her leg had been amputated. Even then she was barely cognisant of the fact when, two weeks after the first amputation, her wound became infected and she needed to have a second amputation above the knee. Because neither the nursing nor medical staff could communicate with MA it was left to me, as her carer, to talk her through this process. In the end, the only reason that she agreed to the amputation was because I encouraged her to do it. I did not tell her that without the second amputation she would surely have died from septicaemia.

## 3. Carer Dealing with Medical Behaviours around Cultural Concepts of Disease.

On the fifth day, MA was transferred to another isolation room in another ward at Royal Perth. This was the beginning of two months of living in an isolation ward. This was because she carried MRSA on her skin. All visitors were expected to put on a gown and gloves. It was not explained about the MRSA for several weeks, and so we assumed it was to protect MA from any illness (e.g. cold) that we might bring in. It was not explained that the gown and glove regime was to protect not MA but the other patients in the hospital from her. When MA was transferred to Shenton Park Rehabilitation Centre she was again accommodated in an isolation ward with the same gown and glove regime. When it was finally explained to MA that she had MRSA she complained that this made her feel "dirty" – as she has no understanding of the science of disease transfer she could not understand the reason why she was being kept in a room by herself and why everyone had to wear gowns and gloves when they came near her. As her full time companion, and someone who had lived closely with her since 1999, and since I was visiting her from 8am to 8pm every day I refused to wear a gown or

gloves because it made her feel uncomfortable. At no time was there an attempt to eradicate the MRSA from her skin. Friends who visited later complained that the hospital should have informed them of the MRSA because they may have contracted it and spread it to unhealthy family members and friends outside of the hospital environment. By not informing us about the MRSA and not providing education about it the hospital put other people at risk. If it was deemed unimportant and unnecessary to inform her visitors, then the question should be asked: why put a remote-areas Aboriginal elder who does not understand Western concepts of disease transference through the embarrassment of thinking that she was “dirty”? It should be noted that MA has her own deeply held beliefs about the causes and processes of illness and while these might clash with those of Western medicine the mismatch should be catered for with a careful and indepth attempt to explain such issues in a way that they can be understood by the patient. As MA’s carer I was left having to explain the reason behind what seemed to her to be unreasonable and discriminatory behaviour on behalf of medical staff.

#### 4. Carer Dealing with Patient’s Immense Loneliness Inherent in Isolating Remote Area Aboriginal Patients

One of the greatest tragedies of the entire hospitalisation period was that, as a carrier of MRSA, MA was consistently confined to a series of isolation rooms. This meant that not only had she been removed from her own family (without her prior knowledge, for she had collapsed in the local clinic before being flown out) but that she was cut off from interactions with other patients. For an Aboriginal woman resident in a remote area community this resulted in a deep loneliness. Her adult granddaughter had been sent with her to Perth but had proven inadequate for the task. Preferring to go shopping with her grandmother’s keycard, she seldom visited her and then only sat by the side of her bed for half-an-hour and read a book or spoke on the phone before wandering off. In the month that she was in Perth she visited her grandmother five times, and MA regularly asked whether her granddaughter had returned to their community without her. Eventually this is exactly what she did do. This hiatus of care was the consequence of a young woman in her twenties being expected to deal with more than she could take on. She was transported to Perth, arrangements were made for her to stay at an Aboriginal Hostel, but other than that she was left to her own devices. She simply couldn’t cope with the city with its extreme contrasts to desert life. The few other family members who might have come instead would have had exactly the same problem and repeated the same ineffectual visiting patterns. MA was aware of this when, given the chance to ask another family member to come to Perth to be with her, she declined saying that they would probably just get “lost” and “drink too much grog” (alcohol).

It was for this reason that the role of carer fell to me – as a non-family member of MA’s immediate circle. It was in awareness of that deep loneliness and the associated trauma and depression which threatened that for two months I spent every waking hour visiting MA, and for two periods of a week each slept in her room on a hospital-supplied camp bed. At Royal Perth Hospital I was invited by staff to sleep in her room on the night of the second amputation, and for several nights afterwards. At Shenton Park I had to present a detailed argument to her doctors before they agreed to allow me to stay, and they were equally concerned about her. They also reported afterwards that they were delighted with MA’s immediate improvement once she wasn’t lonely anymore. I had returned from a period away to find MA totally distressed. She had been left completely bereft of any family connection in a strange city, and was in an isolation room so only had contact with an occasional nurse. Her granddaughter had returned home and I had been in Brisbane for two weeks. She had become intensely lonely and, although I had rung her several times a day, she had been

crying so much that some staff had become worried for her. I slept in her room for a full week before the matron/manager of the ward returned from holidays and my bed was simply removed from the room. When MA threatened to leave the hospital if I wasn't allowed to stay I argued for an extension but was unsuccessful. I was able to convince MA to stay on. Nonetheless, I continue to argue most forcefully that at least in the case of remote areas Aboriginal elders forced into isolation wards allocation should be made to provide accommodation in their rooms for their carers. Given the circumstances I am grateful that I was allowed to stay in both hospitals for at least that time when I was most needed by my friend. I would also advise that meals be provided for the carer wherever fulltime attendance is necessary.

#### 5. Lack of Provision of Accommodation, Meals and Transport for Carers in Hospitals:

Carers should be provided with the facilities necessary to make it possible for them to provide full-time company to their Aboriginal relatives from remote communities. This includes accommodation, meals and transport. During our second visit to Perth so that MA could attend the Shenton Park Physiotherapy Gym I attempted to find accommodation for us both on the hospital grounds. Such accommodation is provided for Aboriginal and other patients but not for their carers. MA was not prepared to go to Perth by herself or to stay there by herself. She would not have gone if I had not been able to go with her. We were forced to make alternative private accommodation. With accommodation on the hospital ground would have some meals which meant that I also had to provide us both two meals a day for seven weeks. Because the hospital-run patient transport will not take carers we also had to provide our own transport to and from the hospital. It was suggested that patient transport take MA to the gym and that I follow in a taxi or bus. MA was also not willing to attend the gym unless I was with her. Without my accompanying her fulltime MA would never have learnt to walk on a prosthetic leg. Because we had to make other arrangements for accommodation, transport and meals it cost us \$3000 over seven weeks – we shared the cost which meant that we had to draw on our aged pension and carer's pension respectively. This because the hospital would not extend their accommodation assistance to include carers, even in instances of cultural need. The Aboriginal hostel equally would not consider housing me because I am not Aboriginal. The consequence of this is that in such instances of mixed-cultural background between carer and the person they are caring for there is no accommodation available. Wanting to have a non-Indigenous carer with her meant that MA was severely disadvantaged.

#### 6. Carer Assisting Medical Professionals with Appropriate Cultural Relations

As a carer of an Aboriginal elder from a remote desert community it fell to me to educate the nursing staff in culturally appropriate communication with their often bewildered and sometimes distressed and offended patient. Most often nursing staff were keen and interested in learning how to communicate with MA directly, to show their respect to her as an Aboriginal elder, to learn about her life. Some nurses were simply too busy to spend much time with their client, often as a result of under-staffed wards. Others couldn't bother to attempt to communication across linguistic differences. Some, however, were downright rude. Whatever the motivation, all of these sectors required some level of cross-cultural awareness education – which was more easily delivered in some instances than others. This is a role which falls on carers of Indigenous patients which would not be required in circumstances where the patient is not of a minority cultural background.

#### 7. Having to Deal with Nurses' Rudeness as a Carer:

Abrupt, stressed and bossy nurses was a regular event, unfortunately. In an environment where one is dependent on nurses and where nurses have the power, efforts should be made to ensure that nursing staff care enough about their patients to ensure that their time in hospital is easier, or at least to ensure that they themselves are not part of the problem. This would result in less distress for the patient. One nurse was repeatedly rude to MA causing her severe distress such that MA threatened to hit her. This coming from one of the most gentle and considerate people I have ever had the pleasure to know was clear evidence that she was significantly upset by this nurse. Unfortunately nurses are in a position of power and can easily cause difficulties for patients who challenge them: and after that so the situation only became worse until I had to report the problem to the Social Worker. The nurse was moved to another room did not bother MA again. Another situation occurred upon MA's discharge from Shenton Park. The discharging nurse had written the details of the plane flight on a piece of paper on which she had also scribbled a note to the airplane company saying that they should make sure that the carer does look after the patient. She gave me the piece of paper with the flight details. Looking at it I naturally read this note. I asked who had written it. She said she had written it. I had never met this nurse before and she had no way of knowing me or how well I had been looking after MA so for her to making such as statement telling the baggage handler at the airport to make sure I looked after my own Pimiri (/aunty) seemed to be unjust. It was quite an insult. I told the nurse that she was very rude and had no right to pass judgement on me like that. She quickly apologized. With the taxi arriving to take us to the airport I put the note in my bag and went to the toilet. When I returned to the room the nurse was going through my bag and was taking the note out of it. I was horrified that a nurse would go through my personal bag. I attempted to take the note from her hand but she refused to release it. I left her with the note. She quickly departed. The discharge was poorly executed, and we were given the wrong forms prior to leaving the hospital, and noone escorted us to the waiting taxi. My immediate reaction after such the incidence was to report this nurse but later I thought that perhaps she must have felt that her job was at stake for she had clearly overstepped the mark. Because she was a recent migrant to Australia I wondered about her family responsibilities and decided to let the matter pass. But this sort of behaviour towards carers is abhorrent and should not be tolerated.

#### 8. Carers Doing the Work of Nursing and Educator Staff:

As I was with MA for 12 hours every day, and because both she and the nurses relied on me so heavily as a conduit for communication, I often ended up doing the work of the nursing and educator staff. For example, on one occasion a nurse asked me to give MA her insulin injection. Although I had done this many times before (and in fact had given MA her first ever insulin injection in 2000) this seemed inappropriate but I did it anyway. I also repeatedly assisted MA with her ablutions and cleaned her afterwards, simply because staff often failed to respond to her bell before it was too late, in which case she would be left sitting in a wet bed. I got rather tired of being relied upon in an under-staffed ward.

On another occasion, the diabetes educator presented me with a video and asked me to get MA to watch it so that she would understand a particular self-applied medical procedure. I had made myself available to all staff as a go-between in communications and willingly agreed. I watched the video first to see how I should explain whatever information it contained to MA. I was shocked. The video had been developed for people with English as a first language, drew completely on Western concepts of medical care and, most importantly, made no allowance for anything other than a Western lifestyle. There was no way that MA

could gain any information from this video had she been prepared to watch it, which she wasn't. The educator had visited her the day before while I hadn't been there and had frightened MA with the news that she would be dependent upon a "kidney bag" for the rest of her life. MA flatly refused the threatened "kidney bag" and the educator's video. When the educator returned I explained the inadequacy of her video to her, and asked if she had any information which was accessible to Aboriginal clients. I was informed that nothing existed in Western Australia and that she had tried to get something from New South Wales but that it needed to be reprinted. I informed the educator that she had failed in educating her client and asked her to get the information and come back. We never saw her again. MA remained uneducated about this option which would enable her to stay at home in her community rather than be forced to move to Perth to go on a dialysis machine.

#### 9. Carers Difficulties with Aboriginal Liaison Workers, Social Workers & Occupational Therapists:

The Aboriginal Liaison staff in both hospitals were inadequate in their relationship with MA. It should not be assumed that just because a staff member is Aboriginal they can communicate with other Aboriginal people from other cultural backgrounds and different regions. For example, there is a vast difference between urban and remote area Aboriginal life experiences and worldviews. In MA's case the Aboriginal liaison staff proved completely ineffectual, on those rare occasions when they made any attempt to visit MA. The Aboriginal liaison people at Shenton Park only met her once in her fifth week, and again while passing in a corridor in her seventh and final week.

The Shenton Park Social Workers were more helpful being always available within a few hours of requesting their assistance. However, although I had clearly been caring for MA since 27 November 2007, I was advised that I could not to apply for a carer's pension until after she left Shenton Park on 26 January, as technically the hospital was looking after MA and not me although I was clearly fully involved in caring for her.

The Shenton Park Occupational Therapists were generally helpful providing equipment for showering and other requests. But there were some difficulties and delays in arranging for repairs to the wheelchair which had developed a puncture while MA and I had returned to Balgo for three months. I had been assured that it was a tubeless tyre. I tried to organise for wheels which were conducive to the city context while we were in Perth, but this resulted in a miscommunication with the occupational therapist until she admitted to not knowing very much about wheelchairs. This was a shocking revelation: that occupational therapists might not be expected to know about the most common equipment for people living with disabilities. As someone who had spent the previous three months pushing the said wheelchair around a remote desert community – with all of the difficulties of terrain that entails – I expected to be communicating with someone who knew more about wheelchairs than me and who cared about my experience as a carer in such an environment. Eventually, the wheelchair situation was improved and we returned to the community with tubeless tyres. It must be said in the occupational therapist's defence, that the wheelchair is a very strong, measured to fit MA's large frame, and adequate to the task of desert life – given the tubeless tyres.

#### 10. Lack of Counselling or Support for the Carer in Hospital Context:

I had no support or counselling in regard to the life-changing role that I was thrown into because of my willingness to provide full time care for MA. I found that was very traumatised



by the entire experience: I spent a lot of time breaking into tears. There were no services available to support me. I was capable of dealing with this, but my experience made me very aware that there was no way that MA's family members would have been able to cope. Her adult granddaughter did come to down to Perth but spent the entire time she was in Perth either in bed or shopping (as she had control of MA's keycard).

When, during our second visit to Perth, I had to go into hospital for a gall bladder operation, I contacted Carer's Link to ask if they could provide some sort of support with getting MA from our accommodation to the Shenton Park Rehabilitation Hospital. I was told that they couldn't help me because I was in Perth and was registered in Halls Creek. I was led to believe that I could not obtain any assistance to assist me to continue caring for MA while I had an operation. After the operation I had the occasion of speaking to someone else at CarersLink and they were very apologetic about what had happened. They explained that there is a funding arrangement that keeps the different units separate but that there are also arrangements for transferring between units. They apologized for not supporting me. But by that time I had already had the operation and was well on the way to recovery. I had found some friends (in a city where we knew noone) and they had come to our assistance – the Quakers or Religious Society of Friends, Perth.

#### 11. Carer Dealing with Lack of Disabled and Aged Facilities in the Community:

There are no aged or disabled care facilities in our community. As the carer of the only Balgo resident dependent on a wheelchair, and as the (voluntary) coordinator of the Kapululangu Aboriginal Women's Association and its Women's House where up to six women live on a permanent basis, I am the only provider of services to the aged and disabled in our community. This has been achieved with no resources and no funding for our organisation.

No facilities or assistance has been provided for MA since her return to the community on the 29 January, other than the delivery of five wooden ramps on the 23 February. This delivery was four weeks after MA had returned back to her community, and 10 weeks after it had become apparent that MA was going to survive and would be returning to her community. As I write this there are still no ramps on any of the public buildings in Balgo – excluding the local Clinic and there the only ramp is through the Emergency Room which cannot be used when that room is in use. This means that nine months after her operation, and eight months and two weeks after her pulling through, there are still no ramps or any other service in Balgo to support MA although it is blatantly clear that she will be dependent on a wheelchair for life. As a carer this means that I have to spend a great portion of my life pushing a wheelchair around – through sand and gravel – and lifting it in and out of the car. Noone has attempted to provide MA or myself with any real support, and this clearly includes the paid staff of various government departments which supposedly service our community.

In my capacity as the voluntary coordinator of the local women's organisation – which is unfunded despite the services it provides: e.g. aged women's residence, local safe refuge for women and children in need – I spend much of my time providing for the day-to-day needs of the women elders – assistance with shopping, transport, cooking, washing and personal care. They have no other services provided to them by any other agency, including the local agency currently funded to provide these services. Because the women's organisation is unresourced these women elders currently sleep on rubber mattresses on a concrete floor, as we don't have money to buy beds. They live in a large room bereft of fridge, washing machine and any other furniture and equipment. There is no Home and Community Care service

operating in Balgo and indeed no service other than what I offer as the voluntary coordinator of the local women's centre. There is a meals service but as it has no wheels (I deliver to the women elders) it cannot be called a "meals-on-wheels" service.

There are many Aboriginal carers in Balgo community, and there are significantly more people in need of care than are being provided with care. Within some families, the role of carer is shared or rotated – even though it is often the case that in some families there is no one available to be the carer. This can be a chronic problem leaving the person in need of care without any support. In some families although carers are registered little or no caring support is provided to those in need. As of August 2008, registered carers are still not receiving the assistance and support that they require and have repeatedly requested from government sources to enable them to look after their relative adequately and well.

There is a prevalence of neglect of the elderly. Elders are often left to fend for themselves. In some families, younger family members see their elderly relative as a source of income and quickly drain their pensions leaving them without funds to purchase food. They leave the elders to complain of hunger over the remainder of the pension period. This creates problems between the carer and the relatives they are caring for on the one hand, and their remaining relatives on the other.

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to reviewing any recommendations you make to improve life for Carers in Australia.

Yours sincerely,

Dr Zohl de Ishtar  
Coordinator, Kapululangu Aboriginal Women's Association, Balgo