

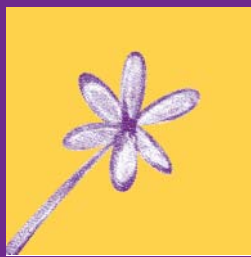
# **Be with us Feel with us Act with us:**

**Counselling and support for Indigenous carers**

**Project Report by  
Roseanne Hepburn  
for Carers Victoria**

**February 2005**





Roseanne Hepburn, whose ancestry lies in Tasmania and Flinders Island, journeyed with Carers Victoria during this project.

The staff of Carers Victoria learned in their hearts, spirits and heads, just a little about what it is like to be an Indigenous Australian, about Australia's past history and about current racist policies.

Carers Victoria is challenged by these issues and is committed to contributing to reconciliation and justice for Indigenous Australians.

We embrace a future in which Indigenous culture enriches Australian society and Indigenous people fairly share Australia's resources.

Thank you Roseanne for sharing your story, your journey, your struggles, and your passions and convictions.

*Mama Bohan*

Maria Bohan  
Executive Director  
Carers Victoria

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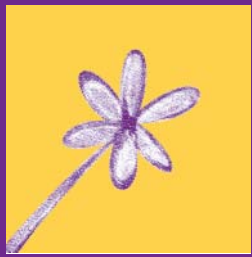
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- ✦ Victorian Aboriginal Community Controlled Health Organisation
- ✦ Aborigines Advancement League
- ✦ Ramahyuck District Aboriginal Corporation, Sale
- ✦ Gippsland and East Gippsland Aboriginal Co-operative, Bairnsdale
- ✦ Njernda Aboriginal Corporation, Echuca
- ✦ Rumbalara Aboriginal Co-operative, Mooroopna
- ✦ Dandenong and District Aboriginal Co-operative
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- ✦ Ballarat and District Aboriginal Co-operative
- ✦ Budja Budja Aboriginal Co-operative, Halls Gap
- ✦ Dhauwurd Wurrung Elderly Citizens Association, Portland
- ✦ Goolum Goolum Aboriginal Co-operative, Horsham
- ✦ Gunditjmara Aboriginal Co-operative, Warrnambool
- ✦ Kirrae Health Service, Framlingham
- ✦ Wathaurong Aboriginal Co-operative, Geelong
- ✦ Winda-Mara Aboriginal Cooperative, Heywood
- ✦ Kookaburra Club, Darebin Community Health Service
- ✦ Western Suburbs Indigenous Gathering Place
- ✦ Our Rainbow Place, Inner South Community Health Service





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- ✦ Representatives from Victorian Department of Human Services and the Australian Department of Health and Ageing
- ✦ Aboriginal Women's Health Business Unit, Royal Women's Hospital

✦ Project Working Group comprised Carers Victoria staff:

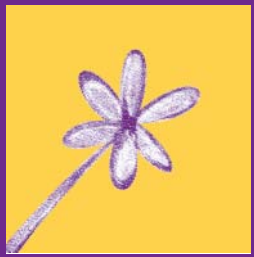
- ✦ Maria Bohan
- ✦ Roseanne Hepburn
- ✦ Louise Monahan
- ✦ Chris Twining
- ✦ Nilgun Yucel



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## Executive Summary

The Australia Aboriginal population is growing at more than twice the rate of the general community in official figures according to the ABS. Aborigines account for 2.3 per cent of Australia's 20 million population the bureau found.

Every Indigenous family is touched by illness and disability.

### What do we know?

Firstly, the true history of colonisation in Australia: acts of genocide, dispossession, segregation, assimilation and loss of land rights continue to have a devastating impact on Indigenous families and communities in Victoria.

Secondly, the Indigenous population is disadvantaged by a range of socio-economic factors which impact on health outcomes. Indigenous people suffer a greater burden of ill health than other Australians. They are more likely to experience disability and reduced quality of life due to ill health. The rates of death are five-six times higher than for other Australians.

Thirdly, many Aboriginal people live in an on-going situation of high stress and chronic depression suffering feelings of failure and hopelessness. The health conditions of Indigenous people are life and death issues affecting every aspect of Indigenous families and communities.

At the same time, the education, employment and housing situation for Indigenous people is worsening.

### So who are Indigenous carers?

Indigenous families and carers care for elders and those with disability, mental illness and a range of chronic illness and conditions, frequently exacerbated by substance abuse and family violence, suicide and premature death.

Very few Indigenous people identify as carers, however many have significant care responsibilities. Most are women and they are of all ages. Most care for more than one person, often for three or four generations of family members with care needs. Caring impacts on Indigenous carers. They experience:

- ✦ depression
- ✦ loss and grief
- ✦ isolation, guilt and anger
- ✦ anxiety, worry and panic attacks
- ✦ difficulty coping
- ✦ significant financial hardship and lack of access to carer entitlements
- ✦ worsening health and well-being
- ✦ interruption to education and employment
- ✦ lack of transport
- ✦ lack of information about carer support, respite and counselling

The loss and grief experienced by Indigenous carers is exacerbated by Australia's past





history and racist policies resulting in transgenerational trauma and grief.

Many Indigenous carers, as do many Indigenous Australians, carry fear and mistrust of mainstream services. Most are not linked to carer support services.

### What would make a difference?

- ✦ A holistic approach is needed when working with Indigenous families and carers.
- ✦ An understanding and sensitivity to culture, spirituality, emotions, community, family and identity is important.
- ✦ Partnerships between Aboriginal community organisations and mainstream service providers is needed.
- ✦ Flexible and culturally appropriate respite, and carer support and counselling.
- ✦ Indigenous sensitive education and information for Indigenous carers and workers about services and entitlements.
- ✦ Indigenous carer support workers and Indigenous workers in mainstream services.
- ✦ Cross cultural training for non Indigenous workers and services.

Carers Victoria has been working with Indigenous workers on carers issues for several years. The findings from this project and the enhanced relationships with Indigenous carers, workers and organisations is sharpening and strengthening all of our work: counselling; information and support; carer respite; education and training; policy, advocacy and carer representation.

*"Recognising that we all have a little part, that we all share the story, that we're all accountable to the story, that we're all responsible to the story. We acknowledge the terrible parts of the story, we recognise the truth of it so that we can go forward with optimism, celebrating our future, feeling secure in it, not excluding any one of us, regardless of how small our part is in the dance, how short our verse is in the song, how such a small snippet we contribute to the rich portrait of that history. We're in it together and we must ensure that those who resist and deny the story are overcome by our strength of purpose, our unity, and our crying desire for a nation that's justly reconciled, that is mature enough to accept the nastiness of our histories, that is willing, as equals to go forward and build something that embraces every little bit of every little story that tells our history."*

*Mick Dodson (Wollongong Talkin' Up Reconciliation Conference, 1999)*

# Introduction

Prior to this project Carers Victoria had demonstrated significant initiatives with Indigenous communities throughout Victoria. Staff had connected with Indigenous organisations and communities, and delivered information, support and education workshops.

The Counselling for Indigenous communities project aimed to:

- Identify the most appropriate ways of consulting with Indigenous carers.
- Identify the most appropriate ways of supporting Indigenous carers and their families.
- Increase understanding of the beliefs about caring in Indigenous communities and of the needs of Indigenous carers.

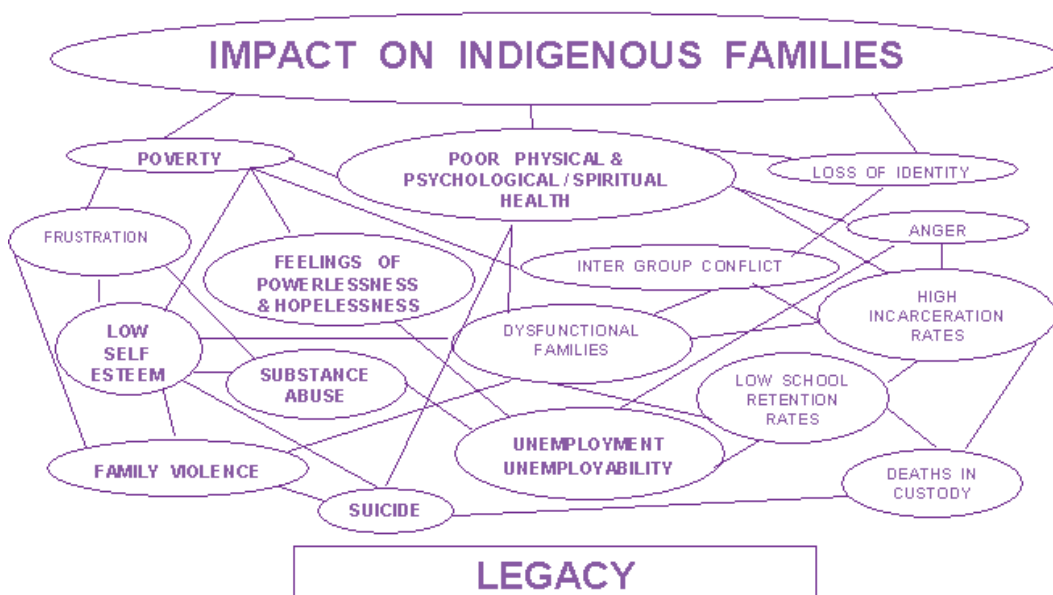
In undertaking this project Carers Victoria understood that the process would not be simple or straightforward. It was of utmost importance to acknowledge and understand the true history of colonisation in Australia. Acts of genocide, dispossession, segregation, assimilation and loss of land rights continue to have a devastating impact on Indigenous families and communities in Victoria. Many people suffer intergenerational grief and trauma.

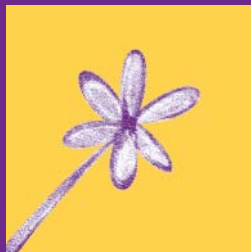
Census data indicates that the Indigenous population is disadvantaged by a range of socioeconomic factors which impact on health outcomes. Indigenous people suffer a greater burden of ill health than other Australians. They are more likely to experience disability and reduced quality of life due to ill health. The rates of death are five — six times higher than for other Australians.

In 1998-1999, Indigenous people in every age group were more likely than other people to be hospitalised for most diseases and conditions, indicating a higher occurrence of illness at more acute levels (Australia’s Health 2002, Page 201).

Considering the devastating statistics documented in the eighth biennial health report (2002) of the Australian Institute of Health and Welfare, the health and welfare of Indigenous people is the responsibility of Indigenous families and elders. The elderly are caring for their children and their children’s children despite their own poor health status.

The complexity of issues that Indigenous people are dealing with should not be underestimated and probably is best demonstrated in this diagram, which is used in Carers Victoria’s training sessions.





## Project Worker

At the outset, Carers Victoria understood the importance of employing an Indigenous person to do the project: someone who Indigenous people could trust to represent them without being judgmental, someone who 'knew' and understood the complexity of issues Indigenous communities are dealing with. Carers Victoria also understood the importance of putting appropriate measures in place to ensure that the worker would feel welcome and supported because they would be the only Indigenous person working in a mainstream organisation.

Maria Bohan, Executive Director of Carers Victoria met with Jill Gallagher, Chief Executive Officer of the Victorian Aboriginal Community Controlled Health Organisation (VACCHO) to discuss the project and seek advice about where to advertise the position. Following these discussions, the position was advertised widely through Indigenous networks and organisations.

Roseanne Hepburn was employed to undertake the project. Roseanne is a member of the 'Stolen Generations'. Her ancestry lies in Tasmania and Flinders Island. During the project, as Roseanne travelled many miles throughout Victoria, she actually made links with missing parts of her family. Previously Roseanne was the Aboriginal Access and Equity Officer at the Inner South Community Health Service, working primarily with the St Kilda parkies.

When Roseanne disclosed to people that she was of Aboriginal descent and explained what her previous work had been, the trust seemed to be instantaneous. People didn't need to spend time 'educating' her about Australian history and the impact that policies had on their families, they could just simply 'tell their stories'.

Carers Victoria acknowledges that in undertaking and progressing the project there was an enormous emotional impact for Roseanne. At times she found it difficult to separate herself and her emotions from the job that she was doing. *"It's difficult to separate and it's difficult to express in words. It's a spiritual connection. It's a connection that Indigenous people have. It's a knowing that is not expressed verbally - they know that you know and it's in that 'knowing' that the pain lies."*

## Project Working Group

A four member working group of Carers Victoria staff was established to assist and support Roseanne and to provide clarity around Carers Victoria's expectations. Each worker brought a range of skills and knowledge to the project.

## Reference Group

The role of the Reference Group was to provide direction and to validate the project by:

- ✦ Representing Indigenous communities and Indigenous carers.
- ✦ Facilitating access to Indigenous communities.

Members of the reference group expressed strong concerns about 'yet another' Indigenous research project — *"Indigenous communities are over consulted!; "What will this project deliver for us?; We don't want a document that is 'more of the same' i.e. the issues are written up but nothing gets done!; We want to move on and go further!; Say what the situation is now and what needs to happen! Make it a living document!"*

## Methodology

When selecting a methodology for this project the working group considered the tasks:

- ✦ To identify Indigenous carers' unmet needs and the impact of caring on carers' health and well-being.
- ✦ To capture the Indigenous carers' personal perspectives and experiences about caring.

It was decided that a qualitative approach would produce a far more in-depth and worthwhile document. This method allows for personal expression and individuality. Sometimes the method may seem not structured enough or 'a bit messy' for non-Indigenous people but it is familiar to Indigenous people. They feel more comfortable because it is inclusive in a process of sharing.

Keeping in mind many previous research projects where Indigenous peoples' interests were seen as less important than the interests of the researcher, and to avoid tokenism Carers Victoria aimed to ensure that:

- ✦ Indigenous communities were involved in the development of the project from the early stages.
- ✦ The cultural protocols involved in approaching Indigenous families and organisations were respected.
- ✦ Both urban and rural areas were covered in order to capture a picture of the diversity of Victoria's Indigenous carers and the issues they are dealing with across the state of Victoria.
- ✦ The language used in the finished document would be accessible (understandable) to both Indigenous communities and mainstream service providers.

The project worker spent the first two months contacting and talking with key personnel from Indigenous peak bodies, networks, co-ops and health services across the state:

- ✦ Explaining what the project was about.
- ✦ Asking for feedback and suggestions about what direction the project should take.
- ✦ Inviting people to join a reference group, which would provide direction and validate the project.

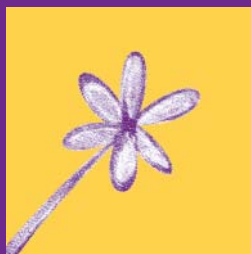
Although this took time it meant that Indigenous communities were given the opportunity to direct the process and to share responsibility for the project with Carers Victoria. Indigenous workers were more than willing to 'come on board' to assist and support the project and they encouraged community participation.

## Interviews

To ensure that Indigenous carers and workers felt safe and comfortable to share their stories during interviews and discussion groups the style of communication and the design of the processes was important. It was decided to:

- ✦ Conduct informal discussion groups rather than formal focus groups.
- ✦ Use simple, accessible, straightforward language so that participants would not feel patronised or intimidated, eg. no jargon or acronyms.
- ✦ Write up all information shared in discussion groups on a whiteboard in front of the





participants so that people had the opportunity to review, reflect and check that the information they shared was not misinterpreted.

- Be flexible about when and where individual interviews and discussion groups would take place.

The key themes of the interviews and discussions groups were:

- Identity as a carer.
- The impact of caring.
- Access to carer specific services.
- Possible models for supporting Indigenous carers.
- What would make a difference.
- What emotional support would be helpful.



During the interview phase of the project the project worker spoke with thirty-nine carers, ten Indigenous workers and two non-Indigenous workers (both employed in Indigenous organisations). All of the Indigenous workers who took part in discussions were family and community carers as well as being paid workers. The geographical regions included: Barwon South West; Grampians; Loddon Mallee; Gippsland; Southern metropolitan and Northern metropolitan.

The discussion groups took place in venues and at times chosen by the workers and the carers involved. Whenever possible advantage was taken of meetings that were already taking place i.e. not expecting people to attend an extra meeting. One rural group did not go ahead because of confidentiality issues, however the carers chose individual interviews instead. The groups were relaxed and the timing was flexible.

After group discussions, participants were given the opportunity to express their thoughts regarding the method and process used by the project worker. Their comments included: "I felt supported"; "There was consideration of different views and opinions."; "It was easy to understand."; "It was empowering and inclusive."; "I felt encouraged to participate."; "We learned a lot."

## Individual Carers

Interviews were conducted with five Indigenous carers and one non-Indigenous carer who was caring for his Indigenous partner. The carers included five females and one male, their ages ranging from mid twenties to seventy years old.

The method used for the interviews was a '*flexible subject driven approach*', which allowed the carer to determine the path and flow of the interview. An Indigenous way of describing the interview method would be '*yarning*' or '*story telling*'.

Consent forms were provided and signed by each of the carers who were ensured that their privacy would be respected and protected. Without exception the carers interviewed were more than willing to share their stories. They also expressed how good it felt to be listened to, even though at times tears were shed they were insistent that their stories be told and were not concerned about their privacy.

It is for this reason and because their stories give depth and meaning to the complexity of issues that we have decided to include the full stories as part of this report. Indigenous carers' names, however, have been changed in the report.

## Literature Review

There has been little literature documented specifically about Aboriginal and Torres Strait Islander Carers. There is one known document "Koori Carer Yarning Resource Manual" 2000, published by Carers NSW.

While documentation specifically addressing Indigenous carers is limited, literature documenting the ongoing impact of Australian history (colonisation, dispossession and racism) on Indigenous Australians supports the research findings of this project.

In the Victorian ATSI Communities HACC Needs Analysis Project (DHS Vic HACC funded), Juliete Frizzle (from Effective Change) identifies a complex range of issues being dealt with by Indigenous communities and individuals across Victoria. Carers' issues were listed both specifically and also linked to significant broader health and well-being issues for Indigenous communities.

The Australian Institute of Health and Welfare in Canberra documents an eye opening view of the Indigenous health status and mortality rates in 'Australia's Health 2002' providing specific data about diseases, chronic illness, housing, unemployment, service provision and more. (Australian Institute of Health and Welfare, 2002).

'The Bringing Them Home Report, 1997' provides a broad overview of Australia's colonisation history, institutional racism and the issues that Indigenous communities are dealing with. The important principle of self-determination is clearly explained along with recommendations.

*"Self-determination is a collective human right of people. It can mean many things: freedom from political and economic domination by others; self-government and the freedom to make decisions about family, community, culture and country"* (Human Rights and Equal Opportunity Commission, 1997, p.8).

Barbra Wingard provides excellent insight into the principles of working with Indigenous people and the different models of approach in the book "Telling our stories in ways that make us stronger, which she co-authored with Jane Lester, Her research, is mainly focused in the South Australian context but there are common themes that can be related to most Indigenous people in Australia (Wingarde Lester, 2001).

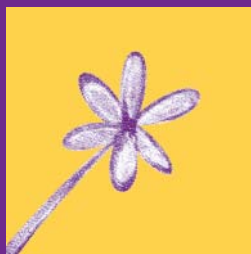
In her book 'Trauma Trails, Recreating Songlines', Judy Atkinson talks about the psychological effects of past history on Indigenous people. Trauma passed down directly from one generation to the next is now being described as 'Intergenerational trauma' (Atkinson, 2002).

'Aboriginal Health: the ethical challenges' discusses the need for an 'holistic approach' when working with Indigenous people. Taking not only the physical into account but a range of aspects that may impact upon an individual's health and well being i.e. cultural, spiritual, social, emotional, country, community, family, and identity (Aboriginal Health: the ethical challenges, 1999, p.74).

Bob Randall in his book 'Song Man' provides great insight into how Indigenous people think and feel towards non-Indigenous peoples.

*"We Aboriginal people overwhelmingly live in a situation of high stress and chronic depression. We have become so used to living with this stress that we regard it as normal, yet deep inside us there is still a quiet murmur, a distant memory of another way"* (Randall, 2003, p.216).





"Not only do Aboriginal people suffer the feelings of failure and hopelessness as a result of high unemployment and all the complex rules of accountability in the modern welfare system, they are also stranded in boredom. Our people are not immune to the lures of material goods. Across this country, even in the outback, you walk into an Aboriginal house and the television will be on all day. For our people, it gives the illusion of company, of community life, and of course it is a distraction from boredom. But we are also susceptible to advertising, to feeling that want for all the wonderful electronic and other goods we see on television. We see also the lifestyle of luxury so many white people seem to have, but we never see how we can gain access to these goods or lifestyle. This leaves with a lingering feeling of dissatisfaction and frustration which eats away at our appreciation of what we do have" (Randall, 2003, p.216).

In deciding upon a research method for the project literature, sighted was 'Social Research' written by Sotirios Sarantakos and 'Do It Yourself Social Research' (2nd Edition) by Yoland Wadsworth. (Wadsworth, second edition, 1998)

Special attention was paid to the fact that the research involved Indigenous people. Linda Tuhiwai Smith, a Maori researcher, wrote a marvellous book 'Decolonising Methodologies: Research and Indigenous Peoples' which provided valuable insight into the cynical attitudes most Indigenous people hold in regards to research :

"From the vantage point of the colonised, a position from which I write, and choose to privilege, the term 'research' is inextricably linked to European imperialism and colonialism. The word itself — research — is probably one of the dirtiest words in the Indigenous world's vocabulary. When mentioned in many Indigenous contexts, it stirs up silence, it conjures up bad memories, it raises a smile that is knowing and distrustful". (Tuhiwai Smith, 1999, p.1)

As John Fielder, Jeannie Roberts and Jill Abdullah wrote in 'Working with Indigenous Australians: a handbook for psychologists'. "However, given the history of previous research practices, and the relegation of Aboriginal peoples', interests beneath the interest of non-Aboriginal researchers research in this area requires 'particularly sensitive attention to ethical issues". (Dudgeon et. al, 2000, p. 350).

Dr.Ian Anderson 'Koorie Health In Koorie Hands' provides a good overview and he summarises Koorie history, modern society, health issues and service delivery (Anderson, 1998)

Pat Dudgeon and Ross Williams in 'Working with Indigenous Australian; A Handbook for Psychologists' (2000) (section 4) provides some worthwhile reading about Culturally appropriate therapies, models and services.

Anthea Coillet of the Southern Carer Respite Centre (SCRC) wrote a paper; 'A Country Retreat For Carers In An Urban Aboriginal Community'. After developing relationships with carers in the inner urban area of Port Phillip, the SCRC started providing flexible respite in the form of carers camps for Indigenous carers. These camps are ongoing and have proven to be very successful.

# Findings

The aim of this project was to find appropriate models to support the emotional well being of Indigenous carers.

Although we thought we had an understanding of the complexity of issues Indigenous people were dealing with, in conducting the research it was at times overwhelming and impossible to contain the complexities. It became necessary to take an holistic approach i.e to look at the *'big picture'*.

In our findings there were contradictions and similarities depending on:

- ✦ The region.
- ✦ If the carer was linked to a service.
- ✦ If the community was proactive in looking after one another.
- ✦ If the carer had a social outlet.

The following are the findings from the discussion groups and carer interviews:

## 1. Carers

Very few Indigenous people identify as *'carers'*. It seems to be a culturally accepted responsibility to *'look after our own'*. Many Indigenous workers and carers believe that caring for the frail elderly is the responsibility of families and communities. It is *'just what you do'*.

*"I was taught Koori ways with strong cultural ties. I have high respect for elders. They are our teachers. We are taught our cultural responsibilities to family from a young age. I teach my children to have respect towards elders and others."*

Most Indigenous families do not want to put elders into nursing homes.

Elders living in the bush or on riverbanks rely on family members coming out daily to transport them into town to assist with personal hygiene and food requirements.

Many elders are caring for grandchildren.

Indigenous carers come in all age groups and both genders but it is predominately women undertaking the caring role.

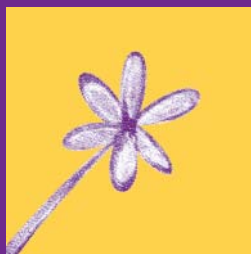
## 2. Indigenous workers

Most Indigenous workers are overloaded, not only professionally, but also personally. Cultural commitments and responsibilities to family and the communities in which they work make it difficult to identify and develop boundaries for self-care. It is even more difficult for Indigenous workers who work in mainstream organisations. Not only are they overloaded with their cultural responsibilities, they often feel isolated and unsupported in the mainstream organisations.

*"If you have a job you are automatically an advocate for your community. Workers are overwhelmed and 'on call' 24 hours a day with work and family obligations"*.

There was a common theme regarding community care:





- Everyone does the caring in the community. If a carer needs to go away there will be others who will look after the person with care needs.

*"Family overrides everything. For example hospital liaison officers will have a cultural obligation to look after their family - priority must be given to family".*

- If it is at all possible families and communities will look after each other however there are people who are disconnected from family who rely on workers as their sole source of support. This places enormous pressure on workers.

*"We are paid to provide care for 10 hours, which isn't enough to look after someone. therefore we work more than those hours. We are concerned about our community members so we go back out of hours to check that they are okay". (Indigenous HACC worker).*

There is an elder who opens her home and cares for people in the metropolitan region. These are homeless people with mental illness who go to her place on weeknights or weekends when they are starting to become unwell. She feeds them and looks after them. She is a community carer who is well known by all. She struggles financially.

*"We are clan, family based. The government has put unnatural boundaries on Aboriginal communities and organisations".*

### 3. Beliefs and values

Despite understanding the European concept of 'caring', everyone we spoke with, identified caring as being more of a cultural response.

*"I do see myself as a carer, but I see myself as a mother first."*

*"It was my choice to have children and it's now my responsibility to look after them despite their disabilities."*

*"We don't see ourselves as carers. Its just part of being in the community. It's part of how you're raised. You just 'take em in.'"*

### 4. Impacts of caring

The impacts of caring include:

- Depression, including contemplation of suicide.
- Loss and grief.
- Anger.

*"Usually one person takes on the carer's role in the family. This can lead to further tension in the family. This causes more stress. You can feel manipulated, intimidated, angry, frustrated, house bound, or as if you have no control over your own life".*

- Anxiety, panic attacks, worry.
- Fear of discrimination.

*"There is a cultural and social obligation to care for family - if you don't do it you can be marginalised - or you feel guilty".*

✦ Feeling trapped, angry, guilty.

*"My relationship with my partner often feels strained. He has different ways of dealing with my son! He blames me for my son's disability. Maybe it is genetic! I don't know."*

✦ Difficulty coping.

*"At times I am fearful of answering the phone or door because it might be someone else needing help".*

## Isolation

There are carers who are isolated and who don't have the opportunity to talk to anyone at all.

*"I don't have time for social relationships."*

When Indigenous people have come from elsewhere - even though they have lived here for thirty years or more they experience additional isolation due to not being traditionally from the community in which they live.

Carers who have children tend not to stay at social gatherings very long because there is nothing for the children to do.

During the project we met two carers who were socially disconnected from their families and communities due to:

✦ Discrimination, from non-Indigenous family members.

*"I found out that I was Aboriginal five years ago! Friends and family discriminated against me, not only because I was Aboriginal, but also because of my daughter's disability."*

✦ Discrimination from their extended family members and Indigenous community due to substance misuse and the carer wanting to protect their children.

*"My social supports are limited outside my immediate family. We don't go to family functions where there is grog. We haven't done this for seven years. Drink changes my partner's personality. He becomes violent."*

Many carers commonly experience these issues however prefer not to articulate them for fear of being further ostracised.

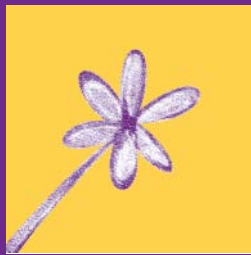
## Financial matters

All groups talked about the extra financial burdens associated with extended family and community members who need assistance: incontinence pads, bedding, medication, funerals, cost of transport, extra clothes, special clothes, special food, extra food, access to transport.

There is no support for grandparents who are looking after grandchildren because their children have drug and alcohol problems.

*"There is no family living close by to give a hand. It's hard to transport her. I constantly have to load and unload the car, i.e. scooter, oxygen, concentrator and nebuliser".*





*"We are expected to do it out of our pension or "they" will take them, put them into foster care and give foster families the money to do it".*

Because of the high mortality rates of Indigenous people, funerals are a constant concern for families. Carers come under added pressure and stress when someone passes on. Funeral costs and the extra costs associated with an influx of extended family who may travel from all around Australia for the funeral and stay for extended periods. This is particularly the case with the passing of an elder.

*"...it is seen as the last payment of your debt to them, because they have always been there for you. An elder's life is seen as pages of an old book". (Indigenous elder, ACES).*

## **Health and emotional well-being**

The high rates of substance abuse, mental illness (often undiagnosed) and family violence are placing an enormous burden on elders who are caring for their children, their grandchildren and in some cases their great grandchildren.

*"Our elders are 'growing up' their grandchildren, and their great grandchildren because there are now 'drug and alcohol missing generations' as well as stolen generations".*

Every Indigenous family is touched by illness. The sick are looking after the sick. Sickness is accepted in communities because most people in the community are sick. Chronic health problems include heart disease, diabetes, cancer, upper respiratory illnesses, kidney failure, depression and mental illness.

People find it hard to identify depression and mental illness within their families and communities because it has been part of their lives since colonisation. There is a stigma attached to mental illness even though it is so wide spread in Indigenous communities.

*"Caring can be draining. You forget about yourself. The demand is so great that you don't have time to think of yourself".*

*"Even if you do get out of the house you still worry. It's at the back of your mind all the time'. 'He wants to cook and I worry that he is going to burn himself".*

*"One carer made the decision to prioritise her children's needs for their father to be part of their life. This meant she was caring for him and this had an impact on her health. 'So it's like my kid's emotional needs for their Dad versus my well being".*

*"The doctor wanted to put me on valium but I don't want to be doped up looking after her. I want to have my wits about me".*

*"She doesn't like strangers coming into the house so respite is limited".*

*"It's very tiring, up early every morning and the last thing I do every night is get his tablets ready for the next morning. It's 24 hours a day".*

*"We all need a holiday break but when you come back it's just the same".*

## **Grief**

*"Over time I have become very close to the person I care for. He has no other support than me. I worry about finding that he has died. I worry about how I would cope if it happened".  
(Worker)*

Some carers spoke openly about grief and the impact of past history and racist policies resulting in trans-generational trauma and grief.

*"There is so much grief it needs a lot of healing".*

*"Because of early deaths and the history, there is just so much grief".*

*"Grief. Hit the drink. Everyone handles grief differently".*

## Education, Employment and Transport

All carers and workers believe that education and employment are issues for the whole community not just carers.

There are extremely high rates of unemployment in families and communities.

*"I think to myself sometimes: What if? It would be lovely to have the opportunity to do a computer course".*

Carers identified that they would be more inclined to use mainstream services if there were Koori people working there.

Lack of transport is a barrier to accessing services for both rural and metropolitan carers.

*"Transport is a real problem for carers and families, especially for people who live further out". (Worker).*

Carers are often unwell themselves; they need transport to go for appointments for themselves and the person they care for.

*"We need more social activities for older people. They are isolated and lonely. Taxi vouchers are harder to get. You just about have to have no legs".*

## 5. Access To services

A common theme is that there is a lack of information about available services.

There is a fear and mistrust of mainstream services as a result of history, government and welfare intervention, and racism.

*"I have been thirteen years with no services or assistance. I have had very little support".*

## 6. Access to entitlements

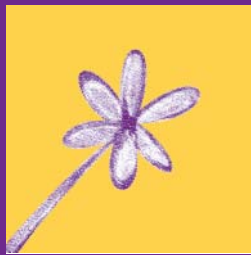
Despite identifying as carers only a few carers encountered were receiving any carer entitlements.

Only five out of 39 carers interviewed during the project were receiving any carers entitlements.

In one Indigenous organisation there is a support group of sixty carers. Not one carer from this group receives the Carer Allowance.

*"I could draw my family tree. Out of my 100 first cousins, 50 of them are dead from drugs, alcohol and mental illness. In a family of 14, three committed suicide due to drug overdoses and three died as a result of alcohol abuse". (Worker).*





*"People don't contact Centrelink because of the long time they are kept waiting on the phone and because it's impersonal. Some people can't read or write, they need assistance with filling out forms. Just the size of the Centrelink forms frightens them, even if they have to fill just a small section. So they don't bother". (Worker)*

*"We don't go to Centrelink. They make you feel so small you want to crawl under the carpet".*

*"One elder has been a carer for many years but has only been on a Carer Payment for the last two years because she wasn't aware of her entitlements". (Worker).*

## 7. Support and respite

A few carers are linked into carer support services and are happy with the service provided, however often there are long waiting lists.

The amount of paperwork, the lack of flexibility and the attitudes of workers puts people off using mainstream services.

*"We pay for everything out of our budget. We have tried to get funding support from mainstream services but in the end we just gave up. They wanted too much say about where we went and what we did". (Worker).*

In some rural regions people, carers and workers, do not even have the most basic information about services.

*"Indigenous people in rural country areas don't feel they are part of, or are welcome, in the rural towns. They feel that mainstream services do not or are not willing or able to provide a service for them. If they need assistance or support they are afraid to ask for help or they feel that it would be a waste of time and effort. Many people have a defeatist attitude towards services. They are more likely to say things like 'They won't help me". (Rural worker).*

It's important to have partnerships between the Aboriginal community organisations and mainstream service providers.

*"We don't access respite - it's seen mainly as a mainstream service".*

*"We need flexible respite and more respite funds to assist carers".*

### Support and respite: What carers reckon would help?

- ✦ More income support for family carers.
- ✦ Community services having some money to provide support on an emergency basis.
- ✦ Time out.
- ✦ Down the stress and up the health and wellbeing.
- ✦ Carer retreats, (without the care recipient) plus counselling.
- ✦ Respite for when the carer is unwell or hospitalised so that appointments for the person with care needs can be maintained.
- ✦ Flexible respite, in home or out-of-home respite, overnight or for a weekend.
- ✦ Carers need time out to: have night out, go out for dinner or to the movies, have their hair done or have a massage.

*"A worker would come to my home and take care of my child. When the worker would come they would tell me to leave my home and go do some shopping or something! I had never left her alone before. I felt really uncomfortable about leaving her, so I would leave the house and go and sit on a corner near home and wait there feeling lost, trapped and guilty about abandoning her. I would worry constantly about her. I felt I was letting her down" (Carer).*

✦ There must be enough time to spend building relationships. *'It starts with cups of tea'.*

*"Must be careful of who who goes into the home. The person does not have to be Indigenous but you must be able to trust them".*

✦ There needs to be education in the community so there is recognition and acknowledgement of the work of carers.

✦ Education resources and information about the impact of caring, services, entitlements, identifying ailments like mental illness and dementia.

✦ Education for carers on entitlements, the Carer Payment, the Carer Allowance.

✦ Mainstream literature and brochures are not Indigenous friendly. There are literacy issues. The resources are too formal, European artwork. Indigenous people don't feel that it relates to them.

✦ Carers, communities and Indigenous health workers and services, need education about what services are available.

*"People talk 'at us' not 'to us'. There is still a mission mentality. Do-gooders."*

One group named a Community Care Options out-reach worker. *'She was good. She came along to elders' lunches. We got to know her and trust her'.*

There is reluctance from some Aboriginal services to make links, or build partnerships with mainstream services or access mainstream services for their clients.

*"Mainstream can't work like we do here. It's not difficult. We are just asking for a little bit of flexibility. While we have rigidity and structure things will never change - rigid, patronising and dictating. Sometimes mainstream services want our names on their books because it makes them look good. Or they are patronising 'do gooders' who want to change the world". (Rural Worker)*

Mainstream services do not provide the same level of support as Indigenous organisations.

Some carers have made links but found that mainstream services are not responsive to their needs. The rules are rigid and inflexible. *'Mainstream can't work like we do. There's no flexibility'.*

There is a lack of culturally appropriate carer respite. Culturally appropriate means Koori workers, Koori faces.

*"There is no Indigenous appropriate respite. To access respite, people have to be taken out of their community". (Rural worker).*

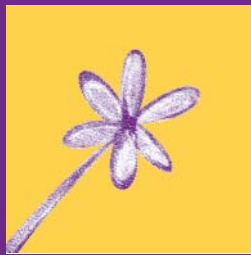
## 8. Counselling

Some people in the groups were more familiar with and open to formal counselling than others. All groups talked about family and friends supporting and listening to each other. A non-Indigenous female counsellor (Glen Ocre) used to visit Echuca for counselling within the Aboriginal community. Glen is very well respected and she wanted to train up Aboriginal people as counsellors but the funding ran out.

When asked about their feelings in relation to Carers Victoria's counselling service for carers there was some resistance from workers, however some carers were open to outside

*"There might be a stigma attached to counselling. A family might feel they have let their own down".*





counselling, if it was culturally appropriate.

*"We wouldn't like to change the system we have here and we don't think that the women would like an outsider - trust takes so long to build."*

*"People are more likely to access support within the family."*

*"They access counselling as a "last resort".*

*"Counselling is a new thing for the community."*

*"The family will get upset if you access counselling."*

*"There is a stigma in accessing counselling."*

*"Sometimes it's good to access counselling."*

*"It's difficult to talk to a stranger."*

*"It helps to talk to someone people have met."*

*"It's good to talk to someone outside family."*

*"Community organisation counsellors are better."*

*"Good to have a choice in counsellors."*

*"Sometimes counselling is good for grief and loss issues."*

*"Face to face - is often a preferred option. You can see body language."*

*"Telephone counselling - people would most likely not use it but it could be a good option for those who want to talk to someone but wish to remain anonymous."*

*"There should be counselling specifically for siblings and young carers."*



## **Counselling: What would make a difference?**

### ***Counsellor qualities***

All three discussion groups had very strong opinions about the qualities and values any counsellor working within their communities should have. A few people said they would prefer an Aboriginal person but most agreed that it didn't matter if the person was non-Indigenous provided the person was passionate and had cultural understanding and knowledge of past history and the impact of the history on Indigenous people.

*"A counsellor may not understand what an Indigenous person is saying."*

Qualifications were seen as less important than life experience. Someone who is *'real'*. Someone who has *'been through the ropes'* and *'can speak your language, uses plain simple words, no jargon or acronyms'*.

-  Someone you can *'have faith in'*. A person who has the time to listen to you and isn't rushed.
-  Someone you can relate to, speak your mind to and come together with.

*"We are all psychiatrists. We all talk to each other. If we have got a problem we talk to each other. You know you are not on your own. We've all got the same problems. Women will talk to each other but generally men don't. They grin and bare it; they don't go to the doctor. Sometimes I get emotional. It would be good to talk to a woman. Just to have someone to talk to".*

- ✦ Someone who doesn't judge you or put themselves above you.
- ✦ Someone who is not pushy and dictatorial but is accepting and has no aspirations or expectations of the carer.

People need to be able to check the counsellors out and have individual choice eg. gender of the counsellor.

The counsellor should have a sound knowledge of Indigenous and mainstream services and make carers access to services and entitlements easier.

### **What would make a difference overall?**

All groups talked about the need for the employment of Indigenous workers in mainstream services. Mainstream services need to employ Indigenous people. Only then will the community use the service. Carers Victoria needs Indigenous people working on 1800 number and Indigenous carer support workers. An Indigenous worker has practical skills and knows how the person on the phone feels.

*"All groups talked about the need for culturally appropriate services from the mainstream. The community needs to start thinking about other options for respite eg. caring for both carer and the person with care needs". (Worker).*

Racism awareness and cross-cultural training is necessary.

Partnership building between Indigenous services and non-Indigenous services.

*"A carer shouldn't have to be in crisis before accessing counselling. It doesn't have to be a big or a medical issue, just an opportunity to get things off your chest".*



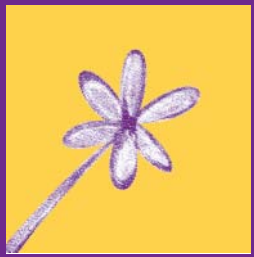


## Recommendations

It is recommended that Carers Victoria:

- ✦ Informs and educates Indigenous communities and organisations about carers and Carers Victoria's services:
  - ✦ Information and support.
  - ✦ Carer counselling program.
  - ✦ Education & training.
  - ✦ Carer entitlements.
  - ✦ Carer Respite Centres.
- ✦ Educates management and staff of Carer Respite Centres about:
  - ✦ Who Indigenous carers are.
  - ✦ What the needs of Indigenous carers are.
  - ✦ How to work flexibly with Indigenous carers.
  - ✦ The impact of prejudice and racism in Australia and the resulting barriers for Indigenous carers in accessing services.
  - ✦ The value of having Indigenous Carer Support Workers and other Indigenous staff across all programs.
  - ✦ The importance of having Indigenous sensitive workers on staff.
  - ✦ Services that Carers Victoria can offer Indigenous carers.
- ✦ Ensures that the Carer Counselling Program (and the National Carer Counselling Program):
  - ✦ Provide Indigenous friendly, flexible counselling for Indigenous carers.
  - ✦ Provide education and training on Indigenous carers and their needs to contracted counsellors.
  - ✦ Develop a list of contracted counsellors who are Indigenous sensitive and responsive.
  - ✦ Work to identify Indigenous counsellors within Indigenous communities.
- ✦ Promotes the following Indigenous sensitive counselling components:
  - ✦ Indigenous worker (sessional or part time) to staff Carers Victoria's Freecall 1800 number (ie. the entry point to the Carer Counselling Program).
  - ✦ The counselling process to be flexible and driven by the needs of the carer.
  - ✦ Awareness of the role of Indigenous carers, and the complexity and magnitude of issues, for example, intergenerational grief and trauma.
- ✦ Seeks resources to employ an Indigenous Community Development Worker who will:
  - ✦ Build support mechanisms for Indigenous workers employed by the Carer Respite Centres.
  - ✦ Resource and advise Carers Victoria staff.
  - ✦ Network and build relationships with Indigenous communities and organisations, Carer Respite Centres and Carers Victoria.
  - ✦ Participate in the development of Indigenous sensitive training for services and staff.





## Definitions

### Carer

For many Indigenous people the term 'carer' has European connotations and is difficult for people to get their heads around. Caring is seen as '*just what you do, look after your own, black common sense*'.

There are many carers of all ages in Indigenous communities, even small children, but the majority of Indigenous carers are 'elders' of families. They love, care and nurture their own — for no payment, they see it as a responsibility '*that's just the way it is*'.

### Community

Describes a group of people living sometimes in close proximity with similar interests who interact with each other for mutual support. Community can also be a network of people and groups who are separate by geographical terms but are interlinked by common concerns and consciousness. Rollo May provides a definition that best describes an Indigenous community on a deeper level. '*A group in which free conversation can take place. Community is where I can share my innermost thoughts, bring out the depths of my own feelings, and know they will be understood*'. (Trauma Trails, Recreating song lines. Effect of Trauma in Indigenous Australia: p ix, Judy Atkinson - Published by Spinifex, 2002).

### Culture

Is a set of beliefs, values and rules for living that is distinctive to a particular human group. Culture is passed down through generations: knowledges, languages, social organisations and life experiences that link diverse individuals and groups together. Culture is a living process that changes over time to reflect the changed environments and social interactions of people living together.

### Elder

Traditionally an elder is the keeper of cultural knowledge within a tribe or community, a keeper of '*lore and cultural values*'. Elders are; teachers, carers, wise people, highly respected within their family, community or tribe.

Today the definition of elder is extremely diverse. Many Indigenous people have their own perceptions and thoughts regarding the term elder. An older person is referred to as an elder but not necessarily in the traditional sense.

Some see an elder as:

- Someone of a grandparent generation and older
- Someone elderly doing community work
- The eldest in a family.

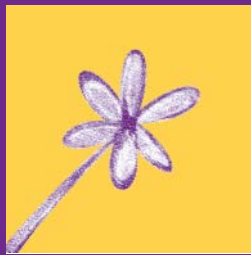
Many believe that age alone is insufficient to merit the term elder.

The term elder has to be earned

Elders are generally perceived to be people who are wise, passing on their knowledge to the next generations.

For many people an elder takes the place of a mother, father or grandparents and may not even be related. '*Someone you select as an elder to you. Someone you hold with high respect who has been there for you, 'grown you up'. A person who has the knowledge and skills of living and can teach you culture*'.





As a sign of respect, anyone who is significantly older is usually referred to as 'Aunt' or 'Uncle' by the community. 'If you are not known by the elder it is best to ask how that person would like to be addressed'.

## Family

The traditional concept of family relates to blood relationships and extended kin networks.



## Indigenous

The term Indigenous refers to Aboriginal and Torres Strait Islander people, this term acknowledges the diversity of Aboriginal and Torres Strait Islanders living within the state of Victoria. Aboriginal and Torres Strait Islander peoples have separate cultural groups that have different histories, politics, social situations and cultural characteristics.



## Indigenous Carer

The Southern Carer Respite Service, Southern Region, in conjunction the Indigenous Access and Equity worker at the Inner South Community Health Service developed a helpful definition.

*Key community members who take on an extended caring role, providing care and support for a number of different people whether they are friends, relations, neighbours, or other members of the Indigenous community.*

*Community members whose homes often function as drop-ins and emergency accommodation - often becoming busy at times. It can be difficult for them to manage with the increased costs, the interpersonal frictions.*

*Community members who take on a broader advocacy and support role for the wider Indigenous community.*

After consultation the project reference group accepted the above definition, however the group noted that this role is often undertaken in a professional and / or voluntary capacity.

## St. Kilda Parkies

Describes a group of people who hang out on a regular basis in a specific park in the St. Kilda area. Up until recently many were homeless. This group has an historical attachment that goes back many years.

## Spirituality

It is difficult to define. It's an essence of self. It's an individual understanding and belief. It's a belief about being part of a higher being, grounded to the earth, family, culture and self. It encompasses your identity, the customs and lore that were provided by your creator and also encompasses your mob, clan or tribe. It's how you relate to the broader clan through family. It is a sense of being – what separates you from mainstream, defines you as a separate race of people (Worker).

## Yarning or story telling

A narrative description of life events, a personal oral history. Having a yarn is about people talking together, communicating with each other or people telling their stories.

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## Carer Stories

### Alice

Alice has five daughters and two sons and is the sole carer for her youngest daughter (18 years old) who was born with a severe intellectual disability. Alice admits to times of feeling trapped, angry and frustrated, by something as little as tying her daughters shoe laces! And then she feels guilty.

The only time Alice received support services was for in-home respite when her daughter was three years old until she was five. This was provided with very little consultation with Alice. Alice felt forced from her home for two hours a week. She consequently sat on the corner of her street and wandered the nearby streets, constantly worrying about her child whom she had never left before!

In the past Alice and her daughter have been subjected to racism and discriminated against by neighbours, family and friends, not only because of Alice's Aboriginality, but because of her disability. Nasty letters and teasing! As a result Alice now suffers severe anxiety attacks. So severe that once she was hospitalised for weeks! Even now, 14 years later, Alice is still fearful of walking to the letterbox.

Alice has asked for support but for the past 14 years has never received any.

### Pam

Pam is a young mother and carer of three young children. Her middle child, a seven-year-old son, is Autistic. Pam is fearful of having a Gubba (white person) caring for him. She feels alienated and ostracised, because she doesn't have strong connections with family due to them having drug and alcohol issues.

Pam has a strong desire to nurture her family in a healthy way. Consequently Pam feels disconnected and unsupported, and has little time left for social relationships. Her relationship with her partner is often strained. She finds caring difficult and physically draining.

Pam has to spend more for specialist childcare, schools, clothing and separate food for her son. She feels it would have been beneficial if she had been informed about appropriate supports and services when her son was a baby. Instead she has only become aware of support available over the past year. Even now Pam still awaits support after assessments.

One response from a service was so negative Pam never rang back! She had been waiting three years for respite. It was recommended she contact her local council, only to be put through a long process of an appointment, plus an assessment, then waiting for a letter of recommendation. It took three months. The result provided a six-hour block once every three - four week periods. When she rang them they suggested two-hour blocks maximum because you just never know when you will need respite! She felt hopelessly let down! Thinking what good is that to me?

Pam feels the need for flexible respite that offers in-home care. She needs a break and her home is the safest environment for her son.





## Marg

Marg is a middle-aged mother and carer of four children, aged from five to nine years old. She also cares for her partner of seven years, who suffers an Acquired Brain Injury and a mental illness due to drug & alcohol misuse. Her eldest child, has an intellectual disability and is incontinent. Last year, for seven months, she also cared for her late uncle, now deceased, who also had Acquired Brain Injury (due to alcohol and having been bashed) had dementia and was incontinent. He was awake from 10pm till 6am every night! Sleepless nights placed enormous pressure upon Marg! Marg said *'He was horrible to look after. He needed to be placed in a locked ward' but health professionals wouldn't listen to me'*.

Though she has only four children she felt she was caring for five and sometimes six because her partner and uncle virtually needed full time care and couldn't be left alone.

She was fearful of leaving her partner and uncle home alone. She had to remove all house fuses from the fuse box otherwise she was fearful of them harming themselves, the children or burning their house down. It took her three years to get her partner on medication for his mental illness. The CAT teams were called many times to help administer the medication because he refused to take it. His medication is still not quite right!

The children are also carers. They too have to watch over and care for their father and sister.

Until recently Marg's daughter was attending a school that lacked the ability and commitment to support the family. However now, the daughter attends a public primary school, which is very supportive and accommodating towards the daughter's needs. The daughter had been self-harming due to frustration over schoolwork and being bullied by other kids at school. The previous school wouldn't listen. Marg had to continually attend the school and advocate for her daughter. The daughter is incontinent. The teacher was aware of this, however would make the child wait! This proved degrading and embarrassing for both child and mother. A constant supply of clothes had to be taken to the school!

Marg is concerned about her other children as they spend a lot of time, sharing the caring role for both father and sister. She believes they would benefit greatly from counselling!

*"My kids need to get out and get involved with activities outside the home more. I feel they are missing out on their childhood. They need time away from the caring responsibilities! They need time out to play more like children!"* This has proved difficult due to racial discrimination.

Financially it has been real tough! Marg's partner receives a disability pension, which he spends on himself and his addictions, leaving little for the children or her.

Last year Marg developed depression due to suffering arthritis, combined with her caring responsibilities. It became so severe she even contemplated suicide. Social supports are limited outside the family due to drug and alcohol issues!

Marg finds it emotionally hard. *"It's like my kids emotional needs for their dad, competes with my needs and my well-being!"*

## Bill

Bill is a non-Indigenous carer, caring for his Aboriginal partner who for the past five years has suffered chronic emphysema and asthma. There is no close family living nearby to help. Bill's physical health is deteriorating: arthritis due to heavy lifting and having to push a wheelchair. *"It's hard to transport her: constantly having to load and unload the car"*, i.e. scooter, oxygen, concentrator and nebuliser! Having to transport all this equipment has forced Bill into purchasing another larger car. Bill's partner received a HACC (Home and Community Care) package a year ago that has helped provide equipment ie. ramps.

Bill's partner relies solely on Bill for everything, including dressing. Bill feels relieved when his partner is hospitalised. This gives him a break. He dreads the phone ringing just in case it's bad news. At times it all gets a bit too much but Bill keeps persevering *"If I break down, who's going to look after her?"*

## Mary

Mary has three children. One is a niece she sees as a daughter. Her youngest son Alan was murdered when he was 23 years old.

*"It's difficult to explain the grief you feel when a child dies or gets killed in a car accident. I keep on thinking about how he died. After Alan's death, I rationalised away thoughts of suicide because I had a daughter and grandchildren to look after"*.

*When Alan was murdered I was very involved with the land council and the co-op. I didn't grieve properly. Then my oldest son took the kids. The house just felt dead: no life. I had a complete breakdown and now I'm on antidepressants"*.

Mary's oldest son has 10 children to different women. *"He owes me money but he will pick a fight with me rather than pay me"*. Mary reared three of his children, two boys and a girl, after he lost custody.

Both her grandsons have alcohol problems. Mary had a restraining order put on the oldest: *"He becomes violent. He and alcohol don't mix, he's ok if he doesn't drink"*. Mary took a stand and *'kicked them out'*. Mary's granddaughter had a baby when she was fourteen. She left home to live with her boyfriend and she is a victim of domestic violence.

Mary's daughter is also a victim of domestic violence. *"He lives with another woman but he still torments her and the kids and he threatens to kill them"*. When she's down Mary takes the kids away.

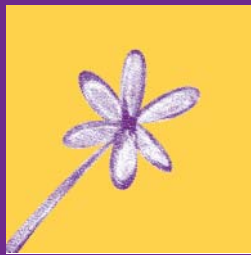
## Brenda

Brenda, 63 years old gave up smoking 14 years ago after being diagnosed with emphysema as a result of her own smoking and passive smoking. *"I reckon I got it from passive smoking, living for years in a house full of smokers"*. She uses a pump and she becomes breathless with over exertion.

Brenda and her husband William had eight children, four girls and four boys. One son died when he was very young as a result of cot death and now her husband and two more of her sons are also deceased. Brenda now lives with her one remaining son, Greg.

Brenda grew up in a large family; her father and eight brothers were heavy drinkers. *"I*





*had a rotten life, I swore I wouldn't marry a drinker".*

William was not a drinker until he injured his back in a work accident. *"He was a good man but he had bad luck at work and he got on the drink".*

William passed away in 1990 when he was 56 and Brenda was 49. From the time of the accident until he died William was hospitalised 52 times and Brenda cared for him at home. *"I nursed him all that time".*



William Jnr was born with a physical and intellectual disability. He went down to Melbourne to live but because of his disabilities and alcohol problems he couldn't look after himself. He was in and out of shelters and he ended up in hospital. Brenda went to a tribunal and 'got custody' of him and he came home to live with her and William Snr.



Simon died at 23 years of age as a result of alcohol abuse after his partner took off with his two kids 'he was so hurt and couldn't talk about it, he just drank and drank until he died'. His partner came from a family where there was lots of sexual abuse. *"Simon had such a kind heart, even before he died he used to say - don't be too hard on her Mum she has had a really hard life.*

1990 was a very hard year for Brenda; Simon passed away and William Jnr died of a cerebral haemorrhage on the day of Simon's funeral. *"During the night before the funeral he took off, people said they saw him staggering and then he collapsed and died in the street' 'the haemorrhage was probably the result of being bashed in the street out the back of St Vincents Hospital in Melbourne".* William Snr. passed away three months later: *"he never got over the death of his boys, he used to just sit and stare out the window, they were his drinking mates, his fishing mates".*

*"I felt so alone, my husband and my youngest and oldest boys, all three of them gone in such a short time, If anything happened to Greg I'd just about die".*

Greg has had problems with alcohol and drugs for years. When he is drinking he becomes violent and abusive. *"Greg was violent with his partner and she took off to Queensland with the two kids. 'I reared those kids but now I can't see them".*

Greg is not drinking at the moment. *"He used to stress me out when he came home drunk and he would give me a hard time".* Brenda is worried that he is starting to get sick again though because he's having a few drinks and smoking. *"When he's sober and going to church he never gets sick".*

Three of Brenda's daughters also need her support. After William and the boys died Gillian had a breakdown and she came home. Gillian has mental health problems; she 'took off' to Melbourne when she was sixteen. Brenda doesn't really know what happened to her when she was down there but she was involved in a serious car accident and she has attempted suicide.

Victoria and Jane are both victims of domestic violence. They have been to refuges and safe houses away from the town but they don't stay long because they feel too isolated, they want to come home. Jane's partner stalks her and the kids and intimidates them. *"He's a horrible bloke, he's so violent and he's on all sorts of drugs. He pulled a gun on a bloke and he even shot the dog in front of one of the little boys. DHS have warned Jane that they will have to take the kids if she goes back to him. If I don't support her and push her she gets so stressed out".*

Brenda believes that there is a need for counselling in the community. *"We have to talk about our problems, I do, I talk it out and I feel great. There is lots of gossip and everyone*

*in the community knows everyone's business, I think its good that we can talk to each other but sometimes we need a counsellor where no one else knows what we say".*

Now Brenda reckons that she lives for her grandchildren and she attributes her strength to God and the church 'God was saving me for something'. *"I believe it's going to church that has helped".*

Brenda is a wise woman: *"The older I get the wiser I get, I would probably make a good counsellor. Now I have learned to let go and I don't worry so much about the kids".*

Brenda likes to get right away for a break. After William Snr died: *"I was so stressed out my sister came to the rescue. You need a break, you need to get right away. They drove all the way up to Bundaberg and we had a great time together".*

Brenda has tried to get a Carers payment for looking after Greg but she hasn't heard back. If she is not eligible there is a possibility that Greg may be able to get a payment as her carer, *"then he will get some money for himself".*



