



Touching Women's Lives

A Final Report
(but the story is far from over)

**A Project for Older Women Carers in the
Upper and Central Hume Regions
2002**



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Women's Health Goulburn North East (WHGNE) was established in July 2000. Previously known as NEWomen, Women's Health Goulburn North East is the government funded, specialist women's health service for the Goulburn Valley and North East Victoria.

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Table of Contents

Acknowledgements	4
Summary	5
SECTION 1 - Overview	6
Introduction	6
Background	6
Gender	7
Demographics	7
Morbidity Amongst Older Women Carers	8
Disability Estimates	8
Carer Issues	8
Economic	9
Centrelink	9
Respite	9
Mental Health	9
Services	10
Hidden Older Carers	10
Political Context	10
Multicultural Consultancy – Information Day	10
Mungabareena Aboriginal Corporation - feedback to the State Disability Plan	12
State Disability Plan	13
SECTION 2 – Project activities	15
Leadership Training	15
Health and Wellbeing Days across the North East	16
SECTION 3 - The Future	17
Project Outcomes	17
Recommendations	19
SECTION 4 - How we did it	21
Leadership training	21
Action Research	22
Advanced Leadership Training	23
Appendix 1 - Doing It For Ourselves - Course Outline	26
Appendix 2 - Doing It For Ourselves - Training Application Form	33
Appendix 3 - Advanced Leadership Training Timetable - Ovens Valley	34
Appendix 4 - Touching Women’s Lives: Action Research Model	38
Appendix 5 - Doing It For Ourselves - Action Research Case Study	40
Appendix 6 - Advanced Leadership Training: Action Research Case Study	43
Appendix 7 - Facilitator’s Guidelines for Action Research Training	48
Appendix 8 – Consent Form	50
Appendix 9 - Interviews and Consultations	51
Appendix 10 - Curriculum and Trainers	53
References	54

Acknowledgements

This project was as much about love as it was about anything else. Love. What an overused and undervalued word that is. A word we shy away from, another stolen word gone into the hyper drive of advertising and mind stealing that is the currency of communication today.

But love is the right word for this project. It was a project marked by the care of women for their community and each other. The first group of women touched by this project will continue to drive it in their own communities.

They said they wanted:

'to go through the door into the unknown'

'to explore – no matter what the outcomes are' and

'make a more inclusive society'

Over the year these women have completed training, lobbied politicians, met with them face to face to tell how it is and taught other carers about their entitlements to a life that does include caring, but a whole lot more as well. They fought for and succeeded in improving service delivery to women across the north east. They researched and educated, and most importantly, they found reason to hope when hope seemed distant. They discovered 'that someone does care about me'.

These are special women and it is necessary for me to say thank you for what you do, and for the friendship and care you showed to me—a stranger in your midst. And for giving me one of the most special years of my life. I now go into my third age with great joy and enthusiasm, a gift of love from these women who touched my life profoundly.

The women at the centre of this project are:

Bev Miller, Smoko; Verushka (Sam) Colyer, Buckland Valley; Eileen O'Reilly, Talgarno; Suzanne Platfuss, Milawa; Helen Greenhow, Wodonga; Chris Sullivan, Wooragee; Kate Graham, Wodonga; Claire Douglas, Rushworth.

There are many women who made up this project and thanks to them also, particularly Sheryl, Fiona and Carly at the Wodonga Carer Respite Information Service. These women are its heart. Finally thank you to the reference group for the project, which had members who were regular attendees and some who were rarely able to come. All provided insight and information for the project. This project relied more on the women involved for planning and implementation, but the reference group was invaluable as a sounding board.

Summary

The Project looked at the needs and services for Older Women Carers in the Upper Hume Region. It was a community development project, defined for this project as: '*the process of ascertaining from the community what the key issues are and working with the community at their direction on the issues of key importance to them*'. We commenced in October 2001.

SECTION 1 – Overview

Introduction

The project was located in north-east Victoria and encompassing the Towong, Indigo, Wodonga, Alpine shires, the City of Wodonga and the Rural City of Wangaratta. The areas are diverse with pockets of poverty and areas of relative affluence.

WHGNE research information upon which this report relies is included in the body of this document and is referred to in this section. This research was planned and implemented by local women, who have essential experience of the health system as carers and are active members of their local communities. This education and research is a critical means of building a more active, dynamic and socially responsive community.

The activities in this project build on the existing skills and experiences of local community members. It generates a sense of empowerment and hope that improvements in the local community are possible and that change is actually able to be affected through the efforts and co-operation of ordinary local citizens. These women are available under the supervision of WHGNE to conduct Action Research in their communities.

Background

Some demographics for the Towong, Indigo and Wodonga Shires

Growth Projections 96-2001 as a Percentage		
Towong	Indigo	Wodonga
21.2% - 40.5%	17.4%-32.7%	11.7%-19.6%

Older women tend to experience comparatively higher rates of chronic disease, disability and depression than men. This is attributed to economic, political and social factors such as poverty, which is partly caused by women's role as carers and the part time nature of their participation in the workforce.

Issues identified by service providers and local researchers reflect the national data that older women carers are often isolated, poor and enduring high levels of stress.

Morbidity factors affecting people in the three relevant municipalities are overall similar to the state as a whole. Some relevant differences include prehensile and senile dementias which are above the state average for Indigo and affective psychosis and neurotic disorders, which are also above state average, for Towong. Fall accidents in Towong were substantially higher than the state average.

In socio economic terms Towong is more depressed than Indigo Shire. Indigo has an influx of families who are living in the shire and working in Wodonga or Wangaratta which affects the figures for this area (NE Division of General Practice Health Profile 2000). Wodonga is one of the fastest growing regional centers.

Gender

Older women and men are generally in good health and usually living rewarding, interesting lives. (Australian Institute of Health and Welfare, circa 1998) There is a tendency to pathologise older people as dependent and sick, a burden on society.

Older women who have been full time carers for most of their lives have not been able to participate in the paid workforce. In old age they are often reliant solely on a pension and have little or no personal superannuation. Thus they are either dependent on their spouse having had a good income or if a single carer, entirely on the community via a pension. Income splitting cannot be assumed and women who have not participated in the fulltime workforce are more likely to be very poor than those that have.

It is still a societal expectation that women will be the primary carers.

Demographics

VicHealth reports, 'Older people are not a homogenous group and ageing affects women and men differently'.

We are aware that older women report keeping very good health. Often women, who are classified as seriously ill or disabled by standard definitions, are actively involved in their community. (Women's Health Australia, Progress on the Australian Longitudinal Study on Women's Health)

Approximately 13% of Victorians are carers (577,000 people). 104,500 Victorians are primary carers. Most carers are 35-64. 17% of over 75's are carers. (Civic Guide to Setting up & maintaining Carer Support Groups, Maggie O'Shea, Carers Vic, 2001)

ABS 1997 Older Australians Report stated that grandparents provided care in almost 70% of households which received informal care for a child aged 11 and under.

Of the 7,700 parents aged 65 and over living with and caring for a child with a severe or profound handicap – almost half of these had been caring for that child for over 30 years.

In Australia, 75% of carers are women. By the time carers are 65 or over they are equally likely to be men or women. Older carers are themselves likely to have a handicap or disability. In the over 65 age range over half of the carers had a disability and 45% had a handicap. (Australian Institute of Health and Welfare, Older Australians at a Glance).

Morbidity Amongst Older Women Carers

Older women tend to experience comparatively higher rates of chronic disease, disability and depression than men. This is attributed to economic, political and social factors such as poverty that is partly caused by women's role as carers and the part time nature of their participation in the workforce.

Disability Estimates

Wodonga 1998	Towong	Indigo
5273	1346	2698

In Carers Victoria Caring Costs, 1998, 32% of women reported delays and difficulties in getting personal treatment due to caring, 49% had no preventative information, 62% reported their physical health as being adversely affected by caring.

Carer Issues

Some issues identified by carers were:

- Lack of comprehensive, jargon free information tailored to carer's specific needs and presented in a format that older people can readily absorb, audio and audio-visual information being considered better than written material. (Australian Law Reform Commission Quality Care and User Rights – Information for Consumers)

Yet carers also identified in action research conducted by the project participants, that they saw their GP as the place they would most like to find out about what services are available.

Economic

Travel was a frequently identified issue. Access to travel, cost of fuel, distances and frequency to attend medical appointments were hardships for many carers. It also meant that spending even more for respite and recreation was impossible.

Centrelink

One of the most significant findings to come out of the project was the perception about Centrelink and the general feeling of non-accessibility of this service.

A story reported by a participant in the project is illustrative. The names have been altered:

My husband had cancer and was considered to be terminally ill. We had been preparing for a trip to a city some distance away for a potentially life saving organ transplant. It had taken some time for my husband to be well enough to receive the surgery. We went to Centrelink to inform them we would have a different address for three months whilst he prepared and recuperated from the surgery.

We were both sitting talking to the worker there, who told us:

'If your husband dies whilst you are away, make sure you inform us within the fortnight. We don't want to make an overpayment...'

My husband was so upset by this that he went walking to work off his emotions and tripped injuring himself. The transplant surgery had to be delayed. My husband died.

Respite

This service is the most important service many carers receive. However, many people don't know about the it. The service is underfunded and many carers don't identify themselves as carers, '*respite is for other people*'.

Mental Health

Carers Victoria report that their research indicates poor mental health amongst women carers. The Caring Costs research conducted by Carers Victoria reported anxiety, depression, irritability, stress and anger in 70% of carers.

Services

Receipt of reliable and satisfactory services for carers is important. Continuity, variability and competence of workers is an identified issue.

GPs and hospitals are usually the primary source of assistance for carers and both are considered poor at referring and linking people into available services.

Carers identify that the people they most want to hear about services from are their own GP.

Hidden Older Carers

Hidden carers remained hidden during this exercise. Anecdotal evidence suggests unidentified carers may include:

- Women of diverse cultural or linguistic backgrounds
- Independent carers of 50 – 65 years
- Married women below retirement age
- Older Aboriginal women

Political Context

Carers and carer organisations have successfully lobbied for increases in funding and changes to service delivery models.

The Liberal party policy on carers in *The Liberal Party 2001* election promises were to increase funding for carers across Australia by \$80m. \$47m of this to be spent after the next election. \$33m to be spread thinly over a large range of programs including some infrastructure in terms of psycho geriatric facilities is what is offered over the next three years. \$10m of this will be for respite services, concentrating on rural and remote Australia. \$10m is to be for the emotional and psychological support of carers. How this translates to the NE of Victoria remains to be seen.

The government has an order of caring, presumably based on need, in descending order - aging carers of people with disabilities, carers of older Australians, carers of people with dementia.

There is to be no increase in the carer's allowance or pension despite 15% of Victoria's poorest people being carers.

Multicultural Consultancy – Information Day

WHGNE in conjunction with the Multicultural Social Network organised an information day on planning for the future. Speakers were from the Albury

Wodonga Legal Service, Centrelink and Disability Advocacy and Information Service (DAIS) to talk on issues about rights. WHGNE consulted with the group on their view of health and wellbeing. They asked about local service knowledge with regard to services available if caring for people with disabilities or for those people who are getting old and unable to look after themselves completely.

The group consulted was the Multicultural Social Network that has members from both Albury and Wodonga. It is a group that has been operating for some time and provides opportunity for support and outings. This was a very lively group of people and interaction was excellent. This group comprised both men and women.

Gender	Country of Origin and Main Language Spoken	Approximate Time In Australia
Female	Kosovo Serbian French English	3 years
Male	Peru Spanish	7 years
Male	Belgium mostly Belgian Congo	20 years
Male	Not Known English	40 years
Female	Croatia English	45 years
Female	Asian English	Considerable

The length of time in Australia proved to be very relevant to attitudes and degree of difficulty in integrating into the community and finding work. There were two in the group who had come to Australia as refugees, but before refugee status was named.

Issues for this group:

- mainly language difficulties
- racism

- access to information about services

Mungabareena Aboriginal Corporation – feedback to the State Disability Plan

Mungabareena Aboriginal Corporation is located in Wodonga and provides a range of services to Koori people in the area.

Mungabareena, in recognition of the high number of Koori people who experience disability/s, held an Education Day on disability on 14 December 2001. As part of this day the State Disability Plan was discussed and many issues were raised. Mungabareena was not part of the initial consultation process. The community attending was a mixture of people who experience a disability and carers/family/friends.

Issues which arose:

- the uncomfortable mix between state and commonwealth services.
- Often needs can be met on the other side of the border, where eligibility often varies
- a reluctance to persevere with government services when initial consultations are not satisfactory

Participant story

'Anne' is a young woman in her twenties with two children. She has a serious physical disability that substantially reduces her mobility. She was not eligible for any services to assist her with her newborn baby because she was able, with aids, to shower and clothe herself.

However, she was not able to care for her child and was not eligible for any assistance such as a carer allowance for someone else to help her or services to assist her in the home.

'Anne' was told she would be eligible for appropriate public housing with no steps and appropriate infrastructure to assist with showering and toilet. This was not made available and she has had to contend with steps and an unsuitable house. She feels unable to complain.

These issues are fundamental and the Victorian State Disability Plan is so far away from the reality experienced and highlights the problems with federal and state responsibilities impacting on individual situations.

A brainstorm of needs elicited the following information, in order of importance:

1. Financial support
2. Information
3. Rehabilitation/assessment/referral
4. Accommodation
5. Transport
6. Community education
7. Sport and recreation

State Disability Plan

The major issues identified were the cross border issues, and that the Wodonga region is a long way from meeting the needs of local Kooris who experience disability or have issues with the disability system.

Issues:

- The Koori community survive on its personal networks. Support for networks is essential.
- Needs of the elderly 'disabled' must be recognised as disability, not merely 'old age'
- Need for access to information, starting at the school level
- Consultation with the community needs to occur allowing a lot of time for full participation of the whole community and ideally to be facilitated by or with a Koori person
- Recognition that Koori communities differ and therefore have different needs
- Need for more trained Koori disability workers
- Recognition of the high stress nature of these jobs
- Attention to effective statewide resourcing and cross border issues
- Recognition of the different needs of people living in isolated areas
- The accountability of disability support providers (to clients and government)
- Protecting the rights of people in residential settings

- Finding point of entry to services
- Access to service including availability, and cost of travel
- Education and/or retraining for disabled people
- Employment
- Use of medical jargon by health professionals and problems with inappropriate or not understood referrals

SECTION 2 – Project activities

Briefly, the activities undertaken as part of this project and as a direct response to the women's statements of need include:

Leadership Training

This eight week (one day per week) training program resulted in the formation of the 'North East Women Carer's Action Group'. The focus was on action research.

At the beginning of the program the women stated the things they wanted to get from the training. These included:

'broaden our horizons'

'go through the door into the unknown'

'explore – no matter what the outcomes are'

'find new ways to reach carers, people with information/power, the community generally'

'be part of building an inclusive society'

'be able to apply the things we learn'

'promotion of issues'

'become involved'

Results included:

- Ongoing lobbying for a respite centre in Wodonga
- Action research into carers' knowledge of services. These results were fed into the Upper Hume Primary Care Partnership Service and Coordination Project and into the shires' planning process
- Research findings regarding Centrelink services were brought to Amanda Vandstone's attention. Further action research with Centrelink workers is planned

Other issues were acted upon during and after the training.

This is capacity building in action.

Further leadership training was undertaken by two of the participants.

Advocacy

Nearly all the women trained reported back on the usefulness of the lobbying, complaints resolution and advocacy skills they had developed during their leadership training. They felt they were now better able to lobby for equipment for carers; for addressing the breakdown between services causing gaps; and of the timeliness of a number of services.

Health and Wellbeing Days across the North East

Seven Health & Well Being days were conducted in different small hamlets across the region. The women carers who trained in the first course were involved in the planning and delivery of these days.

The partners in this project, funded by the Upper Hume Primary Care Partnership were: Upper Hume Community Health Service, Upper Murray Family Care Carer Respite Information Service, Department of Veterans Affairs, Aged Psychiatry and the North East Women Carers. The carers conducted peer education and facilitated some of the outcomes from the days.

Outcomes included:

- women reporting using services, getting together to provide respite for local women in need of a break
- receiving expert information on their own health issues
- going for an internal examination for the first time in 30 years
- setting up support groups, strength training groups, diabetes group, tai chi, etc
- stress relief and management awareness including depression and anxiety related issues

SECTION 3 – The Future

- The project worked with local women, training them in leadership and with service providers, to work within an equity framework, empowering the community and encouraging better participation in existing services available in the community for carers.
- These women will remain in the community and the Upper Murray Family Care Carer Respite Information Service will assist the women to continue their work.

Project Outcomes

There is a loss of community capacity building as young people move away from local communities to take up jobs and education in the city. One of the strengths of this project has been that it has enhanced the capacity and the agency of older women in the community, making their communities better places to live and love. They are better able to support their local services to meet their own needs, and thereby improving their own lives and the lives of other community members. Out comes included:

- Substantial increase in the knowledge and information in local communities of service provision frameworks, legal frameworks, carer entitlements, community resources.
- An ability and confidence to apply that information and knowledge to a range of problems, issues and needs in the local community to build stronger communities and better services.
- Improved health and well being outcomes for carers and people with chronic illness.
- The ability of local women to conduct training in and for their community on a range of social and health issues. The women could apply for Category 4 Workplace Training Certificates to allow the course to be potentially conducted through a registered training organisation and thus have the benefit of trainees receiving a formal qualification on completion.
- Increased capacity building in the local community (including increased capacity to organise support groups, public meetings, volunteers services, self and systems advocacy and to work co-operatively in other ways to ensure community needs are met).

- Increased capacity to articulate and advocate in relation to needs for services for consumers and carers.
- High level of self-care and empowerment for women who are undertaking a caring role. Shaping their communities to be better places to live and work, agency, leadership, role models, and community resource.
- People with chronic illness and disability who receive care and support from the participants will receive the following benefits: enhanced access to services, more targeted service delivery.

Specifically women said:

'This has been one of the best years of my life'

'You expect too much, you haven't trained us enough for this public speaking'. Three weeks later after delivering three sessions this same project participant said, *'I could run one of these myself'.*

One of the project participants has organised a Carer Support Group for her own area. Already she has over 15 people on her list. The women from the Ovens Valley will present their findings from the leadership training there in 2003. Individually the women are advocating both systemically and individually for service responsiveness for other women carers. They are an informed voice, lobbying for improvements and recognition of the role of carers.

North East Carers Action Group

The women will continue as the North East Carers Action Group, lobbying politicians and working with service providers to ensure appropriate effective services. They are specifically seeking to work with Centrelink to undertake a joint action research project about the barriers to good carer service and follow up education on breaking down those barriers.

The women aim to maintain a strong voice across the north east for carers, ideally undertaking train the trainer training and continuing the leadership training in their own right. They plan to develop and publish a carer's handbook on services available locally and how to get them, including tips on how to make the role of caring a little easier.

Further funding will be required to support these outcomes.

Recommendations

Participant Recommendations from the Health and Wellbeing Days:

1. To change the travel limit to an accumulation of medical or health visits, until it reaches the 100 kilometre mark. People who travel often, but shorter distances, are still very disadvantaged by their rural status.
2. A permanent disability or condition should only require a once a year GP signature. Regular trips for this signature are often not possible and result in carers missing out on benefits they are entitled to.

Participant Recommendations from the Mungabareena Information Day:

3. Ensure widespread access to information about Community Visitors, Office of the Public Advocate and other services (by media campaign, TV, radio, posters etc)
4. Create better linkages between services
5. GP education on the importance of feedback

Project Recommendations

6. State and federal governments to provide adequate funds to produce and disseminate accessible information on disability and carer services.
7. State and federal governments to restructure travel allowance requirements to adequately reflect individual need.
8. Federal government to allocate funds for service staff (ie Centrelink, outreach workers, disability workers) to be trained in disability, aged and cultural issues.
9. State governments to allocate funds to resource GPs in disability and carer issues to ensure accurate and informed referrals.
10. State governments to provide funds to conduct research into 'hidden carers', with a view to providing support.
11. Federal and state governments to create uniform policies for services nationwide to overcome frustrating border issues, where services can be available nearby but not able to be accessed because of differing criteria.
12. Federal and state governments to allocate funds to undertake research and build projects to meet the needs of the disabled.

13. State governments to allocate funds to support personal and community networks which support people with disabilities (ie service clubs, provide reimbursement for travel related activities).
14. Ongoing community consultation be a key feature of any further disability planning.
15. Increased disability training places to be made available for Koori disability workers.

SECTION 4 – How we did it

Leadership training

This is a story of a journey undertaken by 15 women. We called it **Doing It For Ourselves**. We had the ingredients, we just needed to develop our capacity and understanding of the way things work. What the training will achieve –

Advocacy

Trainees will be able to act as a resource for their community by having the following competencies:

- Know what resources are available at the local, state and national level or how to source that information - this includes community, health and legal resources
- Utilise their understanding of how the services work in reality
- Have a good knowledge of the legislative frameworks around rights and where to seek further information and provide appropriate referral. Have a basic understanding of some of the laws that are important, eg. duty of care, confidentiality
- Know what the complaints bodies are and how and when to utilise them
- Support community members in an empowering way; know the difference between acting in the best interests of someone and at the request of someone; identify the baggage that comes with our own values

Educator/Facilitator

- The student will have a knowledge of the principles of adult education
- The students will be confident to give a talk to service providers, either alone or more usually with a 'mate', on life as a carer and what carers need from their service providers. Using existing education resources develop role plays, and interactive techniques

Action Research

- Know the principles of action research
- Be able to undertake action research projects within their community with the support and supervision of WHGNE

Training - What we knew

From the kitchens of Smoko and the Buckland Valley –

'we knew there were hidden assets out there, we just had to develop that incredible third age resource and formalise the existing knowledge'

Together we planned what ingredients and what method would make the perfect community jam

Recipe

Ingredients

Wisdom, life experience, care, adventurousness, willingness to take risks, love. Mix together over 8 weeks of training all the joint skills, knowledge and love with a bit of language and 'how to'.

Result

A group of feisty, unstoppable women who are taking on the big issues, advocating, lobbying, researching and educating their community.

The Method

The seven day program (App. 1) prepared participants for their role as active and effective representatives of their communities. It developed skills in advocacy, knowledge of laws and systems and importantly, the ability to teach and share the skills learned.

Advanced Leadership Training

As an extension of the 12 month capacity building project with Older Women Carers, WHGNE conducted a leadership course for a group of women carers in the Ovens Valley. The project operated on a community development model and undertook a wide range of activities, reflecting the evaluation and planning outcomes of each stage. The Ovens Valley training completed a year of community capacity building.

This training project was a follow on from the **Doing it for Ourselves** Carers Leadership Training conducted in Baranduda earlier in 2002. All of the eight women achieved the competencies aimed for. Two of the participants in the training were keen to provide a similar course in the Ovens Valley to build capacity and leadership skills amongst women in that community. These women, in partnership with Jenny Gee from WHGNE, developed a new curriculum and implemented the training program. Funding for this project was successfully sought for and obtained from the Helen La Nauze Trust.

The aim of the Ovens Valley training was to provide local women with the opportunity to learn leadership skills to complement the work they are already doing in their community and expand their range of skills in advocacy, group leadership and action research. (App.6 Ovens Valley Action Research Case Study)

The women who attended the training were from Wandiligong, Bright, Porepunkah, Buffalo River and Harrietville.

Course Competencies

Advocacy

Participants are able to act as a resource for the community by having the following competencies:

- Know what resources are available at the local, state and national level, or how to source that information – this includes community, health and legal resources.
- Utilise understanding of how the service system functions and how to negotiate outcomes.
- Have knowledge of the legislative frameworks around rights and where to seek further information and provide referral, basic understanding of the laws about duty of care and confidentiality.
- Know what the complaints bodies are and how and when to utilise them.

Action Research Competencies

- Know the principles of action research.
- Ability to undertake action research projects within the community with the support and supervision of WHGNE.

Gender and Equity Focus

The women who participated in the training were required to complete an application form (App.2). They are active members of their community and are or have been involved in the care of family or friends. At the time of the training they were either in part time work or the unpaid workforce.

They were all known (in various degrees) as a resource in their community. The intention of the course was to increase the knowledge base the women already had.

Competencies for the course were advocacy, lobbying, action research, group leadership skills and complaints resolution.

Training Providers

The training providers were local women who are community leaders. They shared their extensive work and life experience with the participants. These women are community change agents working as leaders in the community on a volunteer or paid basis.

Outcomes from Ovens Valley Advanced Leadership Training

The action research from this training will be followed up in the new year with the Chamber of Commerce, the local media in Myrtleford and Bright, the shire and health services. All of the women who completed this course are able to undertake supervised action research, conduct a group and have a thorough understanding of lobbying, advocacy and complaint.

The outcomes are future women leaders who are confident about their understanding of government, bureaucracy, using the legal system as a tool and how complaints work. The women from this course may undertake to become leaders of carer support groups, or to continue to work in their community as informal advocates.

This training could be replicated across Victoria, utilising the training information developed and collated into training resource folders.

Postscript from a participant

We have now done action research that has been distributed and we know we can do more whenever it is needed.

We have lobbied our local politicians, all of the political parties, commonwealth, state and local are all fair game. We need a better deal for carers and we are going to get it. We now know how to conduct an interview with a politician and not get fobbed off, or not too badly; when we are being brushed off and when we are being taken seriously. And how to get their attention!

We have shared our knowledge with women across the Upper Hume region informally and formally. We have planned and implemented peer education across the region with service providers, by holding Healthy Women's Days. We have passed on information about services, how to get what you need from them, how to not take no for an answer and how to work towards expanding services. We will continue the fight for a respite centre in Wodonga for as long as it takes...

We will stand beside other carers to support them through the hard times and help them advocate when they do not have the energy.

Appendix 1 – Doing It For Ourselves – Course Outline

Day One

Time	Subject
9.30	Welcome – Find Someone Who - exercise
9.50	Course overview – what you want out of the course, why, volunteering after, actual learning
10.05	Ground rules and why Listening skills, assertiveness, communication
10.30	Morning tea
10.45	Assertiveness
12.00	Lunch
1.15	Summary of the education sessions group will be delivering at end of course – how we learn Evaluation – what is it, what kind/s will be use in this course?
2.15	Afternoon tea
2.30	Assertiveness/presentation skills Explanation of skill plays, why use skill plays?
3.15	Evaluation
3.30	Go home

Homework: Reading on skill plays, thinking about how we get the services we want and deserve from service providers eg: doctor, hospital, nursing home, carer respite service, local government.

Give two participants an icebreaker for the next week. They will go with the group to start the day. Energiser likewise.



Day Two

Time	Subject
9.30	Icebreaker
9.40	Break group up into four groups of two and get them to work out a skill play thinking about win/win Group one – having trouble with a doctor who isn't cooperating Group two – trying to get a service out of local government Group three – hospital isn't telling us anything Group four –nursing home person problem - talking to nurse unit manager about treating person as a child
10.30	Morning tea
11.45	Present their skill play
12.00	Lunch
1.15	Assertiveness training continues
2.30	Afternoon tea
2.45	Communication skills
3.15	Evaluation
3.30	Go home

Homework - Give out Carers Education Session for people to read and consider.
Icebreaker given for next week. Energiser for next week.



Day Three

Time	Subject
9.30	Icebreaker
9.40	Outline of today
9.45	Services available to carers and how they should operate-service representative
11.00	Morning tea
11.15	DAIS - what they do, what is advocacy, legal, systemic, individual – service representative
12.00	Lunch
1.10	Round up from lunch and energizer
1.15	Education – planning for an education session What makes a good session work Public speaking tips Use of overheads / power point / brainstorm etc Being organised – having your materials in the order you need them and adjusting your overhead projector etc.
2.15	Afternoon tea
2.30	Carers Session – do it with critical feedback to make any alterations Who will do which bits of carers' session?
3.15	Evaluation
3.30	Go home

Home work: Carer Education Session

Icebreaker/Energiser



Day Four

Time	Subject
9.30	Icebreaker with Helen
9.45	Revisit the course and why we are here
10.00	A Carer Handbook – do we want to do one? If so what does it contain and who wants to do it?
10.15	Morning tea
10.30	Carer session – why are we doing it?
10.45	Organise pairs and who will present the Carer Session. Do it.
12.00	Lunch
1.00	Energiser
1.05	Letters to DHS and Women's Network and some strategising
2.00	Afternoon tea
2.10	Carer session presenting
3.30	Evaluation
3.40	Go home

Homework: Icebreaker, Energiser, Stretch Monitor, Timekeeper. Read - Action Research Information.



Day Five

Time	Subject
9.30	Icebreaker
9.40	Today's competencies
9.45	What is action research? - WHGNE representative
10.45	Morning tea
11.00	What is action research (cont.)
11.30	Service provider session with critical feedback
1.00	Lunch
1.45	Deliver service provider session
2.15	Afternoon tea
2.30	Deliver service provider session
3.20	Evaluation
3.30	Go home

Homework action research

Icebreaker and Energiser

Think about what you want to know more about.



Day Six

Time	Subject
9.30	Today's competencies – name for the group
9.45	Lobbying and some suggestions for the future
11.0	Values and groups
12.00	Lunch
1.00	Round up from lunch and evaluation energizer
1.15	Group deliver service provider session
3.10	Go Home

Homework – Prepare for report back on action research – what do we want to do next as a result of the research we have already conducted. Who do we want to tell. Icebreaker.



Day 7

Time	Subject
9.30	What's happening
9.45	Legal and health complaints systems
12.00	Action research report back – group
1.15	Lunch and discuss what people want to know more about
2.30	The future

Appendix 2 – Doing It For Ourselves Training Application Form

We are pleased that you are going to participate in the course. Please fill in the following questions:

Name: _____

Address: _____

Phone Number: _____

Email: _____

What is your experience as a carer?

Why do you want to do the course?

What do you think are the three most important things to assist women in their role as a carer?

We are hoping volunteers would be available one day a week for six weeks to undertake the training course commencing Are you able to do this?

Yes No

Would you be available, with notice and after training:

To assist your local community by being a voice for carers and assist individuals who may want information? You will not be an expert, but an informed, concerned community member.

Yes No

To conduct local research from time to time, with supervision.

Yes No

You may at times be told or become aware of matters that are of a private and personal nature. Women's Health Goulburn North East places the highest consideration on the maintenance of strict privacy and confidentiality.

We abide by the Privacy Acts of the Commonwealth and State Government. Please find enclosed our leaflet.

I agree to at all times maintain the confidentiality of all persons I work with in the community and during training. This includes information obtained directly and indirectly.

Signed Dated

Print Name

Thank you for filling in this form. Could you please return this form to Women's Health Goulburn North East. PO Box 853 Wangaratta 3676 Phone: 03 5722 3009 Fax: 03 5722 3020

Appendix 3 – Advanced Leadership Training Timetable – Ovens Valley

Day One	Subject	Who
9.30	Introduction exercise	
10.00	Ground rules and why. Discuss listening	
10.20	Course overview	
10.30	Morning tea	
10.45	Assertiveness around learning	
12	Lunch	
1.00	Assertiveness	
2.15	Afternoon tea	
2.30	Negotiating	
3.00	Evaluation - why you do it	
3.30	Home	

Assertiveness – about attitude, listening, values, negotiation with service providers, fellow carers and people generally. Making sure our values and beliefs don't overrule our ability to hear what people are telling us. Life is about attitude.

Homework

Day 2	Subject	Who
9.30	Icebreaker	Group
9.45	Review last week	
10.15	Lobbying	
10.45	Morning tea	
11.00	Lobbying	
12.30	Lunch	
1.15	Entitlement / Overheads on cost benefits	
2.15	Talking about living and caring in a multi cultural society	
3.15	Evaluation	
3.30	Home	

Day 3	Subject	Who
9.30	Icebreaker	Group Member
10.00	Review Preceding Week	
10.30	Morning tea	
10.45	Women's Health	
12.00	Lunch	
1.00	Services for carers across the region and Victoria	
2.30	Strategies for when the services are not working	
3.15	Evaluation	

3.30	Home	
------	------	--

Day 4	Subject	Who
9.30	Icebreaker	Group Member
10.00	Adult education and learning how to organise a session	
10.45	Morning tea	
11.00	Attitude and group work	
12.00	Lunch	
1.00	Action research - what is it?	WHGNE
2.45	What is our research topic?	
3.15	Evaluation	
3.30	Home	

Day 5	Subject	Who
9.30	Icebreaker	Group person
10.00	How to complain	
10.30	Morning tea	
10.45	Groups - how to set one up and how they work	
12.00	Lunch	
12.45	Lobbying	
2.45	Mental Health Law and Duty of Care and a little Disability if there is time	
3.10	Evaluation	
3.15	Home	

Day 6	Subject	Who
9.30	Icebreaker	Group member
10.00	Action Research Report back	Group facilitated
10.45	Morning tea	
11.00	Action Research Report Back	All
12.00	Lunch	
12.45	Art	All

Appendix 4 – Touching Women’s Lives: Action Research Model

Action Research

This model has been applied by Women's Health Goulburn North East in the training of women to be community action researchers. You may find it a useful tool in your community development/capacity building work. Action research demystification is a great way of making what appears difficult, accessible.

The sample shown here is just one of many possibilities. It is just a guide to how you may ensure ethical, valid action research by the community, for the community. The outcome of the research undertaken by local women with their local communities is available as a report either in the **Touching Women’s Lives Report** or on our website. This group used different sampling methods according to the research. This is available to be used by you either in its current form or modified to suit your requirements. If you use this information please cite WHGNE as the source.

At its simplest, research and evaluation are no more complicated than observing, reflecting and assessing. And we all do it.

Action Research Scenario

Imagine it's Tuesday and you're going to Melbourne by train. You have an hour or so to fill in the city before your 12.30 appointment. You're looking for a café that will serve a great cup of coffee. Last time, you went into the first café you came across and had a very bad experience. So you read the Epicure section of *The Age* really carefully and came up with a couple of ideas (**the lit search**).

Then you start chatting to the people across the aisle. They have a couple of recommendations as well (**the interview**).

You decide on a café, based on a number of factors – it's close to where you have to go, the coffee is highly recommended, it's not expensive (**the research design**).

When the train gets into the station, you catch the tram up Burke Street, and find the café. You go in and order (**fieldwork**).

It's warm inside the very modern and comfortable surroundings. The friendly waitress brings your hot, strong, aromatic cappuccino in a white china mug. It smells and tastes great (**the analysis and conclusions or evaluation**)!

You'll come back again, and you'll recommend it to your friends, but next time you'll sit next to the window (**recommendations and planning**).

Instructions for the Research

This information formed the front page of the kit for the community researchers who had received prior training in action research, chosen the topic of their choice and plotted the questions

1. **Explanatory Statement** – provide this information verbally. Then give a copy of the statement to each participant.

2. **Consent Form** – provide this information verbally. Then get their signature.

3. **Questions** – There should be enough space on each sheet to record the answers. Please write as legibly as you can. A minimum of five would be good. You can work with a partner.

4. **Draft Research Report** - If the participants want to see the draft report before it comes out they will need to give you their name and address on this sheet. These will not be kept with the data and will be kept private. They will have one week in which to respond after the draft report is sent and then we will disseminate it.

5. **Information on the organisation** for anyone who might want to know who you are.

Appendix 5 – Doing It For Ourselves – Action Research Case Study

Carer Knowledge of Services Survey

Women's Health Goulburn North East was funded to undertake a project with older women carers in the north east of Victoria. As part of this project WHGNE trained six women volunteers to conduct an action research project across the Upper Hume, Wangaratta and Alpine areas.

The project aim was to discover the level of knowledge carers had about relevant services. It also asked what is the best way to inform carers of their entitlements.

The methodology

The research method chosen is an action research model. It is centred in the community and community members are the key researchers. We provided the participants with an information sheet, providing information on local services for carers. We also provided information on local counselling services. Carers identify as rarely being asked for their opinions and will sometimes use a sympathetic ear to debrief on a range of issues beyond the research brief. We considered it important to have an appropriate referral to encourage people to use if they displayed distress or interest.

Confidentiality

All people interviewed were assured of confidentiality and that any identifying information would not be used in the research. Participants were given the opportunity of receiving a copy of the draft research report and requesting any information they consider identifying to be removed. Participants were advised that they could stop the interview at any time and withdraw at any time. Two Wodonga participants withdrew during the interview process and their information has been destroyed.

Potential Audience for the Research

The carers involved in the project will be able to use this information for further lobbying and education purposes.

It has also been fed into the local health service provider planning processes, particularly with regard to planning strategies and consumer preferences.

Questions

The questions asked were simple and did not require expansive answers. However people did take the opportunity to talk about their issues as carers.

Who was asked?

In the Ovens Valley nine participants were interviewed one on one and a group interview was conducted with eight women participants.

All of the participants were over 50 years old. Most were looking after aging parents or relatives. None described themselves as carers. This is obviously not a comfortable description for people caring for their family.

Female	Male	Area
6	4	Bright and District
3	2	Wodonga
1	0	Tallangatta
1	3	Other
16	9	N19

The results follow this question format:

Question 1

What can you tell me about carer entitlements with regard to Centrelink?

Knew about and used	3
Had some knowledge of	5
Did not know about	6
Found very good	2
Found difficult and intrusive	9

Centrelink can clearly provide an excellent service and when it is good it works extremely well for people. People seem to either be in the category of it's just too hard to use Centrelink or feel that they don't want to use Centrelink and are okay without it. Some comments about Centrelink indicate that they sometimes provide an appallingly low standard of service.

'Centrelink are too evasive, too many forms.'

One family recently arrived in Australia felt afraid to use Centrelink.

'Centrelink forms seem to relate to mental health things, not to physical disability.'

Question 2

What can you tell me about carer entitlements to respite?

Know about but didn't need	Know about but for other people	Know about and use	Don't know about
1	11	4	3

'We were told by our family that it's not easy to get.'

'Respite is for other people who need it.'

'Mum's in bed so I don't need respite.'

'We knew about it, but we were happy to care for each other.'

Most participants reported having heard of respite but they do not consider themselves carers as they are caring for family and that's just what you do. They thought they should just cope by themselves.

Question 3

What can you tell me about carer entitlements to financial advice?

Knew about and didn't need	Knew about and used	Didn't know about
3	3	13

'Don't need it because I'm working'.

'I'm on a pension already, is there anything else I need to know?'

'I know it exists, but where and who?'

Question 4

What can you tell me about your entitlements when medical treatment is needed far from home?

Didn't know	Know and used	Know but didn't need	Didn't come up
14	1	1	3

Question 5

How would people like to find out about services?

GP	Carer support group	Other service providers	Don't know
6	9	2	2

People who considered the GP to be the provider of information were very convinced of this.

Appendix 6 – Advanced Leadership Training: Action Research Case Study

Ovens Valley

As part of the project, Women's Health Goulburn North East trained six women volunteers to conduct an action research project across the Ovens Valley. The research took place in Wandiligong, Myrtleford, Porepunkah, Bright and Harrietville.

The carers project wanted to find out how older women and people with a disability feel about the way services are provided in their community.

The methodology

The research method chosen was an action research model. It is centred in the community and community members are the key researchers. We provided the participants with an explanatory sheet explaining who we were and what the research was about. We sought around 20 community members to participate and we ended up with a sample of 12 from Wandiligong, Myrtleford, Bright and Porepunkah.

Confidentiality

All people interviewed were assured of their confidentiality and that any identifying information would not be used in the research. Participants were given the opportunity of receiving a copy of the draft research report and requesting any information they consider identifying to be removed. Research participants could stop the interview at any time and withdraw at any time. In compliance with research ethics the data will be stored at WHGNE for five years in a locked file. There will be no identifying information with the data.

Potential Audience for the Research

The volunteers involved in the project will be able to use this information for further lobbying and education purposes.

It can also be fed into the local media, local shires, health and community services and chamber of commerce.

Who was involved?

Participants in the research were all women aged over 60 years to approximately 80 years.

The participants were generally known to the researchers. Only one of these women had an obvious physical disability and was confined to a wheelchair when out in the community.

To analyse the data, the group met and went through the questions one by one, first of all gaining an overall feel for the responses.

General comments made by the researchers about their impression of the survey was:

'Women were really responsive and happy to be involved in the survey. Overall people were happy with services. Their answers reflected a community rather than individual focus. Doing the research was felt to be a happy and rewarding experience by the researchers'.

One researcher undertook two surveys and was impressed with the extremely differing views.

An obstacle to the research was having the time to undertake it.

Questions

What's your feeling about services at local retail and general services?

The answers to this question were generally positive to very positive. The most negative answers were that services were 'sufficient' and 'all right'. The most positive were 'outstanding', 'much better than you would get in the city'.

Age

A number of the participants felt that the service was very good and this could be because of an awareness of the customer's age and that services were age sensitive.

Overall the participants found service provider attitudes to be helpful.

How do you find access (for example, can you get in, is the service easy to find)?

Comments on access varied from 'access is good' and 'services are easy to find', to a range of issues about access.

Transport

This was the most commonly cited issue. This varied from issues about parking to affordability and availability of public transport.

VLine was an appreciated service.

A number of participants were concerned about the need to improve access to community transport, in and around their district.

A significant number of participants suggested that a shuttle bus/community bus would be an important addition to people's access to services and to community connectedness.

It would appear that people are not aware of existing community transport.

Parking

Parking was felt to be a problem by a number of participants, particularly during tourist peak times. Participants from Myrtleford found parking to be quite good.

Wheelchairs

Wheelchair access is an issue. Crossing the road and accessing shops, getting around in the supermarkets are all problematic if you are in a wheelchair. One suggestion was to have the people deciding on services spend some time in a wheelchair to fully understand the issue.

Retailers assist by coming out to provide services on the footpath.

Supermarkets

Supermarkets were cited as being difficult to maneuver in, particularly if there were two trolleys and getting around corners with displays. Lanes are too narrow. People in Myrtleford were generally pleased with their supermarkets, despite these problems..

Heavy doors were cited by a number of participants for mothers with pushers, people in wheelchairs, people who are frail or physically disabled.

Other Issues

One participant felt the Alpine Shire was not doing enough for the elderly and would not help with a possum removal in Bright. Some participants were

concerned about how they would cope when they were older and did not have a licence. One participant suggested that the tiles in the front of the Myrtleford Post Office were slippery and dangerous.

What could be improved?

This question brought a range of responses. Transport was a key theme.

Transport

Solutions included;

- A government bus with a minimum of three trips per week including surrounding towns
- Weekly commuter bus from Porepunkah to Bright and Myrtleford. Community car for hospital visits
- A community daily shuttle bus to cover Bright and district, was a frequent response
- Drivers to drive people to medical appointments in major cities and to other towns for people who did not drive.

Access

This response was general across the communities;

- A number of participants felt that shops needed to improve wheelchair access. This was from people not confined to a wheelchair. People felt that some doors were too heavy, or shops had awkward steps. They felt all shops should have ramps to allow wheelchair entry.
- Street crossings are difficult for people in wheelchairs.
- Footpaths were mentioned as being uneven. The need for made footpaths in Wills Street in Bright was mentioned by one participant.
- One suggestion for improvement was that all utilities and services be checked by decision makers placing themselves in a wheelchair and trying it out.
- A frequent response was public toilets in Bright need to be increased in number and sign posting to them improved.
- A number of people wanted a vet in the Bright area.
- Services missing or inadequate, besides a vet, were local dentists, medical services and counselling services.

- One person thought there are too many cafes in Bright.
- Council staff in Bright were said to be unhelpful.

Can you think of one or two services you would recommend?

- People spoke about this in a general way, saying that the social connectedness of their community was important to them.
- A number of Bright area people suggested that social activities such as bowls, craft, hydrotherapy, gentle exercise, and weight training were good services.
- The kindness shown by a volunteer driver was also mentioned as an example of excellent service.
- District nurses were mentioned.
- The taxi service was mentioned as good by a number of people.

What is it about those services that you like?

The attitude of people mattered significantly:

'Caring attitude'

'Kindness'

'Friendly and helpful'

For people who liked activities:

'Good for people with arthritis'

'Relaxing and meeting people'

'Social contact and exercise'

General Outcomes

The responses were positive.

- It would appear that advertising and improvement of existing community transport would be welcome.
- People found social connection and communication to be the most important ingredient.

Appendix 7 – Facilitator’s Guidelines for Action Research Training

Ovens Valley Advanced Leadership Training Program

Explanatory Statement

Women's Health Goulburn North East has been funded to undertake a project with older women in the north-east of Victoria. As part of this project volunteers are conducting action research in your area.

We want to find out how older women feel about the way services are provided in their community.

The methodology

The research method chosen is an action research model. It is centred in the community and community members are the key researchers. We are seeking around 20 community members to participate. Interviews will take about 15 minutes and will take place at a venue to suit the participant.

Confidentiality

All people interviewed will be assured of their confidentiality and that any identifying information will not be used in the research. Participants will be given the opportunity of receiving a copy of the draft research report and requesting any information they consider identifying to be removed. Research participants can stop the interview at any time and withdraw at any time. In compliance with research ethics the data will be stored at WHGNE for five years in a locked file. There will be no identifying information with the data.

Potential Audience for the Research

The volunteers involved in the project will be able to use this information for further lobbying and education purposes. It can also be fed into the local shires, health and community services and Chamber of Commerce.

Important Points to Remember

Facilitator Checklist:

- Remember to explain the reason for the research and confidentiality provisions and that participants can withdraw at any time.
- Obtain Formal Consent.** This is probably the most important aspect of any ethical research.
- Send out a copy of the report to check for accurate reflection and final consent

Sample Participant question:

I would like to see a copy of the research before it is distributed to the local shire, Chamber of Commerce and service providers and any others.

Your Reply:

In order to do this we will need your name and address, if you don't want to see a copy of the draft report then there is no need for us to take your name and address.

Your name and address will be kept in a locked filing cabinet according to the Privacy Act of Victoria and not be used for any other purpose.

Contact Details

If you have any queries please contact Women's Health Goulburn North East on:
03 5722 3009

Appendix 8 – Consent Form



PO Box 853, Wangaratta, 3677 Phone: 5722 3009

CONSENT FORM

I, of.

.....

have been asked to participate in the research study titled:

'Older Women – Service Satisfaction Survey'

I give my consent by signing this form on the understanding that this research study will be carried out in a manner conforming to Women's Health Goulburn North East principles and further that:

I understand the general purposes, methods, demands and benefits and possible risks, inconveniences and discomforts of the study.

My participation in the research study is voluntary and I am free to withdraw at any time.

The confidentiality of my identity will be safeguarded.

I have read and understood the explanatory paragraph.

Signature Date

Investigator, I,.....have fully explained the aims operation of Services Survey to the person named herein.

Signature Date

Appendix 9 – Interviews and Consultations

Interviews:

Adult Psychiatry

Albury/Wodonga Community Legal Service

Alzheimers Association

Carers Australia

Carers Vic

Centrelink, Multicultural Affairs

Community Nursing, Beechworth

Community Visitors

Disability Advocacy Service

Friday Older Women's Group

Health and Wellbeing Days participants from Everton, Porepunkah, Walwa, Tallangatta Valley, Dederang and Bethanga

Liberal Party

Mungabareena Aboriginal Co-op

Older women in the Upper Hume and Wangaratta

Ovens and King Community Health Service, Health Promotion

The Cottage, Wodonga

Upper Hume Primary Care Partnership

Upper Murray Family Care, Carers Respite Information Service

Wodonga City Council, Community Services

Consultations

Migrant Resource Centre, Wodonga
Multicultural Women's Group, Wodonga
Multicultural Social Network, Wodonga
Mungabareena Aboriginal Co-op

Agencies that WHGNE Older Women Carer's Project worked actively with either presenting, consulting or educating carers across the region.

Aged Psychiatry

Albury Wodonga Community Legal Service

Chiltern Bush Nursing Hospital

Department of Veterans Affairs

Disability Advocacy and Information Service

Intellectual Disability Review Panel

Multicultural Social Group, Wodonga

Migrant Resource Centre, Wodonga

Mungabareena Aboriginal Co-op

Ovens and King Community Health Service, Women's Health workers, Dianne Hourigan and Catherine D'arcy

Tallangatta Health Service

Upper Hume Community Health Service

Upper Hume Community Health Service, Mount Beauty

Upper Murray Family Care, Carer Respite Information Service, Wodonga and Wangaratta

Walwa Bush Nursing Hospital (now Walwa Community Health)

Appendix 10 – Curriculum and Trainers

Assertiveness Training conducted by local educator Elizabeth Hall

Evaluation - Why Do It? – Jenny Gee, WHGNE

Lobbying – Jenny Gee, Bev Miller, Veronika (Sam) Colyer, Bernece Delaney

Entitlements – Veronika (Sam) Colyer

Multicultural Society – local guest Veronica

Services Available to Carers – Bev Miller, Veronika (Sam) Colyer

Services Available to Carers - Keri Baker, Carer Respite Information Service

How to Complain – Bev Miller, Veronika (Sam) Colyer

Groups and How They Work, How to Run Successful Groups – Veronika (Sam) Colyer and Bev Miller

Action Research and Analysis – Jenny Gee

Materials, resources and readings for this program are housed at WHGNE and are available to the community.

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