

STATEWIDE FORUM: 22/5/2009

MIGRANT RESOURCE CENTRE (Southern Tasmania) Inc.

COMMUNITY PARTNERS PROGRAM

**FREE FORUM ON AGED CARE SERVICES AND DEMENTIA SPECIFIC  
ISSUES FOR OLDER PEOPLE FROM MIGRANT AND DIVERSE  
BACKGROUND (CAMPBELL TOWN)**

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Copy of talk : **LOVE MUST ALSO WEEP : A CARER'S STORY**  
**DANIJELA HLIS (MRC CPP)**

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REFERENCES:

THE GARDEN OF THE PROPHET	KAHLIL GIBRAN
LOVE MUST ALSO WEEP	ROBERT A MASTERS
THE POLITICS OF EXPERIENCE	DR D LAING
MORAL HAZARD	KATE JENNINGS
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SHE'S NOT THERE	JENNIFER F BOYLAN
DESIGN FOR DYING	TIMOTHY LEARY
TO SEE DIFFERENTLY	DR SUZAN TROUT
IRIS AND HER FRIENDS	JOHN BAYLEY

\*From Internet: Report on Strategic Directions in CALD Research in Australia Report  
March 2009-05-24 (details from lf.low@unsw.edu.au)

\* [www.MIGRApolis.de](http://www.MIGRApolis.de)

\* [www.abc.net.au](http://www.abc.net.au) Health report 2006 Global Prevention of dementia

\* [http:BJPsych](http://BJPsych) (Mental health of migrant elders Islington study)

\*50something Magazine April/May 2009: page 30 - Home sweet home

(Document: This PDF version has been edited by Danijela Hlis to 10 pages)

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## INTRODUCTION

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“Master, life has dealt bitterly with our hopes and our desires. Our hearts are troubled and we do not understand. I pray you, comfort us, and open to us the meaning of our sorrows” unquote

Writes Kahlil Gibran over seventy years ago in his book *The Garden of the Prophet*. I am sure most of our seniors today feel just the same. After many years of productive life, working, bringing up children, going to war, living through losses and illnesses, always “doing the right thing” , they now find themselves too poor, too lonely, too unwell and forgotten to enjoy the well earned retirement.

LOVE MUST ALSO WEEP, (by Robert A. Masters)

IS A TITLE OF A BOOK THAT I OFTEN LOOK UP; IT IS ABOUT AUTENTICALLY FACING WHAT MUST BE FACED; I LOOK BACK AT MY MANY YEARS AS A FULL TIME CARER TO MY FATHER AND MOTHER WHO MIGRATED TO TASMANIA IN THEIR SEVENTIES, AND WERE WITH NO ENGLISH LANGUAGE, NO DRIVING, QUITE ILL, VERY DEPENDANT ON ME IN EVERY ASPECT OF THEIR LIFE. How much I have cried, in the last 12 years; tears of love, but also tears of anger, frustration and despair, followed by tears of guilt and loss, when mum went into a nursing home. Many books, articles, movies, have helped me maintain my faith and love, my belief that everything happens for a reason. Have assisted me in self help, as have many great human beings; from family and friends, to clinical psychologists, personal counsellors, group therapists. I have travelled to Buddhist retreats, monasteries, have walked in the mountains and prayed on endless beaches. In her book, *TO SEE DIFFERENTLY*, Dr Suzan S Trout writes: “Supporting others is one way in which the blissfulness of life can be experienced. As you open your heart, you begin to live life more fully” unquote-

I am really enjoying working with MRC staff, in my role of Bi Cultural worker. Croatian and Slovene people have been close neighbours in our old homeland Yugoslavia for many years; We share our love for traditional food, our diverse music and folklore and dance, our appreciation of local wines, and much more. When I think of the needs of our older Tasmanians of Croatian and Slovene origin, I know these needs are very similar; food they can recognise, music they know and enjoy; a person who can speak a little of their mother tongue.

What I wish to share with you today are some of my findings and personal experiences, and I hope that it may in some way assist you with understanding aging and associated issues for members of CALD communities, dementia, carers, the changes one goes through, our own mortality.

THERE IS A SAYING. IF YOU WANT TO DO SOMETHING, YOU FIND A WAY, IF YOU DON'T, YOU FIND AN EXCUSE

Parents gave us this life we have, for that alone, we owe them some love and care in old age.

In her book TO SEE DIFFERENTLY, page 136 Dr Trout writes:

“When you hold the Sacred trust of giving in service to others, you live in the spirit of the moment. If you lose sight of the spirit of giving, you are probably experiencing the psychological and spiritual burnt out”, unquote

I can tell you I have had a number of those; caring for loved ones is a difficult journey, but, in my opinion, a very necessary one; It teaches humility, it changes people into more compassionate human being. Unfortunately, many of our politicians and Aged care facility managers forget that they, too, will one day be old. SO THE FACILITIES ARE NOT REALLY A HOME AWAY FROM HOME, AND THE STAFF IS UNDERPAID AND UNDERVALUED, AND THE RESIDENTS ARE NOT PEOPLE WE LOOK UP TO, BUT PUT UP WITH. HOW VERY SAD.

WE ARE NOT OUR BODIES: MY FATHER'S EXPERIENCE

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In DESIGN FOR DYING by Timothy Leary, page 187:

“Lesson: We are not our bodies. As he got less functional physically, his spirit and sheer will pushed his body.” Unquote.

Lesson: we are not just our bodies. And what goes on in our brain, in our soul, is still very much a secret, a miracle. I believe that we all must believe in our spirit, must have faith. How can you be a helpful, caring nurse, doctor, support worker, if you have no faith, or no respect for the soul?

A LOOK AT MY MOTHER'S DEMENTIA AND SOME ASSOCIATED STUDIES

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People can be observed to sleep, eat, walk, talk, etc. in a relatively predictable way. But with a person with dementia, the behaviour is unique and always changing: at present, my mother's talking, for example, reminds me of a radio, when I drive, and I am searching for a frequency, I get a few words here and there, but the stations keep changing. Yet last year, my mother's conversations were still quite intelligent and sentences well structured.

## THE LAST SEVEN YEARS

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What first alerted me to mum's changed behaviour was the increase in her misplacement of her money, her jewellery, two most important things in her daily existence; she would then accuse family or my support or cleaning staff, from stealing from her. This continued for quite some time, in fact only early last year, when she was already in a nursing home, did she stop asking the staff to call the police to catch the thief!

Through my work and volunteering, I have met a number of clients with the similar problem-they misplace their possessions and then blame loved ones for stealing from them. It is heartbreaking for all.

I STRONGLY BELIEVE THAT THE PROGRESS OF THE ILLNESS IS MUCH SLOWER FOR PEOPLE WHO ARE ACTIVE, LIKE MY MOTHER. WE ARE TOGETHER FOR ABOUT 4 TIMES PER WEEK. WE WALK,TALK, SHE DANCES TO OUR MUSIC AT HOME, SHE LAUGHS A LOT, SHE IS PROUD TO BE CHEEKY AND LOVES TO BE BEAUTIFULLY . AT TIMES, WE GET TOGETHER WITH FAMILY AND FRIENDS, HAVE PICNICS, SHE KNOWS HOW LOVED SHE IS. HER 8 YEARS OLD NEPHEW LOVES HER,KNOWS SHE IS SPECIAL, DIFFERENT, AND LOVES HER JUST THE WAY SHE IS...

IN MY OPINION,

NO TWO PEOPLE WITH BREAST CANCER BEHAVE THE SAME, OR DEAL THE SAME WAY WITH THE ILLNESS, AND THE SAME GOES FOR PEOPLE WHO SUFFER FROM DEMENTIA.

At times, I even believe that somehow, my mother's brain has been capable of doing a kind of self hypnosis, using certain defence mechanisms, even denial, to help her achieve the state of peace, joy, health, that she is in;

SURVIVAL MECHANISMS STEPS IN, AND THE GLOOM STARTS BEING SEEN AS THE BLESSING? ...The positive transformation, maybe at a sub conscious level. This may have occurred to my mother, or, the emphasis of her dementia now is more on Frontal Lobe dementia which is responsible for personality changes. WHATEVER IT IS, MY MOTHER IS MORE CONTENT, JOYFUL, AND PHISICALLY BETTER THAN BEFORE SHE GOT DEMENTIA.

So, are we correct in continuing to search for answers, what do our senior really need? I think so; MRC, as well as MCot, where I worked a few years ago on a similar project, entitled Power and Powerlessness, are leaders in this; actively, through forums, workshops, community projects, training, they strive to improve the current situation; its sad to be old, but its double sad to be old and lost, as many of the CALD members feel.

I was recently reading books of one of the best known psychiatrists of modern times Dr Laing; he developed the argument that there may be a benefit in allowing mental and emotional turmoils to go on and have its way, and that the final outcome of such a turmoil could have a positive value. In Doctor Laing's book, The Politics of Experience, there is quite a bit written on defence mechanisms; so my mother could subconsciously say: **why live in perpetual anxiety, remembering 70 + years of unhappiness, mistakes,when one can CREATE RAINBOWS AND BIRD SONGS AND accept the love of her children for what it is?** I strongly believe that within the walls of dementia, the brain cells can kick up a survival mechanism. Bertrand Russell once remarked that the stars are in one's brain. Today, in the seventh's year of her dementia, my mother's brain is full of brightly shining stars. She is the biggest and she loves herself, and this reflects in her physical health, even though she is past 80! And while I am on the subject of the brain, allow me to talk a little about Richard Bergland's stirring exploration of the brain as a gland.

The stuff of thought, he argues is not electricity but hormones. Every time we move or laugh or cry,, hormones spill into our brains, affecting our behaviour. So it could be said that some kind of thinking goes on outside the brain, in the ovaries and testicles, for example. Bergland, in his book THE FABRIC OF MIND predicts that doctors will measure hormones in the brain and link their deficiencies to specific disorders such as senile dementia, schizophrenia and obesity, offering new and effective treatment for all. The disciplines of philosophy, medicine and science have moved back to the position taken 2000 years ago by Plato, Aristotle and Galen. All of them accepted that the brain was a secretory gland. The notion that electricity is the stuff of though is a very recent idea, less than 200 years. The new view that brain hormones fuel the fires of the mind puts all our therapies and medication on the examination table. Do you know that depression is still treated with electric shock treatment today here in Hobart? I pray that the brain experts speed up the research and find less invasive, more hormonal treatments for us.

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## CONCLUSION: EVERY ENCOUNTER IS A LEARNING OPPORTUNITY

Every encounter is a learning opportunity. We are all students and teachers to each other. Today at this seminar, tomorrow at your workplace. And if it happens to be a Day Respite centre or a nursing home, please remember, open your heart and keep on learning. You can learn so much from your clients, too. For example, I watched a staff member and relatives trying to PUSH a lady with dementia into a car, for her outing to family lunch. She was crying and not wanting to go; finally I asked them if maybe she does not recognise the car, or person? And they realised the lady had never seen the new land rover or the new boyfriend of her daughter, so no wonder she was terrified of going someplace with them.

I came to see my mum one day, and a very sweet volunteer lady was sitting with her, to keep her company. But my mother said to me: "Who is this woman? What is she saying to me? What does she want from me? Send her away". Because they could not communicate in a common language, my mum was anxious and upset by the stranger's presence.

DR RALPH HAMSON an Aged care Consultant, researched what residents in nursing homes wished to change: a glass of wine with dinner, clean windows, Net curtains, a bigger wardrobe, some fresh flowers, such simple things, and yet, the residents are not really consulted. And especially those with CALD background.

A simple KAKO SI DANAS?

Will brighten up a day for a Croatian resident in a nursing home ;

"Ecco, oggi si mangia fettucine alla carbonara"...a typical Italian meal once in a while will reassure someone feeling a bit misplaced in a nursing home

VZAMI KOS POTICE...a slice of cake, traditional for Slovenia, especially at Easter and Christmas, would really make my mother happy

And when there is **HAPPY HOUR, BE CREATIVE: A BIT OF BINGO HERE AND THERE, SURE, BUT ADD SOME SLOW DANCE FROM AN AUSTRIAN WALTZ, SHOW THEM A CD OF SPANISH TANGO, INVITE AN AFRICAN GROUP TO SING AND DANCE, DRIVE THEM TO THE BOTANICAL GARDENS, LISTEN TO A MEDITATION CASSETTE WITH THEM...SHOW THEM THAT YOU CARE, THAT THEIR WELLBEING MATTERS MORE THAN A FOUR STAR BEDROOM WITH AN ENSUITE!!**

I have an e mail from a friend in Victoria, who has worked in Nursing homes for the last 10 years:

“I like working in this Aged Care facility; the only downfall is the owner, who is not buying us Superannuation, and we have to complain all the time; I DON’T KNOW WHY WE HAVE SO MANY LOUSY EMPLOYERS IN THE AGED CARE...”unquote. My friend’s learning experiences are not very positive, and like her, I am worried too.

And to conclude, a few words on Dementia and research:

The experts can tell us about what Dementia is, no one yet knows what causes it, we appear to know different stages of it, as well as how there is no cure as yet . And most disturbingly, we are told that dementia is increasing in our society. Because we live longer. Or is it? Dr Blazer states:

“the normal adult forgets, remembers that he/she forgot, and later may even remember what he/she forgot”.

The person with dementia forgets, forgets that she/he has forgotten and couldn’t care less 5 seconds later” unquote.

I disagree. Having lived with my mother for over 10 years, watching her persona, her behaviour, emotions, change, gradually, and having been in contact with other clients with dementia through work and volunteering, I would be much happier if WE ALL accept that every individual is different, is a gift of God, is a beautiful creation with a soul. My mother has been afraid of becoming mad, going crazy, because of her memory losses, for many years now; she knows that she forgets, and she tells people:” sorry, I forget everything” For many years now we are having the same conversation, where I reassure her that she is an intelligent, bright, interesting, beautiful human being who has problems with memory, and orientation, and not to be over concerned about this. Now, with her dementia progressing to a next level, she no longer worries about becoming mad, but she still knows that she forgets everything. Her favourite sentence is : **“I am not switched on”** So, if, like me, you are passionate about caring for a loved one, and learning how to hopefully prevent a dementia happening to you, if you want to make a difference in how we change the perception that

**OLD IS OBSOLETE TO OLD IS ANTIQUE THEREFORE PRECIOUS**

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Then, I urge you, keep learning. Keep asking questions. Do your own research; science and medicine are always improving and changing. Remember the old belief that stress causes ulcers? Well now we know that is not so. I always study results of all the research on the topic of dementia; I read how in Australia, in less than 2 years, more than 23% of people 65 and over and one in every five people, aged 80 and over, will be from CALD background. Who will understand them and care for them? In our overall population, in Australia, we have two children aged under 16 for every older person over 64; Soon, we will have two older persons per child. The research also shows that people of CALD background are generally not included in our research in dementia and drug treatments research, despite their willingness. The excuse being “language difficulty” (Report on Strategic Directions in CALD Research in Australia 2009).

**BUT I ASK YOU: WHERE IS THE DIFFICULTY? I, for example, can converse in Italian, English, French, Slovene, Croatian, yet, I don't see any ads for work as Lifestyle and leisure employee FOR WORKING WITH SENIORS WHO SPEAK ANY ONE OF THESE LANGUAGES, or assisting with interviews and research.**

**Are governments and Managers of Nursing homes really keen in giving the residents of CALD background the best possible attention? Can we all do more? Yes we can!**

And what about elsewhere in the world, what do we read? CURRENTLY WE HAVE ABOUT 60% OF THE WORLD'S PEOPLE WITH DEMENTIA IN THE DEVELOPING WORLD; BY 2040, THIS WILL BE OVER 70%,THE REGIONS WITH THE BIGGEST GROWTH ARE CHINA,INDIA AND LATIN AMERICA.

A Livingston Study in UK, for example, shows a much higher dementia rate among people in Africa, Caribbean, and Cyprus, then Europe and Ireland. In the Health Report on Global prevalence of Dementia, we read that some countries are heading for a 300% increase over the next few years. From about 24 million people around the world, suffering from dementia in 2001, we are told, we are heading to about 40 million by 2020. Another study shows a marked increase of dementia in the modern world; the study was done with people from Nigeria, one group living in Nigeria, the other group living in the United States; with only mild genetic differences, the cause points to environmental factor.

IN GERMANY, WHICH HAS A LARGE MIGRANT POPULATION, THE INFORMATION AND SERVICES PROVIDED FOR PEOPLE WITH DEENTIA AND THEIR FAMILIES IS AVAILABLE IN 20 LANGUAGES (SEE MIGRAPOLIC ON THE INTERNET)

Dr Ajit Shah, findings in London, too, are very interesting (CROSS CULTURAL ISSUES AND COGNITIVE IMPAIRMENT)

He states, for example, Prevalence of vascular dementia is highest in Japan, and the lowest on mainland US; yet for Alzheimer's, the results are in reverse; WHY?? We need to do so much more research;

On the positive note, AUSTRALIA IN SOME WAYS LEADS THE WORLD IN PROVIDING SERVICES FOR PEOPLE WITH DEMENTIA; WE HAVE A HIGH AWARENESS AND THE LEVEL OF STIGMA IS MUCH LESS IN AUSTRALIA THAN IN INDIA, FOR EXAMPLE; IN MANY COUNTRIES, THEY STILL REGARD DEMENTIA A MENTAL ILLNESS.

While we don't have a magic pill, or a cure, as yet, our awareness about prevention is high;

We are often alerted to the RISK FACTORS FOR DEVELOPING DEMENTIA, Doctor Ruth Cilento, in her book AGE WITHOUT ALZHEIMERS , I believe, is on the right track; (page 44)

“At least once every day, take time to just look around you. Marvel at the beauty of nature. We are part of nature.” Unquote

From my experience, I wish to add that we must publicise more the need for inner peace, faith, contentment, acceptance of our life, tolerance and positive attitude. If I eat well, and exercise, don't drink and smoke, that's good, but is not enough. If at the same time I am depressed, discontent, selfish, negative, or critical, and I don't attempt to change, my mental, spiritual, physical health is going to decline for sure.

LOVE MUST ALSO WEEP, LOVE MUST ALSO GIVE .

And now I will read you one of my poems and invite you for any questions you may have, related to my talk;

## **MY SHOPPING LIST**

**A tea spoon of kindness  
A friendly knock on the door  
A cup full of forgiveness,  
A joyful wave of a “hello”.**

**A glass filled with respect  
A slice of compassion  
A spoon full of hope  
A grain of laughter  
A drop of generosity  
A smile, a touch, a voice,  
In my nursing home.**

**The glory of sunrise  
The music, the birds,  
A visit from my family,  
A hug, a friend, a volunteer.  
A cat, a doll.**

**My Aged care home has a corner shop  
Where love, acceptance and respect are  
Sold in pink and blue packets  
And paid for ... with our dignity and faith.**

**Danijela Hlis**