



HEALTH MATTERS

HEALTH CONSUMERS'
COUNCIL
YOUR VOICE ON HEALTH

Health Consumers' Council (WA) Inc Magazine

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Cover: Hon Lynn MacLaren Member for the South Metropolitan Region, Award winner Dr Bernadette Wright and HCC Chairperson, Michelle Atkinson - de Garis, at the Health Consumers' Council Consumer Excellence Awards. (Article page 2)

Disclaimer: The Health Consumers' Council would like noted that we encourage informed debate, the articles by our contributors do not necessarily contain the view of the Health Consumers' Council.

Foreword



Consumer Engagement: The challenge of getting beyond tokenism

The goal of organisations like the HCC is to advocate for a health system that operates in the consumer interest. However, it is important to distinguish between the ‘consumer interest’ and the ‘consumer voice’. They are not the same thing, and there are pitfalls in mistakenly assuming that they are.

Firstly, there is no one consumer voice and the best interests of consumers are not always obvious. Sometimes consumer voices are in conflict and this is not necessarily a bad thing. For example, access to new medicines is often a controversial and contested issue. On one hand some ‘access orientated’ consumer voices shout loudly that governments should fast track access to new, urgently needed medicines. On the other hand, cautious ‘injury orientated’ consumer voices contend that rushed drug approval processes expose consumers to safety risks.

Secondly, the quality of the consumer voice offered by individual consumer representatives (and groups claiming to represent consumers) is highly variable. Some are highly skilled in driving outcomes; like properly informed consent and open disclosure, that benefit consumers. Others struggle to get beyond viewing every issue from their own narrow experience base.

Worse still, sometimes the consumer voice is an industry voice in disguise. A decade ago an international survey revealed that ‘two-thirds of global health charities and patient groups now accept support from drug or (medical) device manufacturers.’¹ Fortunately this has not been an issue for the HCC as we don’t accept industry funding. Nonetheless it is part of our task to ensure the integrity of consumer engagement processes.

Now more than ever it is essential that the quality of consumer representation is assured. *National Safety and Quality Health Service Standards – Standard Two Partnering with Consumers* (endorsed by all Australian Health Ministers in 2011) requires health services to place greater emphasis on consumer feedback and input. As a result the demand for skilled consumer representatives is increasing rapidly. In addition the role of ‘consumer representative’ has become more onerous, creating the need for comprehensive training and support.

This represents both an enormous opportunity and challenge to the health consumer movement. Establishing the independence and competence of voices (both groups and individuals) seeking to represent the consumer interest is a core task. Get it right and the consumer interest can be the key driver of the health system. Get it wrong and consumer engagement may amount to little more than mandated tokenism.

A handwritten signature in black ink, appearing to read 'M. Whitely', written in a cursive style.

Dr Martin Whitely
Senior Advocate

¹ Quoted in Ray Moynihan and Alan Cassels (2005), *Selling Sickness: How the World’s Biggest Pharmaceutical Companies Are Turing us all into Patients*, Nation Books, New York, p. 62.

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Message to Members



Introducing our new Executive Director Pip Brennan. Pip Brennan has worked in the health sector for the last 15 years. Inspired by her own experiences of the opaque maternity care system, Pip initially volunteered for BirthPlace magazine for several years to support women and families to make informed birth choices.

She began her paid health career as an Advocate working at the Health Consumers' Council from 2006. She moved to the Office of Health Review (now the Health and Disability Services Complaints Office) in 2007 and took up a position as a Conciliator of Health Complaints. In 2009 she worked both at Community Midwifery WA (Now The Bump WA) and at Reclaiming Voices.

In the former role she was a Business Development Manager for the small not for profit; in the latter role she developed a pilot advocacy project for women survivors of assault, Reclaiming Voices, and undertook a variety of victim representation roles. Reclaiming Voices was assumed under the aegis of Women's Health and Family Services after the pilot funding was complete and no other recurrent funding options presented themselves.

From 2010 to 2013 Pip took on the role of managing Community Midwifery WA (CMWA), simultaneously enrolling in a Diploma of Management specifically for not for profit managers. She also undertook a considerable number of maternity consumer representation roles including Co-Chair of the King Edward Memorial Hospital Community Advisory Council and Consumer Representative on the Women's and Newborn's Health Service Executive Advisory Group.

In 2012 CMWA moved to outcomes based contracting, which ultimately sparked an interest in Pip to be part of the bigger picture of supporting the introduction of outcomes based contracting in health. In November 2013 Pip took up a contractual position with the WA Council of Social Service (WACOSS) to work on the Towards Better Health Outcomes Project to support contracting reform in the health sector. Prior to leaving CMWA the organisation was successfully re-named and re-branded The Bump WA and the opportunity to re-locate to Cockburn Integrated Health Centre was well in hand. The Bump WA re-located in February 2014 under the new Manager.

The Executive Director role at HCC offers a wonderful homecoming for Pip in the organisation that provided her first professional opportunity in the health sector and a chance to utilise community service organisation management, outcomes based contracting, advocacy and consumer representation skills to continue the work of this unique and important organisation.

Health Consumers' Council Consumer Excellence Awards 2014

Lucy Carter Operations Manager & Health Matters Editor | Health Consumers' Council



From left to right: Dr Simon Towler, Neil Guard & Laura Elkin

The Health Consumers' Council (HCC) Consumer Excellence Awards 2014 were held on the 5th December in the beautiful surrounds of the Palms Community Hall, Subiaco. The Awards were created to celebrate the achievements of the unsung heroes in WA Health, from the administrator to the clinician and to recognise health consumers that go out of their way to make a difference. New award categories were created this year (2014), presented by Dr Simon Towler, Clinical Co-Lead of Fiona Stanley Hospital.

The First award, the Rosemary Caithness Award for personal service to health consumers, was named after a former HCC staff member dedicated to improving WA health, who sadly passed away late last year. Presented by her son, Angus Caithness, the winner was Jane Churchill. Jane has had her share of ill health. Jane is currently undergoing chemotherapy treatment, but she still dedicates time to hospital infection control, from cutting out backing cards to hosting a stand to promote and educate the public on education days during 'Infection Prevention week'. Jane is the mother and carer of a disabled child. She sits on 4 committees as a carer's representative, and holds a movie event each month for carers.

Winner of the Lifetime Achievement Award was Glenda Bosworth. Glenda has been an active member of Coeliac WA since 1988. During her time at Coeliac WA she has held positions on the Board and undertook the role of child liaison officer; where her telephone number was a 'lifeline' for mothers of children newly diagnosed. Over the years she has donated an enormous amount of time to Coeliac WA, going above and beyond the voluntary duties required of a member of the Coeliac Society of WA.

Winner of the Health Professional Award for outstanding service was Dr Bernadette Wright. Dr Wright is a clinical psychologist specialising in working with people from migrant and refugee backgrounds. Dr Wright has been an active board member for several organisations, most recently on the Board of the Ethnic Disability Advisory Council. She has worked extensively in the Transcultural Mental Health Unit at Royal Perth Hospital. This has assisted her to make significant contributions to policy matters in migrant and refugee settlement, services and disability. Among other significant contributions; she is a founding member of the national editorial board for 'Diversit-E', a magazine highlighting the health issues of culturally and linguistically diverse people; jointly planned the seminar series 'Let's Talk Culture'; is a member of Editorial Advisory Panel for the publication 'Transcultural Dialogue' and played a leading role in developing the first WA Transcultural Mental Health Policy, A Transculturally orientated Mental Health Service for WA.

Winner of the Consumer Leadership Award for excellence service to health consumers is Dr Michele Toner. Dr Toner is a leading ADHD Advocate and life coach. She has devoted the past couple of decades to learn more about ADHD. She completed a PhD and Masters of special education in the area of ADHD



From left to right: Glenda Bosworth, Robyn Nettleton, Dr Michele Toner & Sarah Holt-Forman

(Her Master's thesis was on Adults living with ADHD). Her PhD investigated the experiences of University Students diagnosed with ADHD, and identified strategies to help them with their studies and personal lives. Dr Toner is passionate about helping people of all ages to achieve their goals. She works hard to educate the public about ADHD. Dr Toner has also had a long association with LADS, a support group for children and adults who have been diagnosed by paediatricians and psychiatrists as having ADHD. She is on the professional advisory board and gives of her time willingly to support LADS. Her knowledge of ADHD and its effect on adults and children has been of immense value to LADS over the years.

This year two Innovation Awards were presented. The first award went to Advocare, accepted by Project Officer Sarah Patterson for the 'Support Packs for Families Whose Loved One is Entering Residential Aged Care'. The concept was originally developed in 2011, when Advocare identified a large number of calls from family members who were confused about what to do now their loved one had entered care. A large part of their role as a carer had dissipated, and they were unsure about their rights and the rights of the resident now they had entered care. This pack benefits the 300 residential aged care facilities in WA; provides benefit to the over 5000 people either entering care or currently in care; alleviates grief, loss and stress for the over 10,000 family members and carers when their loved one enters care; provides staff and management with a tool to help inform and educate residents, staff and family members; and provides a useful directory for people to be able to access support services within the community.

The second Innovation Award went to Carers WA for the 'Good Practice Model Project'. The Good Practice Model Project is a 2 year project funded by Lotterywest which commenced in March 2013. It encompasses 3 information packs and a DVD. These are, 'Support Pack for Families Whose Loved One is Entering Residential Aged Care' created in partnership with Advocare, 'Information pack for those whose relative or friend with a mental illness is transitioning in or out of an assisted living arrangement', 'Information Pack for those who are supporting a family member or friend with a disability transitioning to independent living' and DVD, 'Why Carers Matter'. The Good Practice Model is in response to the needs identified in WA. The process of development and implementation has been thorough and comprehensive, drawing on all of the knowledge and experience in the community and service providers. The result is a resource that will make a practical difference in the lives of so many and better equip staff to fulfil their roles.

Thank you to all those that attended and congratulations again to our award winners.

A dog 'nose' cancer when it smells it

Frank Smith | Health Consumer



To have the best chance of curing cancer you need to catch it early. But some cancers grow quietly in the body without causing any illness until they are ready to mount a rapid and sometimes devastating attack. But while doctors armed with modern technology are not always able to make an early diagnosis of prostate cancer, dogs are proving more adept.

A study of over 900 urine samples from people with and free of prostate cancer was presented by Professor Gianluigi Taverna at the Annual Scientific Meeting of the American Urological Association. His team found that specially trained dogs were able to detect prostate cancer from urine samples with 98 percent accuracy.

In comparison, traditional prostate-specific antigen (PSA) tests give a false positive in three out of four cases. Men who receive a positive result undergo further invasive tests. Another study found that trained detection dogs were able to detect ovarian cancer in tissue and blood samples through sniffing out volatile organic compounds. Researchers also found that such compounds could also be biomarkers of bladder cancer.

Even more remarkably Japanese scientists have found that dogs can distinguish people with colorectal cancer by the smell of their breath. The scientists think that dogs can smell a chemical produced by the cancer cells which circulates in the blood and is present in the breath of people with colorectal cancer, even in early stages of the disease. The research was published recently in the journal *Gut*. The reason dogs have such an acute sense of smell is that they have about 200 million olfactory cells in their noses, about 40 times as many as humans.

Earlier this year, *Medical News Today* reported that trained Medical Detection Dogs can alert their diabetic owners when their blood sugar levels are too low (hypoglycaemic). Other research has shown how dogs can detect *Clostridium difficile* bacteria in faeces samples and hospital air. *C. difficile* is the cause of many hospital-acquired infections. There have even been reports of dogs used to sniff out lung cancer, breast cancer and melanomas.

Dr Claire Guest, Chief Executive and Director of Operations at UK-based charity Medical Detection Dogs, said millions of pounds has been poured into the traditional test methods, and yet there has been little improvement in their reliability. "This has caused a huge waste of resources, not to mention the distress to the impacted individuals. The detection dogs provide an alternative solution that yields consistently accurate results. If our detection dogs were a machine, there would be huge demand for them."

Dr Trevor Lockett, theme leader on colorectal cancer and gut health in the CSIRO Preventative Health National Research Flagship says this is fascinating information. "Most striking is the ability of the dogs to detect bowel cancer at its earliest stages. Most current non-invasive tests for bowel cancer detect later stage disease far more efficiently than early stage. But detection of early stage cancers is the real Holy Grail in bowel cancer diagnosis because surgery can cure up to 90 percent of patients who present with early stage disease. Cure rates decrease dramatically as the cancers become more advanced."

What did you say? A consultation about language services in the Public Health System

Louise Ford Consumer Participation Manager | Health Consumers' Council

As part of its review of the Health Language Service Policy 2011 the Cultural Diversity Unit (CDU) of the Chronic Disease Prevention Directorate, Department of Health approached the HCC to run two Diversity Dialogues forums in partnership. One was held in Mirrabooka, the other in Cannington to gain input from service providers, individuals and health care workers north and south of the river. They included presentations from Health Department employees, non-government agencies and community members.

The CDU and the HCC would like to extend their thanks to those who participated including speakers, Mr Kenasi Kagisi (former Chairperson of the Congolese Community), Ms Ruth Simms (Senior Social Worker and Project Coordinator, Ishar) and Ms Joansy Pegrum (Settlement Grant Project Officer, Multicultural Services Centre WA Inc.). I would also like to thank Ms Cheryl Taylor (Business Capacity Builder – Aboriginal PIR, Perth Central and East Metro Medicare Local) for agreeing to deliver the 'Welcome to Country'.

To encourage participation and comment attendees were asked to workshop various questions such as "What do you know about interpreting services in the WA Health system?"; "Do you know what your rights and responsibilities are as a health consumer?"; "What are your experiences of interpreting services within the WA Health system?" and "What were the challenges you encountered when accessing interpreting services in the WA Health system?". These questions and others like them encouraged discussion and also suggestions and strategies for improving existing services and their availability.

Both forums received excellent feedback with comments including, for example:

Which part of this forum was of most interest to you? Why?

- Measurement of interpreting services – effectiveness and patient outcomes
- Cultural presentations provided by speakers
- Identification of issues/possible solutions
- Seeing that all interpreters, oral/deaf often face same problems
- Lack of Aboriginal language services provided
- Meeting many end users of language services and getting feedback from their experiences

Any other comments?

- Longer time available – 4 hours
- Thanks for the opportunity
- This was a great forum
- Clear lines of accountability are essential in this area



From left to right: Margaret, Cheryl & Joansy

Once material from the forums has been compiled by the CDU re recommendations and potential changes to the Policy, the Coordinator (Consumer Participation) will provide copies on request to those who are interested.

Are we Closing the Gap?

Laura Elkin Aboriginal Advocacy Manager | Health Consumers' Council

The existing gap in life and health expectancy between Aboriginal and non-Aboriginal Australians is a national shame. In 2008 the Council of Australian Governments committed to *closing the gap* within a generation. The commitments included developing a long-term plan of action that addresses inequalities in health services and ensures the '*full participation of Aboriginal and Torres Strait Islander peoples and their representative bodies in all aspects of addressing their health needs.*'

After promising to maintain national *Closing the Gap* commitments and current level of funding to achieve them, the Federal Government's first budget cut \$500 million directly from Aboriginal affairs, including their support to remote Aboriginal communities across Australia. There is uncertainty about what will be funded in the future after the government merged over 150 program areas into 5. In particular Social and Emotional Well-Being programs including the *Link Up* Program, which supports people who are part of the Stolen Generations and their families to find each other, are unlikely to continue to receive funding. At a time when the National Congress of Australia's First People has been defunded, once again important decisions about us are being made without us.

The WA Government is the only state that has not given in principle support to continue the National Partnership, but last June extended the funding for most *Closing the Gap* programs for a further 12 months, while it conducted a review of all WA Aboriginal health programs. We are eagerly awaiting the outcomes of the review.

Then in November 2014 the WA State Government announced it will close 100 – 150 of WA's 274 remote communities. The National Party Leader and Minister for Regional Development, Terry Redman, has said he would be prepared to use the \$1billion Royalties for Regions money to provide municipal services to remote Aboriginal communities across the state. We hope he is true to his word. But the Premier has stated it is "*unviable*" to maintain support for all remote communities, without explaining which communities he plans to shut and when. He claims it is also because of "*high rates of suicide, poor education, poor health [and] no jobs*".

It's hard to imagine how distressing it would feel to learn through the media that the government intends to force you from your home. For Aboriginal people, this adds to a traumatic history of dispossession that we would already like to think would never happen again. The high rates of suicide, barriers to education and lack of employment opportunities are themselves often a result of the legacy and trauma of dispossession, child removal, control policies of the recent past and an assault on Aboriginal culture and ways of living. It is hard to think repeating government practises of the past without any plan of where people are supposed to move to, will address any of those problems. It will certainly intensify those problems, and force families into regional towns where the infrastructure to rehome them does not exist.

This is also in addition to the WA State Government cutting all funding to the Kimberley Interpreting Service, who provide accredited interpreters in more than 18 Kimberley and central desert languages to clients anywhere in Australia. This is despite WA having the highest national rate of Aboriginal people in prison. The Chief Justice Wayne Martin has condemned the funding cuts, stating that if an accused person "*doesn't adequately understand English and doesn't have an interpreter, then there is a*

miscarriage of justice . . . There are large parts of our state where the primary language spoken is not English. . . I've been calling for a properly funded state-wide interpreter service."

Our program has worked with many Aboriginal patients from remote regions who have difficulty understanding what's happening when they have to access services away from home. The Aboriginal Advocacy Program has met patients who really have no idea why they are here and their need for an Interpreter has often not been recognised or met. Informed consent is one of the most important rights and needs of all patients and this is an area that needs more investment to ensure patient safety, not less. We often highlight the many other difficulties Aboriginal patients from remote areas have when they are unwell and have to leave home to access services. Home is not only where you have family support and familiarity, but for Aboriginal people 'Country' is also a source of spiritual strength and where you want to be in times of sickness to get better. It is hard to believe that in 2014 Aboriginal people still don't have the right and support to live on Country.

Below is an excerpt from a joint statement by a number of groups representing Traditional Owners of Fitzroy Crossing and 35 surrounding communities and near 4000 people who live there:

"We are appalled at recent statements by the Premier about his intention to close down large numbers of remote communities, and we are deeply fearful about the potential impact of such a move on our people and communities and the township of Fitzroy Crossing. We see this as the biggest threat to our people since the shocking events of the 1960s and we believe the impact of such a move could be almost as devastating.

*The reason for this is simple. **Like everyone else in this country, our people love their homes, their families, and the communities where they built their lives. It is astoundingly arrogant of governments to think it is within their power to wipe all this out with a bureaucratic or political decision.***

And for us there is another level. We assert the right of people to live in and on their traditional country, for which they have ancient and deep responsibilities. To be talking of relocating people off their traditional country does indeed take us back 50 years in a very ugly way.

We acknowledge there are real and difficult financial issues for governments in relation to supporting remote communities. We acknowledge that the communities do not have an inherent right to unlimited or unconditional funding support. But dollar and blame shifting between different levels of government is not the answer. Especially when the result is unilateral actions, first by the Commonwealth, and now it seems by the State, of which we are the victims. We are prepared to discuss and address the hard issues. But this can only be done if there is a dialogue. Terrifying announcements of this kind should be a thing of the past. We call on the State and Commonwealth Governments to take the threats off the table, and to enter into a proper, considered, conversation with the people and organisations of the Fitzroy Valley, and of other affected regions, about the long term future of our communities.

Do not turn our people into fringe dwellers once again."

This is joint statement issued by: Bunuba Dawangarri Prescribed Body Corporate, Gooniyandi Prescribed Body Corporate, Karrayili Adult Education Centre, Kimberley Aboriginal Law and Cultural Centre, Mangkaja Arts Resource Agency, Marninwarntikuru Women's Resource Centre, Marra Worra Worra Aboriginal Corporation, Nindilingarri Cultural Health Services, Wangki Yupananapurru Radio, Yununijarra Prescribed Body Corporate and Yi-Martuawarta (Ngurrara People).

Australian Health Practitioner Regulation Agency (AHPRA) 2013/14 snapshot

Regulating health practitioners in Western Australia

This year, for the first time, we offer this snapshot of our work regulating just over 64,000 health practitioners in Western Australia (WA).

This short report complements the more detailed, national profile included in the 2013/14 annual report of AHPRA and the National Boards.



On 30 June 2014 there were **64,015** registered health practitioners in WA, compared to 55,729 in 2012

6,249
people applied for registration as a health practitioner in WA in 2014

On 30 June 2014 there were **36,800** nurses and midwives, **9,889** medical practitioners, **3,340** psychologists, **3,207** physiotherapists, **3,046** pharmacists and **2,422** dental practitioners in WA

There are **167** dental and **5,822** medical specialists in WA

1.1% of health practitioners in WA are subject to a notification



We received **750** notifications about health practitioners in WA during the year, including **88** mandatory notifications

AHPRA is monitoring conditions on registration or undertakings from **370** WA practitioners

There has been a **32%** increase in notifications in WA, compared to a **16%** national increase

There has been a **7%** drop in the number of mandatory notifications received in WA

41% of notifications in WA are about clinical care, **9%** about pharmacy/medication, and **5%** for both documentation and possible health impairment

14 WA practitioners had their registration limited or refused in some way after a criminal history check

38% of notifications were made by patients, **11%** by employers, **10%** by relatives and **8%** were referred by the Health and Disability Services Complaints Office (HaDSCO). **10%** of notifications were initiated by National Boards

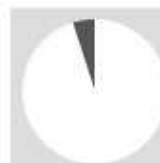
WA boards and committees took 'immediate action' **72** times, leading to a restriction on registration in **64** cases (89%)

There were **43** cases closed after a tribunal hearing, with **42** (98%) resulting in disciplinary action



There were **69** notifications closed following panel hearings, with **42** cases (61%) resulting in disciplinary action

78% of registered health practitioners in WA are women



Notifications about practitioners with **5** National Boards - dental, medical, nursing and midwifery, pharmacy and psychology - account for **95%** of notifications in WA

Advocare Elder Abuse Conference

Mary Kepert Executive Officer | Advocare Inc

Many months of nail biting came to a delicious conclusion early last September, when Advocare hosted the 3rd National Elder Abuse Conference. Two hundred and twenty five delegates representing diverse branches of the aged care industry came together at the Hyatt Hotel, Perth. The conference provided an opportunity to gather and exchange ideas to safeguard older adults from the various types of elder abuse which are becoming as prevalent as Alzheimer's disease in our community.



From left to right: Minister for Seniors, Hon Tony Simpson, Hon Antoinette Kennedy AO, Retired Chief Judge, District Court of WA, Advocare CEO, Greg Mahney

The conference was opened by the Hon. Antoinette Kennedy AO, retired WA District Court Judge. The popular sports presenter Karen Tighe, was the very competent Master of Ceremonies and a delightful "Welcome to Country" was sung by Ingrid Cumming. The Hon. Tony Simpson MLA, Minister for Local Government; Community Services; Seniors and Volunteering; Youth, launched the Elder Abuse Helpline which will be managed from the **Advocare** office in Belmont (the Helpline number is: **1300 724 679**).

The Keynote address was given by Prof Lynn McDonald from the University of Toronto, Canada. Lynn told delegates about the Canadian National Prevalence Study which is currently gathering information about elder abuse from 5000 respondents. One of the aims of the study is to develop helpful evidence-based policy. The data will also inform about the resources required to prevent and reduce elder abuse in the future.

On the second day of the conference, Lynn introduced the topic "Rethinking Elder Abuse-Resident to Resident Abuse." This type of abuse refers to residents of nursing homes and is mostly outside our current definition of elder abuse.



Legal aspects of elder abuse were well represented by lawyers from the Universities of South Australia, Western Australia, the Northern Suburbs Community Legal Service (WA) and the Caxton Legal Centre in Queensland.

The conference embraced a broad spectrum of topics ranging from “Sexual Assault of Older Women” to “Dental Care and Elder Abuse.” Western Australian research was showcased by a paper exploring cross cultural issues in elder abuse policy and another providing an estimation of the prevalence of elder abuse in WA.

The conference concluded with a “Movers and Shakers” workshop. This workshop incorporated a World Cafe style interaction designed to capture the enthusiasm of attendees, tap their knowledge and experience and lay the foundation toward achieving a collaborative national approach to elder abuse issues.

Advocare invites Health Consumer Council members to become aware of elder abuse issues in the community. **Advocare** has a team of advocates trained to provide education and assistance. Our advocates also travel to rural and regional areas throughout the year. Phone: **9479 7566** or Freecall: **1800 655 566 (country callers)**; email: rights@advocare.org.au

Our next major activity will be to promote World Elder Abuse Awareness Day (WEAAD) on 15 June. Please consider supporting this worthy cause and have some fun at the same time. A WEAAD Activity kit containing information about the day together with some participation ideas is available from our website: http://www.advocare.org.au/uploaded/files/client_added/World%20Elder%20Abuse%20Awareness%20Day%20pack%20-%20finalPDF.pdf

The Department of Local Government and Communities has made attractive elder abuse posters available on the following website: <http://www.communities.wa.gov.au/communities-in-focus/seniors/Elder-abuse/Pages/Elder-Abuse-Resources.aspx>

New online elder abuse community

Jenna Aziz Marking & Community Engagement Coordinator | Advocare Inc

At the Third National Elder Abuse Conference in Perth, 2014; it was revealed that there are very few forums within which to share stories, spread information and discuss the complexities of working in the field of elder abuse.

As a leader in elder abuse prevention, Advocare welcome you to this NEW online forum where you can share ideas, work towards solutions and collaborate with likeminded people to help stop elder abuse!

This forum is designed to give anyone working with older people a space to:

- Continue the conversations from the conference
- Get involved with projects, ideas and events
- Join in on a growing network of people who want to make real change

The site is a secure network located at www.elderabusecommunity.com.au and it's FREE to be a member.

Advocare look forward to seeing you in the elder abuse community!

Elder Abuse Posters

Community, health and aged care organisations are being encouraged to download new elder abuse posters produced by the Department of Local Government and Communities. These resources have been designed to assist older people, their families, carers and organisations working with them to recognise elder abuse and seek help. Visit the Advocare website www.advocare.org.au to download the resources.

Your hair may be grey,
but your rights are black and white.



Elder Abuse Helpline: 1300 724 679

Help stop elder abuse

Consumer Participation Program: Overview of 'the year that was'

Louise Ford Consumer Participation Manager | Health Consumers' Council

2014 was a busy and productive year for the Program. Four skills development workshops were facilitated on site with a further two being run at hospitals; St John of God in Geraldton and a tailored session to meet the requirements of the CAC members at Fiona Stanley Hospital. Workshop evaluations have consistently shown that people are finding value in the workshop and gaining confidence and skills by attending.



With Fadzi Whande, Diversity Consultant - Community West, August 2014

Overall the Program received and promoted fifteen requests for consumer comment via forums, presentations and workshops; these present excellent opportunities for consumers to engage and provide a voice, however they often receive little or no response.

Several requests were received for me to present information regarding consumer participation to bodies such as Diabetes WA, Bentley Health Service and ConnectGroups. These were well received and assist the HCC in developing partnerships with other NGO's and organisations.

During the twelve month period twelve requests for consumer representation were received, eleven of these have been filled with one outstanding. The majority of requests received were for high level consumer participation for example the Dental Health Service's committees. Such positions indicate the requirement for specific consumer representative skills such as the ability to process complex information, problem solving and confidence in putting forward an objective and considered perspective.

Bi-monthly CAC (Community Advisory Committee/Council) and Consumer Representative Meetings continue to be held by the HCC; it has been encouraging to see new faces at these meetings and to have new perspectives put forward. The meetings provide an opportunity for networking and support for

members and an opportunity for the HCC to be informed of the concerns and achievements of those who attend.

Throughout the year a total of five Diversity Dialogue forums were held; the aim of these is to provide health care providers with information and skills regarding working with people from new and emerging/ Culturally Linguistically Diverse (CaLD) communities. Four forums were held in partnership with other organisations who recognise the need for such sessions. The organisations were Alzheimers Australia WA, Community West and the Cultural Diversity Unit (CDU), Department of Health (DoH). Feedback and recommendations from the forums are fed to providers and to the DoH. This demonstrates the ability of the Program to provide systemic advocacy as one of its key functions and as part of its efficacy.



Dr Bernadette Wright, Safi Mutambala & Pearl Proud at Diversity Dialogues: Mental Health, August 2014

Between April and December nine cultural competency workshops were facilitated. These were requested by several organisations including Peel Health Campus, Royal Perth Hospital and Community West. These workshops are offered as Fee for Service by the HCC and are assisting to develop sound partnerships with other organisations as well as assist health care staff develop skills and strategies to work effectively with patients and clients from culturally diverse communities. The CDU also requested the HCC be part of the delivery of their “Communicating Effectively Across Cultures” workshops which were provided for DoH staff.

All in all 2014 was a fruitful year. I am looking forward to 2015 being the same. Currently it is full of promise with approaches being made by other organisations like Community West and the Equal Opportunity Commission around partnership and collaborative opportunities. Many thanks to those who have been supportive and encouraging of the Program. I would like to wish everyone a wonderful year ahead in 2015 and look forward to working to further improve health care for all.

Disabled travel in Europe

Frank Smith | Health Consumer

One of the advantages of being a grey beard is that people aren't afraid of you. So I was not surprised when a nun chatted me up in the Royal palace in Warsaw. We had one problem. My Polish is even worse than her English. My wife, who speaks Polish, rescued me. In fact being rescued by my wife from locals became the pattern of my trip.

Generally seniors receive respect and consideration from the young and able all over Europe. Many stately homes in Europe required visitors to wear plastic overshoes to protect the floor. I was spared the indignity of skating over polished floors by kind attendants who saw how wobbly I was. They also often let me use a private lift, usually to descend after I had laboriously climbed a medieval staircase. Sometimes, as in Vienna's Alt Hofburg, I was deposited in a remote part of the ground floor and had to use my mobile phone to locate my wife. Even the notoriously off-handed Muscovites gave up seats for me on buses and the metro. One young lady on a crowded Prague tram gave me her seat and then proceeded to smother me with her ample bosoms when the tram swerved round corners in the narrow street. I suppose there are worse ways to die.

My walking stick provided a timely reminder that I was elderly. Stick it out into the middle of the street and vehicles come to a grinding halt while I crossed the road. Without it you cross Polish roads, even at traffic lights and pedestrian crossings, in imminent danger of violent death. It also came in useful in Art Galleries. When I wandered off, my wife relocated me by the tap-tap of my stick on the polished floor. Or I would wave it above my head to communicate across a crowded Piazza. I nearly became an impromptu Japanese tour guide that way. I cleared a path through crowded St Vitus cathedral in Prague by 'accidentally' tapping ankles with my stick. Even better than my walking stick was my disabled parking permit; if you have one, never leave home without it. In Europe disabled parking bays are frequent, respected by the able-bodied, usually free and best of all without a time limit. Strictly speaking disabled parking permits only work in their home country, but no one seemed to notice that I wasn't a local, even though I was driving a French-registered car in Germany.

There are many discounts available to seniors in Europe, but getting them often demands some language skills. A sign at Manoir du Clos-Lucé in the Loire valley, offered senior visitors a 20 percent discount on the entry price. I hobbled over to the cashier with my stick and seniors' card. "Non!" The discount was only for EU citizens. I then showed her my British passport (I have dual nationality). "Non!" It was issued overseas. Satisfied, she then announced, "Mais vous êtes invalid. Entrée est gratuite" (But you are an invalid, entry is free).

Most Europeans are both willing and able to help the elderly. There are exceptions, however. A small group of teenagers made fun of me when I was wet and bedraggled walking through the interminable rain in Gdansk. They slunk off however when my wife threatened, in fluent Polish to tell their mothers how rude they were. The other exception was a group of women and children in Nevsky Prospekt, St Petersburg. Finding me on my own, they pushed me over and attempted to empty my pockets. Fortunately Velcro delayed them for a few seconds. My wife, hearing my protests, ran to my aid equipped with a copy of Lonely Planet *Russia, Ukraine and Belarus* and laid into them. At the same time she extended my vocabulary of very rude Russian words.

On that trip I discovered that Lonely Planet guidebooks are excellent for self-defense. They are heavy, easy to carry and leave no mark. The contents might come in useful too.

Advance Health Directives: the need for a central register

Dr Martin Whitely Senior Advocate &

Dr Ann Jones Policy Research Officer | Health Consumers' Council

In 2008 the WA Parliament passed the *Acts Amendment (Consent to Medical Treatment) Bill 2008* which allowed consumers to record treatment decisions in the form of an Advance Health Directive (AHD), sometimes referred to as a 'living will'. An AHD is a legal document and is a record of a consumer's treatment wishes if they are unable to provide consent at the time treatment is required.

Theoretically there are a number of ways by which consumers can alert health professionals to the fact that they have an Advanced Health Directive. These include:

- Sending copies to all health providers they attend
- Provide copies to family and friends
- Wear a Medi-Alert bracelet which carries a 24/7 hotline number, or where AHD information can be engraved on the back
- Carry a WA Health Department Alert Card which has details of who has copies of an AHD

However, with the exception of the Medi-Alert bracelet, these methods do not guarantee health professionals are alerted of the existence of an AHD in a medical emergency. Furthermore Medi-Alert bracelets hold limited information and require identification of a caller to the hotline before any information can be forwarded.

A central register of Advanced Health Directives would give health professionals instant access to a consumer's AHD and their legally recorded wishes could be followed. However, despite *The Acts Amendment (Consent to Medical Treatment) Bill 2008* stating that a register must be established and maintained, to date none has been set-up.

In July 2012 the Commonwealth Government launched the *myGov* website which incorporates an eHealth record system. Health information available on this website includes information on prescriptions issued, childhood immunisations, and organ donor details and the site also has the provision to record the existence of an AHD. At present, the website only allows for Advance Health Care Custodians, that is, a record of people or organisations who hold copies of AHDs, but the website could easily be modified to incorporate a register of AHDs.

The Health Consumers' Council recently wrote to the WA Minister for Health the Hon Kim Hames recommending that the WA State Government complies with the *The Acts Amendment (Consent to Medical Treatment) Bill 2008* and ensure that there is a centralised Register of Advance Health Directives. In our letter we suggested the WA State Government consider negotiating with the Commonwealth Government to see if its' *myGov* website could be modified to house a database of Advance Health Directives. This appears to be a sensible low cost way of complying with the law and ensuring that treating doctors are aware of patient's wishes in emergency situations.

Copies of Preparing an Advance Health Directive booklet and Advance Health Directive Form are available at the Health Consumers' Council. For copies please call (08) 9221 3422 or email info@hconc.org.au with your name and postal address.

Turning off life support... Who makes that call?

Chrissy Ryan Advocate | Health Consumers' Council



The decision to turn off someone's life support is a huge responsibility. Through a recent personal experience I found that this decision is actually made by the doctors and not the family as many believe. I thought that by sharing my experience I might ease the burden some may carry if they consider they have to make that final decision.

After many years of being an advocate for people experiencing challenges in the health system, I found myself in a difficult situation. A close family member had suddenly become seriously ill. His heart had failed, causing him to lapse into unconsciousness. He was found in this manner on the floor not breathing. An ambulance was called and he was taken to the intensive care facility of one of our major teaching hospitals. He spent the next 5 days in the ICU (Intensive Care Unit) until he passed away peacefully, 13 hours after the ventilator (a machine that assists or facilitates breathing), was turned off.

It was a painful experience. Overall the care and support provided to the family was fantastic. The medical and clinical care was competent and professional. Sensitive emotional and social support was offered to family and friends who suddenly found they had to deal with the possibility of losing a loved one. Most of the staff were very considerate. Questions were answered promptly except when it was necessary to wait to discuss something with the consultant doctor.

Most people tend to think that the decision to turn off life support is made by the senior family member or nominated next of kin. I too believed that we the family/next of kin would make the decision about when to turn off life support. However this is not the case. The consultant physician, a senior doctor who is experienced in his or her field, generally makes the final decision based on their experience, knowledge, and observations and investigations gathered about the individual. So if it is evident that the brain has suffered serious damage and it is unlikely the person will regain consciousness, to function as a human being, who can think, move, talk, eat, etc., then the decision will be made to turn off the ventilator.

It is very expensive to keep someone alive in ICU on life support. Continuing to keep someone on life support when there is no significant evidence to indicate that the person will ever regain consciousness and be a living functioning human being, is costly and pointless.

In the case of our loved one, an MRI (Magnetic Resonance Imaging) was performed and images of his brain showed damage to the cerebral cortex. This is the largest part of brain, the area that is known as the “thinking brain” or the “human or sophisticated brain”. There was damage to other areas in the brain as well. Unfortunately brain cells do not repair or regenerate. The consultant physician discussed with the family these findings, they were very sad to comprehend. To hear that they will never wake up and be the person you knew and loved is very distressing. The information gained from the MRI, coupled with the observations and investigations they had performed over the 72 hour period in ICU, revealed to these experienced doctors that there was a very unlikely chance of recovery.

In the event that the family are not ready to have life support for their loved one ‘turned off’, the consultant and his/her team may delay turning off the ventilator to give the family some time to feel comfortable with the decision. However there are other factors that need to be considered. Besides the obvious high cost of maintaining someone on life support when there is no hope of them recovering, the staff resources, available bed and equipment required for life support, may be needed to save the life of someone who could recover.

Although it is painful to turn off life support, none of us usually wish to maintain our loved ones in a comatose state for any length of time if they are not going to wake up and be able to breathe, live and be the person that we knew. It must be a relief to most family members who find they are in this position that the decision is ultimately up to the doctors regarding the healthcare and life support of their loved one. It can be a terrible burden to make this call. Some people can agonise over it for days and weeks.

The doctors base their judgement on the clinical presentation/observations and whether or not the senior doctors can see evidence to support the prospect that recovery is possible. No one wants to keep someone alive on life support any longer than is necessary.

HCC Advocacy Service

Our advocacy service assists people with problems in the health system. The service is free and available to people anywhere in Western Australia. Advocates are experienced in consumer rights, knowledge of the health system and consumer responsibilities and are generally not trained in medicine or law. Knowledge gained in our advocacy service assists with our recommendations on health service improvements.

If you are experiencing a problem with a health service you can contact the Health Consumers’ Council on **(08) 9221 3422** or **1800 620 780 (country)**. Or for further information regarding the assistance we provide please see our website www.hconc.org.au

Terminal illness & death

John Barich National Vice President | Australian Family Association

This is a right of reply to the Article 'A time to live and a time to die' written by Murray Hindle, President of the West Australian Voluntary Euthanasia Society (Inc). The HCC as the voice of all health consumers in WA encourages debate on a broad range of health related topics.

Compassion for the sick and suffering is something which unites us all. Many of us have experienced situations where relatives and friends have faced serious, terminal illnesses; causing them and those they love to be apprehensive about the future. In order to allay these fears it is sometimes suggested, by advocates of euthanasia or physician assisted suicide, that the compassionate, sympathetic solution to such problems is voluntary euthanasia. But is it?

Very often these advocates, in order to press home their point, use the phrase that voluntary euthanasia enables those with terminal illnesses to "die with dignity". By doing so they make the mistake of assuming that human dignity is dependent on our usefulness to community, state or nation. However, everyone is entitled to be loved, supported and cared for until they die. As a society, we have a duty of care to ensure adequate pain and symptom control for all terminally ill patients. People need to have their emotional, psychological and spiritual needs met; otherwise mental pain is exacerbated. Doctors cannot control this pain. Killing by voluntary euthanasia does not allow people to die in peace. Humans should be judged not by how useful they are, but by how well society cares for our sick and vulnerable citizens.

Euthanasia always entails the deliberate killing of a human being: either by their own hand (suicide); or a lethal injection administered by a member of the medical profession. Can we as a society ever countenance the deliberate killing of any human being? Can the killing of a person ever be described as "dignified"? Why are people so alienated and lacking in values?

Another common misconception associated with euthanasia is that legal safeguards can be built into legislation to protect against unwanted excesses, such as the unauthorised killing of confused, depressed, vulnerable, elderly patients who have not requested it. Experience in countries which have introduced euthanasia indicates that it is virtually impossible to legislate safely against government authorised killing; no matter how many checks and balances are in place. How would/ could safety from abuse be ensured? Video cameras in all hospital rooms?

With the passage of time, legal safeguards are watered down so that, in some countries, it is now possible for children with terminal illness, people without terminal illness, and those with dementia and psychiatric illness to request euthanasia. Clearly, requirements for legal safeguards are illusory.

The answer to fears surrounding end-of-life situations does not lie in disposing of the problem by killing the patient, but rather in the use of the time-honoured medical practice of palliative care. Palliative Care Australia says that good, well-resourced palliative care gives people the ability not only to live well in their illness, but to die well too, free from pain in the place of their choice surrounded by people they wish to be present. Palliative care works.

We thank you for the opportunity to respond to the article in Health Matters since, as might be expected, not all the members of HCC support Voluntary Euthanasia.

Australians join the international chorus for safety & informed consent

Alex Jones | Save Our Trees/ Pesticide Action Group

We congratulate the Health Consumers Council on its 2014 Health Submission to the Senate Select Committee. The Council's strong position on the need to deliver **transparency and safety** on Pharmaceuticals reflects a growing chorus of concerned Australian and international consumers. There is a commonly held view that the relationship between governments and industry is to the detriment of consumers' health and the natural environment.

Almost word for word, the "cherry picking" of favourable scientific evidence and the "hiding" or "spin" that applies to the Pharmaceutical industry also applies to the Pesticide industry. These are sister industries. In the same way that the post market monitoring of drugs is problematic, so too is the post market monitoring of pesticides.

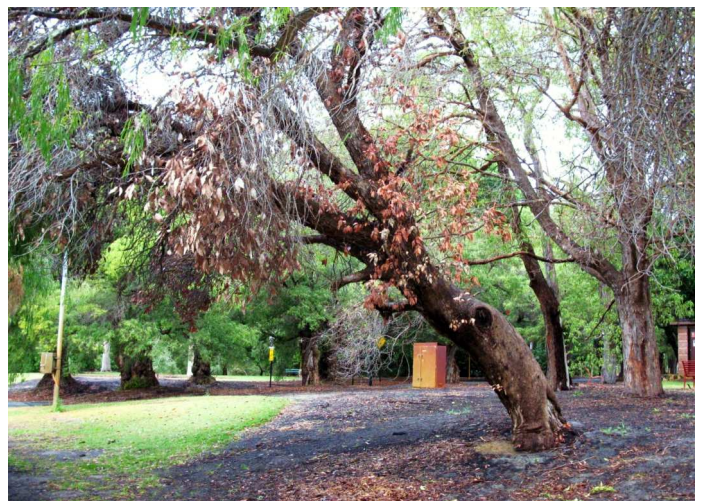
With many thousands of registered pesticides and pressure from industry and certain politicians on the Australian Pesticides and Veterinary Medicines Authority we have seen a slow and cumbersome system that has allowed a toxic chemical cocktail to pollute our air, soils and waterways and poison people, their pets and wildlife. In the same way that consumers have realized the risk of adverse effects to their health from many Pharmaceuticals so too have consumers realized the adverse effects of Pesticides on health and the natural environment. All levels of government as well as consumers must reject the heavy reliance on pesticides that continues to be promoted by industry. Societies globally must use healthier and more environmentally sustainable options.

The Save Our Trees network's photographic evidence of poisoned vegetation on public land and results from independent laboratory testing of soils and foliage from sick and dying mature trees have revealed a link between the use of weed killers, tree deaths and disease.

In 2013, following years of concern about links between exposure to pesticides and common illnesses such as cancers, neurological and autoimmune diseases, the Pesticide Action Group WA was formed with a view to lobby for bans on the spraying of pesticides on public land. In February 2014, on behalf of the network, Honourable Melissa Parke, Member for Fremantle, tabled **Petition 833/1300: Call for a Royal Commission into the Use of Pesticides and Harm to Public Health**. Health Consumers may wish to support this by contacting our federal politicians.



18 June 2012 Kings Park Herbicides signage



Kings Park Fluazifop trees on sprayed land 1 May 2012



**HEALTH CONSUMERS'
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