

HEALTH MATTERS



HEALTH CONSUMERS'
COUNCIL
YOUR VOICE ON HEALTH

Health Consumers' Council WA (Inc) Newsletter

Summer 2014



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WELCOME

We would like to welcome our new staff members Martin Whitely and Carly Parry, it's great to have you on board!

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Amy McGregor	Operations Manager
Lucy Carter	Administration Assistant

Cover: Frank Prokop and Kenasi Kegasi HCC Award winner

FORWARD



Hello all and welcome to 2014.

Things have been very busy over the Christmas break. We welcome new advocates Martin Whitley and Carly Parry. The Christmas morning tea was very successful, with a wonderful range and diversity of winners of the Health Consumers' Council awards.

This year promises to be exciting and challenging. The Board is reviewing the membership policy, corporate governance and we are looking to strengthen our relationship with member organisations. I will be negotiating strongly with the Department of Health to ensure that our funding contract includes incentives for us to demonstrate leadership in the health consumer area.

The Board and staff will be working to determine in which areas we should be taking a strong pro-active stance, and in which areas we will be supporting our members and member organisations. We will also work more strongly on strategic directions and policies such as the 2030 Health and Wellness Strategy which should set the future direction on more meaningful consumer engagement and partnerships.

Louise and I are looking to develop a stronger working relationship with university and vocational researchers to get a better handle on issues such as improving the pre-admission and informed consent processes, improving understanding of agitated and emotionally sensitive patients and their carers, and better understanding the barriers to effective communication between us all.

We are working on improving our presence in the regions, with a successful trip to Karratha resulting in a number of service improvements moving through the system. The HCC is working more closely with the Medicare Locals to improve the transitions between our GP's and the **hospital** system.

With your help, we can help to make a good system better, and work together to improve health outcomes through the primary and tertiary and public and private systems. I hope you enjoy this issue of Health Matters, and thank you for your ongoing support.

A handwritten signature in blue ink, appearing to read 'Frank Prokop', written on a light blue rectangular background.

Frank Prokop
Executive Director

HEALTH CONSUMER PERSPECTIVES ON 2030 PLANNING EXERCISE

Frank Prokop
Executive Director HCC

One of the major health policy initiatives of 2014 will be the release and discussion on the Health and Wellbeing 2030 plan. Executive Director of the Health Consumers' Council Frank Prokop, gives his perspective.

The Health Consumer Council and consumers generally strongly support the 2030 planning exercise being coordinated by the Department of Health. It is only by setting an ambitious vision and then articulating a critical events pathway that credibility and commitment to realistic engagement of consumers can be developed.

Currently, the Health Department is seen as a bureaucracy with such convoluted processes that the needs of the consumer at the collective and individual level are not well incorporated. This is not through negligence or wilful disregard for patient rights, but rather a function of being busy, regularly dealing with patients and so 'knowing' their needs, and working in a system which encourages complaint by disaffected clients. The consequences of error in health are significant to those experiencing them but we need to put effort into improving systems, as well as just repairing damage from mistakes.

We need to make statements like 'patient journey' and 'patient centred care' mean more than buzz words thrown out at meetings to demonstrate that the system is truly caring. First and foremost, we need to all remember that Patients are People.

We need a culture of full disclosure but also increased awareness of the responsibility of patients for their own health care. Culture changes cannot be realistically implemented in a short term planning document.

The HCC would like to see strong leadership, both by health care professionals and administrators, in forging real and meaningful partnerships with peak bodies. As an organisation, HCC needs a clearly defined mandate, with reward and penalty pathways for demonstrating community leadership and facilitating challenging policy debates in the health arena.

Overall, there is a clear need to differentiate between health and wellness and to understand that Health as an organisation is not ideally positioned, and indeed may be legally conflicted, in promoting a wellness agenda to the wider community.

Moving to a wellness framework also takes strong government leadership. This can only be part of our way of life if the community and representative organisations strongly believe that they are engaged, respected and have a meaningful role in the development of policies rather

than ticking consultation boxes in return for funding. There is a strong belief that health is accountable to itself and not the wider community whose interests they are supposed to represent, which must change.

Similarly, the community remains unaware that health is, in a financial, political or administrative perspective, restricted. Obviously, people want and demand their own health issues to be addressed immediately, and without undue impact on them.

Indeed, with a few exceptions, individual behaviour and responsibility is not seen as a factor or contributor to long term health outcomes. The understanding about what has to 'give' in future health planning cannot be delivered by the public service as a lecture, but rather must be 'sold' to and by the public. The community can then drive priorities and resourcing over the longer term to be implemented by the public sector in a more responsible manner.



Lorraine Powell former HCC Acting Chairperson & Mitch Messer former HCC Acting ED at the HCC Christmas Morning Tea & Awards

This is not a threat to existing structures, but we must, through recognition respect and meaningful engagement, get the community to build on the strong basic support for health care professionals. Sadly, we are seeing this principled community support eroding for law enforcement, education and religion where it had once been much stronger.

The document needs to clearly demonstrate outcomes that are engaging, rather than paternalistic, cooperative rather than autocratic. It is time to provide clear penalties and rewards for good and poor behaviour by the health care sector and the community itself.

Instituting behavioural changes, rather than policy changes is extraordinarily difficult. It can only be assured if the community believes that its view is actively sought. This is not through the views of beleaguered individuals on committees dominated by health professionals, but the collective, long term perspective of those who don't yet need the support of a well-integrated health system. The risks must be transparently explained, and penalties for system collapse understood by today's youth, who will bear its brunt in the future.

This 2030 document must be allowed to drip feed a community not used to realistic engagement in matters of this nature. Health has a wonderful opportunity to succeed where law and order, education and religion have all failed; telling the community what is in its best

long term interest is no way to engender support.

We are fortunate to have a strong base of a very good health system; but it is one that has been designed for the people, not by the people. We run the risk of greater political ad hoc decision making and highly variable quality outcomes for the community if we do not use a collective intelligence system to move towards and beyond 2030.

Health consumers are there to help, but we need a clear mandate so that groups such as the HCC can put the incessant complaints of the naysayers into context, and promote improved outcomes with real ownership of the improvements. There is a need to better identify support roles by the NGO's and streamline them, while maintaining transparency and recognising the emotional gradients and personal journeys that are such an important factor in health support networks.

There may be more than 30,000 health workers in the Department, but there are nearly 2 million citizens who also care about health, and we need their support and good ideas to be able to meet the challenges of the future in a cost effective manner.

There are examples of meaningful changes in community attitudes, if the model is right, the outcomes are viewed objectively (as opportunities rather than just as threats), and we all remember that we want the same things in the long run.

2030 OUTCOMES:

To have a well-informed community able to provide objective advice on the transparent development of cost-effective health priorities in their best interest.

To have a health system which operates pro-actively on the best available information and evidence available to it at any time and learns from any and all instances where performance is sub-optimal.

To have well informed and active consumers, carers and health professionals who work cooperatively to ensure optimum cost-effective health care that meets individual and collective needs today and for the foreseeable future.

To better coordinate all aspects of the health care system where wellness and good health behaviours are rewarded rather than having bad health 'fixed' by a tertiary health care system.

To have sufficient flexibility in the system to be able to react to catastrophic events or changes in community behaviours to adequately meet needs as they are identified.

HEALTH SYSTEM 2030:

To have a health system built upon learning, opportunity and praise; where all participants in the development of policy are valued, respected and challenged to meet the highest possible standards of health and wellness in the community.

INTRODUCING

Martin Whitely our new Senior Advocate and Carly Parry our new Advocate.

Martin Whitely

Senior Advocate

I am a former teacher, university lecturer and author, and was a member of the Western Australian Parliament from 2001 to 2013. During this time I advocated for individual constituents and for systemic change to improve outcomes in the areas of health, mental health, education and housing. Ensuring children with emotional and behavioural difficulties received support that matched their individual needs, and protecting the rights of involuntary mental health patients, were two high priorities during my parliamentary career.

As a consumer advocate I am particularly motivated to ensure that health consumers are given the opportunity to make fully informed decisions about their own treatment. This requires that consumers have access to competent health practitioners who provide independent advice based on robust evidence.

I am enjoying the challenge of working with the team at the Health Consumers Council and helping consumers with the enormous variety of issues they encounter.

Carly Parry

Advocate

Moving permanently to Australia from the UK ensured that 2013 was an absolute whirlwind for me both personally and professionally. In England I supported women and children affected by domestic and sexual violence; a job I enjoyed for seven years. However, eager to embark on a new challenge the role of Advocate at the HCC seemed the perfect fit.

Thus far the role has proven to be diverse in terms of the issues raised by our Consumers, therefore I am able to utilise my existing skills whilst developing new ones along the way. To date I have assisted consumers with an array of issues within mental health, chronic pain, home care and serious grievances against service providers.

I see the role as Advocate at the HCC as a new opportunity to develop my knowledge in the area of health. I feel strongly that consumers should have a voice in all matters relating to their health and am dedicated to assisting many in doing so.

Chronic pain medication (schedule 8 drugs) and the complexities that are associated with them are of particular interest to me. The difficult balance between pain and dependency is a subject of strong debate and I hope to raise the issue further in our next issue of Health Matters after attending a pain management course at one of our metro hospitals.

HCC CHRISTMAS MORNING TEA & AWARDS

Lucy Carter
Health Matters Editor

On the 5th of December 2013, the Health Consumers' Council held its annual Christmas Morning Tea & Awards. This was the first event of its kind held in the new HCC premises. The event is an opportunity to thank our members, consumer representatives and Board Members whose commitment to the good governance, accountability and strategic direction of the Council is demonstrated time and time again at the monthly HCC Board Meetings.



Pippa Bagnal ED System Policy & Planning DoH, Frank Prokop ED HCC &
Learne Durrington CEO PCEMML

High profile guests included Pippa Bagnal, Executive Director System Policy and Planning, Department of Health; Tarun Weeramanthri, Executive Director Public Health and Clinical Services Division Department of Health; and Adjunct Professor Kim Gibson Chairperson Clinical Senate WA Health. Also in attendance was Terina Grace CEO Perth North Metro Medicare Local and Learne Durrington CEO Perth Central and East Metro Medicare Local.

HCC Executive Director Frank Prokop announced the winners of the 5 HCC Awards. The first award went to Dr Michael Wright and team. They were nominated for their work which has led to the 'Looking forward project: Culture is a pathway to wellbeing'. Evaluating change in the provision of the mental health and drug and alcohol services to Nyoongar families in the south-east corridor of Perth WA. This Aboriginal led project is the first research project with this level of sophistication that has been undertaken with any Aboriginal Language group.

The second award went to Jamie Potter for his commitment, great sense of respect, passion and understanding while in his secondment to the role of Community Development Officer at Swan Adult Mental Health Service, which involved acting as a liaison officer for the Consumer Advisory Group. The group has successfully contributed to improving service delivery at Swan Adult Mental Health Service.

Anne Healy received the third Consumer Excellence Award for her outstanding contribution to many consumer focused organisations. With limitations of her own, Anne is a person of understanding and is a champion for people with disabilities.

The fourth award went to Kenasi Kegasi for his excellent commitment to provide a consumer voice that is from a new and emerging community. Kenasi has provided invaluable information in understanding the importance of the consumer's voice from a CaLD background.



Frank Prokop ED HCC & Jamie Potter



Frank Prokop ED HCC & Margaret Vikingur

Margaret Vikingur took home the fifth award. Margaret has volunteered with LADS (Learning and Attentional Disorders Society of WA) for 20 years and has had various roles within the organisation including President. She has also resided on many LADS committees. During that time she has spent many hours manning the phones of the help line, organising international guest speakers, coordinating seminars and running information evenings. This is Margaret's final year with LADS and her hard work over the last 20 years, as well as her invaluable support & presence will be sorely missed.

Congratulations to all our award winners and thank you to all who attended.

COMMITMENT TO CARE

'IN SICKNESS AND IN HEALTH'

Karyn Markwell

Australian Pain Management Association



Terina & Graham

When Graham vowed thirty years ago to take his wife 'in sickness and in health', he meant every word – as his ongoing commitment to her proves. Graham has restructured both his life and his business to care for Terina, who has persistent pain.

Terina and Graham worked side by side in their family business until they embarked on a trip to Tasmania in 2007. While on holiday, Terina

became ill with chronic pancreatitis. Back home, she struggled with the heavy medication prescribed by her doctors, was unable to drive and often slept through the day.

In 2010 aware of Terina's growing needs, Graham bought a home-based business and employed two staff, so that he could be constantly near Terina. 'My wife becomes sick so suddenly and I must rush her either to the doctor's or the hospital for emergency care,' explains Graham. 'It's a huge relief that I am now around during the day.'

'When needed, I take over the household responsibilities, including doing the washing and cooking the meals. When Terina is very sick, I help her to get dressed, because she can be pretty wobbly on her legs.'

Terina has been unable to attend a pain-management clinic, due to the distance of the nearest clinic from their home, as well as being too unwell to attend day after day. Instead, the couple gain support from the Australian Pain Management Association (APMA), a non-profit organisation which gives hope, information and life skills to people with persistent pain.

'APMA has made a difference in our lives by providing support and information,' says Graham. 'Their Pain Link helpline and online information mean that we can access options and hope without having to leave home.'

Graham occasionally finds it challenging being Terina's carer, because he is distressed by her pain and anguish.

'The most challenging thing about being a carer is being helpless to take away the suffering of someone you love,' he says.

How to contact APMA

For more information about the Australian Pain Management Association, visit www.painmanagement.org.au.

APMA's Pain Link helpline: 1300 340 357
(First Published in Queensland)

WOMEN'S HEALTH FORUM

THE SOCIAL DETERMINANTS OF HEALTH, & GENDER EQUITY PRINCIPLES

The Health Consumers' Council (HCC) invites you to attend this informative and challenging forum which will examine how the above impact on women's access to health care and the quality of care they receive. It will also explore how women can empower themselves as health consumers.

Speakers:

Sue Lee - Community Development Program Manager - Women's Health and Family Services

Kathy Blitz- Cokis - Manager - Women and Newborn Health Service, Women's Health Policy and Projects Unit

Program: 2 - 3.00 pm	Speakers
3 - 3.15 pm	Refreshments and networking
3.15 - 3.50 pm	Q & A and potential actions

When: Wednesday the 5th March 2014 - 2.00 pm to 4.00 pm

Where: HCC, Unit 7, Wellington Fair, 40 Lord Street, East Perth

NB: Paid parking is available at Royal Street Car Park

RSVP: Info@hconc.org.au or 9221 3422 by COB Tuesday the 25th February, 2014



**HEALTH CONSUMERS'
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CaLD COMMUNITIES HEALTHCARE EXPERIENCE

Louise Ford

Consumer Participation Coordinator HCC

“Refugees and asylum seekers are amongst the most vulnerable people in the world.” (Research Roundup: Issue 16 Dec 2010)



Image source: the Seed Project.com.au

Whilst the majority of people arriving here as refugees and asylum seekers are very grateful for the services and supports they are offered, there are some aspects of life in Australia that they can find confronting, unfamiliar and difficult. These can include but are not limited to:

- Resettlement issues including affordable accommodation
- Qualifications not being recognised
- Living in a secular society
- Freedom of speech
- Gender equity
- No prior experience of democracy
- Difficulties in learning English, particularly written
- Lack of knowledge of a 'western' system of government
- Racism
- Unfamiliarity with accessing services as provided in WA
- Lack of employment skills for Australian conditions
- Loss of social status
- Language barriers
- Lack of formal education
- Services being offered with a 'one size fits all' approach.

During the past 20+ years WA has accommodated people who have arrived as refugees and humanitarian entrants. Many of the above issues exist for them and are, at times, exacerbated by their 'refugee experience' which has, in all probability, included trauma and/ or torture. The impact of this experience on the individual, families and communities cannot be underrated and may lead to:

- Ongoing feelings of grief and loss

- Flashbacks; intrusive memories
- Numbing and disassociation (including avoiding social interaction and experiencing attachment issues)
- Lack of trust
- Domestic violence
- Fear of authority figures
- Collective trauma (i.e. an entire community carries the scars of trauma, this may become generational)
- Centrelink and the way in which money is allocated
- The vulnerability of unaccompanied minors
- A range of health problems including malnutrition, vitamin D deficiency and sexual health – for women often the result of rape in camps
- Social and physical isolation
- Injuries sustained as result of torture may have been untreated or poorly managed
- Food insecurity

On arrival the majority of people want to start a new life. At times they find themselves in what can be called an 'alien landscape' with sometimes minimal tools to navigate it with. Initially people focus on the practical aspects of establishing themselves, sometimes subduing their memories of the horror they have experienced and often feeling glad they are away from danger and extreme hardship. After a period of time the realities of life in a new place begin to sink in. This can be followed by despair, anxiety, grief for those left behind, the re-emergence of symptoms of Post Traumatic Stress Disorder (PTSD) and other disorders which can occur as result of past experiences.

Accessing health care can be difficult if you are unfamiliar not only with service provision as it is here but also the range of services and information which is available. There is also the issue of getting to and from appointments; if you are unfamiliar with the locality, with reading directions, with interpreting maps, don't have English skills and are unsure of using public transport, how do you manage to get to the service/s?

If people have spent time in a refugee camp they are likely to have experienced extreme hardships including, for example, food and water shortage, lack of access to clean drinking water, living in unsanitary conditions, malnutrition and chronic illness resulting from lack of access to adequate health care. Women are at risk, in and out of camps, of rape and other forms of sexual abuse – historically rape has been a weapon of war across cultures. Living under such extreme conditions people's health can and does deteriorate.

People are required to undertake certain health checks before migrating under the Humanitarian Program. However many people arriving here are suffering from health conditions such as anaemia, malaria, intestinal parasites, poor oral health, and Vitamin D deficiency and require treatment soon after arrival. Others will show symptoms of PTSD, some will have a distrust of doctors having experienced torture at the hands of 'health professionals' and many will have difficulty trusting service providers having experienced human rights abuses at the hands of government authorities.

We need to be able to provide services to people from new and emerging communities that take into account their experiences, that offer them interpreting services and which treat them with respect. The issues that are facing health care providers in WA are being faced by many other nations who have similar diversity in their populations. Similarly these issues are being encountered in other parts of Australia where some excellent work is being done, particularly in NSW, Victoria and Queensland, in terms of adapting health service delivery and providing education and resources to staff and communities to assist in the efficacy of health service provision.

CULTURAL COMPETENCY WORKSHOP

In an increasingly diverse population, language barriers and cultural misunderstandings impact on both consumers and service providers.

Nationally and internationally, research has shown the importance of cultural competency to enhanced health care delivery and to patient recovery. As a result the workshop has been designed to assist health care workers to gain knowledge and skills that will allow them to work more effectively with patients/clients from new and emerging communities.

The next Cultural Competency workshop is on Wednesday March 19th, 2014. To be held in Unit 7 Wellington Fair, 40 Lord Street, East Perth.

This workshop will:

- Develop your understanding of the terms 'culture' and 'cultural awareness'
- Build on your knowledge of new and emerging communities
- Increase your skills when working with interpreters
- Identify barriers people may face
- Explore ways of applying the above in your work

Feedback from previous workshops:

- Good to develop the skills and how to apply them to a real setting
- All useful & awareness raising
- Thought provoking workshop
- Overall very good training & 'super' facilitator
- Useful to think about the way different people view health



Places are limited so please book early by calling (08) 9221 3422 or email info@hconc.org.au



**HEALTH CONSUMERS'
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MENTAL HEALTH BILL 2013

A DELICATE BALANCING ACT

Martin Whitely
Senior Advocate HCC

“The creation of mental health legislation is always going to be a delicate balancing act (of)... professional discretion ... the community’s right to feel safe... the right(s) of family members and carers [and]... a patient’s right to privacy and to determine their own individual recovery.”

Health Minister Hon Kim Hames when introducing the Mental Health Bill 2013 (Hansard 23/10/2013)

There are occasions when it is in the interests of people suffering severe mental illness or society to temporarily suspend an individual’s fundamental human right to personal freedom and self-determination. In these circumstances the doctors, police, nurses, social workers and others at the ‘pointy end’ of dealing with individuals who are in crisis, require special emergency powers in order to prevent severe self-harm, or on very rare occasions, harm to others.

In emergency situations, those dealing competently and in good faith with the severely unwell deserve legislative protection. However, people who are believed to be dangerously mentally unwell have, in the vast majority of cases, not committed a crime. It must also be remembered that on many occasions throughout history the power to detain and treat those deemed to be ‘mentally unfit’ has been abused in the guise of therapy and protecting the public.

The majority of mental health practitioners are competent and responsible. They are unlikely to abuse the extraordinary powers they have to involuntarily detain and treat. However, there are too many historical examples of mental health practitioners causing considerable harm, including avoidable deaths. And regrettably there is an unhappy local, national and international history of self-regulatory failure by some in the mental health professions. The Mental Health Bill 2013 currently being considered by the WA Parliament must ensure that this unhappy history is not repeated. This is best achieved by restricting these extraordinary powers to the minimum necessary and through retrospective oversight that ensures they have been exercised appropriately.

From a patient’s rights perspective, the Mental Health Bill 2013 is a significant improvement on the current legislation - the Mental Health Act 1996. For example the bill will allow patient, or carers, or mental health advocates to request a review of any decision affecting a patient’s rights.

However, in Western Australia we are coming from a low base. Therefore despite the improvements there remain significant problems and in a few areas the bill represents a backwards step. Particular attention needs to be paid to ensuring that the criteria for making patients involuntary are not unintentionally broadened.

As the Health Minister and Deputy Premier Kim Hames identified creating new mental health legislation is a “*delicate balancing act*”. This year our elected representatives have the onerous responsibility of ensuring that balance is achieved. The Health Consumers Council is in the process of writing to all Members of the State Parliament suggesting improvements to help protect patient’s rights and make this good bill even better.

DIVERSITY DIALOGUES

HEALTH, HEALTH CARE AND CULTURE

Health Professionals are invited to attend this forum which will focus on men's access to health care e.g. are men from new and emerging communities accessing adequate health care, if not, why not; what are barriers for men accessing health care in WA, are men aware of services that are available to them?



Panel members:

Assaad Salame - Families in Cultural Transition (FICT) Program Coordinator - ASeTTS

Nelson Muhirwa - Rwandan community - Advisory Committee Chair

Sheikh Mohammed - Imam - Mirrabooka Mosque

We welcome you to attend, increase your knowledge, and ask questions in an open and collegiate environment. Attendees will be provided with notes and informed of any actions that result from the forum.

Date: Wednesday 19th February, 2014

Time: 2 – 4.00 pm

Venue: Health Consumers' Council, Unit 7, Wellington Fair, 40 Lord St, East Perth

Parking: Paid parking is available in Royal Street Car Park

Light refreshments will be provided

RSVP: Info@hconc.org.au (9221 3422) by Thursday 13/2/2014 for catering and seating purposes



**HEALTH CONSUMERS'
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3RD NATIONAL ELDER ABUSE CONFERENCE

Advocare is proud to be at the forefront of combating elder abuse in Australia and will host the 3rd National Elder Abuse Conference. Entitled 'Unlocking Solutions', our organising committee will embrace a program that looks into all aspects of elder abuse.

Already regarded by industry leaders as a must attend event, this conference will bring together dynamic global experts to share information on topics that will assist in elder abuse research, intervention and policy. There will also be plenty of opportunities for networking, reacquainting with old colleagues and meeting new ones.

The two day conference will be followed by a unique one day workshop which will look at the practical and theoretical applications that arise from the conference.

Delegates are encouraged to attend from different professions, as unlocking solutions to elder abuse requires a collaborative effort from all counterparts.

Register your interest at www.elderabuse2014.com for the conference and workshop and help change the outcome for thousands of elder abuse victims in Australia.

Advocare
incorporated

**unlocking
solutions**



**Third National Elder
Abuse Conference**
3 & 4 September 2014
Hyatt Regency Perth

ESSENTIAL ROAD CRASH SUPPORT

West Australians seriously affected by road trauma are now able to access free information, support and specialised counselling through Road Trauma Support WA (RTSWA).

This essential service is delivered by the Injury Control Council of WA (ICCWA) and funded by the Road Trauma Trust Account. It is provided free of charge to anyone impacted by road trauma, irrespective of when the incident occurred, or the person's actual level of involvement.

Road Trauma Support WA was officially launched on Sunday 17 November 2013, World Day of Remembrance for Road Traffic Victims, by Acting Minister for Police and Road Safety, Hon. John Day.

Manager of Road Trauma Support WA, Jenny Duggan says: "the potential for mental and social distress following a major road crash is substantial. Research shows that approximately 13 people are significantly distressed by one major crash.

"With Western Australia averaging nearly 200 road fatalities each year, and in excess of a further 2,800 people being seriously injured (28% of which are life-threatening), this is an issue affecting the entire community,' she said.

Road Trauma Support WA's clients comprise:

- those involved and/or injured, the bereaved and their families, carers and friends
- those who may have caused a trauma
- witnesses
- first responders, and
- emergency service personnel.

The service, open to all people affected by road trauma on public roads in Western Australia, whether directly or indirectly involved, offers multiple services to ensure individual needs are addressed through provision of client-centred support, including:

- Information through a toll-free telephone line, fact sheets and information packages, brochure and website
- Peer support
- Specialised trauma and bereavement counselling, and
- Preventative education.

Information and support can be accessed in person, via telephone or Skype, or online. Call Road Trauma Support WA on **(08) 9420 7262** or **1300 004 814** or visit the website at **www.rtswa.org.au**



WHEN MISSING LIMBS HURT

Karyn Markwell

Australian Pain Management Association

Phantom limb pain – pain in the location of an amputated limb – is a complex phenomenon.



Neuroscientists recognise that phantom limb pain (PLP) is caused by the brain and spinal column. The majority of amputees experience PLP, usually shortly after amputation. Amputees generally experience PLP in the furthest part of their amputated limb (feet or hands) as stabbing, burning, aching, crushing or tingling pain. The pain can vary in intensity, from slight to excruciating, and can be either continuous or intermittent.

One man has described the PLP in his amputated foot as feeling like ‘being stung by a thousand bees, all at the same time’. One woman’s experience of PLP feels ‘more painful than giving birth – and it never ends’.

Treatment

Interestingly, children born without a limb can also experience PLP, which suggests that the perception of our limbs is hardwired into our brain. New treatments for PLP are therefore based on a better understanding of the brain.

No single treatment has shown consistent improvement for PLP. Instead, the Australian Pain Management Association (APMA) – a non-profit organisation which gives hope, information and life skills to people with persistent pain – suggests a holistic pain-management plan,

overseen by a GP or pain specialist.

‘With good nutrition, physical therapy and treatments which incorporate the link with the brain, people with PLP can experience pain relief,’ says APMA’s CEO, Elizabeth Carrigan. ‘Even more importantly, they can regain control of their life.’

Treatments for PLP can include:

- **Medication:** Paracetamol and non-steroidal anti-inflammatory drugs, or more centrally acting medications, such as anticonvulsants or strong opioids.
- **TENS:** One man with PLP experienced itching in his amputated foot (which, interestingly, eased when he scratched where his foot used to be), because his nerves continued to carry pain signals. Transcutaneous electrical nerve stimulation (TENS) can interrupt these signals.
- **Graded motor imagery & mirror therapy:** Repetitive brain exercises can retrain the brain that the limb has healed and no longer needs to feel pain. A related treatment uses mirrors to try to trick the brain into believing that the amputated limb still exists. The person with PLP watches their reflection as they exercise their intact limb (imagining that they are observing the amputated limb), to overrule their brain into no longer sending pain signals.

‘APMA understands that pain can be isolating and frightening,’ says Ms Carrigan. ‘We encourage all people with PLP and other forms of persistent pain to call our Pain Link helpline (1300 340 357) to discuss their options.’

How to contact APMA

For more information about the Australian Pain Management Association, including community pain-support groups, visit www.painmanagement.org.au

You can join APMA’s social media communities at www.facebook.com/apma4u and www.twitter.com/yourapma

APMA’s Pain Link helpline: 1300 340 357



WACOSS HEALTH COLLABORATION PROJECT - TOWARDS BETTER HEALTH OUTCOMES

Pip Brennan

Program Co-ordinator

Western Australian Council of Social Service

The WACOSS Health Collaboration Project, which commenced in July 2013 is a formal partnership project between the WA Council of Social Service (WACOSS) representing community service sector and WA Health. The purpose of the project is to progress the Delivering Community Services in Partnership (DCSP) funding reforms specifically in the health arena. The project's overall aim is to increase positive health outcomes for West Australians.

The new DCSP reforms support community organisations to “begin with the end in mind”; to consider what community outcomes they are aiming to achieve through the service they deliver. The reforms also allow community organisations to articulate how much it costs to deliver the services, and supports better financial sustainability of community organisations to continue to carry out the valuable work that they do.

While the reforms were progressing in other arenas, it was noted that Health reform implementations were falling somewhat behind. Thus this partnership project was launched.

The first initiative of the project was to form a Sector Advisory Group (SAG) of not for profit community health providers to strengthen the collaborative relationship between the not for profit sector and WA Health. The SAG is a key strategic and operational component of the project, providing an opportunity for members to influence the effectiveness of the development and implementation of the DCSP policy in this sector.

The project will develop facilitated networking events to ensure more opportunities for community organisations and WA Health staff to get to know each other. Events will highlight and promote the importance of the not for profit sector to our community's health.

Another important purpose of the project is to develop an Outcomes Based Contracting guideline for developing outcomes for Health funded services.

Executive Director of the Health Consumers Council, Frank Prokop has recently become a member of the SAG and will now represent the Council at the monthly SAG meetings.

If you would like more information on this project please contact Pip Brennan (Program Co-ordinator) on wacosshealthcollab@wacoss.org.au or 0406 290 923



wacoss

Western Australian
Council of Social Service Inc

*Ways to make
a difference*

COELIAC AWARENESS WEEK

Since 1979, Coeliac Western Australia has provided support, information and empathy to those diagnosed with coeliac disease or medically requiring a gluten free diet. We are proud to be celebrating 35 years as the peak body for people with coeliac disease in Western Australia.

Held annually in Australia between March 13 and 20 is Coeliac Awareness Week. The 2014 campaign is asking people who are feeling “sick and tired” to consider whether it could be coeliac disease and to get tested today. For many people, tiredness is one of the key indicators of untreated coeliac disease and so we encourage people experiencing unexplained lethargy to discuss having a blood test (coeliac serology) with their GP.

Coeliac Western Australia presents the Coles Gluten Free Food and Healthy Living Expo on Saturday 15 and Sunday 16 March at the Perth Convention and Exhibition Centre. This year we are excited to announce presentations from Dr Jason Tye-Din and Kim McCosker.

- Dr Jason Tye-Din is a consultant gastroenterologist at Royal Melbourne Hospital, and also a world-recognised researcher at the Walter and Elisa Hall Institute with an interest in coeliac disease. Dr Tye-Din will be presenting four seminars covering all aspects of coeliac disease, from gastrointestinal symptoms, through diagnosis, the gluten free diet, to his current research looking at more accurate blood tests and the Nexvac2 vaccine .
- The delightful Kim McCosker, author of 4 Ingredients Gluten Free Lactose Free, is hosting two cooking shows. It's Kim's first time at our Expo and if the 4 ingredient recipes are anything to go by, attendees will be treated to some delicious dishes.
- In another first, Diabetes WA will be providing information and educating the public on all aspects of diabetes. It has long been recognised that people with type 1 diabetes have a higher risk of developing coeliac disease than those in the general population. Coeliac disease affects about 5-10 per cent of people with type 1 diabetes.¹

At the 2014 Coles Gluten Free Food and Healthy Living Expo you will be able to sample a variety of gluten free foods and buy direct from the manufacturers/ suppliers. The daily seminars and cooking shows are always informative and educational.

For further information on coeliac disease, the gluten free diet, Coeliac Awareness Week or our 2014 Coles Gluten Free Food and Healthy Living Expo contact our office on 9451 9255 or email wa@coeliac.org.au.

1. <http://www.diabetesvic.org.au/living-with-diabetes/diabetes-and-coeliac-disease>



coles
gluten free food
& healthy living
expo

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- The latest news and events happening at the Health Consumers Council

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BECOME A MEMBER

As a member of the Health Consumers' Council you will:

- Receive free Health Matters magazines and fortnightly eNews
- Be kept up to date about health issues
- Have your say on health policy as a Consumer Representative
- Work with community groups and health-related organisations
- Work to make the health system more responsive to consumers

The council has three categories of membership - Individual, Organisation and Associate. Individual membership is free. There's a small fee for Organisation and Associate membership (invoices are sent out at the beginning of the financial year).

Contact us on 9221 3422 or via info@hconc.org.au to register your interest!

CONTACT



HEALTH CONSUMERS'
COUNCIL
YOUR VOICE ON HEALTH

Health Consumers' Council

GPO Box C134

PERTH WA 6839

Phone (08) 9221 3422

Country Freecall 1800 620 780

Facsimile (08) 9221 5435

Email Info@hconc.org.au

Website

www.hconc.org.au

Facebook

www.facebook.com/hconcwa

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www.twitter.com/hconcwa

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