Health Matters

Health Consumers' Council (WA) Inc. Magazine
April 2019

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Patient Experience Week 2019

1994 - 2019
Celebrating 25 years

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Patient Experience Week 2019 Sponsors

The Health Consumers' Council would like to thank the supporters who have made Patient Experience Week 2019 possible.

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Patient Experience Week 2019

"Kindness, Connection, Community – see the Whole Person"

Djinang Kwop Wirrin

Our theme for 2019 is 'Kindness, connection, community: see the whole person' and will focus on the Aboriginal Patient Experience of the WA Health system.

Djinang Kwop Wirrin is a Noongar sentiment reflecting the PXW theme that means 'see good spirit'. This translation was made in consultation with Ralph Mogridge. Ralph is a Noongar man with ties to Bindjareb, Yued and Gnarla Karla Boordja areas of the South West of WA. He has represented his people on the State Aboriginal Justice Advisory Council as well as the Aboriginal Lands Trust.

HEALTH CONSUMERS' COUNCIL
YOUR VOICE ON HEALTH

Health Consumers' Council

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Cover image: Stock

In the print version of Health Matters December 2018, the World Kindness Day article on page 12 missed mentioning the Department of Health's Cultural Diversity Unit as a vital contributor and partner who made the event possible. The error has been corrected in the PDF version on the HCC website.

Foreword

Patient Experience Week is a chance to celebrate everyone working in health care and impacting the patient experience. This is our fourth year marking the occasion with a Patient Experience Week event and award ceremony for our Health Consumer Excellence Awards. Our theme for 2019 is "Kindness, connection, community: see the whole person".

We want to focus on the importance of linking health care with the body, the mind and the community. It's no longer enough to treat physical symptoms in isolation, what we need is care that takes into consideration all aspects of being a human.

By marking Patient Experience Week and also celebrating people in healthcare, we hope to inspire the community, acknowledge accomplishments, reenergise efforts and recognise the people who impact patient experience every day, so that we can all work together for a kinder, person-centred health system.

In this special Patient Experience Week 2019 edition of Health Matters, we look at what is in store for our Patient Experience Week events on 30th April, and hear from two of the key participants in the event. By focussing on Aboriginal culture and traditional healing methods, we aim to raise awareness of the elements that contribute to a positive experience of health and wellbeing for Aboriginal people.

Two years of patient opinion

In another exciting milestone for patient-centred care, March 2019 marked two years since Western Australia formally adopted Patient Opinion for all public hospitals. I am so thrilled to see so many people across our state using Patient Opinion to engage in honest conversation and to proactively use patient feedback to create change. Every time someone shares their experience, they are using their voice in a powerful way to drive quality improvements, promote transparency within health care, and boost morale for those working in the health system.

Staff updates

If you've called or dropped by recently, you might have noticed a few changes around the office. We said goodbye to our administration assistant Kirsten Hird, who will be writing a PhD thesis on the topic of health consumer advocacy (so we are very much looking forward to having Kirsten drop in some time to do some research!). We welcomed back Nadeen Laljee-Curran into the administration assistant role after maternity leave, and also welcome Sam Smith who is working in our advocacy team on a two-month student placement. Kieran Bindahneem, who has been volunteering with us in the engagement team for a couple of months, will now be working with us as a project coordinator, and Natasha De Souza has joined the engagement team for a consumer engagement project.

Pip Brennan
Executive Director
Health Consumers' Council

Patient Experience Week 2019

Kindness, connection, community: see the whole person

IMAGE: Brian Ocean Ward "Oceans Image"

HEALTH CONSUMERS' COUNCIL
YOUR VOICE ON HEALTH

Patient Experience Week 2019

"Kindness, Connection, Community – see the Whole Person"

Book Now

Tuesday 30th April 2019

Aboriginal Patient Experience Gathering
10am – 4pm

- Health and well-being from Aboriginal perspectives
- Whispering Wall - people will be encouraged to share their aspirations for Aboriginal health
- Stories of healing – stories from community members and health professionals on the partnerships that have contributed to healing for individuals and communities
- World café approach – "see for yourself"
- Traditional Aboriginal Healers and Bush Medicine
- The importance of a good laugh – Noongar Clown Doctor will remind us all how important it is to our wellbeing to laugh

https://www.eventbrite.com.au/e/pxw-2019-registration-56959267703

Health Consumers Excellence Awards:
4.30pm – 6.30pm

https://www.eventbrite.com.au/e/health-consumer-excellence-awards-2019-tickets-55392487421

Venue: Pelican Point Sea Scouts Club,
12 Australia II Drive, CRAWLEY WA 6009

In 2019, we are focusing on the holistic nature of health for Aboriginal people, including emotional and spiritual aspects as well as physical wellbeing.

At our Patient Experience Week celebration on Tuesday 30 April, we will create an opportunity for Aboriginal health consumers and carers to share their stories and experiences in a collaborative setting, alongside staff from across the health system, to drive systemic change. With a focus on Aboriginal culture and traditional healing methods, HCC aims to raise awareness of the elements that contribute to a positive experience of health and healthcare for Aboriginal people.

Through the activities of Patient Experience Week 2019, participants will learn more about and discuss how aspects relating to emotional, social, spiritual and physical well-being interact and contribute to a positive patient experience and health outcomes for all people.

The event will provide opportunities to develop connections and relationships with individuals, groups and organisations who support the vision of an equitable, integrated, person-centred health system, and strengthen connections to other people, nature and spirit in an environment of collaboration, community and celebration.

Patient Experience Week is an annual event celebrating healthcare staff who have a positive impact on patient experience everyday. An initiative of the Beryl Institute, Patient Experience Week provides a focused time for organisations to celebrate accomplishments, reenergise efforts and honour the people who impact patient experience everyday. At HCC, we have been celebrating PXW since 2016, and we make sure this is a time to also recognise the consumers who share their time and experiences to contribute towards a better patient experience.

Through this event, we hope WA health consumers will be encouraged to spread the word about what contributes to a positive patient experience with their families, friends and colleagues to extend the impact of the event beyond event participants.

We are passionate about partnering with health services to create positive change. We know that the only way forward to achieve the health system we all want, is to work together – which is why we announce the winners of our Health Consumer Excellence Awards as part of Patient Experience Week.

Patient Experience Week 2019

"Kindness, Connection, Community – see the Whole Person"

Djinang Kwop Wirrin

Dr Richard Walley

Richard is one of Australia's leading Aboriginal performers and writers. His life has been incredibly diverse and full of achievements.

Richard became involved with Aboriginal politics at an early age, having active involvement in the formation and operation of the Aboriginal Housing Board, the Aboriginal Medical Service, Legal Service and the New Era Aboriginal Fellowship.

Through his involvement, Richard first became aware of the potential of Aboriginal culture to give the Nyoongar people a sense of pride and identity. This awareness grew throughout the years, as Richard 'learned' about his own culture, moving into the world of Theatre and the Arts.

Richard will be performing the Welcome to Country ceremony at our Patient Experience Week event.

Program highlights

Whispering wall

People will be encouraged to capture their aspirations and visions for Aboriginal patient experience. This will be shared widely across the health system after the event through formal and informal communications.

Stories of healing

Hear stories from community members and health professionals on the partnerships that have contributed to healing for individuals and communities. Learn more about how emotional, social, spiritual and physical wellbeing contribute to a positive patient experience and health outcome for Aboriginal people.

Flavours of bushfood

Catering will be provided by Bindi Bindi Dreaming, a 100 per cent Aboriginal owned and operated business with skills in didge and dance, cultural tour guiding, catering with bush flavours, and exceptional knowledge of Noongar Country and its people. They will deliver a bushfood talk and explore the links between native plants and healing.

Yarning Circles

An opportunity for small group discussions with community members and healthcare staff who are involved in a range of programs aimed at improving patient experience and outcomes.

Traditional Aboriginal Healers/ Clown Doctor

This group activity will allow participants to strengthen their connection to other people, nature and spirit in an environment of collaboration, community and celebration. Hear from Noongar comedian, performer, cultural guide, actor and writer Derek Nannup, who will talk about the importance of laughter for wellbeing.

Health Consumer Excellence Awards

The day will conclude with the announcement of the winners of the Health Consumer Excellence Awards.

Clown Doctor & Bush Food

Exploring culture and connection through food and laughter

On Tuesday 30 April, Health Consumers' Council will celebrate Patient Experience Week with an Aboriginal Patient Experience Gathering, looking at health and wellbeing from Aboriginal perspectives.

This free community day will be a chance to form connections with people, nature and spirit. As well as a celebration of the people having a positive impact on health, it will be a chance to expand our knowledge of Noongar history and culture. We believe that a better understanding of Aboriginal and Torres Strait Islander cultures helps to develop respect and increase appreciation of our country's cultural heritage, for all Australians.

Derek Nannup

Laughter is the best medicine

We are excited to have Noongar comedian, performer, cultural guide, actor and writer Derek Nannup join us on the day, to remind us how important a good laugh is to our wellbeing.

For people of all ages and ethnicities, the therapeutic benefits of laughter are well known. Sharing a smile and having a laugh together not only connects people and develops a sense of community, it can also reduce stress and anxiety, relieve tension, and help boost the immune system.

In hospitals and care facilities, for people of all ages, a clown doctor with a magical sense of humour, a bag of tricks and the ability to get a good giggle can have a huge impact on patients and their families, bringing peace of mind and replacing uncomfortable tests and procedures with fabulous and funny entertainment.

Mr Nannup is known for his sense of humour and loves to share laughter among communities. He visits children in WA hospitals to help spread cheer with what has been called 'distraction therapy', and his ability to take them out of the moment and into a more wonderful world is an incredible gift.

"As the Eco Education Worker for Yanchep National Park for the Department of Biodiversity, Conservations and Attractions, my role is to run Cultural, Eco and Environmental programs for the wider community," Mr Nannup said.

"As my background is clowning, circus and theatre as well as a Cultural didgeridoo player and dancer, I believe that humour can help me deliver these programs in a safe, interactive and fun environment.

"When a child is passionate about something or enjoys what they are doing, they absorb that knowledge and take it to their heart. Humour brings out that joy."

A vibrant food culture

There's a strong connection between culture and food, and it's one of the most delicious ways to bring people together.

We're looking forward to having Bindi Bindi Dreaming join us at our Patient Experience Week event. They're a 100 per cent Aboriginal owned and operated business with skills in didge and dance, cultural tour guiding, catering with bush flavours, and exceptional knowledge of Noongar Country and its people.

Bindi Bindi Dreaming

Marissa Verma

> “For too long a time, Aboriginal people have been disconnected from the lands and waters. It’s vital that we, as the first Australians, share and teach our cultural knowledge of such an enriching culture that has existed since before recorded history. We now need to reconnect to all become caretakers.”

Binding Bindi Dreaming - dark chocolate strawberries with rivermint

Bindi Bindi Dreaming will not only be providing catering they will be talking about bush foods, native plants, and their links to health and healing.

“For too long a time, Aboriginal people have been disconnected from the lands and waters. It’s vital that we, as the first Australians, share and teach our cultural knowledge of such an enriching culture that has existed since before recorded history. We now need to reconnect to all become caretakers,” Marissa Verma of Bindi Bindi Dreaming said.

“We connected to the land and animals for our foods, health and healing for generations. Today, we have the opportunity to continue sharing our knowledge, so we can ensure the planet is well looked after today and into the future.”

Australia is home to thousands of edible native plants species, but their usage has largely fallen by the wayside. This will be a chance to learn more about ingredients like finger lime, Davidson plum, lemon myrtle, mountain pepper, saltbush and sandalwood nuts, and explore how to incorporate them in your own cooking.

“Noongar people are well connected to the land. We are a hunter and gatherer society and these traditions are still continuing today. Such things as hunting kangaroos, emus, fishing, gathering nuts and berries for food are still part of cultural traditions,” Ms Verma said.

Bindi Bindi Dreaming recognises cultural difference and aims to deliver cross-cultural interaction.
By sharing a love of the food that has sustained traditional Australians for centuries, they can connect with different people culturally and share knowledge of Noongar history.

A Call For Extra Care

Things don't change unless people make noise

In 2017, Manuela was 39 weeks pregnant when her little girl, Cielo, was stillborn. She was the second child for Manuela and her partner.

After waking up one morning and noticing she couldn't feel the baby move, Manuela had a scan which confirmed Cielo no longer had a heartbeat.

"From then on, it was a total nightmare. We said goodbye to her, to our lives, to so many, many things," Manuela said.

After a routine investigation to try to work out the cause of Cielo's passing, Manuela was told the most likely reason was acute foetal-maternal haemorrhage, which occurs when foetal blood cells are lost into the maternal circulation. But when she pushed for further information about why this might have happened, Manuela was told that it was going to be marked as an 'unexplained' stillbirth.

"There was our life before Cielo, and life after. Nothing's the same. Nothing. Your relationship with people changes, so we lost friends. In my view I cope better with new people that didn't know me before, because that Manuela there doesn't exist anymore. Even when I look at photos of me with my son, it's not the same – it's a different mum and it's a different kid. Everything is different."

Two years on, Manuela is still searching for answers about where things went wrong.

"At my 20 weeks scan everything was fine, baby was growing nicely and no problems whatsoever. Morning sickness was gone by then and I was feeling back to normal, pregnancy progressing the ways it's supposed to.

"But at 33 weeks they measured my belly size and the midwife had to ask for a second opinion because my belly was too small for the gestational weeks I was in. I didn't really know what that meant so I tried to get a bit more information about it. They recommended we have a growth scan as soon as possible and come back with the results, so we did that a few days later.

"During the scan we were told the baby was fine, Cielo was not small, she was only in the 55th percentile weighing about 2.4kg, so she was all good for the gestational weeks she was in. They said she won't be born a big baby, but she's not small."

It was only after a later miscarriage and a visit to a specialist doctor that Manuela began to realise there was more going on. At an appointment with the specialist, Manuela was told that her placenta had been small, and this could have contributed to her baby being stillborn. She also discovered that while her baby had been in the 55th percentile for weight at the growth scan, no one had told her that the same scan showed that Cielo had low amniotic fluid – in fact, she was in the 5th percentile for amniotic fluid.

Manuela felt that a follow up appointment and scan at the time this was discovered could have changed the outcome of her pregnancy.

"She died six weeks later. They didn't say anything about her being in the 5th percentile for amniotic fluid, just that baby was small but fine."

"I wanted to push it further, to find out more, but I had to leave it because I couldn't find support anywhere. I didn't know where to start. So I left it there but it was still at the back of my mind, I need to do something, I need to find an answer, I need to speak to someone about this."

That's when Manuela reached out to Health Consumers' Council, and Advocacy Manager Carly took on her case.

"I thought, I don't have anything to lose. I already lost what I had to lose," Manuela said.

With Carly's help, Manuela was able to request a meeting with management at the hospital to try to get some answers. They put together a list of questions, and after the meeting Manuela decided to progress things with a lawyer.

"So my baby didn't grow, there was a growth restriction in the 6 weeks between the scan and her death that they didn't pick up.

"The problem was the miscommunication between the hospital and me, because I was never really told she was in the 5th percentile of amniotic fluid, they never mentioned to me that my belly never went back to the size it was meant to be, so when it was measuring small at 33 weeks that scan looked OK, nothing else happened later. She never grew again, she never put weight on, so her weight went down from 55th percentile at 33 weeks to 15th percentile at birth. But nobody checked again.

"I still believe that Cielo could have been saved, easily. Just had one an extra scan at some time. But it didn't happen and we all know the outcome."

The specialist Manuela had been seeing made her aware of a different protocol that could have been used during her pregnancy. The Jason Gardosi growth chart allows for a customised assessment of growth and birthweight from many different perspectives. In the UK, it has been associated with a significant reduction in stillbirth rates. While used at some hospitals, this protocol was not used during Manuela's pregnancy.

The recent *Informing Stillbirth National Action Plan version 7, January 2019* notes that "Stillbirth is too common – 6 Australian babies are stillborn each day. Stillbirth is a serious public health problem with far reaching psychosocial and financial burden for families. There has been little improvement in rates for over two decades, and in Australia it is 35% higher than top performing countries globally".

Health Consumers' Council Executive Director Pip Brennan noted that she simply cannot understand why a change in clinical practice, i.e. use of the Jason Gardosi growth charts, is not standard across all hospitals.

"We need these growth charts implemented at all hospitals. How many more babies have to die before something changes? These babies are unique individuals. It's unacceptable to say to mothers 'you can have another baby'. You can never have that baby again. These are literally preventable deaths."

After having been through this experience, Manuela's advice to other women is to find a second opinion if you are worried or something doesn't seem right.

She hopes that by sharing her story, and working with Health Consumers' Council to implement change around growth charts, a little extra care can be shown in health care.

"I hope they pay more attention. That someone raises an alarm. Extra care, a bit more communication. If I knew so many things that I knew now, I would have done everything differently.

> "Thing don't change unless people make noise. I want women to know about this different protocol that is saving lives. I need to stop what happened to us happening again.

"Unfortunately our account can't be changed, and our lives have been destroyed and Cielo's life has been destroyed the most, but if I can avoid this happening again to other families I would do it with all I can. So it's for her, I have to do it."

Support to Live

Advocating AGAINST voluntary assisted dying

Samantha Connor, Disability and Human Rights Activist

Many terminally ill and disabled people oppose voluntary assisted dying on the basis that people should be assisted to live before they're assisted to die.

Samantha Connor is a disability and human rights activist, wheelchair user, and writer who believes the campaign for voluntary assisted dying bypasses the failures in care and services provided to disabled people to support them in living an ordinary life.

> “PEOPLE SHOULD BE ASSISTED TO LIVE
>
> **BEFORE THEY'RE ASSISTED TO DIE**”

For vulnerable people already facing significant financial, social and emotional pressures, there's a risk that legalising suicide will encroach on their rights, especially for those who may face mental health challenges.

It raises the question of why campaigners are trying to push through legalisation giving people the choice to die, when so little has been done to fix the barriers that often prevent people with disabilities from living well.

“It's not possible to explain that the concept of ‘intolerable suffering' [also referred to as ‘grievous suffering'] in the camapign is flawed, because half of us live in poverty, are victims of abuse, have no access to care and support – our ‘intolerable suffering' comes often not from our disabilities but from external sources.

“Daily discrimination impacts upon our lives and often causes our deaths. Most of us experience poor mental health as a consequence of marginalisation.

“Most of all, it is hard to explain how we are devalued and treated as ‘less than'. And as an activist who fights against violence, abuse and neglect of disabled people, I have hundreds of examples where disabled people have been murdered, where their perpetrators have walked free, sometimes into paid interviews. Where our deaths have been described as mercy killings and our lives have been described as ‘burdensome'.

“We live in crisis and people are afraid of disability. They think we are better off dead, that disability is a fate worse than death. We carefully explain the issues and tell our awful stories and watch them struggle to understand.

“We point out that being given the right to die before being given the supports and right to live a good life is not really a choice.”

Ms Connor makes it clear that “disability and assisted suicide are ill-suited, and disability is not being adequately considered in WA's campaigns for legislation change”.

“As assisted suicide continues to be debated, the concerns of the disabled community must be addressed by the State Government before an eventual conclusion that the legislation is both dangerous and inappropriate.”

Ms Connor, like many other advocates in this space, doesn't know what will happen from here. But she urges legislators and campaigners to put their own personal bias aside to look at the facts of what changes in legislation would really mean for people with disabilities.

> “Laws are made to keep people safe. If you want to make laws that affect disabled people, make laws to help us live – to help us be contributing and productive citizens of this country who can live on the same basis as other Australians.”

End of Life Choices

Advocating FOR voluntary assisted dying

Stephen Walker, Dying with Dignity Western Australia

Dying with Dignity Western Australia (DWDWA) is a charitable organisation that has been well established in the community since the early 1980s, and now has more than 600 members. We work to de-mystify death by getting people to talk about end of life choices. We urge people to sign advance health directives to ensure that those choices are known to their families and medical professionals. Importantly, we also strongly support high quality palliative care – but where not even the best palliative care is enough to alleviate a person's suffering at the end of life, we advocate for access to voluntary assisted dying.

In 2019 this will be our prime focus: a campaign for voluntary assisted dying to be legalised in WA. DWDWA supports the recommendations of the cross-party Joint Parliamentary Committee handed down in August 2018 in its report entitled My Life, My Choice after a year of deliberations. A Ministerial Expert Panel under the chairmanship of Malcolm McCusker QC has been appointed to advise on the content of a bill to implement the recommendations for a law to permit voluntary assisted dying. We expect that bill to be tabled and debated in Parliament before the end of the year.

The report recommends strong safeguards for the protection of the person seeking access to assisted dying and for the health professionals involved in the process. For those who are interested, the full report can be found at https://bit.ly/2OZdZ6Z . The framework for the legislation begins at page 225.

To summarise briefly, to be eligible for assisted dying a person must be 18 years or older and have decision-making capacity. The request must be voluntary and must be made without coercion or duress. The person must also be suffering from an advanced and progressive terminal, chronic or neurodegenerative condition that is causing irremediable and grievous suffering that cannot be alleviated in a manner acceptable to the person, and which is expected to cause death within the foreseeable future. Two independent doctors must assess the person to confirm that all these criteria have been satisfied.

We emphasise that this will truly be a choice, freely made.

A person who satisfies all the criteria will be prescribed a drug that may be used at a time of that person's choosing. If the person is or becomes unable to administer the drug, the help of a doctor may be sought.

According to the latest Roy Morgan poll conducted in November 2017, the legalisation of voluntary assisted dying is supported by an overwhelming 88 per cent of Western Australians. This majority will need to persuade the members of parliament to vote in favour of this change.

In the international jurisdictions where voluntary assisted dying legislation has been introduced there is no evidence that the laws have been abused: that elderly or other vulnerable people have been coerced into ending their lives prematurely or that somehow human life has been devalued by having the right to choose a peaceful death within the safeguards prescribed by law. Abuse and suffering in fact already exist in our society, covert and unregulated. Under the protection of the law people will no longer be driven to end their suffering by taking their own lives – often alone so as not to implicate others – or by refusing treatment and sustenance.

The argument is often made that improved palliative care will render voluntary assisted dying unnecessary, but the two go hand in hand. The ability to choose assisted dying will be available only to those who satisfy the stringent criteria of the law, whose "grievous and irremediable" suffering cannot be alleviated by palliative care.

We believe that the time for this change has come. The proposed law will be both rigorous in its safeguards and compassionate in respecting the choice of people who wish to end their suffering. It will strike the appropriate balance between autonomy, dignity and compassion, on the one hand, and protection of the rights of vulnerable people on the other. It supports life, and respect for life, in all its aspects.

You can find out more about Dying with Dignity at https://dwdwa.org.au and join their campaign by clicking the sign-up button.

Resources for Palliative Care

A revised edition of the highly popular Palliative Caring booklet is now available.

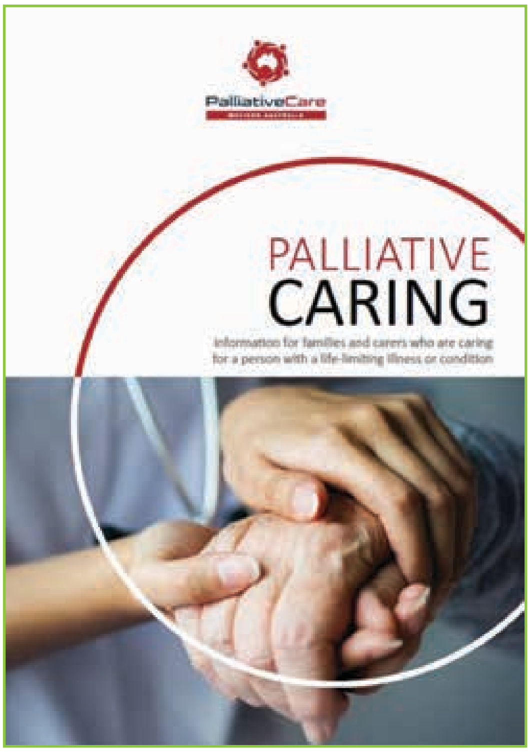
This is a WA specific resource that has been written to support families and carers as they negotiate the often-uncharted waters of caring for a loved one with a life limiting illness.

This booklet is split into sections covering a variety of topics to support and guide people as they care for a loved one. The topics cover all aspect of the palliative caring journey and include planning and decision-making; the role of a carer; providing care; medicine safety; respite; and death and bereavement.

The booklet also includes useful website links and contacts to other organisations that can provide support to families and carers.

This review has been the most extensive since the booklet's first release fifteen years ago, using the experience and expertise of members of a working group drawn from across the palliative care sector.

Tish Morrison, Director of Clinical Operations, Palliative Care at Silver Chain said “transitioning to palliative care can be a difficult time for most people and their loved ones. It is a time when a new team is introduced to your care and there are many new decisions to be made. This booklet provides a compassionate and comprehensive guide to managing this time”.



Thanks to the generous support of organisations within the sector this publication is free and available as a hard copy booklet or can be downloaded in PDF format from the Palliative Care WA website.

To receive a free copy of the book contact info@palliativecarewa.asn.au, telephone 1300 551 704 or download at www.palliativecarewa.asn.au. Note that postage costs may apply for bulk orders.

Considering the whole person

The unique role of palliative care

Lauren Miller-Lewis, PhD. College of Nursing and Health Sciences, Flinders University

Palliative care is a form of healthcare that is often misunderstood as only being about the last days of life – but palliative care is really about maximising quality-of-life and helping a person with life-limiting illness live fully, right to the end-of-life. Palliative care can start early, occurring alongside other treatments for serious illness, and provides compassionate support not just for the patient, but also for their family and carers.

A special aspect of palliative care is that the focus is not just on the patient's diagnosis and physical symptoms. Care and attention are also paid to the psychological, social, cultural and spiritual needs of patients and their loved-ones. Palliative care considers the whole person and all aspects of their life, including their relationships, values, and wishes regarding the type of care they would like. The palliative care support provided is tailored to meet the individual needs of the patient and their family, and what matters most to them. Person-centred care is one of the defining characteristics of palliative care, and to achieve person-centred care, understanding the patient experience is essential.

> Palliative care is really about maximising quality-of-life and helping a person with life-limiting illness live fully, right to the end-of-life.

CareSearch palliative care knowledge network focuses on a key element of the patient experience – easy access to reliable information. Funded by the Australian Government Department of Health and delivered by Flinders University, CareSearch provides trustworthy information about palliative care for patients, carers and families as well as for the health professionals providing their care. All resources are available online free-of-charge and are based on the best palliative care evidence and checked for quality by Australian health professionals.

Listening to the voices of patients, carers, and families is important to CareSearch, so CareSearch is engaging directly with consumer representatives through an Engagement Project to learn about the patient and carer experience. A better understanding of the patient experience is helping to ensure the CareSearch website content is relevant to consumer needs.

Health consumers are now playing an increasingly important role in directing decisions about their own health care. This makes having access to reliable information even more important. When a person is faced with serious illness, having access to trustworthy information can help them prepare for the future. Information about health services and options can reduce fears and help them feel more comfortable making decisions when facing the end-of-life.

You can find out more at www.caresearch.com.au

Unfinished Business

National Mesh Implant Forum

On 5 April, the Health Issues Centre and Health Consumers NSW, Health Consumers Queensland, Health Consumers' Council (WA), Health Consumers Alliance of South Australia, Health Care Consumers' Association (ACT), and Health Consumers Tasmania convened a forum entitled Unfinished Business – National Mesh Implant Forum.

This forum was the culmination of many months work, and we would like to acknowledge the support of the state health departments across Australia who each donated funds to convene the forum and support consumers to attend.

> Senate Inquiry Chair Rachel Siewert attended virtually, and was in tears as she recalled the experience of listening to the women's stories.

The Forum title references the 2017-18 Senate Inquiry into "the number of women who have had transvaginal mesh and other matters". The recommendations were largely endorsed, but some are the responsibility of state governments, while others are the remit of the federal government to enact. In addition, Victoria had undertaken consumer surveys regarding people injured by hernia mesh, and in a matter of weeks amassed more responses than the Therapeutic Goods Administration (TGA) had in several decades.

Senate Inquiry Chair Rachel Siewert attended virtually, and was in tears as she recalled the experience of listening to the women's stories.

> One attendee noted that statistics quoted about the safety of mesh devices cannot be relied on as many woman do not know they have mesh implants or may not be aware that their symptoms are due to having mesh implants.

The TGA sent three staff to the forum, including Professor John Skerritt. Professor Skerritt launched the National Implant Action Plan the day before the Forum. He spoke to the plan fter a powerful and moving collection of consumer and carer videos about the personal impacts of pelvic and hernia mesh. His attention to his phone while the videos were playing attracted negative media attention and was attributed to the claims on his attention of concurrently occurring budget estimates.

Tracey Duffy (TGA), Anne Duggan (Australian Commission on Safety and Quality in Health Care), Joanne McCarthy (Fairfax Media Journalist), Dr George Angus (Specialist Obstetrician and Gynaecologist), and Danny Vadasz (Health Issues Centre Victoria) held an interactive panel discussion which noted that the Health Issues Centre was able to find more hernia mesh injured consumers that the TGA because they were actively looking for them.

Dr Angus was one of very few medical professionals who attended the forum in person. He has never used mesh, but shared memories of the wooing done by medical device companies in the early days of its uptake. He talked about there now being a deeply held belief system among his colleagues, that they were doing the right thing by patients when using mesh implants, and he noted the difficulty in changing these deeply held beliefs.

One attendee noted that statistics quoted about the safety of mesh devices cannot be relied on as many woman a) do not know they have mesh implants and b) may not be aware that their symptoms are due to having mesh implants. A retrospective audit into the number of women who have had mesh implants is yet to occur on the scale required. As a nation, we need to actively go looking for these people through an audit.

Key concerns raised by consumers were for access to full mesh removal services that could be trusted, and for the care required even after the mesh is fully removed.

Technology was not kind on the day and many of the questions submitted using Sli-do were not able to be addressed. The issue of Aboriginal and Torres Strait Islander women who may have had mesh implanted is still outstanding.

The afternoon saw three concurrent workshops. One was filmed and aimed to develop a Score Card for each state on how their mesh clinics are measuring up across the nation.

State Report Card - Mesh Clinics

How does yours rate?

- Consumer-led, meaningful co-design at all levels ☐
- Person-centred care ☐
- Multi-disciplinary team ☐
- Evidence-based policies and guidelines ☐
- Published clinician/ clinic data ☐
- Trauma informed ☐
- Peer support ☐
- Peer Workforce ☐
- Community-based access (telehealth, community pharmacy, satellite clinics ☐
- Social work linkages with disability support, income support, NDIS, home help and aids ☐
- Social work support for partners and families ☐
- Integrated with primary health carer (on-going referral, education, support) ☐
- Information and communication of service – social media, caravans ☐
- Measurable – retrospective and prospective ☐
- Data and PROMS ☐

MBS Review

Calling on Nurse Practitioners

MBS Review recommends growth in the profession

Nurse practitioners are registered nurses with the experience and expertise to diagnose and treat people of all ages with a variety of acute or chronic health conditions.

Registered with the Australian Health Practitioner Regulation Authority and educated at master's level, Nurse Practitioners are focused on improving access to treatment, providing efficient, cost-effective care, and improving health outcomes of all Australians, particularly those designated as at-risk populations, such as aged care, indigenous populations and general primary health care in remote and rural and regional areas.

In February, the Nurse Practitioner Reference Group (NPRG) released their MBS Review Taskforce Report with 154 detailed recommendations. These recommendations push for growth of the nurse practitioner profession, and have been extensively researched and considered to reflect the high standard of Nurse Practitioner care in Australia.

The recommendations focus on these key areas:

- Enabling greater access for patients to subsidised diagnostics
- Enabling access for patients to preventative care and early intervention through MBS care plans and longer consultations
- Removal of artificial barriers to practice, which limit access to Nurse Practitioners services including the collaborative arrangements and improving NP role sustainability
- Enabling patients to access rebates for procedures provided by Nurse Practitioners
- Improving access to services for vulnerable patients
- Improving the ability of Nurse Practitioners to work to their full scope of practice, especially in areas of Australia where communities have poor, or reduced access to health services, including significant improvements to Telehealth arrangements

The Australian College of Nurse Practitioners (ACNP) is the peak body for NPs nationally with more than 1200 NPs and Advanced Practice Nurses across the country, including rural and remote areas of Australia.

"The ACNP supports and advocates for timely and appropriate health care for all Australians. The report from the NPRG represents the opportunity to significantly improve the health of our community, and increase access to quality healthcare for all Australians."

ACNP President Leanne Boase said.

The ACNP believed the changes outlined within the 14 recommendations would lead to significant growth in Nurse Practitioner numbers in Australia, especially in areas of need, and a more sustainable workforce.

Ms Boase called on the ACNP's health professional colleagues and the Australian community to support these recommendations, in the interests of better health and access to care.

The report will be considered by the MBS Taskforce and released for stakeholder consultation, following which the Taskforce will make recommendations to the Minister.

What is the MBS Review?

The Medicare Benefits Schedule (MBS) is a list of the Medicare services subsidised by the Australian government.

In 2015, the MBS Review Taskforce was established to consider how the more than 5700 items on the Medicare Benefits Schedule can be aligned with contemporary clinical evidence and practice and improve health outcomes for patients.

The taskforce has, to date, delivered reports and recommendations on a wide range of procedures, treatments and care including general practitioners, pathology, plastic and reconstructive surgery, colorectal surgery, optometry, pain management, anaesthesia, diagnostic imaging, intensive care and emergency medicine, gastroenterology, obstetrics, renal medicine, gynaecology, urology, and urgent after-hours care.

Endometriosis Treatment

MBS Review recommendations to increase costs

In the lead up to the March endometriosis awareness month, women's health advocates expressed concerns around MBS Review Taskforce recommendations that looked set to drive up the out-of-pocket costs for endometriosis surgery and associated treatments.

Endometriosis occurs when tissue similar to the lining of the uterus grows elsewhere in the body.

It affects 1 in 10 women worldwide, but is still a largely unknown disease that takes, on average, between 7 to 12 years to diagnose.

In this time, the costs of treatments and tests quickly mounts up, resulting in huge out of pocket expenses.

With the release of the Taskforce's recommendations for gynaecology, there are concerns that these costs are only going to go up.

"The out-of-pocket costs for women with endo are already huge," EndoActive co-founder Lesley Freedman told the *Sydney Morning Herald* and *The Age*.

Gynaecologist Stephen Lane, president of the National Association of Specialist Obstetricians and Gynaecologists, shared concerns that the committee's recommendations would drive up costs for laparoscopy, a keyhole surgical procedure used to diagnose and treat endometriosis.

Dr Lane said that if accepted, the proposed changes would increase gap fees by up to 20 per cent, increasing out of pocket expense by up to $400 per procedure.

Just last year, Health Minister Greg Hunt unveiled a National Endometriosis Action Plan – the first ever blueprint seeking to improve the treatment, understanding and awareness of an often misunderstood and crippling condition.

The plan was developed with medical specialists, endometriosis advocacy groups, women with endometriosis and their families, clinicians, researchers and parliamentarians.

In launching the action plan, Minister Hunt noted that even though it was just the beginning of this journey, the plan — which outlines a comprehensive five-year strategy — was a significant step forward for sufferers.

While the gynaecology taskforce has closed for consultation, consumers are able to provide feedback on any aspect of the MBS Review to MBSReviews@health.gov.au

Dancing Robots

Frank Smith

Encouraging aged care exercise

Frank Smith, Journalist

Small, cute robots appeal to many older people. They provide many of the benefits of pet animals without needing the same amount of care. And they can be switched off at will.

Coleen Wright runs Robot Buddy, a business that takes dancing robots into residential care homes to entertain and equally important to encourage residents to take some exercise by dancing and singing along with the robots.

"Our goal was to develop an Australian low cost, easy-to-use robotics therapy for aged care and dementia patients," she said.

"In the last six months we have conducted over 40 sessions in aged care facilities across Perth with a great response.

"Typically a session involves up to 30 residents. We bring along three or more robots who are pre-programmed with appropriate music and dance sequences for maximum engagement and set them up in a common area."

Ms Wright plays popular songs of the 1960s and 1970s, and she and the robots dance in time to the tunes. Residents are encouraged to join in both by singing along and by moving whatever part of their bodies works best in time with the music.

Ms Wright said Robot Buddy was suitable for all aged people with or without dementia. In a performance at Rise Network aged care residence in Mount Richon, Aboriginal residents showed a real interest in participating with the robots, facilitating good interactions between different cultures.

"Most residents get involved with the performance and dementia patients in particular respond positively in ways that carers rarely see.

"Our sessions show that residents benefit from this type of therapy, as those who are normally unable to communicate engage with our robots, mimic movements, sing along to songs and increase social engagement.

"This activity improves the quality of life of the residents, as they are exercising and often reminisce about cherished memories.

"Our therapy also benefits carers by easing the burden of care, assisting with social interactions, general entertainment and allowing more one-on-one time with each patient," she said.

One of Robot Buddy's co-founders has a family member who is living with dementia. This was a key motivation for the family to look for ways to bring some joy into their life.

Ms Wright first sourced over 20 robots from many different countries and tested these for hundreds of hours for durability, reliability, suitability and ease-of-use. She also visited an international robotics expo in Japan in November 2017 to see the latest trends in robotics and aged care.

"We update content on a regular basis to provide new and stimulating therapy for patients and we handle all technical support to further assist staff in aged care facilities.

"We are continually working to improve our robots and in conjunction with a robotics PhD student from the University of WA. We are further developing our own software system and will begin testing these with aged care residents in the next 12 months," she said.

Ms Wright has carried out no formal evaluation of Robot Buddy, however research studies of similar robot-senior interactions carried out by University of Sydney scientists have been extremely positive.

"I just see people enjoying themselves, talking, moving, sometimes getting up and dancing and recalling something from their past," she said.

Private Health Insurance

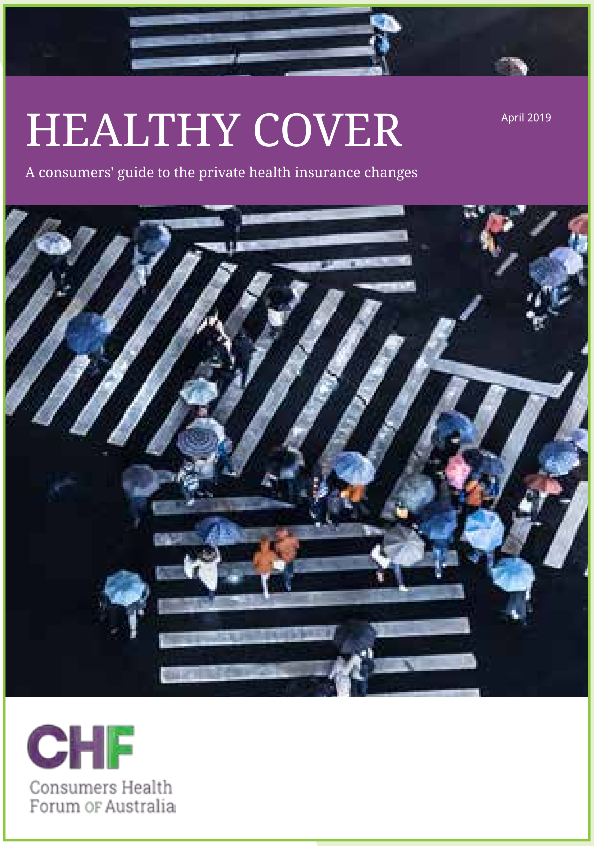
An overview of the extensive changes

On 1st April, private health insurance began its most extensive changes in recent years, designed to make private health insurance easier to navigate.

Whether you already have health insurance, or are looking at taking up a policy, it is important to make sure you are getting the most out of your health insurance arrangements.

The Consumers Health Forum of Australia has put together a guide providing an easy-to-understand overview of the changes and point you to more detailed information. You can view Heathy Cover at https://chf.org.au/sites/default/files/healthy_cover_final.pdf

The main change is that health funds will be required to classify their private hospital cover into four specified tiers: Gold, Silver, Bronze and Basic.



HEALTHY COVER

April 2019

A consumers' guide to the private health insurance changes

CHF
Consumers Health
Forum OF Australia

Funds will also be able to offer limited additional cover above minimum requirements for each of the three lower tiers with products labelled Silver Plus, Bronze Plus and Basic Plus.

“With Basic cover, your policy would be required to offer minimal restricted or limited cover for just three categories of hospital treatment: rehabilitation, hospital psychiatric services and palliative care,” Healthy Cover states.

“At the other end of the scale, with Gold cover, the funds must provide cover for about 40 categories of hospital treatment, ranging from brain and cardiac surgery to child birth and joint replacements.

“In between Basic and Gold levels, the Bronze and Silver tiers offer varying levels of minimum required cover with the option to include treatments from higher tiers via the Plus options.

“There are a range of other aspects you may need to consider in working out whether or what sort of health insurance cover you require, including the rebates which vary with age and income, aged-based discounts for joiners, and penalties for those joining who are over thirty, and the Medicare Levy Surcharge which applies to people on higher incomes.”

The Government has also announced several additional measures to encourage funds to provide more flexibility and more comprehensive cover. These include adding more choices for excess levels for singles, couples and families; excluding some natural therapy rebates (although the Government has recently announced they will reassess this); offering a discount on private hospital premiums to young people aged 18 to 29; and enabling health funds to offer travel and accommodation benefits to regional and rural consumers under hospital cover.

We encourage you to take a look at the Consumers Health Forum of Australia guide, and call your private health insurance fund to find out how these changes will affect you.

Leading the Health Consumers' Council

1994 - 2019
Celebrating 25 years

In 2019, Health Consumers' Council celebrates its 25th Anniversary. In recognition of this milestone, our current Executive Director Pip Brennan spoke to Michele Kosky, who was Executive Director from 1994 to 2012, about the early days and successes of HCC.

Why was the time right in WA in 1994 to establish HCC?
Prior to 1994, the WA Government had convened a provider group and a consumer group to give advice directly to the Minister. In 1994 the consumer group members, including Mitch Messer and Ann White, convinced the Commissioner for Health to establish HCC as an independent not for profit.

Why did you take on the role of Executive Director? What was the potential you could see?
I had finished at the AIDS Council after seven years there, I saw the job, applied for it and was successful, which was really exciting for me. I wanted to help people directly, so we brainstormed what our mission would be.

To this day, HCC is the only health consumers' council in the nation with an individual advocacy service. How did you manage to achieve this?
After brainstorming our mission with staff and Board we agreed on three key areas:

1. Policy influence
2. Direct individual advocacy
3. Getting the consumer voice right across the system at every level

The Health Department, to their credit, saw the Health Consumers' Council brought important intelligence about what was happening in the hospital and health system that they didn't have access to.

This model of service has actually changed very little since then, it has stood the test of time.

Maxine Drake worked at HCC almost as long as you. What was it like working with Maxine?
Maxine did a fantastic job on growing advocacy. She was full of excitement and energy, wanting to help people. She was a strategic thinker and developed a course to help people become effective consumers. She also developed the Aboriginal Consumer Participation Project to ensure patient complaints were listened to and led to a change in the service delivery.

Rosemary Caithness was a key figure at HCC from 2001 onwards. What can you tell us about working with Rosemary?
Rosemary Caithness was amazing. She was a Chartered Accountant and was incredibly efficient. She did the payroll, she managed the financial side of everything, grants, and assisted people who came for work experience. She was so generous, and so hard working, she was an absolute joy to work with.

When Rosemary died in 2013 it gave me pause to think about how important work and office relationships are. They last a long time – you spend as much time with them as you do your partner, or wife, or kids, and they're very meaningful.

The high level of press engagement has been a big part of HCC's success. How did you develop and nurture this?
I never said no. On the day of my son's wedding, they were putting up the long tables in the back yard and there was Channel 9, wanting an interview. I loved giving young student journalists a go, and when they graduated, they would remember me.

What do you see in HCC's future? Where should we look to next?
I think what you're doing is pretty terrific. Partnership is important, but it's also important not to be appropriated by any providers. In this job I think you need to retain a capacity to critique both yourself and the wider health system.

Patient Opinion has been a marvelous initiative, I would just like it to be more advertised, and more available to people who really need it and don't know that it exists.

Patient Centred Treatment Goals

A study exploring what patients want

Tim Leen Service Director, Royal Perth Bentley Group

It has been well published in the literature that healthcare costs are rising in a manner that is not sustainable. Despite the investment in health, over 1 billion people worldwide do not get the care they need and almost one third of all health expenditure is wasted. Basic weaknesses in models of care and associated clinical decision-making contribute to variations in quality, access and harm to patients.

Patient preferences and goals are often overlooked which could have consequences as harmful as misdiagnosing disease. A system where the care and treatment is directed around the realistic goals of the patient (patient centred treatment goals (PCTG)) may reduce waste and improve health, and this concept was the basis for our exploratory work.

PCTGs are goals for an episode of healthcare expressed as a direct measure of how a patient feels, functions, or survives. Literature related to PCTG and goal discussions is sparse and through clinical audit, it was identified that PCTG are not consistently documented in the medical record.

Our study involved conducting in-depth interviews with patient undergoing elective surgery of which admission to ICU was required. We aimed to identify the patient's goals, determine if these goals were patient-centred, and determine if the goals of treatment specified were patient-centred.

The study found that participants could set PCTG either independently or with assistance, but it was not certain whether the goals set were consistent and reliable as the goals seemed dependant on patient's emotions, confidence with the healthcare system, or their frame of mind at that time. The conclusion from this study is such that it is uncertain that the participants knew what they wanted or could achieve from their episode of care.

A patient story from the study that sticks in my mind is that of Brian. Brian was waiting for a vascular operation to help the perfusion of his legs. One of Brian's proudest claims was that he had the best lawns in Busselton, however, his current condition did not allow him to tend to his lawns. So each day, he watched as his lawns got more and more neglected. His wife, under his supervision, provided the care to the lawns but it was not the same. His PCTG was simple – "to get back to mowing his lawn". However, because of his condition, he would never be able to mow his lawns in the same manner as he had done. He was not aware or did not understand that this was the case.

Should our patient assessment incorporate "What matters to you?" rather than "What is the matter?". Too much emphasis is placed on diagnostic skill sets alone leading to care designed around disease. Care has to be structured around patients' needs, values, and preferences as well, where they and their loved ones are given opportunities to co-design their treatment plan. It gives the clinical team a chance to appreciate patient's life priorities and not just as recipients of care. If the clinicians had discussed 'what matters to Brian' the treatment plan may or may not have changed, but it would have allowed for Brian and his wife to be fully aware of his realistic options.

Since the study, much work has been done in terms of patient and carer literacy as well as encouraging the use of platforms such as Patient Opinion (www.patientopinion.org.au) to capture the patient experience. Work needs to be undertaken to evaluate the benefits of such initiatives as well as incorporating contemporary research findings to assist in designing and developing a healthcare system around the preferences of the patient.

Tim Leen is currently leading an innovative project that enhances patient experience, safety and outcomes with the use of technology. He is happy to take feedback from readers, which can be directed to info@hconc.org.au

Updates

Sustainable Health Review

The Sustainable Health Review report was released on 10 April and includes key, audacious goals. The narrative on engagement and working across sectors to better address social determinants of health are strong, and we are encouraged by the commitment to new ways of engaging with consumers and community.

As well as a commitment for the move of the King Edward Memorial Hospital to the QEII site, there were four projects announced in conjunction with the Review:

1. The Home First model of care supporting people who do not require an acute hospital bed to return home for assessment by the right type of clinician at the right time;
2. A 'one-stop-shop' for children, young people and their families where they can access child health, development and mental health services, as well as other government agencies such as education and community services;
3. A 20-bed medical respite centre to provide clinical care to homeless people who may otherwise be admitted to hospital; and
4. A Safe Café where people with non-acute mental health issues can receive support and advice in a supportive environment, after hours.

You can read more about HCC's perspective on the Review at https://www.hconc.org.au/about-us/media-releases/

Empowering Health Consumers with Disabilities

HCC has partnered with People with Disabilities WA to deliver this project. Together we will provide eight training sessions on Disability Health Rights for people with disabilities, and their carers, family and support people. The sessions will cover topics including rights, ideas for getting better care, where to go for help, medical records and information sharing, and navigating the health system.

For more information contact info@hconc.org.au

School for Change Agents

The School for Change Agents builds the power, individually and collectively, to make a difference. The School will provide you with the skills, confidence and community to make a difference in an ever-changing and evolving environment.

You can join HCC during May and June to reflect on the lessons from each of the 5 live webinar sessions as we discuss how they can best be put into practise – please register your interest at https://www.hconc.org.au/school-for-change-agents-2019/

Partners in Change Obesity Collaborative

At the latest Community Conversation, which explored the work done to date by the Obesity Collaborative, the Department of Health gave an overview of how consumer input had informed the discussions at the Summit last year, and the development of the draft strategies. The draft strategies will look at the three main areas: the needs of the community, the needs of service, and the needs of the system. It will cover things like access, community education, respect and support, changing the way we talk about weight, workforce and training, and a commitment to long-term sustainable change.

Health Engagement Network

The Network is an online community for people interested in the practice of consumer, carer and community engagement. We have held two Network meetings so far this year, the latest on 20th March. There is a renewed focus on ensuring the events remain productive for both consumers and providers, and on revisiting the shared vision for community engagement.

Community Conversations

Community conversations offer a relaxed environment for health consumers from non-English speaking backgrounds to share their experiences and views about accessing health services. We also provided information on ways they can give their feedback on health services.

These conversations revealed that many people from culturally and linguistically diverse backgrounds rely on community contacts to find doctors who speak their language. We found that while there was a lot of gratitude towards WA's health system, patients and carers had a lack of understanding about diagnosis, treatments and tests. We were also told several times that visits from family brought a lot of comfort to patients in hospitals.

HCC will look to undertake further conversations with other communities.

Dates for Diary

15th May 2019 - Advanced Consumer Representation

This workshop will take your consumer representation skills to the next level. Keeping your skills honed and your knowledge current plays a key role of being an effective consumer representative. On completion of this interactive workshop you will have an increased understanding of the current international, national and local safety and quality focus in health care and how to integrate these concepts into effective representation.

Find out more, and book, at https://www.hconc.org.au/consumer-rep-advanced-skills/

21st & 28th May, 11th, 18th & 25th June - School for Change Agents

Join fellow change agents in WA as we participate the School for Change Agents modules. It is a five week program involving online webinars and face to face discussions. We encourage people to participate in all five sessions as each one covers different content.

Find out more at https://www.hconc.org.au/school-for-change-agents-2019/

30th June

Health Consumers' Council membership renewals due for the new financial year

Empowering Health Consumers with Disabilities Training Workshops

Cockburn Youth Centre
Friday 31 May 2019, 10am - 1pm

Bridgely Community Centre Northam
Friday 7 June 2019, 1.30pm - 4.30pm

Citiplace Community Centre
Thursday 13 June 2019, 5.30pm - 8.30pm

Wembley Telethon Speech and Hearing
Thursday 20 June 2019, 1pm - 4pm

Joondalup Library
Friday 5 July 2019, 1.30pm - 4.30pm

Bunbury / Advocacy WA
Thursday 25 July 2019, 1pm - 4pm

Midland Hospital
Thursday 1st August 2019, 1pm - 4pm

Kelmscott Frye Park Pavilion
Thursday 8th August 2019, 1pm - 4pm

For more information contact **info@hconc.org.au**

HEALTH CONSUMERS' COUNCIL
YOUR VOICE ON HEALTH

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Monday - Friday 9.00am - 4.30pm
Closed Public Holidays