HEALTH MATTERS

Health Consumers' Council (WA) Inc. Magazine

Spring 2015

How many pills are too many?

The future of Consumer Advisory Councils

SolarisCare Foundation:
Re-humanising Cancer Care in WA

Why telehealth?

Official endorsement of the American definitions of Mental Illness is dangerous & unnecessary

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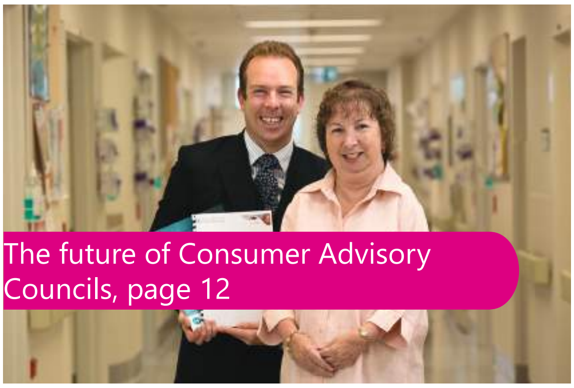
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Foreword

Welcome to the Spring Edition of Health Matters. We have been so pleased by the enthusiastic response to requests for articles. Dr David Joske from Solaris Care, and Melissa Vernon from WA Country Health Services were quick to respond; and Dr Frank Jones, RACGP national President was happy to be interviewed.

As usual we were generously supplied with articles by HCC member and retired reporter Frank Smith. We hope you enjoy this edition and look forward to your comments; we have especially reinstated the Letters to the Editor to ensure we have a space to publish your feedback.

In this edition we explore the theme of Outpatient Care; often we focus on health services provided in hospital; but much of the care we receive is in out-patient clinics, community based services and primary care. The Clinical Senate debate in September was on Outpatient care and aimed to re-orient the focus from our hospitals to our outpatient services and examine what could be better delivered from community and primary settings. Key workshop questions were ""How do we innovate outpatient care?" and "What should we stop doing?" See page 3 for more information.

Telehealth is an important step towards providing health sevices without the need of the patient to travel. Health Consumers' Council has a videoconferncing unit provided by WACHS that has allowed us to run focus group sessions with consumers in country areas, most recently including remote parts of the Northern Territory.

Most importantly it is has given us the ability to communicate face-to-face with consumers we are assisting in remote areas, that we would otherwise have been unable to see.

The theme of next edition of Health Matters is "Patient Experience". If you would like to submit an article, please contact us on info@hconc.org.au so we can provide submission guidelines.

2015-2020 HCC Strategic Plan

HCC Strategic Plan is taking a little longer to hatch than we had hoped, but stay tuned for future updates.

2015 AGM

HCC AGM took place on Wednesday 30th September was addressed by Tarun Weeramantrhi, Assistant Director, Public Health.

Board Elections

Michelle Atkinson - de Garis finished her stint on HCC Board with a star turn as AGM MC. We thank her for all her hard work on the HCC Board in 2014-15. We also farewelled Nigel d'Cruz and Michele Kosky. Remaining on the Board will be Rasa Subramaniam, Cheryl Holland, Tony Addiscott, Tom Benson and Ruth Sims. Joining the Board will be John Burton, Hayley Haines and Ann Banks.

2015-16 Board Executive Positions

Rasa Subramanian	Chair
Cheryl Holland	Deputy Chair
Tony Addiscott	Treasurer
Tom Benson	Secretary

Committee Members: Ruth Sims. Joining the Board will be John Burton, Hayley Haines and Ann Banks.

Constitutional Change

The AGM ushered in some changes to the HCC Constitution, reducing the time that you need to be a Member before being elected to the Board from 13 months to 6 months.

Pip Brennan
Executive Director
Health Consumers' Council

Letters to the Editor...

Lucy Palermo Marketing & Communications Coordinator / Health Matters Editor | HCC

We realised that it was time to re-introduce a Letters to the Editor Section to capture your feedback. We welcome your letters & messages. You can leave messages on Twitter and Facebook using #hconcwa_editor, email info@hconc.org.au or post GPO Box C134, PERTH WA 6839, please include your name, suburb and phone number. Letters may be edited for legal issues, space or clarity.

@LightForRiley
Thanks for including our article about Riley & the importance of whooping cough boosters in pregnancy!

Editor: We would also like to congratulate Catherine and Greg Hughes, the parents of Riley and founders of Light for Riley, who won the Engaging with Consumers award at the WA Health Awards 2015. As if that was not achievement enough, Catherine Hughes has now been named as Young Australian of the Year.

Does a theme work?

Dear Editor,

I have just finished reading the current issue of Health Matters and the idea of a theme for each edition sounds good, I will wait and see if it is as good in practice as it is in the ideas stage.

Margaret Ryan, Ballajura

Editor: We thank you for your feedback Margaret. Although we do have a theme for each issue we don't limit articles to the theme. We always include general articles of interest to our members.

Disappointed at negative comments in Maternity Issue...

Dear Editor,

At request of Alison Comparti I have put together a short article for consideration of publication in a future edition of Health Matters. Having seen the huge amount of behind the scenes work that has gone into expanding the range of maternity models of care nationally and in WA, I was disappointed to read some of the negative comments expressed in the Winter edition of Health Matters.

Whilst progress to date frustrates the ambitions of some midwives and consumers, further integration of midwifery and medical support for women in the private health sector will undoubtedly occur in the years to come with the development of widespread confidence in the currently available care pathways.

Diane Mohen, MBBS FRANZCOG
Bunbury WA

Editor: We thank Alison Comparti for getting in touch with us and prompting us to contact Di Mohen. We thank Di for taking the time to put together an article which you can read on page 18. and Di has been invited to address the forthcoming HCC and Health Networks event Joining the Dots in Maternity Care.

Thank you for publishing our article...

Dear Editor,

I received a copy of the Health Matters today and was delighted to see my article Coeliac Disease, Fertility and Pregnancy Outcomes published.

Christine Woods, Coeliac WA

Editor: Thank you Christine, we love to recieve articles from our Organisational Members. We hope that you contribute articles to future publications.

Clinical Senate Debate, Outpatient Care, a look to the future

Pip Brennan Executive Director | HCC

Jeff Moffet, Executive Director of WA Country Health Services and Executive Sponsor of the debate began his address by asking those in the audience to raise their hand if they had travelled to Perth to attend the Clinical Senate Debate. There was a show of hands – not many, but at least a few rural attendees at the debate on a topic which has so much impact on rural consumers.

He then asked those whose hands were raised, if they would have made that journey if the Clinical Senate Debate lasted 15 minutes. All hands then went down. And yet this is what we expect of rural consumers; that they travel vast distances in order to attend a 15-minute appointment. It was a pointed reminder to us all.

The Consumer presentation by Lesley Ayton was galvanising and engaging. Lesley demonstrated the wonders of telehealth technology, by attending from Albany by video conference. He shared his experience of the benefits of receiving telehealth consultations. Rather than an exhausting three-day affair, attending a consultation now took about 30-minutes door to door. See Les's article on page 7.

The Director General addressed the Senate with feedback from the Recommendations from the prior debate "Dial E for Engagement, Are Clinicians on Hold?" He noted how many of the Recommendations were endorsed by the State Health Executive Forum (SHEF). You may recall in the last edition of Health Matters that there was a Recommendation regarding the utilisation of Patient Opinion by WA Health. This recommendation was the only one not endorsed.

During the Outpatient Care Debate there were two questions that were addressed;

1. "How do we innovate outpatient care?" Key themes for innovation were: universal use of technology, adopting systematic performance measurement tools, establishing a universal definition of outpatient care, improving links between hospitals and primary care, better models of care for general practitioners, using opportunities to build on research and teaching, and improving the patient experience.
2. "What should we stop doing?"Key themes included stopping the traditional practice of bringing patients back repeatedly, minimizing the number of hospital initiated outpatient services, stopping annual reviews, making patients travel when telemedicine is available. Other options discussed included increasing the role of private and NGO providers, and investment of care coordination rather than providing patients with multiple different outpatient appointments with multidisciplinary providers. Patient centred, in other words.

The next Clinical Senate Debate will take place on 11th of December and is entitled "The Patient Will See You Now – Patient Experience" with Health Consumers' Council and WA Health's Quality Improvement and Change Management Unit as the co-sponsors. This is a great opportunity to develop Recommendations to progress key initiatives to ensure the patient is always at the centre of the care equation.

What is the Clinical Senate?

The Clinical Senate is a forum established in 2003 where collective knowledge on clinical issues can be debated. The Clinical Senate involves presentations on the topic of the day, including a consumer presentation, a general discussion of the issues raised, ending with an interative workshop to develop recommendations.

The recommendations from the Clinical Senate Debate are presented for formal adoption and actioning to the DG and SHEF.

The WA Health website page on the Clinical Senate notes; "Matters discussed will include the coordination and development of clinical planning clinical and resource decision making; other relevant clinical issues in health service delivery in Western Australia; and issues of key concern to the Director General".

For more information visit:
www.clinicalsenate.health.wa.gov.au/about/index.cfm

Advocacy Service: Official endorsement of the American definitions of Mental Illness is dangerous & unnecessary

Dr Martin Whitely Advocacy, Policy & Research Manager | HCC

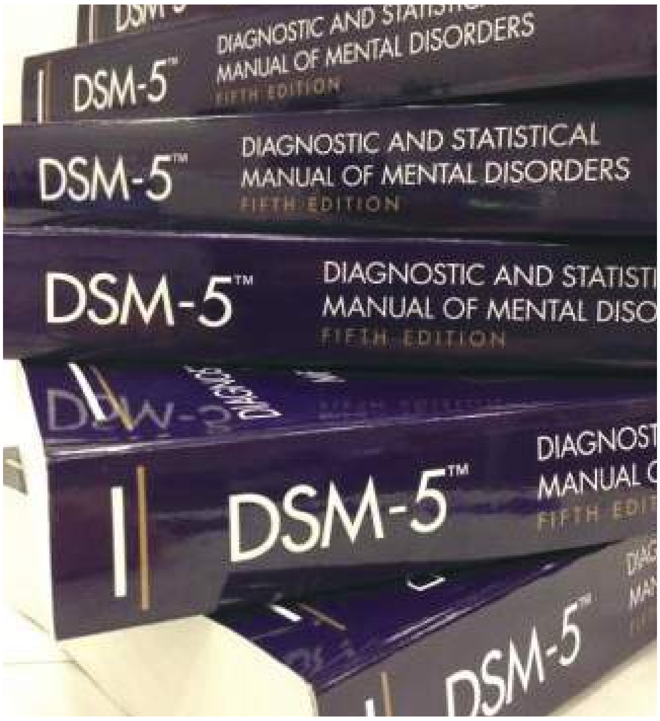


Image source: blogs.scientificamerican.com/mind-guest-blog/dsm-5-caught-between-mental-illness-stigma-and-anti-psychiatry-prejudice/

Section 6 (4) of the soon to be proclaimed Mental Health Act 2014 states: 'A decision whether or not a person has a mental illness must be made in accordance with internationally accepted standards prescribed by the regulations for this subsection'.

The recently drafted regulations state:
For section 6(4) of the Act, a decision whether or not a person has a mental illness must be made in accordance with the diagnostic standards set out in either or both of these publications:

a. The International Statistical Classification of Diseases and related Health Problems [ICD] published from time to time by the World Health Organisation [WHO];
b. The Diagnostic and Statistical Manual of Mental Disorders [DSM] published from time to time by the American Psychiatric Association [APA].

If the regulations are not amended by the WA parliament, psychiatrists will be able to choose whether they use the latest version of the ICD or the extremely controversial DSM5 when exercising their powers under the Act. By defining who is mentally ill these 'standards' will determine who can potentially be involuntary detained and treated against their will, most often with psychotropic drugs with potential serious adverse side effects. The standards must therefore be based on valid and reliable definitions of mental illness.

DSM5 has been globally criticised as arbitrarily broadening the boundaries of mental illness and classifying normal human behaviour and emotions as disease. Significant international organisations including the British Psychological Society and countless prominent international psychiatrists have been very critical of DSM5. (1, 2)

In April 2013, three weeks before DSM5 was published, the Director of the influential US National Institute of Mental Health (NIMH), Dr Thomas Insel, stated that DSM5 lacked 'validity' and that consequently the NIMH 'will be re-orienting its research away from DSM categories'.(3) Put plainly DSM5 is not 'internationally accepted' or even universally accepted in the USA and therefore the proposed regulation is inconsistent with new Act.

A notable individual critic of DSM5 is Professor Allen Frances who on behalf of the American Psychiatric Association led the development of the prior edition of the DSM (DSM4 first published in 1994). Soon after DSM5 was published in 2013 he wrote the lesson of DSM4 should be that 'every change in the diagnostic system can lead to unpredictable over-diagnosis...The recently published fifth edition of the diagnostic manual, ignored this risk and introduced several high-prevalence diagnoses at the fuzzy boundary with normality...These changes will probably lead to substantial false-positive rates and unnecessary treatment.' (4)

In a blog (available at https://www.psychologytoday.com/blog/dsm5-in-distress/201212/dsm-5-is-guide-not-bible-ignore-its-ten-worst-changes) Professor Frances has identified ten changes in DSM5 that will add to the history of psychiatry which he wrote 'is littered with fad diagnoses that in retrospect did far more harm than good'. Some of Professor Frances concerns are:

- Disruptive Mood Dysregulation Disorder: DSM 5 will turn temper tantrums into a mental disorder.
- Normal grief will become Major Depressive

Image source: www.autismconsortium.org/blog/detail/dsm-5-the-new-diagnostic-criteria-for-autism-spectrum-disorders

Disorder, thus medicalizing and trivializing our expectable and necessary emotional reactions to the loss of a loved one.

- The everyday forgetting characteristic of old age will now be misdiagnosed as Minor Neurocognitive Disorder, creating a huge false positive population of people who are not at special risk for dementia
- Excessive eating 12 times in 3 months is no longer just a manifestation of gluttony and the easy availability of really great tasting food. DSM 5 has instead turned it into a psychiatric illness called Binge Eating Disorder.
- First time substance abusers will be lumped in to the definition of long term substance users despite their very different treatment needs and prognosis and the stigma this will cause.
- DSM 5 has created a slippery slope by introducing the concept of Behavioral Addictions that eventually can spread to make a mental disorder of everything we like to do a lot. Watch out for careless overdiagnosis of internet and sex addiction.
- DSM 5 obscures the already fuzzy boundary between Generalized Anxiety Disorder and the worries of everyday life.
- DSM 5 includes a proposal for ‘Somatic Symptom Disorder’. This new diagnosis will encourage ‘a quick jump to the erroneous conclusion that someone’s physical symptoms are ‘all in the head’.

While many of the criticisms of subjectivity of assessment of behaviours are common to both the DSM and ICD, the DSM generally contains looser, less rigorous diagnostic criteria. Studies comparing diagnosis and prescribing rates for a range of psychiatric disorders using DSM and the equivalent diagnostic criteria in ICD have established that for the majority of disorders rates were significantly higher when using DSM. (5)

For the purposes of the Mental Health Act 2014 there is absolutely no need to have two alternate diagnostic frameworks. The ICD is sufficient and it covers the full spectrum of physical and mental illness. Having one genuinely ‘international’ diagnostic framework will deliver greater consistency in the application of mental health law and provide clearer guidance to clinicians applying the law and the Mental Health and State Administrative Tribunals who deliberate disputes.

References:

1. British Psychological Association, Response to the American Psychiatric Association: DSM-5 Development, (June 20111) available at http://apps.bps.org.uk/_publicationfiles/consultation-responses/DSM-5%202011%20-%20BPS%20response.pdf
2. See http://boycott5committee.com/
3. Thomas Insel, Directors’ Blog – Transforming Diagnosis, National Institute for Mental Health, 29 April 2013, available at http://www.nimh.nih.gov/about/director/2013/transforming-diagnosis.shtml
4. Allen J Frances, The New Crisis of Confidence in Psychiatric Diagnosis Annals of Internal Medicine 159 (2): 221–222. 6 August 2013 http://annals.org/article.aspx?articleid=1722526
5. Merete Juul Sorenson, Ole Mors and Per Hove Thomsen, ‘DSM-IVor ICD-10-DCR diagnoses in child and adolescent psychiatry: does it matter?, European Journal of Child and Adolescent Psychiatry, 14; 6 (Sept 2005): p. 339.

Why telehealth?

Melissa Vernon Chief Operating Officer Strategy & Reform | WA Country Health Service (WACHS)

I fly frequently throughout country WA. 'Why telehealth?' is based on the patient experiences of country outpatients. They have fuelled a passion to alleviate the unnecessary and unproductive experiences these country people have in accessing health services. These are their stories.

Sally, 58 is a TB patient, she was a registered nurse and staff member at her local regional hospital. She is a patient at the TB clinic in Perth. Initially she was required to travel to Perth and attend the clinic every fortnight.

Telehealth staff at her local hospital noticed she was becoming less mobile. Her husband had to retire to become her full-time carer. When asked how she was managing, Sally responded: "If this disease doesn't kill me, the travel surely will."

As a result, a telehealth service was negotiated on her behalf and she now attends most of her clinic appointments in her home town via videoconference.

Jeff is a retiree with a premature neurological condition leading to deteriorating physical capacity, he requires a specialist review weekly. This entails regular flights or a five to six hour car trip to Perth. However Jeff can no longer drive and his wife is very uncertain in Perth traffic.

Regular specialist telehealth consultations via videoconference now enable Jeff to be reviewed in Albany where he lives. This also assists Jeff's GP to support his care locally.

On a 8pm flight from Albany to Perth the woman sitting next to me started to become agitated just ahead of the cabin doors being closed. The flight attendant spoke gently to the woman who indicated she had to get off the plane, becoming more and more distressed as the conversation went on.

Eventually take-off was abandoned while the woman disembarked. Passengers also disembarked while the woman's luggage was removed. Outside the terminal, the woman sobbed as she attempted to use the phone. Checking in with her to see if she needed assistance, she indicated she had recently had a cancer diagnosis and was required to be in Perth. She was distraught, alone and facing an unknown future treatment schedule while in an unfamiliar place and health service.

Last week a 7:55am flight from Albany gave two health related travellers a very difficult experience. We were set to board when advised there would be a delay of nearly four hours. A middle aged woman and her elderly mother in a wheel chair were negotiating with service desk staff about the delay.

The mother was due at Sir Charles Gairdner Hospital at 1:30pm that day; they had travelled by car from a small community three hours from Albany. By my calculations, they would need to have been up at 3:30am to prepare and travel to Albany Airport.

They now faced the real possibility that they would not get to their appointment. They also needed to notify the clinic and others waiting to transport the elderly woman to the appointment. The flight eventually departed after 1pm on that day.

We might wonder what happened to the elderly woman and her daughter who, having travelled for three hours, waited at an airport for six or more hours, then journeyed home. Did they take the three hour journey home to start again on another day?

Stories gathered through my travels this year could easily fill all the pages in this issue. They do not include the men and women travelling back and forth for regular chemotherapy or radiotherapy, or the parents with sick infants; travelling away from home and family, often feeling apprehensive, alone and ill.

Telehealth can happen and does happen. The key is for regionally-based consumers to ask their health professional the following questions when being referred to Perth for assessment or treatment:

1. Can this service be provided via telehealth, either locally or within my region?
2. If no, why not?

Regional consumers can contact their local hospital and request contact details for their Regional Telehealth Coordinator (there's one in each region in WA).

Not all outpatient appointments can be conducted via telehealth. In some cases, it may not be clinically appropriate or suitable for a particular consumer.

However, there can also be reluctance by health providers to utilise telehealth based on a lack of information, lack of experience and confidence, or unwillingness to provide a service in a different way. Consumers should work with health providers and investigate if telehealth is an option for some of their appointments.

We may not be able to get a telehealth service to you, but know that we will consistently seek to increase telehealth availability. Every time the question is posed - can I have this service by telehealth and if not why not? - helps to increase the chances of the service becoming available. Join us in seeking to improve access to telehealth for country consumers. To find out more, go the www.wacountry.health.wa.gov.au and search 'telehealth'.

Telehealth Breakdown

In 2014, there were approximately 19,000 consults via telehealth including:

- Outpatients 11,799
- Emergency Medicine 7,314

There are a number of services currently being provided via telehealth including:

- Emergency Medicine
- Plastic Surgery
- Burns
- Pain Medicine
- Urology
- Gastroenterology
- Mental Health

The WA Country Health Service is also developing the following outpatient services to be provided via telehealth:

- Stroke health
- Cancer health
- Renal services
- Diabetic services
- Ear, eye and oral health

Clinical Senate Debate Consumer Presenter: Telehealth - improving access to specialist care for regional residents

Living in Albany Living in Albany, a five-hour drive from Perth, has recently proved to be a burden for 74-year-old Les Ayton since he was diagnosed with an acquired auto-immune disease.

The condition affects Les' eyesight, strength, endurance, balance, dexterity and at its worst, breathing and swallowing. He is under the care of a Neurologist at Royal Perth Hospital and has had to travel to Perth every few months for specialist appointments.

Les can no longer drive and relies on his wife to drive him to Perth and back for what is often only a short appointment with his specialist. The visit to the specialist at Royal Perth Hospital can be a three day event for Les and his wife and includes accommodation and travel costs, stress and inconvenience.

But now, thanks to telehealth, Les is able to stay in Albany and conduct his outpatient appointments with his specialist via videoconference.

"Telehealth videoconferencing as a means of consultation has become very important to us," Les said.

"Taking part in a telehealth videoconference from Albany entails an easy 12km drive to the Albany Health Campus - the trip to the campus, conference and trip home can be completed in an hour compared with the three day round trip to Perth for the same appointment."

Using high definition videoconferencing equipment, specialist and patient are able to see each other clearly and speak in real time, just like having the specialist in the room.

"I see little difference between a telehealth conference and a face-to-face conference," Les said. "We are able to have a two-way conversation and I am able to demonstrate my dexterity issues and muscle weaknesses.

"Being able to see and talk to the specialist is important to me and her response on the screen is just as good as having her sitting in the same room."

Outpatient consults via telehealth videoconferencing are available at regional hospitals and health services across WA for services that include plastic surgery (wound clinics, burns etc), pain management, speech pathology, gastroenterology, paediatrics, neurology, mental health, urology and more.

First Published in Southern Inland Health Initiative, WACHS

Aboriginal Advocacy Service: Away from Country

Laura Elkin Aboriginal Advocacy Manger | HCC

Painting by high school students on Sorry Day 2015 at Wellington Square, East Perth.

Many Aboriginal consumers from rural and remote areas have added difficulties and barriers accessing and orienting their way through health services. These include physical distances and having limited services locally; they include the difficulties people face when they have to travel away from home to access services; they include lack of access to Interpreters; lack of understanding about their cultural beliefs; and they can include assumptions, mis-communication, and discrimination.

WA is a huge state and Perth can be a long way from home. Having to leave family, friends and everything familiar behind to access treatment can be very daunting. Having to find your way around a large city when you are sick and unsure where you're going can be extremely frightening. All kinds of things can get in the way of a patient making an appointment - from accommodation shortages to getting lost.

Sometimes Outpatients end up with nowhere to stay. After their initial appointment they may need further tests or treatment that means staying longer than originally planned, but occasionally their accommodation has been fully booked and they don't know where else to go or who else to turn to. It is often up to the consumer to understand the system so that it works for them.

Our current health system can sometimes consider these as side issues to treating patient's health needs, but in reality they can undermine the patient's understanding of what is happening and their ability to get the health care they need. The Country Health Connect service can alleviate some of these problems, as do increased numbers of Aboriginal Liaison Officers in our hospitals. Expanding those services further would help more Aboriginal people to accessing the outpatient care they need.

A lot of Aboriginal people do not speak English as their first language, and it is common for people to revert to first languages in times of stress or sickness. Understanding what your doctor is advising is crucial for consent and understanding what you need to do after discharge from hospital. Failure to provide adequate interpreter assistance is a serious patient safety issue. It is equally important that the Doctor understands what the patient is saying. We are concerned that health staff don't always realise when an Aboriginal person needs an interpreter or doesn't understand what is happening and being said, especially elderly patients who may nod at the doctor to indicate they are listening. We have seen some very sad stories where patients have missed the opportunity to have treatment because they had not understood their options. We have also had reports from many Aboriginal consumers who do speak English as their first language but who had little idea of what was happening while they were in hospital despite asking many times.

Patients from remote areas have sometimes been through several health services as part of their referral process to Perth, and we are concerned that the discharge summary does not always make it to the clinic that will provide the follow up treatment.

Being away from *Country* is also difficult – where Country is both home and a source of belonging, identity and spirituality. It can be especially important for Aboriginal people to be on Country for births and deaths, but also during any kind of sickness.

How many pills are too many?

Frank Smith | Guest Contributor

Image Source: Shutter Stock

Polypharmacy is not a parrot in charge of your local chemist's shop, nor a new freeway. It is the situation where patients are taking a large number of different medicines daily. Two thirds of seniors aged over 75 are taking five or more medicines a day and that at least one of these is either unnecessary or harmful according to independent organisation NPS MedicineWise.

"Polypharmacy is a real issue for the ongoing overall health of older Australians," says Sarah Hilmer Professor of Geriatric Pharmacology at Sydney Medical School. "The increase in chronic disease, including dementia, in an ageing population means that polypharmacy is commonplace. In addition, there is strong evidence that the use of multiple medications increase the risk of adverse events such as falls, confusion, hospitalisation, mortality and lack of independence."

A meeting last month convened by the NHMRC Cognitive Decline Partnership Centre (CDPC) and NPS MedicineWise drew on a wide range of expertise to explore the development strategies to address the issue of overprescribing. "People with a diagnosis of dementia are particularly at risk of polypharmacy due to the fact that they are not only being treated for the symptoms of the disease but also for typical age related issues," said Professor Susan Kurrle Director of the CDPC.

"The phrase I want to see banned is 'you will take it for the rest of your life'," said Ms Aine Heaney, NPS MedicineWise Client Relations Manager. "It is based on a fallacy. If there is no evidence of continuing benefit it should be stopped. The absence of evidence is not evidence against stopping."
"This has been a key area of focus for NPS MedicineWise for some time. Good medicines management for older Australians will improve patient care by reducing polypharmacy and the associated risks, as well as reducing inappropriate prescribing," she said.

Ms Heaney said there was little evidence of the appropriateness of many medicines for older people, because they were usually excluded from trials as drug companies want to show their product as good and effective as possible. Therefore they choose relatively young and healthy trial volunteers.

Older bodies can become more sensitive to medicines and medicine interactions – so it is important to regularly review and monitor your medication regimen with your health professional. "When you start to get older, medicines may become a regular part of your life. Asking the right questions, keeping records, knowing about brand choices and being aware of interactions are all examples of medicine wise behaviour," she said.

NPS MedicineWise claims to have saved taxpayers $650 million in wasted health costs since 1998.

NPS MedicineWise, MedicineList+ app

To help manage your medicine NPS MedicineWise has created the MedicineList+ smartphone app. It enables you to keep an up-to-date list of your medicines, help you to get to know your medicines, get better results and enjoy better health.

It means that you always have your medicine and health information with you. It can remind you when to take your medicine and help everyone that is involved in your health care to know what medicines you use to avoid mistakes. Use the app and ensure you are given the Consumer Medicine Information (CMI) Sheet by the pharmacist. For more information regarding CMI go to: http://www.nps.org.au/glossary/consumer-medicine-information-cmi-leaflets

To find out more information regarding MedicineList+ go to: http://www.nps.org.au/topics/how-to-be-medicinewise/managing-your-medicines/medicines-list/medicinelist-smartphone-app

Statewide News

Pip Brennan Executive Director | HCC

Release of the Report On Review of Maternity Services in Metropolitan Non Tertiary Public Hospitals

On Friday November 6th the report compiled by Professor Con Michael for WA Health, dated May 2015, was finally released. The purpose of the review was to "determine the proposed configuration of maternity services in the Perth metropolitan area. The review and the recommendations that follow will be integral to the future operational planning of maternity services." (WA Health Report, pages 2-3)

The most contentious recommendation is to close Bentley Maternity services "when possible and after consultation with the medical profession, the Bentley community and providing Fiona Stanley Hospital (FSH) has reached the number projected in its transition strategic plan." There has been no community consultation to date, and the HCC and Bentley CAC members are working on how best to link in with key groups such as the City of Canning's Early Years Group to ensure women in their childbearing years in the area get a say.

The Report comments on the safety issues of Bentley Hospital specifically in relation to staffing out of hours for timely referral for caesarean section as well as the hospital's physical state.
Less noted in the media flurry surrounding the report is Professor Michael's recommendation 12; "The preferred model of care is MGP (caseload midwifery) and this to be introduced where possible in those hospitals providing maternity services." When the Bentley community is consulted, it will be important for them to understand that this is a possibility.

This report's timing will now coincide with our Maternity Services event on December 4th. A copy of this report is available on http://ww2.health.wa.gov.au/~/media/Files/Corporate/Reports%20and%20publications/PDF/2015-Review-Mat-Serv.ashx

Launch of WA Health Pathways

HCC was invited to the launch of WA Health Pathways on the 8th October 2015. Health Pathways originated in New Zealand and aims to form that all-important bridge between GP practices and hospitals. Specifically, Health Pathways is a web portal, a "google for doctors" which provides evidence-based, consistent information about conditions, and how treatment can be provided in the area in which you live.

Pathways was developed to help tackle a range of problems that occurred because of a poorly co-ordinated interface between hospitals and primary care;

- Inappropriate referrals from GPs to hospitals
- Patients not receiving clinic follow up post discharge
- The high rate of patients who are DNAs – "Did Not Arrive", often because the appointment is no longer relevant
- The lack of necessary tests to facilitate the referral from primary care to hospital, creating a longer delay until treatment
- Clinics running over time, patients waiting for hours

All of these factors are impacted by poor referral processes between GPs and hospitals, and back again.

There are important factors to the success of Health Pathways; especially buy-in from GPs and hospital specialists. At its best Health Pathways will be a well-resourced website that can be managed and updated centrally, to ensure ongoing currency of information.

Health Pathways is being developed in WA under the auspices of the new WA Primary Health Alliance. According to the website's spreadsheet, there are 78 complete pathways, 52 pathways with a draft pending, 21 being reviewed, 118 being localised, 11 being partially updated and 7 under –development, a total of 287 Pathways to date.

The website notes that there is "community" input, but also states that "The secure portal is not for use by patients, however there will be appropriate local resources for GPs to provide to patients."
HCC will continue to monitor this project and we feel strongly that there is an important opportunity to develop consumer-related resources as an adjunct to this project.

The HealthPathways website can be found at http://waproject.healthpathways.org.au/Home.aspx

National News

Pip Brennan Executive Director | HCC

Image Source: www.skynews.com.au/news/top-stories/2015/01/16/ley-leaves-m-to-move-on-medicare-reform.html

Minister Sussan Ley's address to the Press Club, 28 October 2018

"I believe we need a health system where the patient is centre of everything."

Progress on the Primary Care Reform Project

Last edition we noted that the launch of the Primary Care Reform Project was officiated in Canberra. Since that time, there have been briefings, consultations and consumer and carer focus groups held across the nation, as well as an online survey with more than 1000 survey responses; 255 from organisations and 770 from individuals.

Key feedback:

Health Care Home – the concept of consumers having a nominated GP practice, was supported by 77% of respondents to the survey, for people with chronic and complex conditions. 92% of respondents supported team-based care for people with chronic and complex health conditions; this was a very clear result and touches on a core reason for the primary care reform in the first place – that people with chronic conditions are particularly disadvantaged by our currently fragmented primary care system. 62% of respondents ranked patient participation as the most important aspect of effective coordinated care.

Technology – consistent feedback identified the importance of the role of technology in improving communication, shared access to records and a reduction in duplication that currently occurs.

Measuring outcomes - 90% of respondents agreed that it is important to measure and report patient health outcomes. This was the second highest result and highlights the well-understood principle of "what you measure, you improve".

Payment mechanisms - a clear majority of individuals preferred a blended payment model of fee for service, capitated payments and salaried professionals.

What's next

The Advisory Group will now focus on the development of reform options for consideration by Government by the end of the year.

Medicare Benefits Schedule Review

Consultation papers were released in September 2015, and a public survey on the MBS review was opened on 27/9/2015 and closed Monday 9/11/2015. The consumer survey asked these questions:

Q. How has the MBS worked well or not worked well for you or someone you know? Can you give an example?

Q. Have you or someone you know ever had a consultation, medical procedure or test you thought was unnecessary? - If yes, what was the medical procedure or test, or what was the consultation for, and why did you think it was unnecessary? - Did you raise this with your doctor?

Q. Have you ever refused or did not have a consultation, medical procedure or test because you thought it was unnecessary? - If yes, what was the medical procedure or test, or what was the consultation for, and why did you think it was unnecessary? - Did you raise this with your doctor?

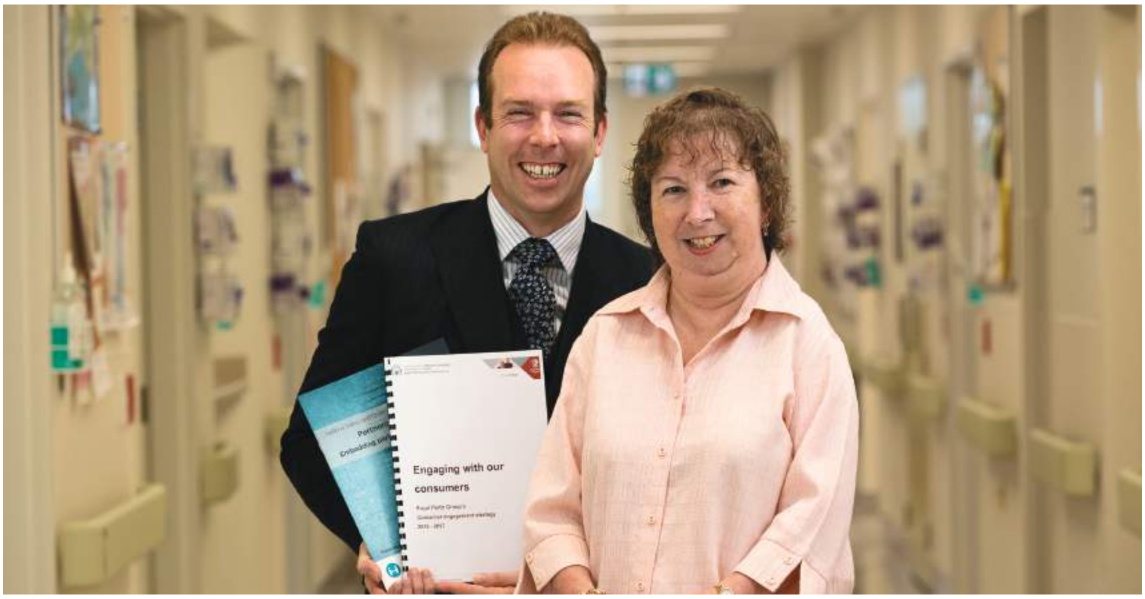
Q. Have you encountered difficulties with Medicare 'rules'? For example had a Medicare benefit denied, difficulties with referral arrangements, or limits on the number of times you can access certain Medicare services in a year. - If yes, please describe what happened.

Q. What kind of information would be most useful to you in making decisions about the services you receive from health professionals?

Responses to the survey are now being collated for the MBS Taskforce.

The future of Community Advisory Councils

Todd Gogol Director Consumer Engagement | Royal Perth Hospital



Todd Gogol, Director Consumer Engagement RPH & Petrina Lawrence, RPH CAC Chair

There is much talk in the community about greater consumer involvement in health care. But what does this actually mean and how does a health care organisation truly develop a more inclusive consumer experience? Royal Perth Hospital (RPH) has taken an innovative approach which many have questioned but is proving to pay immense dividends.

On 12 August 2015, RPH disbanded their existing Consumer Advisory Committee (CAC) in what many openly stated would be a disastrous outcome for consumers. However the chair of the RPH CAC Ms Petrina Lawrence and Director of Consumer Engagement Todd Gogol saw the bold move as a step to making RPH more consumer focussed with better outcomes for patients, carers and their families.

"We developed a Consumer Engagement Strategy which focussed on an expanded CAC supported by a variety of several special interest working groups" Todd Gogol said.

"Our aim is to have consumer engagement across every facet of our organisation with between 60 and 80 consumers from extremely diverse backgrounds available to the hospital."

"We have had a CAC for many years now, but we felt that we weren't utilising them correctly. The Consumer Engagement Strategy recommends how we can use the CAC feedback more effectively to improve the patient experience."

RPH has not done this in isolation however, with CAC Chair Petrina Lawrence full-heartedly supporting the implementation of the Strategy. "I strongly believe in what Todd and RPH are trying to achieve and while many may doubt our approach, the early success shows we are on the right path" Petrina said.

"We have had over 55 applications from people with diverse backgrounds including; refugees, carers, mental health patients, Aboriginal Elders and people whom have transitioned from paediatric to adult care all of whom have relevant experience with RPH.

"The best thing though, is that this has been supported by the highest levels of the organisation. Dr Aresh Anwar, our Executive Director, truly believes in consumer engagement and has allowed us the freedom to implement the Strategy and increase the level of consumer involvement at RPH."

Consumer Advisory Councils or Committees are nothing new to health care organisations but they have often struggled to get adequate numbers of people with relevant experience. So how is RPH recruiting such large numbers and with such diversity?

"RPH has put its money where its mouth is." Todd said. "We are the first hospital in Australia to establish a Director of Consumer Engagement, something that the surveyors at our recent Accreditation acknowledged and supported..."

"RPH has put its money where its mouth is." Todd said. "We are the first hospital in Australia to establish a Director of Consumer Engagement, something that the surveyors at our recent Accreditation acknowledged and supported. Furthermore, the Executive of the hospital support what we are trying to achieve. We know we are a good hospital but we want to be better, and to do that we need a high functioning Consumer Advisory Committee which feeds directly into the Executive Director."

"When I first started in this position, some hospital staff were unclear about the role of the CAC. Now, I have staff emailing me asking for CAC feedback or consumer representation on various hospital projects and committees. The organisation now sees the benefits of consumers and their feedback."

What does this mean for the future of Community Advisory Councils or Committees?

"Consumer and carer input is only going to increase and hospitals need to embrace it" Petrina said. "However, to be effective CACs need to plan their approach and prove their value to the organisation".

"The Consumer Engagement Strategy that RPH developed detailed how this was going to be achieved and gave clear performance indicators for the CAC. This has not only allowed everyone in the organisation to see how the CAC was going to benefit them, but has also provided the CAC with clear objectives."

The RPH model has an overarching CAC made up of 15 members with the working groups reporting into it. The working groups cover Mental Health, Aboriginal and Torres Strait Islander Health, Carers, Disability Access, Paediatric Transition and Patient Publication Review. However the working groups can be expanded or contracted depending on organisational needs.

RPH is also utilising its consumers to undertake patient surveys. "We see patients, carers and families behave very differently around hospital staff. Often they don't want to complain in fear that their quality of health care may be comprised. Having consumers go out and survey patients and carers not only provides us with real-time feedback, but more often than not, it is open and honest feedback so we can address trending issues as soon as they are identified." Todd said.

"As the National Safety and Quality Health Service Standards drive for greater consumer engagement there will be an even greater need for CACs" Petrina stated.

"But just striving to meet the Standards does not necessarily mean better health care for consumers. "This is where RPH is on a different path. They are pushing for greater consumer engagement with a 'What Matters Most' approach to health care. The CAC has a major role in assisting RPH in achieving this. The hospital has also changed its focus to concentrating on what consumers want from the hospital and how hospital staff can better meet the wants and needs of consumers and carers. This approach to patient care, will naturally meet the Standards."

There is little doubt that Consumer Advisory Councils or Committees will continue to be a source of consumer engagement across the health care sector. However, as RPH has identified, consumer involvement needs to be embedded in every aspect of the organisation to give true representation and authentic feedback.

Seeking Expressions of Interest for CAC Representative Positions

If you are interested in becoming a member of Community/Consumer Advisory Councils/ Committees that represent the consumers' voice for hospitals/health services, please contact the Consumer & Community Engagement team; Louise Ford and Stephanie Newell at Health Consumers' Council via info@hconc.org.au or (08) 9221 3422.

Consumer Representative Workshops

HCC also offer free consumer representative training throughout the year. Contact the Consumer & Community Engagement team; Louise Ford and Stephanie Newell at Health Consumers' Council via info@hconc.org.au or (08) 9221 3422 for further information.

Q&A with Dr Frank Jones, President of the National Royal Australian College of General Practitioners

Dr Frank Jones, President of the National Royal Australian College of General Practitioners

Dr Frank Jones has practised as a General Practitioner for 32 years in WA. Dr Jones brings a wealth of experience to the role as a clinician and as a highly engaged GP who has worked in the health reform space for a long time. The Executive Director of Health Consumers' Council heard the grab below on the Health Report, tracked him down and interviewed him about primary care and the raft of current primary care reforms.

> *'"I saw a patient last Friday, who arrived at 5.30 in my surgery with a one pager with a bit of a scrawl on it and a bagful of drugs which took me an hour to sort out ..." Frank R Jones'*

Pip Brennan Executive Director | HCC

(http://www.abc.net.au/radionational/programs/healthreport/vision-for-a-sustainable-health-system-in-australia/6400414#transcript)

Frank thank you so much for making the time to talk with me. What do you see is at the heart of primary care?

Primary care is all about quality patient care. GPs are clinical relationship specialists; when I see my patients, I don't just have a consultation, I have a conversation. It's much more than just the clinical picture – the whole of health, including social and emotional wellbeing needs to be factored in to a consultation.

What are your overarching reflections on health reforms?

The 20th century gave us a massive amount of technology, it's time to take a breath, look at the bigger picture of what we are trying to achieve here.

Naturally people don't want to be in hospital; they want to be at home. While the constant talk is of increased health costs the reality is these increasing costs are in the hospital system, not in primary care. Our present methods of delivering health care are not sustainable.

There is no doubt that countries with strong primary care systems have improved overall health outcomes.

What we are saying from a GP point of view, is that if you invest at the primary care end of the spectrum, health outcomes improve across the community. Emergency Department admissions are reduced, hospital admission rates are reduced, length of hospital stay is reduced; in short, investment in the primary care space is where we are going to get our "bang for our buck". This is cost efficient.

Importantly patient satisfaction is improved also.

I have been a GP in Mandurah for 32 years, and the type of patients I see has changed dramatically, due to increasing life expectancy and the associated complexity of co-occurring diseases and health conditions that go along with a longer life span.

Each disease has a specific drug regime, and the drugs are designed for one disease, but for the patient with a range of illnesses and a complex medical history, they will have to take a range of medications.

This gets complicated as disease-disease and drug-drug interactions are not well understood, and there is clear evidence that a significant proportion of hospital admissions are related to the inability to coordinate medication records across primary care and the hospital system.

What about the newly revamped e-health record?

We've just got to get the e-health record right. Even if we get the basics right, with a patient summary, present medication lists, and allergies, that would be a fantastic start. 95% of GP practices are fully computerised, but our systems in primary care can't talk to the hospital software!

What about Health Pathways?

Health Pathways is an excellent initiative which helps to map locality-specific patient pathways for specific health conditions.

HealthPathways WA is a web-based portal with information on referral and management pathways helping clinicians to navigate patients through the complex primary, community and acute health care system in Western Australia.

HealthPathways is designed to be used at the point of care by general practitioners.

GPs are endorsing this Health Pathways approach and acknowledge the hard work of those who sit on the committees to support the implementation of this kind of initiative.

GPs are extraordinarily busy and have a massive patient cohort. They are snowed under with work, so it's difficult to get our heads above the parapet and get involved in these types of initiatives. It is important that there is someone doing this work such as RACGP and WA Primary Health Alliance, but it is vital that front line GPs are consulted and empowered.

What about the Medicare Benefit Schedule (MBS) Review?

It's very early days of the MBS Review, with multiple committees looking at various specialities. There will be a GP Representative on each and every committee.

The RACGP has recently released a 'Vision for a Sustainable Health system' and the paper has been presented to to the Minister for Health. It has definitely raised the level of debate.

What about medications on discharge? What could happen there?

There are multiple layers and players in our over complicated health system!

Ideally at discharge the patient will have verbal education and a written discharge in hand supplied by the hospital intern and/or pharmacist: this document should then be given to the GP.

Time limitations are not an excuse for maintaining proper due process. Patients 'misplacing' summaries are also not uncommon. In the 21st century this should be possible electronically.

Anything else is second best and unacceptable; Patient safety is paramount

Any final words?

We know that patients who identify with a particular GP or GP practice (the so-called Medical Home) have improved health outcomes, and this happens because the doctor-patient clinical relationship is critical in the maintenance of good health and the prevention of illness.

It's vital that GP's keep going that extra mile for their patients.

eHealth

For more information about eHealth: eHealth.gov.au

Health Pathways

For more information about Health Pathways: http://waproject.healthpathways.org.au/Home.aspx

SolarisCare Foundation: Re-humanising Cancer Care in WA

Dr David Joske Clinical Haematologist | SCGH

Dr David Joske in the SolarisCare Community Garden at SCGH

SolarisCare is there to reach out and help those with cancer, both physically and psychologically. It arose out of a comment from a lymphoma patient and since that moment, SolarisCare has grown to fill a prominent role amongst patient supportive services in Western Australia.

It was approximately 1998, when a man under my care told me, “It has taken me three months to learn how to be a patient.” Upon further questioning, he admitted that people in the waiting room were swapping stories about things they could do to help themselves, including the use of complementary and alternative medicine. He told me they advised each other not to tell their nurses and doctors, as they would be reprimanded and pooh-poohed for doing so.

This was the catalyst. So many of my patients were trying things, I felt I needed to show an open mind and learn about this much-derided area of health care. Otherwise, there would always be a barrier between me and my patients. And I read the latest studies and found more positive evidence than I had suspected. So when the opportunity arose to create a cancer support centre (in 2000), the then-controversial decision was taken to include a range of carefully selected and credentialed (as best we could) complementary therapies.

These treatments were - and - remain free, self-selected by the patient (or carer, or staff member), and based mostly around touch, massage, and psychologically-based therapies. This was from my reading of medical literature as to what worked or might work, was safe, and could involve some kind of shared dialogue about medical endpoints. (An early application to hang crystals over chemotherapy bags didn’t fulfil those criteria and was rejected!)

The original Peters & Brownes Dairy Cancer Support Centre at Sir Charles Gairdner Hospital opened on September 15, 2001. From that day to this, some 100 people a week drop into the centre (or its larger successor in the new Comprehensive Cancer Centre). Some just sit and have a cup of tea in the warm, non-clinical environment. They may talk to our volunteer meet-and-greet staff: this is an extraordinary group of volunteers that has included retired University Professors, farmers, lawyers, university students and people from all walks of life. They all share a desire to help in a real way. Many have been with SolarisCare for 10 years or more. Other visitors read the material and information available (including all the other major cancer support services), and about half choose to access the range of complementary therapies on offer. The services at our centres are open to any and all affected by cancer (except for SolarisCare St John of God Subiaco Hospital which is funded by that hospital and specifically to be used by its patients).

Services vary depending upon therapist availability and other factors, but over 20 different modalities have been offered. The list has included Acupuncture, Bereavement, Counselling, Creative Visualisation, Expressive Art, Mediation, Music & Sound, Narrative, Remedial Make-up, Bowen, Craniosacral massage, Kinesiology, Massage, Reflexology, Healing Touch, Pranic Healing, Qi Gong, Reiki and others.

Cures are not claimed; rather, we set out to have a positive effect on quality of life and reduce the symptoms of cancer and the side effects of treatment. Our in-house and published research demonstrates the benefits from use of complementary integrated therapies for example reduced pain, fatigue, and nausea. We know that some people undergoing Reiki therapy have very profound experiences that can help them manage their cancer journey. Other research by Professor Anne Williams tells us that many see the centres (her research was about the SCGH centre specifically) as an oasis within the clinical hospital environment.

As events have proved, we hit upon a good model which has provided enormous help to so many people. We have treated now over 12,000 Western Australians with cancer and their carers, providing over 50,000 therapies. This is by far and away the largest experience of any hospital-based cancer support centre in Australia. Numerous centres around Australia have sought our advice to benefit from our pioneering and now considerable experience. We have had no medical misadventure. We know our treatments are safe, due to the careful selection, credentialing and supervision of our volunteer therapists. But perhaps what we do is best encapsulated by a comment from a cancer patient, "If I were a cat, I'd purr!"

With the success of the first centre, things took off around 2006. We cut the apron strings from the hospital and became a stand-alone charitable foundation. We opened the "Chemo Club": a supervised exercise program for people receiving chemotherapy, at the Aspire Fitness Centre in Claremont. Our second centre opened at SJOG Subiaco Hospital in 2008. Regional centres followed in the South West, Bunbury in 2010 and Great Southern, Albany in 2011, to coincide with the increase of mainstream cancer services in those regions. The SolarisCare executive group includes David Edwards, CEO; Tres Hansen, Administrator and Ashlee Young, Marketing and Administrative Assistance. But to my mind, Board members, staff, meet-and greet and therapist volunteers, supporters and fund-raisers are all part of the SolarisCare family, which now includes over 250 people, united in a mission to help and serve our fellow Western Australians undertaking the cancer journey.

Other services offered are our community education and support programs. These include the Carer's Courses, offering invaluable advice on diet, exercise, taking medication, handling side effects, talking to your medical team and finding support; we have run "Men In The Kitchen" cooking courses for recently bereaved men; outreach massage is offered in some waiting areas and on the wards at SCGH; and our biennial scientific seminars. In this regard our 2013 seminar on Cancer Survivorship did much to raise awareness in this town about this important issue of after-cancer care and helped to instigate the WA Cancer and Palliative Care Network Survivorship Collaborative (of which this author is the Lead Clinician).

The most recent seminar was held in Albany and drew local cancer doctors and researchers for an excellent day of scientific discussion. Recently, we opened the SolarisCare Community Garden at SCGH with the help of a number of community partners and some very idealistic student leaders at Curtin University. This beautiful space is the physical embodiment of our philosophy to provide an oasis of care and to get people with cancer to a better place, no matter what the medical situation may be.

We are embedded now in the states cancer treatment framework and community. We are recognised nationally as the leader in this area of "integrative oncology" – using ancient forms of therapy alongside the best of modern medicine to "re-humanise" cancer care. At TedxPerth in 2013, I presented my strong beliefs and personal experience in this area with "Bringing Humanity to Healthcare" which can be viewed here: https://www.youtube.com/watch?v=XwbMQYwgzWE

Funding remains a hand-to-mouth existence and if not for dedicated work by the Red Sky Ride group, led by Kim Gilbert, we would not have survived. They have ridden many thousands of kilometres and raised over $2m over the last 8 years.

Sadly, we can't cure everyone yet and even with the best of outcomes, there is hard work to be done getting through treatment. SolarisCare may not be for everyone; I find as a clinician, I can offer it to people under my care, as an extra weapon in my cancer armamentarium alongside chemotherapy, and bone marrow transplants. Good nursing, physiotherapy, and supportive care are important too.

What we can and must do as a society and health community is provide every possible avenue of support. We are incredibly lucky to have the quality of people here in W.A. that has seen SolarisCare flourish and become such a vibrant, important and effective organisation and a national leader. SolarisCare has a unique and important role to play for many cancer patients.

I address my final comments to anyone reading this who has cancer and has treatment planned or already underway. Ultimately, you need to be able to be calm about your situation – to know and understand your mainstream medical plan and to be able to talk openly with your doctors and the health care team about goals, and side effects, and life plans. Then, I believe you need your own plan: what to do yourself to wrestle back control of the situation: good diet, appropriate exercise, sleep, resolving stresses, and what might be called lifestyle management of your cancer. As a cancer doctor, I commend our services to anyone who has to face a cancer journey: I think you will find we can help very much to get you through to a better place.

Maternity Care in WA

Diane Mohen MBBS FRANZCOG | Bunbury WA

Image Source: Stock photo

Readers of Health Matters Winter 2015 edition may have been left with the impression that maternity care in WA is not changing with the times and is in some way inferior to that provided in other Australian states.

The reality in WA is that maternity care is evolving to meet changing community expectations through a wider range of care options. While also continuing to strive to meet requirements that maternity care clinicians and health care systems need to provide a safe environment for their patients, so there is the best possible outcome from pregnancy. A wider range of maternity care options for women helps meet the professional aims of midwives to share their skills, knowledge and time to help women have a positive experience of pregnancy and childbirth.

Collaborative care between midwives, medical and allied health care teams is the norm, not the exception, in maternity units throughout WA - it is not a new paradigm. Quality, safe maternity care relies on family doctors, obstetric skilled doctors and midwives working together with other health professionals supporting women through pregnancy and childbirth, and the care of their newborns.

Options for different patterns of maternity care have been steadily evolving in WA, as in other states. Public maternity units in the north of WA have had well established midwifery antenatal clinics working collaboratively with resident medical obstetric teams, to support women through pregnancy and childbirth, long before the more recent establishment of largely midwifery staffed clinics and maternity care programs in the metropolitan area. The Family Birth Centre at King Edward Memorial Hospital has been running for 2 decades.

WA now has two publically funded home birth programs based in the metropolitan area and Bunbury. Women in both of these, 'continuity of midwifery care programs' are cared for by midwives with the support of obstetric medical teams and family doctors. Culturally respectful maternity care programs for the support of Aboriginal women have been developed throughout the state. Health service attention to monitoring community satisfaction and clinical care standards has advanced significantly in recent decades to provide greater responsiveness and accountability to the public.

Community expectations have driven many maternity care changes in the public health care sector. With respect to access to private midwifery care: Since the publication of the national Maternity Services Plan a great deal of work has been done at legislative, administrative and clinical team levels. WA Health Department now has procedures in place to enable private practice eligible midwives to apply for admission privileges to care for pregnant women in public hospital maternity units. Processes are in place to ensure women have access to appropriate medical care when complications during pregnancy arise.

Once the role of private midwifery practice is well established within collaborative and respectful working relationships in public maternity units, the logical evolution of private midwifery care will be in support of women in the private health care sector. With the support of private obstetric medical practitioners, women will then have access to a full range of private maternity care as envisaged when access to Medicare payments for private practice midwives was legislated.

Coaching patients to gain better health

Frank Smith | Health Matters Contributor

Image Source: http://wellness.utah.edu/services/wellcoaching.php

We all know that changes in lifestyle and appropriate exercise can reduce health risk factors and improve outcomes for patients with diabetes and heart disease. But once away from the surgery it often seems too hard.

Now an innovative program in Queensland is coaching patients to keep them on track and it is succeeding with both Aboriginal and non-Aboriginal communities. The COACH (Coaching patients On Achieving Cardiovascular Health) Program is the first standardised coaching program targeting cardiovascular risk factors and delivered by telephone and mail-out statewide.

“The coaches are registered nurses or health workers that are trained using a standardized model of care based on risk assessments, goal setting and national disease management guidelines,” said team leader Associate Professor Chantal Ski from the Centre for the Heart and Mind at the Australian Catholic University Queensland Health has run the program for five years.

Researchers audited nearly 2000 participating patients with cardiovascular disease and 700 with type 2 diabetes who completed the Coach program between up to June 2013.
They found improvements in cardiovascular risk factor status across all biomedical and lifestyle factors measured during the program, including improvements in serum lipid levels, blood glucose, smoking and alcohol consumption combined with increases in physical activity.
Additionally, there was no significant difference in results between the Indigenous and non-Indigenous patients.

“Our results provide further evidence to support this intervention as an effective strategy for reducing cardiovascular risk and for secondary prevention,” Professor Ski and her colleagues concluded.

“As our cohort comprised patients with coronary heart disease and/or type 2 diabetes, the results suggest the potential for the coach to be adapted for other chronic diseases.”
The managing director of the program, associate professor Margarite Vale says the success of the Coach Program is due to its content and accessibility.

“Uniquely, the program identifies the treatment gaps in each patient’s management – the gaps between guideline recommended care and the care patients actually receive; and works with the patient to close these treatment gaps whilst the patients work with their usual doctors,” she said.
“These methods eliminate barriers often seen with cardiac rehabilitation programs, including geographic isolation, travel costs and the inconvenience of appointments.”

“Most cardiac rehab programs reach approximately 30 per cent attendance and this hasn’t changed much over the past 20 or so years. Reasons for non-attendance include geographic isolation, travel costs, limited appointments and time constraints.

“Delivery by phone overcomes these barriers. More sessions can be offered at convenient times and more often – thus reinforcing messages and using motivational techniques to engage patients.
“The benefits of a Coach-style program could be acheived nationwide. Given the burden of coronary heart disease and diabetes, it offers a sustainable means for optimising health outcomes across diverse populations,” said professor Ski.

CCE Program: Access to outpatient care for people from Culturally & Linguistically Diverse backgrounds (CaLD)

Louise Ford Consumer & Community Engagement Manager | HCC

Image Source: Stock vector

When you look at the research, it is difficult to access information regarding access to all forms of health care by people from CaLD backgrounds.

Noted in the conclusion of research published in 2010, (Representations and coverage of non-English-speaking immigrants and multicultural issues in three major Australian health care publications by Pamela W Garrett, Hugh G Dickson, Anna Klinken Whelan and Linda Whyte: www.anzhealthpolicy.com/content/7/1/1) "The quantum and range of multicultural health research and evidence required for equity in policy, services, interventions and implementation is limited and uneven. Most of the original multicultural health research articles focused on newly arrived refugees, asylum seekers, Vietnamese or South East Asian communities. While there is some seminal research in respect of these represented groups, there are other communities and health issues that are essentially invisible or unrepresented in research. The limited coverage and representation of multicultural populations in research studies has implications for evidence-based health and human services policy."

In its background, the publication stated that "Mainstream healthcare research can be perceived as being neglectful of cross-cultural research. It is frequently seen as methodologically difficult to do with significant interpretative problems [1,2]. Resources may be inadequate for the translation of study instruments or the employment of bicultural researchers and interpreters. Concepts do not always have semantic or linguistic equivalence across languages or cultures [3,4]. Sampling methods, subject recruitment, achieving adequate sample sizes and representative samples may pose additional challenges [5,6]. However, it can equally be argued that to ignore populations with limited English proficiency may result in poor study validity and generalisabilty, could be considered discriminatory in culturally diverse social contexts, and, in a healthcare environment increasingly committed to evidence-based policy, may ultimately produce poor policy."

I would suggest that the lack of cross-cultural research reflects a seemingly general disinterest in migrant health and people's access to health care, including as outpatients. There can be significant barriers to accessing health care for people from CaLD backgrounds, these may include such things as:

- Lack of transport
- Unfamiliarity with the way in which services are provided
- Lack of access to child care
- Lack of English skills, people may have low literacy skills while speaking English quite fluently
- Lack of health literacy
- Lack of interpreting services provided by the health care body
- Cultural/gender barriers

In line with my own thoughts on Partnering with Consumers, National Safety & Quality Health Service Standards and Patient Safety the article continues; "Further, little attempt has been made to understand the crucial relationship between poor language proficiency, culture and patient safety in the Australian context. The question of whether there is ethnic disparity (difference in treatment and care based on ethnicity, race or language ability) in healthcare service provision has not been addressed in these major Australian healthcare journals." Considering such aspects of service provision are imperative…how are Partnering with Consumers Standard and Patient Safety to be applied equitably?

The article concludes: "The review of these three journals over a 12-year period demonstrates that the quantum, range and quality of the research and evidence which is required for equity in policy, services, interventions and implementation is limited. Kagawa-Singer [149] argued that mono-cultural health services' research focus has three major limitations, namely a lack of recognition of different world views, a lack of understanding of the most appropriate and effective means to cope with illnesses based on those world views, and a lack of ability to hear different ways of communicating these perspectives.

Whilst the MJA, AHR and ANZJPH research platforms could certainly not be called 'mono-cultural', they could quite reasonably be called 'limited' and 'uneven'. While there is some excellent quality research in respect of refugees, asylum seekers and Vietnamese immigrants, there are other communities and health issues that are essentially invisible or unrepresented in research."

In previous roles I have had the opportunity to witness first hand some of the issues discussed in the article; I would suggest that culturally competent and inclusive health care provision is impeded by the lack of research in the area and also the limitations mentioned above and which bear reinforcing i.e.

- "a lack of recognition of different world views,
- a lack of understanding of the most appropriate and effective means to cope with illnesses based on those world views,
- (and) a lack of ability to hear different ways of communicating these perspectives."

This article clearly articulates not only why some people may have difficulties accessing healthcare services, including outpatient care, it also offers theories why this may be happening…leaving the questions: Is Australian health care user friendly for all and is it equitable?

Footnote: The journals in the study were the:

- Medical Journal of Australia
- Australian Health Review
- Australian and New Zealand Journal of Public Health

HCC Diversity Dialogues

As part of HCC's Consumer & Community Engagement Program, the Diversity Dialogues initiative has been developed to provide a forum for members of CaLD communities and health care providers to meet, to comment on and to discuss various aspects of health care provision. The aims are to:

- encourage culturally aware and competent health care provision to CaLD health consumers
- educate and inform health care providers
- provide networking and learning opportunities for all who attend

Recommendations are fed onto health care providers and to the Department of Health.

The next Diversity Dialogues is being held in May. Details will be released closer to the event.

Linking neurological care

Kathy McCoy Executive Director | Neurological Council of Western Australia

NCWA Team 2015

The World Health Organisation (WHO) (2006) defines neurological disorders as diseases of the central and peripheral nervous system; and advise they are increasing with expectations they will soon affect as many as a billion people worldwide. The total number of neurological conditions is unknown. Estimates suggest there are approx. 600 neurological diagnoses.

Symptoms can impact upon a person’s physical, emotional, psychological and social functioning (WHO 2006). In the International Classification of Diseases neurology has the highest number of conditions listed (MacDonald et al, 2000). The WHO (2006) states that the burden of neurological disorders has been seriously underestimated and that “there has been a large body of evidence showing that in the years to come policy-makers and health care providers may be unprepared to deal with the predicted rise in the prevalence of neurological disorders and the disability associated with them”. This assertion is supported by the findings of the National Chronic Disease Strategy (2005) which recognised neurological need as the second largest area of health expenditure.

The diagnosis of a neurological condition can be a devastating one, these conditions and disorders cause considerable ill health but few directly associated deaths. However not only is there often no cure, with treatment only at best attempting to delay progression; there is also the predicament of a continuing decline in health, wellness, functioning and quality of life. Loss of cognitive function with disease progression, often physical, together with some profound personality changes and declining bodily control, may result in substantial burdens for informal carers.

These are all critical factors to be considered in the provision of community based care (Lloyd 2000). This results in long term reliance upon health, community and social care systems. Many neurological diseases affect the young and economically active including epilepsy, traumatic brain injury and many inherited disorders. The neurodegenerative disorders such as Parkinson’s disease, Alzheimer’s disease and motor neurone disease largely affect older people. Due to an aging population the amount of people affected is rising.

There is a need for a good understanding of neurological functioning to enable the health or social care professional to impact effectively on a client’s wellbeing, understanding and decision making.

Neurological Council of WA

Supporting people with neurological conditions

The most promising approach for reducing burden of neurological disorders is to develop community care services which are supported by secondary and tertiary facilities, physician and neurologists. This requires a continuing seamless care approach to handle the long term nature of neurological disorders and ongoing care with an established support system. Linking community services without patient and acute services is an ideal model to support integrated services and this interface point is can be seen as being a Vital Integration Point.

Neurological Council of Western Australia (NCWA) have been providing regional community neurological nurses in the Mid-West, Great Southern and South West regions. As part of their continuous improvement process, plans have been made modernise their metro services.
The situation for many patients:

- Long wait for/or between specialist review
- Inequity in service access and provision
- Lack of information on condition and treatment options
- Inadequate disease and medicine management
- Lack of joined up working practice
- Restricted disease specific roles (excluding many)
- Limited to hospital activities only e.g. outpatient clinics with little or no community involvement or based solely in community settings with no links or working relationship with secondary/tertiary care expertise and consequently reduced effectiveness
- Little inpatient liaison with ward nurses and medical staff.
- Many patients cannot use service – "wrong" diagnosis yet have identical problems

Many neurology patients actually face similar problems irrespective of diagnosis eg, spasticity, continence, constipation, side effects, pain, mobility, access other services and psychosocial.

The typical neurological client has little involvement with hospital services for their ongoing support. Smith (2005) states that although diagnosis may determine patient's continuation with hospital-based services, treatment and ongoing support is often devolved to the community setting. It is estimated that about one in six consultations in primary health care relates to a nervous system symptom of some kind and about one in five emergency admissions to hospital are due to a physical and physiological effect of a neurological illness, however many of these cases are managed entirely within the community (Action on Neurology 2005). Simon (2008) states:

"a client with disability or a functionality issue related to a neurological condition spends roughly 3 hours per year with an acute based health professional. The other 8757 hours the person manages their own condition with community support, thus community based support networks and meaningful social connectivity is crucial".

NCWA will be looking to provide a community/acute linkage service into the local hospital settings. This was run as a pilot project at Bunbury Hospital with excellent results. The Community Neurological Nurse has intent to be the community link, interfacing as required. Providing ongoing links with client and family ensuring neurological health needs are supported as much as practicable.

Neurological Council of WA (NCWA) provides a range of Home and Community Care funded care and support services to people with neurological conditions and their carers in Western Australia. NCWA also acts as an umbrella body for various neurological organisations focused on improving services for the neurological community.

To find out more about NCWA you can go to their website: www.ncwa.com.au or email admin@ncwa.com.au or call 1800 645 771 or (08) 9346 7533.

Better wait ‘til Monday to go into hospital

Frank Smith | Health Matters Contributor

Image Source: www.parkinsonswa.org.au/what_is_parkinsons/going-into-hospital

The least risky time to go into hospital is a weekday, according to a study of hospital records in the UK, Australia, USA and the Netherlands published last month in the British Medical Journal – Quality and Safety.

The researchers found the risk of dying within 30 days of admission to hospital was higher for admission to hospitals at weekends in three out of four countries. This risk was 8 per cent higher in 11 hospitals in England, 13 per cent higher in five of the US hospitals, and 20 per cent higher in six Dutch hospitals.

Australian hospitals had the largest proportion of emergency admissions. There was no increased risk of death within 30 days for emergency admissions at weekends in the Australian hospitals, but there was an increased risk at seven days. All patients admitted at the weekend for planned surgery were more likely to die within 30 days than those admitted on other days of the week.

Even Friday was no better in the Netherlands. The risk of death for patients undergoing planned surgery in the hospitals in The Netherlands was 33 per cent higher if admitted on a Friday than on a Monday. Authors, Drs Milagros Ruiz, Alex Bottle and Paul P Aylin of Imperial College London, say no one single factor is probably responsible.

They suggest some diagnoses and procedures may be particularly sensitive to reduced access to test results and diagnostics at weekends. Staff may be fewer in number and less experienced at weekends and patients requiring urgent care may have to wait longer, which might affect the success of any treatment.

Professor Richard Lilford and Dr Yen-Fu Chen of University of Warwick Medical School warn against rushing to conclusions. They say it is more important to focus on possible causes behind the weekend effect. “Understanding the weekend effect is an extremely important task since it is large, at about 10 per cent in relative risk terms and 0.4 per cent in percentage point terms. This amounts to about 160 additional deaths in a hospital with 40,000 discharges per year,” they say.

“But how much of the observed increase results from service failure? And here is the rub, for while a 0.4 percentage point represents a large, potentially scandalous, number of deaths, it is quite a small proportional change.”

While scientists are nutting out the cause of this higher mortality, it is probably safer to go into hospital on a weekday if you have the choice.

New Clue in Coeliac Disease Puzzle: Cause of Oat Toxicity Explained

Christine Woods | Coeliac Western Australia

Image Source: www.fitmamarealfood.com/love-it-oats

There has been a long-standing controversy surrounding the safety of oats for people with coeliac disease. Confusingly, clinical guidelines vary depending on which country you live in. In Australia, oats are excluded from the gluten free diet due to ongoing concerned regarding potential toxicity for some people with coeliac disease.

Melbourne researchers have looked at whether oats consumption in people with coeliac disease truly does induce an abnormal immune response, and if so why does this happen and what part of oats is this directed at. In keeping with feeding studies which indicate that oats are tolerated by most people with coeliac disease, they found that the immune (T cell) response was measurable in only six of the 73 participants (8%) over a ten year period. In other words, oats failed to trigger an abnormal immune response in the majority of coeliac participants.

Walter and Eliza Hall Institute researcher Dr Melinda Hardy said the research was the first of its kind to comprehensively profile immune responses to oats in people with coeliac disease. "The significance of previous studies performed in test tubes was unclear," she said. "By studying people with coeliac disease who had eaten oats, we were able to undertake a detailed profile of the resultant immune response in their blood stream. Our study was able to establish the parts of oat avenins that cause an immune response in people with coeliac disease."
"This study provides specific detail on the parts of oats stimulating immune responses, and highlights the relevance of grains other than wheat in coeliac disease," Dr Tye-Din said. "This is a vital piece of the puzzle that informs the development of targeted tests for oat toxicity and the design of new treatments for people with coeliac disease."
President of Coeliac Australia, Mr Tom McLeod, said the good health of people with coeliac disease depended on strict removal of dietary gluten. "Coeliac disease is not a dietary fad, but a serious health condition," he said. "This study adds to our understanding of oats in coeliac disease, and sets the scene for definitive evaluation on what can be safely consumed by people with coeliac disease."

References:
Hardy MY, Tye-Din JA, Stewart JA, et al. Ingestion of oats and barley in patients with celiac disease mobilizes cross-reactive T cells activated by avenin peptides and immune-dominant hordein peptides. J Autoimmun. 2015 Jan; 56:56-65.

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