HEALTH MATTERS

Health Consumers' Council (WA) Inc. Magazine

Winter 2015

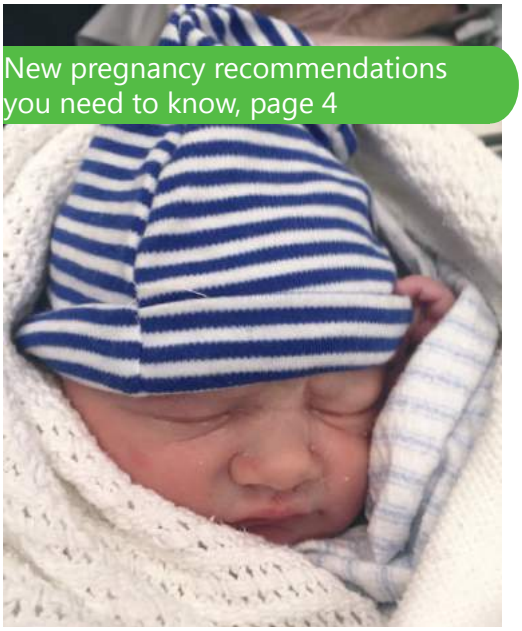
Birthing options, be informed...

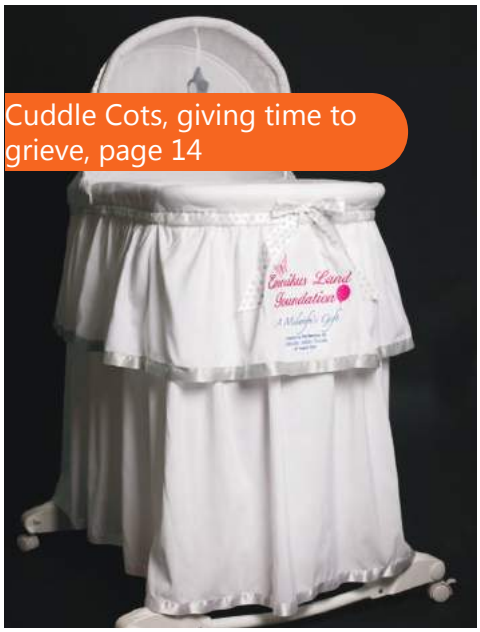
New pregnancy recommendations you need to know

On the verge of being a credentialed midwife in WA

Cuddle Cots, giving time to grieve...

Contents





Joining the dots in Maternity Care Forum, page 3

Features

2 Maternity Services Reform: Where are we now?

3 Joining the dots in Maternity Care Forum

4 New pregnancy recommendations you need to know

10 Birthing options, be informed...

11 Midwifery led care

12 Coelliac disease, fertility and pregnancy outcomes

14 Cuddle Cots, giving time to grieve...

15 On the verge of being a credentialed midwife in WA

16 Gestional Diabetes, what you need to know...

17 'Shine a light on Lung Cancer'

19 HCC NAIDOC Event

21 Health Consumers' Council Annual General Meeting: 30th Sept 2015

Regulars

1 Foreword: Maternal and child health

6 Consumer & Community Engagement Report

8 Statewide News

9 National News

18 Aboriginal Advocacy Service Report

20 Advocacy Service Report

Cover: Stock photo

Foreword

The last edition of Health Matters saw a new-look format; we received positive feedback and look forward to continuously improving our magazine.

We are also committed to have a focus for each edition, this edition's theme is maternal and child health. The theme of next edition is 'Outpatient Care'. If you would like to submit an article, please contact us on info@hconc.org.au so we can provide submission guidelines.

This edition's theme - maternal and child health

Articles cover the latest in maternity health reforms, and also deal with the difficult discussion on neonatal loss, with articles from Riley's Mum (some of you may be aware of the Light for Riley Campaign) and from the Midwife who received the WA Nursing and Midwifery Excellence Award from a Consumer for the work she has done to ensure all WA hospitals ultimately will have cuddle cots.

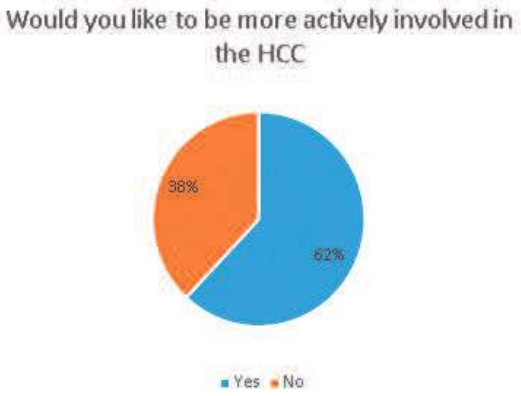
2015-2020 HCC Strategic Plan

In the last edition we asked for your feedback on key questions to inform as we formulate our new Strategic Plan. We included the link to a survey, as well as a hard copy for you to complete to provide feedback. We would like to thank you for your time, and we look forward to being able to share the Plan once it is finished.

We are working on the Strategic Plan as we speak, and your feedback has been very helpful in helping guide our direction. We received just over 50 responses.

Maternal and child health

64% Strongly Agreed/Agreed that they enjoyed reading Health Matters and 62% would like to be more actively involved with the HCC.



The survey is now closed but we are always open for feedback via info@hconc.org.au

Your feedback, staff and Board feedback from the recent workshop held and interviews with key agencies will be compiled into a Strategic Plan which will be available at our AGM. We look forward to sharing this with you.

AGM

The HCC AGM is on Wednesday 30th September at the WA Department of Health Theatrette. For further details see page 21.

Pip Brennan
Executive Director
Health Consumers' Council

Maternity Services reform, where are we now?

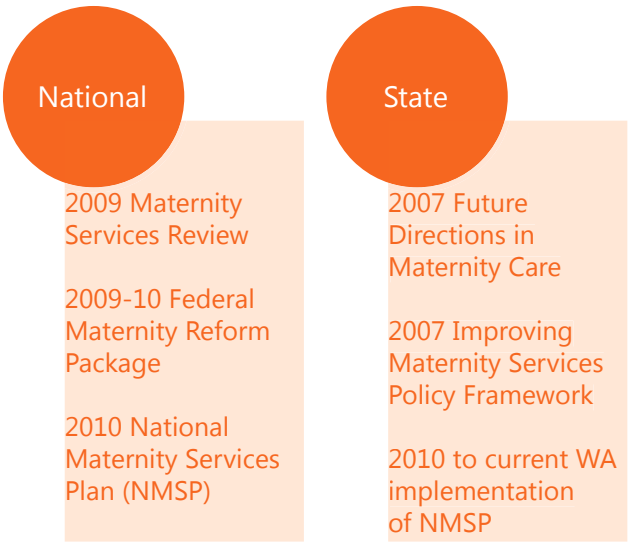
Pip Brennan Executive Director | HCC

Continuity of Care: The evidence

"The provision of continuous care across the maternity pathway by a known carer has been demonstrated to have a beneficial impact on outcomes." (from the National Maternity Services Plan)

The evidence is clear; reports from our government highlight continuity of care by a known carer in maternity health benefits the patient, these results aren't controversial. However what constitutes continuity of care has been hotly debated, and the Australian Institute of Health and Welfare has put in significant resources to ensure there is consistent measurement.

Maternity Reform Agenda



In 2009-10 a $120.5 million federal maternity reform package was announced. This included the somewhat revolutionary step of providing access for Midwives to the Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Schedule (PBS). To access the MBS and PBS, Midwives need to under take further training, including a prescribing course, to be registered as an Eligible Privately Practising Midwife with the newly constituted national Nurses and Midwives Board.

The Vision

In 2010 the National Maternity Services Plan was released which had a five year vision;

- Maternity care will be woman-centred, reflecting the needs of each woman within a safe and sustainable quality system.
- All Australian women will have access to high quality, evidence-based, culturally competent maternity care in a range of settings close to where they live.
- Provision of such maternity care will contribute to closing the gap between the health outcomes of Aboriginal and Torres Strait Islander people and non-Indigenous Australians.
- Appropriately trained and qualified maternity health professionals will be available to provide continuous maternity care to all women

Taken from the National Maternity Services Plan 2010 available at: http://www.health.gov.au/internet/main/publishing.nsf/ent/8AF951CE492C799FCA257BF0001C1A4E/$File/maternityplan.pdf

The reality in WA

The sticking point for the implementation of reforms is that midwives had to demonstrate that they were working in collaboration with medical providers. Medical providers in other states were willing to, in small numbers, but in WA none were able or willing to collaborate, and the reform has stalled.

The West Australian Minister for Health has long been a champion of these reforms. Recent developments have worked to move beyond this barrier, by enabling Midwives to have a collaborative arrangement with a health service rather than an individual provider. This edition looks at the issue from both a consumer and an eligible midwife's view on how these reforms are being enacted.

To broaden the conversation, HCC and Women's and Newborn's Health Network are partnering to create an update event for maternity providers and consumers. This will take place at Fiona Stanley Hospital on Wednesday 21st October, see advertisement on the next page for booking details.

Joining the Dots in Maternity Care

The National Maternity Services Plan is in its final year, with the ongoing implementation of these reforms in WA, it is time to come together and take stock. The Health Consumers' Council (HCC) and the WA Health Networks have partnered to present a Sector Update Forum.

Guest speakers include: The Women's and Newborns Health Network Co-Lead; Tracy Martin, Principal Midwifery Advisor; Tamzin Mondy, Privately Practicing Midwife; Alison Gibson, Coordinator, Moort Boodjari Mia; and Pip Wynn-Owen, Child birth educator. More guest speakers to be announced.

There will be opportunities to ask questions of the speakers and time for networking throughout the day.

FORUM DETAILS

When	Wednesday 21st October
Time	9:30am to 2:30pm
Venue	Fiona Stanley Hospital

Morning Tea and Lunch are provided, please notify the HCC of any special dietary requirements.

RSVP by COB Monday October 12th via info@hconc.org.au or (08) 9221 3422 for catering purposes.

HEALTH CONSUMERS' COUNCIL
YOUR VOICE ON HEALTH

New pregnancy recommendations you need to know...

Catherine Hughes | Light for Riley

Riley Hughes

We know about the importance of folic acid, and avoiding alcohol during pregnancy. But did you know about the importance of pregnancy vaccination? In the wake of our baby son's death to Pertussis (whooping cough), the Australian government has recommended women should receive a dTap (diphtheria, tetanus & pertussis) booster in the third trimester of every single pregnancy. This way, unborn babies receive antibodies through the placenta, and are born with some protection against this terrible disease. This strategy was implemented in the UK, USA and New Zealand several years ago, and has seen infant deaths from whooping cough decrease by over 90%.

Our beautiful son Riley was born happy and healthy on February 13th, 2015 at King Edward Memorial Hospital in Perth. He loved breastfeeding, cuddles with his bigger sister, and rarely cried. His Dad nicknamed him 'little piglet' because when he wanted to feed he'd make grunting noises, and his sister Olivia nicknamed him 'Riley "special" Hughes' – 'because he was really special!'

When Riley was three weeks old, he developed a little sniffle. This sniffle developed into a very occasional cough, so I decided to call out a locum doctor one evening. The doctor examined Riley and assured me he was fine, which put my mind to rest that evening. However, that night Riley didn't awake for a feed, which was highly unusual for a baby who normally woke me every 2 hours! Concerned, we called Health Direct who advised us to take him to hospital, due to his newfound lethargy and lack of interest in breastfeeding.

Riley was admitted to Princess Margaret Hospital that afternoon, and at first doctors suspected he had bronchiolitis. By the next morning, they started discussing the possibility of Whooping Cough, and he was tested for it via swab test. They began treatment for it, but sadly it's not an effective treatment – it reduces the chance of the baby infecting others, but it doesn't reduce symptoms unless caught extremely early (before the cough has started. It is very rare to catch it that early!). Our poor baby boy grew steadily worse, and when he developed severe pneumonia he was taken down to the PICU ward. In PICU, he had an incredible amount of medical intervention, and his body was covered in wires and tubes. On his fifth day in hospital, his lungs completely filled with mucous and his heart began to fail. We held him in our arms and wept as he passed away at just 32 days old.

Catherine and Riley Hughes

I'd heard of whooping cough before. When our daughter Olivia was born back in 2011, WA ran a free whooping cough booster program. My husband and parents received free booster shots then, and I had mine straight after her birth as was recommended at the time. However, this program was withdrawn by the WA state government in 2012. While I was pregnant with Riley, there were

Catherine and Riley Hughes

Riley Hughes

no programs in place to help protect newborns from whooping cough. During Riley's hospital stay, I discovered that other countries had been offering whooping cough booster shots to pregnant Mums since 2011, to help protect newborns from this terrible disease. We realised we couldn't let this senseless and preventable death happen to a family, and promised Riley we'd do whatever we could in honour of his short little life.

Since Riley's death Riley's Dad and I decided to go public to advocate immunisation and prevent this disease from ending the life of another baby. We started a facebook page (www.facebook.com/LightForRiley), took part in media interviews, and raised over $60 000 for whooping cough research. 2 days after his death, the WA state government announced a free whooping cough booster program for pregnant Mums, and other states and territories soon followed. Several weeks after his death, the government announced their 'No jab, no pay' policy. We also started a campaign for the implementation of a National Adult Immunisation Register, and were pleased when the government announced this in the recent budget.

Most recently, our advocacy has included attending all of the Pregnancy, Baby & Children expos around Australia. I managed to rope in some immunisation experts from Sydney's NCIRS to attend, in the knowledge that good advocacy includes both a story and good evidence behind it! Riley's Aunty Jenni has also been a blessing and attended the Sydney expo with me (below).

Our next aim is to get whooping cough booster shots for pregnant Mums and new parents funded federally. State programs come and go, but if we can get these boosters on the National Immunisation Plan, we wouldn't have to worry about having the program withdrawn. We headed to Canberra at the end of May along with Toni & Dave McCaffery (who became incredible immunisation advocates after the death of their daughter Dana in 2009 to whooping cough) and Professor Robert Booy, head of research at the NCIRS. We met with the wonderful Senator Richard Di Natale, who had reached out to us not long after Riley's death (above). We also met with the Minister for Health Sussan Ley, and Shadow Minister Catherine King, and were pleased with their commitments to promoting vaccination in Australia.

Riley may have given up his fight against whooping cough, but we will continue fighting for him. Our ultimate goal is to protect other children and families from suffering a similar loss from a vaccine-preventable disease.

Consumer & Community Engagement Report

Diversity Dialogues: A Multicultural Perspective on Pregnancy, Birth and Postnatal Care

Louise Ford Consumer & Community Engagment Manager | HCC

Asifa Farhat & Christine Rowcliffe

Diversity Dialogues is an initiative of the Health Consumers' Council to provide a forum for members of Culturally and Linguistically Diverse (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 on to health care providers and to the Department of Health.

A Multicultural Perspective on Pregnancy, Birth and Postnatal Care Forum was held in May 2015 in partnership with WA Health's Department of Nursing and Midwifery Education and Research (DNAMER), King Edward Memorial Hospital for Women, with support from Jenny Owen, Midwifery Educator. The panel consisted of Ms Joansy Pegrum (Burma/Myanmar), Dr Asifa Asif (Pakistan), Ms Eva Mwakichako (Kenya) and Mr and Mrs Gabi and Aisha Turi (Ethiopia).

Almost seventy people attended in person and four regional areas engaged via video conferencing. The forum provides an invaluable opportunity for service providers and community members to speak face to face about concerns. It also accommodates community members being able to inform providers on a one on one basis and can help to build relationships between community and provider; it is one of the corner stones of community development and engagement.

Justine Row and Eva Mwakichako

Recommendations

During the panel discussion and Q&A session, a number of recommendations were put forward. Please feel free to share this information; some recommendations can be implemented on site whilst others will require further support.

- A need for greater service provision in this area of health in the southern corridor e.g. there is Ishar in the northern corridor
- It is important that female doctors and nurses are provided as much information as possible
- If a male practitioner has been called to a labour ward e.g. an x-ray is required, forewarn the woman so she can be aware of this and prepared
- Explain more about the placenta well before the birth and what is done with it, in Pakistan it is disposed of
- Admission paperwork, there needs to be room for specific cultural requirements
- Needs to be more information about types of

analgesia

- More information needs to be provided around contraception
- More information about support groups and playgroups
- Assisted delivery, needs to be more information provided about this during pregnancy
- People need the opportunity to build a relationship with their child health nurse, through continuity of carer, this cannot happen when they are changed all the time and discourages some mothers from engaging fully
- Needs to be more community education regarding different medical roles e.g. child health nurses
- Hospital advocacy services for CaLD
- More community mother's groups/programs: child health, could OMI be involved here?
- Redirected funding
- More midwifery group practices
- Identified community members to be liaised with by government departments etc.
- Greater explanation required of various concepts e.g. mother's groups
- Have a paid position for a liaison person who meets with/engages with communities
- More translated books/materials re development of baby, also pictorials
- Greater use of bi-cultural women: see above recommendations
- Increase services around women's health south of the river

Evaluations

Of the fifty five evaluation forms collected the majority of people who attended agreed that the forum had helped them develop greater knowledge and understanding of the importance of considering culture in their practice and that by attending this forum they had a better idea of how to work effectively with culturally diverse patients and families.

It was also encouraging to receive so many ideas for future forums, the HCC will do its best to respond over time. Diversity Dialogues is a great opportunity for sharing information and growing networks; we hope to see you at one of them.

Joansy Pegrum, Dr Asifa Asif, Eva Mwakichako, Mrs and Mr Gabi and Lousie Ford

Statewide News

Pip Brennan Executive Director | HCC

Image source: http://blog.udiawa.com.au/article/access-to-the-cbd-losing-importance

The Acting Director General of Health, Professor Bryant Stokes has made way for the new Director General of Health, David Russell-Weisz. Russell-Weisz will oversee the significant new reforms in WA Health which most people are familiar with, namely the replacement of the Governing Councils and with Area Health Service Boards. This project is known as the Governance and Legislative Reform Project.

See here for further information:

ww2.health.wa.gov.au/~/media/Files/Corporate/general%20documents/Health%20Service%20Boards/Fact-Sheet-Changes-to-the-governance-of-WA-Health.ashx

ww2.health.wa.gov.au/~/media/Files/Corporate/general%20documents/Health%20Service%20Boards/Fact-Sheet-Legislative-Reform.ashx

Fiona Stanley Hospital

The Independent review by the Australian Commission on Safety and Quality in Health Care and MMK Consulting into operational clinical and patient care at Fiona Stanley Hospital was commissioned by WA Health's former Acting Director General the report went public on 23rd July 2015.

There were a range of recommendations, including that their Consumer and Community Advisory Council work with the Safety, Quality and Risk Unit to develop and implement key 'Patient Experience' performance indicators to improve the patient journey. Also that the Customer Liaison Patient and Family Liaison Service to reflect the focus on patients and their families/carers. Many recommendations highlighted the need for better communication, especially between clinicians and health executive staff who make the decisions. See the full report here:

ww2.health.wa.gov.au/~/media/Files/Corporate/Reports%20and%20publications/PDF/FSH-Review-FINAL-26-June-2015.ashx

Clinical Senate Debate: Dial E for Engagement, are Clinician's on Hold?

On 5th June 2015 the Clinical Senate met for the second time in 2015. This time the focus was on clinician engagement. The focus of the debate was on "strategies to engage clinicians so that healthcare reform can occur at the facility level."

John Clark from the Kings Fund in the UK, who is also an advisor for WA Health's Institute for Health Leadership noted "More patients suffer needless harm (and death) through poor management and leadership than due to clinical incompetence". The importance of better engaging with clinicians cannot be underestimated. Child and Adolescent Health's Frank Daly noted that "one of the best predictors of mortality in acute hospitals is the percentage of staff who are working in well-functioning teams".

Recommendation 9 of the Clinical Senate Debate was that "WA Health to adopt an online moderated platform* (specifically 'Patient Opinion Australia' and 'Carer Opinion Australia') in order for health services and clinicians to listen to and engage with the experiences, good and bad, of consumers and carers.

We will await to see the results of these Recommendations, and how many of them will be considered by WA Health, at the next debate on 4th September 2015. The focus of this debate is Outpatient Care.

National News

Pip Brennan Executive Director | HCC

In August the HCC Executive Director attended the Consumers' Health Forum Stakeholder Event in Canberra. The purpose of the event was to highlight to important federal health review projects which are currently occurring.

Professor Bruce Robinson presented on the Medicare Benefit Schedule Review Reform which aims to review the more than 5,500 services listed on the Schedule, many of which are not evidence-based.

The following Clinical Committees and working groups are being set up and they are looking for consumer representatives:

- Diagnostic Imaging Clinical Committee (including Working Groups for priority reviews of: bone densitometry; imaging for pulmonary embolism and acute deep vein thrombosis; imaging of the knee)
- Ear, Nose and Throat (ENT) Surgery Clinical Committee (including priority reviews of: tonsillectomy; adenoidectomy; grommets)
- Clinical Haematology Clinical Committee (including priority reviews of: blood transfusion services; iron studies; coagulation studies)
- Obstetrics Clinical Committee
- Thoracic Medicine Clinical Committee (priority reviews of: sleep studies; respiratory function tests)
- Gastroenterology (priority reviews of: upper and lower GI endoscopy and colonoscopy)
- Rules and Regulations Committee

If you would like to nominate send your name, e-mail contact, and clinical interest to MBSReviews@health.gov.au.

Dr Steve Hambleton spoke to the Primary Care Reform entitled 'Better outcomes for people living Chronic and Complex Health Conditions through Primary Health Care'. Consultations were held across the country in August, and a survey which has since closed sought public opinion on how best to support consumers in primary care. See the Discussion paper here, www.health.gov.au/internet/main/publishing.nsf/ and if you would like further information contact PHCAdvisoryGroup@health.gov.au

The Honourable Sussan Ley introduced the session and spoke very confidently and positively of these two very significant pieces of reform. While it was pleasing to have both project leaders presenting in a coordinated way for the session, there is always concern that the reforms may progress in isolation.

For example, the Primary Care Reform may well identify that having a fee for service model in all situations does not support the Reform's stated objective of being consumer centred. However Dr Steve Hambleton is on both Project Teams and CHF will keep HCC informed of progress.

The final part of the day was the presentation of the CHF Strategic Plan which has these main five objectives:

OBJECTIVE ONE: Develop and promote consumer-centred health system policy and practice to governments, stakeholders, providers and clinicians

OBJECTIVE TWO: Engage with the members of CHF to ensure collective consumer voices are involved in the co-design of health system change and innovation

OBJECTIVE THREE: Generate new and harness existing evidence to shape and co-create consumer-centred health policy and practice

OBJECTIVE FOUR: Partner strategically to achieve a consumer-centred health system

OBJECTIVE FIVE: Sustain and grow a member-driven, values based, reputable and well governed organisation

The full plan can be viewed online at www.chf.org.au/pdfs/chf/CHF-Strategic-Plan-2015-18.pdf

The HCC ED leveraged the trip to attend a meeting of HCCs from ACT, SA, Victoria, Queensland and NSW, with CHF in attendance. CHF CEO Leanne Wells attended for the morning and Policy Officer Jo Root for the whole day. The agencies discussed areas of mutual interest such as membership bases, consumer representative programs, funding, databases etc. HCC presented on outcomes based contracting and there was a general interest in collaborating to report to the same outcomes.

Birthing Options, be informed...

Ms Robyn Wright | Midwife

Source: Deposit photo

Why are women opting to forego the 'perceived' pain of natural labour? When the post-operative pain of a non-medical caesarian section can linger for up to 3 months or longer. Perhaps exaggerated labour scenes in movies (a poor comparison to reality) have created a fear of a natural birth? Or is it because of exaggerated labour horror stories from friends glossing over the truth for effect?

As a midwife for 30+ years I have seen, heard and despaired over the many unfortunate repercussions due to early induction and unnecessary caesarean sections. I advise prospective parents to consider the facts before opting for a non-medical caesarian section.

The Duchess of Cambridge is a glowing modern example of a wise expectant mother who didn't deny the possibility of a caesarean if necessary, but patiently waited for labour to begin in its own time. On July 22nd 2013 a healthy Prince George was born. His first photograph indicated he was 'overdue' with his size and apparent dry wrinkly hands. Catherine appeared healthy and in no apparent discomfort, with her labour from beginning to end within 11 hours, maybe less. We can only assume she was not 'too posh to push!'

Labour can be bearable with a suitable support person and if it not, modern epidurals can help. However an induced labor with medication might imply that the baby may be heading for a delivery via some form of instrumental intervention. In a non-induced labour, contractions rest in between, sometimes even allowing time for a snooze. The third stage is when the contractions are the strongest and the "Yes, I did it!" moment is close!

Early intervention by induction should only be for a legitimate reason with informed consent, following a lengthy discussion with your obstetrician.

Why is this necessary? For example you may be informed that the incessant regular pain of artificially stimulated contractions via Syntocinon, are much sharper and stronger than the labour nature intended. Few obstetricians will mention possible risks, why? Because some prefer to perform the procedure when they're ready, not when you and the baby are!

With little effort expectant parents can research the options available to them and make an informed decision. It might mean the difference between a long or short recovery period and a reduction in risk to you and your unborn child.

Footnote: On 2nd May 2015 Catherine and William's second child Charlotte was born. Her first photo showed a healthy chubby princess, weighing 3.7 kg. A week overdue with 2 to 3 hours of labour, presumably a vaginal birth. Mother and child were discharged home after only 12 hours.

References: drjengunter.wordpress.com/2011/09/09/persistent-pain-after-a-c-section-when-is-it-nerve-pain-and-what-can-you-do/

www.bellybelly.com.au/pregnancy/40-reasons-to-give-baby-40-weeks-of-pregnancy#.Ug2BpssaySM

Midwifery led care

Wallis Hearn | Guest Contributor

Wallis Hearn and daughter

Six months ago I gave birth to my daughter at King Edward Memorial Hospital with the support of a private midwife. When I found out I was pregnant I followed the usual path in Western Australia of being referred by my GP to an Obstetrician/gynecologist (OB/GYN). I expected that because I wasn't keen on a home birth (given this was my first birthing experience), and because I had private health insurance, I would give birth in a private hospital under the care of an OB/GYN.

At 32 weeks pregnant I realised this model of care wasn't going to work for me. Despite the best professional intentions of the OB/GYN, I felt my birthing experience had to fit in with his expectations, not mine. It was disempowering, everything felt 'medicalised' as if I, with a female body, would be unable to cope.

I felt that my hope to have a spontaneous natural birth, with as little intervention as possible was unlikely to happen in his care. So I searched for an alternative, which as it turns out in Western Australia is quite hard to find. I wasn't happy to just 'go public' as I wanted the support of someone during my labour who I had met previously and built a rapport.

Fortunately for me, I came across a private midwife who had been able to negotiate an arrangement to provide labour and birth care to me in hospital.

While I was admitted as a public patient my care was provided by my chosen, private midwife. This felt like the best of both worlds. Here was a woman who believed in the normality and the natural ability of women to experience birth with minimum, or without, routine intervention, but with the obstetric team at a tertiary hospital available should I need their assistance.

This worked for me. My midwife and I were in partnership, with the needs of myself, my partner, and subsequently our new family, assessed on a holistic and frequent basis. Appointments were up to 1.5 hours (if necessary) when all manner of fears, options, planning and referrals to other professionals, were discussed in a loving and supportive environment. It was in stark contrast to the perfunctory 12-minute maximum, box checking, characteristic of meetings with the OB/GYN.

It's no surprise that going through pregnancy and childbirth for the first time is an intensely challenging period for the soon to be mother. Her identity, financial and other independence is changing, her relative physical immobility makes her feel vulnerable, and she is suddenly deemed 'public property' with all manner of unsolicited comments and opinions from (mostly) well-meaning people about her appearance and/or choices.

It is in this hyper-sensitive context that women need to feel even more supported and empowered than ever. For me, I found this by being in the care of a woman:

- who truly believes that my body is incredibly well-designed and made for giving birth;
- was 100% supportive and encouraging of my need to be active during labour;
- who was understanding of my fears of epidurals and gave constant reassurance that I could, and would, be able to give birth without intrapartum analgesia; and
- who was intelligent, knowledgeable, professional but also sensitive and emotionally intelligent.

I would happily recommend this model of care to any new mother, and I wish that this option was more widely known and accepted in Western Australia.

Coeliac Disease, Fertility & Pregnancy Outcomes

Coeliac WA

Image source: www.naturalbalancefoods.co.uk/community/dietary-needs/gluten-free-diets-not-just-for-coeliacs/

Coeliac disease is one of the most common autoimmune disorders in Australia, and also one of the most under diagnosed(1). The classic symptoms are malabsorption related and include chronic diarrhoea, bloating, fatigue, nausea and vomiting. It is now recognised that people living with coeliac disease can experience many non-gastrointestinal symptoms, and important data has accumulated in recent years regarding the association between coeliac disease, infertility and pregnancy outcomes(2).

Coeliac disease is an autoimmune disorder characterised by inflammation of the small intestine's absorption surface, induced in genetically predisposed individuals by ingestion of gluten (a protein found in wheat, rye, barley and oats). The chronic inflammation of the small intestinal mucosa, impairs digestion and absorption of nutrients(1). Some of these nutrients, including folic acid, vitamin B12, zinc, selenium, vitamin D and iron are critical for normal egg, sperm and embryo development and ongoing growth for a normal healthy baby(4).

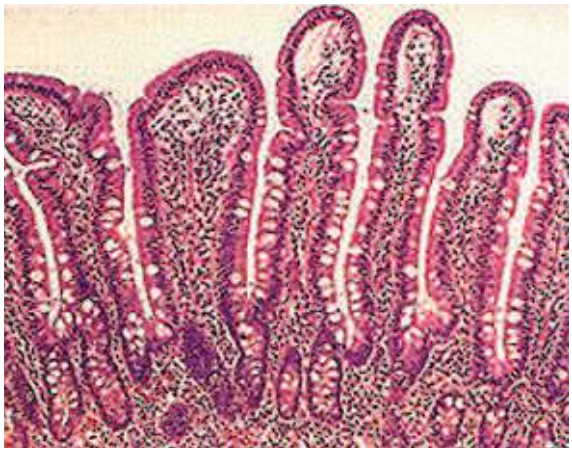
'The prevalence of untreated coeliac disease is at least three times higher in women experiencing fertility problems compared to the general population(3).'

The prevalence of untreated coeliac disease is at least three times higher in women experiencing fertility problems compared to the general population(3). Reduced fertility, menstrual irregularities, earlier menopause, increased risk of miscarriage, preterm labour and intrauterine growth restriction have all been reported in those with undiagnosed coeliac disease. Increased caesarean section rates and reduced duration of breastfeeding have also been reported(2).

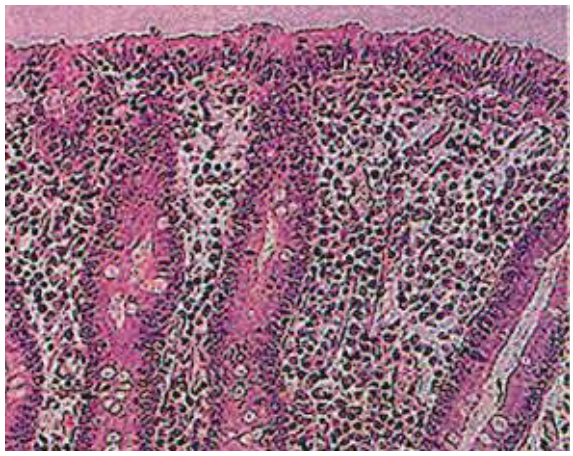
Some studies have reported increased sperm abnormalities, such as a reduced number of normal, moving sperm(6), however more work is needed to determine the effects of coeliac disease on the male's contribution to the baby and reproductive function.

'The consensus amongst researchers remains that coeliac disease should be considered in cases of unexplained fertility(4,5).'

The consensus amongst researchers remains that



A healthy small intestine absorbtion surface (villi)



A damaged small intestine absorbtion surface (villi)

coeliac disease should be considered in cases of unexplained fertility(4,5). In many cases, women with infertility issues related to coeliac disease aren't diagnosed until a family member is diagnosed with the condition. In addition, long-term undiagnosed coeliac disease leaves people at increased risk of other medical conditions, such as osteoporosis, thyroid disease, lupus, rheumatoid arthritis, and lymphoma(7).

Diagnosis of coeliac disease can occur at any age, initially by non-invasive blood testing, so the earlier it is diagnosed the better the long term reproductive and general health of individuals. For those with a positive diagnosis, treatment with a gluten free diet has been shown to reduce the relative risk of miscarriage by nine times in one study(4), and significantly improved fertility(3) and reduce pregnancy complications in others(5).

Important points to remember:

1. **Getting the correct diagnosis of coeliac disease is imperative -** Clinicians should consider coeliac disease for any couple presenting with a history of unexplained fertility problems and/ or a partner with recurrent miscarriage. Infertility may be the only symptom of coeliac disease. Once the diagnosis of coeliac disease is made and a strict gluten free diet is initiated, the chance of getting pregnant should return to what is normal for their age.

2. **Once diagnosed with coeliac disease -** you must maintain a gluten free diet before, during and after pregnancy to optimise your chances of maintaining general and reproductive health. A lifelong gluten free diet is the only treatment for coeliac disease.

3. **You can have a normal pregnancy -** you can have a normal pregnancy and a healthy baby upon diagnosis and commencing the prescribed treatment for coeliac disease

Coeliac Western Australia is the peak body in Western Australia for people living with coeliac disease or medically requiring a gluten free diet. Do not hesitate to contact us for information regarding: diagnosis, membership or support on coeliac disease.

P: 08 9451 9255 | E: wa@coeliac.org.au
W: wa.coeliac.org.au

References:

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Cuddle Cots, giving time to grieve...

Kristy Wiegele | A Midwife's Gift

Cuddle Cot

Lincoln John Cook

Lincoln John Cook

Not so long ago when a woman gave birth to a stillborn baby, she wasn't encouraged to see, hold or even name her baby. Stillbirth was, and to some extent remains a taboo subject. However it is now internationally recognised that parents should spend time with their deceased baby. Cooling begins within 2-4 hours, historically this meant being transferred to the morgue. The Cuddle Cot has made this necessity a thing of the past.

In 2013 a Queensland couple gave birth to their sleeping daughter. The Emerikus Land Foundation was started in her honour with the goal to purchase a 'Cold Cuddle Cot' for all Australian Maternity Hospitals. The Cuddle Cot has been used in the UK for the last 15 years. It is a small, lightweight, discrete refrigerated unit that allows the deceased baby to remain with their parents, instead of being taken to the morgue. It gives families the gift of time, time to hold, to love, to cuddle, to grieve, to bathe and to make memories with their baby.

Lincoln John Cook was stillborn on 29th August 2014. He was the sole inspiration for A Midwife's Gift, to fundraise for a Cuddle Cot. My husband volunteers to photograph sleeping babies in the ST JOHN of God Mt Lawley Hospital maternity ward. After seeing Lincoln's photos I was moved to make a difference. He was so perfect, so divine, but not for this world. My goal became simply, one cot for one hospital.

The support we have received has been overwhelming. Donations have come from friends, family, strangers, hospitals, banks, Rotary Clubs, Mining companies and work sites. It was clear within two weeks that stopping at one cot was't going to suffice. Working in conjunction with the Emerikus Land Foundation, A Midwife's Gift has now raised over $60,000 and donated cots to 7 WA hospitals with another 5 to be donated in the near future. Most recently the WA Health Department has offered support by funding another 8 cots for our WA regional hospitals.

It is bittersweet to know that hospitals are able to offer the Cuddle Cot in such heartbreaking times. We would prefer that they weren't needed, but left to gather dust. However sadly in Australia 1 baby is born sleeping every 4 hours. Six families every day could benefit from the availability of the Cuddle Cot. For families that have used these cots the benefit has been invaluable. A Midwife's Gift will continue to fundraise until all WA Maternity Hospitals have access to a Cuddle Cot of their own.

For more information and updates on our progress or to donate to our project please visit our Facebook page: www.facebook.com/amidwifesgift

Footnote:
For her tireless efforts Kristy Wiegele received the Consumer Appreciation award at the WA Nursing and Midwifery Excellence awards 2015.

On the verge of being a credentialed midwife in WA

Tamsin Mondy | Midwife

Source: Deposit photo

I returned to Perth in the middle of 2013 after a 7 year sojourn on the east coast. Since then I have been both excited and frustrated by the pace of maternity services reform in Perth. I've been advised at almost every turn that 'things are different here in the West' and some have even gone so far as to say that 'I would never be able to do the kind of work here that I was able to do there, as women here are different to their eastern states counterparts and private midwifery practice would never work in Perth'. I have found myself battling to stay positive and proactive, refusing to get bogged in defeatist rhetoric, as I cannot accept either of those statements as fundamental truths.

I established and opened my midwifery business in August 2014, with support and guidance from my eastern states mentors and colleagues. Since then and to my delight, I have been privileged to have been employed by some courageous and wonderful women who had the foresight to understand the importance of midwifery in their journey to motherhood. These women have given me the courage and motivation to continue the relentless push towards the implementation of the maternity services reform agenda. Becoming credentialed as a midwife with private admitting rights is fundamental to the process of maternity services reform, not least because this was always the intention of the amendment to the Medicare legislation. Unfortunately it has been an inordinately slow and tedious process with much misdirection and misinformation.

Currently I am allowed to provide care for my clients in labour, under a casual employment contract at two metropolitan hospitals, however, there continues to be a degree of uncertainty at each admission as to the acceptability of this arrangement and there have been many women that I have been unable to care for as the admitting hospital refuses to engage with me at all. Whilst I honestly believe that generally people's intentions have been good, there has been a tendency to allow bureaucracy and problem-focussed thinking to stall the process. It has been difficult to find individuals who share my solutions-focussed philosophy and those who are prepared to maintain the provision of women-centred evidence based care as the basis for all decision making around service delivery.

For a midwife seeking to be credentialed and provided with an access licence agreement at any health service there appears to be inequity regarding the women we will be 'allowed' to admit and provide care. This is dependent on the personal philosophy of individuals in management, the health services contractual arrangements with other health care providers or a variety of other factors that have little or no direct bearing on what the women who employ a private midwife actually want or care about.

My clients come from a variety of professional and social backgrounds with a range of medical and obstetric risk factors. Whether they are having their first child or their fifth, they all want to engage with a health service that is dynamic, responsive to their individual needs and respectful of their choices, including who they identify as their primary carer. As a midwife seeking to be credentialed and able to exercise my private admitting rights I also want to be able to participate in respectful, collaborative, multi-disciplinary relationships. Having had the privilege of these types of relationships on the east coast in the past, I know that they are possible and I continue to refuse to accept that it can be that 'different here in the West'.

Gestational Diabetes, what you need to know...

Lucy Palermo Health Matters Editor | HCC

Some women still see pregnancy as a licence to eat, throwing good nutrition out the window and giving into all manner of cravings. Unfortunately the old adage 'eating for two' is a misconception and for some it can lead to consequences beyond gaining more weight than they should.

'In 2009-10, over 13,600 ... women aged 15-49 who gave birth as admitted patients in hospital had a diagnosis of Gestational diabetes mellitus (GDM).'(1) 'GDM is a form of diabetes diagnosed during pregnancy that lasts the duration of the pregnancy. Women with GDM are at risk of developing Type 2 diabetes and their babies are more likely to have a high birth weight and suffer birth trauma.'(2)

How to manage Gestational Diabetes during pregnancy

There are 3 things you need to do to effectively manage your Gestational Diabetes:

1. Monitor your blood glucose levels

This will be managed under the guidance of your Credentialed Diabetes Educator. Some, not all diagnosed with Gestational Diabetes will require insulin shots.(3)

2. Adopt a healthy balanced diet

- 'Eat small amounts often and maintain a healthy weight
- Include some carbohydrate in every meal and snack (e.g. Multigrain bread, bulgur, pasta, potato, lentils, chickpeas, beans)
- Choose foods that are varied and enjoyable that provide the nutrients you especially need during pregnancy. This means foods which include: calcium (e.g. Milk and cheese), iron (e.g. Red meat, chicken and fish), folic acid (e.g. Dark green leafy vegetables lightly cooked, low in fat, particularly saturated fat(e.g. use oils such as canola, olive and polyunsaturated oils and margarines and use lean meats such as skinless chicken and low fat dairy foods)
- (Eat foods that are) High in fibre
- Avoid foods and drinks containing large amounts of sugar
- Choose Basmati or Doongara rices – they have a lower glycaemic index and will help you to stay fuller for longer.'(3)

See a dietician who can provide expert advice on the proper nutrients for you and your baby, as well as helping you make healthy food choices. For more information see, www.diabetesaustralia.com.au/managing-gestational-diabetes

3. Undertake regular exercise

Physical activity helps to reduce insulin resistance. (3) It also helps to prepare your body for the added weight of carrying a baby and the physical process of giving birth. 'You will benefit with a combination of.

- Aerobic exercise, which works your heart and lungs.
- Muscle-strengthening exercise, which improves your strength, flexibility and posture.'(4)

There are many exercises suitable during pregnancy. Antenatal classes are run at most gyms and certain group classes' offer modified exercises suitable during pregnancy. To find out what exercise is suitable for you, consult with your Obstetrician or Midwife.

Please note if you do have GMD, treatment methods need to be discussed with your Credentialed Diabetes Educator, Obstetrician and/or Midwife.

Diabetes Australia has a comprehensive booklet called Gestational Diabetes: Caring for yourself and your baby, it is available at static.diabetesaustralia.com.au/s/fileassets/diabetes-australia/6d398ea2-5d33-4369-94e3-413437a151d3.pdf

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2. Australian Government, Australian Institute of Health and Welfare, New Information on Gestational Diabetes in Australia. Available at www.aihw.gov.au/media-release-detail/?id=6442464796
3. Diabetes Australia, Managing Gestational Diabetes Available at www.diabetesaustralia.com.au/managing-gestational-diabetes
4. Baby Centre, Best Exercises during pregnancy. Available at www.babycenter.com.au/a7880/the-best-exercises-in-pregnancy#ixzz3lD5beAWq

Shine a light on Lung Cancer

November is the month to "Shine a light on Lung Cancer". In WA a small group of people with Lung Cancer are working to raise community awareness about the indicators of the disease for example pain in the chest and an unexplained cough.

Lung cancer strikes at both men, women, young and old. More than 23 Australian's, die each day from lung cancer. It claims more mothers, fathers, sisters, brothers, grandparents and friends than breast, ovarian and prostate cancers combined.

'Research carried out by Cancer Australia has shown a stigma surrounds people with the disease in relation to its cause. The perception is Lung Cancer is caused only by smoking, despite non-smokers being diagnosed with the disease.'

Research carried out by Cancer Australia has shown a stigma surrounds people with the disease in relation to its cause. The perception is Lung Cancer is caused only by smoking, despite non-smokers being diagnosed with the disease.

Another issue raised was that between 2006 and 2011 in terms of societal impact, Lung cancer in particular was underfunded. This possibly reflects a long held view that little can be done.

'These perceptions need to be challenged. With new treatments/ interventions now available and lung screening being discussed, there are potential strategies and information available to challenge negative opinions.'

These perceptions need to be challenged. With new treatments/interventions now available and lung screening being discussed, there are potential strategies and information available to challenge negative opinions.

"Shine a light on Cancer", Lung Cancer Awareness Month, November

Lung Foundation Australia invites, those with the disease, their carers and supporters to come and gather to gain an update on current information, knowledge and friendship. There will be music and light refreshments will be served.

When	November 5th, 2015
Where	Australian Institute of Management Leadership Centre Cnr Underwood Ave & Selby St, Subiaco

For further information and to RSVP contact Kristen Mooney or Caitlin Broderick via the following:

Kirsten.mooney@health.wa.gov.au
or 0400 023 296;
Caitlin.broderick@health.wa.gov.au
or 0438 910 582

Aboriginal Advocacy Service Report

Laura Elkin Aboriginal Advocacy Manager | HCC

Sorry Day 2015, Wellington Square

Nine years ago the Aboriginal Advocacy Program first began at the Health Consumers' Council with both state and Commonwealth Government funding. We reported in the last Health Matters that we were unsure of whether the program would retain the majority of our funding from the Commonwealth Government.

We can now report we have received a final year of funding. The challenge is to seek funding for the program beyond June 30th 2016, like many other Aboriginal programs across the country.

Sorry Day 2015, Wellington Square

WA Constitutional Recognition of Aboriginal People

On August 19th the West Australian Legislative Assembly passed the Recognition of Aboriginal People Bill and came one step closer to becoming the last mainland state to recognise Aboriginal people in our state constitution. Introduced as a Private Members Bill by Josie Farrer, a Gidja woman and Member for Kimberley, it will amend the WA Constitution to officially recognise Western Australia's Aboriginal people as the first people of this land.

> *"this is the opportunity for us to stride into the future, not shuffle forward with eyes closed from the truths of the past." (Josie Farer)*

In parliament Josie Farer said: "I say to you here today, fellow members of parliament, that this is the opportunity for us to stride into the future, not shuffle forward with eyes closed from the truths of the past. This is the chance to come together as a Parliament and as a community in a sincere, mature, heartfelt spirit of reconciliation."

Aboriginal and Torres Strait Islander views on Australian Constitutional Recognition

At the same time the Prime Minister has changed his mind and now intends to allow Aboriginal and Torres Strait Islander community consultations regarding recognition as First Nations peoples in the Australian Constitution.

He previously did not support Aboriginal and Torres Strait Islander people having our own forums, claiming it would jeopardise national consensus on the referendum. This is essential as there are diverse views across our communities that must be included in this national discussion for any recognition to be meaningful.

HCC NAIDOC Event 2015

Leah Cooper Aboriginal Advocacy Officer | HCC

Deputy Chair Cheryl Holland and Marissa Verma, Bindi Bindi Dreaming

The Health Consumers Council held our inaugural National Aboriginal and Islander Day of Celebration (NAIDOC) event on the 8th July 2015. Every year the National NAIDOC Committee creates a theme to be celebrated by all states. This year the theme highlights Aboriginal and Torres Strait Islander peoples' strong spiritual and cultural connection to land and sea. The theme is an opportunity to pay respects to country; honour those who work tirelessly on preserving land, sea and culture and to share the stories of many sites of significance or sacred places with the nation. The 2015 NAIDOC Theme was chosen specifically to highlight and celebrate the anniversary of the "Handback" of Uluru (Ayers Rock) to its traditional owners on the 26th of October 30 years ago;

"We all stand on sacred Ground: Learn, Respect and Celebrate".

The Health Consumers Council delivers the Aboriginal Advocacy Program and there was a need to hold such a significant cultural event. As with all NAIDOC events the day was organised to have an environment of celebration for the staff of the HCC and invited guests. The event was attended by approximately 50 people from the various health sector Aboriginal and non-Aboriginal organisations. Children of staff also attended as a powerful symbol of how cultural awareness must be carried forward with the next generation.

The Welcome to Country was performed by celebrated Noongar elder Dr Richard Walley OAM. Richard Walley is one of Australia's leading Aboriginal performers, musicians and writers, who has been a tireless campaigner for the Aboriginal community. Richard is a fluent speaker of the Nyungar language and his special "Welcome to Country" was perfectly suited to the event. As a multi-talented man he played didgeridoo, spoke eloquently about his childhood memories of East Perth, and the significance of the land in the East Perth region where HCC is situation. He set a wonderful tone for the event.

Marissa Verma from Bindi Bindi Dreaming (event sponsor), a Noongar organisation offered a cultural experience with significant knowledge and information. As well as seeing, touching, and smelling the wonders of the natural bush tucker, there were food delights made from natural bush foods found on Noongar land.

Other catering was supplied by event sponsors, Kuditj (meaning think and reflect) Café which included kangaroo, emu and crocodile items, damper and many bush tucker relishes and spreads.

The event was capped off with the cutting of a beautifully designed cake with the HCC logo on top. The room was transformed with balloons in the Aboriginal and Torres Strait Islander flag colours, and information about the NAIDOC history, 2015 theme and the display of the Aboriginal and Torres Strait Islander flags.

Everyone had a great day with much conversation, laughter and sharing information of local aboriginal culture.

Dr Richard Walley

Advocacy Service Report: Time to tackle inadequate disclosure of medication risks to consumers

Dr Martin Whitely Advocacy Manager | HCC

Medicines Product Information sheets provide health professionals with the scientific information they require to safely and effectively dispense prescription or pharmacist-only medications. The information is supplied by the drug manufacturer and covers a range of information including pharmacology, contraindications, adverse effects, clinical trials and the poison schedule of the medicine. (1) Where there are severe risks Product Information sheets will have a 'bolded boxed warning', issued by the Therapeutic Goods Administration (TGA).

Product Information sheets are almost never given to consumers. A Consumer Medicines Information sheet (CMI) is produced for consumers. TGA regulations require that the CMI sheets are available to consumers on request. So consumers only get at CMI if the prescribing doctor or dispensing pharmacist gives them one; or if the manufacturer includes a CMI inside the pill box; or if they ask for one.

The information provided in a CMI includes the ingredients, dosage, side effects, how to use the medicine properly and contra-indications. However, unlike the Product Information sheet, CMI's do not need to carry the highest possible 'boxed warnings' in the same format. The wording can differ and often the format doesn't adequately highlight the warning to consumers.

Despite no standard requirement for the CMI to have a prominent form of boxed warning, the TGA can request this when the boxed warning is imposed on the Prescribing Information. It is up to the drug companies whether they comply or not. Commendably some pharmaceutical companies portray the boxed warning information prominently. For example Aspen Pharmacare Australia have provided a bolded and boxed warning on the front page of the CMI for Doloxene (dextropropoxyphene napsylate), a pain relief medication which can be fatal even with a small overdose.(2) Another example of a prominent warning is for Stilnox (zolpidem tartrate), a drug for insomnia. Although the warning is not in a box, it is bolded and at the top of the CMI.(3)

On the other hand Eli Lilly's ADHD drug Strattera CMI leaflet does not highlight an obvious warning for the risk of suicidal thoughts, despite the issue of a boxed warning in the Product Information by the TGA in 2006. The boxed warning required on the Prescribing Information states;

> 'Strattera increases the risk of suicidal thinking in children and adolescents with ADHD. Patients who are started on therapy should be observed closely for clinical worsening, suicidal thinking or behaviours, or unusual changes in behaviour. Families and caregivers should be advised to closely observe the patient and to communicate changes or concerning behaviours with the prescriber.'(4)

The CMI for Strattera, however, only mentions thoughts or talk of suicide amongst all other signs listed to watch for, including insomnia, irritability, and anxiety.(5) There is no obvious warning on the CMI to alert consumers to the risks.

Companies like Eli Lily should not benefit by being 'less than forthcoming' about safety and efficacy data. Consumers must have easy access to information concerning drugs they are being prescribed. Strengthening CMI requirements to properly reflect issued warnings would assist consumers in making informed decisions. Putting warnings on the outside of pill containers would be even more effective.

References:

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3. 'Stilnox', Consumer Medicine Information. Available at http://www.sanofi.com.au/products/aus_cmi_stilnox.pdf
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Health Consumers' Council Annual General Meeting: 30th Sept 2015

The Health Consumers' Council Annual General Meeting will take place on Wednesday 30th September, 2015 from 5:30 to 7:30pm. At the Department of Health Theatrette 'D' Block 189 Royal Street, East Perth.

We are please to announce that our guest speaker this year is Dr Tarun Weeramanthri (pictured), Assistant Director General of Public Health, WA Department of Health.

Dr Weeramanthri has worked in diverse aspects of public health for the last 30 years, including public health research, policy and practice in the prevention of common chronic diseases, and addressing Aboriginal health gaps.
He was in clinical practice from 1984 – 2007, including 15 years as a part-time specialist general physician, with a particular focus on outreach to Aboriginal communities.

Dr Weeramanthri has been the Chief Health Officer in Western Australia since 2008, previously in the Northern Territory and was awarded the Sidney Sax Medal by the Public Health Association of Australia in 2014.

His goal is to lead a state public health division in Western Australia internationally recognised for its excellence in both traditional and new areas of public health practice.

We hope to see as many members as possible at the AGM to hear Dr Weeramanthri speak. Members are invited to join the Board and staff for light refreshments after the formal proceedings have concluded.

Members please RSVP (for catering purposes) via email info@hconc.org.au or call (08) 9221 3422 by Wednesday 23rd September, 2015.

HCC and WA Department of Health, Public Health and Clinical Services Division celebrated signing a letter of exchange, August 26th, 2015.

HEALTH CONSUMERS' COUNCIL

YOUR VOICE ON HEALTH

Health Consumers' Council

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