

Have You Heard of Rheumatic Heart Disease? As a Midwife, You Should Have!



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A maternal death caused by rheumatic heart disease (RHD) would not have come as a surprise to a doctor attending a pregnant woman in the year 1893. Flora Gilchrist Green, my great, great, grandmother died of 'heart disease and mitral regurgitation, pulmonary congestion at seven

months gestation.' A farmer's wife leaving behind four children (10, 8, 5 and 3 years old) would have been a tragedy, but of its time this was not unusual. You can imagine my surprise when my Mum emailed me a death certificate, asking what Flora died from. This was while I was working on a research project studying RHD during pregnancy.



Kylie's great, great, grandmother Flora

It is a sad story. But what is more disturbing is that whilst acute rheumatic fever (ARF) and its resultant condition, RHD, have been largely eliminated from wealthy countries today, including from the vast majority of the Australian populations, Aboriginal and Torres Strait Islander people still have among the highest rates in the world. ARF/RHD exists almost only in disadvantaged communities and is 100% preventable, by prevention of a simple throat or skin infection!

ARF is an illness caused by an immunological reaction to the group A streptococcus (GAS) bacteria (RHD Australia (ARF/RHD writing group), National Heart Foundation of Australia & Cardiac Society of Australia and New Zealand, 2012). It causes an acute, generalised inflammatory response and

affects the heart, joints, brain and skin. Detection and early treatment of sore throats and skin sores, prevents the development of ARF and therefore RHD. Not everyone is susceptible to ARF and not all strains of GAS cause ARF¹. While addressing the social determinants of health and crowding in households (GAS is more readily spread in these conditions) requires a whole of society approach there is much a midwife can do by providing education specifically on prevention of ARF and recognising the signs and symptoms of ARF and RHD.

Indigenous Australians are up to eight times more likely than other Australians to be hospitalised for ARF and RHD, and nearly 20 times more likely to die from the disease (55 times more likely in the Northern Territory (NT). In the NT in 2010, the prevalence rate of RHD among Aboriginal and Torres Strait Islander people was 26 times the rate for non-Indigenous people. Maori, Pacifica Islander and refugee populations are also affected and at risk of this disease.

Approximately twice as many women have the disease than men and close to 100 women with RHD birth per year across Australia. Pregnancy presents a potentially dangerous time for the woman with RHD and her unborn child. Cardiac output increases during pregnancy between 30-50% placing extra pressure on the woman's heart and its valves. This impacts the ability of the damaged valves to work, and can actually worsen the severity of the disease from mild to moderate/severe. While mild disease is relatively safe if the woman is monitored closely by a team of cardiologists, obstetricians, midwives and Indigenous health workers, moderate and severe disease presents a different story. Heart failure, pulmonary oedema, atrial fibrillation and death can occur with moderate/severe disease. Babies of mums with RHD are at greater risk of stillbirth, prematurity & complications.

How do you know if a pregnant woman has RHD? Women without a known diagnosis of RHD can present with shortness of breath. Not an uncommon complaint is, "I need extra pillows to sleep at night, I wake with no breath." Tragically, what is happening is heart failure and pulmonary oedema filling the lungs. A midwife can 'think RHD' in the 'at risk' population, and trigger referrals for cardiac echo's to diagnose RHD.

Many women with RHD have to relocate to tertiary centres for long lengths of time, away from family supports and their children. This will affect their ability to engage in their care, and consideration needs to be made as to how to support her. Where possible, one important step that can be made

is bringing family to support her (Kelly, Dwyer, Pekarsky, Mackean, Willis, Battersby, & Glover, 2012).

Women who have had heart valve surgery and are on blood thinners are not high in numbers, and require pre conception planning and careful monitoring during pregnancy and birth for best outcomes.

The Australasian Maternity Outcomes Surveillance System (AMOSS) is soon to release findings from a two year mixed methods study, reviewing the outcomes for mother and baby with RHD during pregnancy (<http://www.amoss.com.au/rhdinpregnancy>). Early data from AMOSS shows an alarming disparity, with the majority of RHD cases being Aboriginal and/or Torres Strait Islander, with the majority of cases in the Northern Territory. Women born overseas from Asia, Africa and Pacific region also formed a significant representation in the study. The women who participated in the AMOSS study were all different, and all had unique stories, but one thing was common to all; the women suffered from great social disadvantage. Poverty, hunger, domestic violence, minimal English or access to appropriate education and health service information where there is a major disconnect – the list goes on.

The midwife plays a critical role in achieving best outcomes.

There are so many competing health issues to learn about so why should this disease be such a priority and matter to midwives?

RHD matters because this disease should not exist in Australia. When I relate stories about RHD to colleagues, a common mantra is shared, "This disease is different, RHD is a tragedy." I have heard this from too many midwives, too many times. Stories of woman being mis-managed for asthma or pneumonia, when tragically the underlying condition was was RHD which after 28 weeks, when the cardiac changes are at their highest point, can lead to a critically ill woman, emergency evacuations, dislocation from family and compromised outcomes for the unborn child. It is not uncommon for me to hear from midwives that they do not know how to detect, manage and prevent RHD.

The midwife may be the person best placed to detect this hidden disease or in known cases, assist the pregnant woman navigate complex health systems, fraught with information black holes and confusion.

- Coordination of care is complex for a pregnant woman with RHD.
- Sharing of medical records, including cardiac echo's between services
- Administration of long acting Bicillin injection every 28 days, which is safe during pregnancy.
- Ensuring 'wrap around' services in place (housing, food security, domestic violence support)

- Ensuring health information is provided in the woman's first language. If the woman understands causation of ARF, she can seek treatment for skin sores/sore throats to prevent ARF in the next generation.
- Pre-conception planning, contraception and baby spacing is important.

How can RHD Australia help midwives?

RHD Australia is using the knowledge gained from AMOSS, to ensure the most recent information is available to midwives, as well as working to embed education on RHD into undergraduate and postgraduate midwifery education.

How is RHD Australia achieving this?

- Creation of a steering group of experts in education, midwifery and rheumatic heart disease across Australia.
- Sharing existing resources in this education space.
- Creating a 'grab bag' of multimodal resources for educators to include in midwifery curricula and courses.
- Creating a poster to encourage midwives to do the free eModules specifically for pregnancy. We recommend the health worker module and the clinical module for pregnancy. Recognised by ACM with CPD points (<https://www.rhdaustralia.org.au/e-learning-discussion-forum>.)
- Incorporating cultural awareness and capability through the inclusion of 'Two Worlds Together work to ensure culturally appropriate education is delivered.

RHD Australia has a wide range of resources available from our website. Our new work builds on the current resources, ensuring the whole story is included in the teachings, not merely discussion on the disease process. T

To learn more please visit our website and download our diagnosis App (<http://www.rhdaustralia.org.au/resources/arf-rhd-guideline-app-diagnosis-calculator-iphone>) and see how you could start making a difference as a midwife to RHD today.

References

- Kelly, J., Dwyer, J., Pekarsky, B., Mackean, T., Willis, E., Battersby, M. & Glover, J. (2012). *Managing Two Worlds Together: Stage 2—Patient Journey Mapping Tools*. Melbourne: The Lowitja Institute. Retrieved from http://www.flinders.edu.au/medicine/fms/sites/health_care_management/mtwt/documents/M2W%20Stage%202-5.pdf
- RHDAustralia (ARF/RHD writing group), National Heart Foundation of Australia and the Cardiac Society of Australia and New Zealand. (2012). *Australian guideline for prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease* (2nd ed.). Retrieved from <https://www.rhdaustralia.org.au/node/950/attachment> ■