

THE WINSTON CHURCHILL MEMORIAL TRUST OF AUSTRALIA

Report by:

Dr Fiona Hawthorne – 2007 Churchill Fellow

The Bob and June Prickett Churchill Fellowship to study the provision of specialised antenatal care for women whose unborn baby is most likely to die shortly before, during or soon after birth.

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Signed: Fiona Hawthorne PhD

Dated: 11.08.2008

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Introduction

This Fellowship investigated how specialised antenatal care is provided to women whose babies are likely to die before, during or shortly after birth. The Fellowship involved meeting and working with key clinicians, other staff and families in the London, Cambridge, New York, Chicago, Minneapolis and Austin. I thank them all for the generosity in meeting with me, and allowing me to observe their work and meet with women who have lived through this experience.

This Fellowship was undertaken due to the generosity of Mr “Dusty” Bob Prickett and his late wife June. Without Dusty and June’s investment in the future of Australians’ health and well-being, I would not have been able to undertake such a trip and meet so many people who are as committed to this service as I am. It is an honour to be one of Dusty’s fellows.

My heartfelt thanks to Dusty and June.

Executive Summary

Fiona Hawthorne PhD
Assistant Professor – Clinical Education,
Faculty of Health Sciences and Medicine,
Bond University
fiona_hawthorne@bond.edu.au

Project Description:

I undertook an investigation of the provision of specialised antenatal care for women whose unborn baby is most likely to die shortly before, during or soon after birth.

Highlights:

24th June 2008: Rosie Hospital Addenbrookes, Cambridge.

- Mr Christoph Lees, Director of Maternal Fetal Services,
- Ms Sabine Turpin, Lead Midwife in Prenatal Screening,
- Midwifery Counsellors
- Mr Ian Woodroffe, Neonatal Counsellor

25th June 2008: Antenatal Results and Choices (ARC), Russell Square, London

- Ms Sally George, Principal Counsellor

8th July 2008: Advocate Lutheran General Hospital, Des Plaines Chicago.

- Ms Kathie Kobler RN, Bereavement Counsellor and Diane Boyle RN, Coordinator Pediatric Palliative Care Program.

9th July 2008: Rush University Medical Center

- Ms Judy Friedrichs, Education/Quality Coordinator for Women's and Children's Services, Nursing Systems, Perinatal Death Educator/Grief Counsellor, Women's and Children's Support Program
- Ms Jennifer Misasi, Nurse Practitioner, Pediatric Complex Care Team
- Ms Maria Reyes, Perinatal and Women's Healthcare Nurse Practitioner.

14th July – 17th July 2008: Children's Hospitals and Clinics of Minnesota

- Ms Jody Chrastek, Pain and Palliative Care Coordinator
- Ms Stacey S. Remke, CIPC Coordinator, Psychosocial Team leader
- Dr Stefan Freidrichsdorf, Medical Director, Pain and Palliative Care
- Ms Martha Schermer, Clinical Social Worker
- Rev. Peter E. Lund, Chaplin.

21st July – 23rd July 2008: Austin, Texas

- Dr Robbie Davis-Floyd, Cultural Anthropologist.

Lessons Learned

I have learnt that we have the necessary doctors, nurses, midwives, counsellors and social workers and a strong pastoral care network: all that is required is a coordinated approach to this service that encompasses paediatric palliative care, home and community nursing and strong ethical advice. A service such as the one I am proposing requires no further increase in staff numbers, rather an initial educational process whereby interested people may enhance their existing skills, followed by a figurehead to help all staff liaise effectively with each other to provide the care and support required. Education, awareness and presence on-site where diagnosis is made are the key elements to the success of such a service.

Background

With the increase in both sophistication and uptake of antenatal screening, more and more families are being faced with the devastating news that their baby has a life-limiting abnormality. Traditionally, once these diagnoses have been made, families are offered counselling support as they decided whether to continue with the pregnancy or seek a termination.

For those who choose to continue with the pregnancy, some hospitals in Queensland offer on-going counselling and pregnancy support from specialised units who employ genetic counsellors or midwifery case managers. However, not all hospitals have these specialist staff, nor are they located close to where the mother lives. This is where a perinatal palliative care service would be of great benefit to these women. Loss in the prenatal time is often an unspoken loss, an unacknowledged loss for the mother and family. The potential here is for her grief and that of her family to become unresolved as well.

Currently, estimates are that more than 90% of urban Australian pregnant women undergo at least one ultrasound scan. With such a proliferation of testing available to pregnant women, epidemiologists have noted an escalation in the uptake of prenatal technologies, with now an estimated 99% of all pregnant Australian women being offered some form of prenatal ultrasound screening in their pregnancy. Consequently, it is a rare occurrence for women to go through their pregnancy without using some form of prenatal technology. However, whilst our ability to diagnose many more fetal conditions has advanced, medicine's ability to remedy or provide treatment has not progressed at the same pace.

For some families, the best response to a diagnosis of a lethal abnormality is to seek a termination. However for some, this is not an option, either on religious or philosophical grounds. Traditionally, the care offered to these families has lacked the holistic approach needed. In 2004, 44% of all perinatal deaths resulted from lethal abnormalities (Queensland Health, 2006).

That equates to over 240 families who potentially would have benefited from a comprehensive perinatal palliative care service.

By offering these families emotional, spiritual and physical care during this time, perinatal palliative care providers will help to make their experiences easier to bear. As American philosopher George Santayana said “There is no cure for birth and death save to enjoy the interval”. For these families, it is the interval that is the most precious time of all.

Programme

Rosie Hospital, Addenbrooke

- Mr Christoph Lees, Director of Maternal Fetal Services,
- Ms Sabine Turpin, Lead Midwife in Prenatal Screening,
- Midwifery Counsellors
- Mr Ian Woodroffe, Neonatal Counsellor

The discussions held with Mr Lees and his team introduced me to a perinatal palliative care service that is integrated within a busy maternal-fetal medicine department. This was a valuable insight as this is probably the model that would best suit QHealth.

The consultants review patients from the district. Once an abnormality is found, the woman and her support people meet with the team that consists of the Lead midwife and medical staff. As the pregnancy progresses, if the decision has been undertaken to opt for no critical care or intervention for the baby during pregnancy or once it is born, then midwifery counsellors and other support staff become involved. A detailed birth plan is put into place, with clear communication about the family’s wishes in the medical and nursing notes.

The team at Addenbrooke’s Hospitals are able to provide comprehensive multi-disciplinary approach to this complex and highly emotive event. If the baby survives after delivery, then the family is transferred to the care of the neonatal Unit where the same multi-disciplinary approach to the care and

comfort of the baby is provided. "Journey boxes" are offered to families to take with them after their time spent in the hospital. These may contain any item of significance from a nappy showing how small the baby was or an unused syringe to show how much milk they were being fed.

From my all too brief exposure to the team at Rosie Hospital in Cambridge I have taken away the value of a combined, respectful team approach to the care of these women and their pregnancy. This is achieved through clear communication with all staff involved in the care delivery and for that clear communication to be continued with the family.



Front entrance to Rosie Hospital.

Antenatal Results and Choices (ARC)

- Ms Sally George, Principal Counsellor

My meeting with Ms George came about after a recommendation that I meet with her from Mr Lees at Rosie Hospital. ARC is a charitable organisation that offers unbiased telephone support to people who have found themselves confused or uncertain about events that are occurring during their pregnancy. The service is designed to offer one-off support by directing their callers to other sources of information.

The service offered by the staff at ARC allows for families affected by fetal abnormality to make contact with other families who have experienced what they are currently experiencing. Their use of volunteers, via of parents who have first hand experience of fetal abnormality and psychologists who provide

their time free of charge to offer support is one aspect that I had considered but not been able to conceptualise how I might put it all together.

Advocate Lutheran General Hospital

- Ms Kathie Kobler RN, Bereavement Counsellor and Diane Boyle RN, Coordinator Pediatric Palliative Care Program.

Ms Kobler and Ms Boyle met with me and a colleague from Brisbane. During our discussion, both Ms Kobler and Ms Boyle were able to offer us some insights into the daily challenges of providing such a service to a large community. Here, they reiterated the need for a birth plan that is effectively communicated with all involved. They spoke of the practicalities of their program such as how they define those women, who are eligible for the program, the challenges of providing such a service in an organisation where termination of pregnancy is not offered routinely.

Here the lessons learnt were that it is only through persistence that such a service develops. It is an organic process that evolves from a case by case basis. They strongly recommended I identify “champions” within the system to facilitate acceptance of a new approach to these women. It is key here that the referral to meet with the coordinator be done at diagnosis so that informed choices are made.

Both Kathie and Dianne spoke of asking themselves “what does this case need and how can I provide services to meet those needs?”

Rush University Medical Center

- Ms Judy Friedrichs, Education/Quality Coordinator for Women's and Children's Services, Nursing Systems, Perinatal Death Educator/Grief Counsellor, Women's and Children's Support Program
- Ms Jennifer Misasi, Nurse Practitioner, Pediatric Complex Care Team
- Ms Maria Reyes, Perinatal and Women's Healthcare Nurse Practitioner.

The meeting with the staff from Rush University Medical Centre was as a result of a recommendation from Ms Kobler that they too had a perinatal program. In a short space of time, Ms Judy Friedrichs was able to accommodate us and provide us with a very inclusive meeting and tour of the facilities.

Here the program runs with the families being referred at diagnosis. This includes both actual and potential diagnosis. The aim here is to provide comprehensive care for complex cases, not just those whose outcomes are likely to be fatal. The phrase used was to "nurture the woman's spirit". The service aims to provide a way to address the tension that someone exists between the birth plan and the clinical path.

Again as with previous sites, the emphasis here was on education and the reinforcement that the skills required already exist within the staff pool. This as with previous services is a nurse driven service, with Nurse practitioners taking on the role of coordinator.

Ms Reyes spoke passionately of starting the service and for the strong need for a Clinical Ethicist to guide the clinicians and families through the decision making journey. She also shared with practical ways in which she was able to overcome political roadblocks.

An insight from the team at Rush University was that the service should be started with a view to keeping both qualitative and quantitative evidence of its effectiveness. Feedback to clinicians on the impact their role in providing care

for this woman and her family was seen as a very necessary and professionally rewarding aspect of the coordinator's role.

Children's Hospitals and Clinics of Minnesota

- Ms Jody Chrastek, Pain and Palliative Care Coordinator
- Ms Stacey S. Remke, CIPC Coordinator, Psychosocial Team leader
- Dr Stefan Freidrichsdorf, Medical Director, Pain and Palliative Care
- Ms Martha Schermer, Clinical Social Worker
- Rev. Peter E. Lund, Chaplin.

Here the decision was made to spend more than one day visiting with the staff who operate within the Deeya and Karuna Programs. The opportunity to see how a paediatric and perinatal palliative care team works, along with its concurrent role within paediatric pain management was invaluable. This program was chosen because it most closely aligned to the philosophy I had behind any program I would be involved with here in Australia.

All members of the team were very generous with their time and very obviously passionate about the services provided. The concept of home-based hospice care is not a new one to the state of Minnesota. The first nurse was employed in the late '70s. Approximately 70 patients are active in the home based care program at any one time.

The team has members from all key disciplines: Nursing, Social Work, Medicine, Chaplin services and Child Life Specialists. They are all used to provide a continuum of care to the family as a whole. Here the key element is that all members of the family are supported in the home or in hospital. Families are offered individualised care planning with referral to all team members made at introduction of the service. Feedback from the team members indicated that very few choose not to take up all aspects of the service.

Again, the birth plan is integral to the service, as is clear communication within the team members. All members are housed in the same office space so that

a collegial cohesive team is formed. Team meetings are held in a setting that is conducive to equal involvement and are conducted so that stories of the families in their care may be told and feedback on patients who have died are shared. The team is very aware of the potential for this form of work to be emotionally burdensome; therefore they have factored in a number of strategies for debriefing and assistance with some of the more challenging issues that may arise.

This program of excellence offers support to its families up to 13 months after their loss. Strong links are formed with the Neonatal Palliative Care and Paediatric Palliative care teams, as they are critical in providing ongoing care for those babies who may survive longer than anticipated.

The mantra for the service would seem to be “Education, Presence, Persistence and Resilience”. Staff members regularly present to care review meetings within the hospitals, regardless of whether they have active patients or not. This is to continually remind the staff that the service exists, demonstrate a continued interest in providing support education and guidance for the staff and to provide any feedback they may have.

This service, as with the ones previously mentioned, have a long tradition of supplying the family with a memento of their journey. This is in the form of a quilt or shawl. The significance of this and the team’s service was underscored when I was privileged to meet with Alyssa, who had used the Perinatal Palliative Care Service “Deeya” recently. Her daughter Grace’s story and that of the staff who supported Grace’s family reinforced that whilst the need for such a service may not present regularly, its ability to make a difference in the lives of women and their families when they most need support and guidance cannot be underestimated.

By talking with Alyssa, I also came to understand how she and many other women parented their babies whilst they were still in-utero. Experiences such as taking the baby to a baseball match or to a concert were small ways that

these families were encouraged to share important experiences with their child that after birth they knew they were not going to be able to do.



Grace Kendall Chapman 12.11.07 – 13.11.07

Austin, Texas

- Dr Robbie Davis-Floyd, Cultural Anthropologist.

I was fortunate to spend some time with Dr Davis-Floyd to learn more about the social construction of birth and perinatal loss. I also developed a sense of what it is like to face the death of a child (Dr Davis-Floyd's own experience) and to understand more fully how I might go about increasing the public awareness of this topic as Dr Davis-Floyd is an accomplished public speaker.

Dr Davis-Floyd recommended several strategies to increase awareness of this service. Through our discussions, she also allowed me to understand more about the construction of motherhood, the notion of 'parenting', who 'parents' and how a woman and her family may be encouraged to 'parent' even if the baby is not born alive.



Dr Davis-Floyd

Conclusions

- There is no doubt that a service such as the ones I have visited is an important one. I have learned however, that it does not need to be an expensive one. The skills required to offer a service exists currently within QHealth. All that is required is the identification of some key staff who have an interest in this area and for it to be offered each and every time a potential fetal abnormality is found.
- This service cannot operate in isolation. It must be strongly linked with Neonatal and Paediatric Palliative Care programs.
- No one person can or should own this service. It belongs to the health care team as each discipline brings its own special mix of skills and understanding.
- Mementos of the journey are vital for the family. This may be in the form of the “journey box” used by Rosie Hospital NICU or the quilts and shawls of their American counterparts.
- Persistence, resilience and education are the key words used when describing the creation of and maintenance of such a service.
- The use of volunteers, in a professional coordinated manner is useful.
- The loss of a baby, no matter what gestation it is, is a significant experience in a woman and her family’s life. The grief and loss should never be underestimated.
- Information evenings with key groups such as Palliative Care Qld and nursing special interest groups will generate and identify interested supporters of the program.
- Meetings with those who currently work in the area to highlight the findings will assist in the promotion of the service and the Churchill Trust.
- Publication of articles in professional journals, along with presentations at conferences – one article has been written and is undergoing final editing prior to submission.

Recommendations

I plan to meet with as many staff in both major hospitals in Brisbane as I can. I have already identified two key supporters within the hospitals who are willing to assist me in the development of the program. Meetings will be scheduled to discuss the findings at various after-dinner meetings. I have accepted an invitation to present at grand rounds at Gold Coast Hospital in the mental health rounds.

Awareness of the need for the service should be discussed at various national conferences as well as a meeting of all interested nurses to discuss ways in which each nurse could bring about change in their organisation.