



## Lactation after Infant Death:

*Breastmilk suppression, expression and donation in contemporary motherhood and health service delivery*

# Newsletter – August 2021

Welcome to the 11th Edition of the Lactation after Infant Death Study Newsletter.

The Lactation after Infant Death Study aims to explore both bereaved women's lactation experiences and those of the multidisciplinary health team who are engaged in their care with a view to enhancing care delivery in Australia's maternity, bereavement and milk banking services.

The study is being conducted by ANU researchers: Dr. Katherine Carroll, Professor Catherine Waldby & Dr. Debbie Noble-Carr, with funding from the Australian Research Council (ARC), the ANU and Newborn Intensive Care Foundation. The project is being supported by The Canberra Hospital, Mercy Hospital for Women in Melbourne and Royal Brisbane and Women's Hospital.

The project will operate from August 2018 – June 2022.

We encourage you to discuss this project with your colleagues and friends and ask them to sign up to receive future quarterly project updates by sending an email to: [lactationafterloss@anu.edu.au](mailto:lactationafterloss@anu.edu.au)

### ***The final year of our study...***

We are happy to report that our study's data collection and analysis has now been finalised. We have learnt a lot about the limited nature of lactation information and care currently provided to bereaved families, and how these families wish to be supported when faced with lactation after infant death. These learnings have only been possible thanks to the 114 health professionals, 17 bereaved mothers and 7 bereaved fathers who participated in our study. Your willingness to share your experiences and perspectives has been greatly appreciated and will inform all of our continuing work. In addition we want to acknowledge the many organisations who have worked with us to make enhancements to their website information following our review of the online information presented by 21 of Australia's leading health and infant bereavement organisations.

We will be spending the remaining year of our study disseminating our results. It is our goal to use our study findings to improve awareness about the variable experience of motherhood, fatherhood and lactation after infant death and consequent support required, with an aim to enhance the lactation care provided to bereaved families.

In this newsletter we have some exciting news to share about some recent publications and our continuing work with some of Australia's leading health and infant bereavement organisations.

### ***Creating new knowledge – Publications from our study findings***

Writing and publishing academic papers on lactation after infant death is an important part of raising the profile of this issue and ensuring it is given more attention by leading health and bereavement scholars, health organisations and health professionals. All articles go through a rigorous peer review process which readers rely on to ensure our messages are evidenced based. We have recently published the following article in a leading international lactation journal:



**Noble-Carr, D., Carroll, K., & Waldby, C. (2021). Mapping Hospital-Based Lactation Care Provided to Bereaved Mothers: A Basis for Quality Improvement, *Breastfeeding Medicine*, 1-11, DOI: 10.1089/bfm.2021.0089.**

**Abstract:** The study aimed to identify and map the factors that shape the delivery of hospital-based lactation care for bereaved mothers to inform quality improvement initiatives targeting hospital-based lactation care.

Focus groups and interviews were conducted at three large hospitals in Australia with 113 health professionals including obstetricians, neonatologists, midwives, neonatal nurses, lactation consultants, social workers or pastoral care workers, Human Milk Bank (HMB) staff, and perinatal bereavement nurses. Thematic and interactional data analysis identified the nature, scope, and pattern of bereavement lactation care. A bereaved lactation care pathway was generated from health professionals' reports.

Bereaved lactation care, if provided, was limited to brief encounters aimed at facilitating lactation suppression. The type of lactation care offered, and any exploration of the variable biopsychosocial significance of lactation after infant death, was conditional on (i) availability of health professionals with suitable awareness, knowledge, capacity, confidence, and comfort to discuss lactation; (ii) hospital culture and mode of suppression primarily practiced; (iii) mother's breast milk being visible to hospital staff; (iv) mother expressing interest in expanded lactation management options; (v) availability of, and eligibility to, donate to a HMB; and (vi) support beyond the hospital setting being facilitated.

Mothers should be presented with the full array of lactation management options available after stillbirth or infant death. Inclusion of evidence-based, biopsychosocial and patient-centered approaches to lactation care is urgently required in health professionals' bereavement training and in the policies of hospitals and HMBs.

A paper reporting on our findings with bereaved fathers has also recently been submitted to a leading Australian health journal for consideration and review:

- **Noble-Carr, D., Carroll, K., Copland, S., & Waldby, C. (under review) "It was a shared duty": Bereaved fathers' perspectives, experiences and practices in relation to their partner's lactation after infant death.**

*A study funded by an Australian Research Council Discovery Grant*

These two articles join our previously published articles listed below:

- Carroll, K., Noble-Carr, D., Sweeney, L., & Waldby, C. (2020). The 'lactation after infant death (AID) framework': A guide for online health information provision about lactation after stillbirth and infant death. *Journal of Human Lactation*, 36(3), 480-491. <https://doi.org/10.1177/089033442092694>
- Sweeney, L., Carroll, K., Noble-Carr, D., & Waldby, C. (2020). Lactation after infant death: an analysis of Australian healthcare agencies' online health information. *Health Sociology Review*, 29(1), 45-61.

And our Final Report from our Bereaved Fathers Sub Study:

- Carroll, K., Copland, S., Noble-Carr, D., & Waldby, C. (April 2021) *Lactation After Infant Death: Partners' Experiences – A pilot study funded by the Newborn Intensive Care Foundation*. Accessible via our [project webpage](#).

### ***Assisting leading health organisations to provide information and support***

Australia is fortunate to have many non-government organisations that provide comprehensive lactation and/or bereavement information and support to parents. Health professionals also rely on these organisations for evidenced-based information, resources, education and training.

Over the last few months we have continued to work with our key stakeholders, including Australian Breastfeeding Association, Red Nose (including SANDS) and Miracle Babies to develop information and raise further awareness on the issue of lactation after infant death. This includes:



- ❖ Providing advice and guidance to **Australian Breastfeeding Association** – assisting them to update online information and Fact Sheets.
- ❖ Assisting **Red Nose (including SANDS)** to write a feature news story on lactation after infant death for World Breastfeeding Week. You can find the article [here](#):  
  
Links to the article were posted on Red Nose and SANDS Facebook Pages where it reached 4025 people and received 252 engagements, and Instagram where it reached 2164 people and received 122 engagements.
- ❖ In the lead up to Father's Day, we have also published a [feature article](#) on the **Miracle Babies** Website. The article highlights the meaning that infant feeding and breastmilk often holds for Dads in the NICU, but also emphasises how these meanings and the desire to support their partner with lactation practices and care (including breastmilk donation) often continues following the unbearable experience of infant death.

### ***Educating Health Professionals to provide comprehensive lactation care***

We are very excited to announce that we have been selected to present our study findings to an international audience of health professionals as part of the **GOLD Lactation Online International Conference** to be held in April and May 2022.

We have been invited to provide **Key Note Presentations** at Australian Health Professionals' events in **Brisbane, Melbourne, Sydney and Perth** throughout **2022**. Details will be provided in the next Newsletter before the end of the year.

Dr Katherine Carroll has been asked to join a Plenary on 'Working Beyond Academia In and Outside of Universities' at the **Australian Sociology Association Thematic Week** In November 2021.

On a local level, Dr Katherine Carroll also recently returned to **University of Canberra** for her annual presentation to student midwives, arming them with the knowledge they will need to provide comprehensive lactation care for the bereaved families they may encounter in their future work.

### ***Other dissemination plans***

We continue to work with our colleagues in the **ANU School of Art & Design** on a heartfelt project to design, make and display a piece of textile art in the form of a **cot-sized quilt**.

The quilt will go on public display to visualise the meanings and experiences of bereaved parents, and help raise awareness and understanding of the experience of lactation after infant death.

The quilt will complement academic articles that we are planning now that report on the perspectives and experiences of bereaved mothers and fathers and aim to provide clear direction on the lactation care required by them.

Plans are also underway for the development of **educational videos** and **targeted feedback and education sessions** at each of our three hospitals that assisted us with participant recruitment.

To stay informed about our project and to locate study publications and resources, visit our project webpage: <http://sociology.cass.anu.edu.au/lactation-after-infant-death>

To contact the research team email: [lactationafterloss@anu.edu.au](mailto:lactationafterloss@anu.edu.au)

Until next time, warm wishes...



*Dr Katherine Carroll*



*Professor Catherine Waldby*



*Dr Debbie Noble-Carr*



*Simon Copland*

*A study funded by an Australian Research Council Discovery Grant*