



# Lactation after Infant Death:

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

## Newsletter – April 2021

Welcome to the 10th 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) and the ANU. The project is being supported by The Canberra Hospital, Mercy Hospital for Women in Melbourne and Royal Brisbane and Women's Hospital.

Additional funding received from the Newborn Intensive Care Foundation has also allowed us to employ Simon Copland to conduct our sub-study with the partners of bereaved mothers.

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)

### *Study progress and disseminating our results*

The research team are happy to report that we have finished data collection, and we are now conducting the final data analysis before moving into the dissemination phase of the project. We want to take this opportunity to thank each of 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 that aims to raise awareness of motherhood, fatherhood and lactation after infant death and enhance the care bereaved families receive.

In this newsletter we have some exciting news to share about some recent publications and some new collaborations we have formed to raise awareness and share our research findings about lactation after infant death.

### *Our sub-study with bereaved fathers*

A final report on our sub-study with bereaved mothers' partners has now been submitted to the Newborn Intensive Care Foundation. Funding from the Newborn Intensive Care Foundation allowed us to conduct seven interviews with the partners of bereaved mothers (five of whom had supported their partner to donate milk after infant death).



To our knowledge this is one of the first projects in the world that has sought the experiences and perspectives of fathers on lactation after infant death and bereaved milk donation. Our final report drew attention to significant grief experienced by fathers and highlighted the following key findings:

- Fathers assume a significant support role for their partner and children following infant death.
- Breastmilk and involvement in infant feeding holds significant meaning for fathers especially when their infant is receiving care within the Newborn Intensive Care Units or Palliative Care settings.
- Fathers often have limited awareness of, and role in lactation after infant death except in cases where the mother continues expression of breastmilk after infant death for the purpose of gentle suppression or donation to a Human Milk Bank.
- Fathers provided a great deal of practical and emotional support to their partners throughout the bereaved donation process, often acting as the sole or main supporter to their partner.
- Bereaved breastmilk donation was meaningful to fathers and may assist in their grief and meaning-making post loss, due to them being able to find something positive amidst their painful loss experiences by helping their partner and other families.
- Fathers and their partners require enhanced lactation care information and support regardless of their chosen lactation management options.

A number of recommendations have been made in this report that detail the need for an enhanced focus on family-centred bereaved lactation care and acknowledgement of the positive role that bereaved donation can play in families' grief following infant loss.

The final report is now available for you to view on our project website:

<https://sociology.cass.anu.edu.au/research/projects/lactation-after-infant-death/publications>

### ***Reporting on current hospital based bereaved lactation care***

At our recent Stakeholder Advisory Group meeting we reported on our major findings from data collected with health professionals that has allowed us to identify and map current hospital-based lactation care practices for bereaved families.

Our findings on contemporary hospital-based lactation care have been outlined in an article submitted to an international journal which is currently under peer review. The findings indicated a need for:

- The variable biopsychosocial significance of lactation and breastmilk to be better understood and considered by hospital-based health professionals; and for
- Bereaved mothers to be presented with information on all available lactation management options so that they can make an informed decision on what they would like to do with their lactation and breastmilk.

We can provide further information and a link to this article when it is published and made available by the journal.

### ***Memorialising Women's Experiences of Lactation After Loss: A Textile Art Project***

We are excited to announce that to visualise the meanings and experiences of bereaved parents, and help raise awareness and understanding of the experience of lactation after infant death our research team has formed a collaboration with two textile artists from the ANU School of Art & Design (Lucy Irvine & Dr Rebecca Mayo) to design, make and display a piece of textile art in the form of a cot-sized quilt.

Breastmilk will play a heartfelt role in the memorialising of bereaved parents' lactation experiences through acting as a mordant in the making of this quilt. A mordant is used in the preparation phase of the fabric dyeing process. As part of the quilt-making process we will be testing the use of breastmilk as a mordant to see how the plant-based dyes we will be using will respond to fabric that has been prepared with breastmilk as a mordant.

We will be accessing plant materials from our study sites, and seeking women from the ANU and broader Canberra community to donate surplus breastmilk to be used in the making of the quilt. [Note: Mothers must be able to supply their frozen stores of surplus breastmilk in person to The Textile Workshop, School of Art and Design, Australian National University, Acton Campus – anyone interested in further information on this should contact the research team at: [lactationafterloss@anu.edu.au](mailto:lactationafterloss@anu.edu.au) ].

The quilt will be completed by early 2022 and will then be displayed at a variety of health and community venues and academic conferences to memorialise and raise awareness of bereaved parents' experiences of lactation after infant death and the care they require. We will also be making a short video to document the making of the quilt.

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

In addition to the quilt, and writing further academic papers, we will be aiming to make a short video to share our major research findings. We will also be exploring opportunities for contributing to the development of written lactation after infant death resources for bereaved families and hope to raise further awareness through podcasts and blogs.

Targeted feedback and education sessions will also be provided for our hospital partners in each of the 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*

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