

Giving voice to families of premature or sick babies in neonatal care

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Introducing the partnership and co-design

ACU's Stakeholder Engaged Scholarship Unit (SESU) provides an institutional approach to community-engaged research that enables community organisations to shape ACU's research agenda.

From the outset, our partnership approach was centred on:

- ♥ Sharing and listening
- ♥ Relationship-building
- ♥ Establishing rapport
- ♥ Generating trust
- ♥ Achieving psychological safety
- ♥ Co-designing of the evaluation activities



Project impact

The SESU partnership model shows us:

- ♥ The strength of relationships is a solid foundation for truly collaborative work: so important to get to know the people working on your project
- ♥ Checking in regularly keeps things in motion: regular catch-ups maintain project momentum and enthusiasm within the team
- ♥ Patience and compassion always benefits the work: especially with NFP staff who are not necessarily very academic



Methodology and findings

“It’s a wonderful thing that’s able to be provided, and you know, any kind of little ray of hope in that ... turmoil in your life is wonderful. And it’s lovely to have the support of the community.” - Parent



- ♥ 65% of babies spent time in both NICU and SCU
- ♥ 85% of the babies needed respiratory support after birth
- ♥ The overall average length of stay was 55 days with the shortest being 7 days and the longest 6 months
- ♥ 85.2% of families found the guidebooks to be helpful or very helpful
- ♥ 75.9 % of families who attended a NICU Connections event (to connect with other families in similar situations) found them to be helpful or very helpful
- ♥ 76.7% found the Precious Prem pack (now Little Treasures Welcome Pack) to be helpful or very helpful, with 65.2% saying it had educated them on what to expect in NICU or SCU



“Without our partnership with SESU, we wouldn’t have this evidence to show how our services are making a difference.” – Felicia Welstead

The evaluation highlighted some surprising results:

- ♥ The number of families carrying IVF babies who use LLTF products and services is really high
- ♥ The national average for length of stay in the NICU is about 2 weeks. Overall average length of stay for LLTF families is 55 days, making these families long-termers in the NICU
- ♥ This indicates how much these families wanted to participate and have their say in this project



Visualising the research to amplify the voices of families

Designing outputs for this project and partnership has been driven by human centred values:

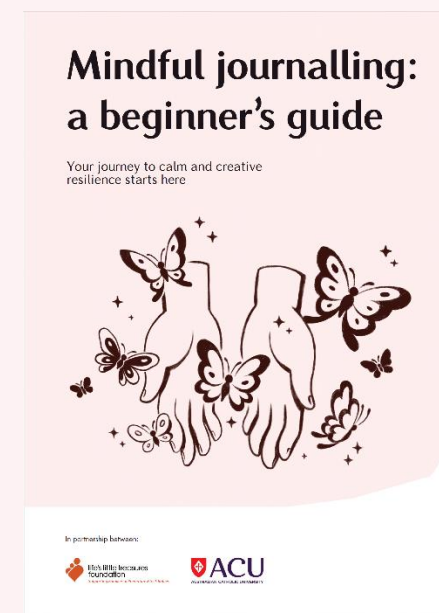
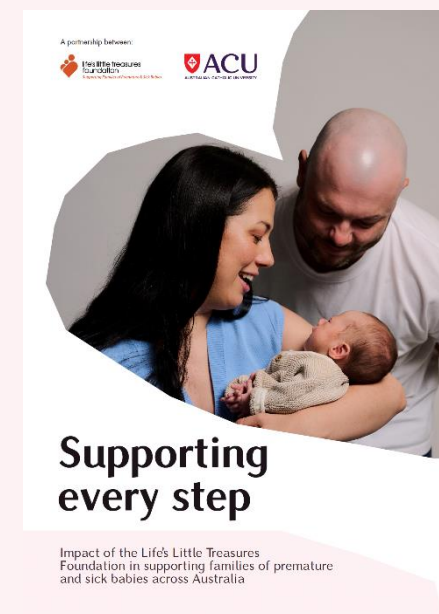
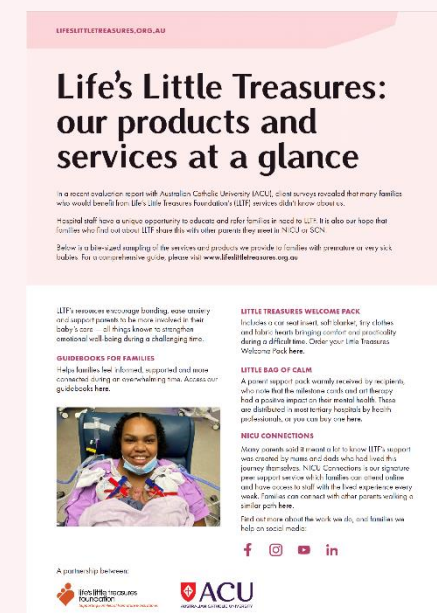
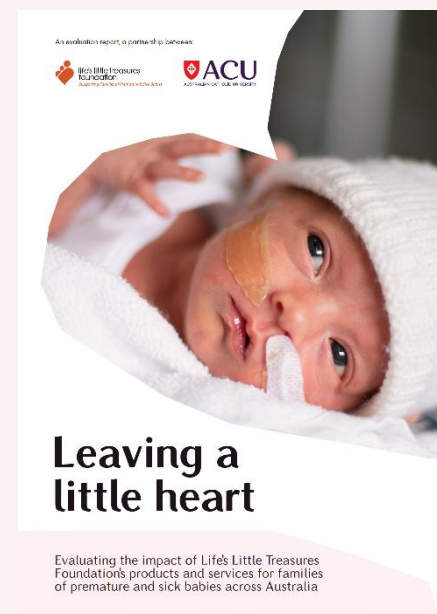
- ♥ Designer operates as bridge between all stakeholders, the research, and the intended audience of those research findings
- ♥ Holding the vision and work of many and gifting it back thoughtfully for the people who need it
- ♥ Creating multiple outputs for greatest accessibility within audience segments
- ♥ Listening and working alongside partners and families rather than assuming what's needed



Project outputs

This project resulted in four key resources:

- ♥ **Leaving a little heart:** the formal evaluation report
- ♥ **Supporting every step:** a guide for families
- ♥ **Life's Little Treasures: our products and services at a glance:** a guide for hospitals
- ♥ **Mindful journalling: a beginner's guide:** a journalling resource for families



Evaluation report

“Walking away from the hospital and leaving a little heart that you had tucked in your bra all day was just like leaving a little piece of myself there with them.” - Parent

This quote inspired the visual identity across all four project resources. The heart motif represents:

- ♥ The love and courage of families navigating a challenging start to parenthood
- ♥ The handmade fabric hearts parents leave with their babies for comfort
- ♥ The beautiful and imperfect patchwork of people who support families along the way

An evaluation report, a partnership between:



Leaving a little heart

Evaluating the impact of Life's Little Treasures Foundation's products and services for families of premature and sick babies across Australia

Supporting every step

Designed with families, for families, this guide:

- ♥ Presents findings in a concise, accessible format
- ♥ Offers reassurance through shared experiences
- ♥ Shows support, connection and moments of joy can exist alongside the challenges of being a new parent

What families told us

Parents shared that LLTF's support genuinely helped their emotional well-being – from calming tools like affirmation cards to creative outlets and peer connection. These thoughtful touches made many parents feel seen, supported and less alone during an incredibly overwhelming time.

Parents shared that LLTF's support helped them feel more grounded and connected during the stress of neonatal care. Through their stories, it became clear that LLTF's resources often encouraged bonding, eased anxiety and supported parents to be more involved in their baby's care – all things known to strengthen emotional well-being during this challenging time.

THE GUIDEBOOKS FOR FAMILIES
After two decades of supporting families with premature or sick babies LLTF produced two important guidebooks: *A Guiding Hand for Families in Special Care Nurseries* and *A Guiding Hand for Families in NICU and Special Care Nurseries*. Many parents said the Guidebooks helped them feel informed, supported and more connected during a tricky time. These experiences show how important it is for families to receive the right information, in the right moment, for their unique needs.

"It provided me with a lot of information, and it just made me more focused... and provided me with some strategies to move forward. Because I kind of felt

helpless and I kind of felt like I wasn't providing for my daughter and I was bit of a failure of a mum."

The Guidebooks supported parents' engagement across the broader range of products and services explored in the research.

PRECIOUS PREM PACK (LITTLE TREASURES WELCOME PACK)
Participants discussed which products were most useful in the Precious Prem Pack. The boxes are used to be very practical.

"There was an insert for the car seat that kind of supported her head, and that's something we used for the longest time. I think until she was nearly six months old. Every time we used that, we were kind of reminded of the kindness that we received at the hospital from the organisation."



What families need

The Life's Little Treasures Foundation (LLTF) is a leading Australian charity committed to supporting families of premature or sick babies. LLTF provides practical resources and emotional support through approximately 150 Neonatal Intensive Care Units (NICUs) and Special Care Units (SCUs) across Australia. These services are available both during hospital stays and after a family's transition home.

Founded by parents with the lived experience of having a premature or sick baby, LLTF's programs are uniquely informed by a firsthand understanding of the emotional and practical challenges that families face. A core element of LLTF's approach is fostering connection between families and others who have shared similar experiences.



Welcoming your baby into the world earlier than anticipated – or facing unexpected health challenges – can turn life upside down. Many parents describe their time in the NICU or SCU as one of the most stressful, emotional experiences they've ever faced, with those feelings continuing after going home.

LLTF and Australian Catholic University (ACU) partnered together to speak directly to families



about what was needed, and to understand how the four main services provided by LLTF help in this especially challenging time. They looked closely at the guidebooks provided to families in hospital, NICU Connections peer support groups, Precious Prem Packs¹ including practical items for premature babies, and the Little Drop of Calm to assist with encouraging self-care.

We captured the voices of families through a large national survey and focus groups, where personal stories were shared. We also reviewed existing research about the emotional impacts of having a premature or sick baby, discovering common struggles like anxiety, depression, and the challenges of bonding during a stressful hospital stay.

By listening directly to parents, the project hoped to understand whether these supports truly meet families where they are – offering comfort, clarity, and connection at a time when everything can feel overwhelming.

Our research has shown that certain kinds of support can make this journey a little lighter and help families feel more confident and connected.

FACTORS THAT SUPPORT WELLBEING FOR PARENTS AND FAMILIES OF PREMATURE AND SICK BABIES

One of the most helpful things is being involved in your baby's care as early and as often as possible – simple moments like holding your baby skin-to-skin, feeding, or helping with changes can build your confidence and strengthen your bond. This kind of involvement has been shown to support both your emotional well-being and your baby's development. Strong communication with the healthcare team, feeling welcomed at your baby's bedside, and having clear, compassionate information also make a meaningful difference.

But being present isn't always easy. Distance from the hospital, transport costs, caring for other children, and emotional exhaustion can all make it harder to spend the time you want with your baby. That's why supportive programs matter so much.

LIVED EXPERIENCE
Many parents said it meant a great deal to know LLTF's support was created by mums and dads who had lived this journey themselves. That understanding made the resources feel more genuine, comforting and trustworthy during an incredibly vulnerable time.

"I think it's just nice to know that people have walked this path before. And having them, you know, I was kind of aware that all the volunteers had had some kind of experience in this space. And it's, I think you can see that in what they pack and what they choose for you."

Many parents said it meant more to know LLTF's support came from people who had lived this journey themselves. It made the care feel personal, genuine and understanding.

¹ Since this project began, Precious Prem Packs have been renamed Little Treasures Welcome Packs.

Guide for hospitals

Designed to increase awareness of LLTF services among hospital staff, this resource:

- ♥ Presents key products and services in a quick-reference format
- ♥ Encourages timely referrals within clinical settings
- ♥ Aims to help families connect with available support sooner

Life's Little Treasures: our products and services at a glance

In a recent evaluation report with Australian Catholic University (ACU), client surveys revealed that many families who would benefit from Life's Little Treasures Foundation's (LLTF) services didn't know about us.

Hospital staff have a unique opportunity to educate and refer families in need to LLTF. It is also our hope that families who find out about LLTF share this with other parents they meet in NICU or SCN.

Below is a bite-sized sampling of the services and products we provide to families with premature or very sick babies. For a comprehensive guide, please visit www.lifeslittletreasures.org.au

LLTF's resources encourage bonding, ease anxiety and support parents to be more involved in their baby's care — all things known to strengthen emotional well-being during a challenging time.

GUIDEBOOKS FOR FAMILIES

Helps families feel informed, supported and more connected during an overwhelming time. Access our guidebooks [here](#).



LITTLE TREASURES WELCOME PACK

Includes a car seat insert, soft blanket, tiny clothes and fabric hearts bringing comfort and practicality during a difficult time. Order your Little Treasures Welcome Pack [here](#).

LITTLE BAG OF CALM

A parent support pack warmly received by recipients, who note that the milestone cards and art therapy had a positive impact on their mental health. These are distributed in most tertiary hospitals by health professionals, or you can buy one [here](#).

NICU CONNECTIONS

Many parents said it meant a lot to know LLTF's support was created by mums and dads who had lived this journey themselves. NICU Connections is our signature peer support service which families can attend online and have access to staff with the lived experience every week. Families can connect with other parents walking a similar path [here](#).

Find out more about the work we do, and families we help on social media:



A partnership between:

Mindful journalling

This final resource was informed by parents' experiences of:

- Extended hospital stays
- Creating space to pause and reflect
- Finding small moments of joy on difficult days
- Using journalling and creative expression to support wellbeing

mindful journalling: your journey to creative resilience



Being mindful means giving your full attention to the present moment, to what is going on inside and around you. Being mindful means not trying to control everything; instead, you're observing your situation, without judgement, and moving towards accepting the things that can't be changed.

If you're new to mindfulness, it might be a relief to surrender to the idea that some things are out of our control and you're just a person doing their best.

Benefits of mindfulness

- Being able to more fully recognise and enjoy good things in life as they happen, contributing to a greater feeling that life is generally good.
- Stronger connections with loved ones, because you're more present and engaged when spending time with them.
- Greater ability to focus on the task at hand, to process memory, move with ease.
- Greater resilience for day to day challenges, allowing you to move forward without getting caught up in your thoughts and feelings.

The five R's of mindfulness

A practical exercise to improve your emotional wellbeing every day.

- Recognise:** Pause. Take a moment to acknowledge your inner weather.
- Relax:** The weight went to relax your eyes for a moment. Focus on your breathing, or complete a body scan from head to toe.

Review: What's happening inside you, and how might it be different to what's happening outside of or around you? Consider honestly what you can change, control or reconsider about your present situation.

Respond: Rather than reacting or acting on impulse, especially in stressful situations, how would you like to respond as your outermost, most thoughtful self?

Return: Come back to yourself in this present moment, hopefully feeling a little more grounded and with a better idea of how to move forward.

Mindfulness and journalling

Journalling can be many things. For some, it's a practical way of organising or documenting their day's activities. It might be a creative outlet. Importantly for you, it can also be a physical, visual way of working out our feelings and separating these from facts. Having a mindful mindset can help you get the most out of your journalling practice, and vice versa.

brain dump journalling



When we're in a chapter of stress, our heads can feel like a noisy place to be. Sometimes, writing things down can quiet these thoughts, or close the many mental tabs we have open.

Below are some prompts to help you start making sense of, simplifying or responding to some of these worries or uncertainties. You can journal however feels good and useful for you: a written sentence or two for each prompt, a free-flowing page exploring just one prompt, a combination of notes and drawings, or even a voice memo on your phone.

You're not obligated to read over your thoughts if they feel too heavy. You might even consider tearing them up, once you've done getting them out, as a way of lightening your mental load and letting those thoughts go.

The brain dump method of journalling is sometimes referred to as 'writing pages'. The idea is that you get all the stuff that's filling up your brain out of your brain, so you can get on with your day. Setting a timer (like before you begin would be helpful. Maybe you could fill a page or set your timer for five minutes.

What thoughts are taking up most space in my brain today?

I'll visualise my page as a bucket where I can dump my thoughts. I won't put pressure on myself to fix problems or make judgements. I'll just focus on getting them out of my head, onto the page.

What am I overthinking?

On a new page in my notebook, I'll create four columns:

- I am worried or thinking a lot about...
- What, regarding this worry, can I do something about?
- What am I already doing to address this?
- What can I do in future?

Now I'll have at it. I'll be honest and factual. I won't write this list from the point of view of someone equipped with the magic to seamlessly change the past. I'll place myself in the here and now, and hold myself with compassion.

Now I've written this list, what thoughts can I release?

Maybe now there's some space to focus on the positives. I don't have to pretend that everything is wonderful when it isn't. Instead, I will recognise good things are important for reducing stress and developing emotional resilience, both of which I need right now. I imagine these heavier thoughts transforming into butterflies, free to fly away.



Date: _____		Notes/ reminders: _____	
Today I'm feeling: 		How I'm showing up for myself today: 	
How I'm caring for myself today: 		Something that grew inside me today: 	
Podcasts, music, books, movies or creator content I enjoyed today, including key takeaways I want to remember: 		Something that happened today that I'd like to work on, amend, or do differently next time: 	
A tiny detail or small noticing from today: 		Today, I was encouraged by: 	
Today's gold star moment: 		A wish I'd like to make for my future self: 	

External impact

These outputs emphasise the importance of differentiating research findings to suit audience segments:

- ♥ **Politicians:** need a detailed research project document to make decisions that might help services like LLTF
- ♥ **Hospitals:** need a summarised document telling them where to find the research
- ♥ **Families:** need something that informs them but isn't too long or complicated

Marketing helps us sing about who we are, what we do, and the difference we make!



What we learned from this project so far

- ♥ Families reported feeling part of something meaningful
- ♥ Our four most-used products and services are valued by families
- ♥ Awareness of LLTF products and services has grown, but further promotion is needed to improve uptake
- ♥ Popular initiatives, such as the Breakfast Bar, require ongoing funding to continue



Thank you so much for joining us today!

You can read the project outputs on the ACU website:



<https://www.acu.edu.au/about-acu/community-engagement/stakeholder-engaged-scholarship-unit/our-projects-and-publications/26-organisation-leaving-a-little-heart>

You can find out more about LLTF products and services, and support their work:



<https://lifeslittletreasures.org.au/>

