

## Issue 3 July 2015

### In this Issue

We have a packed issue for July. Michelle Angletti and Mary Francell steer us through the new LLLI Milk Donation Policy, while Marie Beam and Karin Gausman describe how the breast milk concept was revised. Jill Unwin and Jayne Joyce reveal all the ins and outs of helping mothers over the Internet via Help Forms. Sarah McCann has written about the impact of sudden weaning on mother and child while Lisa Thompson sensitively covers the subject of supporting a mother whose baby has been stillborn. Hanny Ghazi shares her experiences of postpartum depression—both personally and as a Leader helping others. Finally, LLL Italy has shared an attractive way of presenting their statistics in an infographic in English and Italian.

### This issue

**[Informal Milk Sharing in an Age of Social Media](#)**

**[Milk Donation Policy](#)**

**[New Concept Wording](#)**

**[Help Forms: Helping Mothers Over the Internet](#)**

**[Sudden Weaning for Medical Reasons](#)**

**[When a Mother Experiences Infant Loss](#)**

**[Postpartum Depression](#)**

**[The LLLong Road Home: One Leader's Journey](#)**

**[LLL Italy is 35! Infographic](#)**

Send in your ideas and articles

Whether you have an idea for a great meeting plan, fundraising tips for your Group, a photograph, an experience to share, or a request for an article on a specific subject, we would love to hear from you. Please send contributions for *Leader Today* to [editorlt@llli.org](mailto:editorlt@llli.org)

***Philippa Pearson-Glaze, Leader Today Managing Editor***

## Keeping Up to Date

### Milk Sharing in an Age of Social Media

Michelle Angeletti, MSW, Ph.D. Professional Liaison Research Associate for the LLL Alliance for Breastfeeding Education Area Network and Mary Francell, Area Professional Liaison for LLL of Georgia, USA.

*In recent years, there has been a proliferation of social media and Internet sites where breastfeeding mothers can informally share breast milk. Mothers today tend to be web savvy and even if they are not involved in milk-sharing activities, probably most are aware of them. They may also be aware that the World Health Organization<sup>1</sup> refers to “breast milk from a healthy wet-nurse” as an alternative to a mother’s own breast milk. As a Leader, you may have been approached by a Group member wondering how she can become involved in informal milk sharing—either to donate or receive milk. You may wonder whether it is even appropriate to discuss informal milk sharing with mothers. In this article, Michelle and Mary discuss the role of the LLL Leader and La Leche League International’s revised policy on this issue from a US-perspective.*

In March of 2015, the LLLI Board of Directors revised the LLLI policy regarding the sharing of human milk. The Milk Donation policy states;

*“When a mother contacts a Leader seeking to acquire donated milk or to discuss personal options, the Leader’s role is to respond with information and support about the benefits and risks of such practices of induced lactation, relactation, wet-nursing, or cross-nursing.”*

When a breastfeeding mother asks for information about milk sharing, she may have a large milk supply that she would like to share or she might want to seek milk from other mothers. If the latter, a Leader can explore whether the mother could provide her own milk to her child with information about how to increase her milk supply or relactation. As with any other type of situation, our goal as Leaders is to help the mother make the best decision for her family based on the options available to her.

#### **Increasing a mother’s milk supply**

The mother may not be aware that simple measures, such as putting her baby to the breast more frequently, improving the latch, or trying breast compressions, often help to increase milk supply. A Leader can also explain that providing donated milk to her child can interfere with the mother’s natural supply-demand function that regulates her milk production. Like formula, providing donated milk can have the unintended consequence of decreasing a mother’s own supply.

The policy also states that a Leader can offer information about induced lactation, which is the initiation of milk production in a woman who has never been pregnant, or relactation, which is defined as increasing milk production in a woman who has been pregnant. Information on these topics is available in *The Womanly Art of Breastfeeding*,

---

<sup>1</sup> WHO, UNICEF. Geneva: WHO; 2003. [Global Strategy for Infant and Young Child Feeding](#).

2010, pages 354–362. If a Leader feels as though this is beyond her area of expertise, her next step would be to contact the Professional Liaison (PL) Department<sup>2</sup> for support or to refer the mother to a lactation consultant.

### **Sharing options**

The policy goes on to state:

*“If a mother is interested in donating her milk or in receiving donated milk, the Leader should urge the mother to investigate various ways of donating and acquiring human milk. The mother should be encouraged to make an informed decision that is best for her and her baby and meets cultural expectations. A Leader may provide contact information for non-profit human milk banks, other regulated collection centers, and formal/medically supervised or informal milk-sharing networks. Protocols for the careful and safe collection and handling of human milk are the responsibility of milk banks and networks, and the Leader should encourage the mother to evaluate these protocols. It is not the responsibility of LLL Leaders or LLLI to license, recommend, or assess milk banks or networks, but to share information with mothers.”*

Leaders can help parents become aware of the myriad options regarding informal milk sharing. Some mothers (or adoptive fathers) work out an arrangement with one or more donors they know personally. Some use milk-sharing websites such as [Human Milk 4 Human Babies](#) or [Eats on Feets](#). Some [flash-heat](#) donated milk at home and some choose to use it raw. It is important to inform parents of various possibilities and encourage them to research each option thoroughly before deciding what to do. Among other things, parents need to be aware of the possibility that milk that is *purchased* from an unregulated source (rather than *donated*) may be “made to go further” with ingredients other than human milk.

If a mother is interested in donating milk, the Leader might point out that in addition to various forums for informal milk sharing, many countries have regulated milk banks (where most human milk goes to premature or sick babies). Some countries organize their milk banks into milk banking associations eg the [Human Milk Banking Association of North America](#) (HMBANA) or the [European Milk Banking Association](#) (EMBA). In countries such as Brazil, France, and Germany, banked human milk has been incorporated into public health policies.

### **Questions to ask**

---

<sup>2</sup> The PL Department serves as a resource for Leaders working with mothers. It is important to remember to contact the PL Department *yourself* and then relay the information to the mother. This procedure allows the mother to stay connected to you, her local Leader, and allows you to gain new knowledge and skills.

It can be useful to provide parents with questions to help them evaluate an informal milk sharing arrangement, particularly if the mother is considering obtaining milk through classified ads or other anonymous donation sources.

How will the milk be collected and stored, what containers will be used, and will the containers be dated so the age of the milk can be determined? What hygienic practices will be involved in the expression, storage, and overall handling of the milk? If the baby receiving donor milk is preterm or ill, are special collection protocols required? If the baby is preterm or ill, are they aware that donor milk from a licensed milk bank may be covered by their health insurance? Will the milk be received fresh or frozen and how will it be transported or shipped? Does the donor smoke, drink alcohol, use recreational drugs, over-the-counter preparations or take prescribed medications?

Does the donor's diet include potential allergens? Has the donor had her blood tested recently for HIV, HTLV, Hepatitis B and C, CMV, and sexually transmitted diseases? Can the donor provide documentation of such testing and a letter from her doctor about her general health (perhaps including a medical history) and ability to provide milk while breastfeeding her own baby? Has the donor been diagnosed with any other illnesses or has she had any tattoos or body piercings in the last 12 months?

## **Screening donors**

The list of questions to ask (above) does not cover all eventualities. For a thorough list of screening questions, parents can contact a human milk bank or blood screening facility. Some of the online milk sharing sites may also include donor screening tools. There is a sample donor medical history screening form on the informational website [Milk Share](#). In the UK, NICE<sup>3</sup> guidance can be found in [Donor breast milk banks: the operation of donor milk bank services](#). In the US the Leader could share that the US Food and Drug Administration (FDA) advises against informal milk sharing due to concerns that the milk will not have been adequately screened for infectious disease or contamination. The FDA's [Use of Donor Milk](#) is available online. Leaders can share official recommendations in their part of the world and discuss the importance of screening milk donors, including family and friends, who may be unaware of or too embarrassed to reveal personal health information that could affect the safety of their milk for another baby. Infectious agents, like bacteria or viruses, can be found in the milk of seemingly healthy, asymptomatic<sup>4</sup> women. Not every country will have official recommendations. In that case, the Leader can contact the PL Department of her Area.

## **Medications in mothers' milk**

An important risk involved in accepting donor milk is the possible transfer of medications into milk. Leaders can encourage a mother to consult her baby's health care provider about the safety of a medication for her baby. See [Breastfeeding and](#)

---

<sup>3</sup> National Institute for Health and Care Excellence

<sup>4</sup> Showing no symptoms of disease.

[Medications](#) for a summary of books, reputable websites, and international helplines for checking the compatibility of medications during breastfeeding.

## **Legal issues**

The LLLI policy also says

*“It is always important for the Leader to encourage the mother to talk with her own and the baby's health care providers about their particular situation.”*

If a Leader knows that a mother plans to participate in an informal milk sharing, cross-nursing, or wet-nursing arrangement, she can encourage the mother to work with a health care provider who is knowledgeable about screening and testing milk donors to confirm a donor's physical health.

Importantly, the LLLI policy states that:

*“A Leader should never use her position as an LLL Leader to set up any type of milk-sharing network.”*

While Leaders should provide information and support to a mother about informal milk sharing, Leaders must not be involved in linking mothers willing to donate with mothers requesting milk. This statement serves as the proverbial “line in the sand” that Leaders do not cross.

## **Liability insurance coverage**

As Leaders, LLLI liability insurance covers our volunteer service only while operating in accordance with the policies and guidelines of LLLI. In the case of informal milk sharing, our role is to provide information and support. If we *facilitate* informal milk-donation arrangements or act as an intermediary, we may not be covered under LLLI liability insurance, as these practices are not in compliance with LLL policies and guidelines. For example, if a mother shares milk at a meeting (or in the meeting location before or after a meeting) and it results in harm to a child, it is possible that the Leader could be named in any lawsuit that resulted from the situation. In this type of case, it is unlikely that the LLLI attorneys and insurance company would conclude that they are responsible for the Leader's defense. Leaders are encouraged to consider these types of situations from a risk management perspective before making a decision. Your local Professional Liaison Department is available to help with these situations as well.

## **Handling discussions on social media**

You wake up one morning to find that mothers have been happily sharing websites such as [Eats on Feets](#) and [Human Milk 4 Human Babies](#) on a Group Facebook page. What's a Leader to do? Share information, of course!

First, it's important to state that La Leche League Leaders are not allowed to facilitate a milk-sharing network and will need to ask the mothers to please move such a

discussion to another forum. However, LLL Leaders *are* able to provide information and support to mothers who wish to explore this option. Be sure to inquire why milk sharing is being suggested and, if appropriate, share information on breastfeeding management or induced lactation.

Next, discuss the **risks** and **benefits**<sup>5</sup> of donor milk. In addition to the FDA's [Use of Donor Milk](#), one useful resource on the risks might be: [Milk sharing and formula feeding: Infant feeding risks in comparative perspective?](#) Another helpful source of information on minimizing the risks of peer-to-peer milk sharing is the [Four Pillars of Safe Breast Milk Sharing](#) by the founders of the U.S. based organization, Eats on Feets.

Informal milk sharing can be controversial. However, without being involved in any milk sharing in practice, Leaders can still do what we do best: provide information and support to mothers.

## Conclusion

While working with mothers, remember to focus on supporting the mother and her breastfeeding relationship. Also remember that our goal is to offer information and options, not advice and recommendations. By providing multiple perspectives on the topic, parents will be empowered to develop their own conclusions and make decisions that are best for their family. Leaders have a unique opportunity to support mothers with a variety of problems. We can help mothers identify challenges and develop creative plans to avoid or overcome them.

**Michelle Angeletti** is a La Leche League Leader, Area Professional Liaison (APL) for LLL of Florida and Caribbean Islands, USA, and Professional Liaison Department Research Associate (PLDRA) for the LLL Alliance for Breastfeeding Education Area Network. She is an Associate Professor of Health Services Administration at Florida Gulf Coast University.

**Mary Francell** is the mother of three breastfed children. She has been a La Leche League Leader for 20 years and is currently Area Professional Liaison for LLL of Georgia, USA. Mary is studying to take the International Board of Lactation Consultant Examiners (IBLCE) exam this summer and plans to open a private lactation practice.

## Further reading

Akre, J. E., et al. [Milk sharing: from private practice to public pursuit](#) *International Breastfeeding Journal*, 2011 (accessed 23 June 2015)

Akre, J. E. [Sharing Breast Milk: What's Right For You?](#) June 28, 2012, (accessed 23 June 2015). [http://wholepregnancy.org/index.php?id=articles\\_more&moreid=9](http://wholepregnancy.org/index.php?id=articles_more&moreid=9)

---

<sup>5</sup> See [The Science of Human Milk](#) and [Kellymom](#) has a number of resources discussing the benefits of breast milk.

Cohen RS, Xiong SC, Sakamoto P. Retrospective review of serological testing of potential human milk donors. *Arch Dis Child Fetal Neonatal Ed* 2010;95:F118-F120.

Eats on Feets. *Resource for Informed Breastmilk Sharing*, 2011, [http://www.eatsonfeetsresources.org/?page\\_id=2014](http://www.eatsonfeetsresources.org/?page_id=2014) (accessed 23 June 2015).

Gribble, K.D., Hausman, B.L. *Milk sharing and formula feeding: Infant feeding risks in comparative perspective?* *Australas Medical Journal*, 2012;

Keim SA, Hogan JS, McNamara KA, et al. *Microbial contamination of human milk purchased via the Internet.* *Pediatrics* 2013;132(5):e1227-e1235 (accessed 24 June 2015).

Keim SA, Kulkarni MM, McNamara K, et al. *Cow's milk contamination of human milk purchased via the Internet.* *Pediatrics* 2015;135(5):e1-e6 (accessed 24 June 2015).

Roche-Paull, R., *Body Mods and Breastfeeding* Breastfeeding Today, 2012 (accessed 23 June 2015)

Rodriguez, W., MD, PhD. *Potential Risk Which Could be Associated with Consumption of Some Human Breast Milk*, <http://www.fda.gov/downloads/AdvisoryCommittees/CommitteesMeetingMaterials/PediatricAdvisoryCommittee/UCM235629.pdf> (accessed 23 June 2015).

Walker, S., Armstrong, M. *The Four Pillars of Safe Milk Sharing.* *Midwifery Today* 2012. <http://www.eatsonfeets.org/docs/TheFourPillars.pdf>

## **Milk Donation Policy**

The first priority of LLLI is to help mothers to breastfeed their babies at the breast. A second priority is to help mothers when it is necessary for them to express and safely store and handle their own milk for their babies. When their own mother's milk is unavailable, babies may need human milk donated by other mothers. According to the World Health Organization, donor milk is the best option following one's own expressed milk.

It is always important for the Leader to encourage the mother to talk with her own and the baby's health care providers about their particular situation. If the baby or mother is hospitalized and breastfeeding is not possible, the Leader would recommend that the mother dialogue with medical staff regarding

possible hospital policies related to obtaining and using the mother's own milk or donor milk.

When a mother contacts a Leader seeking to acquire donated milk or to discuss personal options, the Leader's role is to respond with information and support, including information about the benefits and risks of such practices of induced lactation, relactation, wet-nursing, or cross-nursing. This discussion may include formal, commercial, or informal (peer-to-peer) forms of milk sharing, which are practiced in various ways around the world.

If a mother is interested in donating her milk or in receiving donated milk, the Leader should urge the mother to investigate various ways of donating and acquiring human milk. The mother should be encouraged to make an informed decision that is best for her and her baby and meets cultural expectations. A Leader may provide contact information for non-profit human milk banks, other regulated collection centers, and formal/medically supervised or informal milk-sharing networks. Protocols for the careful and safe collection and handling of human milk are the responsibility of milk banks and networks, and the Leader should encourage the mother to evaluate these protocols. It is not the responsibility of LLL Leaders or LLLI to license, recommend, or assess milk banks or networks, but to share information with mothers.

A Leader should never use her position as an LLL Leader to set up any type of milk-sharing network.

As with other breastfeeding-related topics, Leaders are expected to keep up-to-date with current best practices and information for their locations.

*(LLLI Policies and Standing Rules, Aug 76; rev Oct 92, Mar 07, Mar 11, Mar 15)*



## Preparing for Leadership

### New Concept Wording:

**Human milk is the natural food for babies, uniquely meeting their changing needs**

*Marie Beam, Maryland, USA, and Karin Gausman, Colorado, USA*  
Adapted from *LADders* 2015-1 No. 20

In December 2014, the LLLI Board of Directors voted to change the wording of the breast milk concept and the accompanying concept policy statement in the *LLLI Policies and Standing Rules Notebook*, Appendix 17. (See sidebar for new wording.)

**Human milk is the natural food for babies, uniquely meeting their changing needs.**

Human milk is a complete food containing all the nutrients in ideal proportion for optimal human growth. Each mother's milk is specifically adapted to the needs of her child. Human milk provides more than nutrition. Beginning as colostrum, it works with the infant's developing immune system to provide protection against a wide array of illnesses and allergens, a benefit that extends well beyond infancy. Human milk is easily digested and eliminated. Furthermore, the psychological effects of breastfeeding are invaluable; frequent opportunities for touching, holding, and eye contact serve as important stimuli for the child's development. Human milk is the unique and unduplicated food for babies. It is an important factor in the healthy development of babies and young children at all economic levels around the world.

*(LLLI Policies and Standing Rules Appendix 17, Apr 94; rev Dec 14)*  
(Sidebar Ends)

It is rare that changes are made to LLLI concept statements. Eight concepts summarizing LLL philosophy were adopted in 1972. One of these stated that **Breast milk is the superior infant food**. The mother-baby relationship concept was added in 1973. The concept on loving guidance was included in 1975 and the wording changed slightly in 1979. For the past 43 years, we have relied on the same "superior infant food" concept.

This new change arose from a request to the Board to reconsider the wording of the concept in a way that would present human milk as the "norm" rather than comparing it to formula. Over a dozen Leaders worldwide participated for a year in an online discussion workgroup, dialoguing about nuances of each word in the concept, as well as how words might translate into languages other than English. The final version passed the required votes of approval at two separate Board readings.

The concept now says:

***Human milk is the natural food for babies, uniquely meeting their changing needs.***

Wow—what a fantastic change in wording! The older wording seemed to imply that out of many appropriate infant foods, human milk was superior. However, human milk doesn't really belong in a list that rates many feeding options. Human milk is not simply another option—it is the *only* natural food for babies. This new wording more accurately communicates what we believe.

With so much emphasis now placed on natural foods, the new wording should strike a chord with many expectant mothers. Indeed, it makes it clear that breastfeeding is more than just one option; it is every baby's birthright.

\* \* \*

*Marie Beam lives in Kensington, Maryland, USA, north of Washington, D.C. She and her husband, Eric, have three grown children and one grandson. Marie has been a Leader since 1992 and a member of the Leader Accreditation Department (LAD) since 1996. She served on the Concept Workgroup, organized by the LLLI Board.*

*Karin Gausman has been a Leader for 40 years and she lives in Loveland, Colorado, USA, with her husband, Jim, and Emmy, an adopted Shih Tzu from the animal shelter. They have three grown children and four grandchildren. Karin joined the LAD 27 years ago serving as LAD Director together with Alison Parkes for five years until 2010.*

### **Helping Mothers**

## **Help Forms: Helping Mothers Over the Internet**

Jayne Joyce, Oxford and Jill Unwin, Berkshire, LLL Great Britain Help Form Coordinators

*Not every mother feels she can pick up a phone to ask a stranger for breastfeeding help. Increasingly in the age of social media, mothers look for an anonymous way to reach out for help through the wonders of the computer keyboard. Jayne Joyce and Jill Unwin explain more about answering LLL Help Forms in Great Britain.*

Each LLL entity has its own way of managing Help Forms. Whichever system is used, each mother gets a personal answer from a La Leche League Leader. In the United Kingdom (UK), we receive between 50–70 Help Forms each month and have a team of about 18 Leaders writing replies.

On receipt, the coordinators forward each Help Form directly to the mother's nearest Help Form Leader (when there is one), who can then also provide additional local support. If there isn't a nearby Leader on the Help Form team, the query will be forwarded to the next available Leader. Help Form volunteers can choose in advance how often they take Help Forms. If circumstances change (illness, holidays, a family crisis) they can take a break or return Help Forms to the coordinator for reallocation.

### **Information not advice**

As with helping calls, Leaders replying to Help Forms are careful to word replies with well referenced information that includes a range of options that take normal child development into account, rather than giving advice. For example, the reply to a query on a baby waking up at night might include:

*“The Infant Sleep Information Source website from the University of Durham summarizes current research on how babies sleep. Here you can read how common it is for children to wake at night well into toddlerhood.”* [https://www.isisonline.org.uk/how\\_babies\\_sleep/](https://www.isisonline.org.uk/how_babies_sleep/)

The Leader might suggest ways this mother could adapt her family's sleeping arrangements so that everyone gets more rest, and discuss gentle ways to nudge a baby to sleep, such as those in *Sweet Sleep*, Chapter 11.

Often information can be offered using links from LLL websites and other reputable sources such as [Kellymom](#), [Biological Nurturing](#), [Dr Jack Newman](#), or [Ask Dr Sears](#). Links to LLL in other countries might be offered to mothers who would find help easier in their native languages. Reassurance and emotional support can be offered alongside resources for mothers to consider. It can be overwhelming to have too much to read in a reply. Providing links for further reading allows a mother to choose which topics to investigate further.

Although the Help Form disclaimer<sup>6</sup> asks mothers not to share the Help Form reply with others, we always have to be aware that she *may* share it with others, including her doctor or other health care providers. It is therefore especially important that our facts and references are accurate, and that we distinguish between information that does and does not come directly from LLL. We also need to be careful not to trespass on territory that belongs only to the mother and her doctor. The section on “The Art of Sharing Information without Giving Medical Advice” in Chapter 1 of the *Leader's Handbook* is invaluable here, as it is in any one-to-one helping situation.

### **Empower the mother**

When answering a written question without the benefit of conversation, Leaders must analyze the question and consider a variety of possible background scenarios that may not be fully explained. The aim is to support the mother in finding her own solutions to her problems, so it is important to offer information even when the focus of the problem is initially unclear. A

---

<sup>6</sup> The Help Form disclaimer is a statement added to the bottom of every Help Form explaining the terms under which information is shared.

variety of links exploring differing scenarios may need to be included. The focus can be narrowed when further discussion gives greater detail. Equipped with information, the mother can take what is useful and leave the rest. If we respond by only asking questions, the mother could choose not to engage further, leaving the Leader unsure how to proceed. Some mothers may ask further questions and may even make contact again months later as new situations arise.

### **Reply when convenient**

Most Help Form Leaders work on replies in spare moments. Many print out the Help Form question and note down ideas on it as they go about their daily tasks, creating the full response later when they have more time. The process is very family friendly and replies can be written at any time of the day or night. Responses can be read over several times or Leaders may even get a second opinion before sending the email reply. It is often a good idea to leave a complicated written response overnight and come back to it fresh in the morning. This can spark new ideas or a new approach and can also give a chance to check that everything has been covered.

### **Orientation process**

In the UK, we have an established Help Form volunteer orientation, which means that no Leader is launched into writing replies without:

- Knowing the relevant Help Form resources
- Looking at the standard practice of other experienced volunteers
- Considering what necessary disclaimers are needed
- Knowing how to ensure that mothers have access to a complaints procedure should it ever be necessary.

We have never had a complaint because Leaders generally phrase their replies diplomatically, but we do need to comply with legal requirements, as a written reply is more permanent than a conversation.

### **Support from Help Form team**

Each reply is based on a template with an initial introduction, information about *The Womanly Art of Breastfeeding* and other LLL books, how to find local support, how to become a member or make a donation, plus the official disclaimer. This, of course, is thoroughly personalized for each mother but the template saves typing the same details over and over. In their orientation, Help Form volunteers receive feedback from another experienced Leader before finally sending a reply to the mother. Once both Leaders feel confident that she is ready, the new volunteer works independently but will always have the support of the Help Form team if she wants it.

### **Facebook support**

The latest support venture for Help Form Leaders in LLLGB is our Facebook group, a space to seek support, share files, swap ideas, trace missing emails, voice concerns, share highlights, or distribute information through the whole group. This is also a rare opportunity to see what our fellow Help Form Leaders look like, and put faces to names.

### **Quotes from Leaders**

“I like taking Help Forms because, unlike taking calls, they allow me to really think about and research my responses, so I know I'm not forgetting something or getting something wrong in the heat of the moment. It's also lovely to hear back from mothers and find out how things are going and how my suggestions have helped.”

“I volunteered to do Help Forms as soon as I became accredited, and it's been a fantastic experience: I've learnt loads, and it really fits around my life; I reply whenever I have some time, and if I have to stop for some reason (such as a certain four-year-old) I simply save the document and finish it later. You can ask for as many Help Forms as you can manage, and if one comes at a particularly bad time, you just reject it and it will be sent to another volunteer. My highlight so far has been answering a query from a mum in India!”

“I like being on the Help Form team as it's often difficult for me to contact mothers during the day, but I can email late at night, or start an email and then finish it later, so I find it fits in well with everything else I do.”

“Help Forms are especially good for those of us who are short of time, and perhaps get interrupted by little ones when we try to achieve anything that requires concentration during the day! Unlike phone calls and meetings, you don't have to “think on your feet.” You can spend time perfecting them before they are sent out into the world. For this reason, they are not only very satisfying to write, as well as a brilliant learning opportunity for new Leaders to practice helping skills. You quickly build up a more thorough knowledge of online and written resources, which is invaluable in other helping situations, and the ‘cut and paste’ possibilities of word processing programs mean that after a while, you can complete a Help Form really efficiently without having to start from scratch.”

### **Best things about being a Help Form volunteer**

1. Rush of adrenalin every time I see “\*\*\*LLLGB Help Form\*\*\*” in my Inbox!
2. Being able to use my skills to help mothers at times convenient to me.
3. Getting lovely emails back (especially the ones with baby photos or videos attached).
4. Mothers who have been helped by the Help Form team coming to my Group, or hearing they have settled in a different Group, or even become a Leader!
5. Having a tangible result from an hour's work (fits in well with my partner putting my youngest daughter to bed).
6. Unusual helping situations I may never have come across before, and the time to find out all about them before I reply.
7. Fabulous online resources; all I usually need to do is point mothers in the right direction.
8. Lovely helpful colleagues and the Coordinators who look after us.

### **Downsides**

1. It can involve a lot of typing!
2. The occasional mother who never acknowledges my email (probably fewer than 1 in 10).
3. Sometimes having to say no to a really interesting Help Form just because I'm too busy.

For anyone who has not seen how mothers can submit Help Forms, here are some examples:  
<https://www.laleche.org.uk/form/submit-help-request>

[http://www.llli.org/help\\_form](http://www.llli.org/help_form)  
<http://www.lllc.ca/submit-question>

If answering online queries sounds like something that could fit into your life please contact your LLL entity's Help Form coordinator.

Jill Unwin co-leads LLL Berkshire, England and coordinates Help Forms in Great Britain. She had four breastfed babies (daughters Yvonne, Nicky and Charlotte and son Alex) who are now all working adults. Yvonne is still breastfeeding Jill's first grandson.

Jayne Joyce has been a Leader since 2003, an IBCLC since 2011, and she currently runs three Baby Cafés a week in Oxford, England and trains peer supporters. She has three daughters: Tilly (14), Kitty (11) and Daisy (7). Jayne lives in Oxford and is married to Dominic.

## Helping Mothers

# Sudden Weaning for Medical Reasons

**Sarah McCann, Carrickfergus, Northern Ireland**

**Adapted from her blog "Breastfeeding Resources, Northern Ireland," posted August 2, 2011.**

*Sudden weaning in order to take a medication comes with risks and difficulties for mother and baby. Sarah looks at the implications of an early end to breastfeeding and explains that many medications are compatible with breastfeeding.*

When a mother is pressured to stop breastfeeding in order to take a medication, those doing the pressuring often don't understand the implications of weaning for mother and baby. A health professional may not have much or any breastfeeding experience and may feel that breastfeeding into toddlerhood is strange. They may see nursing as the baby's food and not be aware of the relationship. They may think that breastfeeding is a nice thing to do if all is well, but that it is stressful if a mother is ill (Calvert, 2014). They may wonder, "Why breastfeed for more than a few months anyway?"

### **Why breastfeed for more than a few months anyway?**

Katherine Dettwyler, Associate Professor of Anthropology at the University of Delaware, USA (2003), suggests that the natural weaning age of humans is probably between three and seven years of age. Both La Leche League and the World Health Organization support breastfeeding beyond the early months and into toddlerhood. As the length of time that a baby is breastfed increases, there is a reduced risk of infection, optimal teeth and jaw development, and development of a normal immune system, which is not mature until about six years of age (Dettwyler, 2003). Breastfeeding also provides pain relief (during teething, for instance), acts as

a nutritional cushion during illness, and helps to avoid hospitalization. Breastfeeding is an easy way to comfort a baby or toddler and helps them to fall asleep. A mother's confidence from these basic activities may have been vital to her parenting experience up until that point.

### **Risks of sudden weaning to the mother.**

Sudden weaning can affect an individual nursing dyad in many different ways and may also have implications for the mother's partner and wider family.

Sudden weaning may:

- Induce pain and engorgement. A mother may continue to make a large volume of milk whatever baby's age.
- Lead to plugged ducts, mastitis, or an abscess.
- Increase mother's stress levels, leading to increased symptoms of depression (Kendall-Tackett, 2007).
- Lead to feelings of loss, grief or incompetency (Sharma and Corpse, 2008), even mimicking child loss (Gallup, 2010) and thus bringing on depression (Sharma and Corpse, 2008).
- Cause mother to lose an easy way to feed and comfort her baby, especially during teething or illness.
- Require dealing with baby or toddler's continued desire to breastfeed, distressing both parties.
- Cause a loss in the calming effects of prolactin and oxytocin, important hormones produced during breastfeeding that help mothers and babies relax and bond.
- Increase mother's fertility, particularly if she has no access to other forms of contraception or chooses not to use birth control (Sears, 2015)
- Increase the risk that mother or another family member will have to put time and effort into caring for a sick baby or toddler.
- Lead a mother to avoid treatment of a potentially dangerous and life-threatening situation for her and her baby to avoid sudden weaning (Amir, Ryan and Jordan, 2012).

### **Risks of sudden weaning to the baby.**

There are many implications for babies, including:

- An increased risk of infection.
- Losing comfort and closeness with their mother, reducing bonding.
- Becoming suddenly totally dependent on outside sources of food, such as baby formula and solid foods. This can be difficult for some babies, especially if they won't take a bottle or cup, or are only accepting a small amount of solid food, which is also stressful for the mother.
- Losing the protective effects of breastfeeding on future mental health, a particularly important issue if a mother is depressed. Research shows that the baby of a breastfeeding mother being treated for depression has better future mental health outcomes than the formula-fed baby whose mother is being treated for depression (Jones, McFall, and Diego, 2004).

### **Risks to the baby of medications in the mother's milk.**

Mothers may hear that early weaning is necessary due to increased risk to the child from medications in the mother's milk. The reality is that:

- Risks to the baby are greater during pregnancy than during breastfeeding (Kendall-Tackett and Hale, 2010).
- If a toddler is feeding only a few times per day, his exposure to the medication will be much lower than that of a newborn.
- Many medications are considered compatible with breastfeeding and are believed to cause no harm to the infant. Many medications don't cross over into mother's milk and most only cross in very small amounts, equivalent to a very small percentage of the mother's dose (Hale, 2015)

See [Breastfeeding and Medications](#) for a summary of books, reputable websites, and helplines for checking the compatibility of medications during breastfeeding.

### **Gentle weaning**

If it is necessary for a mother to wean before she was planning to, here are some questions a Leader can use to encourage a mother to discuss options with her physician and pharmacist:

- Could an alternative, more compatible medication be prescribed?
- Can the medication be delayed until she planned to wean? Could it be delayed long enough to allow gradual, more natural weaning?
- Would the infant's exposure to the medication for a relatively short time be safe, allowing for a more gradual weaning?
- Might the mother temporarily wean and get baby back to the breast later?

### **When weaning is necessary**

Sadly, there will be mothers who are faced with such serious illness that weaning is necessary. Cancer drugs, for instance, are so toxic that it is unlikely a mother could continue breastfeeding while receiving treatment (Jones 2013). As knowledge of the importance of breastfeeding and the safety of most medications spreads and grows, more women will continue to breastfeed who would in the past have weaned. However, not all doctors or mothers will want to take the risk of exposing their patients and babies to the risks of a specific medication, or the mother may be too ill to breastfeed.

Recently a mother phoned to say she had been diagnosed with thrombocytosis (a life-threatening condition of the blood) and was due to start a chemotherapy drug and another, less serious medication for life. We discussed temporary weaning, dry-up medications, and herbs. She decided to go for purely mechanical methods of weaning by pumping when her breasts felt uncomfortable and using cold cabbage leaves and ice packs.

Another mother was told to wean her ten-month-old daughter to start a stronger medication for depression. Once her daughter was suddenly weaned, the mother suffered pain in her breasts, developed mastitis, and her mood took several weeks to stabilize. Leaders cannot make decisions for the mother, yet they may be the only other people who understand how upset she is at having to wean. As La Leche League Leaders, we can give a mother information, support, and compassion.

If a mother does decide to wean suddenly, ice packs, cold cabbage leaves, sage tea, and a supportive bra can all be helpful. Pumping to remove some milk may also prevent and relieve



engorgement (*The Womanly Art of Breastfeeding*, 2010; Humphries, 2003). Speaking to a board-certified lactation consultant may also help. Only the mother knows the full details of her situation. The Leader's nonjudgmental attitude and helpful information may help her return to La Leche League for help if she has another baby and breastfeeds again.

## References

Amir, L.H., Ryan, K.M., and Jordan, S.E. Avoiding risk at what cost? Putting use of medicines for breastfeeding women into perspective. *International Breastfeeding Journal* 2012; 7(14)

Bengson, D. *How Weaning Happens*. LLLI, 1999.

Bumgarner, N.J. *Mothering Your Nursing Toddler*. Schaumburg, IL: LLLI, 1999.

Calvert, H. Breast isn't best, it's just normal. *Nursing children and young people* 2014; 26(10): 15.

Dermer, A. A well-kept secret: Breastfeeding's benefits to mothers. *New Beginnings* July-August 2001; 18(4):124-127.

Dettwyler, K.A. A time to wean: the hominid blueprint for the natural age of weaning in modern human populations. In *Breastfeeding: Biocultural Perspectives*. Stuart-Macadam, P, and Dettwyler, K.A, ed. New York: Aldine De Gruyter, 2003; 39–73.

Dewey, K. *Guiding principles for complementary feeding of the breastfed child*. World Health Organisation, 2003.

Gallup, G.G. Jr. et al. Bottle feeding simulates child loss: postpartum depression and evolutionary medicine. *Med Hypotheses* 2010 Jan; 74(1):174-6

Hale, T.W. and Rowe, H.E. *Medications & Mothers' Milk*. 16th edition. Plano, TX: Hale Publishing, L.P., 2014.

Humphries, S. *The Nursing Mother's Herbal*. Minneapolis, MN: Fairview Press, 2003.

Jones, W. *Breastfeeding and Medication*. Oxon, United Kingdom: Routledge, 2013.

Jones, N. A., McFall, B.A., and Diego, M.A. Patterns of brain electrical activity in infants of depressed mothers who breastfeed and bottle feed: the mediating role of infant temperament. *Biological Psychology* 2004; 67:103–24.

Kendall-Tackett, K. A new paradigm for depression in new mothers: the central role of inflammation and how breastfeeding and anti-inflammatory treatments protect maternal mental health. *International Breastfeeding Journal* 2007; 2(6)

Kendall-Tackett, K. New research on postpartum depression: The central role of inflammation and how breastfeeding and anti-inflammatory treatments protect maternal mental health. *Leaven* 2007; 43(3):50–53.

Kendall-Tackett, K. and Hale, T.W. The use of anti-depressants in pregnant and breastfeeding women: A review of recent studies. *Journal of Human Lactation* 2010; 26(2):187-195.

Pearson-Glaze, P. Medications and Breastfeeding, *Breastfeeding Support* 2014, <http://breastfeeding.support/> (accessed 6th February 2015).

Sharma, V. and Corpse, C.S. Case study revisiting the association between breastfeeding and postpartum depression. *Journal of Human Lactation* 2008; 24(1): 77-79.

West, D. [Breastfeeding and Cancer](#). *Breastfeeding Today* 2011;10:18-19.

*The Womanly Art of Breastfeeding*, 8<sup>th</sup> Edition. Schaumburg, IL: LLLI, 2010; 335, 388.

World Health Organisation. *Maternal, newborn, child and adolescent health* 2014. [http://www.who.int/maternal\\_child\\_adolescent/topics/child/nutrition/breastfeeding/en/](http://www.who.int/maternal_child_adolescent/topics/child/nutrition/breastfeeding/en/) (accessed 18th November 2014).

**Sarah McCann** has been a Leader in Ireland since 1995. She is married to Mike, and they have three children, Ashleen (24), Timothy (21), and Eloise (18). Sadly, Mike and Sarah's fourth child, Nathan, born in 2006, lived only a few hours. Sarah leads with LLL of Carrickfergus in Northern Ireland and has been in private practice as a lactation consultant for the last eight years.

## Helping Mothers

# When a Mother Experiences Infant Loss

By Lisa Thompson, Michigan, Indiana, USA

I remember when I saw the news. I was scrolling through my Facebook feed, looking for a birth announcement. Sarah<sup>7</sup>, one of the mothers in our local LLL Group, had gone into labor the night before. I was eager to hear the details of her birth. Sarah's page had a post written by her partner with pictures of Sarah and the new baby. Her doula doubled as a photographer. She had taken stunning portraits. But something was wrong. Sarah held a tiny baby wrapped in a blanket, but she looked heartbroken. I read the post. "Jacob was born sleeping." I scrambled

---

<sup>7</sup> Names have been changed

to comprehend. Finally, it registered. Her baby was gone. Stillborn. But babies don't die during birth in this day and age, do they?

It turns out, they do, and in far greater numbers than I ever would have suspected. Every day more than 7200 babies are stillborn ([WHO](#)) In the United States, the rate is about 25,000 babies a year (1 in 150) according to [First Candle](#). The numbers don't tell you much about the human emotions behind those losses, emotions that are often hidden away. Odds are good that someone near you has experienced infant loss and no one told you.

### **What to say**

I knew I needed to respond to the announcement of Jacob's stillbirth. Condolences are one of the few things I know how to do. I've prepared appropriate words to say to those who have lost parents, grandparents, or even a spouse. But the loss of a child, a baby who had never really lived, felt like a new level of devastation. I turned to the Internet, scrolling for meaningful words. Most of the sites I found focused on offering direct support to parents after a loss, but several had articles for friends and family. According to [Still Standing Magazine's, "What Do We Say to a Grieving Parent."](#) and the [Compassionate Friends "How Can I Help Brochure,"](#) there may not be any "right words." Sometimes your silent presence, or admitting you don't know what to say is enough. My final message read along the lines of: "I am so sorry for your loss. I don't know what to say. I'm heartbroken for you."

### **Coping with grief**

My co-Leaders and I had a previously scheduled meeting with a Leader Applicant for the following day. We came together to complete our task, but also to talk and connect. One of my co-Leaders was due in a few months. She was using the same midwife as Sarah and her plans suddenly felt unstable. If stillbirth had happened to Sarah, could it happen to her? The thought was terrifying. We wept and held one another.

Leaders may need to support one another when a mother in the Group loses an infant. We have our own emotions and fears to work through. Perhaps we have experienced infant loss ourselves, through stillbirth, neonatal death, or miscarriage. Help your co-Leaders talk and decompress after difficult events and conversations, or if you need help yourself, call a support person. Take turns offering aid to the family, such as bringing meals or babysitting, running errands, or just sitting to talk with the parents. Be sure you and your co-Leaders are following basic self-care as you give of yourselves both mentally and physically. Caregiving can take a toll.

### **Community support**

You might find yourself supporting others in your community as well. As Leaders, we can offer a listening ear and make suggestions about articles to read or support groups to join. I found myself offering emotional and practical support not only to Sarah, but also to mothers in our Group, Sarah's doula, her ICAN<sup>8</sup> leader, and outside friends. I was consulted on proper funeral attire, appropriate gifts, how to find the right words, and how to help. I was not an expert in these things and I didn't always know the answer. I shared articles from the "Loss Resources"

---

<sup>8</sup> International Cesarean Awareness Network

section at the end of this article because the writers knew so much more than I did. I came to realize that it didn't matter if I gave the "right" answer. Just as new mothers need to express their feelings and get a touch of reassurance to keep moving, these wonderful, supportive women needed the same. A friend who is an LLL communications skills instructor told me that sharing grief can be the most powerful kind of support, particularly when you don't know what to say or what to do. She was right.

### **Details can wait**

News began to trickle through the birth community about what had gone wrong during Sarah's birth. We were hungry for details. If we knew what had happened, perhaps we could prevent it from happening to us. But tragedy doesn't work that way. Rumors and stories can come back around and hurt us. As much as we wanted to know the details of Sarah's birth, we decided to hold back from asking. When Sarah was ready, she would share. Until then, we would support her. We knew she was hurting over Jacob's stillbirth. The reason he died didn't matter.

### **Early ideas for future comfort**

Issues that we might have helped with had come and gone. Many mothers appreciate photos of their baby with themselves and family members. Organizations like "Now I Lay Me Down to Sleep" or local photographers can take professional level portraits. Hospitals and volunteers make footprints and create remembrance boxes. There are organizations that provide clothing and blankets for stillborn babies as well. My Group keeps names of local organizations on hand now in case we get the news in time to offer information.

### **The funeral**

The funeral announcement came through Facebook. My co-Leaders called and messaged one another to be sure we could all attend, arranging childcare and carpooling. We discussed having a flower arrangement delivered. We worried over bringing newborns and about how toddlers would weather the service. Sarah looked dazed when we arrived. There was an open casket. I hugged Sarah and used Jacob's name. I told her how beautiful he was. We cried. My co-Leaders and I, and a handful of mothers in the Group, huddled together in the pews of the church, passing a box of tissues. The service was deep and moving. One of my co-Leaders helped with Sarah's two-year-old to be sure she didn't wander away in the cemetery. We stood in the summer heat, swatting mosquitoes. I have never felt the silent presence of people as a physical force before. Those present helped support Sarah's family through their heart-crushing grief.

### **After the funeral**

At first, friends and family surrounded Sarah, staying with her and caring for her family's needs. Over time, that one-on-one support eased off. Sarah began to reach out, asking for help. Sometimes she asked for help babysitting her two-year-old or for someone to come and help her with house work. Sometimes she needed to talk, because her feelings were just too heavy to handle. When Sarah expressed her grief, we encouraged her to continue working through her feelings. She told us she felt pressured to put away her pain, to hide it from the world. As Leaders, we have learned to name and express feelings so we can communicate heart to heart. My co-Leaders and I encouraged Sarah to feel everything: to cry and scream and rage. She started to call this work "feeling all the feels." People who allow themselves to feel deep

emotions often reach equilibrium more quickly. Helping mothers who have suffered a loss find the words to label the feelings can help them express their emotions. They may find peace in “letting it all out.”

### **Anger**

During one of Sarah’s online vents, she expressed anger at everyone involved in the birth. She felt guilty about these feelings, but she wanted to blame someone, even if it was herself. A struggle with guilt and blame is common for people who are grieving. We encouraged Sarah to face her anger, to decide whether anyone or anything was to blame for Jacob’s death. If she did find true fault, she might seek to come to a place where she could forgive and/or accept in order to guide her healing (as much as anyone can heal from losing a baby). It was possible that there was no one to blame. The “what ifs” might not matter. You can do everything right, follow all the rules, and still, tragedy jumps out of nowhere and knocks you flat. Once it begins, you can’t stop it from devastating you.

### **Sharing sad news**

A week after Jacob’s passing, mothers in the Group began asking questions. “Have you heard from Sarah?” “Did she have her baby?” “Wasn’t she well over due?” My co-Leaders and I realized that a Group announcement might be needed. Friends had set up a meal train (sharing meals) for the family. My co-Leaders and I thought that perhaps sharing the sign-up list for that would help us to break the news. But we had read that it was best to allow the parents to decide how to announce infant loss. Sarah gave us permission to share the news with our Group. She requested that we not include the meal train link, since she did not want people calling her or bringing food if she didn’t know them very well.

### **Privacy matters**

Always consult with the parents before you share personal information about their loss, particularly if it involves sharing names, phone numbers, or addresses. Be sure to ask what help would be best for them at this time. For example, some families may not want food. They may have allergies or have picky eaters, and maybe having food brought to their home feels stressful.

### **Donations and gifts**

Sarah’s family had started an online fundraising site to raise funds for a headstone for Jacob. The family was fine with having friends share this information. My co-Leaders and I made small donations, and we encouraged other friends to donate as well. Some families may need financial care along with emotional support. Others might prefer emotional support and request making donations to a relevant charity. If you would like to contribute financially, you might ask if donations would be appreciated. Several mothers in our Group banded together to purchase an engraved necklace for Sarah with Jacob’s name and birth date. Flowers can be unwelcome as they are reminders of death when they fade. Small tokens of lasting remembrance are often appreciated, whether real or monetary.

### **Coping with milk supply**

As Sarah’s milk came in, she began to have trouble. Her two-year-old was still nursing, which helped initially. When they were separated, Sarah was unable to keep up with the abundance

of milk. Sarah turned to the pump, but struggled to gain relief. She sent me a message, asking for help. We talked about whether she thought it was a good idea to use herbs or cabbage to reduce her supply, but she decided against it as her two-year-old was still nursing. I sent Sarah the Stanford Hand Expression video to see if that would help. Then I watched it (lesson learned –always watch first!). The video talked about getting colostrum for your newborn so she could thrive and be healthy. I sent a quick note to Sarah indicating that she should not watch that video! Then I frantically searched for videos without babies or mentions of babies. So many resources assume healthy, happy births and I hadn't thought of the potential triggers before. For a mother who has lost a baby, LLL can be full of painful reminders. Sarah avoided socializing and attending our meetings for a long while. We understood that she needed the space.

The hand expression videos helped. Sarah was able to relieve her engorgement and slow her supply to a manageable level. I shared that some mothers find comfort in donating their milk. Milk banks provide pasteurized human breast milk to sick and premature babies around the world. I provided information about a nearby milk bank. Sarah chose instead to donate her milk to a local mother in need.

### **As time goes by**

Eighteen months later, Sarah has returned to our meetings with her rainbow baby<sup>9</sup> in arms. She smiles and laughs sometimes, and offers patient support to other mothers. Seeing pregnant mothers and newborns still hurts her, I think, but the intense trauma appears to have eased. Mothers sometimes announce their lost babies during introductions at our meetings now. I never would have thought of suggesting that before, but things have changed. We won't ever be the same.

### **Sarah's story**

I went to LLL meetings regularly during my pregnancy, and so after I had Jacob, I had a lot of support from everyone. Someone set up a meal train for us and we received meals for at least a month. Honestly, I don't think we would have eaten if it hadn't been for those meals. Having people visit and support me to continue nursing my two-year-old was also helpful. I felt comfortable going to a Leader for suggestions about engorgement and pumping whenever I had to be separated from my older child. Two of my favorite resources for baby loss are [stillbirthday.com](http://stillbirthday.com), and a great book called *Empty Cradle, Broken Heart*. There are so many wonderful support groups, blogs, and other online resources. Lots of mothers pump their milk to share with other babies, while others decide to try and dry up their milk supply, which comes with its own challenges. Finding people who have been in that situation is extremely helpful. I've since had another baby, and while it was painful to think about attending meetings while pregnant, I've started going again, and I feel just as welcomed as I was before. The support has been invaluable through my loss and subsequently nursing my new baby.

---

<sup>9</sup> Rainbow baby: a baby who is born following a miscarriage or stillbirth.

## **Reducing Milk Supply After Infant Loss SIDEBAR**

### Reducing Supply

1. Pump and/or hand express to comfort
2. If pumping, do not stop abruptly—gradually increase time between pumping sessions or decrease the amount of milk you are removing from the breasts
3. Wear a supportive bra but do not bind the breasts
4. Use ice (to soothe between pumping) or heat (to help milk let down before expressing to comfort)
5. Consider taking a pain reliever that your health professional recommends.

### Substances that can reduce milk supply:

1. Sage leaves, capsules or tea (do not use sage essential oil); to make sage tea, steep 1 tablespoon of fresh whole leaf dried herb in one cup of boiling water for 10–15 minutes. Some suggest drinking three to six cups per day.
2. Strong peppermint: some advise ingesting an extra strong peppermint candy/sweet every hour while awake
3. Ongoing application of cold green cabbage leaves
4. No-more-milk Tea (available online)
5. Other herbs suggested by [Kellymom](#)
6. Sudafed<sup>10</sup> (original formula), taken under guidance of a physician
7. Birth control pills containing estrogen, taken under guidance of a physician
8. Other prescription medications are no longer recommended as a safe way to reduce supply

## **Loss Resources**

### **Support Organizations**

#### International

- [Stillbirth Alliance](#)
- [Still Birthday \(English\)](#)
- [Still Birthday translations](#) (Afrikaans, Arabic, Dutch, German, Italian, Korean, Polish, Spanish, Thai)
- [Still Birthday perspectives](#) Alternative Families, Single Mothers, Teen, Military, LGBTQ +, Cultural, Spiritual Specific; scroll for links)

#### Australia

- [Sands miscarriage, stillbirth, and newborn death support](#)
- [Heartfelt Photographic Memories](#)

---

<sup>10</sup> Contains pseudoephedrine, a decongestant.

## Canada

- [PAIL Network \(Pregnancy and Infant Loss\)](#)

## France/French

- [L'Association l' Enfant Sans Nom - Parents Endeuillés](#)
- [Un bébé est parti, groupe de soutien LLL au deuil périnatal \(LLL specific\)](#)

## Netherlands/Dutch

- [Vereniging Ouders van een Overleden Kind](#)

## Switzerland/French/English

- [Agapa Suisse Romande](#)
- [Expatriant Birth and Bereavement Support](#)
- [Zoe Bailey Photography](#)

## UK

- [Glow in the Woods](#)
- [Sands \(Stillbirth and neonatal death charity\)](#)
- [Saying Goodbye \(Remembrance Services\)](#)

## USA

- [First Candle \(24 hour grief phone support\)](#)
- [National Share Pregnancy & Infant Loss Support](#)
- [MISS Foundation](#)
- [Still Standing Magazine](#)
- [Grieving Dads](#)

## **Loss Doulas**

- [Still Birthday \(International\)](#)
- [Baby Loss Family Advisors \(US/Canada\)](#)

## **Lactation Issues**

- [Lactation After Loss: A Guide for Bereaved Mothers from Empty Arms Bereavement Support \(brochure\)](#)
- [“Post Loss Lactation” from Still Birthday](#)
- [“Lactation Suppression” from the Australian Breastfeeding Association \(PDF\)](#)
- [“Lactation Suppression” from Breastfeeding Basics](#)
- [“Hand Expression” \(video; baby-free\)](#)
- [International Milk Banking Initiative](#)
- 

## **Art/Writing/Photography**

- [Now I Lay Me Down To Sleep \(photography/international\)](#)
- [Carly Marie Project Heal \(self-care and mindfulness inspiration\)](#)
- [The Amulet: Exploring the Hidden World of Infant Loss \(art/UK\)](#)
- [Faces of Loss, Faces of Hope \(stories\)](#)



- [Grieve Out Loud \(pen pal program\)](#)
- [Mikayla's Grace \(knit/crochet/sewing/clothing and blanket patterns\)](#)
- [NICU Helping Hands \(wedding gown donations to make clothing: US, Canada, and Australia\)](#)

### **Self-Care/Gifts**

- [Earth Mama Angel Baby \(US\) & Earth Mama Angel Baby \(UK\)](#)
- [Still Birthday Memento Ideas](#) & [Still Birthday Jewelry Ideas](#)

### **Articles for Parents**

- ["Postpartum Health", Stillbirth Day](#)
- ["Experiences of Grief", Healing Hearts](#)
- ["Practical Information for Parents Coping With Loss in Late-Stage Pregnancy or Early Infancy", Angel Babies](#)
- ["Freya's Gold: Milk Donation After Loss", Lactation Matters](#)
- ["Parenting Gently Through Grief and Loss", Natural Parents Network](#)
- ["Children and Grief: 10 Tips", Journey Through Grief](#)

### **Articles for Family/Friends/Support Providers**

- ["How to Help a Friend Survive the First Year after Pregnancy or Infant Loss", Still Standing Magazine](#)
- ["What do We Say to a Grieving Parent", Still Standing Magazine](#)
- ["How Can I Help", The Compassionate Friends](#)
- ["For Grandparents", First Candle](#)
- ["Guidelines for health care professionals supporting families experiencing perinatal loss", Canadian Paediatric Society](#)

Lisa Thompson is a Leader in Northwest Indiana, USA, about an hour outside of Chicago, Illinois, USA. She completed her accreditation in February of 2006. Lisa has three children, Liam (11), Ryan (7), and Keira (5).

## **Helping Mothers**

# **Postpartum Depression**

Hanny Ghazi, LLLF Spanish-speaking moms, France

LLL believes that mother and baby need to be together early and often to establish a satisfying relationship and an adequate milk supply. And a baby has an intense need to be with his mother which is as basic as his need for food. For women with postpartum depression, these simple aspects of relating to one's child can be difficult. I would like to share a little of [my own](#)

story of dealing with postpartum depression and how I have been able to use what I learned to help other mothers.

Although I believed in the concept about mother-baby togetherness, and I would have given a million dollars to have followed it through, I found it very difficult to put into practice initially despite breastfeeding continually through the first year.

Other people had changed, bathed, rocked, and played with my baby pretty much all the time until he was about nine months old. I did breastfeed him, yes, but I unconsciously avoided spending unlimited time with him because I was suffering from postpartum depression (PPD).

My guilt for not being the mother I had planned to be was eased to a certain degree by the fact that I had succeeded in breastfeeding him exclusively, despite a lot of trouble latching and misunderstanding the process at the beginning. However I didn't engage with my child as much as I wished and I only did the minimum of what the outside world expected me to do.

Even when spending time with just the two of us, I would be looking at my phone and checking my social networks, ironically for websites related to mothering and how to bond with one's baby. I was desperate to make it happen but was completely lost at the same time!

When my little boy was around nine months old, I realized that I had to make drastic changes in order to get empowered and bond with my child. I decided to follow my instinct of protecting my child and I became the only person taking care of him. The expected miracle happened: I fell completely in love with him.

Today, I am (almost) the mother I dreamt I would be (because we all find mistakes in our daily mothering work, don't we?). I have completed my application to be an LLL Leader and have started supporting mothers on the phone, by email, and during monthly meetings.

I think that my experience has made me sensitive to the signs of PPD in other mothers. This can be an advantage if I am supporting a breastfeeding mother struggling with bonding. I will always be grateful for the miracle that saved my relationship with my son: the beautiful breastfeeding hormones and the help from La Leche League.

### **Helping mothers with PPD**

The first mother I helped with PPD came via a phone call: a mother in severe distress after a traumatic delivery. She had not bonded with her baby; she didn't even mention the fact that she had given birth to a baby boy. The mother only discussed the pain and the injustice she had experienced at the hospital. She had all the elements for PPD (traumatic delivery, lack of support, breastfeeding not starting properly due to subsequent interventions after the delivery that required general anesthesia). That first phone call lasted an hour in which she didn't stop talking and I didn't even have a chance to write notes in my Leader's Log. I just listened and felt her pain.

For several weeks we talked on the phone regularly. I listened patiently as she told me over and over again things that I knew already. I knew from my own experience that she needed to tell them many times in order to lessen their weight in her mind and heal.

I helped with ideas without mentioning the fact that I had experienced something similar myself. My most used phrase was “Some mothers find (insert suggestion)... useful.” I talked about eating well (because malnourishment contributes to PPD and it impedes recovery), trying to sleep as much as possible (sleep deprivation is another major element to PPD), and finding support around her. In this mother’s case there wasn’t a father in the picture and her family lived abroad so I suggested she reach out for friends on Facebook and support groups so she could have her daily share of cheering up. I supported her when she told me that she would like to write a letter of complaint to the hospital. We discussed how important it was to do that to help her heal from the memories of what happened and to try to prevent it happening to other mothers in the future. I emphasized the importance of breastfeeding, over and over again, as a way to heal and bond with her little boy.

A month later I called her and she sounded completely different. Her voice was different: she sounded calmer and happier. Previously, her baby would start screaming and she would start crying (and not reaching out to him). This time the baby started crying and she talked to him using sweet words (“Why are you crying now my son?”). She explained to me that he had just nursed so she didn’t understand why he was crying, I casually suggested that maybe he had missed his dessert and she put him back to the breast. I was extremely excited to hear how her voice changed even more as she was breastfeeding him. The amazing oxytocin was doing its work!

### **Listening and talking**

Leaders can help mothers experiencing PPD by listening to them as much as they can and encouraging them to talk. Leaders should also encourage mothers with PPD to look for professional help when things do not seem to be getting better. There are organizations and help groups for mothers experiencing PPD. If possible try to find out if they support breastfeeding before making the recommendation because it is not always the case.

### **Useful books**

In my healing journey after PPD I found two books I would definitely recommend:

1) Thomas, Kim. *Birth Trauma. A Guide for You, Your Friends and Family to Coping with Post-Traumatic Stress Disorder Following Birth*. Nell James Publishers, 2013. - A mother experiencing PPD needs help and support, and so does her partner, her family, and close friends. The book explains ways to cope with the situation and to avoid making it worse. A book of empowerment for a mother’s circle of support.

2) Kendall-Tackett, Kathleen A. *Depression in New Mothers: Causes, Consequences, and Treatment Alternatives*. Routledge, 2009. - Kathleen Kendall-Tackett presents the outcomes of different studies that explain the causes of PPD, what can happen to the mother and the baby if not treated, and alternatives to help the mother recover.

## **Biography**

Hanny Ghazi originally came from Colombia, and now lives in France with her French husband and their son, Emilio, who is almost three years old. She has been a Leader since December 2014. Hanny created an LLL support Group for Spanish speaking mothers in the Paris area in May 2015.

Hanny blogs about mothering through breastfeeding (in Spanish) at [www.cafelaleche.fr](http://www.cafelaleche.fr) and the full story of her postpartum depression can be found in [\*Breastfeeding Today\*](#), August 2014

## **Ayuda a las madres Depresión Postparto**

Hanny Ghazi, Grupo LLL en español, Francia

LLL cree que la madre y su bebé necesitan estar juntos y a menudo para poder establecer una relación satisfactoria y una adecuada producción de leche. Un bebé siente una intensa necesidad de estar con su madre, para él esta necesidad es tan básica como la comida. Para las mujeres que atraviesan una depresión postparto, estos aspectos básicos de la relación con sus propios hijos pueden ser difíciles. Quisiera compartir un poco de mi propia experiencia al respecto de la depresión postparto y como he logrado poner este aprendizaje en práctica cuando madres en situaciones similares me contactan.

Aunque yo creía en el concepto del vínculo entre la madre y el hijo, y habría dado un millón de dólares por haber vivido así la llegada de mi hijo, me fue muy difícil poner este concepto en práctica inicialmente a pesar de haber amamantado continuamente a mi hijo durante su primer año.

Fueron otras personas quienes lo cambiaron de pañal, lo bañaron, lo arrullaron y jugaron con él casi todo el tiempo casi hasta sus nueve meses. Sí, yo lo amamantaba, pero inconscientemente evitaba pasar mucho tiempo con él porque sufría una depresión.

La culpa que sentía por no ser la madre que había planeado ser era en cierta forma paliada por el hecho de haber logrado amamantarlo exclusivamente, esto a pesar de haber encontrado múltiples dificultades para lograr un buen agarre de seno, reconocer sus signos de hambre, y establecer una buena producción de leche. Con los meses, logré superar estos obstáculos pero aún así no lograba conectarme con mi hijo como yo lo deseaba luego hacía lo mínimo para satisfacer a mi entorno en cuanto a mi rol de madre.

Aún en los momentos que pasábamos juntos los dos solos, yo pasaba el tiempo mirando mi teléfono y revisando mis redes sociales, irónicamente buscaba las publicaciones relacionadas con la lactancia y la crianza con apego. Estaba desesperada por crear un vínculo con mi hijo pero estaba completamente perdida y no sabía cómo hacerlo!

Cuando mi chiquillo tenía aproximadamente nueve meses, me dí cuenta de que tenía que hacer cambios drásticos para poder empoderarme y crear un vínculo con él. Decidí seguir mi instinto de proteger a mi hijo y me convertí en la única persona que se encarga de él. El milagro que yo deseaba ocurrió : me enamoré perdidamente.

Hoy día soy (casi) la madre que soñé ser (porque todas encontramos errores diarios en nuestra manera de criar, cierto?). Terminé mi aplicación para convertirme en monitora LLL y comencé a apoyar madres lactantes por teléfono, email y en encuentros mensuales.

Creo que mi experiencia me convirtió en alguien sensible a los signos de depresión postparto en otras madres. Esto puede ser ventajoso si estoy apoyando una madre lactante que tiene dificultades para crear un vínculo con su bebé. Siempre estaré agradecida por el milagro que salvo la relación con mi hijo : las hormonas de la lactancia y la ayuda de La Leche League.

### **Ayudar a las madres en depresión postparto**

La primera madre que pude ayudar en situación de depresión postparto llegó a través de una llamada telefónica : una madre en situación extrema de estrés post-traumático después de un parto escalofriante. No había establecido un vínculo con su bebé, de hecho ni siquiera mencionó a su bebé en toda la conversación. Sólo se quejó de la injusticia que había vivido en el hospital materno. Su caso presentaba todos los elementos para una depresión postparto (parto traumático, falta de apoyo y lactancia en problemas como resultado de las subsecuentes intervenciones postparto que necesitaron anestesia general). Esa primera llamada duró aproximadamente una hora en la cual ella habló sin parar y yo no pude ni tomar notas en mi cuaderno de monitora. Sólo pude escuchar y llorar en silencio.

Durante varias semanas hablamos por teléfono regularmente. Escuché pacientemente mientras me contó una y otra vez las mismas cosas. De mi propia experiencia sabía que ella necesitaba contarlas muchas veces para que se hicieran menos duras de soportar y para sanar.

Le ayudé con ideas sin mencionar el hecho que yo había atravesado una situación similar. La frase que más usé fue "Algunas madres pueden encontrar útil \_\_\_\_ (la sugerencia se inserta aquí). Le hablé del hecho que debía alimentarse bien (porque la desnutrición contribuye a la depresión postparto e impide la recuperación), intentar dormir lo más que pudiera (la falta de sueño también es un elemento fundamental que conduce a la depresión postparto), y la motivé a encontrar apoyo a su alrededor. En este caso no había padre y su familia vive en su país de origen así que le sugerí que buscara amigas en Facebook y grupos de discusión donde pudiera obtener su ración diaria de motivación. La apoyé cuando me dijo que le gustaría escribir una carta de reclamo al hospital donde había dado a luz. Discutimos el hecho que es importante hacer algo así ya que expresar sus sentimientos de rabia y frustración le ayudaría a sanar sus heridas, al tiempo que podría ayudar a evitar que otras madres pasen por situaciones similares en el futuro. Hice especial énfasis en la importancia de la lactancia, una y otra vez, como manera de sanar y crear un vínculo con su pequeño.

Un mes más tarde la llamé de nuevo y sonaba completamente diferente. Su voz sobretodo: sonaba más calmada y más feliz. En ocasiones anteriores, cuando su bebé empezaba a gritar

ella se ponía a llorar (y no hacía nada para calmarlo). Esta vez su bebé empezó a llorar y ella le habló dulcemente (¿por qué lloras, mi niño?). Me explicó que recién había terminado de mamar así que no podía tener hambre de nuevo. Yo le sugerí desprevenidamente que quizás le había faltado el postre y ella decidió ponerlo al seno de nuevo. Fue muy emocionante para mí escuchar como su voz se hizo aún más suave mientras su bebé mamaba. ¡La maravillosa oxitocina hacía su trabajo!

## **Escuchar y hablar**

Las monitoras pueden ayudar a las madres que atraviesan una depresión postparto escuchándolas y motivándolas a hablar. También deben motivar a las madres en esta situación a buscar ayuda profesional cuando las cosas no mejoran con el paso del tiempo. Existen organizaciones y grupos de ayuda para madres en situación de depresión postparto. Si es posible, sería conveniente verificar que la organización o el grupo de ayuda al cual se está orientando a la madre, apoye la lactancia materna, pues no siempre es el caso.

## **Libros útiles**

En el camino que he recorrido para sanar de mi depresión postparto, encontré dos libros que recomendaría enormemente:

- 1) Thomas, Kim. *Birth Trauma. A Guide for You, Your Friends and Family to Coping with Post-Traumatic Stress Disorder Following Birth*. Nell James Publishers, 2013 (en inglés solamente). – La madre que atraviesa una depresión postparto necesita ayuda y apoyo, pero su pareja, familia y amigos cercanos lo necesitan también. El libro explica maneras de sobrellevar esta situación y evitar que las cosas empeoren. Un libro de empoderamiento para el círculo de apoyo de la madre.
- 2) Kendall-Tackett, Kathleen A. *Depression in New Mothers: Causes, Consequences, and Treatment Alternatives*. Routledge, 2009 (en inglés solamente). - Kathleen Kendall-Tackett presenta los resultados de diferentes estudios que explican las causas de la depresión postparto, qué puede ocurrir a la madre y al bebé cuando esta no es tratada, y alternativas para ayudar a la madre a recuperarse.

## **Biografía**

Hanny Ghazi es colombiana y vive hoy día en Francia con su esposo (francés) y su hijo, Emilio, quien cumplirá tres años próximamente. Fue acreditada como monitora LLL en diciembre de 2014 y creó un grupo de apoyo a la lactancia para las madres hispanohablantes en región parisina en mayo de 2015.

Hanny es bloguera en [www.cafelaleche.fr](http://www.cafelaleche.fr) donde publica textos relacionados con el maternaje a través de la lactancia (en español). La historia completa de su depresión postparto se encuentra en el número de agosto 2014 de la revista [Breastfeeding Today](#).

## Series Meetings/Growing Your Group

# The LLLong Road Home: One Leader's Journey

---

by Jessica Starr, Caerphilly, Wales, LLL Great Britain

### Setting Off

I know the exact day and time when my journey to becoming an LLL Leader began. It was Saturday 13 February 2010, 6:04 P.M. Boom! My life as I knew it exploded and I was left, surrounded by the debris of what I thought I knew, with a tiny mewling creature snuggled on my bare chest. When I close my eyes, I am back in that room, back with her, my baby, in her first moments. And she managed to find my left breast and latch on by herself. Amazing!

The weeks that followed were extremely hard. I loved her so very, very much but I was shell-shocked at the urgency and constancy of her need for me. Feeding was agony and I dreaded every time. A combination of inverted nipples, tongue-tie and poor positioning meant I struggled to make enough milk to satisfy her. I needed help but didn't know where to look. Eventually, I contacted the local National Health Service (NHS) International Board Certified Lactation Consultant (IBCLC). In the weeks that followed, everything gradually turned around. Once the feeding was sorted out, everything else fell into place. I was mothering through breastfeeding and loving it.

### Reaching Out

I talked to other mothers about their experiences and was shocked to find that many women had also struggled and hadn't found the help they needed. In the town where I lived there were no breastfeeding support groups, so three friends and I decided to start one. We didn't have any special qualifications apart from the experience of mothering and breastfeeding our own children and our genuine desire to help other mothers who wanted to breastfeed.

Our group grew surprisingly quickly. We had clearly identified a need in our community for that kind of mother-to-mother support. We helped by listening, sharing experiences and directing to other knowledgeable resources when needed. We were making a difference and were pleased with what we were doing, but felt that if we knew more we would help even further.

### Gaining Knowledge

We discovered that we could train with one of the breastfeeding charities in Great Britain or, as we are in Wales, we could train with a peer supporter program paid for by the Welsh Assembly Government (WAG). So, how to choose?

We settled on Association of Breastfeeding Mothers (ABM) for our training, ruling out LLL because we felt confused by the training process and many acronyms. I took the ABM mother supporter course and our group became an ABM-listed group. I then continued on to the ABM Breastfeeding Counselor training.

We also managed to access the WAG peer supporter training. One of the best parts was that all new peer supporters were given a copy of the latest edition of *The Womanly Art of Breastfeeding*. I would never have chosen it, because the title seemed odd to me at that time, but I read it and loved it! This wasn't just a book about breastfeeding: it was about mothering as I now understood it.

### **Meeting La Leche League**

*“Just as women learn about breastfeeding and mothering by observing and interacting with breastfeeding mothers, women learn about LLL and leadership by observing and interacting with Leaders,” Leader’s Handbook (2003) p.136*

I visited other local breastfeeding groups to see how they operated and to find what worked well so that we could use ideas in our group. I found myself at an LLL meeting, not knowing anyone and feeling a bit shy. It seems funny to think now that I had an LLL Group just half an hour away from where I lived all along. Yet I didn't actually go there until I was breastfeeding an 18-month-old and had already started breastfeeding counselor training with another organization.

It was a Series Meeting about introducing solid foods. The Leader gave a short introduction and I made a mental note that it was a great way to start a meeting. We went around in a circle, introducing ourselves and our children. The next couple of hours passed very quickly and pleasantly. One of the Leaders made me a cup of tea. There was beetroot cake. Then it was over. I drove home with my head bursting with examples of how to run a really successful Group.

I kept going to almost every meeting after that. Every contact I had in real life with LLL made me feel more and more at home. So why had La Leche League not seemed like the obvious option from the start?

### **A Philosophical Problem**

The initial barriers for me were the name, the use of the word “Leader,” and the philosophy. The organization’s name, La Leche League, seemed confusing to me. The title of “Leader” did not convey a clear purpose or appeal to me when I compared it to “Breastfeeding Counselor.” And although the concepts felt like a good fit for me personally, I felt they could be excluding some mothers.

Now that I know more, I consider my favorite parts of LLL to be the concepts and philosophy. The concepts are the foundation of the organization for women learning more about



breastfeeding and mothering and deciding what is best for their families. And the philosophy is to draw in those who it resonates with, not a barrier to keep people out.

### **The New Welsh Groups Project**

I was ready to begin my application at a time when LLL Great Britain had received money to fund new Groups in my area of Wales. The application process itself was enjoyable and thought-provoking. I feel every area of my life has been enhanced by the improved communication and listening skills I developed. I gained friends, discovered the history and structures of this huge and diverse organization and, perhaps most valuable, I learned more about myself. The real-life mother-to-mother connections made during my application were the most fulfilling aspect. It was definitely the right choice for me (even if it took me a while to realize it). This support network is just one of the things which, had I known in the beginning, would have perhaps brought me to LLL sooner. Other factors include the quality of LLL literature and publications, and that LLL is internationally recognized and respected within the breastfeeding community. I look forward to the future development of the LLL national and international websites, as well as our Group webpages and social media, so we can meet the needs of mothers today.

If I am honest, I still don't love the name La Leche League. We hope to call our Group "Caerphilly Breastfeeding Mums, part of LLLGB" as a softening of sorts. But I do love what the name stands for—love itself.

I am excited for the next part of my journey.

#### **Bio**

Jessica Starr attended her first LLL meeting in Newport, South Wales, Great Britain when her eldest child was 18 months old and "still" breastfeeding. She was accredited as an LLL Leader in January 2015. Jessica leads a weekly meeting in her hometown, Caerphilly, where she lives with her husband, Neil, and their two children Ella (five) and Dylan (one). She blogs at [www.jessicastarr.co.uk](http://www.jessicastarr.co.uk).

### **Growing Your Group**

#### **LLL Italy is 35!**

LLL Italy has presented its statistics for 2014—the year in which LLL Italy turned 35. We hoped by using an attractive design, it would serve as an incentive to our Leaders to report their statistics, as well as being a quick and easy way to advertise what we do.

Shevawn O'Connor  
ACL LLL Italy

## LERB 2015

Juanita Watt [juanitaewatt@gmail.com](mailto:juanitaewatt@gmail.com)  
Fran Dereszynski [dereszyn@verizon.net](mailto:dereszyn@verizon.net)  
Barbara Higham [barbara.higham@gmail.com](mailto:barbara.higham@gmail.com)  
Toshi Jolliffe [toshijapan@pt.lu](mailto:toshijapan@pt.lu)  
Judith Gibel [judithgibel@gmail.com](mailto:judithgibel@gmail.com)  
Mary Lofton [rmlofton@sbcglobal.net](mailto:rmlofton@sbcglobal.net)

## Reserve

Helen Gray [helengray123@yahoo.co.uk](mailto:helengray123@yahoo.co.uk)  
Katrina Soper [jijmumma@gmail.com](mailto:jijmumma@gmail.com)  
Jaime Gassmann [jaimegassmann@gmail.com](mailto:jaimegassmann@gmail.com)  
Ginny Eaton [ginnyeaton@hotmail.co.uk](mailto:ginnyeaton@hotmail.co.uk)

## Contributing Editors

Mary Francell [mary.frsh@gmail.com](mailto:mary.frsh@gmail.com)