Dear newly bereaved parent(s):

I am so desperately sorry you are reading this. I may not know your exact pain, but I know a version of it. My first child, Briar, was stillborn at 37+4 on October 20, 2022. Our hearts have been shattered and we will carry both the pain of losing her and our endless love for her for the rest of our lives. What you are reading is a document filled with advice, suggestions and resources that I wish we had to begin navigating life without our daughter in our arms. If any of it doesn't feel right, ignore it. If any of it brings comfort, follow that feeling. I know what works for one person may not work for another, but it's a starting point. I hope you are gentle with yourselves and the people around you give you grace to grieve in whatever manner you need to survive this unimaginable pain. I am wrapping you in love and wish you weren't walking this path with my family. Please pass this document along to whoever you think may benefit from it.

With love, Briar's Mom, Erin.

My personal advice:

I highly recommend that patients delegate a friend or family member to help follow up with postnatal appointments to let the staff know about the miscarriage/stillbirth/SIDS/TFMR ahead of time (massage, chiro, estheticians). This allows the patient to broach the subject if they are in the right headspace that day rather than entering an appointment and being asked about their baby immediately.

If they have the energy, I also highly recommend parents experiencing loss to immediately begin reading to or listening to "It's OK That You're Not OK", "Healing Your Grieving Heart After Stillbirth: 100 Practical Ideas For Parents and Families" and/or "You Are Not Alone: Love Letters From Loss Mom to Loss Mom". All of these were so helpful in our grieving process and putting our raw feelings into eloquent words. These books may be available as an audiobook through VIPL and can be accessed through library apps like Libby.

If the grieving parents are overwhelmed by people asking "How can I help?", making meals for the freezer or providing gift certificates to food delivery services are invaluable acts of service. We had a meal train for a month and it was the best thing we could have asked for but didn't know we needed. Delegating chores/tasks like dog walking, laundry, housecleaning, dishes, garden maintenance, grocery trips or taking your living children out for a few hours may also be helpful.

Resources:

Online support group through Butterfly Run Vancouver:

https://www.butterflyrunvancouver.com/our-support-group

I found this the most helpful resource. Connects you with people all over the province who have experienced different types of infant loss. Does not have to be recent. Facilitated by an incredible counselor, Anya, who has also experienced loss.

There is also now an in-person support group that is run every month or so in Nanaimo using the space at Sage Midwifery. This is open to those affected by infertility, miscarriage, TFMR, stillbirth and infant loss at any point in their life.

https://www.butterflyrun.ca/events-1/nanaimo-perinatal-loss-support-group-2024-05-29-18-00

Local counseling support:

Crossroads Pregnancy Centre: https://www.cpcnanaimo.com/ Jennifer Miller used to provide peer support at Crossroads. I am unsure where she is now, but it may be worth reaching out through Crossroads to see if you can connect with her or another peer support. Jennifer is empathetic, kind and incredibly supportive. We have accessed her services for ourselves and referred our grieving family members as well.

Noelle Reimer: https://www.claritycounsellingnanaimo.com/

Noelle operates out of her home office in north Nanaimo and out of a shared office space in the Old City quarter. She facilitates the in-person support group offered by Butterfly Run as well. I have seen her many times at different stages of my grief and find her support incredibly helpful.

Vancouver Island Crisis Line: 1-888-494-3888

Please emphasize to patients that this isn't just for suicidal people. I was reluctant to utilize this service as I thought it was only for people with suicidal thoughts. It is available 24/7 for anyone who needs to talk to someone. I had many sleepless nights alone with my thoughts and would have benefited from talking to someone.

Nanaimo Hospice: https://www.nanaimohospice.com/
Book an intake appointment to determine what program would fit your grief/trauma experience info@nanaimohospice.com 250-591-8811

Brooks Landing Crisis Response and Counselling (self-referral):

https://www.islandhealth.ca/our-locations/children-youth-locations/central-island-access-services-brooks-landing-children-youth-families

250-739-5710

The quality of counselor will be variable as they are not geared towards pregnancy or infant loss but this is a free resource available in Nanaimo for drop in sessions. If you need to talk to someone immediately, this may be helpful.

Brief Encounters Pregnancy and Infant Loss Support (Orgeon): https://www.briefencounters.org/

Virtual support groups and resources

Mothering Your Heart: https://www.motheringyourheart.com/
Free loss journal available as well as online classes and personal support

Books:

It's OK That You're Not Ok - Megan Devine https://www.amazon.ca/lts-That-Youre-Not-Understand/dp/1622039076

Healing Your Grieving Heart After Stillbirth: 100 Practical Ideas For Parents and Families - Alan Wolfelt (Provided by Crossroads through Jennifer Miller) <a href="https://www.amazon.ca/Healing-Grieving-Heart-After-Stillbirth/dp/1617221759/ref=asc_df_1617221759/?tag=googleshopc0c-20&linkCode=df0&hvadid=309344616184&hvpos=&hvnetw=g&hvrand=4497900587636844688&hvpone=&hvptwo=&hvqmt=&hvdev=c&hvdvcmdl=&hvlocint=&hvlocphy=1001927&hvtargid=pla-563828321260&psc=1

There are versions of this book for miscarriage, stillbirth, SIDS etc

You Are Not Alone: Love Letters From Loss Mom to Loss Mom - Emily Long (Provided in the hospital care box we received)

https://www.amazon.ca/You-Are-Not-Alone-Letters/dp/0996555625

Still - Emma Hansen

https://www.amazon.ca/Still-Memoir-Love-Loss-Motherhood/dp/1771643919

Ask Me His Name: Learning to Live and Laugh Again After the Loss of My Baby - Elle Wright

https://www.amazon.ca/Ask-Me-His-Name-Learning/dp/1788701798/ref=tmm_pap_swatch_0?_encoding=UTF8&qid=1690499206&sr=1-1

An Exact Replica of a Figment of My Imagination: A Memoir - Elizabeth McCracken https://www.amazon.ca/Exact-Replica-Figment-My-Imagination/dp/8004WB19VC

How To Live When A Loved One Dies - Thich Nhat Hanh https://www.amazon.ca/How-Live-When-Loved-Dies/dp/1946764809

Kids books:

Someone Came Before You

My Sibling Still

The Invisible String

I Am A Rainbow Baby

The Story of My Purple Butterfly
(Personalized book for loss of a twin)
https://www.lossbooks.com/product/purple-butterfly-books/my-purple-butterfly/

Podcasts:

As Long As I'm Living

https://open.spotify.com/show/7noA1nInyII4vPjSz9a9BK

https://podcasts.apple.com/us/podcast/as-long-as-im-living-rebuilding-our-happier-ever-afters/id1601461648

Stillbirth Happens

BC Women's Hospital and Butterfly Run Vancouver

(I am one of the guests for episode 2)

http://www.bcwomens.ca/health-info/pregnancy-parenting/stillbirth-newborn-loss/podcas t-stillbirth-happens#:~:text=Through%20stories%20of%20lived%20experiences,%2C%2 0grieve%2C%20and%20feel%20connected

Here After with Megan Devine

https://open.spotify.com/show/5ZRfGMz5XI8hJmriO7jkNe

https://podcasts.apple.com/us/podcast/here-after-with-megan-devine/id1595914505

Stillbirth Matters

https://starlegacyfoundation.org/category/stillbirth-matters-podcast/

The Morning

https://www.themorning.com/listen

Forums:

Baby Loss: https://www.reddit.com/r/babyloss/

Facebook groups:

Healing Hearts Foundation Vancouver Island

https://www.facebook.com/BCHealingHeartsFoundation/

Human Milk 4 Human Babies - Vancouver Island (Connecting with other families who may need colostrum, milk or formula)

https://www.facebook.com/hm4hbvanisle/

Grace Baby Loss Support Group

https://www.facebook.com/gracebabylosssupportgroup/

Footprints: Infertility & Pregnancy Loss Support Group https://www.facebook.com/groups/footprintssupport/

Instagram accounts:

@westcoast_lossjourney https://www.instagram.com/westcoast_lossjourney/?hl=en

@wpsugrief <u>https://www.instagram.com/wpsugrief/?hl=en</u>

@breathingafterloss https://www.instagram.com/breathingafterloss/?hl=en

@griefandhopecoach https://www.instagram.com/griefandhopecoach/

@thegrievingmoms https://www.instagram.com/thegrievingmoms/?hl=en

@aslongasimliving https://www.instagram.com/aslongasimlivingpodcast/?hl=en

@pregnancyandinfantlosssuport

https://www.instagram.com/pregnancyandinfantlosssupport/?igshid=YmMyMTA2M2Y% 3D

@tfmrmamas

@mamasmatterhere

Websites:

Babyloss:

https://www.butterflyrun.ca/ https://stillapartofus.com/

https://thestillmamatribe.wixsite.com/stillmamatribe

TFMR:

https://Emptyarmsbereavement.org

Grief:

https://www.dougy.org/news-media/podcasts

https://mindfulnessandgrief.com/

https://podcasts.apple.com/us/podcast/grief-works/id1218890840

https://whatsyourgrief.com/grief-podcast/

https://podcasts.apple.com/us/podcast/the-grief-girl/id1089796160

I am also happy to be a resource if anyone wants to connect with someone local.

Email e.sowerbygreene@gmail.com

Instagram: e_sowerbygreene

Text 778-988-4987

Erin, Cameron, Briar & Aura

Advice for other people related to the loss:

(This may be a helpful list to distribute to your support people)

Support people (friends/family):

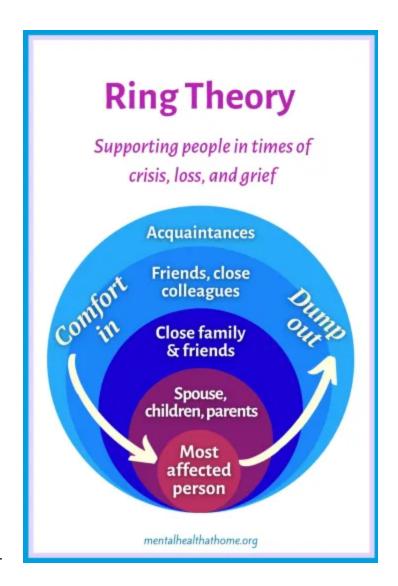
- Set up a meal train
 - Variable dinners (fresh, frozen, snacks, sides, non-perishables)
 - Healthy, comfort food, snacks, meals, soups, sweet, savory, spicy, bland
 - Try to use containers you don't need back (dollar store or thrift store)
 - Individual portions so the food doesn't go off and they can freeze what they don't eat
 - Be mindful of dietary preferences (dairy, beans, meat, cilantro etc)
 - Drop off at the door and either make the visit very short or just leave it and shoot them a text/message
- Meaningful gifts
 - Flowers (not everyone will want these as flowers die and that is a heartbreaking time as well). I appreciated the flowers and then I composted them to use in my garden for my baby. Flowers/shrubs/trees to plant in the earth may be a nice alternative.
 - Jewelry (necklace/bracelet) with the baby's name or birthday or birth flower on it
 - Coffee mugs and comfort drinks (hot chocolate, coffee etc). It can be really impactful to get a mug that says Mom/Mama/Dad/Dada if they don't have living children as they may struggle to "prove" their parenthood to people who don't understand
 - Registering a star in their baby's name
 - Donating to a charity in their baby's name
 - Purchasing a Molly Bear (weighted Teddy Bear). The parent will have to fill out the information about their child but you can offer to pay the shipping fees if outside of the US. (https://mollybears.org/)
 - Candles
 - A wind chime for the garden
 - A hummingbird feeder
 - Really good Kleenex
 - Face moisturizer
 - Bath products (bath bombs, bubble bath, epsom salts, really cozy towel)
 - Cozy blanket/robe/socks
 - Padsicles (if vaginal birth) or heavy maxi pads if not

- Cabbage leaves, sage tea, peppermint tea, benadryl to help with milk suppression
- A subscription to HelpTexts. This is a service that sends helpful texts
 throughout the year during holidays and heavy anniversaries and is
 personalized to the person's loss (gestation of loss, birthday, due date,
 baby's name etc). The parent should fill out the information to prevent
 errors, but you can offer to pay for it (https://helptexts.com/)
- Gift certificates
 - Groceries
 - SkipTheDishes/UberEats/DoorDash
 - Self care (hair, facial, massage etc)
 - Restaurants

- Chores

- Offering to walk the dogs
- Babysit their live children (and take them out of the house) so the parents can fully break down
- Move the laundry, do the dishes, sweep up while they go for a drive or walk around the block
- Pick up groceries for them
- Drop off Starbucks/Tim Hortons/comfort food
- For all of these, I recommend saying "I'm in the area, can I do
 _____?" or "I'm at the grocery store, what do you need?" so all they
 have to say is yes or no. Saying "Let me know how I can help" is
 daunting and puts the task back on to them.
- Offer to take on tasks related to telling friends/family members/coworkers the news or organizing a ceremony.
- Similarly, offer to update/cancel/reschedule appointments. If they want, this may include telling the provider what happened so they don't ask potentially triggering questions like "How is the baby?"
- Continue to check in every now and then. If they tell you meaningful days, make note of them (birth date, death date, due date) and reach out on those days with a text, a note, a small gift.
- If you're thinking of them, send them a text/note telling them this with the caveat of "No need to respond."
- Light a candle for their baby and send them a photo or let them know when you see something that reminds you of them or their baby.
- Silence hurts more than the wrong words said out of love
 - Do not let your fear of saying the wrong thing prevent you from saying anything. Silence is awful.

- If you do say the wrong thing and you are corrected, please do not take this personally as they are trying to protect themselves from further hurt. Accept the correction and continue to support them.
- Ask about their baby. What **is** their name? How did they pick that name? What did they look like? Who did they look like? Ask to see photos.
- Listen. Validate. Say "I'm so sorry" and "It's so unfair" and "I wish I could take the pain away for you".
- Do not identify silver linings for them AKA don't use the words "At least". They can choose to do this if that feels right. It is not the role of a supporter.
- Do not placate them with Hallmark sayings like:
 - Everything happens for a reason
 - This wasn't meant to be
 - They're in a better place
 - You can always try again
 - I can't imagine (instead say I can only imagine)
 - Personally I am triggered by people saying "You're so brave/strong/wise". I am just trying to survive a situation no one should have to experience.
- Do not compare this loss to other losses (animals/grandparents/parents). All loss is valid and different. However, comparing this loss to yours turns the narrative/focus away from the grievers.
- Remember that they are hurting the most.
- Provide comfort in. Grieve out. Do not tell the person if you're struggling or having a hard time with their loss so they feel obligated to comfort you. You can let them know how heartbroken and sad you are, but don't add to their plate.



Care providers:

- Send a card and/or email from the clinic signed from everyone expressing condolences and acknowledging the loss (miscarriage, stillbirth, TFMR, SIDS) and using the child's name.
- Ensure that any standing orders (ultrasounds, NSTs or bloodwork) are canceled.
- Confirm whether they want the additional support of the hospital social worker. If they do, you will have to reach out to the social worker to refer them. This was not done in our case so we were waiting for her to reach out and she thought we didn't want her help.
- Provide a list of resources in an email (or printed out) for the grieving family as they are likely overwhelmed, exhausted and unimaginably sad and unable to

- remember advice given verbally. If possible, make separate lists of resources specific to early miscarriage, late miscarriage, early stillbirth, late stillbirth, SIDS.
- Provide written and verbal information about milk suppression, vitamins, bedrest/return to exercise, being mindful of their core/abdomen, pelvic floor therapy at 6 weeks (I loved Emily MacHattie at 3 Cedars Wellness. Alexzandra Hale is also a pelvic floor PT that offers complimentary visits for loss parents. Email her at elevate.pt.nanaimo@gmail.com and mention "Lily's Referral").
- Offer and provide medication for milk suppression as this can be overwhelming to navigate without it
- Communicate with them and allow them to make choices about their postpartum care/support. Ask them who they would like to see at their postpartum visits and final discharge appointment so they can get the closure they need.
- Wherever possible, make sure the resources are provided verbally, physically and digitally. In early grief, the smallest tasks are incredibly daunting which includes looking up online resources rather than having a digital file with hyperlinks to click on.

Labour & Delivery/Maternity Unit Staff

- Refer to their baby by name.
 - If there is a shift change, tell the next staff the name of their baby
 - Put it in their chart or on the door
- Offer the family the opportunity to get photos from a volunteer photographer
 - Now I Lay Me Down To Sleep Resource for editing self taken photos (or photographer photos) https://www.nowilaymedowntosleep.org/
 - Suggest that they are able to take their own photos or have their midwives, partner, doula or family members take photos of every little detail (hands, feet, nose, ears, neck, cheeks, everything), the labour, the family etc.
 - The volunteer will only give them 20-50 photos and may not provide colour photos
- When the family is with their baby, tell them to use the call button if they need a break or when they're ready for staff to come back and take their baby
 - We have donated CuddleCots to hospitals in Nanaimo, Cowichan, Port Alberni, Courtenay and Saltspring Island in Briar's name. If your hospital does not have one, please let us know and we can support you in fundraising and donating one.
- Ask the family if they want to know their baby's eye colour and then look for them (my husband and I were scared to look)

- Ask them if they want to be involved with bathing and cleaning their baby (we wish that we had)
- Encourage them to unswaddle their baby and see every detail of their body (my husband and I regret not doing this)
- Encourage them to take a lock of their baby's hair (my husband and I were uncomfortable with this but grateful we did it)
- Encourage them to read a story or sing a lullaby to their baby
 - If possible, provide them with a baby book to read
- Offer them the opportunity to dress their baby if appropriate (and have clothing)
- If the family is going home before coming back to be induced to deliver, encourage them to bring meaningful items (books, blankets, clothing, stuffies) to put with their baby and take home as a keepsake/comfort item
- Communicate with them if there are any decisions they can make or be involved in
 - Eg. whether they want to bathe their baby, dress their baby, get hand prints and foot prints or impressions.
- Check in with the family and see if they have any questions
- Encourage them to have their family members meet their baby
- If appropriate, offer skin to skin contact