MISCARRIAGE:
A POCKET GUIDE FOR HEALTH PROFESSIONALS

Dr. Martina Galeotti

Dr. Eric Spikol

Dr. Martin Robinson

Dr. Áine Aventin

QUEEN'S UNIVERSITY BELFAST

TITLE PAGE

This pocketguide was made possible by a grant from the Economic & Social Research Council (ESRC) Impact Acceleration Account.

The information in this guidebook is based on results from the study '*The emotional needs of women who experience miscarriage in hospital settings: A mixed-methods needs assessment in Northern Ireland*' and all quotes utilised were provided by participants of this study.

The study team would like to thank all of the participants who volunteered to share their experiences of miscarriage in hospital settings in Northern Ireland.

This pocket guide has been created with the primary aim of supporting health professionals in practice who may care for women and their partners through miscarriage.

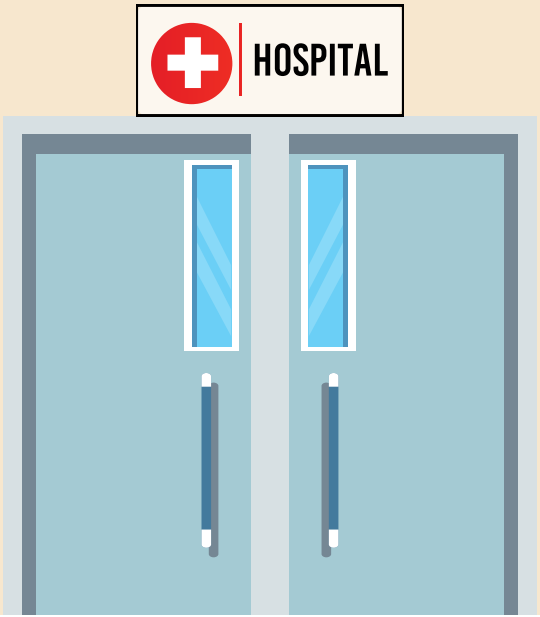
The information contained within this guide is evidence-based, ensuring that it aligns with the latest research and best practices in the field. Some health professionals may not have extensive experience in managing pregnancy loss, and it is our hope that this guide serves as resource, equipping you with the knowledge and tools necessary to provide the highest standard of care.

The content of this guide reflects the journey that women may experience when they come to the hospital for pregnancy loss. However, it is crucial to understand that pregnancy loss is an individual experience, and no two journeys are the same. The suggestions and guidelines presented here are meant to serve as general recommendations. We appreciate that they may not fully encapsulate the unique experiences of every woman and their partner.

As you navigate through this guide, we encourage you to use an approach acknowledging the individual needs and circumstances of each patient. Your role is vital in offering not just medical support, but also emotional and psychological comfort during an exceptionally vulnerable time.

Dr. Martina Galeotti

TABLE OF CONTENTS



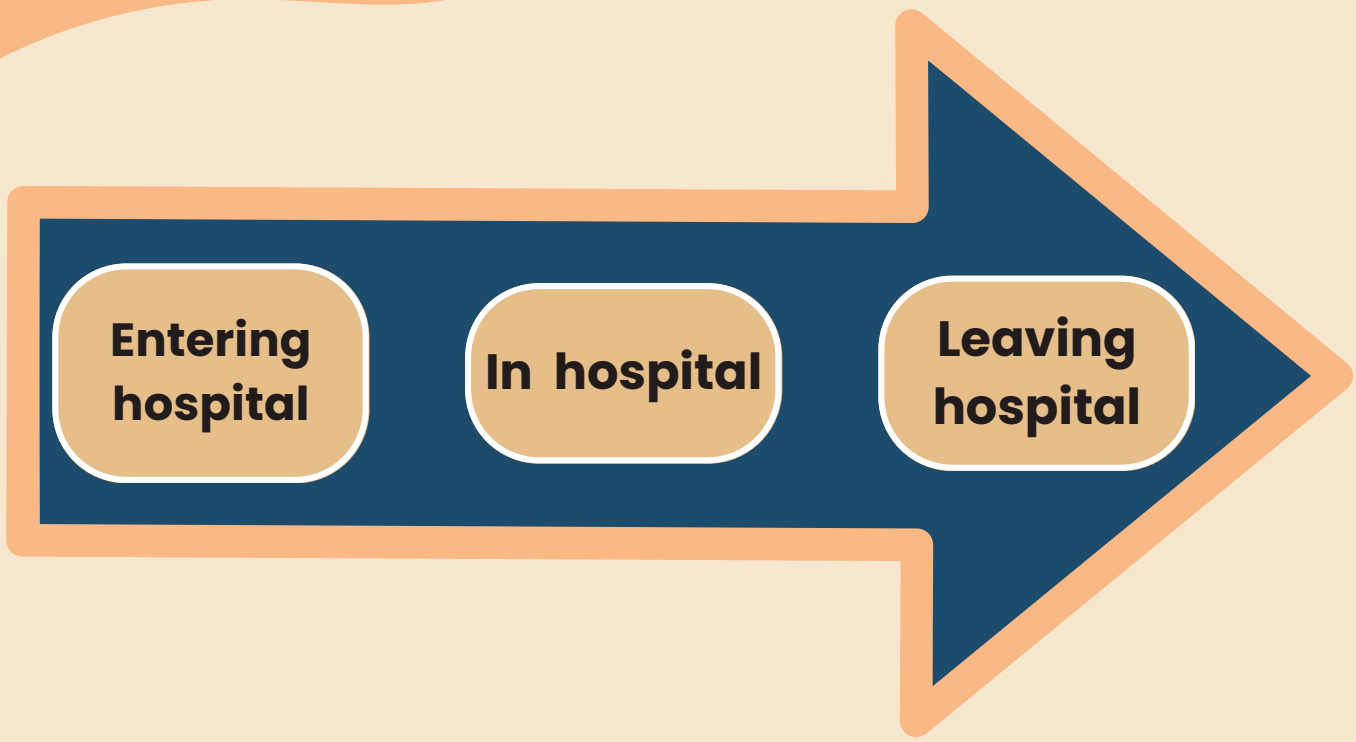
TYPES OF MISCARRIAGE

- **Miscarriage** can be differentiated from **biochemical pregnancy**, which occurs when a positive urinary beta human chorionic gonadotropin (B-hCG) or raised serum beta-hCG are present but there is no ultrasound confirmation of pregnancy.
- **Ectopic pregnancy** is defined as a pregnancy that has implanted itself outside the uterus.
- There can be **uncertainty around diagnosing a miscarriage**, and health professionals can find it challenging to deliver a formal diagnosis, as miscarriage can be classified as **complete**, **incomplete**, **missed**, **threatened**, or **inevitable** based on clinical history, findings on speculum, and digital pelvic examination.
- In **complete miscarriage**, the fetus has been expelled from the uterus and bleeding has stopped.
- **Incomplete miscarriage** is a diagnosed non-viable pregnancy in which bleeding has begun but pregnancy tissue remains within the uterus.
- **Missed miscarriage** (also known as **delayed or silent miscarriage**) is diagnosed when a non-viable pregnancy is identified on ultrasound scan, without associated pain and bleeding.

TYPES OF MISCARRIAGE

- **Threatened miscarriage** is diagnosed when there is vaginal bleeding in the presence of a viable pregnancy in the first 24 weeks of gestation. In this case, it is often possible the pregnancy will continue to full term.
- **Inevitable miscarriage** is a diagnosed viable or non-viable pregnancy in which bleeding has begun and the cervix is open, but the fetus is still in the uterus and the pregnancy will proceed to incomplete or complete miscarriage.
- **Molar pregnancy** is a gestational trophoblastic disorder as a result of abnormal fertilisation and gametogenesis, characterised by hydropic swelling of the placental villi, hyperplasia of villous trophoblast and absent, or abnormal, fetal development. It is potentially a malignant pregnancy condition, broadly grouped under gestational trophoblastic disease (GTD).
- Finally, miscarriage can be defined as **early** or **late**. In the UK, **early miscarriage** occurs during the first trimester (up to the 11th week of gestation), while a **late miscarriage** is a pregnancy loss between the 12th and 23rd week of gestation.

FRAMEWORK



This book covers five main themes which reflect women's experiences of miscarriage from the time they entered hospital, their time in hospital, and after discharge:

- Interactions with Health Professionals
- Communication
- Management of Miscarriage
- Hospital Environment
- Follow-Up

These themes describe their wants and needs after presenting to hospital with the symptoms of miscarriage.

INTERACTIONS WITH HEALTH PROFESSIONALS

- Build an empathetic relationship with women and their partners where **their emotions are acknowledged and addressed appropriately**. Failure to do this may result in aggravating their psychological wellbeing.
- It is beneficial in supporting women's journeys through miscarriage to **acknowledge that pregnancy loss is a significant event** for women. Ensure that your interactions with women and their partners reflect this.

INTERACTIONS WITH HEALTH PROFESSIONALS

- **Consider women's wishes and involve them in their care**; encourage women and their partners to express their feelings and address them.
- Miscarriage is a complex phenomenon with **both emotional and physical implications** for a woman. Providing information on how women may feel emotionally could help to better understand miscarriage and its implications.

INTERACTIONS WITH HEALTH PROFESSIONALS

- **Making memories** is particularly appreciated by women. In early pregnancy loss it might be harder to create memories, as often there is an absence of physical remains, while death certificates or scan pictures are not often given to women.

"As I said, they're as real as my [child] is, so I like having physical things to remember. You know, what has happened and to remember that they were part of my life and that they exist for me." (Yasmine)

"I have the little scan picture of my baby's heartbeat and [...] and I was happy." (Grace)

INTERACTIONS WITH HEALTH PROFESSIONALS

- **Mourning rituals** such as funeral and burial ceremonies that **symbolise public recognition** may be particularly important for bereaved parents who have experienced miscarriage, as there is a lack of social recognition.

“We buried him. My husband's family had a plot. So we were able to bury him in there, which is lovely because I am able to go down all the time and you know, have a chat with him.” (Aditi)

INTERACTIONS WITH HEALTH PROFESSIONALS

- It is important to **acknowledge and address partners**. Ensure they are involved in the conversation as it is their loss as well.

"I remember like, not being able to walk and my husband sort of, half carrying me back to the car and he found it really, really hard. Uhm, no one spoke to him. No one looked at him." (Mary)

"It's very much towards me, he felt very much that his presence was ignored, that everything was directed to me." (Zoe)

COMMUNICATIONS

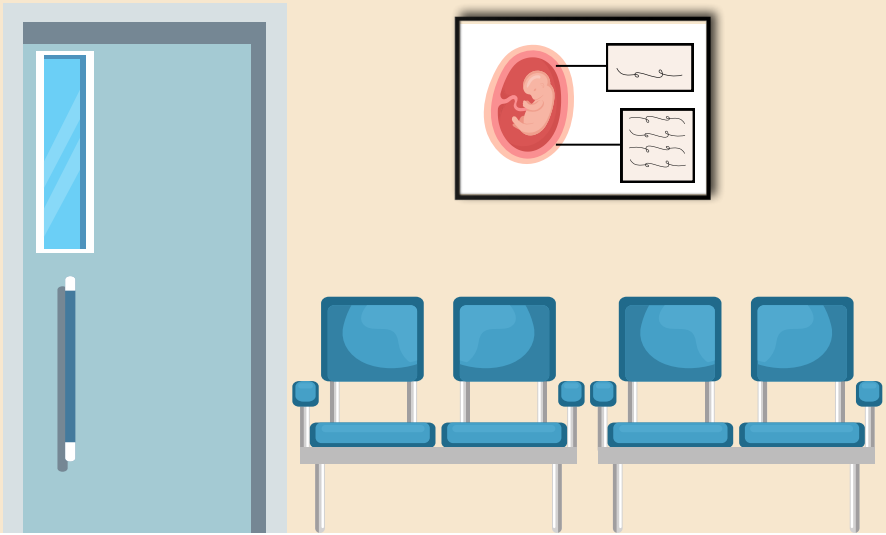
- Many women reported that the **use of language is important**, and they particularly remember expressions used by healthcare professionals.
- **A lack of compassionate communication has a negative impact** on women's emotional wellbeing, especially around the time of receiving news of miscarriage, or presenting with its symptoms.
- **Mirror the language** used by women. For example, if they use the word "baby", you should use it as well.

➡ **Avoid** using sentences such as: *"At least you can get pregnant!"* or *'product of conception.'*

COMMUNICATIONS

- It is essential to **deliver a clear diagnosis of miscarriage** to women, using sensitive language without use of unambiguous terms.
- Many women report how the news of miscarriage was not clearly delivered, leaving them **confused and unsure** of the outcome of their pregnancy.

"The midwife at the 12th week scan [...] failed to explain that she thought I was having a missed miscarriage." (Hina)



COMMUNICATIONS

- Women stress **the need to have time to absorb the news of miscarriage** before moving on to discuss different information about their care. During a trauma response, cognitive processes might be altered and therefore comprehension of new information might also be impaired.

- Taking time to **assess their level of understanding** and allowing them **sufficient time to process negative information and the emotions** associated with it is fundamental.

COMMUNICATIONS

- Women should have **the right to decide how to dispose of fetal remains**, and they should be **provided with adequate information** to make this decision.
- While there is **no legal requirement to bury or cremate miscarriage remains**, parents have the option to bury, cremate or incinerate their baby's remains.

HELPFUL COMMUNICATION

- Use neutral terminology.
- Be clear about the purposes and processes of the care.
- Make eye contact and remember that your words will have impact.
- ‘Translate’ clinical or technical terms.
- Communicate the next steps of care clearly and honestly

- Show kindness and compassion.
- Keep parents’ emotions and distress in mind.
- Signpost parents’ options for care, immediate support, and follow-up support.

MANAGEMENT OF MISCARRIAGE

- **Northern Irish Health and Social Care Trusts follow NICE guidelines* on management of miscarriage** and ectopic pregnancy. These include three different approaches to the management of miscarriage: expectant, medical and surgical.
- **All management options should be available to every woman** accessing maternity care services, where clinically appropriate.

Need a refresher? Scan the QR code to access NICE guidelines.

SCAN ME

MANAGEMENT OF MISCARRIAGE

- Midwifes, nurses and obstetrics & gynaecology doctors should **inform women about treatment of miscarriage and provide them with information on their care.** The context for this might vary depending on gestational age.
- **Women need to be equipped to make an informed decision**; it is important to **involve women in the decision-making process** and provide them with adequate information about the different strategies available to manage a miscarriage.

MANAGEMENT OF MISCARRIAGE

- Women are particularly affected by the description of “expectant” and “medical management” of miscarriage as **“resembling a heavy period”**, which many reported was not a true representation of the experience. For some women the **experience of their miscarriage more closely resembled labour in terms of pain and contractions.**

- Many women experience their miscarriage at home and point out that **precise information on what to expect** would have avoided leaving them scared and unprepared.

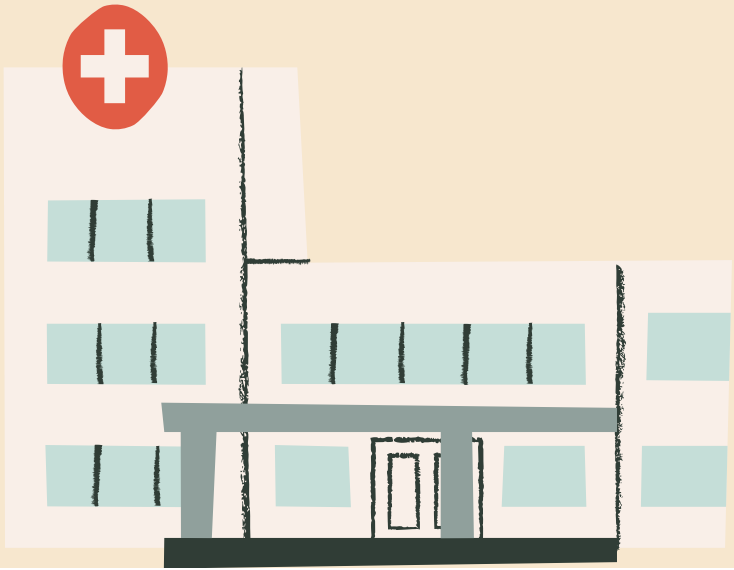
- It is important to **explain to women any decisions made about their treatment** and not just say, "*Come back in 10 days,*" without providing adequate information to support the rationale behind this information.
- Women describe how they felt **unprepared and anxious** about passing remains in the toilet and how they would like to **receive practical advice** on the eventuality that their baby might pass in the toilet.

"I delivered the baby in the toilet. If I didn't have a specimen pot, what was I meant to do? Flush it away like a goldfish?" (Sofia)

HOSPITAL ENVIRONMENT

- Women expressed the need to be cared for in **an environment where their privacy and dignity is maintained** at all time (i.e. cubicles, side rooms).

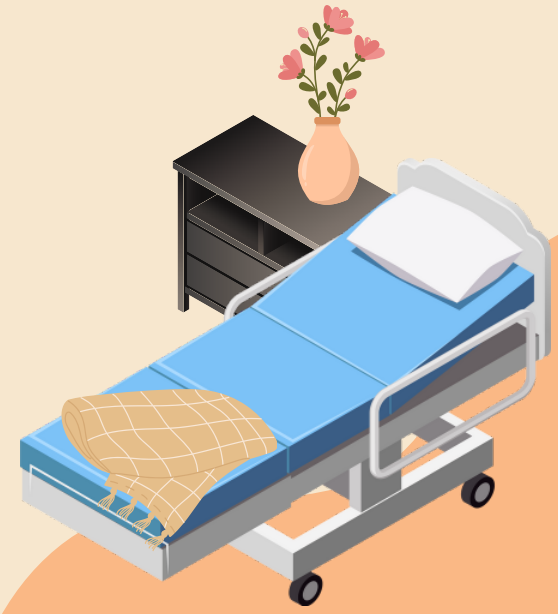
"[The doctor] said it to me in the waiting room with people beside me who I didn't know, they didn't know me and there was no privacy. He didn't call me over to one side or anything to tell me that, he just said it like it was a matter of fact and I just started to cry." (Zahra)



HOSPITAL ENVIRONMENT

- Women found it **particularly hurtful to be cared for in general wards** with other patients with different conditions, expressing the need for dedicated side room.
- Being cared for **around other pregnant women and/or their babies can be traumatising** for women who just received the news of miscarriage.

"If they had a room even with just like, a sofa or something to sit on and to go in and think a while. And if they gave you 20 minutes to sit alone [...] I think that could be really beneficial." (Eva)



HOSPITAL ENVIRONMENT

- Findings from this study show how **waiting time is perceived as a stressor** when women access care.
- **Waiting for scans and hospital appointments increases their level of distress** and has a negative impact on overall care.
- Where an interval between scans is indicated to assist in making a diagnosis, **this should be explained** to the woman.

"But I think it's just the waiting, the waiting. Mentally, you're not ready for that. [...] I didn't want to wait three days."
(Shayma)

HOSPITAL ENVIRONMENT

- Where possible, try to ensure **continuity of care**.

"So that made a huge difference [having the same doctor] 'cause we went in and we knew her [...] it meant that she didn't have to ask all the same questions." (Anne)

"I wouldn't have a clue who I was chatting to. And then the next time it will be somebody else, [...] it was like I don't know who I'm chatting to. That was the hard thing, not having a face-to-face, that everything was impersonal." (Ruoxi)

FOLLOW-UP

- Women are **not provided extensive information on available investigations** after pregnancy loss.
- Furthermore, at times they attend follow-up appointments **without knowing the reason**.

"Also a real lack of clear information on why treatment wasn't being given or the likely outcome, even though I could overhear phone conversations, they weren't having those conversations with me." (Isla)

"I wanted to get a test [autopsy] to prove that it wasn't my fault, you know?" (Olivia)

FOLLOW-UP

- Miscarriage has been reported to be **a lonely and isolating experience** for women, with a statistically significant difference in loneliness between women who experience miscarriage at home and those in hospital settings.
- Women discharged home can **experience a higher sense of loneliness and isolation**.

"My husband was with me the whole time. We were very lucky that way. It was pre-COVID. So he was with me the whole time."
(Charlotte)

FOLLOW-UP

- It is vital for women to be **signposted to emotional support**, in order to ensure the presence of a support system they can rely on, if required.

"Signposting to support services should be a basic expectation. I benefited greatly from the opportunity to speak about my experience months down the line." (Aoife)

"There was no follow-up care in between the two appointments, a wellbeing phone call would have been appreciated." (Hannah)

FOLLOW-UP

"I think honestly the thing that helped me the most is being able to see the bereavement midwife. I've found that really helpful and useful in terms of adapting to not being pregnant." (Chloe)

"I was given a flyer, you know like that really old font they used to use back in the 90s and on a piece of paper that would have been clearly photocopied from the original, like 100 times. So the writing isn't even on the paper." (Aylin)

"No one asked me how I was feeling emotionally following the miscarriage." (Ruth)

SUPPORT RESOURCES

Sands

sands.org.uk
0808 164 3332
helpline@sands.org.uk

CRADLE

cradlecharity.org
0333 443 4630
info@cradlecharity.org

ARC
Antenatal Results & Choices

ark-uk.org
0207 713 7486
info@arc-uk.org

MISCARRIAGE ASSOCIATION

miscarriageassociation.org.uk
0192 420 0799
info@miscarriageassociation.org.uk

STUDY TEAM

Dr Martina Galeotti is a Lecturer at the School of Nursing & Midwifery, Queen's University Belfast. Her research focuses on improving patient care & outcomes in bereavement maternity services.

Dr Áine Aventin is a Senior Lecturer at the School of Nursing & Midwifery, Queen's University Belfast. Her research focuses on sexual & reproductive health, maternal mental health, & pregnancy loss.

Dr Martin Robinson is a Lecturer at the School of Psychology, Queen's University Belfast. His research focuses on psychotraumatology, global mental health, pregnancy loss, & resilience.

Dr Eric Spikol is a postdoctoral researcher at the School of Nursing & Midwifery, Queen's University Belfast. His research focuses on trauma, PTSD, posttraumatic resilience, & pregnancy loss.

Thank you for taking the time to read this pocket guide. We hope that it will be a useful resource in supporting parents experiencing miscarriage.

A free digital version of this guide can be downloaded in PDF format from the Queen's University Belfast website:

https://tinyurl.com/bdhu8hcz

SCAN ME

QUEEN'S UNIVERSITY BELFAST