Early MAGE TED Pregnancy Complications and Loss

a conversation guide to help people who experience early pregnancy complications or loss receive high-quality care



Health Quality Ontario

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Health Quality Ontario is committed to helping patients, health care providers, and organizations improve the quality of health care in Ontario.

As part of our work, we create patient conversation guides on specific topics (such as early pregnancy complications and loss) to help patients play an active role in getting the best quality care.

These guides reflect our quality standards, documents that outline what quality care looks like for a given condition. Quality standards are **based on current best evidence and input from patients**, **caregivers**, **and health care providers**.

Together, patient conversation guides and quality standards are designed to address the gaps in care that occur with specific conditions and to ensure everyone in the province receives quality care.

To read more, <u>download</u> Health Quality Ontario's quality standard for early pregnancy complications and loss, developed in partnership with the Pregnancy and Infant Loss (PAIL) Network.

WHAT IS THIS GUIDE?

This guide is designed to help you play an active role in getting the best possible care if you are in early pregnancy and have pain or bleeding or think you may be having a miscarriage.

Throughout you will find questions you may want to ask your health care providers, as a starting point for conversations, plus space for taking notes, which may be helpful as you receive care.

WHAT DO WE MEAN BY EARLY PREGNANCY COMPLICATIONS AND EARLY PREGNANCY LOSS?

Early pregnancy complications include vaginal bleeding (more than spotting) and/or pain in the belly, lower back, or pelvis, and occur in the first 13 weeks of a pregnancy.

If you experience pain or bleeding in early pregnancy, you may need medical attention. Contact your family doctor, midwife, or obstetrician (OB), or go to a hospital emergency department.

Early pregnancy loss—a miscarriage in the first 13 weeks—happens in about one in five pregnancies. Not all pain or bleeding will result in a miscarriage. As well, some people do not have any symptoms, but may learn through a routine ultrasound (a medical scan) or blood test that their pregnancy is not developing as expected, or that it has ended. Even though early pregnancy loss may be a fairly common experience, this does not make it any less difficult or painful.

Important to know

People who experience a loss in the first 13 weeks of pregnancy often ask: "What did I do wrong?" "Could I have prevented it?"

Health care providers tell us there are three things they'd like patients and families to know:

- A miscarriage is no one's fault
- In most cases, a specific cause cannot be identified
- There's no treatment to stop a miscarriage

"Knowing about [how common it is] can help someone else going through it."

PERSON WHO EXPERIENCED EARLY PREGNANCY LOSS

Learn more

There's a lot of information out there about early pregnancy loss and complications, but it can be challenging to know what's reliable. The patients, caregivers, and clinicians we spoke with to put this guide together told us these are resources they find useful:

- Pregnancy and Infant Loss (PAIL) Network
- October 15—Pregnancy and Infant Loss Awareness Day

Though these resources may not always say the same thing as what's in the quality standard for early pregnancy complications and loss, you may also find them useful.

START TALKING

People experience a range of emotions, and sometimes mixed emotions—sadness, grief, relief, fear, and more—during early pregnancy complications or loss. It can feel difficult to talk about miscarriage, both to health care providers and even to family or friends. This is especially true if you have not shared the news of the pregnancy with many people yet.

Talking through your concerns with your health care providers and letting them know a bit about you can help your providers give you the best possible care. (See "About you" on page 7.) Asking questions can also help you make decisions about your treatment. Use the topics outlined here to guide your conversations with your doctor, midwife, or other health care providers:

- During pregnancy complications or loss
- In the days after
- For future pregnancies

There are many topics to cover—you may have more you'd like to add, and you may decide that some are particularly important to you. They may not all be addressed in a single visit or by a single provider, but you can adjust them and refer to them over time. It's okay to ask lots of questions and to get advice from a range of health care providers.

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If talking feels hard ...

Depending on how you are feeling, you might find it difficult to ask questions and give your health care provider more information about you. If you are feeling this way, this is normal.

Let your health care provider know you want to be able to share more information with them, but it may be hard for you to do so. You may want your support person to do some of the talking, if you are comfortable that they can represent your needs at the time.

Write it down

It may help you to write down your experience if you have symptoms. Having written details on hand when you talk to your care providers will help you give a more complete description of your experience.

Consider making your notes right in this electronic file, or in a printed copy, and use this guide each time you visit and review your care plan with your health care providers.

"You may have this mix of emotions and may not be sure how you're supposed to be feeling. So, it's hard to know what questions to ask."

PERSON WHO EXPERIENCED EARLY PREGNANCY LOSS

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About you

As you begin to receive care, it's okay to pause the conversation and give your health care providers some information about yourself—even in a busy emergency department.

Sharing details about your physical or emotional health history, your personal situation, or your preferences can help your health care providers give you the right care.

Some information you might want to share with your health care providers:

- If you've had pregnancy complications or a previous pregnancy or infant loss
- Who your support people are, and who you would like to be involved in your care (partner, friend, family member)
- If this pregnancy was planned, and if you used fertility treatments such as in vitro fertilization (IVF) to get pregnant
- How you would like health care providers to refer to your pregnancy (for example, "fetus" or "baby")
- Results from any recent ultrasounds or pregnancy blood tests

Start talking: During pregnancy complications or loss

Most people go to a hospital emergency department when they are experiencing early pregnancy complications or loss. Others may receive care in their doctor's or midwife's office or clinic.

Wherever you are getting care, remember, you have the right to ask questions of your health care providers and receive compassionate care. Asking for more information and telling health care providers a bit about yourself can help them understand your concerns, and can help you get the information you need.

Some things you might want to discuss with your health care providers: Is there a place we can talk about this in private?
What are the tests you're recommending? What do they involve?
Where and when will these tests happen?
When and how will I get the results?

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Am I going to be okay? Is the baby going to be okay?
Is there something I can take for the pain?
Is there an early pregnancy clinic nearby that I can be referred to?

An early pregnancy clinic is a patient-centred clinic, staffed by health care providers and support professionals with special training in diagnosing and caring for people experiencing early pregnancy complications or loss.

Start talking: In the days after

Everyone's experience of early pregnancy complications or loss is different. But before you leave the hospital or your health care provider's office, you'll want to be clear on what to expect in the days ahead. That includes knowing what to do if your symptoms get worse and how to cope with what is happening to you physically, and also taking care of your mental health and asking for support if you need it.

Some things you might want to ask your health care provider:
What symptoms do I need to watch for?
If my pain or bleeding gets much worse, what should I do?
If I'm having a miscarriage, what will I see? What should I expect?
If I miscarry at home, what should I do?

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Will I have pain or nausea? How can I manage them?
Do I need follow-up appointments or tests?
Are there peer support groups in my area?
How can I share the news of my loss with family or friends? What are some common reactions to loss that I should be prepared for?
How can my family and I support one other?

"[Peer support connects you with people who say,] 'I've been there too.'

For healing, that was the most important thing for me."

PERSON WHO EXPERIENCED EARLY PREGNANCY LOSS

Should I go to the emergency department?

Call your health care provider or go to the nearest emergency department if you:

- Suddenly have severe pain in your belly that is not going away or helped with medication
- Suddenly feel faint or like you are passing out
- Have very heavy bleeding (soaking more than three pads in three hours)
- Have chills or a fever higher than 38°C

Start talking: For future pregnancies

You may find that an early pregnancy loss affects you and your family in ways you didn't expect. In addition to the physical impact, people tell us that their grief about a miscarriage can come back as they begin to consider getting pregnant again, or when they try to or do get pregnant again.

Here are some questions you may want to ask your health care provider:
When can I try to get pregnant again?
Will I have problems getting pregnant again?
Will my recent pregnancy loss affect my chances of having a healthy baby in the future?
I don't want to get pregnant again now. What do I need to know about using birth control after a pregnancy loss?

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If I get pregnant again, where can I get support to help manage the emotions that may arise after this loss?

WHAT'S NEXT?

Remember, everybody is different.

The support you need and the care plan you land on with your health care providers will be unique to you.

This conversation guide is meant as only a starting point.

You may have other topics you want to cover with your health care providers. It's important to speak with them should any questions or concerns come up.

Need more information?

If you have any questions about the quality standard or feedback about this guide, please contact us at qualitystandards@hqontario.ca or 1-866-623-6868.

For more reading on early pregnancy complications and loss, read the quality standard at: hqualitystandards

FOR YOUR REFERENCE: THE QUALITY STANDARD IN BRIEF

The quality standard for early pregnancy complications and loss is a reference document that outlines what quality care looks like for this condition. It is based on the best evidence and input from clinicians, patients, and their families.

Below is a summary of the quality standard. For further reading, download the full version <u>online.</u>

Comprehensive Assessment

People with signs or symptoms of early pregnancy complications receive a comprehensive assessment that includes a serum beta-hCG measurement and transvaginal ultrasound.

What this means for you

If you have pain or bleeding during the first 13 weeks of pregnancy, your health care provider should ask you about your symptoms and medical history. They should offer you a blood test and a transvaginal ultrasound (an ultrasound using a probe inserted into your vagina). These steps will help them assess your pregnancy and offer the next steps in your care.

Pregnancy of Unknown Location

People with a pregnancy of unknown location (not visible in the uterus or adnexa, on ultrasound) receive repeat ultrasound assessment and serial serum beta-hCG measurements until a final diagnosis is made.

Diagnosis of Intrauterine Early Pregnancy Loss

Pregnant people who experience intrauterine early pregnancy loss receive a diagnosis as quickly as possible based on transvaginal ultrasound. While waiting to learn whether or not the pregnancy is viable, they receive information on who to contact, where to go, and how long it should take to receive a diagnosis. A diagnosis of early pregnancy los is also communicated to the person's primary care provider.

What this means for you

If you have a positive pregnancy test, but the pregnancy cannot be seen in an ultrasound picture, repeat ultrasounds and bloodwork should be performed until your pregnancy is located or a pregnancy test is negative (your beta-hCG, a pregnancy hormone, returns to zero). Your health care providers should offer you information on what to do if your symptoms get worse and how to access emergency care.

What this means for you

Your health care providers should diagnose your early pregnancy loss as quickly as possible. They should give you information about who will contact you with a diagnosis and how long it should take. They should encourage you to have a support person with you at appointments.

Management of Intrauterine Early Pregnancy Loss

People with intrauterine early pregnancy loss receive information on all potential management options (expectant, medical, and surgical) and are supported in making an informed decision on the most appropriate management approach for them, based on their diagnosis, clinical situation, values, and preferences.

What this means for you

You and your health care provider should discuss your options for managing your early pregnancy loss so you can choose the one that is best for you and your family. Your health care provider should offer you written information on what to expect, plans for follow-up care, and how to access support services for pregnancy loss.

Management of Tubal Ectopic Pregnancy

People with a confirmed tubal ectopic pregnancy receive information on all potential management options and are supported to make an informed decision about their care. They have access to their preferred management option. Health care providers closely monitor signs and symptoms and arrange appropriate access to follow-up care.

What this means for you

If you are diagnosed with an ectopic pregnancy (where the pregnancy implants in your fallopian tube), discuss your options for managing it with your health care provider and choose the one that is best for you. Your health care provider should offer you information on what to expect during treatment and what to do if your symptoms worsen or you have new ones. They should continue to perform blood tests until your beta-hCG hormone level returns to zero.

Compassionate Care and Psychosocial Supports

People and families experiencing early pregnancy complications and/or loss are treated with dignity and respect, and receive support in a sensitive manner, taking into account their individual circumstances and emotional responses. They are offered psychosocial supports.

What this means for you

You and your family should be treated with dignity and respect at all times. Health care providers should consider your emotional and physical needs when giving you support and information. They should discuss options for mental and emotional supports with you and your family.

Peer Support

People who experience an early pregnancy loss and their families are offered information about peer support services and organizations.

What this means for you

Your health care providers should offer you information on—and a referral to—peer support groups for early pregnancy loss.

Early Pregnancy Assessment Services

People experiencing early pregnancy complications and loss have access to early pregnancy assessment services that are available 7 days a week. People referred to early pregnancy assessment services are seen within 24 hours when clinically indicated.

What this means for you

A health care professional (family doctor, nurse, midwife, or emergency department doctor) should assess you. If you are referred to early pregnancy assessment services, the appointment should take place within 24 hours, if appropriate.

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For more information, please visit:

Health Quality Ontario: hqontario.ca
Pregnancy and Infant Loss (PAIL) Network: pailnetwork.sunnybrook.ca

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