# Understanding & Navigating the Maternity Care System

#### **Informed Decision Making**

### Who is responsible for making informed maternity decisions?

When pregnant, giving birth, and in the postpartum period, it is your responsibility to make informed decisions for yourself and on behalf of your baby. It is your legal right to give "informed consent" or make an "informed refusal" of any care that you might undergo. The national *Listening to Mothers* survey found that most women fully understood their right to make informed maternity care decisions, strongly supported having choices about mode of birth, and wanted to understand potential complications before agreeing to have major maternity interventions.

Maternity professionals are responsible for providing scientifically supported care and for meeting the legal standard of informed consent. Legally, more and more states are adopting a "patient viewpoint standard." This means that clinicians must tell you about the possible benefits and harms that a reasonable person in your situation would want to know to make an informed decision. This is replacing a "clinician viewpoint standard," what a typical clinician feels you need to know.

It takes time and work to meet these legal and ethical standards for informed consent. It is crucial to have full and accurate information about labor and birth decision points and interventions well before labor in order to pursue the care of your choice and make informed decisions around the time of birth.

# Why is my involvement in maternity care decisions important?

The decisions you make and the maternity care that you receive can have lasting effects on the health and well-being of your baby, yourself, and your family.

It is always important to understand whether there is a clear, well-supported rationale for having any procedure, drug, test or treatment that is being considered. In many care settings, medical interventions are used freely and even routinely, even when the mother or the baby have not shown a clear need. Although these practices may be of value to women or babies in certain situations, they may be unnecessary for most. They may be disruptive and uncomfortable, can cause more serious side effects, and often involve extra interventions to monitor, prevent, or treat unwanted effects. They also contribute to needlessly high costs of maternity care. For these reasons, interventions should not be used routinely or unnecessarily.

Research about maternity care decision making shows that care processes often fail to meet legal standards for providing adequate information and choice of care. As you cannot count on the health care system to meet these standards, it would be wise to be pro-active about recognizing decision points, seeking needed information, making informed decisions, and communicating these to your care team. If, during pregnancy, you have concerns that your care team or planned birth setting is not a good match for your values and preferences, you may want to explore other options.

## What are important factors for informed maternity decision making?

Making informed decisions means learning and thinking about the best available information on maternity care, and using it to decide what's right for you and your baby. Key questions include:

- What are the possible choices?
- What does the best available research say about the benefits and harms of each of these choices?
- What are your needs and preferences and those of your partner (if you have one)?
- What choices are available and supported in your care setting and by your caregivers?
- If you want an option that will not or may not be available, would you consider switching to a care setting or caregiver that does offer that option?

It is not possible to know ahead of time exactly what your labor experience will be like. Being as informed as possible in advance can help you deal wisely with any new decisions that may arise at the time. It is important for you to learn about options, get answers to your questions and think about your preferences well before labor begins. It is also important that your partner and any other support people are aware of your wishes and are prepared to speak on your behalf if the need arises.

# Where can I find the best evidence about safe and effective maternity care?

This website can help you learn about <u>evidence-based maternity care</u>. The unique features in the <u>For Women</u> area of this site provide trustworthy information about safe and effective maternity care, with tips and tools to help with decisions and carefully selected resources for learning more.

You may feel uncertain about becoming actively involved in decision making. Information and advice from studies, news reports, online features, and friends and relatives can differ. It can be challenging to know what or whom to believe, especially when facing decisions that can have lasting effects on you and your children.

Many women trust their caregivers to provide care that is safe and effective for themselves and their babies. Yet, some forms of maternity care are overused and provided to many women when they are not needed but may cause discomfort, side effects, and extra expense. Examples include labor induction, episiotomy, cesarean section, and staff-directed pushing. Some types of beneficial care are not provided often enough. Examples include help with quitting smoking, support for breastfeeding, continuous labor support, and vaginal birth after cesarean. We urge childbearing women to become active participants in their care by becoming informed, clarifying goals, and seeking care that is right for you and your baby. Our goal is to help you make informed decisions about care that is best for you and your baby by providing you with the best, up-to-date information on common maternity care practices. This website also helps you understand that your choice of caregiver and choice of a place of birth can have a major impact on the care that you receive. We urge you to make those decisions with great care.

#### What does it mean to give "informed consent?"

Informed consent is not a form or a signature. It is a process between you and your caregivers that helps you decide what will and will not be done to your body. In the case of maternity care, informed consent also gives you the authority to decide about the care that affects your baby. The purpose of informed consent is to respect your right to self-determination. It empowers you with the authority to decide what options are in your best interest and the best interest of your baby. Your rights to autonomy, to the best available information, and to protect your children and yourself from harm are very basic human rights.

### What are my legal rights to "informed consent" and "informed refusal?"

Whenever a medical procedure, drug, test, or other treatment is offered to you, you have the legal right to "informed consent." This means that your doctor, midwife or nurse is responsible for explaining:

- why this type of care is being offered
- what it would involve
- the harms and benefits that are associated with this type of care
- alternatives to this care, and their respective harms and benefits, including the possibility of doing nothing at the present time ("watchful waiting").

You have a right to clear and full explanations about your care and answers to any questions you may have. You also have the right to request and receive a copy of your medical records and to get a second opinion.

Then, by law, you have the right to decide whether to accept the care that is offered. If you disagree with your caregiver and decide not to accept that care, you have a right to this "informed refusal." Even if you signed a form agreeing to a particular type of care, you have the right to change your mind. Although these are well-established legal rights, they have been challenged in a few recent cases.

It can be difficult to carry out the informed consent process in busy health care settings. Even so, it is wise to set aside the time to discuss these issues in advance with your caregiver whenever possible, and again when it is time to make a decision. Avoid learning about procedures and options for the first time while you are in labor and facing important decisions. At that time, it may be too late to get all questions answered, weigh options, and pursue specific preferences.

#### What are some tips to help me explore these issues with my doctor or midwife?

Make a list of questions before each visit, and during the visit jot down the answers. You may wish to bring your partner or someone else who is close to you to listen to what is said. This is not the time to be shy; nothing is off limits.

While talking with caregivers, you can say:

- I don't understand.
- Please explain this to me.
- What could happen to me or my baby if I do that? Or if I don't?
- What are my other options?
- Please show me the research to support what you're recommending.
- Where can I get more information?
- I have some information I'd like to share with you.
- I'm uncomfortable with what you are recommending.
- I'm not ready to make a decision yet.
- I'm thinking about getting a second opinion.

Any question that you have is worth asking. When answers are not clear, ask again until you understand.

#### What happens if I disagree with my caregiver?

Caregivers have rights, too. They have the right to agree or disagree to provide care that you may request. For example, if a woman requests a cesarean and has no medical need for this procedure, her caregiver has the right to refuse to do the surgery. Increasingly, fear of lawsuits and other factors are leading caregivers and hospitals to refuse to provide some types of care that would be a good and reasonable choice for many women, such as vaginal birth after cesarean (VBAC).

These issues speak to the importance of having a good working relationship with your provider that includes open communication, mutual respect, and shared points of view. Be sure to take care to choose a doctor or midwife who respects your needs, values and goals. If you discover in the course of your care that you disagree with your caregiver or your policies at your planned birth setting on important issues, it would be wise to explore other options. Early action is recommended when seeking another caregiver: it can be hard to find a good match who accepts care transfers later in pregnancy.

#### Shared decision making: The growing standard

More and more leaders take the position that "shared decision making" is a standard that should replace "Informed Consent" and "Informed Refusal." They argue that it is difficult to know what a typical patient wants to know and that informed consent can involve giving in to preferences of caregivers through a fairly brief process, and often after a decision has been made and just before it is carried out. Shared decision making, especially when it involves carefully prepared and updated patient decision aids, can provide carefully high-quality, balanced, up-to-date information; incorporate patient values and preferences; and increase patient autonomy, knowledge, and satisfaction with the decision process. The Patient Protection and Affordable Care Act of 2010 includes (but does not fund) provisions lending strong support to shared decision making.

Unfortunately, few decision aids that meet international standards are available for maternity care topics at this time. We expect that a growing number of high-quality maternity care decision aids will be available in the coming years.

Next > 10 Ways To Get Good Maternity Care

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