

Learning about Cancer and Fertility

A Guide for Parents of Young Girls

Right now, you are focused on your child and her survival. Thinking about her life after cancer may not seem like a priority in this moment.

However, some cancer treatments can affect your daughter's fertility.

This means that she may have trouble getting pregnant or having a healthy pregnancy when she is an adult.

There might be decisions you can make now to try to preserve her fertility.

Even if you cannot or do not want to use these options, this guide may give you information that will help you talk with your doctor now and talk with your child about this topic as she grows.

**Fertility:**

The ability to produce children.

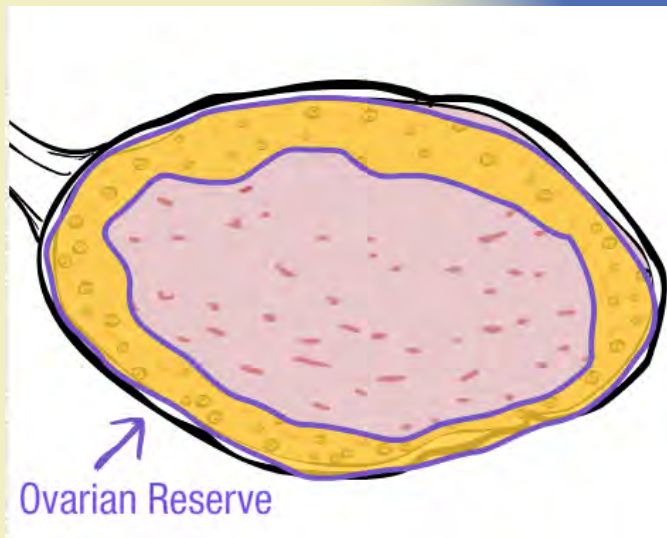
Can I do anything to protect my daughter's fertility?

Maybe.

First, not all cancer treatments affect fertility.

Second, even those that do are different in terms of how likely they are to affect fertility.

It is important to understand how cancer treatment affects fertility, and then you'll better decide if you can or if you want to take steps to protect your daughter's fertility. If you have questions about the short term and long term effects of cancer treatment on fertility, ask for a referral to a **fertility specialist**, such as a reproductive endocrinologist.



Ovarian reserve:

The number of eggs stored in the ovary.

How does normal fertility work?

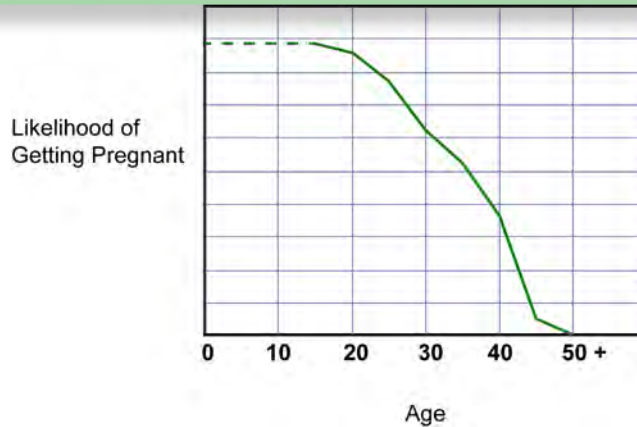
A baby girl is born with all the eggs she will ever have. This is called the **ovarian reserve**. The ovaries are the organs where the eggs are. Once a girl reaches puberty, she will usually release one mature egg per month. This mature egg can combine with sperm and become an embryo.

How does cancer treatment affect fertility?

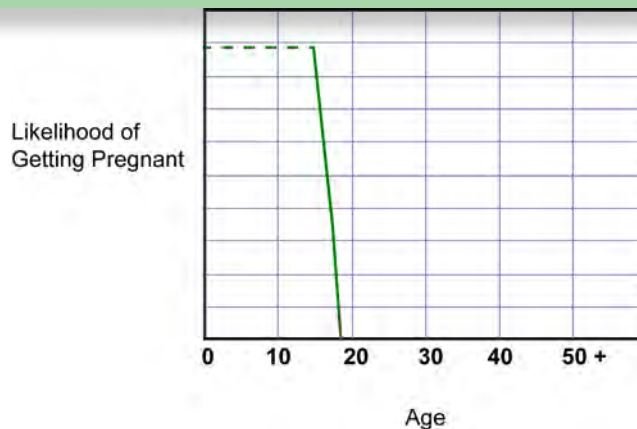
Chemotherapy can destroy some or all of the eggs. This means that as the girl gets older, she may not have as many eggs in the ovarian reserve as other girls.

Radiation therapy can also destroy eggs, if the ovaries are in the path of the radiation. Radiation to the brain can also affect fertility. This is because the brain controls hormones that are needed for normal puberty and development.

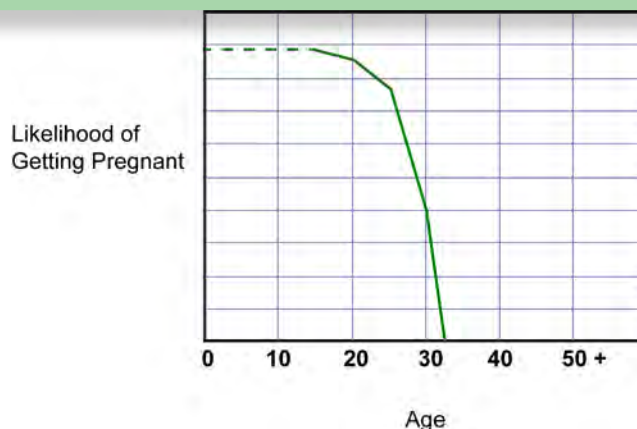
The figure below shows an average woman's fertility as she gets older. This is what you can expect if your daughter's fertility is **not** affected by treatment.



In some cases, a girl undergoing treatment may lose her fertility right away.



In other cases, she may stay fertile at first but go into menopause earlier than average.



Does that mean my daughter will not be able to have children if she has cancer treatment?

Depending on the treatments she receives, your daughter may or may not have fertility side effects during or after treatment.

For **pre-pubertal** girls (girls who have not yet reached puberty), the effects of treatment on puberty and fertility might not be clear right away. It is difficult to know if their ovaries or hormones have been affected. Some pre-pubertal girls may need medication to enter puberty if the cancer affected their hormonal system.

For older girls, there are three different things that can happen:

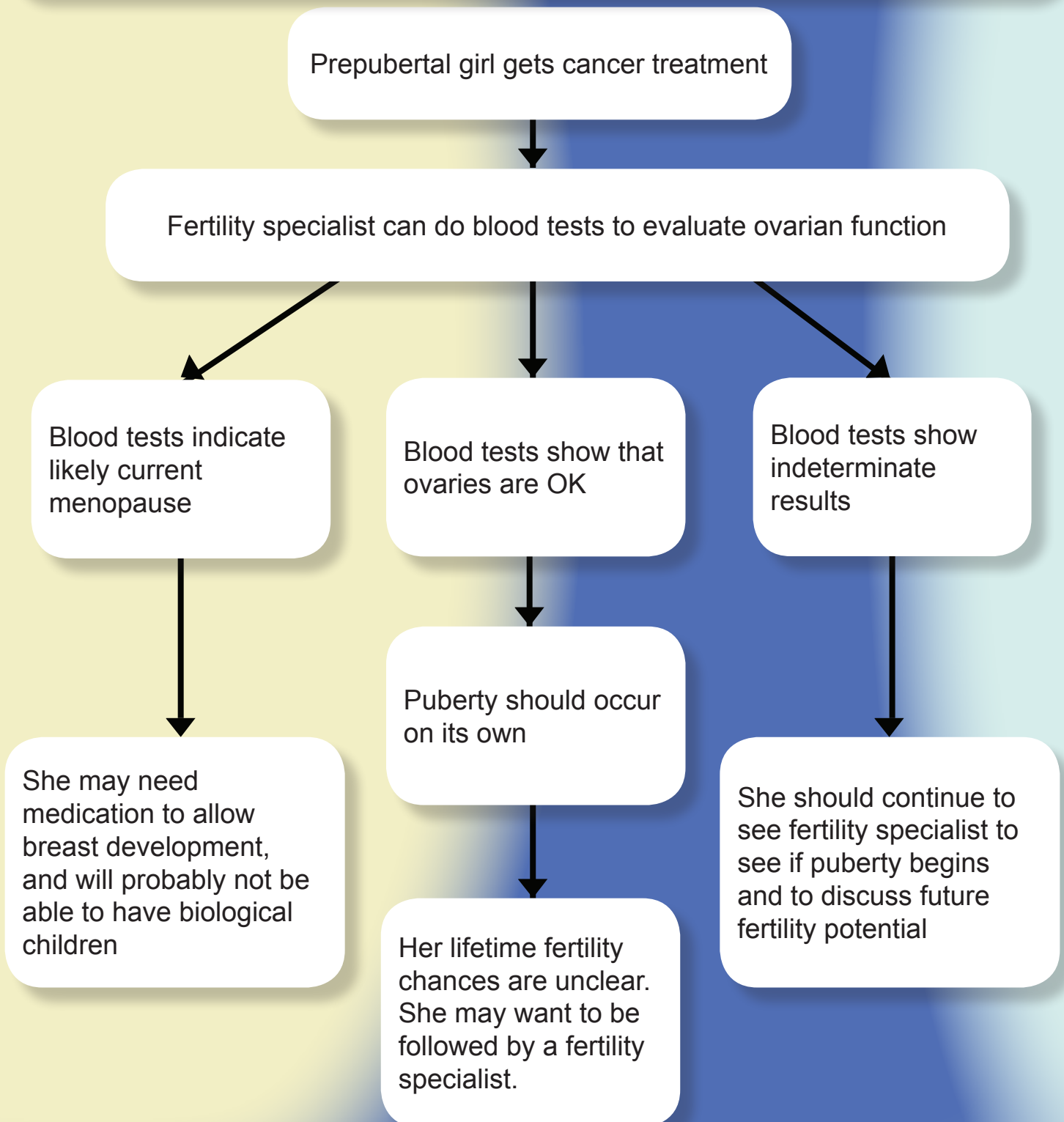
1. Some girls experience no effects on their fertility.
2. Some become infertile right away.
3. Others become infertile during treatment but get fertility back after treatments are over.

A young woman who has had cancer treatment, seems fertile, and gets her periods each month may still have fertility issues. For example, she can go into menopause earlier than usual because she has fewer eggs than other women her age.

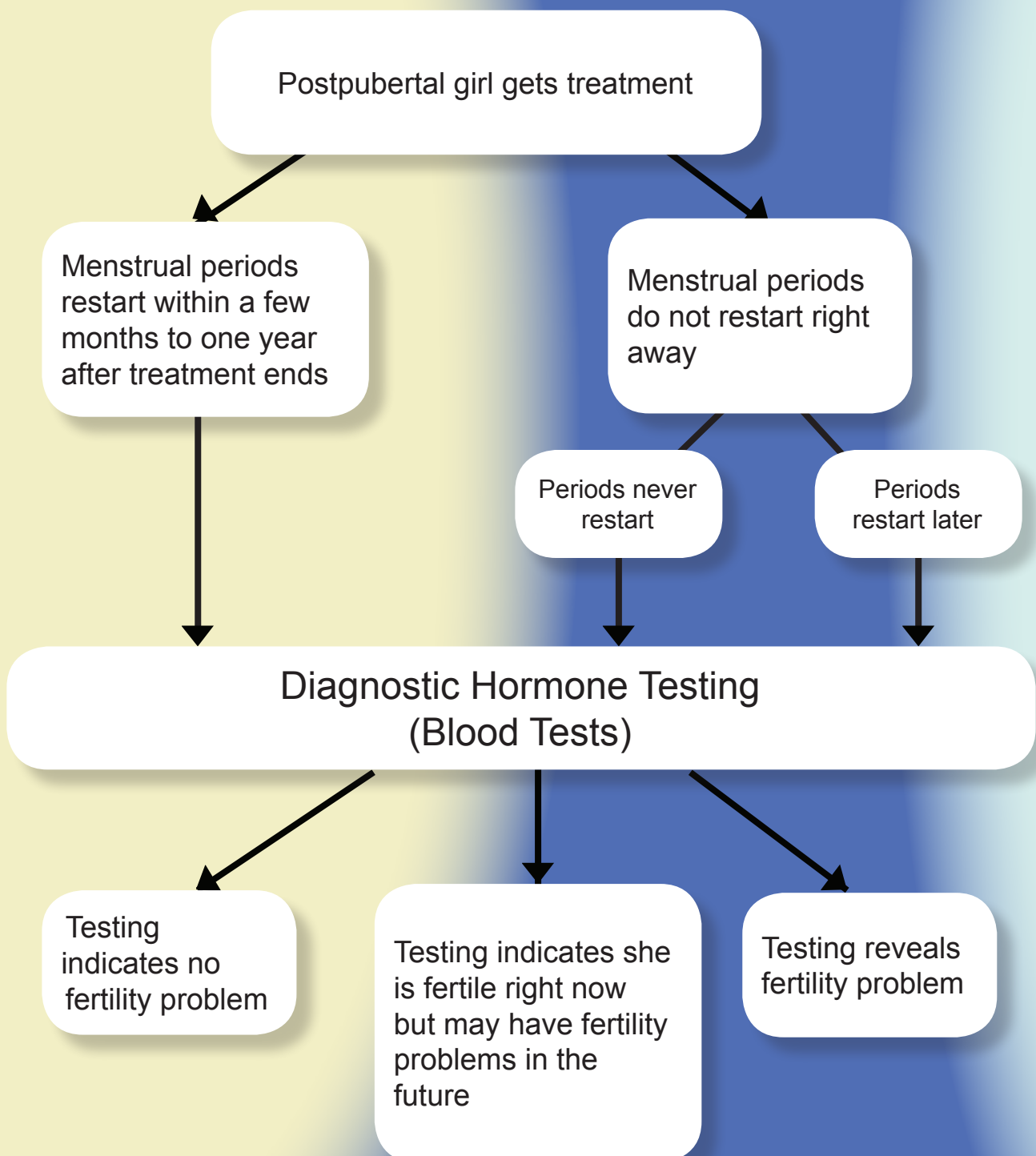
If your daughter knows her risk and her options, she can be prepared to make decisions when she's older.

*How can cancer treatment affect my child's fertility?
What are some possibilities?*

For prepubertal girls (younger girls who have not had their menstrual periods):



For postpubertal girls (older girls who usually have had their menstrual periods):



Things to consider before treatment

How can I, and why should I, make a fertility preservation decision right now?

Many survivors of childhood cancer have said that becoming a parent became important to them as they grew older.

You may have the greatest number of options before treatment starts. The window of time to act is short.

Many families report being overwhelmed with helping their child confront a cancer diagnosis. It may be hard for you to think beyond the sick child you have today to imagine your child as a healthy adult who may want to have a biological child someday.

This is understandable. If you are interested in fertility preservation, it is best to start talking about it with your child's oncologist and a fertility specialist right away. Fertility preservation options may need to be discussed and coordinated while developing your daughter's treatment plan. For example, sometimes a procedure can be done at the same time as another procedure or surgery your daughter already needs to have.

You may choose not to use any of these options. That's OK too.

Fertility preservation:

Ways of helping cancer patients be able to have a child someday. For example, egg freezing is one type of fertility preservation.

Fertility Preservation

What do other families do?

Some people choose not to make a decision about preserving their daughter's fertility. They decide not to decide. Some parents find it helpful to get as much information about fertility and fertility preservation as they can, so they can understand what may happen and what is possible. Your own beliefs and values are important, and there is no right or wrong decision.

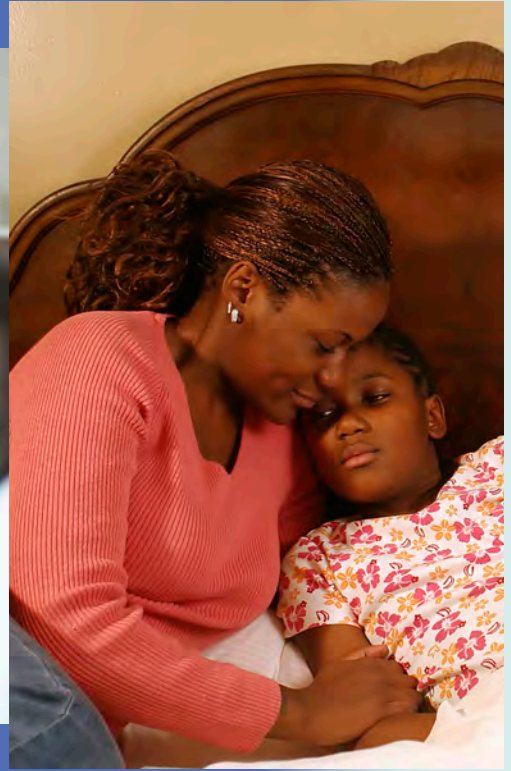
What is some advice that parents whose children had cancer have given?

- Ask questions.
- Don't be afraid to bring up fertility preservation with your daughter's doctors.
- Some options are only available before treatment starts, so ask as early as possible.
- Find out how likely these options are to work.

Things to think about

Is there anything you need to know from healthcare professionals that would make your decision easier to reach?

Are there social workers available? Can someone connect you with families who have gone through a similar decision?



Has your doctor told you how likely it is that your child will have difficulty having a baby when she is an adult?

The risk to your daughter's fertility will depend on the type of cancer, the type of treatment, her age, and other factors. In some cases, doctors may not know how likely it is that your daughter will have problems having a child someday.

What type of fertility preservation might your daughter be eligible for?

You can ask your doctor(s) or a **reproductive endocrinologist** (fertility specialist) what types of fertility preservation your daughter may be eligible for. Some factors are:

- How old is she?
- Is she in puberty yet?
- Has she started her period?
- What type of cancer does she have?

If your daughter has started puberty already she might have several options, including egg freezing, embryo freezing, or ovarian tissue freezing. If a child has not started puberty, she may only be eligible for ovarian tissue freezing.

Some options may be experimental. This means that doctors are not sure if choosing that option will allow your daughter to have children someday.



Reproductive endocrinologist:

A doctor who specializes in fertility.

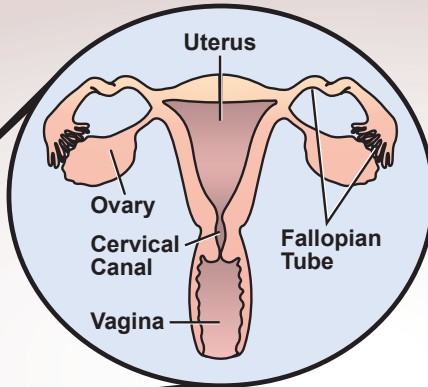
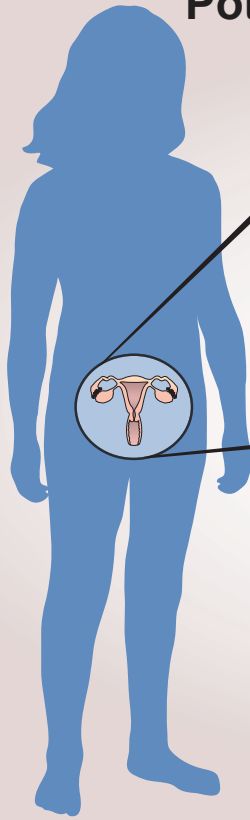
Experimental options before treatment

	Egg Freezing	Ovarian Cryopreservation
Who it's for	Only for girls/women who have entered puberty	For girls/women whether or not they have entered puberty
Preparation before procedure	Patient usually takes hormones for about 2 weeks	No hormones needed
Procedure	<p>Doctor gives patient light sedative</p> <p>Doctor takes out eggs</p> <p>How long: 20-30 minutes</p>	<p>Patient put under general anesthesia</p> <p>Doctor makes a small cut in the belly button to remove one ovary (girls and women normally have 2 ovaries to start with). They may be able to do this at the time of another procedure (for example, port placement)</p> <p>How long: 45 minutes to an hour.</p>
What is done with eggs/ovary:	Eggs frozen and stored in a facility, marked with patient's identifying information	Ovarian tissue frozen and stored in a facility, marked with patient's identifying information
What happens when she is ready to try to have a baby?	A fertility doctor can fertilize the eggs with partner or donor sperm. (IVF, or in-vitro fertilization). Then the fertilized egg can be put back in her body so she can get pregnant.	<p>When your daughter is ready to have babies, what happens next depends on what kind of cancer she had.</p> <ol style="list-style-type: none"> 1. If she had a solid tumor (like a sarcoma), doctors may be able to put the ovarian tissue back in the body and she might be able to get pregnant on her own. 2. If she had a blood-based cancer (like leukemia) a fertility doctor may be able to fertilize the eggs outside of the body and then implant fertilized eggs. Using fertilized eggs takes away the risk of reimplanting cancer.

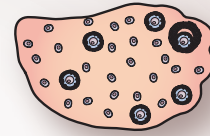
Questions and statistics to ask your doctor about:

	Egg Freezing	Ovarian Cryopreservation
Things to consider and/or ask your specialist about:	<ul style="list-style-type: none"> • If you are worried that there is not enough time for egg freezing, ask your oncologist: Is there enough time to take hormones and still get my daughter treated in time? Your daughter may still be able to freeze eggs, even without hormones. • What happens while the eggs are stored? Would I pay for storage, and if so, how much would it cost? Are there assistance programs? 	<ul style="list-style-type: none"> • How long after the procedure could my daughter safely start chemotherapy or radiation? • Can they do the ovarian cryopreservation at the same time as another surgery (for instance, port placement)? • I know the surgery is outpatient, but how invasive is it? What is involved?
Some statistics to ask your doctor or specialist about:	<ul style="list-style-type: none"> • What does it mean when people say that this procedure is experimental? How long has it been around? • How many births have there been? Out of how many tries? • How likely is it to work? • How is this different from embryo freezing? (Note: One difference is that the eggs aren't fertilized in egg freezing) • Are there other options that might be better for my daughter? 	<ul style="list-style-type: none"> • What does it mean when people say that this procedure is experimental? How long has it been around? • How many births have there been? Out of how many tries? • How likely is it to work? • Can this still work for girls who are not in puberty yet? • Are there other options that might be better for my daughter?

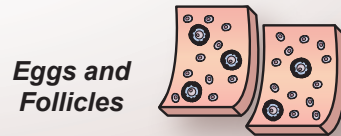
Potential Options for Fertility Preservation



Now:
Fertility Sparing Procedure



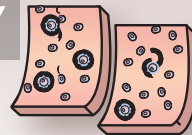
Ovary Surgically Removed



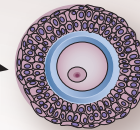
Eggs and Follicles

Ovarian Tissue Frozen

Later:
Two Options for Future Pregnancy



Thaw Frozen Tissue



Mature Egg In Lab

Mature Egg

Fertilize Egg

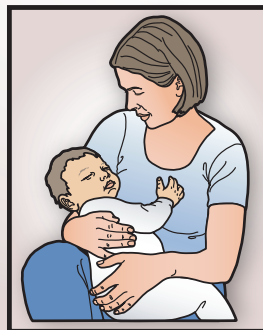
Embryo



Implant Embryo Into Patient

Transplant Back to Patient

Conception



Birth

Some babies have been born using this option



Birth

No babies have been born yet using this option

Thinking about your daughter's future

When you imagine your child as an adult, what do you see for her?

- Is it important that she be the biological mother to her children?
- Some parents find it useful to ask their daughter what she thinks.
- You may want to discuss your values with a partner, family member or friend.





Should your daughter help to make the decision?

This may depend on your child's age and maturity level. Teens are often involved in decisions about their treatment and its side effects, including fertility.

It can be difficult to talk to children about this topic, because it may be hard for them to think about being parents. It also may be difficult to know what decision to make if a child disagrees with her parent.

If family members disagree on the best thing to do, consider bringing in someone else, like a counselor, to help with the discussion.

What has helped other parents make this decision?

Some parents said it was important to them to help their child to have the most choices in life, others said they just wanted to focus on their child's cancer treatment. There is no right or wrong in this case.

Things to consider during treatment

What happens if my child's treatment protocol changes?

Different treatments may have different risks. If your child starts a different treatment, you may want to ask about new side effects (including fertility).

What are other things doctors do to protect fertility?

If your daughter will receive pelvic radiation, you may also want to make sure her team of doctors will try to protect the ovaries (through ovarian shielding and/or ovarian transposition). There may be other experimental options, too.

What if ovarian cryopreservation doesn't work? Can a woman conceive with only one ovary?

Most girls and women have two ovaries. Ovarian cryopreservation would take out only one, leaving one ovary still there.

If the cancer treatment does not damage the ovary, your daughter might still be able to conceive even with one ovary.

A fertility specialist can help explain this.

Things to consider after treatment

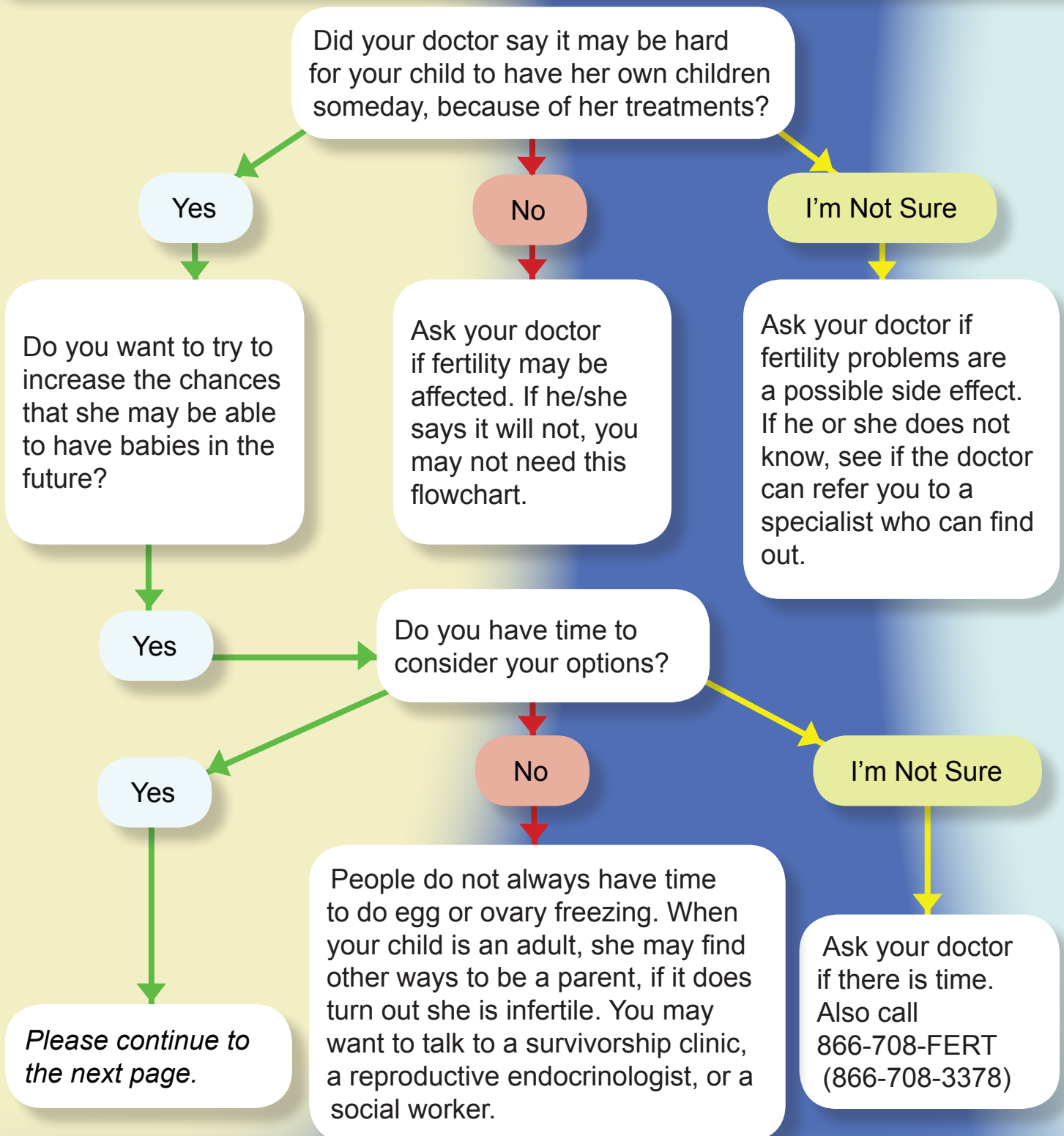
If my daughter gets her period after treatment, does that mean everything is OK with her fertility ?

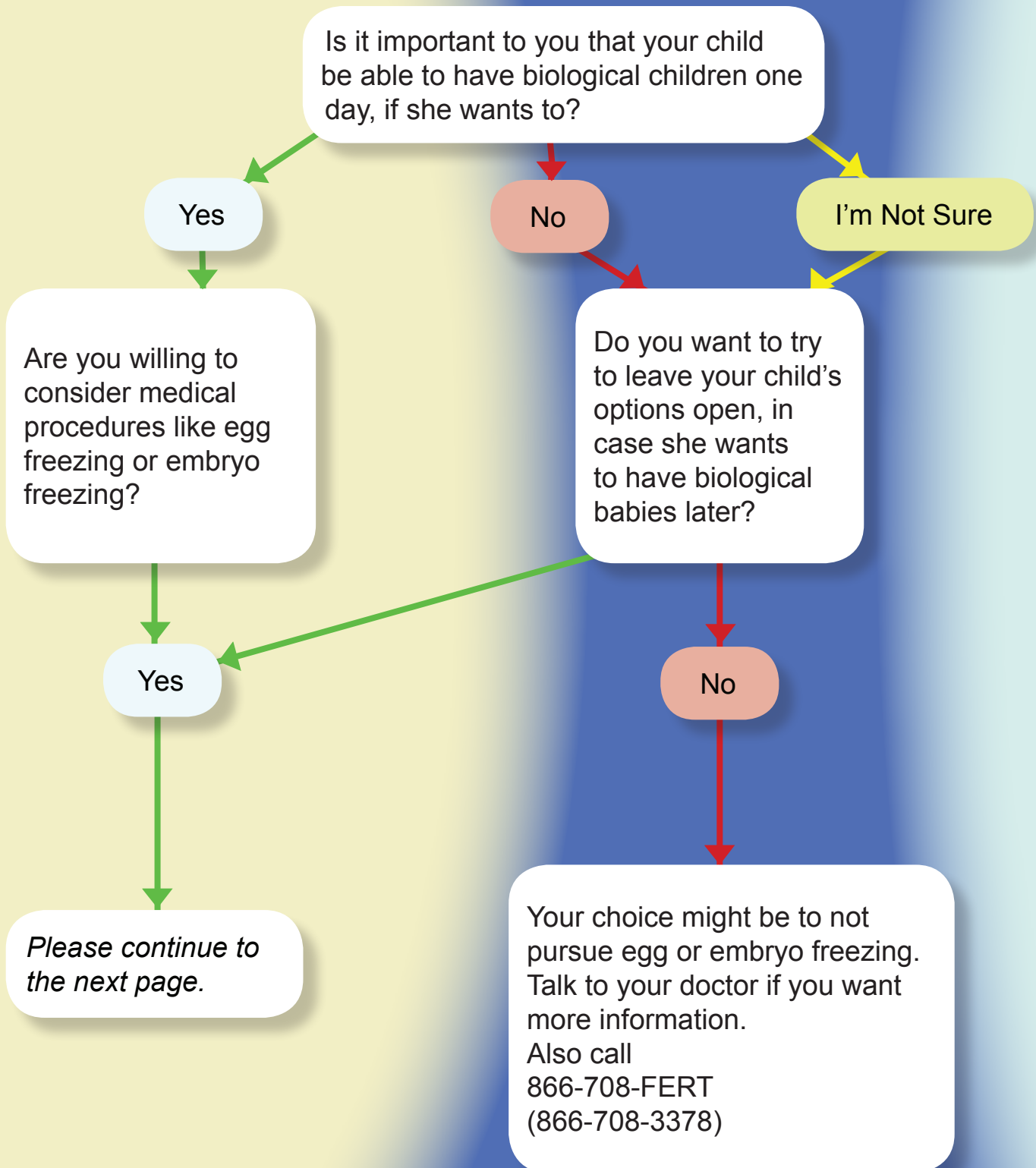
Not necessarily. If your daughter is an adolescent already, she may not have a period during treatment but have a period a few months later. Just because she gets her periods back, though, **does not** mean that there were no effects of treatment on her fertility. If you have questions or concerns about her fertility, she can be seen by a fertility specialist.

Decision Guide Flowchart

Please talk with your child's doctors about whether your child may have future fertility problems related to her cancer or its treatment.

The color coding in this guide is designed to help you move from one section to the next.





The best option for your child depends on whether or not she has entered puberty. Has your child started puberty?

Yes

Your daughter might have two options: egg freezing or ovary freezing. A fertility specialist can help you decide which option is right for your daughter. Please follow the decision aid to find out more.

No

If your daughter definitely hasn't entered puberty, your only option may be ovary freezing/ovarian cryopreservation.

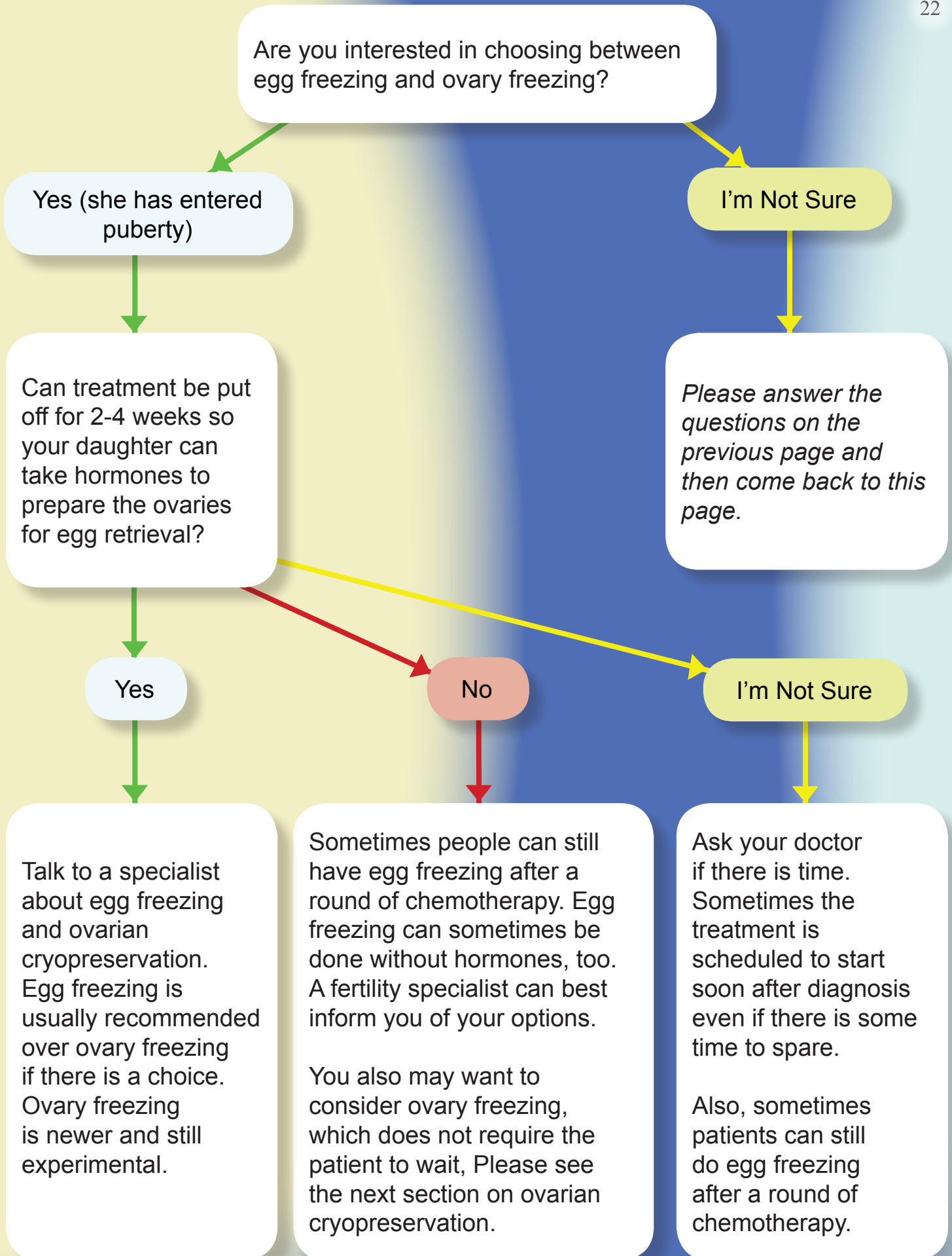
*Please see the section on **ovary freezing** on page 19.*

I'm Not Sure

Having a menstrual period is one sign of puberty.

However, it is possible for a child to be in puberty even without having a period.

You may want to ask your doctor for blood tests to see if she has entered puberty.



Would you be willing to have your daughter undergo surgery for ovarian cryopreservation?

It is laparoscopic (through the belly button) and takes about 45 minutes to an hour.

Yes

No

I'm Not Sure

Is there enough time for your daughter to recover and start or continue treatment?

Usually treatment can continue 2-3 days after the procedure.

Ovarian cryopreservation might not be a good option for you.

1. Talk to specialists. If she already has to have another surgery (such as port placement) find out if ovarian cryopreservation can be done at the same time.

2. Find out if there's enough time for her to recover and start or continue treatment. Usually treatment can continue 2-3 days after the procedure.

Yes

No

I'm Not Sure

Ovarian cryopreservation may be an option for you. Please note, it is still experimental. Ask a specialist for more information or call 866-708-FERT (866-708-3378)

Ovarian cryopreservation might not be a good option for you.

Talk to a fertility specialist to be sure.

Ask your oncologist, and then come back to this page.

Other resources

Livestrong/Fertile Hope <http://www.fertilehope.org/>
MyOncofertility.org <http://myoncofertility.org/>
Fertility Hotline 866-708-FERT (866-708-3378)



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