

## A Family Systems Approach to Primary Ovarian Insufficiency

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### ABSTRACT

Receiving the diagnosis of Primary Ovarian Insufficiency (POI) can be emotionally difficult and confusing for young girls and their families. Parents need assistance in knowing how to help their daughters understand and live with the diagnosis in a way that allows for healthy growth and development. This paper provides a starting point for parents and clinicians with "Tips and Tools for Talking: Helping Your Daughter Understand Primary Ovarian Insufficiency".

**Key Words:** Primary ovarian insufficiency, POI, Premature ovarian failure, POF, Premature menopause, Adolescence, Family systems, Emotional, Psychological, Parenting

### Introduction

By the age of 20 years approximately 1 in 10,000 girls and young women will develop primary ovarian insufficiency (POI).<sup>1</sup> The condition, also known as premature menopause and premature ovarian failure, is characterized by the presence of menopausal level gonadotropins and estrogen deficiency in association with oligo-amenorrhea.<sup>2</sup> There are metabolic sequelae related to the sex hormone deficiency that are of paramount importance as well as potential emotional sequelae related to the threat to parenthood that need to be addressed.<sup>3-5</sup>

When communicating information to adolescents it is important that parents and clinicians realize that this time of life encompasses a broad range of emotional maturity. For most girls and young women a threat to parenthood is a threat to self-identity. This threat presents a challenge to existential well-being both to the girl's parents (their threat to grandparenthood) and to the girl herself. All societies value childbearing and parenthood and generally childlessness is stigmatized in most cultures.<sup>6-8</sup> There is historical evidence suggesting that in the United States reproductive conformity has been manufactured, promoted, and at times even coerced.<sup>9</sup> When an adolescent and her family are faced with a health crisis that impacts her reproductive capacity, and introduces associated stigma, the family must adapt to the disruption of the normal state and the associated unknowns and uncertainties.<sup>10</sup> This requires approaching the situation from a family systems perspective. The nuclear family rather than one individual is the

emotional unit.<sup>11</sup> A health crisis impacting reproduction will reverberate through the family and the issues must be addressed in this context.

Clinicians must integrate many factors into their approach. How best to deliver the news? How much should be disclosed, to whom, at what time, and in what order in the family? Is there merit for "just in time information" for the child? How do we know we are not manufacturing and promoting reproductive conformity and possibly even being coercive in ways we don't even appreciate with regard to the child's reproductive future? How can we hope to know what the child's unencumbered future dreams around reproduction would have been as a fully mature adult absent this disorder? How can we as clinicians and parents approach this? How can we avoid sending the message to the child in a subliminal manner that "in order to be normal as an adult woman you need to have a child and be a parent"?

Getting the diagnosis of primary ovarian insufficiency is emotionally traumatic for most women. The most common words they use to describe how they feel after getting the diagnosis are "devastated," "shocked," and "confused."<sup>4</sup> The diagnosis embarks women on what is perhaps best termed a psychosocial transition to find their new identity.<sup>5</sup> As a group (Table 1), we have come to the conclusion that adult women with this condition would benefit from having access to a "POI Recovery Program." This would be a structured psychosocial intervention based on evidence. The goal of the program would be to facilitate not only the recovery of emotional well-being in this specific population, but also the maintenance of good physical and emotional health over the long term. At this point the nature of this program has not been formulated. As members of the POI Recovery Group we take this opportunity to bring awareness to this need. In many ways, in view of the multiple

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**Table 1**  
Primary Ovarian Insufficiency Recovery Group

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parameters, helping adolescents and their parents navigate this psychosocial transition is expected to be the most challenging situation. The dilemma is that there are teens and their families in our clinics right now who need guidance on how to approach this, and there are no evidence-based methods currently available.

One of the authors (LMN) had a mother request written guidance on how to discuss the elements of primary ovarian insufficiency with her 14-year-old daughter as she matured and naturally wanted more information. This particular mother was vehement that she did not want to discuss the reproductive issues related to the diagnosis until the daughter raised the question, an “information just in time” approach. She wanted her daughter to develop in her peer group without having potentially stigmatizing information before she needed it. The daughter at the time was concerned only about developing breasts and having menstrual periods as her friends were doing. Her main question was, “Can I still play soccer?” This mother’s request for guidance was the stimulus for developing a trial document for this one mother. We call it, “TIPS AND TOOLS FOR TALKING: Helping Your Daughter Understand Primary Ovarian Insufficiency.”

Our intent with this communication is to bring these issues out into the light of day, and to share an example of one such document. As a group we have concerns that these tips may cause more harm than good if used improperly. We view the tips at this point along the lines of a prescription drug. The clinician needs to decide when and how to provide this guidance. We as a group have some reservations about making this guidance available outside of a clinician-family relationship. Clinical judgment is required here. For example, for families that already have major dysfunctional communication dynamics it would be best to address this aspect of the clinical situation first before tackling how to best provide more detailed clinical information about the primary ovarian insufficiency to the child.

Our purpose is to start a dialogue around these issues. Each clinician will need to assess the proposed tips and adapt to their own clinical situation. We hope this is a first step toward developing an evidence-based recovery program for families that have teens with primary ovarian insufficiency.

Here is the document as currently configured by our POI Recovery Group:

### Tips and Tools for Talking

#### *Helping Your Daughter Understand Primary Ovarian Insufficiency*

Parents are foundational cornerstones of their children’s lives providing nurturance and direction that permits children to develop self-confidence, self-sufficiency, and independence. Typical child and adolescent development has normal ups and downs, but when parents learn that their child has a health problem, the emotional well-being of the entire family is affected. Parents often find themselves dealing with their own concerns about their child’s health, while at the same time trying to help their child/teen understand and cope with a new diagnosis. Each parent may have a different perspective and react differently to the news. And yet it is important that both parents work together to help their daughter.

This information sheet is intended to help you talk to your adolescent daughter about common questions and concerns following a diagnosis of Primary Ovarian Insufficiency (POI). In many cases, POI is the only disorder in need of care when the diagnosis is made. In other cases, POI is part of a larger health care plan, as in the case of POI that develops after treatments for cancer.

Before starting a discussion with your daughter, it is important that you have an opportunity to learn the facts about POI. Parents should talk with each other, and seek guidance from their daughter’s clinicians, to understand how they can best help her. You will want to be clear on the medical information provided by your physician regarding health implications and treatments for POI. It is, also, important that you take the time to process your own feelings about the condition before discussing it with your daughter. The goal is for you to be able to talk with your child without becoming overly emotional, as adolescents are capable of picking up on signs of distress from parents. Understandably, you may feel anxiety and uncertainty about how POI will affect your daughter and your family. However, if you talk to your daughter when you are upset, she will likely pick up on this and fear the worst. Take some time to work through your own reactions before talking to her. If you can be calm, confident, and positive in your message, your daughter will be better able to process what she is learning about herself.

### General Tips:

1. *Begin by working with your daughter’s clinicians to help her understand her diagnosis.* You will want to share with your daughter’s clinicians your concerns about how your daughter will react to this diagnosis. You may have thoughts about what you feel is the best way to discuss it. Ideally, her physician will have had experience in discussing this diagnosis with adolescents, as well as caring for teens. Most clinicians who take care of adolescents will be guided by the teen’s own questions. Physicians who care for adolescents know that it’s

important for them to hear YOUR concerns as parents, but that they must also listen carefully to your daughter's concerns. Clinicians who take care of adolescents typically take time to talk with your teen alone to allow her to raise her concerns privately. These physicians are not trying to leave you as parents out of the discussion but know that privacy and confidentiality are very important to teens. Most clinicians know that providing important information over several visits can be helpful, rather than attempting to address all concerns at the initial visit. Thus most will schedule a follow-up visit with your daughter to answer additional questions that might emerge. As parents, you will likely want to have a discussion with your daughter between the time that the clinician first confirms the diagnosis, and the follow-up visit to address additional concerns.

2. *Start early and remember that communicating with your daughter about POI is an ongoing process.* You need to take a “staged approach” that builds on information over time and considers your daughter's emotional and cognitive maturity and readiness. Avoid overloading her with more information than she desires or is ready to hear. When you initiate a conversation on POI, choose a place that allows for privacy and provides sufficient time for discussion. As she comes to deal with and process what you have discussed, she will undoubtedly have questions. It may also be helpful to let her know when you will plan to talk again. It's also useful to provide feedback to the clinician about how your daughter reacted to your additional conversations. Remember this is not just a one-time discussion. For instance, your daughter may have new questions down the road when she enters a serious romantic relationship for the first time and needs guidance on sharing information on POI with her partner.
3. *Keep responses short and simple.* You don't want to overwhelm her with too much information at one time. Respond to what her current concerns are, even if they differ from yours. Adolescents are likely to be more concerned with their growth and physical development so as to be more like their peers, and likely may not be thinking yet about fertility or parenthood.
4. *Encourage dialogue and ask for feedback.* Ask your daughter to describe what her understanding of her diagnosis is. If you have explained something to her about POI, ask her to tell you in her own words her understanding of your explanation. If there are questions about POI that you cannot answer, encourage her to write her questions down so that she can discuss them at the next visit with her clinician. Create an open environment for ongoing discussions. Try to answer her questions as they come up. Her questions will tell you how much information she has been able to understand and process.
5. *Listen with a third ear.* This means to listen for questions, comments, or remarks from your daughter that initially may seem irrelevant. Observe her body language for clues about how she is feeling. Girls sometimes have questions and comments about things going on in their daily life that, although seemingly unrelated to POI, actually reflect concerns related to their diagnosis. Notice subtle changes in behavior and actions, such as sadness, moodiness, or withdrawal, which may indicate she is experiencing worries or concerns.
6. *Help your daughter have a positive outlook.* POI is a medical diagnosis that is treatable, allowing her a long, healthy, and productive life. Remind her that this is just one aspect of her life and she has many special strengths and abilities as a person. Help her put the diagnosis of POI in proper perspective in the total experience of her life.
7. *Acknowledge how your daughter feels.* It is hard to see your child feel upset, but it is important that she be allowed to feel all her emotions, understanding that they are normal. Consider counseling for you and/or your daughter, if you feel it would be helpful, communication seems to be breaking down, or if these feelings become unmanageable.
8. *Help your daughter develop a sense of herself and her purpose beyond biological motherhood.* Help your daughter realize that there are many ways to lead a happy adult life. Identify how families come in different forms (single women or couples without children) and through different choices (adoption, donor egg, donor embryo, and families blended together by marriage).
9. *Remember that secrets can be destructive.* It is important that you be open and honest with your daughter about the implications of POI, including the likelihood of impaired fertility *when the question arises*. If you fear upsetting her and try to keep information from her when she is requesting it, she may conclude that this is something bad or shameful that cannot be discussed. When something is so frightening that it has to be hidden, children sense secrecy, and it often causes conflict in the family. A child's imagination about a secret grows and may become far worse than the reality. Secrets in a family can undermine trust and stability in relationships. Discussions about fertility should begin when your daughter asks questions and makes comments about her body or future family. Or you may initiate the discussion as part of educating her about POI, when you feel she is ready. You know your child better than anyone else. Nonetheless, do not underestimate her curiosity prompted by doctor visits or by her own observation of her physical growth or development.
10. *Seek out resources for support.* Learning about living with the diagnosis of POI can feel isolating, yet it is important to realize you are not alone. Talking with supportive family members and friends about issues you and your daughter are experiencing can help address these feelings. You may also use this opportunity to educate others about POI. Ask your caregiver for information, organizations, and resources in your community to meet and talk with others who are familiar with the condition.
11. *Share your faith or sources of hope and understanding with your child.* Children, like adults, try to make sense of negative things that happen to them using belief

systems of religion and/or spirituality. Religious faith and spiritual beliefs may give meaning to the illness or otherwise convey a sense of hope. Listening to a child's understanding about why bad things happen, beliefs about God, or anger at God (without challenging or correcting), and sharing your own beliefs about this, can help build intimacy as well as teach children positive coping skills.

### Talking Points

*What does "Primary Ovarian Insufficiency (POI)" mean?*

Girls' bodies develop in different ways and at different times—some very early when they are much younger and others when they are much older. While each girl's physical development is unique, most follow a predictable path towards becoming adult women. Hormones are chemical messengers in the blood that allow one part of your body to communicate with other parts of your body. For normal growth to take place, certain hormones (like estrogen and progesterone) are released in a girl's body, causing breasts to develop, hair to grow under the arms and around the genitals, and menstrual periods to begin. These hormones are produced by the ovaries, which are also the place where eggs are stored and grow for a future pregnancy. However, with Primary Ovarian Insufficiency or POI, the body isn't making all the hormones needed for this to happen. POI is a term used to describe a condition when a girl or young woman's ovaries are unable to provide enough ovarian hormones to allow for these changes to take place. When a girl does not have enough ovarian hormones, then her body has difficulty making the changes needed to become a woman's body. This is why your doctor will give you hormones to replace those that your body is not producing and which are important for your health. Ovaries are also the place where eggs grow and are stored for a future pregnancy.

*What is wrong?*

Most girls find out they have POI because their bodies aren't growing and developing the way they should. You may not have started your period or developed breasts and pubic hair, or may not be getting taller as fast as friends. Some girls with POI start their periods and then the periods stop or come less often. All of these things may indicate that there is a problem.

*Why did this happen?*

POI is a mysterious condition, and in many situations doctors have not been able to find a specific cause. Sometimes ovarian insufficiency is caused by medicines used to treat another illness such as a cancer. We are working with the doctors to try to find the reasons for your POI.

*What does it mean to my health?*

POI can affect several organs of your body and if not managed correctly might contribute to other health issues later in life. While there is no cure for POI, it is treatable. In fact, there are many things we can do to effectively manage POI, both now and when you are older. For example, estrogen is important in keeping your bones strong and healthy. Bone health is very important as you grow older, as

healthy bones resist breaking. Hormone treatment will help prevent your bones from becoming fragile. To help your bones grow strong it is also important for you to do regular weight-bearing exercise (i.e., walking and running). In addition, you may need more vitamin D and calcium. It is important that you take care for your body throughout your life. You are the expert on your own body and know your body better than anyone. You can help by letting us know how you are feeling and if you have any problems, concerns, or questions. Taking good care of your body will help you be able to better meet the goals that you set for yourself throughout life.

*What do I say to my friends?*

You choose how much information you decide to share with a friend. It will probably depend on with whom you share other personal things. You might want to say something like, "I have a medical condition that is personal, and I'd rather not talk about it," or, "I have a medical condition that is called POI. Do you want to hear more about it?" When and what you share with others about POI may depend on the type of friendship or if it is a serious romantic relationship. Whether you talk about POI and how much you share about it is completely up to you, but it will be important for you to tell other doctors that you see in the future that you have POI.

*Will I be able to have children?*

Families come together in many different ways, and, whether you have children or not, you will always be a part of a family. Children come into a family through birth, adoption, and when people who already have kids blend two families. When the time is right and if you chose to do so, there are medical treatments that may help you become pregnant, or there are other ways to bring a child into your life, such as adoption. However, if you are choosing to be sexually active and don't want to be pregnant, don't assume you cannot, because sometimes women with POI become pregnant. Therefore in this situation, you should use birth control—like foam and condoms—that will prevent an unplanned pregnancy as well as help protect against sexually transmitted diseases.

*What can I do about it?*

You will be involved in all decisions on how best to treat your POI. We will make sure we answer all of your questions so that you understand all treatments. However, when you have POI or any other health problem, your feelings are also affected and you may be worried, upset, concerned, confused, or scared about what it all means. It's important to talk with us about your feelings because talking helps you clarify what you need to do to make the most of your situation. You may want to think about whom else would be helpful for you to share your thoughts and feelings with—like your grandmother, your aunt, or maybe a best friend. And, the doctors tell us that talking with a counselor about POI helps many girls. We will find a counselor for you to talk to when you are ready. It is important to realize that you are not alone with this diagnosis. Talking about it and learning more about it helps you. Finally, like other teenagers, you

need to make sure you are getting enough sleep, eating healthy, getting exercise, and having fun with your friends. Remember, POI is a treatable condition and it is only one part of who you are as a person.

#### Website Resources

**POI at NIH:** <http://poi.nichd.nih.gov/index.htm>

**Kid's Health:** (for parents and kids), also in Spanish: <http://kidshealth.org>

**Rachel's Well, Inc:** <http://RachelsWell.org>

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