

FERTILITY SOLUTIONS SUNSHINE COAST

HELPING OTHERS UNDERSTAND A GUIDE FOR FAMILY AND FRIENDS

I want to share my feelings about infertility with you, because I want you to understand my struggle. I know that understanding infertility is difficult; there are times when it seems even I don't understand. This struggle has provoked intense and unfamiliar feelings in me and I fear that my reactions to these feelings might be misunderstood. I hope my ability to cope and your ability to understand will improve as I share my feelings with you. I want you to understand.

You may describe me this way: obsessed, moody, helpless, depressed, envious, too serious, obnoxious, aggressive, antagonistic, and cynical. These aren't very admirable traits; no wonder your understanding of my infertility is difficult. I prefer to describe me this way: confused, rushed and impatient, afraid, isolated and alone, guilty and ashamed, angry, sad, loss of control and hopeless, and unsettled.

My infertility makes me feel **confused**. I always assumed I was fertile. I've spent years avoiding pregnancy and now it seems ironic that I can't conceive. I hope this will be a brief difficulty with a simple solution such as poor timing. I feel confused about whether I want to be pregnant or whether I want to be a parent. Surely if I try harder, try longer, try better and smarter, I will have a baby.

My infertility makes me feel **rushed and impatient**. I learned of my infertility only after I'd been trying to become pregnant for some time. My life-plan suddenly is behind schedule. I waited to become a parent and now I must wait again. I wait for medical appointments, wait for tests, wait for treatments, wait for other treatments, wait for my period not to come, wait for my partner not to be out of town and wait for pregnancy. At best, I have only twelve opportunities each year. How old will I be when I finish having my family?

My infertility makes me feel **afraid**. Infertility is full of unknowns, and I'm frightened because I need some definite answers. How long will this last? What if I'm never a parent? What humiliation must I endure? What pain must I suffer? Why do drugs I take to help me, make me feel worse? Why can't my body do the things that my mind wants it to do? Why do I hurt so much? I'm afraid of my feelings, afraid of my undependable body and afraid of my future.

My infertility makes me feel **isolated and alone**. Reminders of babies are everywhere. I must be the only one enduring this invisible curse. I stay away from others, because everything makes me hurt. No one knows how horrible is my pain. Even though I'm usually a clear thinker, I find myself being lured by superstitions and promises. I think I'm losing perspective. I feel so alone and I wonder if I'll survive this.

My infertility makes me feel **guilty and ashamed**. Frequently I forget that infertility is a medical problem and should be treated as one. Infertility destroys my self-esteem and I feel like a failure. Why am I being punished? What did I do to deserve this? Am I not worthy of a baby? Am I not a good sexual partner? Will my partner want to remain with me? Is this the end of my family lineage? Will my family be ashamed of me? It is easy to lose self-confidence and to feel ashamed.

My infertility makes me feel **angry**. Everything makes me angry, and I know much of my anger is misdirected. I'm angry at my body because it has betrayed me even though I've always taken care of it. I'm angry at my partner because we can't seem to feel the same about infertility at the same time. I want and need an advocate to help me. I'm angry at my family because they've always sheltered and protected me from terrible pain. My younger sibling is pregnant; my mother wants a family reunion to show off her grandchildren and my grandparents want to pass down family heirlooms. I'm angry at my medical caregivers, because it seems that they control my future. They inflict discomfort and sometimes pain on me, pry into my privacy, sometimes patronise me, and sometimes forget who I am. How can I impress on them how important parenting is to me? I'm angry at my expenses; infertility

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treatment is expensive. My financial resources may determine my family size. My insurance company isn't always cooperative, and I must make so many sacrifices to pay the medical bills. I can't miss any more work, or I'll lose my job. I can't go to a specialist, because it means more travel time, more missed work, and greater expenses. Finally, I'm angry at everyone else. Everyone has opinions about my inability to become a parent. Everyone has easy solutions. Everyone seems to know too little and say too much.

My infertility makes me feel **sad and hopeless**. Infertility feels like I've lost my future, and no one knows of my sadness. I feel hopeless; infertility robs me of my energy. I've never cried so much nor so easily. I'm sad that my infertility places my partnership under so much strain. I'm sad that my infertility requires me to be so self-centred. I'm sad that I've ignored many friendships because this struggle hurts so much and demands so much energy. Friends with children prefer the company of other families with children. I'm surrounded by babies, pregnant women, playgrounds, baby showers, birth stories, kids' movies, birthday parties and much more. I feel so sad and hopeless.

My infertility makes me feel **unsettled**. My life is on hold. Making decisions about my immediate and my long-term future seems impossible. I can't decide about education, career, purchasing a home, pursuing a hobby, getting a pet, vacations, business trips and houseguests. The more I struggle with my infertility, the less control I have. This struggle has no timetable; the treatments have no guarantees. The only sure things are that I need to be near my partner at fertile times and near my doctor/clinic at treatment times. Should I pursue adoption? Should I take expensive drugs? Should I pursue more specialised and costly medical intervention? It feels unsettling to have no clear, easy answers or guarantees.

Occasionally I feel my panic subside. I'm learning some helpful ways to cope; I'm now convinced I'm not crazy, and I believe I'll survive. I'm learning to listen to my body and to be assertive, not aggressive, about my needs. I'm realising that good medical care and good emotional care are not necessarily found in the same place. I'm trying to be more than an infertile person gaining enthusiasm, joyfulness, and zest for life.

***You can help me.** I know you care about me and I know my infertility affects our relationship. My sadness causes you sadness; what hurts me, hurts you, too. I believe we can help each other through this sadness. Individually we both seem quite powerless, but together we can be stronger. Maybe some of these hints will help us to better understand infertility.*

I need you to **be a listener**. Talking about my struggle helps me to make decisions. Let me know you are available for me. It's difficult for me to expose my private thoughts if you are rushed or have a deadline for the end of our conversation. Please don't tell me of all the worse things that have happened to others or how easily someone else's infertility was solved. Every case is individual. Please don't just give advice; instead, guide me with your questions. Assure me that you respect my confidences, and then be certain that you deserve my trust. While listening try to maintain an open mind.

I need you to **be supportive**. Understand that my decisions aren't made casually, I've agonised over them. Remind me that you respect these decisions even if you disagree with them, because you know they are made carefully. Don't ask me, "Are you sure?" Repeatedly remind me that you love me no matter what. I need to hear it so badly. Let me know you understand that this is very hard work. Help me realise that I may need additional support from professional caregivers and appropriate organisations. Perhaps you can suggest resources. You might also need support for yourself, and I fear I'm unable to provide it for you; please don't expect me to do so. Help me to keep sight of my goal.

I need you to **be comfortable** with me, and then I also will feel more comfortable. Talking about infertility sometimes feels awkward. Are you worried you might say the wrong thing? Share those feelings with

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me. Ask me if I want to talk. Sometimes I will want to, and sometimes I won't, but it will remind me that you care.

I need you to **be sensitive**. Although I may joke about infertility to help myself cope, it doesn't seem as funny when others joke about it. Please don't tease me with remarks like, "You don't seem to know how to do it." Don't trivialise my struggle by saying, "I'd be glad to give you one of my kids." It's no comfort to hear empty reassurances like, "You'll be a parent by this time next year." Don't minimise my feelings with, "You shouldn't be so unhappy." For now, don't push me into uncomfortable situations like baby showers or family reunions. I already feel sad and guilty; please don't also make me feel guilty for disappointing you.

I need you to **be honest** with me. Let me know that you may need time to adjust to some of my decisions. I also needed adjustment time. If there are things you don't understand, say so. Please be gentle when you guide me to be realistic about things I can't change such as my age, some medical conditions, financial resources, and employment obligations. Don't hide information about others' pregnancies from me. Although such news makes me feel very sad, it feels worse when you leave me out.

I need you to **be informed**. Your advice and suggestions are only frustrating to me if they aren't based on fact. Be well informed so you can educate others when they make remarks based on myths. Don't let anyone tell you that my infertility will be cured if I relax and adopt. Don't tell me this is God's will. Don't ask me to justify my need to parent. Don't criticise my course of action or my choice of physician even though I may do that myself. Reassure yourself that I am also searching for plenty of information, which helps me make more knowledgeable decisions about my options.

I need you to **be patient**. Remember that working through infertility is a process. It takes time. There are no guarantees, no package deals, no complete kits, no one right answer, and no "quickie" choices. My needs change; my choices change. Yesterday I demanded privacy, but today I need you for strength. You have many feelings about infertility, and I do too. Please allow me to have anger, joy, sadness, and hope. Don't minimise or evaluate my feelings. Just allow me to have them, and give me time.

I need you to **be strengthening** by boosting my self-esteem. My sense of worthlessness hampers my ability to take charge. My personal privacy has repeatedly been invaded. I've been subjected to postcoital exams, semen collection in waiting room bathrooms, and tests in rooms next to labour rooms. Enjoyable experiences with you such as a lunch date, a shopping trip, or a visit to a museum help me feel normal.

Encourage me to maintain my sense of humour; guide me to find joys. Celebrate with me my successes, even ones as small as making it through a medical appointment without crying. Remind me that I am more than an infertile person. Help me by sharing your strength.

Eventually I will be beyond the struggle of infertility. I know my infertility will never completely go away because it will change my life. I won't be able to return to the person I was before infertility, but I also will no longer be controlled by this struggle. I will leave the struggle behind me, and from that I will have improved my skills for empathy, patience, resilience, forgiveness, decision-making and self-assessment. I feel grateful that you are trying to ease my journey through this infertility struggle by giving me your understanding.

The author, Jody Earle, frequently felt the need for a brochure like this one during her own eleven-year infertility struggle. She experienced three pregnancy losses, one in each trimester and eventually, the premature births of her two sons. She continues to be a peer counsellor for those working through infertility.

This brochure was prepared by **Jody Earle** and the Educational Materials Advisory Committee of the Ferre Institute, **Derwent A. Suthers**, editor.