

Coping with Infertility: How Family and Friends Can Help

Fact Sheet 6

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After a particularly difficult visit to her infertility clinic, Karen* came home angry. Discomforted and embarrassed by this latest test, Karen was still upset when her best friend telephoned. Wanting to help, the friend suggested that Karen just relax and quit trying so hard. "All you need," she said, "is a vacation and a few sexy nightgowns." Karen broke into tears and the friend wondered what she had said wrong.

The emotional impact of infertility creates problems not only for the infertile couple, but also for their family and friends. Like Karen's friend, many people want to be helpful and supportive, but don't know how. Despite their best intentions and efforts, they often say or do the wrong thing, hurting the infertile person or getting hurt themselves. Growing numbers of parents, siblings, co-workers, and employers are encountering similar difficult situations—and they don't know how to respond.

One of the main reasons that family and friends have trouble helping is that they know so little about the emotional aspects of infertility. From the shocking diagnosis and demanding treatment to the disruptive day-to-day experiences, this emotional assault can leave an infertile individual depressed, angry and guilt ridden. And family and friends often add to this pain by well-intended but uninformed comments and actions. Moreover, people can be hurtful if they are unsure of their own feelings, unable to deal with another person's pain and mood swings, uncomfortable with the sexual connotations of infertility or unwilling to accept the method of coping.

THE PROFOUND LOSSES OF INFERTILITY

* Real names have not been used. Examples come from the personal and professional experience of the authors.

Needing help, many individuals and couples turn to support groups where they can express the hurt, anger and resentment they cannot or will not reveal to those closest to them. Secure among others who share the same pain, many support group participants voice their overwhelming sense of loss. Infertility counselors believe that if family and friends could understand the magnitude of this loss, they would have new insight into infertility patients' motivation and behavior and be able to respond more appropriately to their needs.

"The loss I feel is more than not being able to conceive," says one woman. "After months passed without a pregnancy, I went to my doctor and then a specialist. Slowly I entered a world of tests, medications and surgeries. Treatment seemed to take over our lives, and I began to lose the sense of who I was and where I belonged. I felt out of control, out of place and out of luck."

This woman, who was becoming depressed, is actually describing several losses typical of infertility patients. Of the eight types of loss researchers have identified which can lead to depression in the average man or woman, the infertile individual may experience them all: loss of self-esteem, status, important relationships, health or an acceptable body image, control, security, important fantasies and someone or something of symbolic value. The cumulative effect is profound, creating a life crisis that impacts a person's ability to cope and has no immediate or foreseeable resolution.

LOSS OF SELF-ESTEEM

Parenthood is so much a part of life that it is not just anticipated, it is expected. The inability to reach such a basic life goal comes as quite a shock, especially to those who are accustomed to orchestrating their lives. It can

injure their self-image and make them feel inadequate, like failures. "It's so natural, why can't I?" is often the anguished plea. To remain childfree may even threaten their sexual identities, since some men equate fatherhood with masculinity and some women consider childbearing the ultimate expression of femininity. As their self-esteem is diminished, men and women often say they feel "incomplete" or "unworthy."

Self-esteem also suffers with the surfacing of intensely negative feelings, and this is often an unwelcome surprise. Some women have great resentment toward pregnant women. Others can't stand TV commercials with adoring moms and cute kids. Says one woman, "I'm surprised at my own feelings. I've discovered a negative and bitter part of myself that I don't like." Another woman who works in a hospital says, "Whenever I see one of those maternity blouses with big arrows pointing to the woman's stomach, I get a stomach ache."

One consequence of such damaged self-esteem is that people may turn their anger and resentment on friends or loved ones. Bewildered and embarrassed by their own words and actions, infertile women and men have difficulty integrating such raw emotion into their self-images. "I feel like a bad person," is a common admission. With their self-esteem so battered, people become unsure of themselves and may suddenly feel alone or out of place. "I keep trying to fit in, but everyone is having baby showers or doing things with their kids," comments one discouraged patient. "I just don't belong anymore." In turn, couples with children may exclude their childless friends. The infertile person feels further isolated and begins to avoid social gatherings where they feel awkward, different, or "unwanted." The cycle then perpetuates itself.

LOSS OF STATUS

Because our society greatly values and encourages parenthood, infertile women and men may worry that they have lost status or prestige in the eyes of others. From the inevitable question, "Do you have children?" to messages at church to "multiply and replenish the earth," childfree couples are duly reminded of society's expectations. As one patient ruefully asks, "My church constantly reminds women of their special duty as mothers. Does that mean they consider my worth to society is less because I am barren?" Adds a teacher with many colleagues on maternity leave, "No one asks me about my work anymore. They only want to know when I'm going to start my family." In addition, other people often make unfair judgments about the infertile couple. "Es-

pecially if you are active in a career," says one childfree female attorney, "everyone thinks you have put your job before children. We can't even buy a new car or a bigger house without appearing selfish and materialistic."

LOSS OF A RELATIONSHIP

As partners attempt to cope with diagnosis and treatment, they may worry that their relationship will change. Sometimes the change can be great, and relationships are damaged or destroyed. A problem between partners may begin because both are hurting, stressed and depleted of physical and emotional energy. Less able to fulfill each other's needs, they feel worlds apart. This is especially true if their ways of coping are different, as when one partner who prefers privacy feels embarrassed or abandoned by the other's candor or desire to talk to others.

Relationships with family and friends can be strained if the couple believes they are not taken seriously or their decisions are not respected. This can happen even between infertile couples. "My friend and I commiserated with each other as we went through treatment," says one woman, "but I finally had enough and wanted to get on with my life. We have adopted and are very happy, but my friend is appalled that I 'gave up.'"

Another problem is that people need and expect a certain kind of support which others may not know how to give. Parent/child relationships especially suffer with the parent asking, "Why can't I help my own child?" Moreover, other people often lose patience with the infertile person's apparent "obsession" with getting pregnant. They have little idea how infertility impacts every aspect of a person's life, forcing them into great soul-searching: "What is wrong with me?" "Will my partner leave me?" "Am I becoming depressed and driving friends away?" "Is parenthood what I really want or just what I think I should want?" "Why do I even have to question my motives?" Too much of such introspection can create turmoil, make people defensive and moody and inhibit communication.

Those couples who try to express their feelings find that the sexual connotations of infertility make it a difficult and awkward subject. The scheduled sex and treatment demands are intimate aspects which may be embarrassing both to the couple and to other people. If a couple talks frankly about their condition and treatment, they may put other people off. One mother recalls, "When my daughter told me how she carried her husband's sperm sample to the doctor's office, it was just too hu-

miliating.”

On the other hand, very private people are likely to make others feel left out or rejected. The father of an infertile woman expresses his hurt, “I kept asking when she was going to give me a grandson. I would never have done that if she had just told me there was a problem.”

LOSS OF HEALTH OR AN ACCEPTABLE BODY IMAGE

Whatever the cause of a person's infertility, he or she may feel unacceptable, damaged or defective. One woman who has ended treatment remembers how “all the medications and surgeries made me think of myself as a ‘sick’ person. When the doctor could not make me ‘well’ and nothing seemed to be working, those feelings of being unhealthy or ill were intensified.” The patient may feel like a “specimen under glass.” And there may be an actual change in health. Both women and men can become tired, listless and ambivalent about previously important activities. Stress can trigger headaches and irritability; medications may cause such side effects as cramping, bloating and nausea; surgery patients require a recovery period from the procedure and anesthesia.

Perhaps the most troubling change in self or body image is the way a person sees himself/herself sexually. The medical evaluation probes a couple's sex life, violates their privacy, and eliminates sexual spontaneity. The course of treatment may require scheduled sex, so sex becomes divided into “sex for pleasure” and “sex for baby/doctor.” Many couples notice significant changes in their sexual relationships, especially if sex becomes only a means to achieve pregnancy. Either partner may feel “used,” particularly if one is relentless about the timing and mechanics of their most intimate moments. Some men respond to such command performances with resentment, anger and even impotence; some women cannot reach orgasm. To cope with the pressure, the partner who feels intruded upon may not cooperate fully, either physically or emotionally.

LOSS OF CONTROL

Infertility patients in treatment have lost control over much of their lifestyle, as doctors' appointments, temperature charts, medication schedules, medical procedures and programmed sexual relationships overwhelm their normal routine. Comments one businessman, “There are so many ethical and practical decisions to make, but I feel like my life isn't my own. Even my sex life is decided by someone else.” As the patient's priorities shift, other people and regular activities take a back

seat to the all-consuming job of getting pregnant. Career and vacation plans are thrown into chaos. Faced with constant decisions which they often feel powerless or inadequate to make, patients worry, “If I go back to work, will it interfere with my treatment? Should I change doctors, take this new medication or have another surgery? Will I be infertile forever? If I stop, will I always regret it?” As one patient notes, “It's like being lost in a maze and always trying to find the way out.” Even medical professionals do not always agree about the proper course of treatment. Lack of definitive medical answers and uncertainty about treatment decisions accentuate feelings of powerlessness.

Of particular concern to most infertile women and men is the loss of their privacy. Many complain that the clinical aspects of treatment are dehumanizing. One man was furious when he got to the lab to give a sperm sample and was directed to a bathroom with a large sign on the door reading “Sperm Count in Progress.” Another patient who finally got pregnant after years of trying miscarried in her third month. When she went to her doctor to learn the lab results, the nurse appeared in the doorway of the waiting room and called to her across the room full of pregnant women, “Oh, Mrs.____, it was just a bad egg. Go home and try again.”

Certain necessary tests seem especially intrusive. A post-coital check, for example, determines the presence, number, and motility of sperm moving up the vagina. It requires the couple to schedule intercourse so that the woman can be examined approximately one hour later at the doctor's office. One woman describes how unsettling this can be: “My doctor did these checks on Saturday mornings. I hurried to his office and entered the waiting room where five other women turned towards me. I felt undressed. There we were, strangers, knowing we just had had sex with our husbands.”

LOSS OF SECURITY

On many levels, infertility can undermine a sense of security. Occupational security is affected as patients try to fit their work into their treatment schedules. Some people avoid changes at work which would prevent time off for treatment. One woman, who has turned down two transfers with her company to stay with her doctor, worries about the consequences of turning down another. On the other hand, some patients are forced to uproot and move if they want a particular doctor or to a reputable infertility program.

The financial burden can be staggering, and doctors' visits, routine lab work, tests, surgeries and medications are only part of the story. Time away from work, parking, gasoline and other "hidden" costs quickly add up. Some people also spend enormous amounts on travel to centers that specialize in certain procedures such as in vitro fertilization (IVF). Medication for IVF is approximately \$3,000-\$5,000 per cycle on average; the average cost of an IVF cycle (in addition to medications) is \$8,200—the costs can be prohibitive. Some people even choose jobs because of good medical benefits.

Finally, infertility challenges one's views of the world, making them insecure about the present and the future. The "life isn't fair" axiom has real meaning for infertility patients, especially in the face of unwanted teenage pregnancies, abortions and increased child abuse. Infertile women and men can become anxious that "if this can happen, anything can." Accompanying this insecurity is a belief that they may have caused their own infertility. "I tortured myself with thoughts that God was punishing me, that I had failed to take care of my body, or that I had waited too long," says a woman in her late 30's. Such feelings of guilt shake the confidence of many innocent people.

LOSS OF AN IMPORTANT FANTASY

Most people fantasize about and eagerly anticipate all that accompanies parenthood—personally, socially and religiously. There are those who even consider having a child a unique rite of passage into adulthood, tantamount to growing up; being a parent is part of their idealized self. The inability to turn this fantasy into reality is a powerful blow. One man likened the experience to being suited up but sidelined at every game. He adds, "I'm tired of being only an uncle or the nice neighbor next door. I want to be someone's dad, to take my own kids trick-or-treating or to go to a father/son outing." His wife reveals *her* fantasy by joking, "You mean, a father/daughter outing."

LOSS OF SOMEONE OR SOMETHING OF SYMBOLIC VALUE

Infertile couples may feel they have lost a child, whether they have never conceived or they have conceived but could not carry the baby to term. The paradox is that they mourn this child that never was and still yearn for him to be. "Each month when I realize that I am going to have a menstrual period, it is like a death because it means there is no life, no baby to come," says one woman. The sense of loss is punctuated because there is no funeral, no sense of finality. And without a clearly

defined loss for family and friends to see, it is difficult for them to truly empathize; some even dismiss the deep grief as simple self-pity. "Our hearts are broken," responds one couple. "We don't want people to feel sorry for us; we just want them to understand that we are hurting."

A child is also a symbol of new life and the continuation of life. A man who grew up in a large family says, "I miss a relationship with a child, the opportunity for us to grow together and affect each other's lives."

HOW FRIENDS AND FAMILY CAN HELP

Ultimately, many infertile women and men become enraged over these multiple losses. They are upset by other people's insensitivity, hurt by criticism from their families, tired of treatment, frustrated by limited options and resentful of their "fishbowl" existence. They feel the wound of infertility in every part of their being, and there are no simple remedies to ease such deep pain and extensive loss. But support from family and friends can help -- making infertile women and men feel better about themselves, relate better to those who care about them and respond better to treatment. One Houston endocrinologist has even suggested there would be "more successful pregnancies if family and friends knew how to be emotionally supportive." This task will be easier if those who want to help respond in some way to the losses of infertility. A few guidelines to remember:

Admit there is a problem. Pretending the problem does not exist or avoiding it is not helpful. You may first have to deal with your own feelings about infertility, work through disappointment and thwarted expectations of being a grandmother or grandfather, for example, and examine deep-rooted beliefs about conception, child-bearing and medical intervention. Can you really support your child/sister/friend in her choice of treatment and doctor, her decision to adopt or even her decision to remain childfree? Are you prepared for a possible change in your relationship? Acknowledge the infertility by asking how things are going with treatment or how they are feeling. This shows your interest and offers them a chance to confide in you if they choose. If they do not elaborate on their activities, do not question them further at that time. At least they will know someone recognizes the significance of this experience in their lives.

Become informed. Hurtful comments like: "You've got to get hold of yourself and calm down;" "You shouldn't feel that way when you have so much to be grateful for;" "You're becoming obsessed with having a

child;" "Just relax;" "Quit work and you'll get pregnant;" or "Adopt and you'll get pregnant" reveal serious misunderstandings about infertility. Broadly defined, infertility is a medical problem which prevents a couple from carrying a pregnancy to term or conceiving after one year of unprotected sexual intercourse. The problem may be with the woman (40% of the time) or the man (40% of the time). In the remaining 20%, both individuals have problems or the reason for their infertility is unknown. Only 5% of all couples who adopt later get pregnant. Furthermore, adoption is not an option for all couples. Waiting lists are long, babies are few, screening procedures are daunting and parental age limits are restrictive.

Ask your friend/loved one to share any literature or information they have about their own infertility. This is often the icebreaker that leads to discussion. You might suggest they find a RESOLVE support group. There are also psychologists and social workers specializing in infertility who offer individual and group counseling. For people who find certain issues too sensitive to discuss with family and friends, short-term counseling provides an opportunity to express pent-up frustrations. Physicians who deal with infertility will know about local resources and can make recommendations.

Be realistic. Often people believe that to be helpful, they must be able to eliminate another's pain. This is impossible; caring people cannot take away the pain, but can only help them to manage it. Be honest with yourself as well as with your friend/loved one about your discomfort and emotional limitations. Do not expect more of yourself than you can give. Share your concern that you may unintentionally say or do hurtful things, and then ask for understanding, patience, and guidance. Ask yourself whether you are willing to discuss sexually-related matters if your friend/loved one decides to confide in you. If you feel overwhelmed, say so. Don't be afraid of gentle humor -- it can often ease difficult moments. If your overtures are rejected or ignored, try not to be hurt or defensive, but reach out at another time. Anticipate potentially awkward situations or discussions so you can handle them with greater confidence if they arise. The underlying purpose of any discussion is to communicate concern; relay that message if the discussion gets tense or confused.

Listen. Don't be afraid of your friend's/loved one's depression, anger, or guilt. If they will talk about their infertility, allow them to freely and fully express their emotions. They may grieve, going through a process of crying and repeatedly talking about what has happened and

what might happen in the future. By venting negative feelings and releasing tension, they can often move on to a more positive, optimistic perspective. Suppressing emotional pain may just delay the grieving process or protract it. Bear in mind that people experiencing infertility want a sounding board more often than an opinion.

Accept different ways of coping. Each person must discover how to cope best with their problem. People come from divergent economic, religious, and cultural backgrounds all of which influence their responses to infertility. Don't expect them to act or react as you think you might. Some people want to be included in all family and social gatherings which involve children, while others actively avoid such events. Some talk openly about their treatment; others share nothing. Moreover, treatment demands are so varied that needs change.

The woman who is offended today because someone asks about her treatment is the same woman who may be hurt tomorrow because someone does not ask about it. She may talk incessantly about the treatment or condition one time and another time burst into tears at the mention of it. Often a caring friend can only help by doing nothing -- a difficult thing to learn.

Partners often have different coping styles and may be in different stages of grieving. As a result, it is sometimes difficult to help one of them without alienating the other and adding to the tension. As couples learn to deal with the problem, however, they will try various methods of coping, and you will have different opportunities to help.

Ask them how you can be supportive. Do they want you to ask how things are going or do they want you to wait until they initiate discussion? Would they like you to accompany them to the clinic? Would it be helpful for you to bring over the evening meal, particularly after certain procedures or surgeries? If they don't know, encourage them to think about what they expect so that they can let you know. This acknowledges that they are the authority on what they need, when they need it and from whom they would like to receive it.

Make the invitation. Baby showers, christenings, family reunions and holidays are especially difficult times. An invitation lets the infertile woman or man know they are thought of and wanted; it's always nice to be asked. If they choose to decline, accept their choice. If you know them well enough, ask them what kind of social involvement they want. What would make events easier for them? One man who always played Santa at the family Christmas dinner finally told his brother that it was

just “too painful now.” Another person admits, “I didn't realize how I was overcompensating by always offering to take care of my friend's children. It was actually very hard for me.”

If you have children, you may have to work a little harder to maintain a friendship with someone who does not. Take the initiative and invite your friend to lunch or at least call occasionally. Be sensitive to his/her needs of the moment, even if you have to rearrange your own schedule. One woman who can't have children has a friend who always brings her baby to their get-togethers.

“I don't want to be rude, but we just can't talk or be ourselves. I need time with my friend alone,” she says. At least some of the time, the friend should arrange for a babysitter.

Respond to the need for dignity and respect. Let your friend/loved one know that you see them as multi-faceted people and that infertility is only one part of their lives. Remind yourself that infertility does not make them helpless or their lives less meaningful. Respect the desire for a child, even if you do not agree with the method of attaining that goal. By the same token, respect the decision to stop treatment or rule out adoption.

When possible, offer opportunities to help them regain control of their lives by allowing them privacy, being available when they need you and giving them the pleasure and freedom to make what choices they can. Most important, reaffirm their importance to you personally, letting them know that you love and accept them, not as an infertile person but as a person who also happens to be infertile.

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