Working with Your Medical Team:
Tips on Changing from the Difficult Patient to the Perfect Patient

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"I am angry at my clinic. I feel dismissed, and when I have questions I don't ask them because I don't want to be considered a "difficult patient". Do you have any tips for working with my medical team?"

Infertility is an experience that may bring out our most primal emotions (anger being but one) and it is often difficult to differentiate the source—infertility itself or the process. Determining the source of your anger is the first step in finding ways to deal with your feelings in a productive and appropriate manner. It is important to start by examining why you are angry at your clinic. Anger about infertility (and anything and everything that goes with it) is very common and frustration, irritation, and dissatisfaction can surface for any number of reasons--whether valid or invalid. Infertility is a frustrating and unhappy experience, as is infertility treatment when feelings of helplessness, vulnerability, dependency, and uncertainty are exacerbated by the treatment process. As a patient, it is your right to have your questions and concerns about treatment answered by your caregivers. If there is a conflict or problematic situation at your clinic, it is important that you bring it to your caregivers in a calm and open fashion. In addressing a problem, it is often not what you say but how you say it that influences the response you get. Your identification of a problem will be helpful to you and other patients, particularly if your caregiver(s) is unaware of the problem. By contrast, if your anger is due to your feelings of overall frustration with infertility, it may be an indication of your need for additional support, understanding, and comfort which your medical staff cannot provide. Consider getting some counseling with a mental health professional experienced in infertility and ask your caregivers for a referral. Since anger and frustration are sometimes a symptom of depression, counseling is an important step to feeling better.

No one wants to be identified as a 'difficult' patient, so it might be helpful to outline what makes a 'perfect' patient. There are things you can do to increase medical efficiency and minimize emotional suffering from the treatment process. You need to see yourself as an active participant in the treatment process, informed and educated, rather than a passive recipient of medical intervention. Here are some suggestions on how to be the 'perfect patient':

1. <u>The 'perfect patient' communicates honestly, openly, directly, and calmly with the physician and other caregivers</u>. This begins by abandoning the concept of the doctor as a person with special (god-like) powers. Communications should flow naturally and

without reservation or intimidation. People often have difficulty bringing about problems or doing so in a calm manner. It is alright to bring aids—such as a written list of issues you wish to address. If it would be easier to communicate in a letter, do so but schedule an appointment to discuss the issue(s) in person as well. Avoid accusatory, blaming, or critical statements. Instead focus on a clear statement of the problem or complaint, your position, and what you would consider a satisfactory resolution of the problem (e.g., apology, different way of handling problem in future).

2. The 'perfect patient' asks questions about the treatment regime, follows instructions carefully, and is an active participant in the decision-making process. Direct questions about the shortcomings, possibilities of failure, and alternative tests and therapies might include: What are the advantages of this test? Why does this test need to be timed in this manner? Does this test cause any pain, discomfort, or complications? What are the benefits of this treatment over others? If this treatment is not successful, what is the long-range plan? Answers to these kinds of questions, or anything else you do not fully understand, should be very clear before undergoing tests or treatments. Having this understanding and knowledge, will make it easier to follow directions and instructions accurately, a crucial aspect of treatment. It is also very helpful to come prepared to appointment with a list of questions and concerns. Take notes or ask for written literature on any tests or treatments you are considering. Ask about the clinic's policy on calls about lab results, returning phone calls, and after hour emergencies. Your physician can give you information about treatments available to you, but don't expect that he/she can or will make decisions on treatment for you: these are ultimately up to you.

3. The 'perfect patient' tells the doctor when he/she is failing them. Sometimes one of the hardest things for patients to communicate to physicians is their unhappiness and/or dissatisfaction with the way they are being treated. For example, perhaps one of the office staff responded curtly or the doctor sounded demeaning. The hurt from such incidences can go deep and ultimately effect the doctor/patient relationship. However, your doctor cannot be held accountable without first being made aware of your feelings in a non-combative manner, and then being given the opportunity to respond. As in any relationship, both the positive and negative issues that occur between doctor and patient need to be discussed and not avoided. Finally, if you have discussed an issue with your physician and it cannot be resolved, thus undermining trust, it may mean you should seek treatment (or at least a second opinion) from another clinic.

4. The 'perfect patient' seeks education on both the medical and emotional aspects of fertility problems. Traditionally, infertility patients are often the most medically well-versed of all patients. However, many infertile patients overlook or avoid considering the emotional aspects of infertility in hopes that they will get pregnant and not have to deal with it. Avoidant coping is one way of managing emotional distress, although not the healthiest. And the isolation of infertility can be lessened by finding other people with whom to share unhappy feelings. Infertility patients should become as educated and attentive to the emotional side of infertility as they are to the medical aspects. A good way to become educated is RESOLVE, books that include information about how to handle the *feelings* of infertility, educational materials available at your clinic, attending a professionally led support on infertility and seeing an infertility counselor. Increasingly patients are turning to the internet for education about infertility, although this can be risky at times. Besides Resolve's website, www.resolve.org, two excellent sites that provide information on the medical and emotional aspects of infertility are The American

Society of Reproductive Medicine www.asrm.org and the European Society of Human Reproduction and Embryology www.eshre.org.

5. The 'perfect patient' finds ways to reduce the stress caused by infertility. Patients need to understand and accept that infertility *is* stressful—that stress is a normal, expected, and impermanent aspect of infertility. The stress of infertility, its treatment, and the interaction of stress, emotions and optimum body functioning is increasingly referred to as the mind/body connection. Do not mistake this as a form of the old cliché "If you'd just relax, you'd get pregnant." However, there *is* something to the mind/body connection and being attentive to one's stress level, keeping stress at a minimum, and practicing good self care are all good ideas. Additional ways of dealing with the stress of infertility can be found in hobbies, vacations, social interactions, exercise, massage, spirituality, acupuncture, relaxation techniques, and other coping mechanisms that help make the stress imposed by infertility less overwhelming and easier to manage. Stress management improves your overall quality of life.

6. The 'perfect patient' realizes when infertility treatment "burn-out" is being experienced and takes an 'infertility holiday' if necessary. 'Burn-out' may come out in unresolved marital conflict, sexual problems, or ever-present feelings of apprehension, anxiety, anger, or depression. It may surface in one or both partners and is usually an indication that the stress of infertility and its treatment has 'overwhelmed' an individual or the couple. It can also be an indication that a vacation from treatment, stress management, or counseling may be in order. It might be helpful to ask your partner (or friend or caregiver) for feedback on how you are coping, e. g., "Do I seem overwhelmed or overpowered by infertility? Does it seem that I am not myself?" Couples experiencing 'burn-out' might consider finding ways in their sexual relationship to separate 'work' (trying to get pregnant on schedule) from 'play' (love-making), take a vacation together, take an 'infertility holiday' in which they suspend treatment for a period of time, or seek couple's counseling with a therapist experienced in infertility counseling. 'Infertility holidays' are not permanent decisions to end treatment but rather breaks from treatment in which one partner or the couple get a welcome breather from the demands of treatment. This holiday also means no 'trying'—it is a real vacation from infertility on all fronts.

7. The 'perfect patient' approaches infertility as a couple problem. The fact that one's spouse may be identified as having 'the problem' does not negate the effect it has on both husband and wife. The infertility work up, evaluation, and treatment is much better dealt with when both partners participate in at least some office visits, have an understanding of all testing and treatments, and participate in decision-making. The more involved a couple is together in the medical process, the better able they are to support each other and make decisions on options—including those not involving medical treatment. For example, one partner may be resolutely opposed to an alternative to treatment (e. g., adoption or donated gametes) but as an inactive or inattentive participant in treatment, hostility and resentment may arise impeding problem-solving.

8. The 'perfect patient' tries to have realistic expectations of caregivers and of treatment. Caregivers are people too and have bad days, personal stressors, and make mistakes. They are not miracle workers and do not enjoy inflicting pain or delivering bad news (any more than patients enjoy experiencing either). It is important to have realistic expectations of caregivers and treatment—as unrealistic expectations of perfection,

success, or extra special care will surely lead to disappointment and frustration. Finally, patients should keep in mind that there may be other explanations for abruptness, delays, or preoccupation and not personalize these events as purposeful actions to irritate or hurt the patient. Considering a variety of perspectives can reduce the stress of infertility and its treatment.

In summary, feeling angry and frustrated does not feel good and should not be ignored, once the source is identified. Being an infertility patient means you are an integral part of the infertility team, with equal responsibility for facilitating healthy communication and cooperative teamwork. And it means acknowledging problems and solving them as they arise.

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