

When Should Infertility Patients Consider Stopping Treatment?

Fact Sheet 17

A PHYSICIAN'S PERSPECTIVE ON WHEN TO STOP TREATMENT

By Frances W. Ginsburg, MD

In the 20 years I have been a reproductive endocrinologist, breakthroughs in science and medicine have brought tremendous joy to many infertile people. However, as options and possibilities expand, the decision to stop treatment becomes a hard one to make.

The impact of age on treatment is definitely our most important dilemma. The argument often is, "Men can have babies when they are 60, so how can we deprive women?" While we would like to push biology to the limits, patients have to acknowledge that declining fertility comes with age; they should also have a realistic idea of their health status and how that might impact their families.

Not all decisions regarding the continuation of treatment are age-based, however, and physicians play an important role in helping their patients make treatment decisions. To best serve their patients in every aspect of infertility treatment, I believe physicians have the following obligations:

- To outline all of a patient's options, including honest assessment of their chances of getting pregnant and any possible side effects of treatment,
- To maintain their skills and knowledge to be able to offer the newest, most effective treatments,
- To be available so that, no matter what the outcome, patients realize that their doctor gave their our best effort, and
- To help patients make a logical plan for the future.

The most difficult discussion I have with my patients is the "final" discussion about ending treatment. Most couples find some type of closure. Some decide to try every available technology until they are emotionally and often financially exhausted. Others may postpone treatment until the woman exceeds the age for treatment. Sometimes patients need to do an essentially futile procedure or treatment in order to know that they tried everything.

I had a 45-year-old patient who insisted on doing in vitro fertilization (IVF) knowing full well our program had never had a pregnancy in someone that age. When the procedure didn't work she thanked me for trying—and went on to use donor oocytes. As long as the procedure is not dangerous I feel the patients must have some control over their plight, making their own informed decisions about the next step.

The faith that treatments will work if you keep trying is very common. But patients and physicians must make certain we really do understand (and accept) the odds. Despite the enormous strides we have made, not every patient will conceive and deliver. People who defy the odds are the exceptions.

I often tell my patients that my biggest frustration is that I only deal in probability rather than in true prediction. I wish there were a crystal ball that would let me predict the future. If I could tell a couple that they will absolutely never conceive, the conversation would be painful, but it would enable them to move forward with whatever alternatives they consider acceptable. In the meantime I continue to try to distinguish between a "sure thing" and a long shot. I wish there were a better way.

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A THERAPIST'S VIEW

by Linda Hammer Burns, PhD

Making the decision to stop medical treatment for infertility can be a psychological minefield. Although a couple may be more than ready to stop, they may not always be supported in that decision by family, friends, physicians or other infertile couples. Stopping may be interpreted as giving up or failing. In our "can do" culture, we are exposed to heroic examples of "try, try again" everywhere from the Olympics to *People* magazine. Yet knowing how to consider the realities of one's life wisely and courageously and how to choose to redirect one's energies and efforts can be equally heroic.

Deciding when to stop treatment will vary from couple to couple and individual to individual. What is extreme medical treatment for one may be routine for another. What one considers intense emotional distress may be only minor strain to another. Therefore, each couple/individual must carefully assess their resources, not simply their financial resources, but the social support of their family and friends, their well-being and their physical health. When medical treatment begins to endanger the stability of any one of these resources, it is time to consider stopping.

Sometimes patients put off decision making, expecting others to make their decision for them. For example, they may look to their physician to tell them when to stop treatment, not realizing that most physicians will not or cannot do this. Others may pursue adoption, assigning the decision to stop to the agency or the child, thinking that once they are adoptive parents they will stop trying for a biological child. In the end, the decision to stop medical treatment is one the couple/individual must take responsibility for and make themselves.

Often one partner is ready to stop treatment before the other, resulting in considerable tension and conflict. One partner may be in denial, refusing to accept a physician's best judgment or the reality of the unlikelihood of success. Denial may provide temporary psychological reprieve, making way for readjustment and acceptance. However, when medical treatment continues in order to keep psychological defenses intact, not for medical reasons, there is a problem. Sometimes individuals or couples continue medical treatment in order to avoid stopping and facing the grief and loss associated with letting go of their dream for a pregnancy and/or a biological child.

Fundamental to the decision to stop treatment is communication. Each partner must figure out his/her own

readiness or what it will take to get to the point of readiness. Then they must honestly share their thoughts and feelings and actively listen while their partner does the same. Most couples will have to go through this process several times.

Talking about these issues can be painful, and sometimes couples will avoid these conversations simply to avoid encountering tears and sadness. It is always painful to give up something you have hoped for and worked toward for a long time. But couples must not forget that feelings are important in making decisions. Avoiding painful feelings will only leave the couple without the valuable information they need for the tough decisions facing them.

Good decisions are ones in which there is sufficient and accurate information, both partners participate (not coerce or bully the other) and there is a win/win solution. Win/win decisions provide each partner with something he or she wants; although both partners will probably not get everything they want.

Gathering accurate information means considering all alternatives even those that have been contemplated in the past and rejected. In seeking medical information, the couple should search for many opinions not only for those that support their own. They should gather up-to-date information from a number of resources when considering alternatives such as a childfree family or adoption. This is especially important if the couple is reviewing decisions they made in the past, since their information may not be current or their feelings may have changed over time. The couple may come to the same conclusions, but they will have greater confidence in their choices. Finally, if the couple cannot come to an agreement, they should not hesitate to see an infertility counselor.

To help in the decision to stop medical treatment, a couple may try to project themselves 20 to 30 years into the future. Will they look back at infertility treatment with regret or peace of mind? Will they have misgivings about not pursuing medical treatments, not investigating adoption, refusing to consider a childfree family, or continuing treatment too long? If they have regrets, they must re-evaluate their decisions in an attempt to minimize them. Peace of mind does not necessarily mean parenthood or getting what was originally wanted or planned. It means satisfaction that the choices and decisions they made were the best they could make.

The philosopher Paul Tillich wrote that life is accepting the unacceptable. Infertility may always entail the unacceptable: the unfairness of it, failure of medical treat-

ment, impaired health, losses and heartaches. Nevertheless, these unacceptables must be accepted in order to move on. Allowing grief and acknowledging the unacceptable gives the couple the freedom and energy to transcend the pain of infertility so that they can invest in other hopes, dreams and plans. It allows the couple to put infertility in a different place in their life--no longer at center stage.

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DECISIONS TO MAKE AFTER STOPPING INFERTILITY TREATMENT

by Diane N. Clapp, BSN, RN

As a couple or individual decides to end medical treatment for infertility, certain other issues need to be addressed. The first and simplest one is what to do with leftover infertility drugs? If you have expensive medication used during your infertility treatment that has been stored properly and has not passed the expiration date written on the vials, then consider notifying the nurse coordinator at the clinic where you have had treatment. Often, clinics keep a list of patients who have medications which they no longer need.

The second issue to think about is relevant only if you have frozen embryos in storage from previous in vitro fertilization (IVF) cycles. Find out how long the embryos can be stored, and what the storage fees are. If you are certain you will not use the embryos in the future, you may want to consider the option of donating the embryos to another couple or donating the embryos for research. Review the written contract that you signed at the time the embryos were cryopreserved and make sure it reflects your current wishes.

The third issue to consider is what type of medical follow-up to have after stopping infertility treatment. Some studies have shown that women who never conceive and never give birth regardless of whether they took fertility drugs are at higher risk for developing cancers of the reproductive system, specifically ovarian, uterine and breast cancer. For that reason it is important to have a gynecologist do a yearly pelvic exam and PAP smear

exam, and mammograms and pelvic ultrasounds as recommended. If you have very irregular cycles and rarely have a menstrual bleed, your doctor may want to “cause” a bleed by prescribing a drug like Provera™ to induce shedding of the uterine lining.

It usually feels like a relief once you decide to stop medical treatment for infertility, but the challenge of being an informed consumer, advocating for yourself, will continue.

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