THE CONSUMER'S LEGAL GUIDE TO TODAY'S HEALTH CARE

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Your Medical Rights and How to Assert Them

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1

FINDING YOUR WAY THROUGH THE MEDICAL MAZE

If you are like most people, you find the health care system confusing and intimidating. Doctors in crisp white coats, officious administrators, insurance companies with forms written in what appears to be a foreign language, all seem designed to reduce you to a helpless child. To deal successfully with today's complex health system, you must learn how it works and make it work for you. This means knowing your rights.

Until something goes wrong, most of us don't think about our rights; fewer still think about how our health and the law intertwine every day. Consider the following:

- Your employer asks you to choose between an HMO, a PPO, and an indemnity health insurance plan. You have no idea what these are or where you can get a clear explanation.
- You were hospitalized and sent home before you felt well. How can you prevent this from happening in the future?
- Your elderly mother has early signs of Alzheimer's disease. How can you find out what the government covers?
- You are horrified every time you read about comatose patients in a vegetative state being kept alive by machines. How can you prevent this from happening to you?
- You are planning to move out of state. Your doctor refuses to give you a copy of your medical records. Are you legally entitled to them?
- You had cosmetic surgery to get your nose fixed. The result is grotesque. The plastic surgeon says it's not his fault and, be-

sides, nobody's perfect. Do you have a case? How do you find a good malpractice lawyer?

Without resorting to complicated Latin phrases or legalese, *The Consumer's Legal Guide to Today's Health Care* answers these and hundreds of similar questions. We tell you what your rights are, how to assert them, and what to do if you need help. Knowing your rights and standing up for yourself will enable you to protect your health and, in the bargain, get the best care for your dollar. Whether you are frustrated by the medical system, have been injured and don't know whether to sue, or simply want to be aware of your rights, *The Consumer's Legal Guide to Today's Health Care* can put *you* in control.

The book grew out of our personal experience and professional expertise. Here are our stories.

Ava Swartz

I was thirtysomething, in optimum health and pregnant. With an obstetrician I'd known for years, one who had a voice like Valium and manner like Dr. Welby, I planned on Lamaze classes, birthing rooms, and breast-feeding. But eight months later, I lay in a hospital bed, IVs in both arms, listening to the Dr. Welby look-alike tell me that my condition was "catastrophic."

It began somewhere in my sixth month. Without warning, a steak dinner sent me straight to bed with sharp, shooting abdominal pain. Indigestion, I thought, not bothering to call the doctor. But after several more days and sleepless nights of the worst pain I have ever known, I called. "Braxton Hicks contractions, perfectly normal," he replied in his most soothing voice. The pain got worse. By day it made routine tasks almost impossible. At night I lay in bed gasping for relief, afraid to take an aspirin for fear of harming the baby. I went back to the doctor. In honeyed tones he gently talked to me about the fears of first-time, older mothers. Was it all in my head? Willing to try anything, I dragged myself to a psychologist, a lovely lady who lived in a loft on a small, crooked street in Greenwich Village. Once a week I talked through the pain. I talked

about my mother, my sister, my family, and my fear of having a baby. Still the pain continued. I tried yoga, practiced Lamaze.

After the psychologist diagnosed "psychic pain," I marched over to my obstetrician and demanded a blood test. When it showed low platelets and elevated liver enzymes, he sent me to an internist, who suggested mononucleosis or pneumonia and insisted on taking an X ray. I wasn't crazy after all. After my platelets dropped to an alarming level, my doctor insisted I go straight to the hospital, where he called another internist — this one hypothesized lupus. A hematologist took a painful bone marrow biopsy from my hip and grinned. "Well, you don't have leukemia." An ear, nose, and throat specialist left his tennis game to treat me for an infected salivary gland. The one person the good Dr. Welby look-alike should have called but didn't was the most obvious choice: a high-risk-pregnancy specialist.

After becoming progressively weaker, unable to eat, and barely able to stand, I delivered my daughter by emergency Caesarean section under general anesthesia in the middle of the night. My doctor deferred to his partner to perform the surgery. She botched the job, severing muscles and leaving my stomach deformed and with an infected scar.

So much for birthing rooms and breast-feeding. Rushed to the intensive care unit as soon as my daughter was born, I first saw her days later through a haze of drugs. The miracle of this story is that she was born healthy, albeit underweight, and continues to be a delightful little person filled with joy.

As for my condition, it turned out I had HELLP (for hemolysis elevated low platelets) syndrome, an unusual, but not uncommon, pregnancy-related syndrome that has been recognized for about thirty years.

This did not happen at a backwater clinic, but at the renowned Mount Sinai Hospital in New York City. When I got out of the hospital, I spent hours in a medical library poring over journals that described my condition. I consulted with obstetric specialists in high-risk pregnancy. When I described my symptoms, the majority of them said, without missing a beat, "Oh yes, you had the HELLP syndrome." But when I challenged my obstetrician's partner with this and with the botched surgery, she said, "How dare you! I saved your life."

2

YOUR RIGHTS AS A PATIENT: SEVEN PATHS TO PATIENT POWER

CONTENTS

NOT LONG AGO, a doctor's word was law. Patients were taught to follow orders, not to ask questions. If something went wrong, a patient would no more sue a physician than take a beloved relative to court. Today, high-tech specialists have replaced the fabled family doctor who did everything from delivering babies to setting broken legs.

Superficially, the health care system appears to be tilting away from physician omnipotence and toward patient power. Notices of patients' rights hang on hospital walls. Women demand a greater role in gynecological and obstetrical care. Medical textbooks laud the health benefits of active rather than passive patients. Leaders in the health field publicly extol the importance of serving patients. "I would like to see hospitals become true advocates for the interests of hospital patients," said Dick Davidson, president of the American Hospital Association, in *Hospital* magazine.

Still, most people are intimidated by the health care system. Scared and often in pain, patients enter the land of the sick. Stripped of their clothing and identities, they are pricked, prodded, and told what to do. Even the definition of patient as "bearing pain without complaint" reinforces an image of passivity.

But it is when you are sick and vulnerable that you need to be most aware of your rights. In this chapter, we give you seven paths to patient power to put you on a more equal footing with the medical profession. They are:

- Informed consent
- Your right to medical treatment
- Refusal of medical treatment
- Keeping your records confidential and conversations with your doctor private
- Your right to see your own medical records
- Selecting a health professional
- How to complain

Informed Consent

Knowledge Is Power

Before undergoing any surgical or medical procedure, you are legally entitled to an explanation in plain language you understand of what is going to happen to you so that you can give what is called informed consent. Informed consent is such a fundamental principle in American law that a doctor who does not obtain your permission prior to operating or performing other medical procedures could be found guilty either of battery (unauthorized touching) or negligence. Almost seventy-five years ago, Benjamin Cardozo, one of America's most respected judges, wrote, "Every human being of adult years and sound mind has a right to determine what shall be done with his own body." (Obviously you can't give your consent when you are unconscious or bleeding profusely. In these and similar types of emergencies, such consent is implied.)

Crucial Elements of Informed Consent

Before you can give informed consent, your physician must tell you the nature of the treatment, its benefits and risks, alternatives to the treatment, and the probability of success.

The Diagnosis

The physician must tell you what's wrong with you. If you do not understand, ask for a further explanation. It's your body and your right.

The Nature of the Treatment

You have a right to a detailed explanation of the procedure or treatment. Surgery raises particular concerns. Remember that you are authorizing an operation to correct a specific problem, not a general search-and-destroy mission. In one venerable case, Belinda Chambers went to her doctor suffering from abdominal cramps. He said the cause was a cyst on her left ovary. The young Maryland woman authorized an operation to remove her left ovary and left fallopian tube. But while she was under anesthesia, the doctor also removed her right ovary, right tube, and uterus. As she told the

jury during her 1979 lawsuit, "He woke me up, asked how I felt, and then told me he had given me a complete hysterectomy. I thought I was having a nightmare." The jury awarded her $1.2 million.

If the surgeon discovers an unanticipated problem during the course of an operation, it can be corrected, although there must be reasonable limits.

The Benefits and Risks

Most people are nervous before an operation or medical treatment. Knowing the potential risks and anticipated benefits can help calm your fears — or give you reason to walk away.

Learning about the benefits is rarely a problem. Doctors gladly tell you why the treatment is good for you. But risks and side effects are another story. No area of informed consent arouses such passion or incites more lawsuits. There is no simple mathematical formula to govern how much you should know about the risks of an operation or treatment. A lot depends on the seriousness of the risk and the likelihood of its occurring. A 1 percent chance of death or paralysis is serious. A 3 percent chance of a mild stomachache isn't.

Courts have ruled that physicians don't have to tell you about remote risks, although what this means in practical terms varies from state to state. In one influential case, decided in 1972, nineteen-year-old Jerry Canterbury, a clerk-typist for the FBI in Washington, D.C., saw Dr. William Spence, a neurosurgeon, about his agonizing back pain. After performing a series of tests, Dr. Spence recommended surgery for a probable slipped disc. Not wanting to alarm his patient, Dr. Spence failed to warn Canterbury about the 1 percent chance of paralysis and told Canterbury's mother that the risk was no more serious "than with any operation." Then the worst happened: Canterbury became paralyzed. In the resulting lawsuit, the court said that a doctor must tell his patient about all serious side effects — even those with a minimal risk.

As this example tragically illustrates, doctors are not omnipotent fortunetellers. No matter how well you think you know and trust your physician, the rule is to *ask* about any procedure. If your doctor brushes you off or doesn't have time for your questions, go

elsewhere. Even if there is only a 1 percent risk of serious damage, you don't want to be that statistic.

On the other hand, many physicians argue that telling patients about risks that rarely occur might alarm them and scare them away. "Trust me, don't ask me," they say. The decision not to disclose certain risks is known as therapeutic privilege. This use of medical discretion — or medical paternalism — was the norm and still is in some states. Current legal thinking limits its use. A doctor is neither legally nor ethically justified in withholding information because he feels the patient might refuse treatment. Remember: knowledge is power.

Treatment Alternatives

Since one condition can be treated several ways, doctors may disagree about which is best. Cancers can be treated by chemotherapy, radiation, or surgery. Anesthesia can be local, spinal, or general. More than a dozen methods of birth control are available. Every option has advantages and disadvantages, and it is your right to be informed about each of them, including their risks and benefits. Ask about alternatives to recommended treatment, including the alternative of doing nothing.

Eleven-year-old Maria Marino and her parents learned this the hard way. While on vacation in 1980, Maria fell off a snowmobile and broke her arm. As the court records attest, her parents took her to a nearby hospital, where Roberto Ballestas, an orthopedic surgeon, told them he had to operate immediately. When Maria's parents said they wanted to go home to see their family doctor, Dr. Ballestas told them that any delay might cause permanent nerve damage. At no time did he tell them of a medically accepted alternative to surgery — putting the child's arm in a splint and letting time heal the break. Maria was left with a metal plate and two screws in her arm (later removed by her family surgeon), ugly scars, and the trauma of an unnecessary operation. Her parents sued, and the court ruled that the surgeon had failed in his duty to tell them about the alternative treatment.

The Probability of Success

This can be tricky. You should know about your doctor's success rates as well as your overall chances for a successful result. Al-

though it takes some nerve, ask your surgeon how many times he or she has performed an operation and with what success. If the doctor tells you that an operation is "100 percent effective," beware. It ain't so. Even male sterilization (vasectomy), which is almost foolproof, runs a small risk of failure. In one old case, a cosmetic surgeon who promised to make his female patient a "model of harmonious perfection" was held liable for breach of contract when his reconstructive surgery resulted in a repellent mess.

What to Do with What You've Got

Say you know the surgeon's success rate, the risks, benefits, and alternatives. You're not a doctor. How do you evaluate the information or know what is the best choice for you? One way is to get a second medical opinion. Many insurance companies now demand — and pay for — a second opinion before surgery and may help you locate a doctor who can give it. The Department of Health and Human Services runs a toll-free second surgical opinion hotline: (800) 638-6833.

When Informed Consent Is Not Valid

Informed consent is null if it is given under pressure or if the patient is hysterical, drunk, or on drugs. In an emergency, consent is assumed. In most nonemergency situations, there is time to think about the options, to consult family and friends, and to seek a second opinion. Take advantage of it.

Informed consent is void if the patient is not legally capable of understanding the nature of the procedure and its risks and consequences. Adults are presumed to have this capacity. (The unique problems of informed consent for children are discussed in Chapter 10.) Mentally incapacitated people may or may not be able to consent to treatment, depending on the nature and severity of their condition. As a practical matter, but one that has been accepted as law, close family members are often asked to authorize decisions to treat — or increasingly, not to treat — an incapacitated relative. Only rarely is it necessary to get a court order to appoint a relative as a guardian or conservator with the power to make treatment decisions.

Consent Forms: Read Before You Sign

Take time to read the consent form before you sign it. If there is ever a dispute, your signature can be used as proof that you knew what was going to happen. But you can still protest. "The signature on a consent form is not *conclusive* evidence of informed consent, particularly if no real information was given to the patient," says Professor Frank Grad of Columbia Law School.

The consent form should be specific and reflect your discussions with the doctor. If there is anything in the form that you have doubts about or that you don't agree with, cross it out or change it. It's your right. Just be sure to initial any changes you make.

Many hospitals insist that you sign a general consent form when you enter, which is supposed to protect them against future legal action and give them the right to treat you as they believe necessary. In reality, these forms are vague and, unlike the detailed forms for specific procedures, have limited legal clout. Even if you signed and something goes wrong, you can still go to court. Judges have found that patients did not have any choice and are, in effect, coerced into signing.

Although general consent and admissions forms may indicate your willingness to have your temperature and blood pressure taken, they are not binding when questions arise about your consent to specific procedures, such as exploratory surgery. Consent does not always have to be written. It can be oral or implied by behavior. For example, a man who went to an immunization clinic, rolled up his sleeve, and said, "Go ahead," could not argue later that he did not know what was happening, even though nothing was in writing. In practice, for procedures other than minor ones in which the risks are obvious or well known (for example, taking a blood sample), doctors and hospitals require a written consent form. If you are in a hospital and have questions about the consent form, ask to see the patient representative, an employee whose job is to deal with patients' questions. Most hospitals now have one on staff. Or simply ask for more time to consider it.

Avoid Cost Shock

One question that is not normally considered part of informed consent but should be is "How much will it cost?" It is not unusual

for a person to go into a state of shock when the bills come. And they do come — from the hospital, doctors, anesthesiologists, pharmacy, and others you never even heard of. Only rarely does insurance cover all treatment. To avoid cost shock, find out beforehand approximately how much the total bill will come to.

If there is a disagreement about your medical or hospital bill, first ask for an explanation. "When a hospital is involved, make sure to get an itemized bill and go over it with the administrator or patient representative. Under the American Hospital Association's [AHA] Patients' Bill of Rights, this is your right," advises Ila Rothschild, an attorney with the AHA. If the disagreement cannot be settled amicably, report the matter to your county medical board. You can find the number in the white pages of your telephone directory. If it's not listed, call the American Medical Association, (202) 789-7400. If the local medical board cannot solve the problem, your next step is to seek the advice of an attorney. (See Chapter 14 for guidance on finding a lawyer.)

Before agreeing to surgery or treatment other than simple and relatively harmless procedures, discuss the following questions with your doctor:

CHECKLIST: BEFORE AGREEING TO SURGERY OR MEDICAL TREATMENT

- What is wrong with me? What is my illness or condition?
- What will happen during my surgery or treatment? What is the name and nature of the treatment?
- What is likely to happen if I decide not to be treated?
- What are the benefits of the treatment?
- What are the risks and side effects? What is the probability of their occurring?
- What is the name of the doctor who will treat me or perform the surgery? How many times has he or she done it? What is his or her success rate?
- What is the probability that the treatment will succeed?
- What alternative treatments are available? What are the risks and benefits of each of them?
- How much will it cost?

- Finally, ask yourself, Have I had enough time to decide in an unpressured environment?

Consent for Medical Research and Experiments

"The history of medical progress is to a large extent the history of medical experimentation," writes George Annas, professor of health law at Boston University. Without research on people, there would be no polio vaccine, kidney dialysis, or birth control pill. Yet mention human experimentation and some see repeats of Dr. Josef Mengele's experiments at Auschwitz or the Tuskegee, Alabama, study. In that infamous project, begun in 1932, four hundred black sharecroppers with syphilis were followed for forty years, but were never treated or told they had the disease.

As a result of public outrage, the federal government passed regulations governing the rights of human experimentation subjects. The states mandated additional protections. The most important safeguard was the creation of institutional review boards whose job it is to review medical research proposals, judge the risks and benefits, examine the methodology, and make sure that the rights of participants are protected.

If you are asked to be a subject of medical research, follow the rules of informed consent described above. In addition, be sure that

- the research has been approved by an institutional review board.
- you understand the purpose of the experiment.
- your name will be kept confidential unless you authorize its use.
- you know where to turn for assistance in case of side effects or unanticipated problems.
- it is clear who pays the cost of treating side effects (it is often free).

By law, you cannot be penalized for refusing to take part in medical research. Don't be afraid to say no if you do not want to participate.

Your Right to Treatment

In an Emergency Room

Under federal law and the law of nearly every state, if you show up at an emergency room, the hospital staff must examine you. If it's an emergency, or if you're a woman in active labor, the hospital must treat you and keep you there until your condition has stabilized, to quote federal law. Although the definition of "stabilized" is not wholly clear, at the very least, emergency room personnel cannot legally turn you away because your Blue Cross card is at home or you don't have health insurance. An emergency room physician or hospital that refuses to treat a person in need of immediate care risks fines from the government, loss of accreditation, and lawsuits.

The first major lawsuit brought under this law designed to prevent patient "dumping" involved Dr. Michael Burditt, a Texas obstetrician/gynecologist. According to court documents, Dr. Burditt, head of obstetrics and gynecology at the DeTar Hospital in Victoria, Texas, refused to admit Rosa Rivera, an indigent woman in labor with her sixth child, who had come to the hospital's emergency room. When Ms. Rivera arrived, her blood pressure was dangerously high. Dr. Burditt ordered her transferred by ambulance to a hospital 170 miles away, saying, "Until DeTar Hospital pays my malpractice insurance, I will pick and choose those patients that I want to treat." En route, Ms. Rivera gave birth to a healthy baby.

The U.S. Department of Health and Human Services (HHS) charged Dr. Burditt with violating the patient-dumping law. In his defense, Dr. Burditt argued that Ms. Rivera's blood pressure was so high that she could not be treated properly at DeTar Hospital. HHS fined him $20,000, and Dr. Burditt went to court to appeal the fine. In 1991, five years after the incident had taken place, a federal court of appeals upheld the fine.

If you have a medical emergency and someone tries to deny you entry because you can't prove you're insured, insist on seeing a doctor or the hospital's patient representative if there is one. But once safely inside, don't think that a doctor will see you immediately. Emergency rooms are chaotic, jammed with people who

4

ON THE JOB

CONTENTS

APRIL 18, 1986, is a day neither Robin Meyerson nor her husband, Dennis, will ever forget. A New Jersey schoolteacher with a master's degree in reading, Mrs. Meyerson was traveling that morning between the two schools where she taught when a triaxle dump truck slammed into her car from behind. She ended up in a hospital with multiple injuries to her neck, head, and back. She had five operations and for four and a half months wore a "halo," a device mounted on her shoulders and bolted to her head. She was thirty-five years old.

Yet Mrs. Meyerson's injuries were only the beginning of her misery. When she applied to the school district's insurance carrier to collect workers' compensation, her odyssey of suffering began. "They paid the medical expenses for the first year and then told us to go to their doctor for more tests," says Mr. Meyerson, an accountant. "Then they said they wanted to find out how bad her injuries were." But when the results came back, the insurance company refused to pay any more. "They said, 'Sue us,'" says her husband.

Despite this, Mrs. Meyerson continued to see her own neurologist for treatment. But because the insurance company cut off her benefits, the hospital refused to treat her further. "She went from having an injury to having a major injury," says her husband. "Damage to her spine became irreparable."

In New Jersey, workers' compensation hearings are held only once every three weeks. As a result, cases drag on. And on. Mr. Meyerson estimates that his wife had more than twenty-two hearings. Finally, after five years, she won her case. But she has yet to see a penny. The insurance company immediately appealed. Mr. Meyerson expects that his wife's case will be decided by the state supreme court.

Mr. Meyerson estimates that his wife's medical expenses have come to more than $350,000. "She is totally incapacitated," he says. "And this was a schoolteacher who spent her life teaching the gifted and talented."

As the Meyersons' story indicates, it is not easy to be compensated if you are injured on the job. Every state has enacted a workers' compensation law, but benefits are low and claiming

them can be a tremendous hassle. In some cases, a union will go to bat for you, but this is true only part of the time; to many unions, job security is more important than job safety. The four out of five Americans who are not union members are left pretty much to their own devices and are relatively vulnerable.

Nor is it easy to have a dangerous workplace fixed. Although Congress created the Occupational Safety and Health Administration in 1970 to get companies to clean up their act, the agency's performance has been disappointing. People have been fired for complaining about working conditions. "When you agree to take a job, you give up many of your basic civil rights," says Jim Moran, executive director of the Philadelphia Project on Occupational Safety and Health.

Despite this generally discouraging panorama, you can take some measures to protect yourself and there are places you can turn to for help. In this chapter we tell you what to do:

- if you are working in an unsafe or unhealthy workplace.
- if you are injured on the job and plan to claim workers' compensation.
- if you want to protect yourself beforehand by buying disability insurance or if you become disabled.
- if your company introduces a drug-testing program, ostensibly to improve workplace safety.

Protecting Yourself

Unsafe and Unhealthy Worksites

Every year, millions of workers are hurt on the job. A survey by the U.S. Bureau of Labor Statistics revealed that 6.8 million employees suffered job-related disabilities or injuries in 1990, the highest since 1972, when the bureau began collecting statistics. "As a form of violence, job casualties are statistically at least three times more serious than street crimes," writes Ralph Nader.

The Occupational Safety and Health Administration (OSHA) distinguishes "unsafe" from "unhealthy" working conditions. "Unsafe"

as clearly in their best interest and if procedural safeguards to tect against abuse were followed.

Abortion

e Legality of Abortion

rma McCorvey was an unmarried, pregnant twenty-year-old an whose search for an abortion changed the law of the land. der Texas law, abortion was allowed only to protect the life of a gnant woman. Using a pseudonym to protect her anonymity, . McCorvey sued to have the Texas law declared unconstiional in a case that worked its way up to the Supreme Court. January 1973, well after Ms. McCorvey's baby was born, the preme Court announced its opinion in *Roe v. Wade.*

n its decision, the Court ruled that abortion is protected under constitutional right of privacy. During the first trimester — to ut the thirteenth week of pregnancy — a woman has the right terminate her pregnancy without any obstacles imposed by te or local government. After the first trimester, a state or local ernment can restrict abortion as long as the laws are aimed at tecting the pregnant woman's health — for example, by requirthat clinics have a hospital backup. Once a fetus is viable, that ible to live outside the womb, state and local governments can s laws designed to protect the fetus. They can ban abortions, ept those necessary to save the life or protect the health of a gnant woman.

Roe v. Wade is probably the most controversial decision in Sume Court history. It gave women a new constitutional right, rturned the law of every state, and spawned a right-to-life vement devoted to making abortion illegal again. Abortion has ome a critical political issue — sometimes *the* critical issue — everything from federal court appointments to local mayor's es.

The Supreme Court itself has gradually chipped away at *Roe v. de,* upholding the constitutionality of laws that restrict abor-n. In 1980, it decided that a law cutting off federal funding of rtions, even medically necessary ones, for poor women was

constitutional. In 1989, it upheld a Missouri law that, among its other restrictions, prohibited public hospitals from providing abortions. In 1991, it ruled that a federal regulation preventing doctors who practice family planning in federally funded settings from discussing abortion with their patients was constitutional.

Many people believe the Supreme Court will overturn *Roe v. Wade*. Whether it does or simply continues to erode the 1973 landmark decision, the practical implications for women wanting to terminate a pregnancy remain the same. Many conservative state legislatures will pass restrictive laws, secure in the knowledge that federal courts are not likely to strike them down. But these laws may violate *state* constitutions. As a result, supporters of the right to choose will look increasingly to state rather than federal courts for protection.

Among the issues likely to arise in the future are: Must a husband be told about his wife's decision to have an abortion? Can he exercise veto power? Can states make a woman wait, say, twenty-four hours, before getting an abortion? Can states limit abortions to those performed during the first or early second trimester? Can governments require doctors, as part of the consent process, to give women graphic descriptions of abortion designed to scare them away? These issues will be decided on a case-by-case basis by state and federal courts and perhaps the Supreme Court.

Where to Turn for Help

To find out about the law in your state or to get assistance, contact one of the following organizations:

- National Abortion Federation, (800) 772-9100
- Planned Parenthood offices. If you run into difficulty finding one, contact the national headquarters, 810 Seventh Avenue, New York, NY 10019, (212) 541-7800.
- National Abortion Rights Action League, 1101 14th Street, NW, Washington, DC 20005, (202) 408-4600
- National Women's Law Center, 1616 P Street, NW, Washington, DC 20036, (202) 328-5160
- American Civil Liberties Union. If you cannot locate a nearby chapter, contact the ACLU's headquarters, 132 West 43rd Street, New York, NY 10036, (212) 944-9800.

Adolescents

When New York City school chancellor Joseph Fernandez proposed that schools distribute condoms to students without parental consent, angry opponents charged that he was destroying the sanctity of the family, fostering immorality, and trying to usurp the role of parents. Fernandez's supporters responded that dramatic solutions were needed to attack the devastation of AIDS, that distributing condoms promoted safe sex, and that students had a right to obtain contraceptives without their parents' knowledge.

Although a closely divided board of education gave Fernandez the green light, the antagonism that characterized the board's deliberations illustrates the depth of feeling that adolescent sexuality arouses. While everybody agrees that teenage pregnancy is a national tragedy, there is bitter disagreement about how to prevent it or what to do when it occurs.

The legal issue can be stated very simply: Do one or both parents of an adolescent have the right to consent to, or even know about, their child's decision to use contraception or have an abortion? The answer is not so simple. Although the policy of all family planning organizations and clinics is to involve parents whenever possible, teenagers often want to keep them in the dark. People on both sides of the issue are haunted by the death of Becky Bell, the Indiana teenager who couldn't bring herself to tell her parents she was pregnant and died during a botched abortion in 1988. The law, reflecting society's lack of consensus, varies from state to state and is subject to rapid change as the composition of courts, particularly the Supreme Court, shifts.

The key to understanding the law is to recognize that courts and legislatures must strike a balance between the rights of adolescents and the rights of their parents. As we point out in Chapter 10, children have constitutional rights, including a right of privacy, that grow stronger with age until they reach adulthood at eighteen or twenty-one. Parents have a constitutional right to bring up their children without government interference. When the rights of the two conflict, courts and legislatures must decide whose should prevail.

The Supreme Court has established emancipation and maturity as the points at which the balance tends to shift in favor of adoles-

cents. As a general rule, when teenagers are emancipated — living away from home, married, or serving in the military — they can consent to their own reproductive health care. This is also true if they are mature enough to understand the risks and benefits of contraception or to grasp the implications of abortion and its alternatives.

Contraception

Under current constitutional law, mature and emancipated minors can probably obtain over-the-counter contraceptives without their parents' consent or knowledge. Although it did not face the issue directly, the Supreme Court indicated in 1977 that a state law requiring parental consent or notification for nonprescription methods would be unconstitutional.

Whether the same logic would apply to contraceptives that must be prescribed is unclear. Whether a state or local government could constitutionally require doctors to obtain the consent of, or to notify, parents about a daughter's use of prescription contraceptives has not been tested in the courts. The only relevant case, also decided in 1977, involved Michigan parents who sued a birth control clinic for allegedly dispensing the Pill to their teenage daughter without their knowledge or permission. A federal appeals court, finding that the daughter's rights outweighed those of the parents, ruled that the clinic could keep information about the girl confidential.

Twenty-four states and the District of Columbia have laws allowing teenagers, usually emancipated or mature ones, to obtain contraceptives without their parents' consent, according to a survey conducted by the Alan Guttmacher Institute, a public policy group specializing in reproductive health issues. Some of the laws prohibit notification of parents. Others allow parents to be informed, either before or after the fact.

Abortion

The Supreme Court has returned to the issue of parental consent and notification for abortion in half a dozen cases beginning in 1976, one indication of the difficulty of writing clear guidelines. Although the rules are still somewhat murky and may change with the next decision of the Court, the current law can be sum-

arized as follows. Parental *consent* requirements are unconsti-
tional. Parental *notification* requirements are constitutional as
ng as they do not unduly burden access to abortion. While a state
vernment has no obligation to require parental notification, if it
cides to do so, it must also give a pregnant teenager an opportu-
ty to go to court and ask a judge to authorize an abortion without
r parents being told. A judge *must* grant the young woman's
quest for an abortion if she is emancipated or mature. Even if she
ils to convince a judge of her maturity, the abortion must be
thorized if the judge believes it would be in her best interest to
ve one.

State laws on parental consent and notification are a hodge-
dge. In some states, a pregnant teenager can get an abortion on
r own, without any parental involvement whatsoever. In others,
ne or both parents must be notified and the pregnant teenager is
ven the alternative of having the abortion confidentially author-
ed by a judge. In still others, old laws requiring parental consent
notification remain on the books, usually unenforced. To learn
ie law in your state and obtain assistance if necessary, contact
ne of the organizations listed in the "Where to Turn for Help"
ction of this chapter.

8

INFERTILITY AND NEW REPRODUCTIVE TECHNOLOGIES

CONTENTS

Infertility

Eight years ago, my husband and I decided that we wanted to have a baby and assumed that when we stopped using birth control we would get pregnant. However, after two years it hadn't happened. My doctor suggested that I take my temperature every day and keep a chart of my cycle. I did it for the next five years, and sex for us became timed around that cycle chart. Not very romantic.

I spent the next two and a half years going to doctors who were gynecologists and claimed that they also did infertility. By the fifth year we were doing vaginal inseminations, which meant that I was racing to the doctor with my husband's sperm in a jar. That was pretty much what sex had become for us.

We began to wonder if the dream we shared — to have a baby — was going to kill our marriage. We did not know why we were not getting pregnant. No one could give us any answers or solutions, except to "relax and not think about it." By the sixth year I would cry every time I saw a mother and baby and felt angry and jealous when I saw a pregnant woman.

My sense of failure was so strong that I began to feel I must be guilty of something terrible, that I was being punished, but I did not know for what. That I could not do the very thing my body was designed to do — conceive and carry a child — must mean that I was not fully a woman, I felt. All my other accomplishments in life seemed to fade into the background in the face of this failure.

When I found this infertility specialist, I felt such relief. Four months later a miracle occurred — I became pregnant. My husband and I were ecstatic. At twelve weeks, during a routine sonogram, the radiologist informed us that the baby had died.

My infertility specialist sent me to an in vitro fertilization program in Los Angeles. We did the GIFT procedure, and to my surprise, I got pregnant again. But I was one of the unlucky one or two percent who had an ectopic pregnancy.

> After this second loss, we decided to adopt, and now we have a beautiful baby boy. However, we have decided we want another child, and we are planning to give GIFT or in vitro another try. The seed of hope never dies.
>
> — *Actress Jo Beth Williams, excerpts from testimony, Subcommittee on Regulation, Business Opportunities, and Energy, U.S. House of Representatives, 1989*

Infertility affects one out of every twelve couples in the United States. This translates to 10 million people who are unable to have a baby after a year of trying — the medical definition of infertility. A couple may not be able to conceive or, perhaps, it may not be possible to bring the pregnancy to term.

There are many causes of infertility. Some are men's problems, such as an inability to produce enough sperm or sperm strong enough to penetrate the egg. Others are women's problems, such as endometriosis or blocked fallopian tubes. Often the difficulty can be traced to the biology of both partners. Many couples who delay childbearing until they are in their mid-thirties or early forties find that the woman can get pregnant only with great difficulty, if at all. The biological clock is a reality, and it starts to tick rapidly when a woman reaches her thirties.

Finding an Infertility Specialist

Couples desperate for a child are often willing to try anything — and often do, only to end up with shattered hopes and depleted savings. To spare yourself emotional, financial, and perhaps physical trauma, get as much information as you can *beforehand*. Investigate the cause of your infertility and what can be done. Find out about alternative treatments and their risks, likelihood of success, and cost. Many books available at libraries and bookstores can tell you about infertility in nontechnical language. Two organizations provide excellent information:

- RESOLVE, a national network of more than twenty thousand members and fifty-two chapters, can do everything from giving you the names of reliable infertility specialists in your area to putting you in touch with other couples. Contact the head-

quarters at 1310 Broadway, Somerville, MA 02144-1731, (617) 623-0744.

- The American Fertility Society is a professional organization for doctors and others interested in infertility. It publishes pamphlets on all aspects of infertility and can refer you to clinics and doctors who adhere to its standards. It is located at 2140 Eleventh Avenue, Birmingham, AL 35205, (205) 933-8494.

Since any doctor can hang out a shingle saying "Infertility Specialist," look for one who is board certified or board eligible in reproductive endocrinology and whose practice is devoted largely to couples with infertility problems.

Diagnosis and Treatment

The standard workup and treatment for infertility can be time-consuming, expensive, and embarrassing. Your bedroom may become a laboratory. Listen to Deborah Gerrity, president of RESOLVE's Washington, D.C., chapter.

> I have taken my basal body temperature approximately 1,260 times for about forty-five inconsecutive months. Imagine not being able to move a muscle in the morning until you reach for a thermometer. It is hard to relax and stop thinking about your infertility when it has to be the very first thought that enters your waking mind. And that is the easy part.
>
> During the diagnostic phase, I had three endometrial biopsies, which consist of taking tissue from the inside of the uterine wall to determine hormone levels, and two postcoital tests — removal of the cervical mucus to analyze sperm activity. I have also had two diagnostic laparoscopies — the navel surgery, done with general anesthesia, to look at the ovaries, tubes, and uterus. The second of these surgeries included a hysteroscopy — examination of the inside of the uterus — and a D and C. Both times I had minor complications and was forced to take a week off of work, although the average time for most women is three to four days. All of that comprised the diagnostic workup. My diagnosis was unexplained infertility. Medical treat-

ment for unexplained infertility involves trying a variety of things to see if anything will work. We did six months of artificial insemination by husband, a year of hormonal treatment, and an attempt at in vitro fertilization.

During the surgery, they found that I had moderate endometriosis — growth of the uterine lining outside of the uterus — which had not previously been detectable. Major surgery to remove the endometriosis required a month off work to recuperate.

During this time, my husband was tested a couple of times and the results came back as normal. With the updating of technology, he recently had a different type of test and was found to have a high percentage of antisperm antibodies in his semen. As this is a highly controversial diagnosis and not a well-documented cause of infertility, there are very few treatments available for us at this time.

To summarize this to a bare sentence, I have accumulated a total of ninety-two failures — ninety-two months of trying with no children to show for it. During those months I had three miscarriages, the longest pregnancy lasting six weeks. The grief and depression that I felt after those losses changed me as a person. Considering the present state of medical technology and research in infertility, I will probably never have a biological offspring. I won't be able to produce a child who will have my husband's smile and his wonderful eyes. And that thought is devastating to me and my family.

— *Excerpts from testimony, Subcommittee on Regulation, Business Opportunities, and Energy, U.S. House of Representatives, 1989*

Standard medical treatment, such as drugs to induce ovulation or surgery to clear obstructions of the fallopian tubes, succeeds in about two thirds of cases, meaning that two out of three couples have a pregnancy within eighteen months. When you ask your doctor about the risks of drug treatment, be sure to discuss the likelihood of having twins or triplets or an ectopic pregnancy, and of bearing a child with birth defects.

If drugs or surgery do not work, in vitro fertilization, artificial insemination, and surrogate motherhood are available to help Mother Nature along. With these reproductive technologies,

babies can be created in glass dishes and women can give birth to children who have no genetic relation to them. They make it possible for a child to have up to five people claiming to be parents — a sperm donor, an ovum (egg) donor, a woman providing a womb for gestation, and a couple rearing the child — and raise legal and ethical problems that would perplex King Solomon if he were alive today.

In Vitro Fertilization (IVF)

When Louise Brown was born in England in 1978, she became known as the world's first test-tube baby, although no test tube was involved. It was the first time that fertilization took place outside a woman's body. Since 1978, more than five thousand IVF children have been born in the United States. The procedure is legal, has become standard medical practice, and is offered at nearly two hundred clinics throughout the country. Here's how it works: A woman is given a drug to stimulate the development of several eggs simultaneously, instead of the one that normally develops each month. When the eggs are mature, they are removed by a thin needle guided by ultrasound or the surgical procedure laparoscopy. The five to seven eggs that are retrieved are placed in a glass dish (hence the name in vitro, which means "in glass") and allowed to mature further for several hours. Then they are mixed with a man's sperm. About two days later, if fertilization has occurred, some — usually two or three — of the embryos, as they are now known, are transferred to the woman's uterus. The rest are frozen and stored for later use if necessary.

Offshoots of the in vitro method of uniting sperm and egg include GIFT and ZIFT. In GIFT (gamete *intra-fallopian transfer*), the eggs and sperm are mixed and immediately placed in a woman's fallopian tubes, where fertilization is supposed to take place naturally. ZIFT (zygote *intra-fallopian transfer*), an even newer procedure, is like GIFT except that the eggs are fertilized in a laboratory dish and then inserted into the woman's fallopian tubes. The technology is mind boggling. Ask your doctor about the latest developments.

The Right IVF Clinic: Getting Past the Hype

In vitro fertilization has become big business. Some IVF clinics hype their product and exaggerate their success rates, practices that some lawmakers feel border on the fraudulent. "Many infertile couples are desperate to have children. They are vulnerable to exploitation and to those who would unfairly try to rip them off," stated Congressman Ron Wyden in 1989 as he opened congressional subcommittee hearings on IVF clinics. Although federal legislation to set standards for IVF clinics has been introduced, they remain unregulated. Only two states, Louisiana and Pennsylvania, regulate these clinics, and their main purpose seems to be giving legal rights to the embryo.

With so little consumer protection offered by state and federal government, you must be your own watchdog. Before you sign on with any clinic, get as much information as you can about the facility, its personnel, and its success rates. Here is what you can do:

CHECKLIST: FINDING AN IVF CLINIC

- **Contact RESOLVE or the American Fertility Society for the names of IVF clinics.** RESOLVE recommends clinics and doctors. The American Fertility Society sends a list of clinics that meet its standards. Their addresses and phone numbers appear earlier in this chapter. Both organizations have useful booklets for couples considering in vitro fertilization.
- **Ask about the success rates of the clinics you are considering. Clinics give their rates in a number of different ways,** some quite misleading. "The key question, the bottom line, is 'Over the past two years, how many women about the same age and with a similar problem have been treated at the clinic and how many have gone home with babies?'" says Joyce Zeitz, spokesperson for the American Fertility Society.
- **Ask about the risks of treatment, particularly the likelihood of multiple embryos, ectopic pregnancy, and bearing a child with birth defects.**

- **Find out how long the IVF team has worked together.** "The longer a team has been working together, the better the chances of success," says law professor Alta Charo, an IVF expert at the University of Wisconsin. "All things being equal, choose the place with the most experience."
- **Get a feeling for how comfortable you are with the team.** You will spend a lot of time with them and share some very private moments. It's important to have a good fit. Make sure you can reach a team member day or night.
- **Ask how much it will cost.** In vitro fertilization can be expensive. The cost runs between $6,000 and $10,000 per *attempt*. Find out whether IVF is covered by insurance. Although some insurance companies and health maintenance organizations cover it, most do not. Currently, ten states — Arkansas, California, Connecticut, Hawaii, Illinois, Maryland, Massachusetts, New York, Rhode Island, and Texas — have laws requiring insurance companies to include IVF in the plans they offer employers. In some states, employers must provide coverage of IVF treatment as a health benefit to their employees. In others, employers are free to decline to offer that coverage. Even if the procedure is not included, the clinic may be able to write the bill so that legitimate items, such as laparoscopy, will be paid by insurance. Your insurance company or the state insurance commission should have information about coverage of IVF.

Unimplanted Embryos

Recall that five to seven eggs are normally retrieved from a woman during IVF. Normally, all are mixed with sperm in the hope of their being fertilized, but only two or three are inserted in a woman's uterus or fallopian tubes. The remainder are usually frozen. If another IVF cycle is necessary, they can be thawed and inserted. Profound ethical problems arise when the unimplanted embryos are no longer needed. Can they ethically be destroyed? Can they be used for research? Should they be stored indefinitely? The arguments are similar to those heard in the abortion debate.

Some, including the Catholic church, believe that life begins at the moment of conception and equate the destruction of these

embryos with murder. Others contend that life does not begin at conception and that it makes little sense to consider a three- or four-cell embryo as a human being; they argue that excess embryos can ethically be used for research purposes or destroyed. At the moment, the federal government prohibits research on such embryos, and any decision on keeping or destroying them must be consistent with the law on abortion.

The moral questions raised sometimes shade into legal issues. Give some thought to them beforehand. You don't want to be in the position of Junior and Mary Sue Davis, a Tennessee couple whose divorce and reproductive history became news in 1989 when they wrangled publicly over possession of their frozen embryos. Newspaper accounts told of their unsuccessful attempts to have children. Married in 1980, Ms. Davis had five ectopic pregnancies, one of her fallopian tubes ruptured, and she nearly died. She had the other tube tied. In vitro fertilization offered some hope, and between 1982 and 1988, the Davises spent almost $50,000 on five unsuccessful attempts. On the seventh attempt in early 1988, nine eggs were removed and fertilized; two were implanted and the remaining seven were frozen and stored at the Fertility Center of Eastern Tennessee in Knoxville.

In February 1989, the Davises began divorce proceedings. They agreed on everything but the fate of the fertilized eggs. Ms. Davis wanted to have them inserted in her uterus after the divorce. She argued that the embryos were her only chance at having a baby and that because she had gone through the surgery and the programs, she had a better right to them. Mr. Davis responded that because he no longer wanted her to be the mother of his children, he had the right to decide whether he wanted to become a father and asked the court to allow the embryos to be destroyed. A Tennessee judge awarded Ms. Davis custody of the seven embryos. On appeal, the decision was reversed. The Tennessee Court of Appeals ruled that the embryos were joint property and that both parties must agree about what becomes of them. They remain in cold storage.

Before you decide on this procedure, consider the legal implications should you divorce or die. Like many couples who blithely sign prenuptial agreements thinking divorce will never happen to *them*, those who embark on the financial drain and emotional

roller coaster of in vitro fertilization rarely think about the dread *D* words. Think about them. Try to agree in advance on the disposition of the embryos. The contract with an IVF clinic should include a clause setting forth the couple's decision on how long to keep the embryos frozen and what disposition to make of the eggs should the couple separate, divorce, or if one or both of them dies.

Artificial Insemination

From California's Repository for Germinal Choice, which actively seeks semen from Nobel Prize winners and other geniuses, to more than one hundred sperm banks across the country that recruit less celestial donors, artificial insemination is a thriving business in America. More than 11,000 doctors offer it as a treatment for infertility. Each year, at least 172,000 women use artificial insemination, which results in about 65,000 births, according to a survey by the U.S. Congress Office of Technology Assessment.

When the California "genius" clinic opened in 1979, there was great concern that a brave new world was approaching. Years later, these fears have not been realized. A more realistic worry is sperm that is damaged, lost, or mixed up.

Julia Skolnick went to a Manhattan sperm bank to be inseminated by the sperm deposited by her husband, who was dying of cancer. Both she and her husband were white, so when Ms. Skolnick gave birth to a black daughter, she sued the sperm bank. In 1991, the case was settled out of court for $400,000.

Since sperm banks are regulated only loosely and mix-ups can occur despite precautionary measures, there is no way to be 100 percent sure that the same thing won't happen to you. One safeguard is to use a sperm bank affiliated with the American Association of Tissue Banks or one that follows the guidelines of the American Fertility Society. Contact the American Association of Tissue Banks, 1350 Beverly Road, McLean, VA 22101, (703) 827-9582 and the American Fertility Society at the address provided earlier in this chapter.

If you decide on this procedure, you probably already know that there are three types of artificial insemination. The first, artificial

insemination by husband (AIH), which uses semen from a husband, is the most popular, accounting for about half the procedures done today. It was the procedure Ms. Skolnick used.

In artificial insemination-combined (AIC), a rarely used procedure, the husband's semen is mixed with that of a donor, thus offering the possibility of the husband's being the biological father.

The third is artificial insemination by donor (AID), or as it is increasingly called, therapeutic donor insemination (TDI), which uses the semen of a third person, usually an anonymous donor. Some early court decisions held that AID was adultery and that the resulting children were illegitimate. Today, AID is lawful in every state, although legal questions arise concerning the legitimacy of children, parental responsibilities, informed consent, and confidentiality of records.

Legitimacy of Children Born of Artificial Insemination

Artificial insemination is so simple that it can be done by a woman with a turkey baster. Despite its simplicity and accessibility, the law defines artificial insemination as a medical matter. The laws of thirty-five states specify that if insemination is done by a doctor with a husband's consent, the children are the legitimate offspring of the couple. Although the children of married parents would probably be declared legitimate in any case, it's best to have a physician perform the insemination, just to be sure and to avoid future legal headaches.

Bringing Up Baby

A husband who consents to his wife's insemination with another man's sperm is considered the legal father of the child, with all the rights and responsibilities of fatherhood. He is no different from a biological father. In case of divorce, he has the obligation to support his child and visitation rights if he does not have custody. Courts go to great lengths to assure that children are part of a family and that parents carry out their responsibilities in bringing up and supporting the child. This holds true even for nontraditional families that stretch the definition of "parent" to its limits.

Consider the truly bizarre case of Karin versus Michael/Marlene. When she was in her twenties, Marlene tried to shed her female identity and live like a man. Changing her name to Mi-

chael, she dressed in men's clothing and worked on construction gangs. Michael and Karin started living together and shortly thereafter obtained a marriage license (nobody bothered to ask for a birth certificate) and were married. They had two children through artificial insemination. After the birth of their second child, Karin and Michael split up. In the divorce proceedings, Karin sued for child support. Michael argued that, as a woman, she obviously couldn't be the children's father. A New York court found that Michael, aka Marlene, was the legal parent and therefore could not dodge child support.

The other side of the equation is that the donor is free and clear of any responsibility to the child. He donates his sperm, is paid, and moves on — no responsibility, no rights. About the only exception is the rare case in which a donor is selected by a woman and acts as a father to the child.

Consent: What You Should Know about Artificial Insemination

As with any medical procedure, you should be fully informed about artificial insemination before undergoing it. This means knowing about the benefits, risks, and other considerations discussed in Chapter 2. The most significant risk appears to be that of being inseminated with infected semen.

Semen that is not properly tested may carry a sexually transmitted disease such as gonorrhea, a genetically transmitted disease such as cystic fibrosis, or AIDS. In 1985, before screening tests for the AIDS virus were developed, a man whose sperm was used to inseminate nineteen women was later found to be HIV positive. More recently, infected semen was inadvertently used in at least two instances, although no cases of AIDS from this source have been reported in the United States. By following two simple rules, you can help protect yourself against being given infected semen:

- Use only *frozen* semen that has been quarantined for at least six months and came from a man who, six months after donating it, was tested for the AIDS virus. These procedures do not eliminate the risk of AIDS entirely — nothing does — but they certainly reduce it.
- Use semen that comes from a sperm bank affiliated with the American Association of Tissue Banks or follows the guide-