Chapter 12

Dealing with Mad Scientists: Biomedical Ethics

In This Chapter

- Getting the scoop on principles of biomedical ethics
- Examining the ethical issues surrounding abortion
- Analyzing cloning and its morality
- Realizing the ethical impact of new genetic technologies
- Discussing the positions on euthanasia

How human beings deal with their bodies and the bodies of others has always been a huge concern in ethics. This chapter is home to two of the most intractable disputes in societies across the globe: abortion and euthanasia. You won't solve these problems here, but you can see why getting to the bottom of these difficult debates isn't easy.

With the exception of the Internet, in recent years no sector of business and society has grown as fast as biotechnology. Some experts even speculate that the Information Age will quickly be followed by the Age of Biology, wherein humanity will take charge of the human genome and dramatically improve everyone's quality of life.

But with such great power comes an unfathomable responsibility. Advances in biotechnology, such as stem cell research, cloning, and in vitro fertilization, challenge centuries of entrenched thinking about the place and possibilities of reproduction in society. These new technologies are coming fast — and each comes with its own Pandora's Box of ethical problems.

Whatever your position on these issues, you (and anyone who lives and votes in the 21st century) must be informed about how all these new technologies work. But it's even more important that you become familiar with the ethical debates accompanying these new technologies, and this chapter gives you just the information you need.

Examining Some Principles of Biomedical Ethics

Biomedical ethics is the application of ethical principles to medicine and biotechnology. Applying ethics to medicine is generally thought to be a good thing, because it promises to cut down on the number of mad scientists and evil doctors out there. Doctors do a lot of good in the world, but you don't need to watch too many episodes of your favorite hospital TV drama to notice that situations can get out of hand pretty quickly. All professions need principles, and the medical field is no different.

In this section, we look at three views that have governed physician-patient relationships and examine how they have evolved over the years. Although these principles are staples of what's considered ethically appropriate patient-physician interaction, keep in mind that the values that underlie them also flow through many other issues in biomedical ethics. In subsequent sections, you can see how they apply to other issues as well.

Paternalism: Getting rid of the old model of medicine

Substituting one's own judgment about what's best for someone else without her consent is called *paternalism,* which comes from the Latin word *pater* meaning "father." This name comes from the fact that in the past fathers often made family decisions for their children based on what they thought would be best, regardless of what the child (and sometimes even the mother) thought.

People are generally in awe of doctors, so they tend to get the idea that doctors always know best. In fact, doctors themselves sometimes have this idea; in the past doctors regularly treated patients in whatever way they thought was best, often without asking for the patient's input. Patients often expected this kind of treatment and typically submitted to the doctor's authority without question. After all, the patient didn't go to medical school; the doctor did.

If you think in terms of good outcomes, paternalistic practices work as long as the doctor really does know what's best for a patient and can successfully act on it. But many high-profile cases have shown that an essential component of knowing what's best for a patient comes from the patient! Patients can have very different values from the doctors treating them. As a result, what a patient needs is a doctor who properly informs her about her medical situation and options so she can make an informed choice.

Purely paternalistic practices in medicine are now considered quite unethical because they directly bypass a patient's own decisions and thus her values. Despite glorious TV depictions of doctors tricking patients into doing what they think is right for the patients, in real life that kind of doctor would be broke and bankrupt from patient lawsuits — if not languishing in jail. And more importantly, these doctors probably would have unethically forced some patients to do things they really didn't want to do.

Autonomy: Being in the driver's seat for your own healthcare decisions

The new model of medicine encourages something very different from paternalism (the old model we discuss in the preceding section): autonomy. If paternalism can be described as the doctor-knows-best method, then focusing on patient autonomy can be described as the informed-patient-knows-best approach.

Autonomy means having control over your own life. Most people in the Western world see autonomy as an absolutely necessary component to living a good life. (In fact, people have built whole ethical systems around the idea of autonomy. For an example, see Chapter 9.) The key to giving people autonomy in a medical setting is asking their permission before you do anything to them.

However, note that consent doesn't always imply autonomy all by itself. You may agree to a hemispherectomy if the right doctor told you it was necessary. But before the surgeon scrubs in, you should at least be told that the procedure requires cutting out half your brain. So, medical professionals don't just have a duty to convince their patients to agree to procedures. Ideally, they also should give them enough information to make a *good* decision.

In response to this problem, bioethicists and medical professionals have developed the notion of *informed consent.* Informed consent can't be achieved by simply convincing a patient to sign a consent form. In addition, the burden is on the physician to make the reasons clear about why some treatment is the right option. Being informed means fully understanding the situation, the various options, and the possible consequences that come with each option. Informed consent is a two-way street. Doctors talk to patients, but sometimes patients also need to ask many questions, think things through, and talk to family or friends before providing informed consent.

Informed consent is necessary to protect patient autonomy because sometimes patients have values or know things about their lives that a physician couldn't reasonably anticipate. Essentially, the modern stress on autonomy sees the aim of good, ethical medical care as the combination of actual treatment and the values of the patient. In contrast, the past emphasis on paternalism saw good medical care as solely a function of what the doctor thought was best, potentially disregarding the patient's values.

The curious case of elective cosmetic surgery

Many plastic surgery procedures are reconstructive, meaning that the patients need them in order to lead good lives. But not all of them are. Elective cosmetic surgery — to do things like reduce wrinkles, straighten one's nose, or enhance lips — has become a very profitable industry.

But elective cosmetic surgery does raise some interesting ethical questions. Surely people have the right to do what they want with their bodies, but if physicians are expected to also abide by principles like beneficence or nonmaleficence (see the section "Beneficence and nonmaleficence: Doing no harm" for more information), then cosmetic surgery will be trickier to justify in some cases. Sometimes, for example, a physician may come to think that a certain procedure won't actually provide a benefit to a person's life; but after his reasoning is made clear, the patient may still desire the surgery. At this point the cosmetic surgeon can refuse to perform the surgery, but his denial will almost certainly result in the patient simply getting the procedure done somewhere else. Many doctors make a good living supplying medically unnecessary procedures.

One response may be to kick these doctors out of the profession, but doing so could have some serious risks. Elective cosmetic surgery procedures may simply go underground, resulting in many more people suffering from botched or unsafe elective cosmetic surgeries. No one wants that to happen either, so elective cosmetic surgery remains a troubling but important part of medical practice.

Beneficence and nonmaleficence: Doing no harm

Even if you think that autonomy is important, medical professionals also have to respect other important values. Enter beneficence and nonmaleficence. Don't be scared by these big words. They're two very simple concepts: valuing *beneficence* means you try to help people, and valuing *nonmaleficence* means you try to avoid harming people.

If you watch enough medical dramas on TV, you may have heard of something called the Hippocratic Oath. The core principle of the oath is that one should "first, do no harm." That's the nonmaleficence principle.

In a way, the duty of nonmaleficence comes before the duty to respect a patient's autonomy, because even if a patient gives informed consent to a treatment, a medical professional still has to make sure the procedure wouldn't be worse for the patient in the long run. For example, say that you had a daredevil patient who gave informed consent to a procedure for a minor condition that had very little chance of success and a high probability of leaving her in severe pain for the rest of her life. Surely doing such a procedure would be wrong, even if the daredevil wants and accepts it.

Still, even when taken together, nonmaleficence and autonomy can't take care of all biomedical ethics by themselves. Sometimes a patient may give informed consent and the treatment won't hurt her, but it may fail a further test: It doesn't do anything to make her better. It sounds pretty commonsensical to say doctors have a duty to make people better, but they need to be reminded of this in some cases. Most bioethicists agree that prescribing a treatment, even one that does no real harm and with informed consent, would be unethical if there's no chance it will benefit the patient. Doing good — the principle of benevolence — can be as powerful a motive as preventing harm in many cases.

Taking a Closer Look at the Intractable Issue of Abortion

Abortion, the termination of a pregnancy, has been one of the more polarizing ethical and political issues in the past 40 years in the United States. When a woman intentionally terminates a pregnancy, people tend to have strong emotional reactions about the ethics of it, and these emotions can lead to sometimes less-than-reasonable confrontations among even the most rational of people.

The following sections don't provide any final answer whether abortion is right or wrong, but they do examine the basic arguments presented by each side. We hope this information can help you navigate your own way through this thorny issue.

Before you jump in, notice that two different levels of disagreement about abortion exist. You need to keep these levels straight because otherwise you'll get lost in lots of arguments about abortion. The first is whether (and under what conditions) it's ethically permissible for a woman to terminate her own pregnancy. The second is whether it would be ethical for society to make laws about whether (and when) a woman can terminate a pregnancy. These are separate ethical questions! Just think about it: It may be unethical for a woman to have an abortion, but it also may be unethical for society to have a law against it.

Deciding who is and isn't a person

Much of the debate over abortion revolves around what ethicists call *personhood.* To be a *person* is to possess a certain number of rights, in particular the right not to be killed. (For other examples of human rights, see Chapter 15.) If you're reading this book, you're a person, and you have rights.

No one's really sure when this mysterious personhood starts. Before you were conceived (when you were no more than a twinkle in your mom's eye, as they say), you clearly weren't a person. At some point you became one. But putting a finger on when exactly the magical moment of becoming a person takes place is notoriously difficult.

Generally, philosophers have tried to argue that something achieves personhood when it meets certain criteria, like consciousness, self-consciousness, the ability to reason, and so on. But, sadly, people even disagree about what these criteria are, so you can expect debates about abortion to be tough from the very start.

Given the uncertainty about what is and isn't a person, people try to avoid the issue altogether in two important ways:

- **You can admit that no one's certain when personhood begins, so someone considering an abortion (or considering social policy) should err on the side of caution.** If you're not sure whether something hiding in the brush is a person or a deer, you don't shoot at it. Perhaps the same kind of caution is warranted in the case of a fetus.

  The problem with this point is that it's not clear whether it's always wrong to kill persons. Killing in self-defense or when someone is trespassing on your property (and won't leave) is often viewed as ethically permissible. Some people defend abortion under exactly those terms.

- **You can admit that embryos or fetuses aren't full-fledged persons but they're at least *potential* persons.** With the right treatment and a little luck, embryos and fetuses will become persons and enjoy the rights associated with personhood.

  

  The problem with this latter point is that generally being a potential X doesn't entitle something to the rights of an actual X. Being a potential employee of a company doesn't entitle you to the rights of an actual employee, for instance. So supporters of rights for potential persons would have to show that somehow the potential to be a person entitles one to rights.

A right to life from the beginning: Being pro-life

People who think abortion is unethical in one way or another tend to label themselves *pro-life.* The thought that drives the pro-life argument is that an embryo or fetus is a person with a right to life. This thought motivates the conclusion that even if a woman has a right to say what happens to her own body, she still shouldn't be allowed to terminate a pregnancy.

Some pro-lifers believe abortion is never ethically permissible; others think that abortion is generally impermissible but may be permissible in cases of rape, incest, or a danger to the life of the mother. Sometimes the former group doesn't think the latter group is sufficiently pro-life, and the latter group doesn't think the former group is being reasonable. Here we focus on the most popular pro-life argument: that fetuses are persons who have rights.

The pro-life argument that abortion is (generally or always) ethically forbidden and that society should pass laws prohibiting it actually turns out to be quite simple. It goes like this: Persons have the right not to be killed unjustly, and fetuses are persons. Therefore, fetuses have the right (as persons) not to be killed unjustly. Societies generally don't condone murder. Abortion is unjust killing, so it's unethical and should be illegal. Not killing a fetus may make a woman's life terribly difficult (to the point of death in some pregnancies), but lots of variables in life make things terribly difficult. If one of those variables involves persons, you don't have the right to kill them in order to remove the difficulty.

One consequence of the strict pro-lifer's argument can rub people the wrong way: If fetuses are persons, then all fetuses are persons — even those that come about because of rape. Rape is one of the most devastating things that can happen to a woman. To ask her to surrender her body to a pregnancy resulting from rape risks taking this devastation to a whole new level. Yet if fetuses are persons with a full right to life, it hardly matters how they came about. A right to life is a right to life. Yet given this argument, saying ethics requires a woman to carry her rapist's baby seems to go too far for many people.

The freedom to control one's body: Being pro-choice

People who think abortion may in some circumstances be ethically permissible tend to label themselves as *pro-choice.* The thought that motivates the pro-choice position is that a woman has a right to say what happens to her own body. The centrality of this right to all human life drives the conclusion that even if a fetus or embryo is a person, a woman still has the right to terminate a pregnancy in defense of her rights.

Some in this camp believe that abortion is always permissible; some believe it's rarely permissible; and others believe that even if abortion is always unethical, society still shouldn't have laws against it. And as with pro-life groups, people with these different pro-choice viewpoints don't always see eye to eye.

Although pro-choice advocates offer a number of different arguments, their primary argument is fairly simple: Women, like men, have a right to say what happens within their bodies. (This is the right to autonomy, which we discuss in the earlier section "Autonomy: Being in the driver's seat for your own healthcare decisions.") The way nature works, fetuses are carried within women's bodies, so women have a right to say whether a fetus stays in her body or is removed. An unintended pregnancy can be devastating to a woman with plans for her future that don't involve nine months of pregnancy and the expenses that go with it. It's her choice, and no one else can make it. To allow anything less by law would seriously compromise a woman's autonomy. Of course, not all women will choose to have an abortion when pregnant, because many want a baby or can live with having a baby. But some don't, and they have a right to take the action to end a pregnancy.

As with the pro-life position on abortion, many people see the pro-choice position as having a large flaw. Saying that a woman has the right to her own body is all well and good, but if defending that right involves killing a person, perhaps this right is being taken too far. Many pro-choice advocates respond by denying that embryos and fetuses are persons, suggesting that they have no right to life. But still others believe that even if an embryo or fetus is a person, a woman's right to control her own body can trump a person's right to life.

A 21st Century Problem: Attack of the Clones

Clones are exact genetic copies of another organism. In other words, they're beings with exactly the same DNA. Clones were the stuff of bad science fiction until the end of the 20th century, when all of a sudden they were everywhere in the news. The most famous clone of all time is Dolly, the world's first cloned sheep. But people really aren't worried about the ethics of cloning animals (and if they are, they aren't making much headway in adopting new policy; lots of people clone animals nowadays).

The big ethical question (and controversy) comes when people start thinking of cloning human beings. People are tempted to clone humans for two reasons:

- Stem cells from cloned human embryos could be used to grow genetically compatible organs for use in transplants and biotechnology.
- Cloning may allow infertile couples to have children that are genetically related to one of them.

The following sections examine these two reasons in greater depth.

You need to know that no one (unless you live in a bad prequel in a galaxy far, far away) is going to be able to create a whole army of clones of the same person any time soon. Even if you could get a human clone started, you would need to bring it to term in the womb and raise it like any other child. That's a lot of work — just ask your mother. If you're 30 years old and want a 30-year-old clone of yourself, it's going to take at least 30 years to do it. That's not a very efficient way of making an army!

Understanding the growing use of cloning in medicine

Cloning sounds like something only a mad scientist would attempt, but a great deal of legitimate research could benefit from human cloning. In reality, scientists want to clone human embryos so they can extract stem cells from them. They can then use those stem cells to grow organs for transplants or research.

So what exactly are stem cells and how can scientists use them in cloning? *Stem cells* are special cells that can become other kinds of cells. Some stem cells can be coaxed into becoming blood, bone marrow, heart wall cells, or even whole kidneys and livers. Having extra blood and livers laying around can be really useful when people need them in transplants. But most normal transplants have a downside: Because the organs come from other people, the recipient's immune system tends to attack them. So getting the body to accept a transplant can require the use of drugs that suppress the immune system. Unfortunately, a suppressed immune system opens the transplant recipient up to all kinds of nasty diseases. Not good.

With cloning, doctors may be able to take one of your skin cells and use it to make an embryonic clone of you. One day they could then extract stem cells from the clone to grow organs and tissues that your body wouldn't reject. You wouldn't need organ donors or immune suppressants, and you'd have a vastly higher chance of organ acceptance.

This kind of cloning wouldn't result in copies of whole human beings, but it still has one ethical problem with it: You would have to destroy the embryos you grow in order to get at the stem cells. And some people have major issues with destroying embryos (for more information, see the section on abortion earlier in this chapter). Interestingly, though, the destruction of embryos isn't a problem with cloning *per se* so much as what happens after the cloning. So if some enterprising scientist finds a way around destroying the embryos, it's difficult to see what ethical objection people would have to cloning for medical purposes. You can read more about the morality of stem cell research in the later section, "Finding cures for diseases with stem cell research."

Determining whether cloning endangers individuality

Although creating an exact duplicate of a grownup from a single cell isn't plausible unless you actually have many years to wait around for it to develop, some people see the value in bringing a cloned embryo to term. Some parents, for instance, may believe cloning is a viable option for these reasons:

- **A couple may want children but be unable to conceive a child on their own.** The general response to this problem in the past has been adoption, but adoption can be a long, drawn-out process and also doesn't result in children who are genetically related to their parents. So instead of choosing adoption, infertile couples could opt to make a cloned embryo from one of their cells and implant it just as one would implant any other embryo from a fertility treatment.
- **A couple may suffer the tragic loss of a child and be unable to conceive another.** If they saved cells from the lost child, scientists may be able to make a cloned embryo of that child for implantation.

Both scenarios can freak out people. In the first scenario, the parents are raising a clone of one of the parents. In the second scenario, the parents are raising a clone of a child who has already lived. Welcome to the 21st century! Admittedly, both situations are pretty strange. But strange doesn't mean unethical. So the question becomes, are there any actual ethical problems with these situations?

At least one problem occurs to most people rather quickly: What happens when clones grow and discover they are cloned? If you thought the "you're adopted" speech was awkward, the "you're a clone" conversation should be a real winner. The worry most people have is that clones may be deeply harmed when they find out. Of course, the harm isn't physical, but rather psychological. Clones may believe that they have been raised to be a copy of someone else rather than a unique individual. As one philosopher says, that genome has already "been lived." In a sense, part of what gives people their own sense of dignity and worth may derive in part from the fact that they're in some ways different from everyone else. The clone would be robbed of that sense of individual dignity.

But perhaps a reply to these kinds of worries exists. A human clone is an exact genetic copy of another human being. But being an exact genetic copy doesn't guarantee that someone will be an exact copy in other ways. Genetics are only one part of who you are. Even if you're an exact genetic duplicate of your father, your experiences would be entirely different from his. You would have grown up in different houses, had different friends, used different technologies, and so on. Experience has as much of an effect on who you are as genetics, and maybe even more. So it seems appropriate to say that your genetic

makeup is only part of what makes you who you are. Your experiences, and your way of responding to them, make up the other component. From this point of view, clones still would have a great deal of individuality and so still would have a healthy basis upon which to ground their own dignity.

People who are genetic copies of one another actually are walking around all over today. We're talking about sets of identical twins. These twins have the same genetic material, and no one believes that one twin challenges the other's dignity just by existing. (Quite the contrary, in fact, identical twins seem to be just as psychologically healthy as anyone else and tend to have close relationships with one another.)

So would it matter that a clone is essentially the much younger identical twin of its father, mother, or deceased sibling? The answer seems mixed. It certainly could be a problem if the parents attempted to force their cloned child to be just like the person who donated the genetic material. But then again, it's not as if parents don't do such things with normally conceived children as well. All parents shape their children in their own image to some degree. The fact that parents may do this doesn't seem like an ethical problem when raising normally conceived children, so why should it be a good reason not to have cloned children?

Anticipating Ethical Problems with Genetic Technologies

Discovering how genetic material works and its potential applications is sort of like discovering fire. Scientists didn't even know what DNA was 75 years ago, and today it's at the center of biomedical research. The implications of genetic research for the future are staggering. Understanding genetics may one day allow scientists to discover cures for cancer, diabetes, heart disease, and maybe even aging itself. But with this tremendous potential comes a host of ethical concerns. Like fire, genetics can be used for bad purposes as well as good ones. Check out the following sections for an overview.

Testing to avoid abnormalities

Advances in genetic technologies allow scientists to examine someone's DNA for genes that can lead to terrible conditions later on. Unfortunately, once someone is grown, these conditions usually can't be cured. Thus, preventative genetic testing has to be done slightly after conception and in the confines of a laboratory. After embryos with genes for diseases have been identified, though, ethical problems set in: Should these embryos really be denied a chance at life? Asking this question leads to a virtual jungle of ethical concerns.

Determining your baby's sex

How far do you think trait selection should go? Knowledge of modern genetics allows doctors to screen for certain genetic diseases, but doctors also now believe they can discover the sex of an embryo before it's implanted in the womb. This isn't too far in the future. Some companies already offer the service!

Of course, the process of conceiving a baby of a certain sex is quite complicated and requires much medical supervision. First doctors have to extract eggs from the mother, and then they have to fertilize them with the father's sperm. After the doctors have created several embryos, they have to genetically test them for markers common to boys or girls. Several are then implanted back into the mother's uterus to grow. If the couple is lucky, one embryo of the desired sex will come to term. Traditional methods are definitely a lot more fun!

Say that a couple already has a girl and wants a boy for their next child. Would it be ethical for the couple to use such a service? What if they had leftover embryos that weren't implanted? Are there aspects of reproduction that should be left to chance, or is this just the next step in human evolution?

Say, for example, that your parents had some terrible genetic disease that you don't want to pass on to your kids. Conceiving a child in the traditional way makes screening for that genetic disease difficult. But if the child is conceived by the union of a sperm and egg outside the womb, the resulting embryo can be screened for the disease. This screening is done by looking for *genetic markers* associated with the disease. Genetic markers are genes that are almost always found in people with certain genetic diseases. As soon as an embryo without the genetic marker is identified, it can be implanted in the womb to grow to term without fear of the genetic disease. This process is called *preimplantation genetic diagnosis,* or PGD.

Yay for modern medicine! Right? Well, not so fast. Although genetic testing does identify abnormal genes, it also introduces two new problems:

- **What do you do with the embryos that have the defective gene?** According to some people, embryos (as persons or potential persons) have rights, including the right to live. If the embryos are destroyed, some folks see this as an unethical abortion (for more discussion of this topic, see the earlier section on abortion).
- **What counts as an abnormality that could rightfully be screened out?** If people begin to screen out embryos to avoid awful diseases, should they also be allowed to screen out embryos with traits that are simply less desirable, such as short stature or a predisposition to obesity? We discuss these issues more in the context of genetic enhancement. (See the later section "Manipulating the genome to create designer people.")

Finding cures for diseases with stem cell research

Because scientists now know more about genetics, they've been able to get a better grasp on how cells create other cells. As it turns out, certain kinds of cells can create many different other kinds of cells; these very creative cells are called stem cells. As we mention in the earlier section "Understanding the growing use of cloning in medicine," scientists would love to be able to harness the power of stem cells. If you can create cells, you can create tissues and organs, which are terribly useful when people need new ones (or when researchers need to conduct experiments).

Scientists have a number of different classifications for stem cells, but to understand the ethical issues, you really just need to know two. We explain the two and their ethical problems in the following list:

- **Embryonic stem cells:** These are stem cells that can create any kind of cell you find in the body, so the medical possibilities are greater. They're called *embryonic* cells because they come from embryos, which can develop into full-fledged people (who need all the different kinds of cells in the body!).

  As we note in earlier sections, despite their usefulness, ethical issues arise with embryonic stem cells. Here's the problem: With today's biotechnology, researchers must destroy embryos in order to obtain the stem cells. Some people consider this abortion, which is a difficult ethical issue of its own. (Refer to the section "Taking a Closer Look at the Intractable Issue of Abortion" earlier in the chapter for more information.)

  

  Should the destruction of potential human life be used for research that may save actual human lives? This situation creates a potential trade-off. The overall benefits of lives saved may be greater than the potential lives destroyed. However, some people believe that you shouldn't make ethical judgments this way (unless you're a consequentialist; head to Chapter 7 to find out more about these folks). If embryos have a right to life, it shouldn't matter how many people can be saved by using them. Rights are rights, plain and simple.

- **Adult stem cells:** These are stem cells that replenish cells needed for proper functioning of a body. They're found in all human beings and can produce many different cell types, such as blood cells, muscle cells, and skin cells — though not as many as embryonic stem cells.

  Using adult stem cells is relatively unproblematic from an ethical standpoint. They seem very useful and, unless you count surgery as ethically problematic, it's ethically unproblematic to acquire them. But as many scientists point out, limiting our research to adult stem cells would mean bypassing many potential avenues for curing people with intractable diseases.

While using adult stem cells is unproblematic, limiting scientists' usage to them creates a problem of good not done. And when people are dying from treatable conditions, you face an ethical problem. After all, it would appear that human suffering is preventable but humanity as a whole has chosen not to pursue the research required.

Considering genetic privacy concerns

If modern genetics has made anything abundantly clear, it's that no one is perfect. Every person has a long genetic past that has left risks for all sorts of conditions. Scientists recognize particular elements of the genetic code by looking for genetic markers. In recent years, scientists have discovered genetic markers for everything from Huntington's disease to high blood pressure. Genetic markers also are used to solve crimes through DNA evidence. In the future, however, some people are worried that identifying genetic markers could get out of hand and be used to violate people's privacy.

Consider the possibilities of how genetic testing could be used:

- **When you apply for a new job:** Employers want the best employees, of course, so they'll be tempted to choose those people without genetic predispositions to high blood pressure, heart disease, and other chronic conditions.
- **When you apply to college:** If intelligence or one's work ethic turn out to have a genetic link, one could imagine schools denying admission to people without good genes or tailoring scholarships to attract those with genetic advantages.
- **When you buy health insurance:** Maybe the price of your health insurance will one day depend on how many bad genetic markers you have. Talk about preexisting conditions!

The use of such information in these instances has the potential to make life difficult for people who didn't exactly win the genetic lottery. (And life is probably already difficult for them given their genetic predispositions!) This worry has led many bioethicists to recommend that discrimination based on genetic conditions be outlawed. Furthermore, they've provided considerable pressure to make genetic information private, or solely under one's own control. These measures will be a staple of emerging rights in the 21st century.

Manipulating the genome to create designer people

The final issue to discuss in terms of genetic technology is the one with the most potential for making bad science-fiction movies: genetic enhancement.

Genetic enhancement is basically tinkering with DNA to bring about advantageous traits. Although scientists aren't doing much genetic enhancement on human beings now (that your humble authors know about), with growing understanding of the genome and how to manipulate it, this type of genetic engineering is inevitable.

Imagine parents being able to not only screen embryos for traits they don't like, but also being able to order off a menu of desirable traits for their children. Want little Sally to be as tall as an NBA forward? Want Tyrone to possess innate musical abilities like perfect pitch? In the future, parents may be able to select elements of their children's genetic code for optimal performance. The potential for such practices has some people very concerned.

On one hand, genetic enhancement is just a better way of doing something that human beings have done for millennia: making life better for their children. If you want your kid to grow up to be a basketball star, your odds are much better if you mate with someone tall. Some parents also spend all kinds of money to give their kids the best education, music lessons, and healthcare they can. Selecting certain genetic traits could simply be the next level of giving children the best chance possible by assuring that they have just the right genes.

As with education and healthcare, genetic enhancement brings up serious ethical issues for society, including the following:

- **Inequality:** Getting a specialist to help genetically enhance your child will no doubt be a pretty expensive endeavor — just like sending the child to the best schools. Thus, at least initially, only the rich and powerful will be able to afford genetic enhancements. This limitation creates an ethical problem of inequality that threatens to snowball over time. The children of the rich already have tremendous advantages as it is. To give them genetic advantages on top of this could leave the poor and middle class hopelessly behind, perhaps intractably so. If such technologies were ever safe enough to be useful, equality would seem to require their availability to all income levels. And that equality would be mighty expensive.
- **Unintended consequences:** Setting your child's genes for her could rule out other life plans the child may desire. For example, although being 7 feet tall is great for aspiring basketball players, it eliminates other life plans like being a gymnast or a jockey. (Seeing over crowds at concerts, on the other hand, becomes a whole lot easier.) This has led some ethicists to advocate for a child's right to an *open genetic future,* or having no life plans ruled out by one's genetics. Unlike typical overbearing parenting, choices parents make about their child's genetics could be much more difficult for the child to overcome in adulthood. At some point, you have to ask whether parents are crossing an important ethical line.

Dying and Dignity: Debating Euthanasia

The issues discussed earlier in this chapter tend to emphasize the beginning of life and the medical issues that come up throughout a normal lifespan. However, ethical issues exist at the end of life too. *Euthanasia* is the practice of intentionally ending the life of someone who's suffering from an incurable illness or is in an irreversible coma. In the last stages of a terminal illness, for instance, patients who don't want to live the rest of life in agonizing pain may ask a doctor or family member to help them end their lives.

This kind of request has a number of ethical issues associated with it. The following sections examine these issues in more detail.

Dealing with controversy at the end of life

Two important distinctions are at the center of the debate over the ethics of euthanasia:

- **Euthanasia may be active or passive.** With *active* euthanasia, a person physically helps a person end her life. For example, it may involve a doctor taking steps to end a patient's life, such as prescribing a lethal dose of morphine. With *passive* euthanasia, on the other hand, a person has no active role in ending life. A doctor, for instance, won't provide a means to end a patient's life, but she may order the end of life-sustaining treatments.
- **Euthanasia may be voluntary, nonvoluntary, or involuntary.** *Voluntary euthanasia* denotes that a patient has actively consented to ending his or her life. *Nonvoluntary euthanasia* means that a person's life is ended without knowledge of his or her wishes. And *involuntary euthanasia* happens when a terminally ill person's life is ended against that person's wishes.

Table 12-1 compares these two different combinations of distinctions and what people generally think of them.

Table 12-1 The Different Euthanasia Positions

	Voluntary	*Nonvoluntary*	*Involuntary*
Active	Patient choosing physician-assisted suicide (what everyone gets worked up about)	Physician-assisted suicide (according to the wishes of a person's family)	Involuntary ending of life (pretty much murder)

	Voluntary	*Nonvoluntary*	*Involuntary*
Passive	Patient deciding to end life-support (which happens every day in hospitals and hospice)	The doctor deciding to end life-support (according to the wishes of a person's family)	Deciding to end life-support against a patient's wishes (also pretty much murder)

Stopping life-support is something many families have to deal with at some point or another. Although some people still believe this kind of intervention requires a person to "play God," most believe that passive voluntary or nonvoluntary euthanasia generally is ethically permissible. Ethical problems with nonvoluntary euthanasia can be avoided to a great extent by the presence of an advanced directive, which details what kind of medical treatments should be given if one is incapacitated.

The following sections focus on the debate over active, voluntary euthanasia, where a patient — usually in the last stages of a terminal disease — elects to take steps to end her life with the help of a medical professional.

Making autonomous choices about death

Death is difficult for many people to deal with, but sometimes life itself can be pretty rough too. In the final stages of a terminal illness, a patient can be in so much pain that he may come to see ending the pain as preferable to living on for a short period of time. To deprive someone of this wish seems unusually cruel to many people. After all, most of society says it's okay (and often better) to put animals out of their misery when they're suffering. Surely such a person should be allowed to die with dignity rather than be forced to stay alive to the bitter end.

In normal circumstances, someone seeking to commit suicide would be seen as mentally ill and in need of help. But typically it can be shown that someone contemplating suicide is making an irrational decision with regard to his future life. When contemplating suicide, a person often can believe that he'll never be happy again, when in reality pain often subsides. This means the person contemplating suicide often discounts the worth of the future compared to the present. Such discounting is irrational, because the future will be worth more than the person currently believes.

The terminally ill patient often has much more specific information than the typical suicide, however. He can be assured that the future is indeed short and that the pain won't subside. In this case, the two obstacles to seeing his behavior as irrational go away, and then he can again see his decision as potentially autonomous. (The earlier section "Autonomy: Being in the driver's seat for your own healthcare decisions" discusses autonomy in greater detail.)

The decision becomes even more difficult, however, when the patient asks for a physician's assistance in ending his life. Physicians are obligated not to harm their patients, and death is certainly a harm. But compared to living the rest of a short life in significant pain, death can sometimes seem like the considerably lesser of two evils. (Check out the earlier section "Beneficence and nonmaleficence: Doing no harm" for more information on a physician's obligations.)

Recently, a number of countries have begun to legalize euthanasia under very strict conditions. Patients must go through multiple checks with mental health professionals and other physicians. They also must sign several waivers indicating that no one is pressuring them to die, and they must wait a period of time in order to ensure that the desire for euthanasia isn't the result of a passing depression.

Killing the most vulnerable

Some view suicide as a serious moral wrong that's akin to murder. After all, with suicide one is killing someone. That person just happens to be oneself. With this view in mind, not existing is always worse than being alive, so killing oneself can't result in a gain in well-being — despite appearances — to a terminally ill patient. If a day spent in agonizing pain is indeed preferable to a day without existence (or worse, being punished eternally in an afterlife of some kind), the opponent of euthanasia has an important argument to make.

But active euthanasia isn't just suicide — it's enlisting another person to help hasten one's death. According to opponents of euthanasia, active euthanasia has another name: murder. In regular life, one can't justify murder even if the person wants to die. (You'd be far better off checking the person into a mental hospital.) So why should it be any different when the person is terminally ill?

Furthermore, it's not just anyone doing the killing in cases of active euthanasia. The person writing the prescription for lethal drugs must be a physician. This behavior is a dramatic departure from a physician's usual professional duty to cause no harm. (See the earlier section "Beneficence and nonmaleficence: Doing no harm.") Opponents of euthanasia worry that physicians who help patients commit suicide will tarnish the medical profession and make people more afraid of doctors.

Opponents of active euthanasia need not oppose passive euthanasia as well. They defend the practice of passive euthanasia by distinguishing between killing a patient and merely letting him or her die. It's ethically permissible, they believe, to let a patient die (essentially letting the disease kill the patient). But killing the patient is much more ethically problematic, because another human being (rather than natural circumstances) brings about death.