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Better Healthcare Newsletter from Patrick Malone



Dear Jessica,

Here's a puzzle. Although 95 percent of Americans adults say they support organ donations, just 54 percent of us sign up to give.

The unmet need is a killer, literally: [8,000 Americans died this year for lack of a timely transplant](#). And more than 100,000 patients nationwide sit on waiting lists for hearts, kidneys, livers, lungs, pancreases, and more.

So as the days of 2017 dwindle, and we make gift lists for friends and family, maybe it's time to take a few moments to consider giving a gift of life.

It can be easy. But first, put your mind to this important choice. Turn down the holiday clatter and learn how to make an informed decision

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BY THE NUMBERS

116,000

Number of men, women, and children officially awaiting transplant organs as of August, 2017

33,611

Number of transplants

to help as many as eight people with one huge gift.

The need is great, the supply is poor: Organ donation's easy but few follow up



The human body is a wondrous machine that mostly chugs along for decades with minimal maintenance. But its various and many parts can fail for many different reasons. Some organs get damaged by disease or accident, others by age or abuse. Some don't grow right to start. Others just stop working too soon. Once, people pretty much had to accept the dire consequences, though doctors and medical scientists for centuries studied how to fix this too often fatal flaw.

Big breakthroughs in this research began to occur relatively recently—starting in the 1950s.

That's when bold surgeons pioneered modern transplants. Joseph E. Murray and his colleagues in 1954 [successfully transplanted a kidney](#) from an identical twin to his brother. Thomas E. Starzl, throughout the 1950s and 1960s, developed complex surgical techniques to make kidney transplants work. He also [blazed the way for successful liver transplants](#). In the 1960s, [heart experts followed suit](#), with doctors Norman Shumway and Michael DeBakey making key advances in cardiac surgery. This eventually led to South African surgeon Christiaan Barnard transplanting a car wreck victim's heart into the chest of Louis Washkansky, a 55-year-old man dying of heart damage.

Washkansky, alas, lived just 18 days after his pathbreaking procedure, which occurred [a notable half century ago](#). He and many other early patients benefited from transplants but then died from their body's own attacks on "foreign" tissues implanted in them. Solving this [also boosted the study of the human immune system](#) to new heights.

performed in 2016

2 out of 3

Number of transplant candidates who are older than 50

57%

Percentage of total organs transplanted that are kidneys

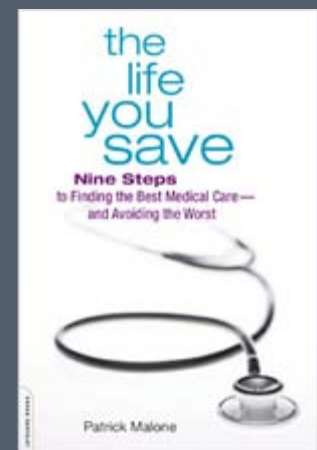
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[The life you save](#)

[Nine Steps to Finding the Best Medical Care — and Avoiding the Worst](#)



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The cost and complexity of transplants, then and now, has forced patients, doctors, and hospitals to carefully weigh who might benefit best from them and to struggle to develop a fair way to determine who receives still all-too-scarce organs.

In some parts of the world, such as [Iran and China](#), [transplant organs can be bought](#) and sold. But in the United States, the United Network for Organ Sharing—an independent, nonprofit under contract with the federal government—runs the system to:

- maximize the efficient use of deceased organs through equitable and timely allocation
- collect, store, analyze and publish data about the patient waiting list, organ matching, and transplants
- inform, consult, and guide persons and organizations concerned with transplants to increase the number of organs available

UNOS isn't controversy-free (see below). But some of its biggest challenges focus on you and me and getting us over information hurdles so we donate. The agency joins with patient advocacy groups, academic medical centers, and hospitals nationwide to [dispel common transplant donor myths and concerns](#).

Experts say that most adults older than 18 can be donors, and those older than 50 shouldn't limit their sign-ups due to age. Those with medical conditions shouldn't disqualify themselves, because they still may be able to give select organs or tissues. Those with [possible religious objections should consult with their clerics](#)—and they may find that they may have been misinformed.

Your decision to donate will not affect your medical care. Rigorous standards exist to determine which, if any, of your organs may be suitable for donation on your death. Most donations occur postmortem, though some—notably for kidneys—can be made while you are alive. Recipients, not donors, cover the cost of transplant surgeries, mostly through their insurance. (The costs can be formidable, with the total expenses for a [heart procedure running near \\$1 million](#), with those for a [kidney transplant exceeding \\$250,000](#)). Donors who wish can have open-casket services, as their bodies aren't disfigured in the organ-harvesting procedures.

With organs in short supply and with the idea of donations seemingly so popular, why don't Americans adopt a process in place in many other nations—making these [gifts an “opt out,” rather than an “opt in” procedure](#)? Researchers say they fear that this step could backfire,

Read our Patient Safety Blog, which has news and practical advice from the frontlines of medicine for how to become a smarter, healthier patient.



PAST ISSUES

Coping in an age of anxiety

Disastrous storms prove that now is the time to research nursing home quality

Deflating the hype and exposing the risks of stem-cell treatments

Medicine's dirty secret: Tens of thousands die of preventable error
Read this before you get a metal joint put in your body

You Can Eat This... But Why Would You?

Looking Ahead: Preparing for Long-Term Care

Managing Chronic Pain: It's Complicated

Secure Health Records: A Matter of Privacy and Safety

Standing Tall Against a Fall

[More...](#)

leading the independent-minded to rebel against any measure that might be viewed as Big Brother exercising control of their bodies.

It's easy enough to become an organ donor, and many states incorporate the sign-up as part of getting a driver's license or renewing it. To ensure that your important wishes get followed, however, you may wish to take the additional step of going online and joining a national registry, [available by clicking here](#). You also should be sure to let your family, friends, and loved ones know about your decision. It can mean a lot to organ recipients, with eight on average benefiting from a single donor ...

By the way, the choice to [donate your body for medical study or research](#) is different from consenting to organ donation, and you should research this separate decision extensively, given some recent investigations into some sketchy practices in this area.

When life-and-death decisions get made, controversies are sure to follow



It's an unenviable task, working with those with grave illness and in need of a lifesaving and life-changing "commodity" in too short supply. If you've heard negative reports about hospitals, doctors, UNOS or others involved in organ transplants, it's likely due to disputes on the recipient side.

Doctors and hospitals across the country [perform more than 30,000 organ transplants annually](#). But every 10 minutes or so, there's a new patient in need, and only about 3 in 1,000 Americans die in a way suitable for organ donation. Combine this all with a dearth of donors and dealing with organ demand can be daunting.

Receiving a transplant is a detailed, complicated process. Those in need of organs need first to be qualified as potential recipients by expert doctors. They then face some tough choices about the many factors that put them into a pool — not a list, per se — of those waiting for available organs.

UNOS works with transplant experts nationwide to develop criteria for which recipients might get organs, in what order. Experts consider how well a patient matches with a donor, how sick recipients are, and how many donors are available in their local area compared to the

number of patients waiting.

Geography plays a key role in transplant decisions, as potential recipients take their physician referrals to one of 200-plus transplant programs at various hospitals and academic medical centers nationwide. They then must be deemed a suitable recipient by a program, which itself qualifies for available organs within its geographic area. (This decision making has historic roots: Recipients needed to be near to donors because it was hard to keep organs alive during long transports).

Wealth can matter: Most patients may choose for cost and convenience to work with one transplant program nearby, while others may try to improve their statistical options by both getting with a close program and picking a more distant center with fewer competing recipients. Because each program may require different tests and in-person exams for a recipient to be one of its potential recipients, costs can add up.

When a transplant hospital adds patients to the national lists, they are placed in a pool of names. When an organ donor becomes available, UNOS says, “all the patients in the pool are compared to that donor. Factors such as medical urgency, time spent on the waiting list, organ size, blood type and genetic makeup are considered. The organ is offered first to the candidate that is the best match. The organs are distributed locally first, and if no match is found they are then offered regionally, and then nationally, until a recipient is found. Every attempt is made to place donor organs.”

In theory, experts apply sufficiently varied, rigorous, and smart guidelines to determine which recipients get organs, that the process is fair, and that the patients most in need and most likely to benefit will receive transplants. But, as in any life and death decision making, controversies erupt.

Some of these focus on the [geographical distribution of organs](#), most notably in recent days with the [number of regions that the nation is divided into and the qualifying metrics for how sick liver patients need to be to get transplants in different parts of the country](#). The criteria different centers employ to qualify recipients also come under fire, again, with livers generating notable acrimony. That’s because these organs, unlike many others, often fail [due to factors related to patients’ lifestyles and histories of substance abuse](#), and some recipients object to sobriety requirements tied to their receipt of a new liver.

Non-Americans, in theory, also can fly here, undergo testing and qualification at a transplant center, and then wait for — and receive — one of the scarce organs donated in the United States. They pay a premium to do so, and, with shortages so widespread here, the [idea of rich non-nationals receiving American-donated organs is attracting new attention and heat](#).

It shouldn’t be surprising, too, that as medical science advances and

pushes the horizons for sustaining life, the process of transplantation faces persistent questions as to how doctors determine when death occurs and it is appropriate for post-mortem organ collection. Many donors and their families, as well as transplant programs, do not begin organ and tissue collections until a patient is formally declared to be brain dead — now a key standard. Some advocates argue that many organs could be donated when a patient is deemed to be cardiac-arrested or dead for circulatory reasons.

The distinctions can matter: Los Angeles police are conducting a criminal investigation of an eight-year-old boy's death four years ago at UCLA's Ronald Reagan Hospital. Doctors told the young patient's parents that he would never regain consciousness and was neurologically dead. They agreed to allow some of his organs to be donated. But police are asking if criminal charges should be filed because the boy also received a major dose of fentanyl, a potent painkiller, after he was removed from life support. Was that drug given to hasten his death to allow for the organ donation? The anesthesiologist who gave the injection flatly rejects that claim and has denied any wrongdoing. She says the painkiller was given routinely to ensure the boy wouldn't experience discomfort when removed from life support. West Coast doctors and hospitals are closely watching this rare case.

There is, of course, a way for donors to work around issues surrounding determinations about their death and their organ giving: They can become "live" donors. You should consult your personal physician and research carefully if you wish to participate in this option, which is increasing and now affects 4 in 10 organ donations. Medical advances have made it possible for some patients in need to benefit significantly from another's donation of one kidney, a lobe of the liver, or part of the lung, pancreas, and intestines, as well as other key tissues. Kidney transplants can be a boon to recipients, who, otherwise, might face the difficult, costly, continuing, and less preferred option of dialysis.

But live donors need to know and to consider well how their organ gift may affect their own short- and long-term health, as well as their health insurance and finances. Your insurance, for example, may not cover this procedure. Please be sure you are giving an informed consent to become a live donor or to undertake any medical services. Some live donors participate because they know and can designate a loved one, friend, or colleague as the recipient. Others do so with great altruism.

That's inspiring at this time of year, when we all need to think hard about how we can better others' lives, especially by signing up to some type of organ donor. You also need your health to better the world, of course. And so, I'm hoping you stay healthy and have a holiday season full of great happiness and cheer! Here's also looking forward to a terrific 2018!

Can porcine pals, stem cells provide new organ sources?



It might make some animal lovers squirm. But America's shortage of organs for transplantation soon may be [solved by some four-footed friends: pigs](#). Their organs are similar in size and function to those of humans. People have eons of experience in raising and humanely caring for porcine pals, 100 million of which already are slaughtered annually in this country for food.

Could specially raised pigs help save 22 human lives a day by providing livers, hearts, kidneys, lungs, and other tissues in critical need?

Researchers in Boston and China have reported a big step in making this possible, [publishing results this summer](#) from tests indicating that the new technology of "gene editing" could be applied to pigs to eliminate in them worrisome viruses that might cause diseases in humans.

Earlier experiments with pigs as potential human organ donors broke down when scientists discovered porcine cells carried in their DNA genes for viruses akin to monkey leukemia. When pig cells were cultivated in labs, they also showed that they could transmit retroviruses, or strands of genetic material that can build into viruses. This cellular detection caused scientists to fear they might fuel the spread of animal infections, some potentially bizarre, to people. But, using the new gene editing chnique known as CRISPR and cloning, researchers have eliminated the problematic DNA and produced more than a dozen retrovirus-free piglets. The little guys may pave the way soon for raising pigs for organ transplants.

That's a hope down the road. Researchers also are pushing along efforts that [might allow humans to grow their own organ replacements or fixes via stem cells](#). The capacities of these

Key rights and valuables



If you've decided to become an organ donor, you should be congratulated for making a clear, conscious, and informed decision. Here's hoping the process also helps you know how medical choices get made so no one hits you with [sneaky ways that could compromise one of your most precious possessions](#): your own body and the storehouse of information it contains.

Medical science is in a time of dizzying advances, many involving tiny snippets of DNA and data that can be extracted from them that could lead to innovative therapies, drugs, and devices. These can be pulled from relatively small bits of tissue or organ. [Rigorous rules exist to strip personally identifiable information from such human samples but to allow researchers to study these](#)—and to benefit from notably long, costly experimentation on them.

But how OK are we as a society about the proliferating, invasive collection of this material and highly personal, private information on each and every one of us, even if it is stripped to a degree of identifiers like our names, Social Security numbers and the like?

Would you want to be like the surprised heirs of [Henrietta Lacks, a poor African American woman in Baltimore whose cancerous cells were harvested without her knowledge or consent and then became one of the major sources of research material for decades?](#)

Will you be happy if, on a lark, you agree to a [DNA mouth swab at an NFL game only to discover much later that data gleaned from you led a Big Pharma company to a gold-mine drug?](#)

How good will you be if, long after your [cancer care with personalized medicine, you learn that your tumor and your tissues contained information that led to a profit-rich therapy for](#)

undifferentiated cells, which possess the capacity to transform into specific types of other cells, may be combined with other rapidly evolving technologies like 3D printing to someday allow bioengineers to “build” organs and limbs in labs, then implant them in or on humans.

Stem cell studies, however, remain works in progress. Don't be [gulled by the hype surrounding this evolving technology](#). It has a long way to go, and, as of now, thoughtful and careful experts aren't promising miracles or breakthroughs. Scammers are. Beware.

Photo credit: eGenesis

your disease?

Medical news can be tough to take in sometimes. Some of it is pure hokum, particularly when it tackles futuristic topics. But don't let yourself or the ones you love ignore advances, especially if they in any way hint to you that doctors or medical researchers aren't providing you with [your fundamental right to informed consent about any medical services](#).

The law and medical ethics place a simple duty on all doctors: They must give patients the important facts, so they can make intelligent decisions about what treatment to have and where to get it. That's why the word “informed” comes before the word “consent.” Information comes first. Consent is meaningless without the facts. Informed consent is about building a bond between the doctor and the patient, through a candid dialog that doesn't leave out anything important.

Tissues and organs may seem like yuck stuff, materials that may be left on an operating room floor or in a collection test tube or even on the end of a swab. It's stuff we no longer can neglect, because entrepreneurs are zooming in on it as never before.

Recent Health Care Blog Posts

Here are some recent posts on our patient safety blog that might interest you.

- Tens of millions of Americans, starting with Thanksgiving, hit the roads for a hectic season of family get-togethers and holiday social events. And though [the alarms have sounded for a bit now, there's yet more evidence that our highways are killing us at far worse rates than Americans have a right to expect](#). David Leonhardt, writing in the New York Times Upshot column, points out that America has become “a disturbing outlier” in road deaths—and its inattention to slashing them to levels that might be expected in a wealthy, developed nation.
- Hundreds of thousands of times each year, doctors [install stents \(tiny wire cages\) in blocked heart arteries, not only to provide better blood flow to the body's most important](#)

muscle but also ostensibly to provide pain relief to patients. Surgeons also perform tens of thousands of different, minimally invasive procedures with the help of elaborate and expensive robot devices. All these surgeries, which cost patients tens of thousands of dollars and carry real risks, are evidence-based and well-supported in their outcomes, right? Wrong. And here's hoping, not dead wrong.

- When the private equity firms move into [skin cancer treatment](#), you know the story is not going to end well for patients. Think lots of treatments, but hit or miss on protecting you from serious cancers. There's a simple self-protection solution for the many boomers – like me – who need to get skin lesions regularly looked at by the skin doctor. Just ask this question whenever you meet a new practitioner who proposes to examine your skin and cut or freeze off the growths there: What is the degree behind your name?
- Did you feel yourself just get less well? U.S. heart experts have just issued new [guidelines on what Americans' optimal blood pressure should be](#)—effectively and suddenly shifting just under half of the adults in the nation younger than 45 into an unhealthy status as hypertensive. Doctors say there's no doubting data that shows that blood pressure readings exceeding 130 over 80 can be detrimental to patients' health. That's down from the previous warning level of 140 over 90. But what exactly has the medical establishment wrought with this sweeping metric? Have they deemed so many of us unwell in this way that we're about to see public doubt and confusion—even profiteering—as has surrounded the description of tens of millions of Americans as “prediabetic?”
- Here's another [painful reminder to grownups about youngsters and sports](#): Moderation matters, and youthful games are supposed to fun, diverting, and character building—and most definitely should not leave today's aspiring athletes as tomorrow's hobbled adults. The New York Times has reported on what a pediatric sports medicine expert has described as a “dirty little secret” of orthopedics, which is “the chance of getting arthritis within a decade of tearing a tendon or a ligament in the knee is greater than 50 percent.” And more and more youths, as they participate aggressively and frequently in sports programs, are undergoing surgeries on damaged or torn anterior cruciate ligaments, a procedure well-known as the ACL repair.

HERE'S TO A HEALTHY END OF 2017!

Sincerely,

Patrick Malone

Patrick Malone

Patrick Malone & Associates

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