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Chapter

The Results Are Positive for Both Sides in the Great Majority of Cases When Organ Donor Families and Their Recipients Decide to Communicate with Each Other, US Experience in Tens of Thousands of Cases Shows

Reg Green

Abstract

Many countries restrict the ability of organ donor families and their recipients to communicate with each other; many make it virtually impossible. These restrictions were made for the best of reasons, mainly because of fears that one side or the other might suffer psychological damage. In the United States, however, for more than 25 years, communication has been strongly encouraged if both parties want it and under conditions set by their medical advisers. In literally tens of thousands of cases, a great majority of those contacts, which can range from the exchange of anonymous letters to face-to-face meetings, have proved to be therapeutic for both sides and significant problems have been very rare. Indeed, it is the families who are kept apart who may suffer most. The author is an American journalist, whose seven-year old son was shot on a family vacation in Italy whose organs and corneas were donated there. He and his wife have met all seven recipients and everyone, he says, has benefited.

Keywords: organ donor communication, organ donor contacts, transplant families meet, organ donor families, transplant families, Nicholas Green, Reg Green

1. Introduction

Imagine the thrill of opening an unsigned letter that says, “You don’t know me but you saved my life.” For a moment your mind goes blank. Is this someone’s idea of a joke? Did it come to you by mistake? Then you make the connection and your mind is flooded with half-buried memories. The letter is from Andrea, the 15-year old boy who received your son’s heart when you donated his organs. You remember Andrea was “struggling to stay alive” before the transplant, his doctor told you. At the time you could not get the phrase out of your mind. He was “grossly

undernourished,” weighing only 27 kilos, the doctor added, had to go to the hospital twice a week for blood transfusions and shuffled around like an old man. In short, for all practical purposes his life was over.

You read on: “I have a job, I can even play soccer.” It sounds like a miracle. It is a miracle: the transplantation of organs, a medical miracle that was first successfully done in my own lifetime and has become not simply the preferred cure, but the only cure, for many terminally-ill patients all over the world. Andrea’s story is not imaginary: it is all too real and with a far better outcome than for many patients on the transplant waiting list.

His story became part of our family’s life when my wife, Maggie, and I and our two children, Nicholas, aged seven, and four-year old Eleanor were on vacation in Italy. We had traveled from our home in Bodega Bay, California to Rome and were driving on the main highway from Naples to Sicily. It was at about 10 o’clock at night in Calabria, the toe of Italy, when a car that had been behind us drove alongside and instead of overtaking stayed there. “There’s something wrong here,” I said half to myself.

Maggie, who had been dozing, woke up immediately, in time to hear savage, angry yells from the other car, not a word intelligible, but obviously telling us to stop. From the corner of my eye, I saw some rust or dirt marks on the hood of their car. It looked older than our rented car and it flashed into my mind that we could probably outdistance them if we needed to.

Maggie looked over and saw a few feet away two masked men, one of them waving a pistol. Obviously, if we did stop we’d be completely at their mercy so instead I accelerated. They accelerated too, I floored the car, they floored theirs, and the two cars raced down the road side by side until there was a deafening explosion and a bullet shattered the rear passenger window, where the children were sleeping.

Maggie immediately turned around to make sure they were safe. Both appeared to be sleeping peacefully—it seemed a blessing at the time—but now it was beyond doubt that these were not young thugs out for a thrill but dangerous criminals. A moment later the driver’s side window was shattered by another bullet, glass flying everywhere, and how it missed the two of us on the front seat we will never know. But by now we were doing what I’d hoped, pulling away and from seeing them alongside I saw their headlights in the wing mirror, then in the rear-view mirror, and then they disappeared back into the night.

What a relief. We’d escaped. I kept driving at top speed, however—who knew if they might come back?—and, as it happens, a few miles further there had been an accident. The police were there, an ambulance was getting ready to take an injured man away. I pulled over and stopped, the police shouting at us to move on. I got out of the car to explain but when the interior light came on Nicholas did not move. I looked closer and saw his tongue was sticking out and there was a trace of vomit on his chin. One of those bullets had hit him in the head.

Shocked beyond belief, I said something to Maggie. She looked too and cried out in horror: it was the only time through everything that followed that she raised her voice. Nicholas was in a coma and was rushed to hospital in Messina, Sicily. An interminable two days later, without ever regaining consciousness, he was declared brain dead. I have never known such bleakness.

2. The shot was heard around the world

That was 26 years ago but I remember in exact detail sitting in the sunny hospital room as the doctors told us there was no more hope, holding Maggie’s hand, trying to come to grips with the idea that he and I would never again go out for one of our

walks where I could make him helpless with laughter at some tale that one of his inventive questions provoked, never again hear him say “Goodnight, Daddy.” It was then that Maggie said quietly, “Shouldn’t we donate his organs?” and I said “Yes.” It was that simple. Until that moment, everything had been totally black. There wasn’t a shred of good in it. Now, for the first time since the shooting, I could see that something could be pulled from the rubble.

Nicholas was a magical little creature, who brought sunshine into every day. I don’t think he ever hurt anyone in his life. His teacher said she always knew he was her teacher. As one of his classmates said “he would always play with some other kid when no one else would” and since he died nothing has ever been quite the same.

But neither Maggie nor I have ever had a moment’s regret that we made the donation. In fact, having met the recipients and knowing what would have happened to them if we had made a different decision, I know that if we had packed our bags and shrugged off their problems as none of our concern, neither of us could ever have looked back without a deep sense of shame.

As it turned out, a lot more good came out of it than anyone could have imagined. There were seven recipients, five organs and two corneas—that surprised me, it seemed too many for such a small body. Four of them were teenagers and most of them were very close to death. In Italy at the time organ donation rates were almost the lowest in Western Europe but the story so electrified the whole country that in the next ten years donation rates tripled, a rate of increase no other country has ever come close to, and literally thousands of Italians were saved from an early death [1]. Now its donation rates are among the highest in Europe.

Better still, the story captured the world’s imagination. I do not suppose any serious newspaper or television station anywhere did not run the story prominently then and later as key developments occurred, including our highly-publicized meeting four months after the shooting with six of the seven recipients (Andrea was still recovering in hospital); the birth two years later of twins to Maggie and me, filling up what had been an empty house and putting the sparkle back in life for Eleanor, by then seven years old; the arrest of the two men, minor Mafia figures, who attacked us on one of the main roads in Italy because they had received a tip that a car delivering jewelry was coming through that night and seeing the Rome license plates on the rental car jumped to their fatal conclusion; and their trial, conviction and sentencing (twenty years in prison for one, life for the other—later commuted to house arrest for cooperating with the police for helping solve other crimes, though there is room for doubt about how much he actually helped).

As a result of all this publicity tens of millions of people saw clearly for the first time that if someone they loved died of a brain injury they could save multiple families from devastation by a simple decision. Organ donation—then a mysterious, somewhat weird, not-to-be-talked-about process that, if it happened at all, happened to someone else—became a subject of conversation of serious-minded people around the world.

At that time, almost no one in the general population understood the crucial distinction between normal death and brain death: that in the first case the organs wither too quickly to be used so that only patients who are on a ventilator that can keep the organs viable for a few hours after the brain dies can be donors. Brain death is usually sudden death—a road accident, violence, a stroke—where the victim, though fatally injured, can be taken to a hospital with the blood still flowing through the body.

Since those deaths are only about 1 percent of the population it’s no wonder that every donation is so precious and that so many patients die on the waiting list. It is also no wonder that many families who have said they are in favor of donating cannot go through with it when the time comes: they arrive at the

hospital to find someone they love, often painfully young and until then perfectly healthy, is dead or dying; their minds are in turmoil; they cling to the thought that there may still be hope. In those circumstances to be asked there and then if they will donate the organs is too much for many people: they say “no” and often realize only the next day that they have turned down what will probably be the best opportunity they will ever have to make the world a better place. But by then it is too late.

3. Donor families who want to know more about their loved one’s recipients

Of the donor families whom we have met across the world virtually every one of them says what we say: that donating was the one uplifting thing to come out of a time when everything else was empty of meaning. Even so, for many of them there is a feeling of incompleteness because in many countries they are allowed to learn only a few sparse details about the recipients: how old they are, whether the transplants were successful, what organs were used. That’s all. It’s quite impersonal, nothing much to go on to build a picture of what the recipients are like.

They have to imagine it—and what they imagine can be wildly wrong. In a few months they do not know how the recipients are doing, even whether they are still alive. It’s shabby treatment (isn’t it?) for people who resisted an almost overwhelming instinct to turn inward in sorrow and bitterness and instead put their grief on hold long enough to help people in desperate need whom they had never met and could not even visualize.

Originally the restrictions were imposed for the best of reasons. When transplantation was in its infancy and half the cases were unsuccessful, those who set the rules thought it would be heart-breaking for donor families to find their decision, which had often caused them such an emotional wrench, had after all been in vain. They also wanted to protect the families from unwelcome publicity.

As the treatments matured, and successful transplants became the norm, the objections to any form of contact between the two sets of families became more strained and to smack more of authority wanting to impose control than for the benefit of the families. Suppose the donor family does not like the recipients, opponents asked, will they wish they had not agreed to donate? What if a strongly religious family of donors finds out the recipients are of a different faith? What if the donor family had lost a child and had set its heart on saving other children but instead finds all the organs went to grown ups? Suppose a donor family asked the recipients for money?

These fears, though they are still cited, were always hugely overblown. Families who are willing to donate have already been through a crushing experience and few of them doubt that saving the lives of several other people is far more important than whether those people have a lifestyle similar to their own. By the act of signing the consent form they know they have agreed the organs will go to those who are most in need and that is what they want.

Indeed, it is one of the inspiring aspects of organ donation that it is a gift free of all restrictions. In the expression commonly used in the transplant community, it is “a gift to the world.”

That is why so many white women are walking around with black women’s hearts inside them—and vice versa, why so many Latinos are breathing through Asian lungs—and vice versa and why Muslim kidneys go to Jews and vice versa [2]. It is the glory of transplantation that it leaps over all the normal barriers between us: age, gender, nationality, color, religion, politics, wealth.

It's true that for many donor families the restrictions are not worrisome. They know they have done the right thing but want to put that phase of their life behind them: to get on with their lives as best they can and let the recipients do the same. Others, however, do care and some care a lot. They are full of questions. Was the young woman who got their daughter's heart able to marry the sweetheart who'd been so loyal to her throughout her long sickness? Was she able to have a baby? Did the athlete who could not get out of a wheelchair take up sports again? Can the blind mother now see her baby's face?

Similarly the views of recipients vary just as widely. Some prefer not to hear from the donor family. They are all very, very grateful but they shrink from a relationship with people who might be too intense, too possessive. On the other hand, many others want nothing more in life than to meet and thank the people who rescued them. For those people getting to know the donor family can save them from a lifetime of unease. All recipients of deceased donors know they are alive only because someone else died. Many harbor feelings of guilt. They suppress those feelings but the best cure is to receive a letter from the donor family or hear them say, "We hope you will have a long and happy life. We want our gift to be as valuable as possible."

4. Meeting our son's recipients was uplifting

For Maggie and me there is nothing theoretical about this. Having met all seven of Nicholas' recipients has enriched all our lives, theirs as well as ours. We can hear about or see for ourselves lives developing that would have ended long ago and they can see we do not hold it against them that they are enjoying themselves while Nicholas is dead. They know instead that nothing gives us more pleasure than their being healthy and happy.

After 26 years only two have died, though one is back on dialysis and another needed a second corneal transplant. You already know about Andrea, the heart recipient who died after 22 years, though even then the final cause of death was respiratory failure: his heart (Nicholas' heart!) was beating strongly to the very end. That was a sad day but I have to say neither Maggie nor I felt any of the secondary grief some psychologists warn about. It never occurred to us that we were losing Nicholas again. Our sadness was for the Andrea we had watched grow up from boyhood to manhood and who had finally succumbed because his body had been undercut by his debilitating heart troubles when he was a child.

So let me instead tell you about one of the five who is still living: Maria Pia Pedala, a 19-year old from Sicily who was in her final coma from liver failure the very day Nicholas died. "We had given up on her," her doctor told us. With a new liver she quickly bounced back to good health, married two years later and two years after that had a baby boy, something that at one time was unthinkable. She called him Nicholas—and spelt the American way rather than the Italian Nicola. You imagine what pleasure that gave us. I always hope many people will ask him how he got his name.

After all she had gone through Maria Pia was understandably nervous when her Nicholas was a baby. She comforted herself by picturing our Nicholas standing on guard, keeping him safe. The family called our son Big Nicholas, the baby Little Nicholas. Now Little Nicholas is fit enough in a family with a long history of liver disease to be training as a non-commissioned officer in the Italian navy. He is a tall, slender, handsome young man and next to him our seven-year old would be a little shrimp. But, whenever Maggie and I meet or write to Maria Pia and her husband, Salvatore, one of us usually mentions the Big Nicholas story and we all smile, though a little sadly.

5. Changing the way organ donation is thought of

From the very beginning the global explosion of interest showed us that we had an opportunity to make a permanent change in the way organ donation was thought of. Everywhere we went the media came too.

Building on this, one or other of us has given speeches in countries as diverse as Venezuela and New Zealand, Russia and South Korea, written dozens of articles for or been interviewed by publications ranging from *The Times of India* to Oprah Winfrey, from Buddhist television in Taiwan to Vatican radio, spoken in evangelist churches, synagogues and cathedrals, to Muslim and atheist groups and to every age from nursing homes to primary schools.

I have written two books on organ donation. One of them, “The Nicholas Effect” [3], was the basis for the made-for-television movie, “Nicholas’ Gift” [4], starring Jamie Lee Curtis and Alan Bates which has been seen by 100 million people worldwide. The other, “The Gift that Heals,” has been used by hospitals across the United States as the easiest and most comprehensive introduction available to the human side of organ donation.

One result is that people all over the world feel close to Nicholas and have responded with an enthusiasm that has multiplied the message. To give just one example: a school in Sicily put two clocks in its hallway, one set for local time, the other set to ‘Bodega Bay time,’ the village in California where we and Nicholas lived, so that every day students are reminded that as they go through life there is always something they can do for others.

The message traveled up as well as across. Pope John Paul II was so moved by Nicholas’ story that he authorized the casting of a magnificent bell for a tower designed and built by a San Francisco sculptor, Bruce Hasson, in Bodega Bay, which is dedicated to all children who have died [5].

I always felt, however, there was one cause that needed to be taken up in Italy where the law effectively prevents the two sides of a transplant from making any sort of contact, even by anonymous letters. For more than twenty years I stayed clear of the issue not wanting to be seen as interfering in the laws of a foreign country. But in 2016, at the age of 87 I thought time was running out, so with the help of just one friend, Andrea Scarabelli of Rome, I started a lonely campaign—we called ourselves Don Quixote and Sancho Panza—bombarding the media with information, writing articles, being interviewed on national television. Key elements of the media responded so enthusiastically that we reached tens of millions of people and everywhere in Italy those people began to ask, “If two families want to meet, why not?” Marco Galbiati, the bereaved father of a much-loved 15-year old boy, for example, collected 50,000 signatures in favor of changing the law.

Faced by these two prongs, the Italian National Transplant Center referred the issue to the National Bioethics Committee, which almost everyone saw as a delaying tactic. We bombarded the committee with evidence, most tellingly of how in the great majority of cases in the United States, when families have contacted each other, the health and happiness of both have improved. To general surprise, having scrutinized all the information presented to it, the committee decided in favor of allowing contact—including face-to-face meetings—under the usual conditions and if both sides express a wish for it. The Italian Department of Health endorsed the decision [6] and legislation has been introduced into the Italian Parliament.

6. Contacts between families are strongly encouraged in the United States

Unlike most countries, communication between the two sides is strongly encouraged in the United States, and it works with great success. Naturally, how families

respond to that possibility is different in every case. Some do not want any part of it. Others embrace it eagerly and for them the steps are carefully chosen and watched over by their doctors all the way. The normal procedure is for both sides to be asked if they are willing to receive an anonymous letter from the other. If either of them says no, the process stops cold and is abandoned however persistent the other family is. If both agree to communicate, however, one side writes an unsigned letter.

If it is the recipients who make the first move their letters typically start by saying they do not know how to express their gratitude: but then they dig deeply into themselves and even the ones for whom writing is difficult find a power they did not know they had. On reflection, this should not be surprising: they are speaking their most intense thoughts. They then say the transplant has worked well (it generally has) and that they can now do things that were impossible while they were sick.

That part of the letter astonishes many donor families: they had not fully understood until then that before the transplant many of these people had stayed indoors permanently and were afraid to be alone at any time; or that their hopes of marrying, having a baby, getting a degree, traveling, playing games or having a career had been put out of their minds as impossible fancies; or that every night when they went to bed they wondered if they would wake up in the morning. Accompanying that understanding comes a surge of pride in the donor family that even in death their loved one is still bringing peace of mind to complete strangers.

The process of communication is handled by one of the organ procurement organizations (OPOs) designated by the US Department of Health to look after transplant families and staffed by specially trained health professionals. Before the letter is sent it is read at the OPO for signs that it might cause difficulties: does it suggest the writer is looking for a closer relationship than normal? Does it indicate extreme views that might not be compatible with the other family's lifestyle? If something seems wrong the letter-writer may be warned to go easy or the letter may be stopped entirely. If all looks well, however, as it generally does, it is forwarded, unsigned.

Reading it, the donor families might weep a little at the memories it stirs, but the predominant feeling is one of excitement and fulfillment. Having read the letter they have complete freedom of action, anything from putting it away and never doing anything more or, if they wish, replying with an anonymous letter of their own, which will also be scrutinized by the OPO, and if it sends up no cautionary signs (as it rarely does) will be passed on to the first family. Alternatively, it might be the donor family who makes the first move but the process is the same.

If all goes well (as it normally does) the two families can start sending letters that they sign and tell more about themselves. In time (with their medical advisers' approval) they may want to telephone, send photos or email each other—each stage an exciting step that reveals more and more about themselves—and, ultimately, if both agree, they can meet, like families who happen to come into contact with each other under any other circumstance. Why not? Here the bond is far more meaningful than two families who meet because they have a common interest in yoga or their kids' baseball team.

7. Contacts that turn negative are rare

If the people who want to know more about the other side were just a handful, and unrepresentative of the typical family, this would be a side issue. But it is not. This is what Alexandra Glazier, CEO of New England Donor Services, an OPO responsible for organ donation in six states with a population of 14 million, says: "A recent review of our data indicates, that about 52 percent of donor families will connect with a recipient, either by receiving a communication from or sending a

communication to, within the first two years of their loved one's organ donation." In 2019 in the US as a whole, a total of 29,000 letters were forwarded through OPOs from one side to the other.

Just like any other relationship, these people may find they do not have as much in common as they would like. They may find the other family uninteresting or uncongenial. In that case they do what everyone else does in life: they stop seeing them so often and if they are asked why they have become distant they answer diplomatically or bluntly, depending on temperament, just like any of us do. In fact, they are in a much stronger position to free themselves from unwanted relationships than the rest of us are. They have behind them the full weight of the health service saying: "We've been talking to the Smith family who say they think you are phoning them a little too often. We'd prefer that you didn't contact them for a while or wait till they contact you. Okay?" It would be a brazen family who persisted after a warning like that.

In fact, although worst cases can always happen, these relationships are overwhelmingly positive and many become very close. On one side these are people who helped you when no one else could: why would you feel anything but well of them? On the other they are people who have something inside them of someone you both love. So it seems natural if they choose to go to each others' houses for Sunday lunch, phone each other on birthdays, console each other when they feel unhappy (who better?).

Against this opponents of contact typically respond with generalized stories of how some contacts went astray—rarely anything that can be checked and generally long ago when best practices were still being worked out—or some hypothetical objection built on theory. However, my observation after meeting hundreds of transplant families is that, if the case is handled by the book, the risks are very low. In fact, I believe it is the people who are denied contact whose health and contentment are more likely to suffer. Like many of us, they much prefer the certainty even of bad news to a lifetime of doubt.

8. Two families meet and find happiness

The story of Inger Jessen shows what happens in real life. It has not been easy for her: she has lost both a husband and a son. She herself had a leg amputated because of diabetes and when she was 55 her heart was so weak that she could not walk out of her house without help.

But instead of all that bringing a sense of isolation it has encouraged her to share with others. So, when in 1997 she received a new heart, her overwhelming instinct was to thank the donor family for their generosity and commiserate with them on their loss. Knowing nothing about them, she wrote an unsigned letter through OneLegacy, the organ procurement organization in Southern California.

She received no reply. She was disappointed but understood and put it out of her mind. Years later, however, when she had won two gold medals in swimming at the World Transplant Games—Olympic-style events open only to organ recipients—she decided to write again, thinking that the news would show them in the most vivid way what a difference their donation had meant to her.

But she had no idea how shattered the family had been. The heart had belonged to an 18-year old, Nicole Mason, who had been knocked down by a car while she was walking on a road near home. Nicole's father, Dan remembers how nothing seemed to matter anymore. "I had no feeling for anything. Sometimes when I was driving I had to pull over to the side of the road to sob," he remembers. "I had a four-year-old grand-daughter and I couldn't even play with her."

But time passed and for the Masons too thoughts were stirring and in the end they decided they would like to know more about this kindly lady with whom they had such an unusual bond. They contacted OneLegacy, saying they would like to meet. Inger says that for days after she received the call, she went around in a dream.

On the 20th anniversary of Nicole's death, a date crammed with memories for all of them, they met and melted into each other's arms, the climax coming when the Masons listened by stethoscope to the strong, regular beat of their daughter's heart, which has worked perfectly from the start. Everyone cried but through the tears of sorrow shone the joy. "I couldn't believe I was listening to Nikki's heart," Dan recalls with awe. "I think of her every day. She seems so far away. But here she was again."

For Inger too the meeting has had a profound effect. "Since then," she says, "I have felt a peace I haven't known in years." But the proof is not in anecdotes but in the statistics and there the evidence is very strong. *Tens of thousands of contacts* by letter or in a minority of cases in person have taken place and have been documented by medical professionals in the United States in the last thirty-some years and the results in the great majority of cases have been therapeutic for both sides.

9. The organ procurement organizations are enthusiastic

In the United States bodies called Organ Procurement Organizations are designated by the U.S. Department of Health to oversee the welfare of families involved in a transplant, both donors and recipients. There are 58 of them, one for each state, more than one for the largest states. All 58 agree that in the great majority of cases communication is beneficial to the two sides.

To take a few examples, Kathleen Lilly, Executive Vice President of LifeLink Foundation, which covers areas as diverse as the modern cities of central Florida, rural portions of Georgia, the high-class tourism of the U.S. Virgin Islands and Spanish-speaking Puerto Rico, says "Our foundation's experience with donor family and recipient communication has been overwhelmingly positive for all involved." At the opposite corner of the country is Life Center Northwest, whose territory includes states in the northwest of the United States and Alaska. Its CEO, Kevin O'Connor, says the same thing: "The ability to exchange letters between donor families and recipients is profoundly healing and therapeutic for both parties." And in the middle of the country, Jennifer Prinz, CEO of Donor Alliance, the organ procurement organization covering Colorado and most of Wyoming, agrees. "Correspondence between donor families and recipients is a tremendously powerful and positive practice in the donation. We see many donor families and recipients go on to have incredibly close, family-like relationships, across many years and great distances." It's difficult to argue against all that first-hand experience, isn't it?

Can things go wrong? Of course. What can't? But Tom Mone, CEO of OneLegacy, which covers 20 million people and 200 hospitals, says that in twenty years "no families who met each other have regretted it." Even for the small minority of cases which go bad, remedial action can usually be quickly taken. Meanwhile, should that small number prevent families who have suffered so much from experiencing what could be one of the most meaningful encounters of their lives? Should an impersonal medical bureaucracy be able to stop two mature families from even exchanging anonymous letters? Does it know better than the families themselves and their medical advisers what is good for them?

You only have to ask the questions for the answers to be in no doubt.

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