

Giving and Receiving When Vital Organs Fail

Donald L. Madison, MD (with Andrew, Jim and Susan Pike)

Andrew Pike is 25 years old. He lives in Chapel Hill. Seventeen years ago, when he was eight, Andrew received a heart transplant. He received a kidney transplant on June 24, 2003. The donor of the heart was an unknown child. Andrew's father, Jim, donated the kidney.

Seventeen years is a long time for a heart recipient to remain free of life threatening complications (although kidney failure was in fact a complication of one of the immunosuppressive drugs that was administered following the heart transplant). Andrew Pike is not yet setting the bar, but he is approaching it. The longest survival for a first heart transplant in a child that Dr. Michael Mill (who heads the heart and lung transplant team at UNC Hospitals) knows of is 25 years.

Andrew's mother, Susan Pike, had been the donor of choice for his new kidney, but she failed to pass muster during the workup.

SUSAN: My kidney was fine, but the blood vessels weren't. Instead of being straight and having regular thickness of the walls, mine were curved and had overgrowth of some kind. So the doctor did not want those blood vessels because you must take part of the vessels along with the kidney to transplant. And they thought that it was not going to be good for me to have only one kidney.

JIM: They had a name for that condition.

SUSAN: Dysplasia. Some kind of dysplasia. It's nice that we've forgotten.

DLM: Dysplasia means shaped wrongly.

SUSAN: That's me alright.

DLM: Actually, it means that something developed wrong. That's pretty common in and around the kidney.

Jim and Susan have another son, Ben, who is six years older than Andrew. Ben lives near Chicago and might also have qualified as a donor except for his high blood pressure. But beyond that physical disqualifier was another, social one: Ben is the recent father of triplets.

When Andrew was born, on the second day of 1979, the Pikes were living in Wilmette, Illinois, a suburb just north of Chicago, not far from the lake.

ANDREW: I was born between two of the worst blizzards. I've only heard stories about it. I guess it was the day after I was born that they noticed that I had transposition of the great vessels.

DLM: I imagine that it doesn't take long to notice.



Susan, Jim and Andrew Pike

ANDREW: I think it was my dad who looked in on me when I was lying in the isolette, and he noticed that I was breathing twice as fast as the other babies. And I was turning blue. After that the cardiologists came in to figure out what was what. I'm a little fuzzy on all the details. But between then and my ninth birthday I had, I think, five open heart operations, with physical therapy, I suppose, after each one, and probably hundreds of tests and procedures. And when I was eight years old I had my heart transplant. I was in the

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hospital for seven weeks. Finally, I think it was on Christmas Eve, I was released from the hospital.

It was a struggle to get used to everything after that. I had to relearn a lot of things, because I had a stroke during the procedure.

DLM: While you were on the operating table?

ANDREW: I think that's the way it happened. And after that the right side of my body was pretty much paralyzed for a while. I had to relearn how to use my right hand, which still has a lot of weakness—a lot of physical therapy after that, speech therapy, too. But it was also a time to celebrate even while I was going through so much hardship. I would have to make sure I wasn't around people with germs, because after an organ transplant—any organ transplant—you have to take anti-rejection medicine, and a side effect of that is that you are immune-suppressed. Well, actually, that's not a side effect; it's the main purpose of it.

It was difficult for me, being at such a young age, to understand why this was all happening to me. I would see my friends, who would be leading normal lives, going to school, playing outside and all that, and they didn't have to deal with any of this. That was probably the most challenging part for me—not having the slightest idea why this should happen to me and not somebody else. I've been on medication since, I guess, day one. My nickname when I was in the hospital used to be Human Pin Cushion, because I had to get so many shots. By now I'd guess it's probably been 2,000 or so. I'm used to it. After the transplant I had to have heart biopsies done, I guess twice a week to start out with, and then every week, and then every other week and so on. Now it's every couple of years.

DLM: What are they looking for?

ANDREW: A biopsy is the surest way to check to see whether or not I'm experiencing rejection. They take a catheter, which is really a long, thin wire, and insert it into a vein, thread it up to my heart, and take a sample of tissue and then look at it under a microscope to determine if there is rejection. That was probably the most difficult thing for me as a kid in terms of dealing with pain. I would wake up sometimes maybe 10 or 15 minutes before the whole thing was over, and they would have to hold gauze with pressure against the site. I remember that as the most painful thing.

DLM: And there has been no sign of rejection?

ANDREW: So far, no. Most people experience rejection or coronary artery disease after about 10 years. To go this long without experiencing either of those is—not unheard of, but it's unusual.

Jim and Susan Pike met in Madison, Wisconsin. Susan was a graduate student in Spanish at the University of Wisconsin; and she attended the church where Jim came as Associate Pastor following his graduation from divinity school at Colgate Rochester (in Rochester, New York) and his ordination in the American Baptist clergy.

Susan's roots are in North Carolina and Tennessee. She was born in Elizabeth City and attended school in Lexington and Raleigh before moving to Nashville, where she finished high school and attended college at Vanderbilt. Her father was a Southern Baptist minister who became editor of a Sunday School periodical and other church literature for young people.

Jim grew up in Terre Haute, Indiana. After high school he attended his hometown college, Indiana State. Both of his parents were high school teachers: his mother taught Latin, and his father was a football and basketball coach whose most illustrious pupil—probably—was the Terre Haute Terror, future inductee into the Basketball Hall of Fame, future teammate of both Dean Smith and Bill Russell and, eventually, the most physically imposing one-term sheriff in the history of Vigo County, Indiana. (I think I impressed Jim by knowing that Clyde Lovellette was from Terre Haute.)

After graduate school, Susan taught for five years. She and Jim married and moved to Chicago, where he became Pastor of the Community Church of Wilmette. They lived in Wilmette for 22 years and during that time raised their two boys.

Eight years ago the family came to North Carolina when Jim accepted a call to become Pastor of the Olin T. Binkley Memorial Baptist Church in Chapel Hill.

On the day after he was born Andrew underwent his first heart operation. His congenital malformation included transposition of the great arteries (the aorta emerged from the wrong ventricle and so did the pulmonary artery) with stenosis of the pulmonary valve, along with a faulty tricuspid valve, and a defect of the septum between the two atria (a hole in the wall that separates them) and also of the septum between the two ventricles. Transposition of the great arteries means that the stronger left ventricle is pumping blood into the lungs (instead of out into the body) and that this oxygenated blood when it returns from the lungs comes back to the same side of the heart, only to be pumped through the lungs again and again. At the same time, the right side of the heart is pumping blood out into the body, and this blood returns to the right side of the heart, bypassing the lungs altogether. The entire circulation looks like a figure 8, except that the two loops of the 8 don't connect. One loop has oxygenated blood; the other one doesn't. The only way that any oxygenated blood from the lungs can reach the rest of the body is through the defect: The small hole in the septum between the two atria allows mixing of oxygenated blood from the left heart with deoxygenated blood from the right heart. This mixing allows *some* oxygen—though not enough—to reach the rest of the body. But the greater amount of blood that is being forced into the lungs by the stronger left ventricle causes pulmonary hypertension; and the extra work placed on the weaker right ventricle (which now has to pump against the much greater resistance put up by the circulatory system of the entire body) causes heart failure. So if the defect (hole) between the atria can be enlarged by performing a balloon septostomy, which was Andrew's first operation, more of the blood can be mixed and therefore oxygenated, and the heart failure can be slowed, temporarily.

The balloon septostomy didn't require opening Andrew's chest, but later operations did. When he was 18 months old, he underwent a Mustard Procedure. During this operation (no longer performed in the U.S.) the surgeons actually used the pericardium (the sack that surrounds the heart) to construct a baffle inside the atrium that then forced more of the oxygenated blood returning from the lungs to pass down into the right ventricle, which in transposition of the great arteries is the pumping ventricle for the aorta and the rest of the body. At the same time the surgeons also repaired Andrew's ventricular septal defect, the stenosis of the pulmonary artery, and the tricuspid valve. But during the post-operative course Andrew developed a complication—an infection beneath the sternum, which required a second, clean-up operation.

Three years later, Andrew's heart was again opened, this time because his tricuspid valve was failing. The surgeons then put in a new, artificial St. Jude valve.

DLM: When you were very young, before the heart transplant, could you exert yourself at all? What kind of shape were you in physically?

ANDREW: I wanted to be active—run, climb, jump—I wanted to do everything, which made it all the more difficult for my mother and father to prevent me from going against the doctors' instructions and what not.

JIM: When he was a baby Susan had to check his heart rate

every two hours. Once, we were on vacation, and I can still picture her putting him on the hood of the car and counting his heart rate. It was a pretty constant thing.

SUSAN: Later, the doctor had to say things like, "Well, I don't want you to become a couch potato, but..." and asked him not to play quite so hard. Before he was ready for the transplant he won two blue ribbons in the Cub Scout Olympics, which involved foot races, throwing a basketball and the like. And the next week he was in the hospital with congestive heart failure.

Physical activity mixed with a taste for high adventure has been a theme of Andrew's life both as a child and adult. But his active life came to an abrupt deceleration at about age seven.

SUSAN: When Andrew experienced a TIA (transient ischemic attack)—I'm going to say he was six and a half—the doctor said, no, he should not use his skateboard anymore, should not ride a bicycle, should not climb trees. And that was hard.

JIM: That's when we talked with him about having a heart transplant and asked him whether he wanted to do it. And he said, "Will I be able to climb a tree again?" And I said, "Yes, you will." "Then I want to do it," he said.

Andrew's heart failure progressed from that point. In September of 1987 he underwent yet another heart operation, an attempt to reverse the earlier Mustard Procedure and take greater advantage of the stronger of the two ventricles' capacity to pump blood to his body. The surgeons referred to this as a "last ditch" operation. Susan remembers that Andrew did show some modest improvement afterward, but only for about two weeks. It was clear that he would need a heart transplant to survive.

In 1987 only three centers—Stanford, the University of Minnesota and Childrens Hospital of Pittsburgh—were performing heart transplants in children. Michael Mill was, at that time, the transplant fellow in cardiac surgery at Stanford; he recalls that in those days hearts were "relatively plentiful, mainly because so few centers were performing transplants, and we could establish direct personal relationships with other hospitals that would often put us in touch with a donor." The national organ procurement regulations were still in the future. Today, instead of three hospitals performing heart transplants in children, somewhere between 60 and 70 hospitals have pediatric heart transplant programs. Altogether, the United States now has 141 heart transplant programs (adult and children) and 245 kidney transplant programs. In the year 2000 these centers performed a total of 2,246 heart transplants and 14,283 kidney transplants.

In the summer and fall of 1987 eight-year-old Andrew Pike was in severe congestive heart failure. He needed a transplant; but there was a problem.

JIM: We were told that the scars from Andy's previous heart surgeries would keep him from having a transplant. They told us that he wasn't going to make it.



Andrew at seven months with his mother, Susan.

Then our cardiologist—her name was Theresa Berry—went to New Orleans to a heart convention, and she talked to the people from Pittsburgh, and they said that they'd like to see Andy and maybe consider him, but that it would be an exception.

I remember that weekend was Halloween. I had carried him out trick-or-treating, because he couldn't walk at that point; he just didn't have the strength. The next week he was on an "Angel Flight" to Pittsburgh, and a week later he had a new heart.

(NOTE: "Angel Flight" is an umbrella organization of regional associations of volunteer pilots who provide free emergency transportation for medical purposes such as this one.)

DLM: So you went to Pittsburgh for evaluation?

ANDREW: Well, before the transplant I think everyone had decided that it was going to happen. Right?

SUSAN: Well, you had to be evaluated. And the surgeons pointed out that there were risks, including the risk of stroke.



Disney World, July 1987. Suffering from severe congestive heart failure, eight-year-old Andrew would have a new heart four months later.

JIM: But they determined after a couple of days that he was a candidate. And the last few days we were just waiting.

SUSAN: It just happened that a heart was available after a week. The same donor who gave Andrew a heart also gave a liver and two kidneys.

DLM: Do you know anything about the donor or the circumstances of the donor's death?

SUSAN: At that time they did not introduce donor families.

But it was a good heart, they said. The doctor would not tell Andrew the gender of the donor. We did understand that an auto accident caused the other person to lose his/her life. And the person was older than Andrew—I think 13—so the heart was a little bigger than what he normally would have had.

DLM: When you say that at that time they did not introduce donors' families to recipients and that the doctor wouldn't tell you the donor's gender, it suggests how terribly important it was that the identity of the donor be kept confidential.

ANDREW: Yes, and even now, the only way I could meet the family is if I wrote a letter to the organ procurement organization of North Carolina—they have people there who would evaluate the letter and decide whether or not it was possible and appropriate to contact the family. If it was they would make contact and ask them how they felt about this. And if the family wanted to meet with me then that agency would help set it up.

DLM: It sounds like you've looked into this.

ANDREW: I have, and there was one time about three years ago when I thought seriously about going to see them or at least getting in touch. So I did learn then about how it was done; but in the end I decided that my life just wasn't where I wanted it to be, and I wanted to be at my best when I did that. It's really important to me that I be at least somewhat successful and independent and on my own before I meet them.

DLM: So it's still something that you have on your agenda, long term?

ANDREW: Yes, it is.

JIM: At the time of the transplant we did write a letter to the family, anonymously, and the hospital saw that they received it. We did not hear from them.

DLM: After the heart transplant, your main medical problem, besides the need for immunosuppression, must have been rehabilitation from stroke.

ANDREW: Yes, the stroke was a main issue. I was in the hospital for seven weeks after the transplant. I did have to take third grade over again. I had missed 117 days of school that year. That was difficult getting stuck back a year away from my friends. How long after the operation did I have to stay there (in Pittsburgh)?

JIM: We rented an apartment not too far from the hospital with the help of the social work department there, and Susan and Andy stayed there almost until the middle of February, and then they came home for a few days and then had to go back. Because Andy had to have these biopsies every week or so for so long, it was well into April before we gave up that apartment. But his care was not transferred to Chicago until that summer. So we continued to make trips to Pittsburgh until June or July.

SUSAN: Andrew had to deal with the stroke, of course, but



The summer after the heart transplant.

there were other problems. He always had strong side effects from the medications. Cyclosporin and his body were just not compatible. Not only did he have overgrowth of hair, and darker hair—he did not look like his old self. One of his friends told him: “You’re not Andy.” And by junior high and the onset of puberty, he was having terrible headaches that would cause him to miss school. Or he’d get to school and then call me and say, “I’m in the nurse’s office.” They tried to play around with the medication to alter it or do something that would help. And he took Neurontin for a long time—to be sure there were no seizures. We finally sought help from a man who was both a neurologist and knew acupuncture. He was about the only one who could get the headaches to stop.

JIM: It turned out that they were Cyclosporin headaches. It took a while for them to decide that. We thought they were migraines.

SUSAN: Andrew’s older brother had headaches, so we were predisposed to think that Andrew was getting the same kind. I don’t think they knew then that Cyclosporin in some people caused these severe, debilitating headaches.

JIM: One of the immunosuppression problems is warts. Remember that horrible wart, two inches wide, on your foot, the year after the transplant? You were on crutches for a long time.

ANDREW: I remember that. It was right on the bottom of my foot, and it hurt. It was not fun.

SUSAN: He couldn’t do gymnastics because of it. One of the other patients in Pittsburgh, a little Canadian girl, had little tiny warts all over the bottoms of both feet. She had also had a stroke, but hers was such that she had to learn to write with her left hand. And the Make-A-Wish Foundation gave her a computer so that she could do her work that way.

Andrew is reminded of the part in his story played by the Make-A-Wish Foundation, an organization that took on the important responsibility of providing a pleasurable episode at a painful time.

ANDREW: They came into my hospital room—some representatives of the Make-A-Wish Foundation. They asked me what I wanted and, as I remember, the first thing I wanted to do was go skydiving. I’d seen it on TV and I thought it was what I wanted to do. The doctors thought that would be a little too risky for someone who has just had a heart transplant, so that was out. Then I thought about maybe meeting Arnold Schwarzenegger, because he was my hero at



Andrew at 10 years of age. He is holding his “old” heart, which he wanted to see after being told that it was in a repository (of congenitally malformed hearts) at Children’s Memorial Hospital in Chicago.

the time, the big action hero in the movies, and I loved all that stuff. I wanted to be in a movie with him. But then I realized that it would be just meeting and talking to him for maybe 15 minutes and it would be over. Eventually I decided I wanted my own tree house. So the Make-A-Wish Foundation paid for a builder to come to our home and build this two-story tree house with rope ladder, bridge, monkey bars, trap doors, and a slide and a pole and all this fun stuff. It was pretty much the biggest news in our neighborhood. All the kids were really impressed. It was the coolest thing in the world. My brother was disappointed, though. He wanted to go to Hawaii. But he couldn't convince me of that.

Apart from dealing and coming to terms with the side effects of Cyclosporin and Prednisone, Andrew was soon able to lead a more active life than he had ever been able to before.

JIM: The summer after the transplant we were at Ben's Little League baseball game. Ben is our older son. And we couldn't find Andrew anywhere. We finally did. He was at the next diamond, and he'd climbed up the backstop and was perched on the top.

I asked Andrew when it first became apparent that kidney failure had progressed to the point that he might need a kidney transplant.

ANDREW: Well, the kidney failure started when I was born. It came from the heart failure. And then the anti-rejection medication (Cyclosporin) after the heart transplant caused the progression of the kidney failure. So, pretty much that's been going on my whole life. They said that my Creatinine level was OK where it was and as long as it didn't go any higher... But it continued to go higher, little by little. And then ...

SUSAN: Wait. When he was in high school, just before we left Illinois, Andrew got a kidney infection. He had to go to Children's Hospital and have a kidney biopsy. And at that point they said that he was 50% below normal functioning. I would say he had more fatigue after that, but it did not become more than that until this past year.

JIM: I remember that when we were still in Chicago, and I had just accepted the job at Binkley (in Chapel Hill) and we went to see the doctor, who told us that Andrew had glomerulosclerosis and might need a kidney transplant. I know that's when it was because I said, "How can I go to a new church and have this facing us?" It wouldn't be fair to the new congregation; that was my fear. I remember that Andy and I went for a walk and talked about it, and he encouraged me to do it. I thought—and maybe I said it then: "Well, it feels like God is in this, so it must be alright."

Andrew also remembers the Pike family's decision to move to Chapel Hill, but he recalls a different "sign."

ANDREW: Actually, this is the way it was: There was a program by all the singing groups at my high school; all the

groups were there. And the very first song that these 400 or 500 kids sang at that concert was "Nothing could be finer than to be in Carolina in the Morning." That was the sign that it was time to go.

JIM: When we got to North Carolina one of the first things we did was to get Andrew connected with a neurologist, a cardiologist, and a nephrologist.

DLM: No primary care physician?

SUSAN: Oh, yes, Dr. Allen Daugird. And he's done a good job, not only with the ordinary medical things that happen, but also things like helping Andrew get a driver's license.

ANDREW: Every couple of years I have to have a form filled out that says that I'm taking all my medications and doing what the doctor says, and so on, and that I can drive a car safely.

JIM: Well, after we got here Andrew went to see the nephrologist, Dr. Ronald Falk, and he said that most of the deterioration of the kidneys had probably occurred before the heart transplant. And he weaned Andrew off of the Prednisone he'd been on, which required biopsies once a month for about four or five months to assure that there was no rejection. Prednisone is a mean drug that causes a lot of side effects. Andrew was much better after that for quite a while.

During this time Andrew graduated from Chapel Hill High School, took some classes at Durham Tech, and got a job at Blockbuster Video. He also, finally, indulged his long-held wish to try skydiving.

ANDREW: Even today being active is very important to me. And when my kidneys prevented me from doing that, it was really hard. But when I was 19 I wanted to try skydiving. We knew someone in our church whose son did it, and so I got together with them, and I got to do it for the very first time. I remember going up in the airplane and thinking, "I can't believe I'm going to do this." But I was also so excited that it took the fear away. I remember getting to the door of the plane—I was doing a tandem jump so I was actually attached to someone behind me, the expert, who was wearing the parachute. Anyway, I remember kneeling down at the door, looking down 13,500 feet, and thinking this is the most exciting thing I've ever done, this is just awesome! And the next thing I know I'm given a little shove, and I go out, and the first three seconds my stomach did ten or twelve flips. But after that we got into neutral position, which is just hands raised like you are surrendering to the police or something. It was just incredible. We were falling at 120 or 125 miles per hour. It was so fast, and the wind... It was very windy, let's put it that way. And then when he pulled the cord we went from 120 miles an hour to 20 in just a split second. It's just like going from total, complete, amazing exhilaration to the most peaceful experience—because you're just floating down like a bird. I did it seven more times. The next four were tandem (you have to do five tandem) and then I did a few solo. But it eventually became

too expensive. It was about \$150 per jump. But it really taught me something: my limits were not as much as I thought they might be.

So, for much of the time between age eight, when he had his heart transplant and age 24, when he had the kidney transplant, Andrew was an active boy and young man who liked to push his limits and was sometimes able to. Then, last January a year ago he had a scheduled heart biopsy. At the same time the doctors ordered a Creatinine level—he hadn't had that particular blood test (a test of kidney function) for about a year. His serum Creatinine was elevated significantly and alarmingly. The test was repeated every other week, and the level continued to



Graduation day, Spring of 1998. Andrew, posing here with Ben, is 18 years old.

rise until by the end of April it was at seven and a half. By then Andrew was starting to be "...not incoherent, but fuzzyheaded." He was showing the signs of kidney failure.

ANDREW: I was feeling a lot of disorientation and dizziness, confusion, and a lot of fatigue.

This is when the testing for a donor began, testing that Susan eventually failed and Jim eventually passed. But Andrew's advanced kidney failure signaled that he could not wait for a transplant. He began hemodialysis. I asked him to describe it.

ANDREW: Imagine all of your energy being drained out of your body completely. That's what it was like. I didn't have all that much energy to begin with by then. But it made me feel so miserable. I was tired all the time. The only hope I had of getting better was the transplant.

DLM: What was your schedule for the dialysis?

ANDREW: Three days a week for two and a half to three hours.

DLM: And did you feel different afterward?

ANDREW: I felt more disoriented afterward. And very weak. I just think that being on dialysis means that you don't have a life anymore. You're alive, but there's nothing good about it.

JIM: My observation was that the day of the dialysis you felt horrible, the next day was not quite as horrible, and the next day you were back in dialysis. On the day off you seemed to feel a little better. But let me go back. Andrew had a temporary port for his dialysis. And when Susan couldn't be a donor Dr. Falk arranged for him to have whatever the next stage is to get started, because this temporary port did not function as well as another kind of dialysis would do—the abdominal kind. What's that called?

DLM: Peritoneal.

JIM: Yes. Andrew chose that. And he was scheduled to begin it two or three days after I was approved, so they cancelled it. And the surgery was performed a little more than a week later, on June 24. They began testing on Susan in early April and that went on for four or five weeks. And when she was disqualified, they started on me, and I was at the hospital two or three days a week for three weeks just going through the tests. We were both so thoroughly examined it was incredible. I think that at one time I counted that there were 27 different tests that they did on me, including adding tests like colonoscopy. It was so thorough that you wonder how anybody could qualify after all those tests. That I did is a miracle.

DLM: You may qualify more easily, though, if you have health insurance.

JIM: That's true. Before any of this started they verified that our insurance company would cover all of it, including our testing.

SUSAN: However, the insurance will only pay for testing one potential donor at a time. I had to finish before Jim could begin.

DLM: Then, I suppose, at some point they said to you, "You pass."

JIM: Yes, my blood pressure and cholesterol and lipids were all at acceptable levels. Which was amazing. They told me that if my blood pressure were too high I would be disqualified, or if my cholesterol or lipids were too high. So the testing was

not just to see if I were qualified to give a kidney to Andrew, it was also to see whether I would be healthy enough, whether my health might be compromised by making this donation. And they determined that I was fit, physically. And then we had meetings with the social worker, financial consultant, and an interview with the psychologist to make sure that I was doing this for appropriate reasons. Those were all appointments required by the hospital—in addition to all the medical things. But we had wonderful experiences with all of the staff at the hospital. We're very grateful.

DLM: Who does the surgery? It must take two different surgeons.

SUSAN: Yes. There are four on staff who do kidney transplants. One was in Afghanistan with the Army. And so they had to schedule it among the other three. Otherwise they could have done it sooner.

DLM: What was the post-operative course like for both of you?

SUSAN: They told us ahead of time that it would be easier for Andrew than for Jim. The donor would have a harder time because the surgeons would be doing more traumatic things inside—in order to take the kidney out whole. In the recipient they just need a place to put it in. They don't have to twist things around so much.

JIM: They did not take out either of Andy's kidneys. So he now has three. But, of course, two of them don't work. They needed a place to put in just one kidney. With me the surgery was more extensive, but we both had quite a time.

ANDREW: I remember thinking before the operation that with dialysis I don't have a life. So it was a choice between not having a life and having a life, and if that meant having a transplant.... On the day of the operation they took me in and on the operating table, and before they put me to sleep I thought, "Well, here we go," and, "I hope it works." And when I woke up there were maybe four or five nurses screaming at me, telling me to wake up. I was having a really hard time waking up. I don't know if they were afraid that I was never going to wake up or what, but it seemed like they were screaming their heads off. Finally I did wake up, and as I remember, they put me in a hospital bed, and they brought my dad alongside me on another hospital bed, and we just looked at each other and said, "We did it."

DLM: What was the screaming to wake up about? Do you know?

ANDREW: I have no idea. Maybe the anesthesia was... I've always had trouble waking up.

JIM: Even without anesthesia!

ANDREW: Anyway, during the course of the next week I experienced severe cramps and lots of sharp pains where the



Assuming the "neutral position."

incision was made, just like everybody. But it was easier for me to deal with being in the hospital and all the tests and people coming in and out, because I was so used to it. They did say to me that it would be a lot easier for me in terms of the surgery and recuperating from it because I had already been through so many of them. But for my dad it was all very new.

JIM: And the transplant was easier for you than for many other recipients because you were already immunosuppressed.

SUSAN: And the kidney started working very soon after the operation. So Andy felt better.

JIM: The hardest part of the whole thing for me was the fear that I might not be able to do it, that I might be disqualified and that Andrew might have to continue the dialysis, which was so hard. So we were elated when we learned that it could happen, and we went in with a sense of celebration, even though they were very clear that it was going to be a difficult recovery.

They told me to plan to take eight weeks off work, which I did. I think they said, "You'll be able to function after eight weeks off work." But they didn't tell me very vividly how I would feel after that. I found that I needed lots of rest and was very weak and tired. But as for the surgery itself, I just woke up in the room and it was all over and the worst part afterwards was gas pain. They did it laparoscopically—made a four-inch incision and then two other incisions for camera and lights and all. I haven't really noticed any difference in terms of kidney function or urinary function. But regaining my energy level has taken a long time, much longer than I thought. I had mistakenly thought that after eight weeks I would be ready to go back full steam, and that was definitely not the case.

ANDREW: After the procedure was done—I don't remember why it happened—I became diabetic.

SUSAN: Many people after this surgery become diabetic, and Andrew did, too.

JIM: Because of the additional Prednisone.

ANDREW: Because of the Prednisone, that's right. And just like anybody with diabetes I had to check my blood sugar levels with the machine, four times a day to start with. And it wasn't until I got out of the hospital, the very first day, that I took it and it was down.

DLM: This was an additional dose of Prednisone to guard against rejection of the new kidney?

ANDREW: Yes.

DLM: With your new kidney do you have to have biopsies or something else that's analogous to the way you still have to test your heart—to see if there's rejection?

ANDREW: Luckily, the only thing I have to do now is blood work. It's much easier. I go in once every couple of weeks now, for blood work and to see that all of my medications are where they need to be.

JIM: And they're continuing to lower Andrew's medications, like Prednisone, over a period of time, so that he will be taking much less medication after a year.

DLM: But transplant recipients must continue to receive some level of immunosuppression medication for their lifetime, isn't that right?

ANDREW: Yes, absolutely. Anytime you have an organ transplant there's a foreign object in your body and the immune system's going to think it's not supposed to be there. So it's going to try to kill it. So you have to take immunosuppression to make sure that the immune system won't be strong enough to (do that).

JIM: One thing that was very helpful in terms of recovery time was home healthcare. For the first three weeks home, a nurse came here every other day, the first week almost every day. Andrew's wound was open, so it needed to be dressed and packed for about six weeks. And they came to do the blood work for several weeks. It meant that we didn't have to take Andrew and get over to the hospital ourselves. We were very grateful for that service; it made a lot of difference.

SUSAN: We also took care of the wound, but being rank amateurs we needed the home healthcare here to get us started. I should point out, too, how very helpful friends and church members were, especially to bring food from church. And then Jim's twin sister, and my sister came; our other son came, and Jim's brother and sister-in-law and niece also came for a couple of days right after the surgery. So we were well supported, and it was good to have them here. So many people have helped, both then and earlier. Andrew's third grade teacher taught him to write again after the stroke. The community where we lived then began a fund to help on their own accord when he needed the heart transplant. They sent letters and a videotape and all kinds of things to the hospital when we had to leave Chicago and go to Pittsburgh, which back then was a place of last resort for kids with severe problems,

when transplants weren't done very frequently.

DLM: Is Andrew eligible for Medicare?

JIM: Well, that just took effect, what was it, two months ago? We did not apply until after the kidney transplant, although Dr. Daugird had suggested it two years ago.

DLM: He would have been eligible then as someone who had end-stage renal disease.

JIM: With end-stage renal disease you're automatically qualified for Medicare. But if you get a transplant then the assumption by the government is that you're going to be fine and be back in the workforce. So Medicare coverage lasts for only three years following the transplant. But Andrew is on Medicaid now. And we have yet to experience how that's going to function. I don't know whether Medicaid would have supported a transplant or not. We've been trying to reach someone who will talk to us about questions like that. Of course, I would like to know the facts before we take Andrew off of my private insurance. Which is going to have to happen when I retire, but right now it doesn't. That's one of the big worries of transplant families.

SUSAN: How to pay for the medicine.

JIM: I have piled up here probably three or four hundred letters from UNC Hospitals that have come in the mail since June 24th. Literally—and the cost of the mailing from the hospital must be enormous. And for every one we get from them we get another letter from the insurance company. It's just bizarre. I need a full-time accountant here.

SUSAN: When Andrew was quite small, I could recite by heart all of his medications. I had them on the tip of my tongue. In the process of his growing up and taking over his own care, I don't now have all the facts at my fingertips. And I don't have to do it the same way. But it makes me extremely anxious when we start talking about it, because I'm thinking that some of the facts may not be right or that we may not have them straight.

The volume of clinical information that Andrew's father and mother—and now Andrew himself—have had to remember is enormous. Each of the many first-doctor-visits over 25 years in two different communities (three, counting Pittsburgh) involves taking a new history. Finally, the family has gotten in the habit of taking along a four- or five-page synopsis of the history and handing it to the doctor. But, says Jim, "They don't pay attention to that, they still want to hear it all verbally."

DLM: I'm wondering, is there a support group, locally, for organ transplant recipients?

ANDREW: Well, not long ago I got a letter from a person who had had a heart transplant and a kidney transplant, and who just wanted to get together some people who had had these experiences, to meet casually and talk, and that sort of thing. And I'm planning on getting together with that group, which is just now starting. I don't know much more about it yet.



Brother Ben feeding Andrew's three nephews.

Twice a recipient, Andrew Pike is now an advocate and campaigner for organ donations.

He referred to his own experience when he spoke briefly at church on the occasion of National Organ Tissue Donor Sabbath.

"It marks a chance for you to become a true hero," he told the assembled congregants, mentioning also that one of his own heroes, Michael Jordan, was the Organ and Tissue Donor Spokesperson.

Andrew then told the story of the family that invited him to visit with their ten-year old son, who was in the hospital awaiting a heart transplant. A week after the visit, still waiting for a heart to arrive, the boy died.

A year and a half ago Andrew wrote of the reason the pleasures of his own life had been his. It was "because of the good faith and kindness of one family... whom I have never met..."

Become a donor, he says, "if you are looking for a chance to show God's love. Give the gift of life."

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