Medical miracle and a moral burden

They Decide Who Lives

by SHANA ALEXANDER

John Myers has known about his kidney trouble ever since a routine physical examination at the time of his Army discharge in 1945. But until two years ago he felt fine. Then the headaches began and his blood pressure began to rise. By last summer there were days when he could barely drag himself out of bed to get to his office. He was 37 years old. Neither he nor his wife, Kari, had any idea that he had come, irresistibly, to the terminal stage of his disease. But a glance at his case history was enough to tell any physician that John Myers' death would be ugly and soon.

Last Christmas morning when Myers awakened at his home in Bremerton, Wash., his heart was pounding violently. He could not stop coughing. Blood was running from his nose. He had an indescribable headache, a horrible taste in his mouth, dreadful nausea. His face and limbs were grossly swollen. He was rushed to a hospital where it seemed certain he would be dead within a matter of hours. But today, 11 months later, Myers is still alive. He is no longer even invalid in the usual sense of the word. He is back at his old desk with an oil company, and he is living comfortably at home with Kari and their three young children. To the casual observer, John Myers looks and acts just like everybody else. But he is different, in a very special way. There is now a small U-shaped plastic tube sutured into the blood vessels of his chest.

Every Monday at 4 p.m., after an afternoon trip on a long ferryboat ride to Sound from Bremerton to town Seattle. By 5 p.m., he is walking his way down a sidewalk, steps to an unmarked door in an annex of St. Joseph's Hospital. Inside, he exchanges traveling suit for a green hospital gown.
of a small committee

Lives, Who Dies

Seattle committee members, who are kept anonymous, meet periodically to determine which patients may receive treatment at the kidney center.

At present the miraculous machine requires 10 to 12 hours to cleanse Myers' blood of accumulating poisons which otherwise would kill him. The procedure is quite painless, and Myers has now become so accustomed to the whole idea of surrendering his life's blood to a medical laundromat twice a week that during the cleansing he just goes to sleep. A

burden

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burden. He is back at his old desk at the insurance company, and he is comfortably at home with Kari and their three young children. To casual observer, John Myers' life seems just like everybody else's except that he is different, in a very special way. There is now a small plastic tube sutured into the blood vessels of his left forearm.

Every Monday and Thursday afternoon Myers takes an hour-long ferryboat ride across Puget Sound from Bremerton to downtown Seattle. By 6 p.m. he is making his way down a short flight of steps to an unmarked basement door in an annex of Swedish Hospital. Inside, he exchanges his business suit for a green hospital gown and climbs into bed. A compact hunk of medical plumbing which looks like a stainless steel washing machine is wheeled to Myers' bedside. From its innards a technician unfurls a pair of clear plastic tentacles six feet long. A nurse connects these to the little tube in Myers' forearm, and twiddles a few controls. Suddenly, in one bright spurt, one of the tentacles becomes red as John Myers' blood rushes out to fill the bedside machine.

The machine is an artificial kidney. Because it can be coupled at will to the U-shaped tube in Myers' forearm, it has become the first true artificial organ in medical history. For the rest of his life Myers will spend two nights a week joined by a plastic umbilical cord to this machine which keeps him alive.

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COMMITTEE CONTINUED

nurse monitors the blood-flow and makes sure he does not roll over and kink the tubing. Every Tuesday and Friday morning his nurse brings Myers his breakfast—jam, tea, cracker bread—checks his blood pressure, and un-buckles him. He carefully weighs himself (he usually finds he has lost two to four pounds of excess fluids overnight), showers, drives back to the ferryboat and sails off to work.

John Myers knows that so long as he keeps his regular rendezvous with the machine, and so long as he sticks faithfully to a diet consisting chiefly of cornstarch mixtures, leafy vegetables and fruit, and so long as he takes scrupulous care of what is in effect a permanent open wound in his forearm, he should be able to live the semblance of a normal life. He knows too that without regular access to the machine he would die within a week or two.

Talking about his unique way of life, Myers today says, "When you go on the machine you feel absolutely nothing at all. You just watch the gal hook you up. I have no emotional reaction, and I'm glad I don't. I don't feel I'm a prisoner of the system—even though I know perfectly well I am." In the opinion of Myers' doctors, this matter-of-fact attitude is as important to Myers' continuing good health as the diet and the rest of his strict regimen.

The cause of John Myers' multiple agonies last Christmas is properly known as uramic poisoning and congestive heart failure due to end-stage kidney disease. Each year it kills about 100,000 people in the U.S. alone. Of these 100,000 doomed patients, only one in 50 at present can be considered a suitable candidate for wearing Seattle's new U-shaped tubes. These few have kidney disease in a fairly pure form, uncomplicated by other afflictions. They are both physically-and emotionally-able enough to endure the treatment.

Today Seattle's Swedish Hospital cares regularly for five patients who wear the tubes. In addition to Myers, they are a car salesman, a physicist, an engineer and an aircraft worker. By the end of the year there will be five more. All 10 will be part of an unprecedented two-year trial program to determine whether and how the rugged and expensive new treatment—at present the cost is $15,000 a year per patient—can be made feasible on a mass, nationwide basis.

Until the results of the trial in Seattle are known, many doctors feel it would be premature to set up additional treatment centers elsewhere, even if unlimited funds were available. The same treatment which keeps John Myers and his four companions gratefully alive has driven less carefully selected patients to pray for a soft and merciful death.

As medicine advances and invents assorted other mechanical organs, millions of people with "fatal" diseases may be given the same second chance at life which John Myers was one of the first men in the world to receive. But the Brave New World in which people may literally have hearts of gold or nerves of steel is not yet at hand. In the interim, agonizing practical decisions must be made.

For the present, someone must choose which one patient out of 50 shall be permitted to hook up to Seattle's life-giving machines, and which shall be denied.

There is in Seattle a small, little-known group of quite ordinary people who have now made this choice five times, and will make it five times more before this year is

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For example, the doctors recommended that the committee begin by passing a rule to reject automatically all candidates over 45 years of age. Older patients with chronic kidney disease are too apt to develop other serious complications, the medical men explained. Also, the doctors thought that the committee should arbitrarily reject children. The nature of the treatment itself might cruelly torment and terrify a child, and there were other purely medical uncertainties, such as whether a child forced to live on this dietary restrictions would be capable of growth. In any case, the doctors believed it would be a mistake to accept children on the committee and thereby be forced to reject heads of families with children of their own.

Finally, the two doctors conducting this initial briefing offered to sit in on all the committee's future meetings in an advisory capacity. They also voted to keep their own names strictly anonymous. At their second session, they decided they did not want to know the names of the patients either. They will be reading John Myers' real name for the first time in history. Then they drew up a list of all the factors which they would weigh in making their selections: age and sex of patient, number of dependents; income; net worth; emotional stability; particular regard to the patient's capacity to accept the treatment; educational background; nature of occupation, past performance and future potential; and names of people who could serve as references.

At the committee's third meeting they finally got around to fixing the problem of choice head-on. Somehow they must drastically narrow the field of candidates. "Where do we begin—the universe, the solar system, the earth?" one committee member asked wryly. Finally they agreed to consider only those applicants who were residents of the state of Washington at the time the feasibility trial got under way. They justified this stand on the grounds that, since the basic research to develop the U-shaped tube had been done at the University of Washington Medical School and at its new University Hospital — both state-supported in—
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Committee continued

A patient using the Seattle treatment has two plastic tubes permanently seen into his forearms, one leading into an artery and the other into a vein (shown by dotted lines in drawings above). Through them he can be repeatedly hooked up to the artificial kidney machine. The tubes stick through the skin and between hook-ups are connected to each other by a U-shaped tubing called a shunt (shown on drawing of arm at right) which allows blood to flow from artery to vein and thus prevents clotting. When the patient comes for treatment, the shunt is removed and the artery and vein tubes are connected by long tubes to the machine (arm at left). The patient's heart pumps blood containing harmful waste products (black dots) to the kidney chambers of the machine. Here the blood passes between sheets of porous cellophane immersed in a special cleansing solution. As the blood moves through the chamber, wastes are drawn through the cellophane into the cleansing solution by a complex chemical process called dialysis. The cleansing solution is constantly renewed from a tank below. The blood itself does not penetrate the cellophane, but by the time it reaches the end of the chamber the harmful quantities of wastes have been removed. The cleansed blood then passes through a rewarmer which reheat it to body temperature before it returns to the patient's vein.

While this kidney machine treatment is saving lives in Seattle, it is still too experimental for mass application in hospitals throughout the country. Researchers are also working to perfect two other techniques. One would enable the patient periodically to introduce cleansing solution into his own abdominal cavity at home. The other would make feasible surgical transplants of healthy human kidneys. Since the need is so urgent, the National Kidney Disease Foundation is calling a conference soon to plan ways of speeding research and extending treatment to more patients.

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A new baby is in this Metropolitan family.

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Committee continued

intimate for casual informality. To protect the integrity of their work, the members of the committee do not disclose exactly how many meetings they have held or how many patients they have considered. But neither do they wish to conceal the way they try to reach a decision, and all seven members have contributed to the preparation of the following transcript of an actual discussion. The dialogue has been pieced together from the memories of the people who spoke during the discussions and, as changes as recorded here seem still, the people are nonetheless real, as are the five patients under discussion, and the dynamics of the debate are wholly accurate. The lawyer, who is the committee's chairman, has just called the meeting to order.

Lawyer: The doctors have told us they will soon have two more vacancies at the Kidney Center, and they have submitted a list of five candidates for us to choose from.

Housewife: Are they all equally sick?

Dr. Murray: (John A. Murray, M.D., director of the Kidney Center.) Patients Number One and Number Five can last only a couple more weeks. The others probably can go a bit longer. But for purposes of your selection, all five cases should be considered of equal urgency, because none of them can hold out until another treatment facility becomes available.

Lawyer: Are there any preliminary ideas?

Banker: Just to get the ball rolling, why don't we start with Number One—the housewife from Walla Walla.

Surgeon: This patient could not commute for treatment from Walla Walla, so she would have to find a way to move her family to Seattle.

Banker: Exactly my point. It says here that her husband has no funds to make such a move.

Lawyer: Then you are proposing we eliminate this candidate on the grounds that she could not possibly accept treatment if it were offered?

Minister: How can we compare a family situation of two children, such as this woman in Walla Walla, with a family of six children, such as patient Number Four—the aircraft worker?

State Official: But are we sure the aircraft worker can be relitigated? I note he is already tied to work, whereas Number Five, the chemist and accountant, are both still able to keep going.

Labor Leader: I know from experience that the aircraft company where this man works will do everything possible to rehabilitate a handicapped employee.

Housewife: If we are still looking for the man with the highest potential of service to society, I think we must consider that the chemist and the accountant have backgrounds of all five candidates.

Surgeon: How do the rest of you feel about it?

Labor Leader: Perhaps one man is more active in church work than another because he belongs to a more informal group.

Banker: We could rule out the chemist and the accountant as economic grounds. Both do have jobs worth the salaries they receive.

Lawyer: Both these men have made provisions so that the deaths will not force their families into the lowest strata of society.

State Official: But that would seem to be placing a penalty on the very people who have been most provident.

Minister: And both these families have three children too.

Labor Leader: For the children's sake, we've got to reckon with the surviving parent's opportunity to remarry, and a woman with three children has a better chance to find a new husband than a very young widow with six children.

Surgeon: How can we possibly be sure of that?

The central problem of such a Life or Death Committee is, of course, that nobody can be sure of anything. But at the end of an hour-and-a-half's discussion the patients actually were chosen. Both are alive and well today. One is the aircraft worker. The other is the small businessman, John Myer. Because of the careful groundwork by the trustees of the medical society in appointing the seven members, Seattle's Life or Death

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selections would have to be made in the basis of inadequate information. Yet oddly enough, in the choices I have made, the correct decision appeared quite clear to me in each case. The principle of this thing has bothered me more than the practice.

"As we tried to work out our pound rules for selection, I felt a deep sense of awe, almost that we were going beyond our domain. As a clergyman, I have to deal a great deal with life and death, and there has been something helpful to me in recognizing life with some degree of reverence. I know that even with the best of care, there comes a time when life—physical life, as we know it—ceases to be. The realization that each one of us is going to die suggests to me that, so long as we are a part of life, we are in a position of responsibility to use that life to help others.

"In the years since my ordination, I find too that my own viewpoint toward death has changed. Death itself is not the worst thing that can happen to a man, and just to live is not the greatest blessing. I've often lain awake nights wondering: would I want to take this treatment, if it became a medical necessity for me? But then I've thought: well, wouldn't refusing treatment be a sorry admission of cowardice—an easy way to escape my responsibility to my wife and children?"

In my work on the committee, I tend to favor those candidates who have younger children. My thinking on this is—a child who is older has had the privilege of a parent longer, and ought to be better prepared to face life alone. But I often wonder—suppose I should somehow meet a man I had voted against? What would I say to him? I believe I would face it. I would tell him my reasons. The purpose of our committee is to protect the medical men from just such highly emotional situations. If they have to go through emotional stress, they cannot conserve their energies for their own work. A doctor's job is the practice of medicine. My job is to help people form a set of life values. And to help them accept the fact that, like birth, death itself is a part of life—not, what, the door slams! The HOUSEWIFE is an uncommonly pretty grandmother and she is no fool. She says, "All my life I have always been disgustingly healthy. Perhaps for that reason, I am not at all medically minded. In fact, the truth is that I think doctors are apt to be terribly stuffy—especially about new things. So it is wonderful to me to have a chance to help in a real breakthrough. This is not something like cancer, where you still don't know. This treatment works! That gives me terrific hope. "I realize the doctors must use people, not animals, for this research, and I think in a funny way that actually helps me to serve on the committee. Because I do like people so much. I feel our own anonymity is vitally important too, because it is only if we are truly unknown that we really can be a buffer for the medical profession. "At the same time I do wish we could somehow see the patient and get a personal impression. It is so hard to judge from a sheet of paper whether or not a man could take the treatment and hold on. I know he'd have to be an optimist by nature, because it does limit your life. "You know, the doctors usually give us their estimate of how long a patient will live without treatment, and this information affects our thinking a good deal. We always have hope that by some miracle the facilities can be enlarged in time to save the patient who has some chance of living longer without this treatment." The BANKER is direct and peppery. He looks like a retired general. He says, "I've never had any idea how a kidney works, and I still don't. But I do have reservations about the moral aspects, the propriety of choosing A and not B, for whatever reason. I have often asked myself—as a human being, do I have that right? I don't really think I do. I finally came to the conclusion that we are not making a moral choice here—we are picking guinea pigs for experimental purposes. This happens to be true; it also happens to be the way I rationalize my presence on this committee.

"The situation, as I see it, is life and death, complicated by limitations of money. In this situation
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"I have limited funds, we take whom we can, and that’s it. So far, fortunately, we have not had to make a choice between two absolutely equal candidates. I suspect that somehow the doctors started us out this way deliberately, to make things easier on us until we got used to the idea of choosing. But what happens when we get two men with the same job, the same number of children, the same income, and so forth? We could face that dilemma at any moment.

"I have asked myself—suppose I got this kidney disease, would I apply for treatment? Well, I think I would, like a shot! And if I was denied it, I’d feel bitter. I’d think society would owe it to me if they owe it to another individual.

"We send billions of dollars overseas to people we know nothing about, many of whom despise us. If Congress or somebody wanted to provide the money, we could take care of all our kidney people. But where do we stop? Who decides who needs treatment? The federal government would soon be treating the medically ill, alcoholics, old people, blind people, deaf people, people who need false teeth—everybody! Is this what we really want? I frankly don’t know."

"The central problem here is that medicine has moved forward so rapidly it has advanced beyond the community’s support. Our committee must try to bridge the gap. Our chief problem so far has been inadequate information. We have forced ourselves to make life-or-death decisions on a virtually instinctive basis. I do have real faith in the ability of kindly, conscientious, intelligent people to make a good job guided simply by their instincts, but we ought not to push on this way.

"Up to now, our only source of information has been the patient’s personal physician, and he is in position to ask the questions we want answered because he knows we might turn his patient down. In any case, a physician isn’t granted to this approach. He is under the pressure of urgent medical problems. The committee needs to meet with staff of private investigators, social workers, a vocational guidance counselor and a psychiatrist. We agreed to set up such a staff at our next meeting. We did not do this sooner because for a long time we feared that going directly to the patient for information would cruelly raise false hopes.

"I have come to believe we can tell the patient, if we say some-thing like this: in order to help you best—a person who has a chance..."
illness, and who may be expected to have it for a long time—it is necessary to know as much about you as possible. I believe patients will understand our attitude. The resources of the human spirit in adversity are truly remarkable. These people can face more than we give them credit for!"

The Labor Leader wears an old-fashioned gold watch chain and the scuffed, pragmatic expression of a railroad conductor with long tenure. He says, "The way I look at it, if the Seattle trial is to be a pilot for other committees, we cannot afford any human failures. Also, we just haven't got the funds. So I want to pick the man with the most will power, the fellow who is least likely to give up.

"Suppose we take someone on the program, keep him going for three months, and then he blows up on us? Suppose he fails to take care of himself, or follow his diet, or gets depressed and tries to take his own life? That can happen in these cases, you know. Well, this would deprive another patient of the opportunity we can offer. That's why knowing about a candidate's past life would rate so heavily with me—it's an indication of character. A man's job, his education, his wealth—that means nothing to me. But I do think a man ought to have some religious belief because that indicates character. And I imagine a large family would be a great help—a lot of kids help keep a man from letting down, even when the going gets rough."

"The wonderful thing to me about this work is that we are finally past the stage of experiment. We know we can prolong life. These doctors got an idea and they made it work. With the mass production facilities we have in this country, I believe we can eventually take care of everybody. Meanwhile, we say to these patients, in effect, 'We're going to help you prolong your life by choosing to put you on this machine. Now, what can you do for us?'"

The Surgeon is an enormous man with a tiny voice, a Courant air and great patience. He says, "Medical-looking, I am not a disciple of this particular approach to kidney disease. But in the larger view, this project will not just benefit one disease—it will benefit all aspects of medicine. We are hoping someday to learn how to transplant live organs. So far, the body will not accept foreign tissue from another person, but eventually we will find a way to break this tissue barrier. Meanwhile I serve on this committee not as a doctor but as a citizen and, I hope, a humanitarian."

"You know, at our committee's first meeting we seriously discussed selecting candidates by drawing straws. We were going to make it easy on ourselves by having a human lottery! Frankly, I was almost ready to vote for the lottery idea myself. In my practice as a surgeon, the responsibility of making a life-or-death choice faces me practically every day, and I can tell you this: I do sleep better at night after deciding on one of these candidate cases than I sleep after deciding a case of my own. I'm awfully glad, too, that we just know these candidates by number, not their actual names."

"Being a medical man, I sometimes hear it via the grapevine when a patient whom we have passed over dies. Each time this happens there always comes a feeling of deep regret, and then that dreadful doubt—perhaps we chose the wrong man. One can just never face these situations without feeling a little sick inside..."

The concept of the little U-shaped tube that started it all germinated two years ago in the mind of a deceptively mild professor of medicine at the University of Washington Medical School named Belding H. Scribner. Within a week the first experimental tube was made and sutured into the arm of a patient who was on his deathbed from Bright's Disease. It worked—the man is alive today—and within a month it was successful again in three more "hopeless" cases. Then abruptly, for 13 months, the entire experiment was shut down. Before taking on any more patients it was necessary to perfect certain practical techniques. In the beginning, the tubes wore out too fast, or clotted, or became infected and had to be removed and resewn into other parts of the body. The early machines themselves were tricky to handle. The primary need was to simplify the entire technique from a complicated "operating room" type of procedure to a relatively simple routine, like making X rays. Until this was done, the technique would remain more a research triumph than a new treatment. The problem was solved literally in the bodies of the four original patients at University Hospital. The very first was Clyde Shields, a 42-year-old machinist, who has
COMMITTEE CONTINUED

now survived the implantation of 11 successive sets of U-shaped tubes and has lived totally without any natural kidney function for over two years. Despite his ordeal as a human guinea pig, Shields says he feels better now than at any time since his treatment began.

The most battle-scarred of the original patients is a high-spirited shoe salesman named Harvey Gentry. One month after his treatments began, Gentry felt so well he decided to go clam-digging. He got sand in his first set of tubes, lost others through infection, and is now on his 13th set. "I've given the docs a pretty bad time, but they've learned a lot from me and they always manage to keep ahead somehow," he says with apparently indestructible optimism.

Another of these research patients is 37-year-old Kathy Curtiss. Between visits to University Hospital for treatments, she is able to carry on a full schedule of cooking and housekeeping for her husband and two teen-age sons. These patients and the dedicated University of Washington medical team which works with them have now proved that the new technique can be made to work. At the same time these patients are living proof that the possibilities of mass treatment must be determined at once.

During the 13-month moratorium on the experimental program, no new patients were accepted, and truly cloak-and-dagger measures were taken to keep the story out of the newspapers. Already, as word of the experiment circulated within the medical fraternity, the doctors were receiving agonizing appeals from colleagues to take on more patients than they could possibly care for. To avoid such intolerable pressures, the novel double-screening device of a medical board backed up by a lay committee was proposed in the written application for a $250,000 research grant which was made to the John A. Hartford Foundation. Then, even before they were sure the money would come through, the doctors went to the trustees of their own county medical association and asked them to appoint the members of both the board and the committee.

The trustees agreed to act. This was a crucial decision. It meant acceptance of the principle that all segments of society, not just a medical fraternity, should share the burden of choice as to which patients to treat and which to let die. Otherwise society would be forcing the doctors alone to play God.

As a buffer between the doctors and the public, the committee has functioned well. It has protected doctors from having to make intolerable choices among their own patients. But in the 11 months of its operation a host of new problems has arisen to plague both doctors and laymen which neither group anticipated at the outset.

What happens to the kidney patient who has been maintained in good health by the machine for some time and then suddenly has stroke or gets cancer? Is he now moved from the machine in favor of a "healthier" patient who only has one fatal disease, not two? Who decides? The patients? The doctor? The committee?

Compared to other vital organs, the kidney is relatively simple in function. It is a filter. What happens when, sooner or later, machines learn to manufacture other artificial organs? Are we moving toward a nightmare world in which a segment of our population is kept alive by being hooked up to ingenious machines operated by the few?

In any event, the facts at past meetings have seemed inadequate. But in the future, when the committee has in its employ a professional social worker, a vocational counselor and a psychologist, the committee can be expected to produce a far more comprehensive and complete report on each patient, how the relative abilities of these staff members—say, their ability to write up case reports—be judged.

And won't they have unconscionable prejudices? And won't they have to be anonymous too? And if all these questions are fairly answered, then won't the committee be adjudicating its own responsibilities and making the little three-man sub-committee bear the dreadful burden of choice?

No matter who decides, aren't the final choices all shaky, all arbitrary, all relative? They depend not on a patient's unique worth, but on what the doctors decide will be of value to society.