

Dedication



In Living Memory of

Norman C. Yanco

Charter Member and Past Vice President of the

Kidney Transplant/Dialysis Association, Inc.

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PREFACE

This book was written for you, the kidney patient, in order to explain the forms of treatment available and what they mean for the quality of your life. It has been prepared by the Kidney Transplant/Dialysis Association, Inc., a non-profit, all-volunteer organization of dialysis and transplant patients, their families, and friends.

We of the KT/DA have been through what you are experiencing, and we understand your fears, doubts, and anxieties. It is our hope that this book will answer many of your questions and indicate where you can find the answers to others.

Chapter 1 explains what the kidneys are and how they function, both in healthy individuals and in persons with kidney failure. Chapters 2 through 9 deal with dialysis. Chapters 10 to 13 pertain to transplantation, while Chapters 14 to 21 treat a variety of topics of interest to kidney patients. The chapters are largely self-contained and may be read in any order. Since some are more technical than others, you may want to skip around.

Some of the chapters, especially those written by patients, were contributed years ago for the first edition. Wherever appropriate, we have updated the information or added explanatory footnotes where figures are out of date.

We wish to thank the many professionals and patients who contributed chapters to this handbook.

Richard L. Faber, Ph.D.
Stephen W. Wilde

ABOUT THE KT/DA

The **KIDNEY TRANSPLANT/DIALYSIS ASSOCIATION, INC.**, is an organization made up of artificial kidney and kidney transplant patients, and their families and friends. Now with over 2,100 members across New England, as well as throughout the country, the KT/DA is dedicated to providing financial aid, information, and emotional support to chronic renal disease patients and their families.

The KT/DA is an all volunteer organization which uses 100% of all the funds raised to benefit kidney patients. We pay no salaries, rents, or administrative fees. Donated funds are used for such projects as the following:

- The **Patient Assistance Committee (PAC)** provides funds for kidney patients in financial need. Hospital social workers direct applicants to the PAC. Funds granted to these patients are used to pay for transportation to and from treatments and for basic living expenses, such as food, rent, clothing, and utilities.
- Each year, the KT/DA awards scholarships to kidney patients or members of their immediate families for continuation of post-secondary school education.
- Social activities sponsored by the KT/DA include regular meetings at which refreshments are served and patients and family members can get together in an informal, non-medical setting. Most meetings feature a talk by a renal professional.
- A quarterly newsletter, the *RenalGram*, informs members about recent medical advances, facts relating to treatment, important legislation, and the progress of their fellow patients.
- The KT/DA designed and built the Kidney Patient Lounge at the former Peter Bent Brigham Hospital (now Brigham and Women's Hospital) at a cost of over \$30,000 in 1975.

The KT/DA places special emphasis on individual contact between kidney patients. We are especially interested in helping new or prospective patients overcome their fears and anxieties, and to learn more about what dialysis and transplantation will mean for them. We urge you to call upon us for information and assistance.

If you would like to join the KT/DA, obtain further information, or be contacted by one of our members, please write to us at P.O. Box 51362 GMF,

Boston, Massachusetts 02205-1362, or e-mail to ktda@ma.ultranet.com, or leave your name and phone number with our answering service, (617) 641-4000. Meetings are held approximately every two months (except during the summer) at various locations throughout the Boston area. Annual dues are \$10.00 for individuals, \$15.00 for families, \$25.00 for health professionals, and \$100.00 for corporate/facility memberships (non-voting).

Note: Financial assistance is limited to New England residents.

Chapter 1

NORMAL AND ABNORMAL KIDNEY FUNCTION

Marguerite A. Hawley, M.D.

The kidneys are essential organs in the body which function to remove water and waste products. They also produce important hormones such as erythropoietin, Vitamin D, and renin.

The kidneys are located in the back of the abdomen, one on each side of the spinal column, at about the level of the lower ribs. The average weight of an adult human kidney is approximately one-quarter pound. Each kidney is approximately 4 inches long, 2.5 inches wide, and 1.5 inches thick.

The kidney receives about 20 percent of the blood coming from the heart each time it beats. The rate of blood flow through both kidneys is approximately 1.2 liters per minute.

The basic functioning unit of the kidney is called the *nephron*. The kidneys together comprise greater than 2 million nephrons, and each is capable of forming urine. The nephron's function is to clean the blood of unwanted substances as it flows past. The nephron is composed of the *glomeruli*, through which the blood is filtered, and then the *tubules*, which receive and process the filtered fluid. Kidney function is estimated using the *glomerular filtration rate* or GFR. This is the amount of filtrate formed in all nephrons.

The normally functioning kidney controls the concentration of body fluids. It accomplishes this by excreting excessive amounts of water in the urine if body fluids are too dilute or by excreting excessive solutes when body fluids are too concentrated. Despite large intakes of salt and water, almost no change in blood volume or concentration occurs. Another important function is acid-base balance. The body maintains a constant pH via several buffering mechanisms. The kidney plays a major role in this by the net excretion of hydrogen ions when the blood is too acidic and the net excretion of bicarbonate ions when the blood is too alkaline.

The kidneys also have a hormonal role. They are in part responsible for the conversion of Vitamin D to its active metabolite, which is important in the absorption of calcium from the intestine. *Erythropoietin* is

manufactured by the kidney and stimulates the bone marrow to produce red blood cells. With renal failure there is decreased production of this hormone and anemia results. With a decreased number of red blood cells and therefore fewer cells to carry oxygen to the tissues, patients may tire easily and become short of breath after only minimal activity. Often patients benefit by taking injections of synthetic erythropoietin to achieve and improved blood count (see Chapter 19). *Renin* is another kidney-produced hormone that is important in sodium and blood pressure control.

Renal failure occurs from a variety of causes, and the time course and clinical symptoms vary from individual to individual. A person's kidney failure may occur suddenly or progress slowly over a period of many years. As failure progresses the kidney is less able to maintain a steady volume and concentration of body fluids. For many, as fluid and salt become increasingly difficult to remove, high blood pressure occurs as well as *edema* or fluid in the tissues. Patients may have problems with swelling of their legs and shortness of breath from accumulation of fluid in the lungs (*pulmonary edema*). Medications may be necessary to control blood pressure and assist in fluid removal (diuretics). The kidneys also are no longer able to excrete the waste products of metabolism, and substances such as potassium and phosphorus can accumulate in the body. Elevated phosphorus levels cause calcium levels in the blood to fall and result in the stimulation of a hormone from the parathyroid glands. This hormone increases the release of calcium from bones and if not suppressed can result in bone pain and progress to weakened and demineralized bones.

As failure progresses patients are required to modify their diets—usually decreasing sodium, potassium, and phosphorus intake and ultimately restricting fluids. Patients will generally need to take phosphate binders as well as Vitamin D supplements.

As waste products accumulate, patients may have problems with fatigue, headaches, nausea, vomiting, and decreased appetite resulting in weight loss. Itching may also be prominent if the body's phosphorus levels are high. Patients may note a decreased ability to concentrate. Finally, there may be an increased tendency to bleed.

The decision to start hemodialysis is based on a combination of symptoms and laboratory data. Emergent indications to start are encephalopathy (change in mental status), seizures, and coma due to uremia, as well as severe hyperkalemia (elevated potassium), acidosis, pericarditis (or inflammation of the heart lining) from accumulated toxins, and pulmonary edema which no longer responds to medications. Most patients reach the need to initiate on hemodialysis gradually. The goal is to begin when a patient's symptoms are no longer responsive to conservative management and before there are serious complications. Practically speaking, most patients will start dialysis when the creatinine clearance (CRCl) is very low, 3–5 cc per minute (normal 100 cc per minute) and the serum creatinine is greater than 12–14 mg/dl (normal 1.0 mg/dl). These are not absolute numbers, however, and must be carefully interpreted for the individual patient. In a small person, a creatinine of 5 mg/dl may represent a level of function which requires dialysis.

Fortunately, if your kidneys fail there is a choice of treatments to sustain your life. Options available are hemodialysis, forms of peritoneal dialysis (refer to Chapter 3), and transplantation (refer to Chapter 11).

Chapter 2

WHAT IS HEMODIALYSIS?

(Adapted from various sources)

It is the purpose of this discussion to bring to you, as a prospective user of an artificial kidney, some understanding of the working of this device, its usefulness, and its limitations. The application of an artificial kidney is sometimes referred to as *hemodialysis*, and the apparatus itself may be called an *extracorporeal hemodialyzer*. *Hemo* simply means blood. *Dialysis* is of Greek origin, meaning “to pass through”; the present use implying a filtering (or passing through) process. *Extracorporeal* means “outside the body”; hence an extracorporeal hemodialyzer filters the blood outside the body.

Hemodialysis has long ago gone from an experimental procedure and last ditch stand against end-stage renal disease to a well established and effective therapy for the rehabilitation of the patient with chronic kidney disease. Although the artificial kidney approximates only some of the human kidney’s many functions, the body nevertheless adjusts remarkably well to the state maintained by the machine. There are now many patients who continue to thrive and function as productive citizens after many years of hemodialysis (including the editor, now beyond twenty-five years on dialysis). Among these are people from all walks of life.

How does it work? Consider for a moment a container or tank divided by a vertical partition. We will make this partition a sheet of cellophane. One compartment of the cellophane-partitioned tank will be filled with blood. The other will be filled with a solution of certain minerals and water (the dialysate bath).

The cellophane partition forms what is known as a *semipermeable membrane*. By semipermeable, we mean that some substances will permeate, or pass through it, but others will not. The sheet of cellophane may be thought of as having microscopic holes or “pores” through which particles of small molecular size may pass.

Normal blood is 90% water. Molecules of water in our two compartment tanks will pass freely back and forth through the cellophane

membrane between the blood and the bath. However, blood also contains red and white cells, protein, fat, sugar, minerals (called *electrolytes*, such as sodium, potassium, calcium, magnesium, chloride, bicarbonate, and phosphate), and waste products (such as urea, creatinine, uric acid, and others). The red and white cells of the blood are much too large to pass through the cellophane, so they remain confined to the blood compartment. The same is true of the fat and protein molecules.

However, electrolytes, because of their small molecular size, pass freely (or “dialyze”) through the cellophane membrane in both directions. In this situation, the principle of diffusion applies. According to this principle, particles in a solution of high concentration pass through a semipermeable membrane into a solution of lower concentration until there is equal concentration of particles on both sides of the membrane.

The concentration of the various electrolytes in blood must be maintained within narrow limits if serious harm to the whole person is to be avoided. Therefore, in the bath compartment of our dialyzer, we adjust the concentration of sodium, potassium, chloride, and other electrolytes to approximate the levels in normal human blood serum. Thus, through the process of dialysis, the concentrations of these particles will become nearly equal on both sides of the cellophane membrane.

Metabolic waste products in the blood—urea, creatinine, and others—are some of the substances we wish to remove. These are larger molecules than the electrolytes, but they are still small enough to pass through the cellophane membrane (although more slowly). Therefore, again utilizing the principle of diffusion, if we have none of these substances in the bath solution, they will pass from the blood compartment to the bath side. We thus “dialyze out” the undesirable waste products in blood. After a while the concentration of urea and other wastes will build up on the bath side of the membrane and eventually reach the same concentration as in the blood. In actual hemodialysis, the bath solution is changed either periodically or continuously, so that a constant supply of fresh bath is provided to keep the bath waste level low, thus allowing more wastes to be removed from the blood.

The clinical use of hemodialysis to remove accumulated wastes from the body of the person whose diseased kidneys can no longer do so depends upon the process outlined above. Blood is taken from an artery through a system of tubes. It is then passed through the dialyzer unit of the artificial kidney so that the blood is separated from the bath fluid by a cellophane-like membrane. The exchange of water and electrolyte molecules and the transfer of waste particles from blood to bath occur as the blood courses along the membrane. Eventually, the blood is returned by a tube to the patient's vein. (Anticoagulant is added to the blood to prevent clotting in the dialyzer.)

There are several different kinds of hemodialyzers or artificial kidneys in use. The most common is the *hollow fiber* dialyzer. This is a plastic cylinder containing a bundle of thousands of tiny hollow cellophane-like fibers through which the patient's blood passes in one direction. Dialysate circulates around and between the fibers in the opposite direction.

In the layer or *parallel plate* type, two, four, or more sheets of cellophane are stacked in sandwich style between supporting boards. Gaskets around the edges prevent leakage. Blood flows between two sheets of cellophane, while dialysate fluid passes along the other side of each cellophane sheet.

All operate on the same basic principles. Typically, treatments are received two or three times weekly, the duration of treatment depending upon the type of equipment, the patient's medical requirements and other factors.

Another function of the artificial kidney is known as *ultrafiltration*, the removal of excess water from the patient. Inside the dialyzer, there is a certain resistance to the flow of blood. This resistance puts the blood in the dialyzer under a high pressure with respect to the surrounding dialysate bath. As a consequence, water is "squeezed" out of the blood. If the patient has gained more than the recommended amount of fluid weight since the previous dialysis, negative pressure (suction) can be applied to the dialysate (in the case of a hollow fiber dialyzer).

Dialysis is not painful, although most patients will from time to time experience some discomfort, such as headache, leg cramps, or nausea, particularly during the initial period of adjustment to the treatments. These temporary side effects may respond to the administration of saline solution (infused into the dialyzer's blood lines), or to being placed in a head-lower-than-feet position, or to other appropriate medical therapies.

In order to do well on dialysis, you will be required to limit your intake of fluids and certain foods, as described in Chapter 17. At this point, you may wonder why, if dialysis takes over the work of a patient's diseased kidneys, it is necessary to have these dietary restrictions. Normal kidneys do their work around the clock; the artificial kidney, only for several hours every two to four days. Moreover, the artificial kidney can perform only a few of the many complex functions performed by normal kidneys (see Chapter 1).

At present, artificial kidney machines are cumbersome and require considerable supervision. Their operation consumes time the patient would prefer to spend doing something else. Moreover, their operation is costly. Eventually, there may be simpler and more economical dialyzers that could be used perhaps one or two hours each day. Wearable and even implantable dialyzers are envisioned. Such devices would entail less interference with the patient's activities; he or she may feel better, and could have greater freedom in food and fluid intake. The future looks promising for the development of improved techniques and equipment.

It is possible for some patients, under highly controlled circumstances, to stay alive with a single hemodialysis (on today's equipment) every two or three weeks. But the patient would be pretty sick and feel poorly. One could have dialysis every day and feel better for it, but there would be little time left for anything else, and the cost would be prohibitive. Accordingly, the amount and frequency of dialysis prescribed for most patients is a compromise between what would theoretically be best for them, and what is most practical in terms of time and money.

In order for you to be dialyzed, it will be necessary for you to undergo a minor surgical procedure to create a means by which blood can easily be removed from and returned to your body during the dialysis treatments.

This may be the insertion of a plastic tube into an artery and a vein, the tube being connected to the artificial kidney during each treatment. This plastic tube is called a *shunt*. More commonly, a surgeon connects an artery directly to a vein under the skin; this results in a gradual enlargement of the vein with a high blood flow through it. This type of connection is called an *arterio-venous (A-V) fistula*. Needles can readily be inserted into the enlarged vein and connected to the machine. These and other types of “circulatory access” are described in Chapter 9.

HIGH FLUX DIALYSIS

Didier Mandelbrot, M.D.

The term high flux dialysis refers to a form of hemodialysis that was developed in recent years to improve the efficiency of dialysis. It has succeeded in both improving the quality of dialysis and in shortening dialysis times.

The essential element of high flux dialysis is the use of dialyzers (artificial kidneys) that have larger pores for the removal both of uremic toxins and of fluid. Blood urea nitrogen (BUN) is measured and followed as a reflection of all the toxins that the kidney normally removes. With high flux dialysis, BUN clearly is removed more quickly. But there is also now evidence that larger molecules may also play an important role in causing the uremic symptoms that are both annoying and dangerous to dialysis patients. Such molecules are too big to be removed by conventional dialysis, but are removed with high flux dialyzers. For example, a molecule called beta 2 microglobulin, which can have a role in causing arthritis in dialysis patients, is removed only by high flux dialysis. In fact there are already reports of patients with less joint pain when switched from conventional to high flux dialysis. Thus, the removal of larger molecules may prove to be a crucial benefit of high flux dialysis.

The larger pore size with high flux dialysis also allows much faster removal of fluid. Because of the risk of removing fluid too fast, and causing dangerous drops in blood pressure, a special device, called an ultrafiltration controller, is required. This device allows precise regulation of the volume that is removed, and avoids ever overshooting the amount removed. It also allows the accurate removal of very small volumes, as well as volumes up to four liters per hour, which can never be achieved with conventional dialysis. Finally, since the fluid is removed continuously and evenly, removal of large volumes is better tolerated with fewer symptoms.

Another important aspect of high flux dialysis is that higher blood and dialysate flows are used. With conventional dialysis, increasing the rate of blood flow (for example above 300 ml/min) minimally increases the amount

of dialysis. In contrast, with high flux dialyzers, when blood flow is increased up to 450 ml/min, significant improvements in dialysis efficiency can be obtained. Similarly, increasing the rate of dialysate flow allows faster removal of the toxins that are being cleared.

Nephrologists typically use some form of the technique called urea kinetic modeling to determine their dialysis prescription. Using national standards for adequacy of dialysis, and after taking residual renal function into account, urea kinetic modeling uses the dialyzer's performance characteristics and the patient's weight to derive an estimate of the time required for dialysis. Since high flux dialysis (also called high efficiency dialysis in some centers) is so much more efficient, it can allow significant reduction of dialysis times, often by 25 percent. Thus, the patient receives adequate dialysis, but minimizes the discomfort of long dialysis times. However, it is important to note that adequacy of dialysis must be maintained. Some patients may not be able to greatly shorten dialysis times when switching from conventional to high flux dialysis.

Several other aspects of modern dialysis, including the use of bicarbonate dialysate, are an essential part of high flux dialysis. However, they are now typically part of conventional dialysis as well. Bicarbonate is now routinely used as the dialysate buffer because the acetate that was used previously caused dilatation of blood vessels and resulted in low blood pressure. Another characteristic of high flux dialysis is that the membranes used are more biocompatible, and therefore are less likely to stimulate the body's immune system. This minimizes the allergic symptoms as well as the changes in white blood cell counts that were previously caused by less biocompatible membranes.

The major possible disadvantage of high flux dialysis regards pyrogen reactions. These reactions, characterized by high temperatures in patients during dialysis treatments, are caused by small pieces of dead bacteria that can be found in the dialysate. Although these reactions are not dangerous, they are uncomfortable for patients, and typically require short hospitalizations for observation. Some nephrologists feel that because high flux dialyzers have larger pores, the bacterial particles can pass more easily

into the patient's bloodstream, and that patients on high flux dialysis have more frequent pyrogen reactions. This observation remains to be confirmed.

Patients are not required to make any changes from their point of view in using high flux dialysis. Typically, they actually feel better, especially in terms of having less post-dialysis fatigue. High flux dialysis requires only minor technical adjustments in the dialyzing system, and will continue to be adopted by more and more dialysis centers throughout the country.

Chapter 4

WHAT IS PERITONEAL DIALYSIS?

Howard J. Alfred, M.D.

Peritoneal dialysis is similar in principle to hemodialysis. Both of these forms of renal replacement therapy depend upon the passive movement of water and dissolved substances (solutes) across a semipermeable membrane. This process is called *diffusion*. The direction of movement of solute is determined by the relative concentration on each side of the membrane, so that a substance goes from the side of greater to lesser concentration.

But that is pretty much where the similarities end, for the techniques themselves are very different from one another. Those differences are what provide for true treatment options for the person who requires dialysis therapy. Hemodialysis is a very efficient method of ridding the body of accumulated metabolic waste; the patient's blood is circulated outside the body through a filter (the artificial kidney) and then returned continuously for several hours, usually two or three times each week. In between treatments, the levels of solute (waste products) and water increase gradually: the rate of accumulation depending primarily upon what the patient eats and drinks between treatments. The treatment itself removes the waste products fairly rapidly. This rapid change in body composition can lead to dialysis disequilibrium syndrome, which may explain symptoms, such as fatigue and headache, which patients often experience after a hemodialysis treatment.

Peritoneal dialysis, on the other hand, is a slower, more gradual process which utilizes the natural lining of the abdomen, the *peritoneum*, as the exchange membrane. In the past, peritoneal dialysis was performed intermittently: the patient would do a series of fluid exchanges over a period of eight hours or more (usually overnight), three or four times a week. A number of automated machines were developed to help make the process simpler and easier. Using this intermittent technique, however, many patients were underdialyzed.

While peritoneal dialysis has been available for many years, even pre-dating hemodialysis, it was not until the mid-1970's that it gained substantial popularity with the development of the technique of *Continuous Ambulatory Peritoneal Dialysis, CAPD*. With CAPD, the apparent disadvantages of peritoneal dialysis have become the strengths of this form of renal replacement therapy. Variations of CAPD have also been developed. For example, *Continuous Cycling Peritoneal Dialysis, CCPD*, uses an automated machine called a cycler to perform fluid exchanges while the patient is sleeping at night. The principles, and problems, of both CAPD and CCPD are very similar, and since CAPD has been more popular, the remainder of this discussion will focus on CAPD.

The technique of CAPD is quite simple, and there have been a variety of devices developed to make the solution exchanges even easier, especially for individuals with reduced manual dexterity or with visual handicap. Briefly, the patient's abdomen (body cavity) is always filled with dialysis fluid, *dialysate*, a specially designed solution consisting of electrolytes and dextrose. This fluid needs to be changed periodically, as the concentration of waste products, which diffuse from the patient's blood, across the peritoneal tissue, and into the peritoneal fluid, increases. The dextrose, or sugar, in the dialysate draws water, by the process of *osmosis*, from the body into the peritoneal space. As some of the dextrose is absorbed (by diffusion) *into* the patient, and as the concentration of dextrose within the abdomen decreases as water from the patient is added, fluid removal decreases.

Access to the peritoneum is by means of a small tube, or *catheter*, which is inserted surgically into the abdomen. Since the incision is small, and the procedure is fairly quick, it is best, and safer, to use a local, rather than general, anesthesia for this operation. The catheter should exit the abdomen towards the patient's side, and away from the belt line.

To do a solution exchange, the patient should first find a quiet place, with no drafts or air currents, which might increase the chances of contamination. After washing his hands carefully, and then preparing the few pieces of equipment, he begins to let gravity drain the old solution from his abdomen. This usually takes about ten to twenty minutes.

The next step is to disconnect the dialysis tubing from the old dialysate bag, and connect the tubing to the bag with fresh solution. This can be done manually, which requires a fair amount of hand-eye coordination, as well as physical strength, or with the aid of any one of a number of mechanical (and easily portable) devices. For example, one very popular machine combines mechanical transfer capability with ultraviolet light for sterilization of the plastic “spike” which is at the end of the tubing. A battery pack is available to allow freedom of travel. With these earlier devices, the patient was always connected from the catheter to the tubing and empty dialysate bag, which was tucked beneath the clothing. There has recently been introduced a technique to permit separation of the bag and tubing from the catheter, so that patients no longer need to find ways to “store” the bag between exchanges.

Once the tubing transfer has been accomplished, the bag must be lifted above the patient’s abdomen, so that the new dialysate can be drained into the patient. The patient then puts his supplies away, discards the used solution and disposable bag, and goes on his way. A complete solution exchange takes about twenty to thirty minutes.

Most patients do four solution exchanges daily: first thing in the morning, around noon time, late afternoon, and at bedtime. The exact timing is not critical. For maximum efficiency, the *dwell* time, or time that the solution remains in the abdomen, should be at least four hours. Unless a cyclor is being used (as in CCPD), no exchanges are done during the night: this dwell time is therefore substantially longer, depending upon the patient’s sleep habits.

Since dialysate is always within the abdomen, the patient is always being dialyzed. The removal of waste products and water is therefore both *gradual* and *continuous*. The dialysis, therefore, begins to approximate the excretory function of normal kidneys. Furthermore, there are no symptoms of disequilibrium, because waste product levels remain relatively constant. CAPD is particularly suited to people with severe heart or lung problems. Poorly tolerated fluid build-up is avoided by the continual removal of water.

Many people have enjoyed this liberation from a machine, in spite of having to perform the exchange procedure four, or sometimes even five, times daily. They adjust quickly to the sensation of having two (or more) liters of fluid in their abdomen. Patients have reported an increased sense of well-being, improved appetite (because the treatment is continuous, dietary restrictions can be liberalized, but not entirely eliminated), resolution of symptoms such as itching and insomnia, and better control of blood pressure.

Most of the problems associated with peritoneal dialysis relate to the catheter. Catheter obstruction, abdominal pain, or malpositioning of the catheter tip may all limit the efficiency of the treatment. Infection of the skin exit site, the subcutaneous catheter tunnel, or the peritoneum (*peritonitis*) are all potentially serious, and not uncommon, problems which require prompt attention. While these infectious problems can usually be treated very effectively with antibiotics, occasionally the catheter does need to be removed in order to completely eradicate the infection. If a new catheter cannot be placed immediately, the patient will temporarily require hemodialysis.

Peritonitis is perhaps the most common major problem associated with peritoneal dialysis. Symptoms may be very mild at first, but if ignored, can become quite severe. Patients with peritonitis complain of abdominal pain or discomfort, nausea, vomiting, or diarrhea. Fever may or may not be present. The drainage fluid from the abdomen is usually cloudy. Treatment consists of antibiotics, which can be added to the dialysate, or given intravenously. Unless the patient is very sick and unable to do his or her own exchanges, most episodes of peritonitis can be managed without hospitalization.

Symptoms of peritonitis usually subside within one or two days, and the fluid should clear as well. If the problem does not resolve quickly, or if peritonitis recurs shortly, there may be a more serious underlying complication or a more unusual type of infection. Bacteria have been shown to adhere tightly to the catheter, and even to become encased in a protein called *fibrin*. This may prevent adequate exposure of the bacteria to the

antibiotic and prevent treatment. In such a situation, it is best to have the catheter removed to allow complete eradication of the infection.

Hernia may occur in patients treated with CAPD because of the increased pressure within the abdomen caused by the presence of the dialysis solution. A bulge may develop either in the groin, or at the site of a new or old abdominal incision. Coughing and straining also increase the risk of hernia formation. As mentioned earlier, general anesthesia should be avoided during catheter placement to prevent post-operative coughing, which could result in a hernia at the site where the catheter exits the peritoneum. Hernias need to be repaired surgically. CAPD can be continued after repair, but the volume of dialysate should be reduced until wound healing is complete. The patient must exercise great caution to avoid straining.

As noted above, the dextrose, or sugar, which is contained in the dialysate in order to remove fluid, is absorbed to a significant extent. The amount of dextrose absorbed per day depends upon the concentration of dextrose used for each exchange, and on the number of exchanges. The dextrose concentration can be varied to either increase or decrease the amount of fluid removed. As of this writing, there are three concentrations available: 1.5%, 2.5%, and 4.25%. While increasing from the lower to higher amounts will generally increase the amount of water removed, it will also increase the amount of sugar absorbed. This absorbed sugar directly contributes to the number of calories ingested by the patient.

There are several consequences of this sugar absorption. The most obvious is *weight gain*. Fortunately, this usually tends to be limited and generally tolerated, but occasionally, people do have to modify their diets, both to avoid excessive caloric intake, and to reduce the need for aggressive fluid removal. Body fats, especially *cholesterol* and *triglycerides*, have also been observed to be increased during CAPD patients. These elevations are thought to be related to the continuous absorption of sugar. The concern is that elevated blood cholesterol levels are a risk factor for cardiovascular complications.

No one knows yet what the long term effects of the dialysate will be on the peritoneum. There have been a very few reported cases where the ability of the peritoneum to allow adequate solute and water exchange has been lost. At the present time, this topic has received a great deal of interest from researchers. In addition, investigators are looking for new substances that will reduce the complications caused by the dialysate.

Drugs can also be put into the dialysate and absorbed. The example of antibiotics was given above. In addition, people with diabetes can add their insulin to each exchange and avoid having to give themselves injections. Because the insulin is given with each exchange (four times daily), blood sugar control is often greatly improved.

CAPD is a valuable adjunct to the treatment of people with chronic kidney failure. It is a simple and safe technique, so that patients can do it themselves at home. For some people, especially those who are prone towards low blood pressure or those with advanced heart problems, CAPD avoids the large changes in fluids that accompany hemodialysis. With careful planning and an appreciation for the strengths and weaknesses of this form of therapy, CAPD can often help increase the ability of the patient to deal with many of the problems of kidney failure.

Chapter 5

HOME AND CENTER HEMODIALYSIS *

Richard L. Faber, Ph.D.

The patient who is unable to have, or does not want, a transplant in the foreseeable future and who has a spouse or other family member willing and able to assist in the treatments, may be a candidate for home dialysis. (Even a patient without such an assistant may be eligible, for there are now vendors that will supply the equipment, supplies, and a dialysis nurse in your home.) There are advantages and disadvantages of which the patient should be aware before making a decision.

On the plus side, home dialysis affords the patient a degree of flexibility in scheduling not possible in a center. The time or day of dialysis can be chosen to suit the patient and family and may be changed to accommodate social engagements or other activities. Moreover, some patients feel more relaxed when dialyzing in the comfort and familiar surroundings of their own home. Although food is not permitted in many dialysis centers, home patients can have meals during dialysis.

However, home dialysis involves and restricts the family, in particular the family member-therapist. This person, who must train for 6 to 8 weeks along with the patient, will be tied down to the same schedule as the patient, and in addition, have the psychological burden of feeling responsible for the patient's safety.

Nevertheless, many families have found home dialysis eminently satisfactory and indeed preferable *for them*. There is little doubt that a well-motivated couple can master the technique of treatment. No prior experience nor medical "savvy" is required. No center would send them home before they had demonstrated full competence. When difficulties arise, the patient's physician and the staff at the training center or hospital are just a phone call away. A home patient who is having problems can be temporarily dialyzed in-center.

* See Chapter 4 for a discussion of CAPD (Chronic Ambulatory Peritoneal Dialysis), a third alternative.

The occupation of the patient in some cases may be a determining factor in the decision for home dialysis, as is the distance to the nearest center. For example, for a traveling salesman with a variable schedule, home dialysis might be preferable.

On the other hand, some patients may feel more secure being dialyzed on a fixed schedule by trained professionals in a center. Moreover, the center patient is freed from the tedium of setting up and cleaning the machine. Also, the center patient will ordinarily be seen by a physician more frequently.

For some, a cost comparison between home and center dialysis may be an important consideration. Another is the availability of space in the home for the machine and supplies. For a single person, for a married person whose spouse is unable or unwilling to perform home dialysis, or for a person who desires early transplantation, center dialysis may be the only choice.

As with many other choices regarding your care, only you can make the decision, but it would be wise to consult your physician as well as patients receiving both forms of care. If the idea of home dialysis is totally repugnant to you, you should probably reject it. Otherwise, arrange to visit several home patients, to talk with them and their spouses, and to get some idea of how the equipment fits into a home. Any of the officers of KT/DA (whose names and phone numbers appear in every issue of the *RenalGram*) will be happy to put you in touch with both home patients and center patients who would be glad to describe their experiences.

(Note: In some areas, other alternatives may be available: one is in-center “self-care.” In this method, the patient usually sets up the dialysis machine, attaches himself or herself to it, and monitors the treatment with a minimum of staff supervision. Another option, for a patient without a family member as home dialysis partner is a vendor that supplies a nurse to perform dialysis at home as well as home dialysis equipment and supplies. You might want to inquire if either of these modes of treatment is a possibility for you.)

Chapter 6

DIALYSIS—HOW THE PATIENTS SEE IT

6a—A Second Chance

Mary Zocchi

The afternoon is glorious, a typical Indian summer day with balmy southern breezes, and the trees with an abundance of color etched against a light blue sky. Before me is a pond's tranquility, only occasionally interrupted by the honks of the remaining squadrons of ducks, mallards, and gulls. All that beauty, God's gifts to us to savor before the onslaught of a cold and sometimes cruel New England winter.

In spite of all this loveliness, somewhere deep inside of me is a picture I can never quite erase, and perhaps do not really wish to. The scene drastically changes to a brightly colored, windowless room where row upon row of machines unceasingly toil at their life-giving task of refreshing blood for the next forty-eight hours.

It is so easy to describe the beauties of nature, so difficult to plunge ahead with the story of life artificially but gratefully prolonged, so I pause and look around me, as the birds peacefully glide by. But discipline, a key to survival, slowly ebbs back, as I do my best to describe a typical evening on a dialysis machine.

Arriving at the cold stainless steel front of the center, you pause with quickened heart beat, enter, nod a perfunctory "good evening" to the receptionist, and pass through a brightly colored corridor to the dialysis room. Walking to one of the four large bays, a technician and your life line, the kidney machine, await you. An elevated platform in the middle of the large, immaculate room serves as a control center and nurses' observation post.

Greeting your friends in your bay, you settle into a bright blue chair for your four-hour cycle, and hope you have lucked out with a good sticker (a nurse or technician skilled in inserting the large dialysis needles into your arm). After weight and blood pressure are noted on your chart, the needle insertion begins.

To digress a little, before you begin your dialysis treatments (days or weeks before), one of several surgical procedures is performed to ready your

arm. One of the favored techniques is called the *fistula*, which involves the connection of a vein and an artery to dilate the vein and provide easy access to and from the artificial kidney.

Back to the moment of needle insertion. The technician determines whether you want zylocaine, a local anesthetic, administered just below the skin, then the real sticking begins. If your fistula is reasonably good, your insertion usually goes quickly without much discomfort. Next, heparin is administered to prevent the blood from clotting the lines and dialyzer during the run. Then your blood is rapidly pumped through the tubing to the artificial kidney filter that will allow toxic and other waste substances, but not the large blood cells, to pass through it. This will purify the blood, a job normally done by the body's kidneys.

If you have any of the following vein problems, the sticking may be unpleasant. Some patients have small, rolling, zig-zag or collapsing veins. to mention a few. Some have two or more of the above.

The rest of the evening will probably go fairly smoothly. If one has a pleasant neighbor, conversation turns to politics, news of the day, T.V. programs, and, inevitably, some discussion about the technicians, doctors and your own particular medical situation. Unless you are experiencing serious problems, most chatter is not depressing nor are the medical problems emphasized.

If you have a smattering of curiosity, you'll learn more about the miraculous machine that is your life extender, as well as how your anatomy reacts to it. If you have any sense of gratitude, you'll thank God and your lucky stars that you are living in an era that allows you the privilege of dialysis.

Most people on the artificial kidney machine are remarkably cheerful, have great zest for life, and many accomplish a lot in between treatments. Some make very good use of their time on the machine as well. For example, teachers grade their pupils' work and scientists read their technical journals. One cannot help but be inspired by the courage of these and other patients.

At the center, you meet a number of people who are on dialysis because of transplant rejection. Organ transplantation is successful for many. The lucky ones are leading completely normal lives. Some, unfortunately, have gone through that critical medical procedure two or three times. One young lady, now 20 years old, has had three unsuccessful transplants and is always bright and cheerful, even though the last time I saw her, she was on crutches. Another young man, a senior at M.I.T., also had a transplant that rejected. After much trauma and ill health, he is struggling to maintain his college grades. The main thing is that those young people, and others, continue undaunted and are making it.

The gamut of patients is varied in health, occupations, and avocations. As hinted at before, many on the early evening shifts are gainfully employed. Several are medical doctors; no one is shown any favoritism as far as kidney disease is concerned.

One special friend of this writer is a fine, bright gentleman in his late sixties. Although officially “retired,” he would outdo many a younger person. He swims vigorously three times a week, drives twenty-five miles each way to dialysis, gardens, takes courses, and in general enjoys life and his family.

As the evening progresses, blood pressures are monitored. One problem, commonly referred to as “crashing,” may rarely occur. This is a polite term for a rather nasty experience, namely losing or nearly losing consciousness, vomiting, etc. This condition usually responds to the administration of saline solution to the ill patient.

Finally, the four hours are over. The needles and tubing connecting the patient to the dialyzer are removed. After a period of time to clot the blood at the needle sites, bandaids are placed on the punctures and the patient is weighed and charted. Soon he is on his way home, only to repeat this all again two or three days later.

This article would not be complete without recognition and special thanks to the doctors, nurses, and technicians who keep the center running day in and day out. Although dialysis for the majority of patients is at a center devoted specifically to dialysis, many acutely ill patients are treated

in hospitals with much care, love and dignity; and many others dialyze at home.

Finally, besides the patient's own will to live and determination to abide by the rules of diet and medications, is the love and support the patient's family and friends give. Without this, even the most determined patient would have difficulty struggling against a difficult disease in a sometimes uncaring world. With it, life *can* be beautiful, if not idyllic.

6b— Thirty-Four Years on Dialysis

Richard L. Faber, Ph.D.

(Editor's Note: The following article, adapted from *Hemodialysis: Principles and Practice*, Academic Press, Inc., New York, 1972, was originally written in 1970 when I was still on home dialysis. In 1973, I began center dialysis after an unsuccessful transplant. The *Updates* following this article present more recent thoughts on my earlier views.)

Three times a week, I spend six hours^{1*} of my time in a “health spa.” The benefits are not smoother, younger-looking skin and sinewy, rippling muscles, but continued life itself. I am referring to a spare bedroom that houses a remarkable machine that substitutes for my own failing kidneys.

Three years ago (in 1967), I was entering the latter stages of uremia. I had resigned from my job (as a mathematics professor), and could do little more than mope around the house and try to conserve what little energy I had left. Even standing for more than a few minutes made me breathless.

Now, except for the time spent with the kidney machine, my life is essentially normal, professionally and socially. I can mow a lawn, shovel snow, paint ceilings, take walks, bowl, dance, dine out, play with my child—everyday things that seemed forever lost to me. I even help out with housework occasionally (though I try not to make an obvious display of my talents in this area, especially in front of my wife). I enjoy exercise, and feel better for it. During summers, I play golf and ride a bicycle.

My diet is practically normal, and although eating had never been an especially great attraction for me in past years, I am now somewhat of a glutton who is becoming literally too big for his own breeches. Since the initial dialysis, in June 1968, I have gained 20 pounds. I feel as well as I've ever felt in my 30-year lifetime—perhaps better—because I value all the joys of living so much more today.

Of course, there is still no perfect substitute for a real kidney, my own success notwithstanding, and I would be deluding the prospective patient if

^{1*} With today's more efficient dialyzers, treatment times are now typically three to four hours.

I did not delve into the difficulties and problems of adjustment inherent in home dialysis. If I extolled only the virtues of this therapy at the outset, it was because the virtues far outweigh the disadvantages in my own mind. Nevertheless, there are problems which cannot be overlooked, and which any prospective patient should be prepared to accept.

To begin with, six hours is a long and uncomfortable time to sit in one place. I feel also that this loss of valuable time is a minor professional handicap, even though I often perform certain light duties, such as paper grading, during dialysis. The sessions usually run from about 4:00 p.m. to 11:00 p.m., including cleaning the machine, so I have dinner during the treatment. The loss of time was particularly annoying during the training period. Dialysis in the hospital kills the better part of a day. Treatment in the comfort and privacy of one's own home and at one's own convenience is much less of a hardship. Many patients feel tired or "washed out" after being dialyzed, and find it more pleasant to run the machine in the evening and then retire.

There are various side effects to hemodialysis, especially during the first few months of treatment. Many of these, such as nausea, headaches, dizziness, and cramps—not all of which are experienced by every patient—either subside or disappear after a few weeks. New complications may sometimes occur. Those who are so inclined may easily find something to worry about. Side effects are as varied as the patients themselves. However, many (though not all, of course) of the minor discomforts patients experience are just physical manifestations of their mental anxiety. In my own case, worry over the death of another patient—worry of which I was consciously unaware at the time—caused me to have shortness of breath and chest pains for several nights in succession.

After many months of home dialysis, I believe that 90% of the problems the patient encounters can be lumped under the heading "psychological adjustment." There is absolutely no pain associated with the treatment, nor any sensation of blood entering and leaving the body. But many patients have great difficulty in adapting to the idea that their lives are dependent on a mechanical contrivance. It is my contention that this problem of adapting counts as much as any physiological factors toward the

variations found in the degree of success derived from chronic hemodialysis. In particular, a great deal of anxiety is attached to shunt care. This piece of plastic^{1*} is an admittedly vulnerable addition to one's anatomy. It is the patient's lifeline: a clearly visible symbol of the precariousness of his existence. Concern for its integrity is always lingering in his mind, and he must not partake in any exercise sufficiently violent to endanger it. It may last but a short time, or for years.

Problems can be kept to a minimum, however, through proper shunt care. A shunt never clots without some warning, and frequent, visual inspection of the top of the shunt loop will usually preclude any serious clotting. Daily washing of the shunt area minimizes the problem of infection. The patient has little control over possible leakage or skin erosion, but these are rare. In short, I try to think of my shunt in the same way most people think about eyeglasses, hearing aids, or dental appliances. It is only a minor inconvenience. Hemodialysis is only a minor inconvenience—minor, because I never allow it to dominate my thoughts. Minor, because I really do not think of myself as a sick person. Certainly, only those who have been told of my condition would have any reason to think me anything but quite healthy.

The attitude of the spouse plays a critical role also. If she (or he) shelters her/his mate from the minor chores and other activities of a normal life, he/she cannot possibly feel fully well. The wife who treats her patient-husband as a semi-invalid and who constantly laments the plight of her "poor, sick" husband before friends and neighbors is giving the man a second handicap. My wife does not wait on me hand and foot, nor would I want her to. There is absolutely no reason for me not to do things for myself. Her attitude parallels my own: it is not a terrible thing that I must depend on this machine; but, rather, it is a wonderful thing that this machine makes me well.

Of course, my wife was nervous in the beginning about becoming a dialysis nurse and wondered if she could ever learn all that had to be learned. I was apprehensive, too, but my scientific curiosity was greater

^{1*} Nowadays, most patients have an arteriovenous fistula or an artificial vein graft rather than an external shunt.

than my fear. Now, operation of our dialyzer is a routine matter, which either of us can handle without giving much thought to it.

As for our 3-year-old daughter, she is, of course, too young to understand why her daddy spends three evenings a week alongside that strange machine whose knobs and switches are such fun to play with. Nevertheless, we make no attempt to keep her away from the machine, or from me when I'm on it, or when I'm cleaning my shunt. She probably thinks that everybody's daddy has a machine like mine. We even make her feel a part of things by letting her "help" me with my dialysis supplies inventory. She hands me the items one at a time, and I place them on shelves. It makes her feel useful and important, which, of course, she is.

Returning to work is a necessary part of good patient morale. A healthy attitude and a sense of purpose in life go hand in hand. There are few occupations too strenuous for a properly dialyzed patient, although those with sedentary duties or flexible schedules have an advantage. The dialysis patient needs something non-medical to worry about. Feeling sorry for himself is a disastrous state that must be avoided at all costs. Personally, I am much too busy with my mathematical research and teaching to worry about my kidneys—and that is how it should be. I have told almost no one at work about my condition, for I neither want nor need any special consideration from my employer. I enjoy my work and am very grateful that I can carry on with it.

Nothing offers more encouragement to the prospective dialysis patient than listening to one who is being successfully treated by this therapy. It helps him to realize that he is not about to submit himself to a mere maintenance measure that will just delay the inevitable, but, rather, that he will be receiving effective treatment that will keep him well and permit him to resume an essentially normal life. With this thought in mind, I have tried here to describe my feelings about home dialysis, with the viewpoint that mental attitude and adjustment are just as important for success as proper therapeutic technique. Life is a mental as well as a physical state. Home dialysis can truly be a gift of life, provided the patient can adjust his thinking and accept his plight. He really is not so badly off after all.

UPDATE — MAY, 1971

It is now nearly three years since my first dialysis, and a little over one year since the preceding was written. I can state frankly that my attitudes toward this therapy have not changed significantly. My shunt was replaced by an arteriovenous fistula in my left arm in June 1969. This is a marvelous improvement over the external shunt, for it requires no care between dialyses. Clotting, leakage, and infection are no longer problems, the patient need not be on anticoagulants, and physical activity is not limited for fear of shunt injury.

Admittedly, it was difficult for my wife to master the required needle technique, and the first month or two with the fistula was a trying period. But now she never misses, and I have even learned to make the venipunctures on myself.

I still keep as active as possible and feel one hundred percent healthy. My wife and I regularly bike ride around our neighborhood and play golf together (eighteen holes, unless my wife tires after nine). I have played softball, volleyball, and have ice-skated. I have been teaching a full schedule this year as well as an additional evening course. I have had some problems, of course, e.g. two episodes of bronchitis, but all in all we have been very fortunate.

UPDATE — JUNE, 1978

Following an unsuccessful transplant in 1973, I began center dialysis. My main reason for transferring from home to center dialysis was the cumulative effect of the stress of home dialysis upon my wife and daughter, stress of which I was not fully aware in the earlier years. Although home dialysis is an excellent mode of treatment for many people, it is important to realize that it places a serious psychological burden on the family member who assists in the treatments. The decision to dialyze at home must be carefully considered by both parties—and reviewed from time to time, since the choice of therapy method should not be viewed as unalterable in the future.

My own condition remains quite favorable after ten years of dialysis, and I remain fairly active, although I get out of breath a little easier than in the beginning years on dialysis. Whether this is due to ten years of aging or long-term side effects of dialysis, or both, is hard for me to say. I am not planning a second transplant in the near future, but look forward to one some day.

UPDATE — JULY, 1981

At age 41, I am now in my 14th year of dialysis and still doing well. I am still teaching full time, have written a textbook, and am doing some consulting work besides. My diet is more or less normal, although my body seems to be a little less tolerant of overindulgence than in the earlier years.

Physically, I am somewhat less active than before and have been paying others to do such chores as lawn mowing and auto maintenance, which I used to do myself. Recently, I began an exercise program of sit-ups and push-ups to regain some of my lost muscle tone.

At my dialysis center, I initiate my own treatments unaided. I am convinced that those patients who take the responsibility for their own treatments (determine and regulate their own pressures, flow rates, etc.) invariably do better on dialysis than those who just sit back and leave it to staff (who vary in competence and experience).

I have been thinking more about transplantation lately and might consider a second go at it one day.

UPDATE — MAY, 1983

I have now completed 15 years on dialysis. A little over a year ago, I put myself on the transplant list and am awaiting a cadaver kidney. Unfortunately, I am highly presensitized^{1*}, so it may be a long wait. I am still working full time as a mathematics professor.

^{1*} This means that I have built up a great many antibodies in my blood that would cause me to reject a kidney from almost anybody but a near-perfect immunological match.

UPDATE — JUNE, 1988

I have now completed 20 years on dialysis. I have been very lucky, since I've been able to work the entire period. I've carried a full teaching load and published three textbooks. I also manage to do a small amount of consulting and assist my wife with a desktop publishing and word processing business she began several years ago. I look forward to seeing my daughter graduate from Boston College next year.

I'm 48 years old now, so my stamina is not what it once was, but I have no trouble walking or climbing stairs. Giving a 75-minute lecture sometimes exhausts me, especially if I lost a little too much fluid during the previous evening's dialysis treatment. I keep telling myself to exercise more, but I don't seem to be taking the advice.

I am still awaiting a second transplant, but by now hardly with bated breath. Treatment times are down to only four hours now, which is a lot easier to take. I may try high flux dialysis in the near future, which should reduce the time further.

UPDATE — JUNE, 1993

This month I completed 25 years on dialysis.

I switched to high flux dialysis about two years ago and feel this mode of treatment represents a definite improvement, not just because of the reduction in treatment duration (now 3 to 3.5 hours for me). Judging by tests that measure adequacy of dialysis, I am quite well dialyzed. I notice that I feel better on Mondays (after a three day interval between treatments) than with conventional dialysis. Neurological problems—I had five surgical procedures for carpal tunnel syndrome during the eighties—seem to be diminished; at least the symptoms of this condition, which is a compression of a nerve in the wrist due to inflammation and scarring, have not recurred.

Last summer, my wife and I played golf a lot, and I was able to walk eighteen holes while pulling a golf cart behind me. I am still a mathematics professor at Boston College, although I am currently on a temporary medical leave of absence (see below).

My wife and I recently celebrated the marriage of our daughter, now 26 years old. It was always my wish that I would live long enough to see this. Now I look forward to becoming a grandfather some day.

On November 18, 1992, I developed chills and a fever during my dialysis treatment and was transported by ambulance to the hospital. There it was discovered during exploratory surgery the next day that my pancreas and gall bladder were inflamed, and the latter had to be removed. I had to have a second surgical procedure because of internal bleeding and then ran into other complications, including dangerously low blood pressure. I wound up in intensive care and on a respirator for about 11 days. I very nearly died. After a total of six weeks in the hospital, I began a period of several months of recuperation that is still continuing as of this writing. Needless to say, this episode had profound emotional and psychological effects on me that may well outlast the physical toll. For many weeks, I was no longer in control of my health, but dependent on others. That was very difficult for me.

I hope to regain my strength and resume teaching next year. The support of my friends, family, and coworkers has been invaluable to me.

And of course, words are inadequate to express my gratitude to my wife Susan for standing by me through the difficult times as well as the good, and for always being there when I needed her.

UPDATE — AUGUST, 1999

It is now nearly seven years since my medical crisis in 1992 and over 31 years since beginning hemodialysis. As it turns out, I decided not to return to work at Boston College. After 31 years of hemodialysis, at age 59, the side effects of long-term hemodialysis, especially bone disease, often called renal osteodystrophy, have greatly limited my mobility.

In January of 1997, I fell and fractured my right hip. It was then that I learned about a condition called β_2 -microglobulin amyloidosis, a serious problem for nearly all patients who have been on dialysis for more than a decade. This type of amyloid is a protein substance with the consistency of week-old chewing gum, that can deposit in bones, joints, the hands, and

other places in the body. In my case, it weakened the hips and eroded the rotator cuff in my right shoulder, among other things.

The hip was repaired by pinning with large screws. Unfortunately, the screws did not hold, and so in September of 1997 I had a total hip replacement. That worked beautifully for the better part of a year. It felt like a normal hip! Then I began to have hip pain after walking or standing for more than a few minutes. It is possible that the prosthesis is loosening (a hip arthrogram was inconclusive). I have been using a cane for several months.

Recently I began having lower back pain, and it was discovered that I need to have spinal fusion surgery, which is scheduled for the end of this month. I also learned that my hip pain may, at least in part, be caused by nerve compression in the lower back, so I am hoping that the back surgery will alleviate much or all of the hip pain. If so, I hope to return to my former mobility.

Although physically limited, I have kept active mentally and socially. I visit my grandchildren, Alexandra, 5, and Brett, 3, as much as possible, I have a new hobby, digital photography, and like to play around with my computer. I also read a lot.

I have been on the cadaver transplant list at Mass. General Hospital since 1981 and would jump at the opportunity for a transplant, but this is highly unlikely because of my high presensitization—I reject essentially everybody's tissue.

UPDATE — JANUARY, 2001

In August 1999, I had spinal surgery that largely eliminated my back pain. In March of 2000, I had to have a second total right hip replacement because the first prosthesis loosened. This time, the prosthesis is held in place by bone pieces from the bone bank and five loops of wire. It will probably take a couple of years to heal fully. Ten months after the surgery, I am still walking with a cane, but the hip is pain-free. I wonder if I'll ever play golf again.

My wife and I decided that we had been saving all our married lives for our old age, and that now was it. So we rented a newly built one-bedroom apartment in West Palm Beach, very close to where my wife's twin sister and her family live. We've been in Florida only a few weeks now, but are starting to feel relaxed and refreshed. The only drawback is that we won't see our grandchildren—now numbering three—until mid-April.

We both feel pretty well, although my wife has a pacemaker (as does her twin sister) and had a mild stroke last year (as did her twin sister). Because of improved dialysis technology, I feel I am better dialyzed than at any other time in my life.

We'll chat again in a few years.

Chapter 7

A PERSON, NOT A PATIENT: A Prescription for Learning to Live a Normal Life on Dialysis

Vincent Brady

A few months ago, I had made a promise that I would write an article concerning dialysis. I had delayed in fulfilling this promise for quite some time now. The reason for the delay was simple: writing an article meant disclosing a part of my life which sets me apart from the norm. In the past ten years while on dialysis, I've managed to carve out a normal existence. I am recently married, well-educated, and have an interesting career. Disclosing my medical condition could very well disrupt my normal existence.

Experiences have taught me that “healthy” people pass through four phases of adjustment when first learning of my medical condition. The phases are: shock, curiosity, adulation, and finally, the phase in which I am now, treating me as if I had no medical condition. In *shock*, people can't believe I'm “sick.” Instead of engaging in a conversation based on free information, such as, “How is the weather,” the conversation begins with dialysis/patient jargon such as, “How do you feel?” or a very popular tune, “I know a person who has been on dialysis for five years.” The message I receive from this is that I am unique. Not unique in an exemplary manner, but unique in that I am perceived as “sick.” The perception that you are “sick” does not contribute to your self-esteem.

The second phase is *curiosity*. In curiosity, people are interested in the specifics of your condition. They want to know how many times per week you need dialysis or if the treatment hurts. Sensitive people refrain from asking too personal questions. Some people, however, need to know every detail of every operation.

After satisfying their curiosity, the next phase begins, *adulation*. In adulation, you are perceived as courageous and heroic in handling your personal problems. This becomes particularly true when people begin comparing their problems with yours. In many instances, this adulation is mixed with a high degree of paternalism. This paternalism reveals itself when relatives or friends lower their expectations of you. For example, I

have a friend who happens to have a friend on dialysis. My friend feels this person is doing well, well enough in fact “to eat pizza, drink beer, and dance.” When asked if this person had any intention of returning to her clerical job, she felt that was an unfair expectation considering her condition. The adulation is comforting to hear while the paternalism is easy to ignore. The combination though act as a perfect catalyst for self-pity.

The last phase means being treated as if you had no medical conditions. It means being accepted for what you are and do. It means having a job or career and outside interests. It means living a full life, regardless of dialysis. It also means learning the physiological parameters of dialysis and realizing that you are still worthwhile to yourself and others and that you can be loved. The illness and the events surrounding the illness make this a very difficult adjustment. In fact most “healthy people,” who have the same needs to be loved and the same needs to feel worthwhile vary remarkably in their ability to fulfill them.

For a person on dialysis, it is much more difficult to have these needs met. Physiologically, one of your most basic requirements for life, the need for the removal of waste, is now being performed by an artificial device, which operates far less successfully than your original healthy kidneys. Psychologically, because of a whole series of internal reasons and external events, you may very well have stigmatized yourself and have been stigmatized as a dialysis “patient.” The word patient connotes sickness. The word patient perpetuates the assumption that a person on dialysis is non-functioning and dependent. If the people around you treat you like a patient, it is pretty normal to start viewing yourself as a patient. If you view yourself as a patient, then the expectation that you should meet your needs while on dialysis is severely diminished. How can a person who has been stigmatized as being “sick” and non-functioning and dependent feel worthwhile or have a positive self-image?

When you begin dialysis there are many adjustments to make. For most people it may well be the first time you’ve needed surgery. You must learn to live with a shunt and tolerate multiple punctures of either your arm or leg. Your diet and drinking habits are drastically changed. You lose weight and your muscles may atrophy. You may look pale and jaundiced. In

the hospital you're bombarded with information about blood pressure, fluid overload, calcium, potassium, medications, diet, transplant, cadaver list, TMP, Medicare, and blood flow. It is an endless stream of information presented to you when you're feeling the worse you've felt in your life. To complicate matters, your first few dialyses are uncomfortable. Your access sights ache and you itch. You might cramp and shock. Dialysis appears as an endless array of problems. As a patient in the hospital you live according to the institutional routine. Dialysis at seven-thirty, back to your room at one, a snack at three, dinner by five, family at six and sleeping pills by nine. The procedures in the hospital and your first few uncomfortable dialyses have established a pattern and attitude of dependence.

This attitude of total dependence is transferred with you when you are transferred for dialysis at a free-standing facility. At the free-standing facility, you arrive early and sit dutifully in the waiting room with the other somber faces. At precisely the scheduled time you're allowed to enter the unit. Once you have hung up your coat and greet your therapist, you're escorted to the scale for the ritual weigh-in. As you stand on the scale you're reminded by the sign that you must have your weight verified by a staff person. At one time you might have been responsible enough to raise a family, but now you're not responsible enough to weigh yourself.

Once you have had your weight verified, the staff person escorts you back to the chair, takes your pressure, cleans your arm, computes your weight loss, brings you a blanket, adjusts your chair, and gives you a pillow. In a most insidious and subtle way, the institutional procedures of the free-standing facility and the behavior of the staff reinforce the attitude that you're a patient.

There may be further problems which compound your condition. You may have enormous medical bills and in most instances have not worked in the past few months. In fact you might even question your capability to work. You sense there is a change in the relationships with your family members, and you might question your sexuality. The only hope appears to be a transplant. Experience has taught me that people in this predicament are analogous to the drowning man grabbing a piece of straw hoping it was a log. However, in my opinion, there is a sequence of events which, upon

completion, will lead to a better self-image, an improved quality of life, and an objective approach for selecting your modality of treatment.

The first step in adjusting to dialysis is learning the clinical aspects of kidney failure and dialysis. It is imperative that every person on dialysis know the diet, understand blood chemistries and medications, learn the process of dialysis, and how to deal with the side effects of the illness. If a person can learn the clinical aspects of the disease and the treatment, and can apply this knowledge on a daily basis, that person will physically feel better. Once you're following your diet and watching your fluids, your treatments will be less traumatic. In some instances, the itching will be less pronounced and the number of cramps may become less frequent.

In terms of the effects of the treatment, it means understanding a simple concept like your blood pressure. For example, if your pressure is low, this doesn't mean the entire day must be spent on your back with your feet in the air. It does however mean rising slowly and drinking extra fluid. A low hematocrit doesn't mean huffing and puffing when you take in the groceries, but merely means taking in four light bags instead of two heavy ones.

Third, learning the process of dialysis enables a person to control the machine that keeps him or her alive. Only the person on dialysis really understands his or her dry weight and stamina. If you can understand dialysis and its effects, you will be better able to relate to the medical staff. A person on dialysis who has gained the confidence of the medical staff will be given some degree of latitude in his or her treatment. For example, if your medical record indicates your dry weight is 63 kilos and you feel your dry weight is 65 kilos, chances are that you may not be dialyzed as hard. Imagine every time you dialyzed you ended up weighing two kilos below your dry weight. You certainly wouldn't feel well after each treatment.

Finally, controlling your dialysis means controlling your health. Controlling your health means being less dependent on the people around you and the medical staff. Being in control and acting independently is the first step toward a better self-image.

Once you're feeling better and have an understanding of the circumstances of your medical condition, start thinking about long-term and short-term objectives. Long-term objectives involve your career or education. Short-term goals pertain to daily or weekly activities. An attitude I have found prevalent in many people is that dialysis is only a phase of their lives and they will lie back and wait for the transplant. Once they have had the transplant, they will resume all their previous activities prior to dialysis. This attitude is naive. Statistically speaking, transplants are merely a reprieve from dialysis. Many transplants fail over time. Lying back waiting for the "cure" is a waste of time which could be used in a productive manner.

A productive use of this time while on dialysis could be continuing your education or finding a new career. A long-term goal of a business executive on dialysis might be resuming a full-time career, while for a coal miner it would mean a career change. Choosing long-term goals should involve professional assistance from a social worker or a rehabilitation counselor. A short-term goal of increasing your outside activities could be either joining a bowling league or making your own snack instead of relying on your family.

These goals should be realistic and obtainable. When you're feeling badly about yourself, you don't need to be reminded that you're a failure by establishing goals beyond your capabilities or means to achieve them. Nothing succeeds like success. Once you've accomplished an objective, establish another. If you graduate from high school, go on to college. If you walk four blocks a day for exercise, increase your walk by a half block every two days. Establishing goals and achieving them is the second step which will enable you to learn to live a normal life while on dialysis.

The last step involves choosing the treatment which best coincides with your long-range objective. People on dialysis have three alternative methods of treatment of end-stage renal failure: home dialysis, dialysis in a hospital or free-standing facility, or a kidney transplant. Each of these options has its own peculiar positive attributes and negative consequences. I suggest that each person discuss the consequences of each form of treatment with his or her physician, particularly the negative side effects of

a kidney transplant. Once you have learned the consequences of each method of treatment and have begun to achieve your long-range objectives while on dialysis, choose the method of treatment which best fits in with your long-range objectives.

For myself, this means continuing dialysis at a free-standing facility, continuing my career as a health planner, and eventually trying for a third transplant. I will not, however, put myself on the cadaver list until I have made certain arrangements. The first is to educate my co-workers and supervisors of the time I will need to recover from the transplant. I certainly would not want to have a transplant and lose my job because of excessive absenteeism due to the surgery. Secondly, I want to set aside a sum of money which will enable me to take a six month leave of absence after the transplant, to be used either for recuperation if there are medical complications, or a vacation. After ten years of dialysis, I feel I have earned at least six months of travel.

In essence, I am advising people that if they choose a transplant, they should be in a position, whether the transplant fails or succeeds, to continue (after a brief recovery) with their career objectives. Do not place yourself in the position where your entire future depends on a successful transplant. Desperation is a fool's reason for a transplant.

By no means do I wish to suggest that every patient who reads this chapter is capable of living a normal life while on dialysis. There may be medical problems beyond your control which prevent your total rehabilitation. All I ask is that you evaluate your life on dialysis and strive to be more independent.

Chapter 8

SPOUSE: A WIFE'S VIEW OF DIALYSIS

Susan Faber

While we, as spouses, are not the patients, we live day-to-day with the disease and the successes and problems that are associated with living with end stage renal disease. Whether the method of treatment is chronic hemodialysis, peritoneal dialysis, CAPD or transplantation, loving and living with a patient who is faced with extending his/her life with this treatment does not let us escape some of the turmoil patients feel. Though we are not the “*sick*” member of the family, surely we face the problems with them, and our lives are affected by their varying degree of “*wellness*.”

First, let me review some of the history which I have found during the years can be so similar for all families. My husband, then 27 years old, hadn't been feeling well, so he saw a doctor. We knew he had a kidney problem, but never realized its potential seriousness. We were only kids then. I was 26, we had a baby three months old. We didn't expect to hear that he had a major health problem. In retrospect, I think we just expected he would get some medication and be fine. As I remember, we initially were told not to expect anything radical to happen for five years, which seems a long time when you are in your 20's and just starting out with a young family, a new job, and a new house, all in a new state and no family around. But, like many of you, we soon found out that kidney disease progresses slowly until the kidneys reach about 10% of their kidney function, which in most cases is rather late in life. That is when the patient starts to get the familiar symptoms, and it becomes apparent that treatment is necessary.

Over 26 years have passed since we faced that problem in 1967, and shortly we will have celebrated the completion of his 25th year on dialysis—that's three treatments a week, 52 weeks a year or 3,900 treatments ago. Twenty-six years ago people were dying for lack of kidney machines, transplantation was only a one-shot affair, and chronic dialysis was a medical experiment. Our hope was that transplantation would be the ultimate cure.

For the first 5 years of his treatment, we were on home dialysis. Since then, he has dialyzed at a kidney center. I have no recommendation regarding home dialysis, except to say that it is probably best for the patient—given the freedom of treatment. However, the whole family is on dialysis (time, schedule, routine, and responsibility for the spouse who helps with the dialysis treatments). Today many families are able to afford nurses or technicians, either as a permanent or temporary assistant, to take the burden of responsibility and some vacation or free time from the family caregiver. While the patient has to adhere to a rigid schedule when treated outside the home, the family, and in this case the spouse, has more freedom and no responsibility regarding treatment. Some of us have used this “free” time to extend our education, get a job, drive our kids to endless after-school activities (gymnastics, sports, etc.). If you talk to people regarding their feelings about various methods of treatment, they will usually favor their current mode of treatment. Although everybody wishes for a successful transplant.

My husband had his ups and downs for the first year. He was one of the first patients to receive the arterio-venous fistula, and I was one of the first spouses to learn to put the needles in his arm so that he could receive dialysis treatments. This was quite an improvement for the patient over the external shunt (there was no longer worry about external tubes, infection, or daily care regarding the access site). I remember those days well. I never looked forward to dialysis treatments and was relieved when the treatment was started. I must say here that all the spouses I have known that had to master the technique of placing needles were able to accomplish this task.

When children of a patient are young, they may think everybody’s daddy is on dialysis, that dialysis is fun, and it is no big deal. As they get older, they too must learn to live with the disease. We thought our young daughter, now 26, knew and understood about kidney disease, dialysis, and kidney transplants. She did, but it took us a long time to realize that her level of understanding was much different from ours. She once told me that when she heard her daddy had a transplant, she thought a miniature kidney machine had been placed inside his stomach—even though we had

explained in detail why daddy was away and what was being done; she was five years old at the time. (The transplant was unsuccessful.)

As a family, we took one day at a time—cherishing the times we spent together. It was nice when the baby got up after dialysis and we played with her for a while. We even enjoyed it when, on home dialysis, she went to check on daddy. We made her a part of the treatment. She assisted him in fixing the television, bringing him a snack, or anything she could or wanted to do. Mostly, she kept him company. Sometimes she even pretended she too was on dialysis. I remember sometimes I would place a piece of plastic tubing on her arm so she could sit like daddy.

We always made the family time special—doing things with our daughter and sometimes with her cousins when dialysis didn't interfere. Our Saturdays were usually spent going out for Chinese food (which we all love) and then to the movies. Just watching television together was something we liked to do. Sharing is the operative word here.

The first three years were especially hard for me. Our daughter required care as all toddlers do, and the home treatments consumed eight hours (including setting up the machine and cleaning afterward). Gradually, as time went on, my husband came home earlier from work to set up the machine. After the treatment he helped clean up. He also decided to learn to become more self-sufficient on the machine and started putting in his own needles, which he does to this day. He initiates and monitors his own dialysis treatment at the kidney center.

If I had to give advice to any family facing dialysis treatments the following would be on my list:

- Let the patient treat himself whenever possible.
- Let the patient make sure that he/she has his/her medications, that it is the patient's responsibility to take them and to have them on his person.
- Don't become the patient's nurse or doctor.
- Understand what dialysis is, how it works, and how it affects the patient and make sure that the patient has the same knowledge. Usually it turns out that you have complementary knowledge. As the years go on you should know equally the when, how and why about dialysis and transplantation so that you can make future

decisions which may become necessary with knowledge and understanding. Of course, in the final analysis, the patient must make all decisions in his/her care. Usually, however, families become involved in major decision discussions.

- Understand that the patient has limitations and don't make him/her feel guilty because those limitations might interfere with "normal living."
- Share your fears and apprehensions with your spouse, the patient, whenever possible. He/she must know that you have anxieties too.
- He/she is not your "poor sick" husband, wife or significant other. Patients have handicaps, but like most people with medical problems they can live a normal life with few limitations—if they make up their minds to do so.
- Be prepared for changes of treatment—starting dialysis, going on the list for transplantation, changing methods of treatment. Patient, as well as spouse, should be informed as to what to expect. Hope for the best results, but be prepared for the unexpected.
- Moral support of the patient is extremely important.
- It is hard to say try not to worry about what might be. That is the hardest thing to do (not worry). Enjoy the present. Spending ten years worrying about whether my husband was going to live or die affected me, not him. Since I learned I have no control over what happens to him, I am much more free of fear. I still have anxieties, but I don't wake up in the middle of the night to check to see if he is breathing.
- The patient must make the final decision (after discussion with his/her spouse) about the type of treatment he/she selects.

In the past 26 years, there have been a lot of changes in the treatment of patients with end stage renal disease. Treatments in 1968 were six hours—now they typically last three to four hours, and there are more treatment options (patients can have more than one transplant, and there are several different types of dialysis treatment). There are new drugs being used to prevent rejection and transplants are lasting longer. Both dialysis and transplant patients have a better quality of life as each year passes. Many patients work full time jobs (including my husband); others, who are unable to work, still fill their hours with non-traditional work like volunteering their time and holding down the fort at home. Role reversal sometimes becomes the necessity rather than the option we find in today's society.

Today, there is the added burden and anxieties connected with employment. Our economy is in a recession and many two income families have now become families with one income. or worse yet no income. Money is short, insurance costs are increasing, and there may never seem to be enough money to cover expenses. Of course, we are not unlike the general population in the United States, except that most people do not have the added problem of end stage kidney treatment.

In 1967 I didn't know whether my husband would live six months and I would become a young widow. Now after 26 years, we have seen many friends and relatives die (who were healthy and did not have any illness in 1967). Sometimes I think they never realized how important the little things in life were that we all take for granted. We realized early in our marriage to live each day and appreciate life.

My husband has been on the list for a second kidney transplant for several years. Having gone through one unsuccessful transplant 20 years ago, I know something about the possible problems. Knowing successful transplant patients whose kidneys have lasted more than 25 years has also helped us look with optimism to the future.

I would be misleading you if I said marriage as the wife of a kidney patient is all fun and games—it is not. In 26 years we have had our ups and downs. I have found out that sharing experiences and feelings with other spouses of kidney patients is very beneficial. That is one reason why I have shared our experiences with you in this Handbook, and why I have been active in the Kidney Transplant/Dialysis Association. Seeing the look on the face of a patient or spouse who is new to treatment (or an experienced patient/spouse who never considered this treatment long term) when they hear my husband has been on dialysis for 25 years is a boost for both of us. Twenty-six years ago we looked to life in the short term (months, years), now we know that patients can go on indefinitely (for decades) to live near normal lives—to have children, raise them, and see them graduate from high school and college and marry, and to see their grandchildren.

Much as we wish to deny it, as the years have gone by and I have come to know many patient families, I realize that chronic illness in a family

affects children. Supermom (or Superdad) is a definition of the 80's, but we as spouses of patients and patients themselves defined that word long ago. It took the businesswomen of the 80's to give it a title. It is my hope that as children grow up, they will take comfort in the fact that their parents adjusted and survived the trials and tribulations of their life with courage and dignity. Seeing that, I hope will give our children the courage to live their lives with the same fortitude as their parents. If children learn by example, they too shall overcome.

In closing, I wish to dedicate this chapter to the many spouses and patients that I have known during the past 26 years. We have developed a bond that will last forever. We have lost many friends during these 26 years, but they were the very best of people. They were the kind of friends most people never meet. We shared experiences, feelings, fears, and joys with each other with pain and grief mixed in. But we learned to love and care for each other in a way most of the population never learns. Through the KT/DA, we have met people we never would have met. We learned we are all the same (whether patient or spouse)—helping, sharing, living; we are survivors helping others survive. And we are better people for the experience even though we would all agree we wish we could have achieved this outcome without the problems associated with a chronic illness.

September 1992

I have reviewed this chapter, making some of the changes to dates and references to treatments. Dialysis is very common now. Many people I meet often know of someone on dialysis or a patient with a successful transplant. My husband and I went through the usual years of career goals. Now, both in our early 50's, we have come to the realization that we want to "*stop and smell the roses.*" We both limited our work this summer and played a lot of golf (yes, both of us walking 18 holes of golf). It is something we both enjoy and can do together.

Our daughter is now engaged and we are planning a wedding in May next year. We have been married over 28 years, which even for a healthy couple is unusual in this day and age. Our lives are not as perfect as we had hoped 28 years ago, nor did we expect that someone could live a nearly

normal life on dialysis for a quarter of a century. My husband remains active in KT/DA. I have limited my activities in KT/DA just because I need some time for me.

June, 1993

Well, another year has past since my last update. I am glad to say that our daughter, Lynn, was married on May 15, 1993, and I am still basking in the glow of the evening and the events of the year filled with planning the wedding and becoming part of another family. We have a wonderful relationship with my son-in-law and his family. Seeing her settled and married is wonderful for both my husband and I because she was so young (three months old) when my husband initially took sick. The newlyweds are planning on having a family, and we are looking forward to becoming grandparents within a few years.

On the down side, my husband took very sick (for the first time in 26 years) and almost died twice at the end of 1992. He was hospitalized for six weeks. It was a very difficult time for all of us. We have been fortunate that he had no major problems during these 26 years. Certainly, sickness in one's family is a test of love and courage, but love is not always enough to sustain a marriage, as evidenced by the fact that divorce is common among families living with all kinds of chronic diseases. Facing those catastrophic times and not knowing sometimes from day to day whether he would survive, reminded me of how much I still loved him. Seeing our daughter, not as our child, but as a women (26 years old) face this time with courage and support for both of us, gave us strength as we watched husband and father gain his strength back and become the person we knew. He is still not back to his former strength of playing and walking 18 holes of golf, but we plan to work on it. We believe his physical activities during the summer of 1992 made him strong enough to survive his health crisis in November and December 1992. We face new challenges in the future, but then doesn't everybody.

As I reviewed this article, I realized that life has come full circle. We are now our "parents" and our daughter's generation is the future. As we look to a future with health care for all, I hope that illnesses will be caught

before they become serious. I hope that beside helping the patient, that the new health care system proposed by President Clinton, will help families caught in the hassles of catastrophic illness.

Most of all, I hope that sharing some portion of our lives during the past 26 years will prove to you that kidney failure is not a death sentence, but an adjustment to a different way of life.

We'll "talk" again the next time this handbook is revised.

Chapter 9

THE HEMODIALYSIS ACCESS

James D. Rawn, M.D. and Nicholas Tilney, M.D.

INTRODUCTION

The function of human kidneys which have failed from disease or injury can be assumed by treatments with an artificial kidney. The hemodialysis machine (*hemo* means blood) removes wastes from the blood stream and regulates the body's fluid and chemical balances. A vascular access device connects the patient's blood stream, or circulation, to the machine. Blood flows from the patient to the machine, is cleansed, and returned. Temporary access devices are plastic tubes (catheters) which are inserted directly into a large vein. More permanent access is obtained by creating a high flow connection between an artery and a vein, typically in the patient's arm, which can be hooked up quickly and easily to the dialysis machine.

The circulation consists of a pump (the heart), and blood vessels. Arteries carry blood away from the heart to the tissues at high pressure; veins return blood to the heart at low pressure. Renal arteries and veins typically allow up to one quarter of the heart's output to flow through the kidneys, roughly one quart per minute. Similarly, the dialysis machine requires a high blood flow (at least one third to one half quart per minute) to replace kidney function.

This chapter answers many of the most common questions patients ask about access devices: what they are, how they work, what to expect during and after the operation, and what can go wrong.

TEMPORARY ACCESS

A temporary access catheter is necessary if dialysis is required before a permanent device has been placed, before it is ready for use, or if it stops functioning. Temporary access is achieved by placing a catheter into a large vein in the groin, under the collarbone, or in the neck. These catheters (often called *Quinton catheters*) actually contain two separate tubes; one carries blood from the patient to the dialysis machine, and the other returns

blood to the circulation.

These temporary catheters can be inserted in two different ways. *Percutaneous* placement (inserting the catheter through a puncture in the skin) can be performed in the dialysis unit or a hospital bed. The skin is first cleaned with an antiseptic solution, and the area is surrounded with clean paper sheets to insure sterility. Local anesthesia (lidocaine) is then injected to numb the skin and make the procedure as pain-free as possible. The catheter is placed into a large vein and secured with a stitch.

The second technique uses a slightly larger catheter (a Quinton/Hickman—see Figure 1) and is performed in the operating room. It can frequently be done with local anesthesia alone; sedation or general anesthesia is often used as well. (See “HEMODIALYSIS ACCESS OPERATIONS,” below.) After cleaning the skin and draping, a small incision is made in the neck just above the collarbone. The surgeon locates the internal jugular vein beneath the neck muscles and inserts the catheter directly into it. The catheter is tunneled under the skin and exits the body on the upper portion of the chest. These catheters are usually placed on the right side of the neck. Catheters inserted in this fashion are preferred if longer use is anticipated. They are less likely to become infected and can therefore be used for longer periods of time (weeks or even months) than percutaneously placed catheters.

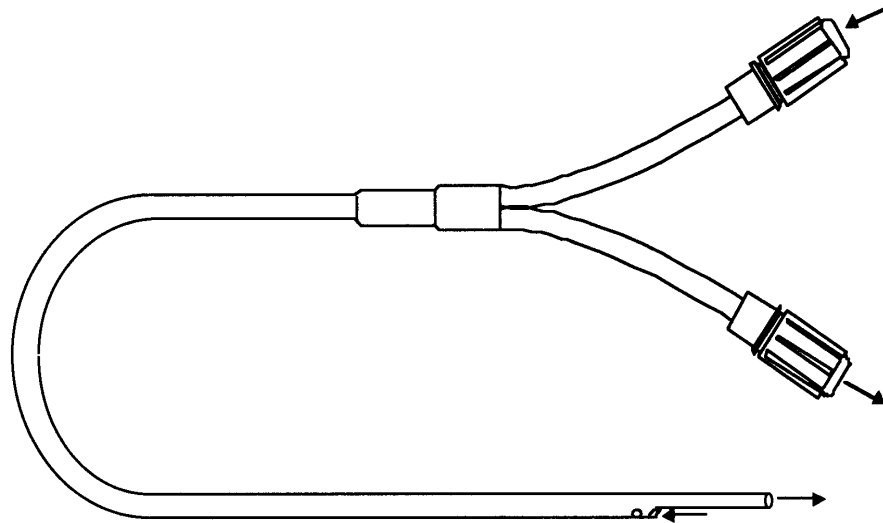


Figure 1

This is an illustration of a tunneled dialysis catheter (Quinton/Hickman catheter). It contains two channels. The tip (at the bottom of the illustration) is placed in a large vein by a surgeon in the operating room. The other end contains two ports which are connected to the dialysis machine. Arrows illustrate the direction of blood flow.

These temporary catheters require regular flushing with heparin to prevent clotting. Despite these measures, clotting and consequent diminished flows are not uncommon. Clotted catheters can often be opened with injections of medicines which dissolve clots (*thrombolytic agents*). Streptokinase and urokinase are examples.

Clotted catheters that cannot be reopened need to be replaced. In addition, catheters which are left in place too long carry a significant risk of infection. If a patient needs dialysis for an extended time, more permanent access is required.

PERMANENT ACCESS

Permanent access for hemodialysis requires the creation of a high flow connection between an artery and vein. They are typically constructed just beneath the skin to provide a quick and easy connection to the dialysis machine. When it is necessary to connect the patient's circulation to the dialysis machine, a dialysis nurse places two needles in the access after (optionally) using a small amount of local anesthetic. One needle provides

arterial blood to the dialysis machine, and the other returns blood to the venous side of the circulation. There are two principle types of permanent access: the *Cimino fistula* and the *synthetic graft*.

The Cimino fistula is the preferred type of permanent hemodialysis access; it has a lower incidence of clotting and infection than synthetic grafts. Unfortunately Cimino fistulae cannot be made to work for all patients. (A fistula is any abnormal connection between one part of the body and another; in this case the fistula is created between an artery and a vein and is therefore called an *arterio-venous fistula*. Cimino was the physician who originally described this technique in 1966.) A Cimino fistula is created by joining a large vein directly to an artery, typically in the forearm at the wrist, or higher in the arm near the elbow crease. Figure 2 demonstrates the creation of a Cimino fistula at the wrist using the cephalic vein and the radial artery. This procedure can easily be performed under local anesthesia on an outpatient basis. After local anesthesia has been injected into the skin, the artery and vein are isolated. The vein is then divided, and the end leading up the arm and back to the heart is sewn with fine suture to a hole made in the side of the artery. Blood circulating down the artery flows both up the vein fistula and down into the hand; this arrangement lessens problems with blood flow to the hand. Rarely, coolness and numbness develop in the hand following placement of a Cimino fistula. These symptoms usually improve.

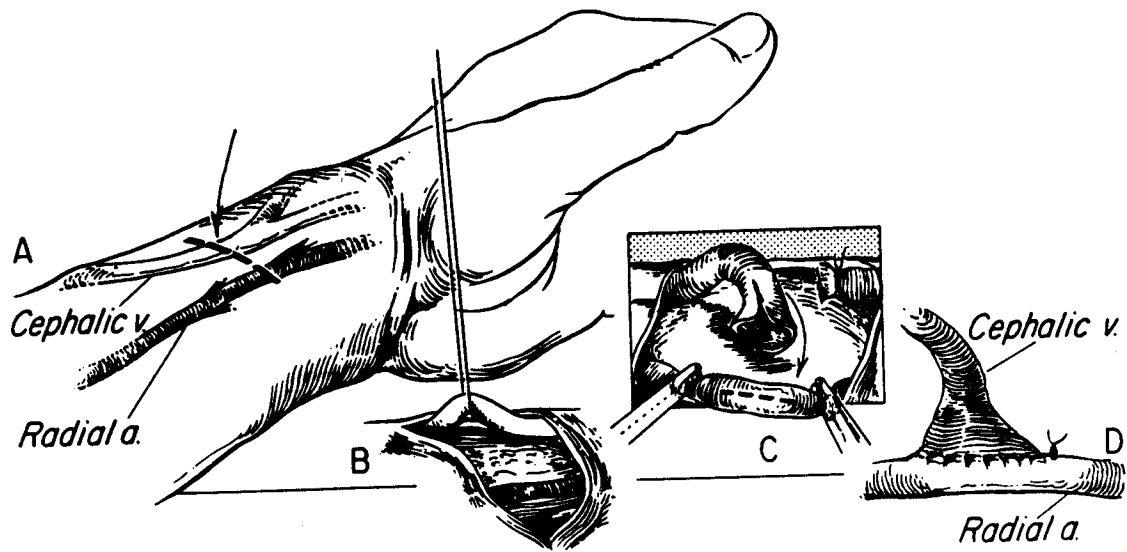


Figure 2

Details of how the Cimino fistula is made. In C the dotted line shows where a slot will be cut in the artery. The cut end of the vein is stitched to it to form the T connection shown in D..

To work effectively, the vein used for the Cimino fistula must be relatively large. About one third of fistulae will fail during the first few weeks because of small or thin veins. Following creation of a Cimino fistula the vein will dilate and its walls will thicken in response to the higher pressure of arterial blood flow. These changes enable the vein to provide the high flows needed for dialysis and to withstand repeated needle punctures. It typically takes 4 to 8 weeks before a newly created Cimino fistula is ready for use.

Since the onset of renal failure and subsequent need for dialysis is often slow, many patients can easily wait for their fistula to mature without requiring temporary access. Since a well functioning fistula depends upon good veins, it is wise for patients who expect dialysis to discourage the use of their forearm veins for blood drawing or the placement of intravenous catheters. (Hand veins can be used without causing a problem.)

If a patient's veins are too small or thin to use for a Cimino fistula, a synthetic graft can be used. Today, most of these grafts are made from polytetrafluorethylene (PTFE), the same material used for Teflon coatings and Gortex laminates. When used for hemodialysis access, the PTFE graft is

typically a 6 millimeter diameter tube. The tube is tunneled in a loop under the skin and sewn to an artery and vein at the elbow to create a fistula similar in function to the Cimino. See Figure 3 below. Occasionally, if the forearms have been used previously, grafts may be placed in the upper arm or run up to the shoulder.

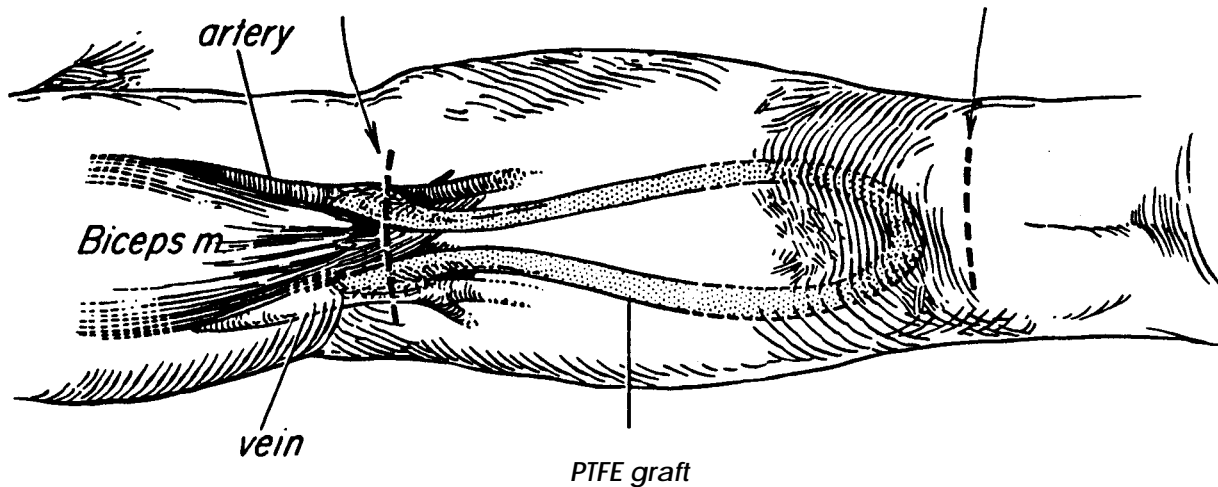


Figure 3.

An under-the-surface view of a PTFE graft in the forearm (the hand is to the right). Blood runs through it from the artery (top) to the vein (below). The graft is used by placing two needles in it, one upstream, one downstream.

It is possible to use local anesthesia to create access with a synthetic graft. The tunneling can be uncomfortable, however, and it is common to use general anesthesia or a nerve block to insure patient comfort. (See “HEMODIALYSIS ACCESS OPERATIONS,” below.) PTFE grafts are rarely placed in the thigh, usually because both arms have been previously used for access. Grafts in the thigh have more problems associated with them than grafts placed in the arm.

HEMODIALYSIS ACCESS OPERATIONS

The placement of a tunneled temporary access catheter, Cimino fistula, or PTFE graft takes place in the operating room. Anesthesia is used to make the procedure comfortable for the patient. The form of anesthesia is chosen by the patient, the surgeon and the anesthesiologist. Selection of the appropriate anesthetic depends upon the patient’s needs, medical problems, and the type of access procedure performed.

Local anesthesia uses lidocaine to numb the skin. Although the medicine burns or stings when it is first injected, it allows many procedures to be performed with little or no discomfort. Cimino fistulae are often placed with local anesthesia alone. There is minimal recovery time required, and the patient usually goes home soon after surgery.

Intravenous (IV) sedation uses medicines injected through an IV catheter into the blood stream to relax the patient. These medicines often make the patient quite sleepy. An anesthesiologist is needed to give these medicines and to monitor the patient during the procedure. A short recovery time is required to allow them to wear off.

A brachial nerve block is performed by an anesthesiologist to make the patient's entire arm numb. Lidocaine is injected around the nerves which supply the arm and transmit sensation to the brain. The injections are made in the arm pit or around the collarbone. Occasionally the block works only partially and local anesthesia or IV sedation is also required. The block requires several hours to wear off.

General anesthesia uses intravenous medicines and inhaled gases to make the patient unconscious during the procedure. It usually requires that a breathing tube be placed in the trachea or windpipe after the patient "goes to sleep." General anesthesia requires the longest recovery period.

Unless the operation is performed with local anesthesia only, the patient should not eat or drink anything after midnight the day before the procedure. If there is uncertainty as to what form of anesthesia will be used, it is best to keep the stomach empty. Prescription medicines, however, should usually be taken at their usual time with a small sip of water. The patient should check with the surgeon or anesthesiologist to decide which medicines to take before the operation.

Many access procedures can be done on an outpatient basis; that is, the patient comes to the hospital on the day of surgery and leaves several hours after the operation. In general, it is necessary to have some one come to the hospital with you if you are going home the same day unless a straight local anesthetic is used. It is common for people having PTFE grafts placed to stay in the hospital for a day or two to allow the surgeon to keep

an eye on the graft. In addition, the patient's medical problems may make a stay in the hospital necessary.

In the operating room the patient lies on the operating table. In addition to the surgeon, an anesthesiologist and surgical assistants may be in the room. There are usually two nurses present: one hands instruments to the surgeon; the other helps insure that the patient is comfortable and that the procedure runs smoothly. The region of the body where the surgery will take place (the arm, for example) is cleaned with an antiseptic solution, sterile drapes are then used to ensure that everything touched by the surgeon is absolutely clean. After the operation, a bandage is placed over the incision(s), and the patient is taken to the recovery room. Many Cimino fistulae can be created with one incision; placement of a PTFE graft requires several small incisions.

AFTER THE OPERATION

If the access procedure has been performed in the arm it is important to keep it elevated to reduce swelling and discomfort. Ideally, the region operated on should be kept above the level of the heart as much as possible. The incision should be kept dry for two days. After this period, the bandage can be removed, and the area can be gently washed with soap and water. Avoid scrubbing the incision or soaking it until the sutures have been removed. A bandage is not necessary after the original one has been removed as long as the area is kept clean and dry. Stitches can be taken out in about ten days by the surgeon, a family doctor, or a dialysis nurse.

The incision may be sore for several days after the operation. Again, keeping the arm elevated is very important. Many people find that they require only acetaminophen (Tylenol™, and others) or ibuprofen (Advil™, and others) for adequate relief. Your surgeon will often give you a prescription for stronger pain medicine to have available if you should need it.

Light activity is safe after an access procedure as long as it does not cause discomfort. Heavy work is not advisable, and you should also avoid putting pressure on the graft or fistula.

Some pain, swelling, redness, and bleeding after an operation is normal and should improve over several days. If these problems get worse rather than getting better, you should contact your surgeon or your dialysis doctor. You should also call your doctor if you have a fever (temperature greater than 101°).

Both Cimino fistulae and PTFE grafts require several weeks to mature before they can be used for dialysis. If a Cimino fistula is used, the vein needs to become larger and thicker. If a PTFE graft is used, the tissue around the graft needs to heal and incorporate the graft. If dialysis is needed in the meantime, a temporary access catheter can be used. When the permanent access device is ready to use, two needles are placed through the skin and into the vein or the PTFE graft. One needle receives arterial blood flow, the other returns blood to the venous side of the circulation. These needles are connected by plastic tubes to the dialysis machine. After dialysis, the needles are removed and small bandages are placed over the puncture sites to prevent bleeding. These bandages should not be too tight and should not encircle the arm. Do not press tightly on the access to stop the bleeding unless the bleeding is very brisk. It is important that the needles be placed into different locations in the access for each dialysis treatment to avoid creating a large hole in the fistula or graft. Careful attention to the technique used to connect to the access will keep it working longer.

Your access will last longer if you avoid wearing restrictive clothing on the arm containing the access. Do not allow anyone to draw blood from or allow blood pressures to be taken on the arm containing the access.

ACCESS PROBLEMS

Clotted Access. The most common problem experienced with dialysis access devices is clotting, or thrombosis. Blood clots can form in temporary access catheters, Cimino fistulae, and PTFE grafts. Clotting can decrease or stop blood flow and make dialysis impossible.

As mentioned previously, clotted temporary catheters are injected with special *thrombolytic* agents or are replaced.

Clotting is a more common problem for PTFE grafts than for Cimino fistulae. (Blood is stimulated to clot by artificial substances; blood vessel walls contain substances that help to prevent clotting.) It is usually possible to tell by examining a fistula or graft if there is good flow through it. Good flow is turbulent and often produces a rhythmic buzz or *thrill*. If a previously appreciated thrill is gone, it usually means that flow has diminished significantly. The access should be checked three times a day, especially in the morning, to insure that there is still flow. If it appears that the device has stopped working, notify your dialysis doctor or your surgeon. Clotting occurs more frequently in the summer months when patients are more likely to become dehydrated and flow through the access device decreases.

A clotted fistula or graft is typically fixed in the operating room. Removing the clot is known as a *thrombectomy*. Anesthesia is usually local with IV sedation, or a brachial block (see “HEMODIALYSIS ACCESS OPERATIONS,” above). The surgeon makes a small incision into the graft and uses a special catheter to remove clots and restore flow. If this is successful, the surgeon repairs the incisions with several stitches and the operation is complete. Sometimes an obstruction forms which cannot be fixed with this technique, and the graft needs to be repaired by bypassing the obstruction with another segment of PTFE graft. Rarely, grafts cannot be successfully repaired and a new graft is needed. This happens most frequently as grafts become older and undergo more frequent repair.

In some cases it is possible to use thrombolytic agents to dissolve the clot. newer grafts are more successfully treated with this technique.

Infection. All access devices can become infected. A Cimino fistula, because it does not introduce foreign material into the body, is only very rarely infected. Bacteria can be introduced when needles pass through the skin and into the graft. If bacteria become adherent to graft material it is difficult for the body’s defenses to control and eliminate infection. Signs of infection can be local or systemic. *Local* signs include redness, tenderness, and swelling over the graft. *Systemic*, or generalized symptoms of infection, include fever, chills, and a washed out, achy feeling. When these signs and symptoms are present it is important to be seen by a doctor to be sure that an infection is not present. If the graft appears to be infected, it can

sometimes be treated with antibiotics alone. Most serious infections require removal of the infected device in addition to treatment with appropriate antibiotics.

Bleeding. Significant bleeding is a very rare problem. It usually occurs after a graft or fistula has become weakened by repeated punctures in the same area. Bleeding is always controllable by placing direct pressure at the site of the bleeding. Stopping the bleeding is more important than preserving flow in the graft or fistula. After the bleeding has been controlled you should call your surgeon and go to the hospital.

CONCLUSION

Every year more individuals enter dialysis, and the time on dialysis lengthens for many others. Although a good proportion of access devices may function well for prolonged periods without difficulty, others may begin to wear out or function so poorly that a bypass or replacement becomes necessary. Knowledge and careful attention can help to extend the useful life of these devices and minimize access problems.

SHOULD YOU HAVE A TRANSPLANT?

Richard L. Faber, Ph.D.

Although the degree of rehabilitation of some patients on dialysis is truly remarkable, most persons with a well-functioning transplanted kidney who are on small doses of medication, will generally feel better, look better, and be far healthier than most dialysis patients. After receiving a working kidney, many patients will describe their experience as “being reborn.” In many cases, an almost overnight rejuvenation takes place.

Unfortunately, not all transplants are successful. “Successful” means that good kidney function is maintained for a sufficiently long period of time, usually at least a year. It is nearly meaningless to call a transplant successful after only a few days or weeks. Even though the surgery goes well, the real hurdles come afterward. Aside from the ever present possibility of rejection, there are numerous possible side effects from the toxicity of the drugs given to prevent rejection, as well as from the increased risk of infection. Some patients seem to have very mild side effects, while others are plagued by problems. This points up what is to many the biggest drawback of transplantation—uncertainty.

After an initial period of adjustment (usually a few months), most dialysis patients settle into a relatively stable pattern in which they know how they nearly always feel during and between dialysis treatments, what their physical capacities and limitations are, and what the quality of their lives will be. On the other hand, there is no way to predict with any certainty what the results of a transplant will be. You should discuss success and mortality rates with your physician and with physicians of your hospital’s transplant service.

Some of the factors you should take into consideration and discuss with your physician before deciding upon a transplant are the following:

1. Do you have additional medical problems that make it impossible or unwise for you to have a transplant? For some, this consideration will make further deliberation unnecessary.

2. Do you have a prospective, willing, living related donor? Information concerning success rates for both living donor and cadaveric kidneys should be obtained from the doctors at your center.

3. How are you managing on dialysis? Are you extremely uncomfortable during treatments? Is your state of health (physically and/or mentally) poor? Or are you well-adjusted to dialysis and able to lead a nearly normal life between treatments? If you are doing quite well on dialysis you might want to consider waiting until further advances in transplant immunology or immunosuppressive therapy are developed.

4. What are the immunological factors which might favorably or unfavorably affect your particular case? This is a complicated and ever changing technical subject. It deals with *presensitization* (antibodies you may have against foreign tissue) and the immunologic similarity between you and a potential kidney donor. These are matters for you to discuss with your physician.

5. Which modality of treatment (transplantation or dialysis) will best fit in with your vocational or other goals in life?

TRANSPLANTATION—HOW THE PATIENTS SEE IT

11a—A Tale of Two Kidneys

Al Sabatini

For many people, being told that their kidneys are not functioning properly and they will need to undergo hemodialysis on a regular basis is a frightening and unfathomable experience. For me, however, it was a heavenly relief when my doctor called me one Tuesday morning and said, “Al, we’ve found a spot for you even sooner than we thought we could. You start tonight.”*

During that final predialysis afternoon, I devoured a final farewell banana and washed it down with a quart of ginger ale. The reason I was not severely disturbed about starting dialysis was that for a year and a half I had been wearing a little black bag that collected my urine as it dripped through the exposed ureters on my stomach. I was informed that this ureterostomy was needed to keep me alive and shall we say well until my kidney function deteriorated to the point that hemodialysis was needed.

At age 19, as a college freshman beginning to meet a variety of people including some attractive young females, I found my little black bag a great hindrance to my then nonexistent love life.

Not long after beginning dialysis, I entered the Peter Bent Brigham Hospital (now Brigham and Women’s) to have my kidneys removed because they were believed to be swollen and infected. When my kidneys were removed, the ureterostomy was terminated, and I was informed that I would never again have to wear that bag; that when I received a kidney transplant the ureters would be rerouted inside of my body and I would once again use the normal means of getting rid of my kidneys’ wastes. The week I returned from the hospital I held a bag burning party and officially cremated that LITTLE BLACK BAG!

Being told that I should refrain from indulging in certain beloved foods and dramatically restrict my fluid intake as conditions necessary for successful dialysis were relatively slight discomforts when I knew that I would no longer have to see those ureters staring up at me every few days

* This article was written many years ago. At that time very few dialysis centers existed.

when I changed that bag. I had a wonderful feeling of personal solidarity once again. Ah!

And how faithful I was to my dietary and fluid restrictions during that first year. I tried very hard not to drink too much or eat foods that would cause my blood chemistries to spiral out of sight. I used to watch longingly at social outings and parties as pieces of pizza and chocolate cake and other such tabooed goodies were consumed before my eyes by my family and friends while I sat quietly with my thimbleful of ginger ale.

However, after about six months of this ascetic living, I began to loosen up a bit and occasionally sneak a bite of chocolate cake or a potato chip. Time, however, proved the old commercial jingle to be true, in my case anyway, for as it turned out I couldn't eat just one. By the end of that first year on dialysis, I was a full-fledged cheater. Now when my friends and I went out and they consumed cheeseburgers with french fries, mushroom and pepperoni pizzas or chicken chow mein, I not only went along but aided in the consumption of the goods.

I began to put on some weight and regained some of my physical strength and self-confidence. As a result I became much more active physically. I engaged in such activities as handball, basketball, swimming, and bicycle riding, to name just a few. At college, while still on dialysis, I organized and became captain of an intramural gym hockey team that came in second in our division and advanced to the quarterfinals. When the league statistics were released my name was number six on the list of top scorers in our division.

I would frequently go on long bicycle trips or go hill climbing with friends. Although I usually fell behind, I always finished! Of course, there were times when I overstepped my physical capabilities and got sick or, on a few occasions, even passed out. But on such occasions, as soon as I was able to stand I would swear, pound my fist against the nearest inanimate object, and continue on with whatever it was I was doing! Regardless of the obstacle I always and without reservation continued my education and physical exercise.

However, there were not infrequent interruptions in my schooling and physical exploits over my five years on dialysis because of one surgical or medical procedure or another.

The most traumatic operation I underwent during those dialysis days was the unsuccessfully transplanted kidney that my father gave to me. It had taken doctors and my father almost two years to convince me to take that kidney. My father had told me how happy it would make him feel to give me his kidney so I could be free of that machine. When the kidney lasted only five days I felt worse for him than I did for myself. I felt guilty for having subjected him to that painful surgery only to see his loving gesture fail. I vowed never to even consider taking another kidney from a family member even if it meant spending the rest of my life on the machine.

As fate would have it, however, three years later I received an early morning phone call from a doctor, as I had five years earlier. Only this time I was informed that a kidney had been found that might take to me. By midnight, that kidney was part of me and so it remains upon this writing two years later.

I cannot really say that my life style was drastically changed by that transplant, but I think it is safe to say that some notable adjustments of both a physical and psychological nature were made, especially as I began to regain my physical strength.

For the first few months there was that unsightly swelling and puffiness that often comes with fluid build-up in the body because of the still far from perfect functioning of the new kidney. During this period my fluid intake was just as severely restricted as it had been when I was on dialysis; only now I was more mindful of adhering to those restrictions because I now had something definite and immediate to lose by cheating.

In any case, after only a few months the swelling subsided and my fluid ban was lifted. In fact, I was told to flood the kidney, which I now for some strange reason nicknamed “Junior,” with water to help keep it functioning properly. Suddenly, for the first time in years, I was drinking as much as I wanted. I turned in my thimble for a stein and made good and frequent use of it! I no longer felt guilty when eating a chocolate bar or a piece of pizza.

I didn't feel guilty, that is, until upon one of my clinic visits a few months after the transplant. It seemed that my blood pressure had become elevated as a result of the kidney. Since links have been found between blood pressure and the sodium in normal table salt, I was told never to lift a

salt shaker with the intent to shake and to avoid salty types of food and beverages. And since salt in some form and amount is detectable in an infinite number of foods in western man's diet, I was given an extremely difficult if not impossible task.

While on dialysis I knew that even if I cheated excessively on my diet the machine could purify my blood and contain my blood chemistries to within reasonable limits. Now there was no more machine to rely upon to take off the harmful metabolic end products and excesses. I was on my own with Junior. I had to pay more careful attention to my diet and take the prescribed medications or risk the consequences of an out-of-sight blood pressure, which could include the loss of my new found friend.

It was unfortunate that these were not my only post-transplant problems. I had been experiencing slight rejection episodes with the kidney for the first three months. Then during the fourth month, something happened that opened up the kidney and ended my rejection problems permanently. The problem was that it almost ended me as well. You see I had somehow contracted a form of encephalitis called cytomegalovirus. It was touch and go for a few days. No one really knew what was going to happen, including the doctors.

Well, over the years I had had plenty of practice fighting a variety of ailments and the pain that accompanies them. Through it all I had always kept my body in good physical shape, even if it had been at the expense of my diet. Also, I had never stopped my college education. There were some postponements, but I always kept my mind well exercised, as well. If ever I had need of these strengths it was then.

I did survive that incident as I'm sure you realize. Junior is alive and well. I feel great and not long ago I finally got my bachelor's degree, *cum laude*, I might add!

Well, I hope you'll excuse me now. I'm going to challenge Mount Chocorua in New Hampshire with some friends in the morning, and I really must get a good night's sleep.

11b—Transplant: One Man's View

David Dangel

Nine years ago, at the age of 46, my somewhat static nephritis took a downward turn. I can, to this day, vividly recall my feelings of fear and desperation when my doctor informed me that within a few months I would be faced with the choice of dialysis or transplantation. I hope that my own experiences and feelings may be of some small assistance to those who have been, or are about to become, members of our most exclusive club. During these past years, I have had two kidney transplants and spent three and one half years on home dialysis. My last transplant took place in June of 1972 and so far has been successful.

Fortunately for my wife and I, a social worker and several doctors at my hospital, the Peter Bent Brigham, took the time and effort to explain and indoctrinate us into this strange and fearful new world we were facing. It appeared as though dialysis was the least risky and most practical route for me to follow. My wife, with absolutely no medical training, and terrified at the prospect, went along with the idea of dialyzing me at home. There were many sleepless nights for both of us as we contemplated the inevitable upcoming problems. At the time our three daughters ranged in ages from 14 to 20. They were of great moral support and eventually also learned to help with the running of the dialysis machine.

Our training period at the hospital and the first year of home treatment were mostly uneventful. My family was wonderful, and we had many pleasant evenings eating dinner, talking, and watching television while I was being dialyzed.

Physically, I fared well on dialysis, but after a year, I began to get the urge to sever the umbilical cord to the machine. Long range, I could see that dialysis would become increasingly wearing and trying for all of us, and as my children grew up, that my responsibilities to them would be lessened. Therefore, I felt that I could assume an additional risk and could consider transplantation.

My sister was willing to give me a kidney and as we were an excellent match, I decided to take a try at transplantation. The operation was sched-

uled for the following year, which was the normal waiting period in those days.

By this time, my second year on the machine had passed and I was totally convinced that transplantation was the route for me to follow. The operation was successful and the transplanted kidney started functioning on the operating table. I went home within two weeks with a normally functioning kidney, and I fully expected that my problem days were behind me.

Unfortunately, this was not to be the case, and I started to reject the transplanted kidney. I returned to the hospital and spent long anxious days and nights that stretched into weeks, getting sicker and sicker as the attempts to reverse the rejection failed. These were indeed dark and sick days. The psychological blow of such a setback was almost unbearable. The depression I felt lasted for a very long time.

However, the short space of time that I did enjoy the transplanted kidney eventually whetted my appetite to try again. The traumatic experience of the past eventually faded away, and I placed myself on the cadaver kidney transplant waiting list. Physically, I seemed to be doing at least as well as before on dialysis. However, the original desire for transplant was still there. My ever patient wife, although she never complained, was beginning to suffer from the tedium and restrictions of my dialysis.

A little more than a year later, I received a call that a kidney was available for me and was a reasonably good match. This time the kidney did not work on the operating table but did start functioning about three weeks later. Cadaver kidneys have the tendency to “go to sleep” and quite often do not function for periods extending to many weeks. I did have two slight rejections during the first few months, but these were easily treated. As with most operations, there is a period of problems that follow, but looking back after several years, they now all do seem minor. Believe me, I never cease to be thankful and also am considerably in awe of what has been my good fortune in this last period of my life.

Some of the thousands who have tried the transplantation route have fared better than I have in that their first attempt was successful. However, unfortunately, many more have not been as fortunate and have never had a successful transplant.

There is no way that I can unconditionally recommend transplantation for everyone. It is a nerve-racking experience. The mental torture that one goes through before the operation, and especially afterward if the kidney does not function immediately, can try the strongest of us. The many long, lonely nights one can spend in the hospital wondering whether it will or will not eventually work is often more than one can endure. There is no track record to follow, as no two transplants act quite the same, except that most go through short periods of usually reversible rejection shortly after surgery.

The physical discomfort from the surgical phase of transplantation is fairly limited. Usually, you are free of all tubes and encumbrances within seventy-two hours and if you are lucky, sitting down to the first “no restriction” breakfast in a long time. Orange juice, bacon, ham, eggs, coffee, and anything you want! For most transplants, there are no eating restrictions, and no physical restrictions, except that contact sports, such as hockey or football are out, as the kidney could be damaged by a sharp blow. Swimming, tennis, golf, etc., are all great!

Prednisone, one of the drugs that is taken daily, does increase one’s appetite, and it may be difficult to keep from getting fat. Also, all of those foods that have been forbidden for so long do taste so good! You are returned to a normal life, a miracle! The two basic drugs that are taken daily are usually Imuran and Prednisone, in pill form. At times these drugs can produce personality changes, such as irritability, particularly in the initial high dosage stage.

There is no guarantee that the transplanted kidney will work, if successful, for one month, six months, or many years. Only time will tell. So much depends upon individual circumstances, age, blood sensitivity, how well one is faring on dialysis, and what quality of life he or she is willing to accept. These factors can make for many months or even years of soul searching before going the transplant route.

11c—Our Miracle Baby

Lauren Marks

I found out about my chronic kidney disease in November of 1987. I had just turned 24 and had also just married in October of that same year. Upon returning from my honeymoon I had to undergo a complete physical for a new job I was starting. This physical exam started a ball rolling which led me to nephrologist Ted Steinman of Boston's Beth Israel Hospital. That fateful day at the end of November, as I sat in Dr. Steinman's office with my husband and mother, I felt like a bomb had been dropped, like my whole world was caving in. One of my first thoughts was "Would I ever be able to have a baby?" At first I assumed no. I was devastated with the thought of not being able to have my own child. Soon after, the miracle of a successful kidney transplant was explained to me. I realized that it might be possible for me to have a successful pregnancy.

I spent 2 years on dialysis waiting for a cadaver kidney. After receiving my transplant, it was necessary for me to wait at least a year before trying to become pregnant. Dr Steinman wanted to be sure my kidney was stable and that my medications were at a safe level for the baby.

When I became pregnant, I started seeing Dr. Steinman on a two month interval instead of three. I saw my obstetrician, Dr. Ralph Aserkoff the usual once a month. My pregnancy seemed perfect. I felt great. I didn't have any morning sickness or excessive tiredness. I exercised almost daily. Everything appeared perfect. Then in my sixth month my blood pressure was a little high. Dr. Aserkoff began seeing me more often: every two weeks. It was comforting to know that both my doctors were in touch with each other throughout my pregnancy. In my seventh month, my creatinine had gone from 1.3 to 1.6. When I had only five weeks to go, Dr. Steinman called me the day after my visit with him to tell me my creatinine had gone up to 2.2. He wanted me admitted to the hospital the next day. I knew there was a possibility of this happening, but I never really thought it would. I suddenly became nervous.

Dr. Steinman decided that my baby was going to have to come out to protect my kidney. My due date was September 25th. On August 21st labor was induced. The next evening, on August 22nd my daughter Elana Beth

was born. We call her our miracle baby. Despite being five weeks early, she was 5 lbs. 3 oz. and perfectly healthy. We couldn't have asked for more. As for me, I went from being very sick, to being a dialysis patient, to being a transplant patient, and actually having a baby. My kidney function stabilized after Elana's birth. If it stays at 2.2 forever, I can be perfectly healthy.

But, I am hoping that it will recover so that I can try to have another baby. There isn't anything in the world like having your own baby with someone you love. It is going to be a very serious consideration though. I wouldn't want to do anything to risk losing my kidney and the wonderful lifestyle it has allowed me. I am truly grateful that at least I'll always have Elana Beth.

KIDNEY TRANSPLANTATION

A Guide for Patients

Brigham & Women's Hospital
Kidney Transplant Staff*

The Most Commonly Asked Questions About Transplantation

What is a kidney transplant?

A kidney transplant is a surgical procedure in which a healthy kidney from one person is placed into another whose kidneys have stopped working.

Who is a candidate for a kidney transplant?

Any patient whose kidneys have permanently stopped working is a potential candidate for a kidney transplant. However, many factors must be considered in choosing between transplantation and chronic dialysis for a given individual. Among these factors are age, other medical problems, and personal considerations of work and lifestyle. You should discuss the options with your doctor and attempt to obtain as much information as possible in reaching your decision.

Where do kidneys for transplantation come from?

There are three sources of kidneys for transplantation: living related, living unrelated, and cadaver donors. Living donors are usually members of the

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recipient's immediate family, such as siblings, parents or children. Only such close relatives are likely to have an acceptable tissue match, although recent data suggests that success with living unrelated kidneys is closer to that of related grafts than that of cadavers. This may be due to better state of the donor and less storage time. Cadaver donor kidneys are removed from victims of brain death, usually the result of an accident or a stroke.

Can an unrelated living person donate a kidney?

As the results seem better, and the supply of cadaver kidneys remains low, living unrelated kidneys are being considered increasingly. Spouses are the usual donors, although rarely, friends can be used if extensively screened.

What are the chances my transplanted kidney will work?

The success rate following transplantation depends upon the closeness of the tissue match between donor and recipient. A kidney from a brother or sister with a "complete" match has a 95% chance of working at the end of one year. A kidney from a parent, child, or "half-matched" sibling has an 85% chance of working for at least one year. Finally, a cadaver donor kidney has an 80% change of working at least one year.

All of these statistics assume this is your first transplant, and that you will be taking the anti-rejection drugs described elsewhere in this chapter. If you are having a repeat transplant, the success rate will be 10%-15% less.

These kidneys are not immortal, however, with 50% of cadaver kidneys declining over 6 – 10 years, a rate faster than the relatively stable success of related kidneys.

What happens if my new kidney fails?

If the transplant fails, patients return to dialysis as before. The transplant will be removed only if it is causing symptoms, such as fever or pain. This is often necessary if the kidney fails soon after transplant, but rarely if it fails after several months. You may be able to have another transplant later, if you desire.

What are the chances that I will die as a result of receiving a kidney transplant?

One of the major achievements in the field of transplantation in the last ten years has been a major reduction in the risk of death. Currently at this hospital, the risk of death in the first year after a kidney transplant is about 3 – 5%, occurring primarily in high risk patients, particularly those over 60 – 65 and, to a less extent, those with juvenile diabetes. This includes death from any cause, whether or not related to the transplant. This risk is not significantly different from that sustained during a year of dialysis. During your transplant evaluation, any risk factors you may have that will increase your risk for transplantation will be identified and discussed with you.

What are some of the factors which would increase the risk of transplantation?

Advanced age is a significant risk factor. Generally, patients over the age of 60 have done less well than younger patients. Significant heart disease, particularly a history of angina or prior heart attacks, will also increase the risk.

Because of the high incidence of heart disease in diabetic patients, all

diabetics must undergo an exercise stress test before being accepted for transplantation. Chronic lung disease increases the risk of pneumonia after transplantation.

Smoking will also increase this risk, and all potential transplant patients are urged not to smoke. Patients who are significantly overweight are more likely to have complications in any surgical procedure, and should attempt to reduce before transplantation. A history of other systemic diseases such as cancer or hepatitis may also affect the risk; indeed, many patients with a history of cancer or abnormal liver enzymes secondary to hepatitis may not be accepted for transplantation. All of these factors vary in importance in different individuals, and should be discussed with your doctor, as well as with the transplant surgeon when you have your transplant evaluation.

Will my own kidneys be removed?

It is rarely necessary to remove your own kidneys prior to transplantation. This may be required if you have severe high blood pressure uncontrollable by medication and dialysis, or if your kidneys are chronically infected. However, whenever possible, your own kidneys will be left alone. Even if not functioning normally, they continue to make erythropoietin, a hormone your body requires to make red blood cells, and they may make some urine. This is particularly important if your transplant should fail.

What is rejection?

The body has a normal defense mechanism, called the immune system, which protects it from foreign substances, such as bacteria and viruses. The body sees a kidney transplant as foreign and attacks it to get rid of it. This process is called rejection, and is a

normal response of the body's immune system. Even though rejection may be prevented by medication, the possibility of rejection never goes away. The body will not adapt to the kidney, nor will the kidney change to accommodate the body, although after the first 3 – 6 months, rejection is less of a problem.

How is rejection prevented?

To prevent rejection patients are given drugs, called *immunosuppressive* medications. These drugs work by lowering the body's immune response, making it incapable of destroying the kidney. There are now several immunosuppressive medications available, giving transplant physicians new flexibility in treating recipients. Most patients will receive a combination of drugs. The newest of these medications is called *cyclosporine*, a highly effective drug which has considerably improved the results of transplants of all sorts.

Much of the early testing of this drug was done at the Brigham and Women's Hospital. Cyclosporine works by interfering with the ability of your lymphocytes to cooperate normally in attacking the transplant. It is now given in pill form in combination with *prednisone*, a steroid medication with anti-inflammatory properties. The combination of cyclosporine, Imuran (an older drug), and prednisone, all in low doses, is used currently at the Brigham and Women's Hospital for all recipients of unrelated kidney transplants, and for all living related donor transplants that are not perfectly matched.

The additional immunosuppressive drug mentioned above is *azathioprine* or *Imuran*. Occasionally, patients are switched from cyclosporine to Imuran several months after transplant to avoid some potential side effects of long term cyclosporine administration. Your

doctor will advise you if this is necessary.

How long will I have to take these drugs?

It will be necessary for you to take some immunosuppressive medication for as long as you have the transplant. Because the body never accepts the kidney as part of itself, rejection can occur even years later, particularly if you stop your medicines. However, it will be possible to reduce the dosage of medications gradually over time, as the risk of rejection lessens with time.

Do these immunosuppressive drugs have side effects?

All currently available immunosuppressive medications have side effects. Some of these are common to all such drugs, and some are particular for the individual drug. The most important side effect these drugs have in common is that by reducing the body's immune defenses, they may actually increase the risk of infection. Because they depress the body's immune system in a non-specific way, the body is less able to fight off some kinds of infection. This does not mean that you will be ill frequently, but rather that there are some kinds of infection only contracted by patients taking these or similar drugs. Most of these infections are treatable, if detected early enough. Therefore, it is very important that you report any symptoms such as fever or a cough to your doctor without delay. Despite the risk, these infections are not common; only about 15% of transplant recipients ever have any significant infection.

Cyclosporine has a number of special side effects, of which the most important is kidney toxicity. Sometimes cyclosporine will cause your creatinine to rise, even in the absence of any other problem. Usually this improves with a reduction in the dose. Serial

cyclosporine blood levels are currently available to help decide the best dose for an individual patient. Other side effects rarely caused by cyclosporine include mild hand tremors, hair growth, and inflammation of the gums. These generally improve if the dose is lowered.

Side effects secondary to prednisone occur much less commonly now than they did years ago, because so much lower doses are used. The most common side effect now rarely seen is a tendency to gain weight and develop a fat face. Other possible effects include fluid retention, stomach irritation or ulceration, thinning of the hair, acne, mood swings, bone disease, and delayed wound healing. Sugar control will be more difficult for diabetics, and an occasional borderline diabetic may require insulin for the first time. Many of these side effects improve as the prednisone dose is lowered over the first year and, in general, are infrequently seen..

Is any research being done to improve the treatment and prevention of rejection?

Considerable research is being done across the country to improve the immunosuppressive medications available. Much of that work has been and continues to be done at Brigham and Women's Hospital. When you receive a transplant, you may be asked to help in a research project. Complete information will be furnished before any research is undertaken, and you will be under no obligation to participate.

What is tissue typing?

Tissue typing is a series of laboratory blood tests which compare the genetic makeup, the natural differences and similarities between the recipient and donor. These tests cannot compare all genetic differences, but look at those which have been found to be important

for the success of a transplant.

HLA (human lymphocyte antigen) typing examines a set of six antigens, three of which are inherited from each parent. Four of these are the A and B antigens which have been known for a long time; two are the Dr (region) antigens which have been more recently discovered. Cadaver donor kidneys may be matched for from 0 to 6 of these antigens. Living related donor kidneys are generally matched for three or six of these antigens, because they are inherited in groups of three. Individuals are classified as high or low responders.

How does tissue typing help?

Tissue typing enables your doctor to determine if a relative is an appropriate kidney donor. The tests also help to predict the outcome of a transplant. Tissue typing is also used to determine who would be the best recipient when a cadaver donor organ becomes available, particularly if there is a six antigen matched donor available.

How is the operation done?

General anesthesia is most frequently used for kidney transplantation, although occasionally a spinal or epidural technique may be recommended by the anesthesiologist. Antibiotics are given to prevent infection, and a catheter is placed in your bladder after anesthesia has been given. The transplanted kidney is placed in the pelvis just above the pelvic bone, on either the right or the left side. The kidney's artery and vein are sewn to

to your iliac artery and vein, which are the large blood vessels leading to your leg. The ureter is connected directly to the bladder. This technique is illustrated in the drawing on this page. The operation normally takes about three hours.

Is the operation risky?

The kidney transplant operation itself is quite safe. Over 1,500 kidney transplants have been performed at Brigham and Women's Hospital, the technique is well established, and technical complications are rare. Nevertheless, as with any operation, difficulties may arise.

During the operation, you may require a blood transfusion, particularly if you are already anemic. After surgery, the most common complication is a urine leak, occurring about 5% of the time. This may occur because of damage to the ureter during harvesting of the donor kidney that was not recognizable at the time of the transplant. The problem is almost always correctable, but may require a second operation. Wound infections are very uncommon, thanks to modern

How long will I be in the hospital?

antibiotics.

Most patients will remain in the hospital for one to two weeks following transplantation. Recovery from the surgery itself is generally rapid. Patients are encouraged to be out of bed on the day following surgery, and many are eating solid food within two or three days. However, the possibility that the kidney may not work right away, and the risk of rejection, may prolong your hospitalization.

How long will I be out of work?

Most patients return to work after six to eight weeks. This will vary with each individual, depending upon your response to the transplant, any complications which develop, the type of work you do, and most importantly, how you feel. Because close follow up is particularly important during the first three months after transplantation, you should plan on frequent visits to the transplant clinic and your own physician during this period.

However, transplantation is intended to return you to as normal a lifestyle as is possible, and you will be encouraged to return to your usual activities as soon as you are able.

Will I need a special diet after the transplant?

After a successful transplant you will have a wider variety of food choices and will no longer need to restrict fluids, protein, or phosphorus. However, you may need to restrict sodium if you have high blood pressure. You may also need to limit potassium, as some patients have high potassium levels while taking cyclosporine. A feeling of well being and increased appetite may follow transplant and cause you to gain weight, and you may need to watch your calories.

Will my new kidney work right away?

About half of cadaver donor kidney transplants do not make urine right away. During the process of removing the kidney, storing it as long as one or two days, and placing it in the recipient, some damage may occur. This damage is called *acute tubular necrosis (ATN)*, and is almost always reversible. It may be one to three or more weeks before the kidney begins to make urine. During this time you will require dialysis. ATN can also occur after living related donor transplantation, but it is much less common.

What is a rejection episode?

Sometimes your body may make an extra effort to reject the kidney despite the immunosuppressive medications. This is referred to as a *rejection episode*. The symptoms and signs of such an episode may be decreased urine output, fever, tenderness over the kidney, high blood pressure, and a rise in creatinine, although not all of these will necessarily be present. Sometimes a biopsy of the kidney is required to make the diagnosis. This is done with a needle under ultrasound guidance and is a minor and non-painful procedure.

When a rejection episode occurs, an addition to your immunosuppression is required. Normally, this is a steroid pulse, three daily intravenous injections of high doses of a steroid drug called *Solu-medrol*. Administration of a pulse requires hospitalization. Rejection episodes can also be treated with *monoclonal antibodies*, which are designed to destroy the cells which trigger rejection. The transplant team will discuss these options with you. Many rejection episodes can be successfully reversed, but not all. Limitations on the amount of treatment for rejection are observed in order to prevent complications of overimmunosup-

pression. No more than three pulses are given in the first six months after transplantation.

Who determines the recipient for a cadaver donor organ?

Almost all cadaver donor organs in the six New England states are distributed through the New England Organ Bank, an independent organization that serves the transplantation centers in the region. These centers have agreed on an objective set of rules to determine who gets a particular organ. When a donor becomes available, tissue typing is performed to determine the characteristics of the donor. A computer then compares this information with a list of the available recipients to determine the best match.

The place of a patient on the list depends on the length of time waiting; those waiting longest are on the top. In addition, if a 6-antigen match becomes available anywhere in the country, this will go to the most appropriate local matched donor. Other factors determining the average waiting time for a kidney include the number of donors, red blood cell type of the recipient, and the level of *sensitization*.

What does sensitization mean?

Your body is capable of making antibodies against other people's HLA antigens. These antibodies may arise because of blood transfusions, prior transplants, pregnancy, or for unknown reasons. The more people against whom you have antibodies, the more highly sensitized you are.

Sensitization levels are measured by reacting a sample of your serum with a panel of lymphocytes from many people. The results are expressed as the percent of the panel to which you react, and are sometimes called *PRA's (panel reactive activity)*. It may be difficult to find a kidney for you if you are highly

sensitized, because you cannot receive an organ from a person against whom you have antibodies. Such a graft would be rejected immediately. To prevent this possibility, patients waiting for cadaver organs are requested to send a monthly serum sample to the tissue typing laboratory. These samples are screened for antibody levels and stored. If the computer assigns a kidney to you, these serum samples will be tested directly against the prospective donor. This final test for antibody against the donor is called a *crossmatch*.

Should I have a living related or cadaver donor transplant?

A number of factors enter into this decision, including success rates following transplantation and the availability of donors. The best results following transplantation are obtained with HLA-identical (6 antigen matched) living related donors, which almost always come from a sibling, rarely from a cadaver. As noted before, the available results on living unrelated donor kidneys show them to be better than those for cadavers.

A major advantage of living donor transplants is the ready availability of the donor. This allows the transplant to be performed without a long waiting period, as there are currently more potential recipients than available cadaver donors. For this reason, we encourage living related donation whenever the family situation is appropriate, and, if circumstances are correct, donations for spouses.

How is a living related donor chosen?

Potential living related donors usually are identified in discussions with your family and your doctor. Tissue typing is then scheduled; the required tests include blood group typing, HLA typing, and a mixed lymphocyte cul-

ture. Based on these tests it is frequently possible to identify the donor most likely to result in a successful transplant. Choosing the donor is best done in consultation with your doctor and the transplant team.

The selected donor is then scheduled for admission to the hospital for a donor evaluation. This evaluation is primarily on an out-patient basis and involves a wide variety of tests to ensure the health of the donor. Included in these tests is an arteriogram, an x-ray procedure in which dye is injected into the arteries supplying the kidney. This test allows the surgeon to decide which kidney would be best to remove. After completion of all tests, the physician responsible for the donor evaluation, who is not a member of the transplant team, will discuss the results with the potential donor privately. Only donors who are healthy and have two completely normal kidneys will be accepted.

Are there any risks to the donor?

The short term risks of donation are those associated with major surgery, including the risks of general anesthesia, wound infection, and the possible need for a blood transfusion. These risks are very small in healthy people. The donor evaluation process is designed to identify any special factors which would place a donor at increased risk; such donors would not be accepted. The longer term risks are slightly more uncertain. Some studies of donors 10 – 15 years following donation have suggested a slightly higher incidence of mild high blood pressure and protein in the urine; although these changes are not particularly different from the general aging population.

The significance of these studies is unknown, and there is no evidence of

renal failure in prior donors. The remaining kidney expands and takes over the function previously performed by two. Because most kidney diseases affect both kidneys simultaneously, the donor is not at increased risk of kidney failure should he or she contract such a disease. Donors are cautioned to avoid contact sports or other activities which could cause major trauma to the remaining kidney. We believe that donors will lead perfectly normal lives. It is fair to state, however, that possible consequences of donation after more than twenty years are unknown, primarily because transplantation of kidneys in significant numbers only began about twenty years ago.

Who pays for kidney transplantation?

Medicare and/or your private insurance will cover the expenses of your kidney transplant. After the transplant, Medicare will pay for 80% of your outpatient clinic visits. Your Medicare will terminate 36 months after your transplant, unless you have restarted dialysis before that date. In addition, Medicare pays for 80% of the cost of FDA-approved immunosuppressive medications for one year following hospital discharge after the transplant. No one will be denied the best possible medical care because of his or her financial circumstances. The transplant social worker is available to assist with any financial or insurance concerns.

How does one enter the transplant program at Brigham and Women's Hospital?

Inform your physician of your interest and ask him to arrange a referral for transplant evaluation. This can be arranged conveniently through our transplant coordinator. Prior to your appointment, the following information should be sent to us:

1. A recent medical summary and/or

- copies of pertinent hospital and office records
2. SMA 20 (serum chemistry tests)
 3. Report of a chest x-ray within the last year
 4. Report of an EKG within the last year
 5. Report of a recent urine culture
 6. Blood transfusion history
 7. Record of blood type (ABO)
 8. Hepatitis screening tests
 9. Names and blood types (ABO) of potential living donors.

During your evaluation you will meet with one of the transplant surgeons, a transplant nurse, a social worker, and the transplant coordinator. Your medical condition will be reviewed and further information about transplantation will be provided. Tissue typing is frequently performed during this visit. A tour of the transplant unit can be arranged if you desire. You are encouraged to ask as many questions and to spend as much time with us as you like. We believe it is very important for you and your family to be as well informed about transplantation as is possible.

After your evaluation, a letter will be sent to your physician informing him of the results and requesting any further information needed. If you are to receive a living donor transplant, arrangements for both the donor evaluation and the transplant will be completed by the transplant coordinator. If you are to receive a cadaver donor transplant, your name will be listed with the New England Organ Bank. You will be required to send one red top tube of blood to the tissue typing laboratory each month for sensitivity screening; instructions for this will be

furnished during your transplant evaluation.

What do I do if a cadaver donor kidney becomes available for me?

Normally, you will not be informed of the possible availability of a cadaver kidney until it has been assigned to you. Occasionally, you may need to be told before the final crossmatch has been completed, particularly if the kidney has already been stored for a prolonged length of time. Normally, a cadaver donor kidney can be safely stored for 48 hours. About 12-18 hours are required for tissue typing, leaving 30-36 hours to make arrangements for and to perform the transplant.

Once the kidney has definitely been assigned, you should not have anything further to eat or drink. If you are a diabetic, be sure to discuss this with the physician who notifies you of the transplant. You may need to be dialyzed before the transplant, depending upon when you were last dialyzed, your blood chemistries, and your general medical status. This dialysis will be arranged at either your own unit or here, depending on the dialysis schedule and the timing of the operation. You should make arrangements to travel to the hospital as quickly as possible. However, extreme speed is not required, so please drive normally and safely. It would be preferable to have someone else drive for you.

How can I check my status on the transplant list?

You will automatically be placed on the transplant list as soon as all your tests are completed and the tissue typing laboratory has received two monthly screening samples. You will then remain on the list as long as monthly screening blood samples are sent, until such time as you receive a transplant. If you develop medical problems which require that you be

temporarily removed from the list, please be sure your doctor notifies us when you are able to be relisted. Your position on the list will not be affected by temporary inactivation. If you have any questions about your current status, please contact the transplant coordinator.

Chapter 13

SPOUSE: A HUSBAND'S VIEW OF TRANSPLANTATION

John Pappone

May 15, 1993 marked the 20th anniversary of my wife Josephine's kidney transplant. I have never been asked to put down my thoughts or emotions about it, but I will attempt to do so as best I can.

It seems like yesterday that Jo and I were sitting in our backyard just 30 days after she received her new kidney. Ten months of dialysis had ended, and now, as if someone had merely thrown a switch, it was over and a new life was beginning. Fears of complications were always on my mind. Rejection was a word that wasn't in my vocabulary.

Not all that clear about transplantation—or dialysis for that matter—I always worried that something would go wrong. At that time, lack of understanding about kidney disease was my biggest problem to cope with.

Weeks and months that followed proved to be a little more tolerable in terms of worrying about the unknown. I found myself relating this experience with life's ups and downs. Sometimes it helped, sometimes it didn't. At times I would become a bit depressed, looking for answers as to why this problem was on my shoulders. However, being a stable-minded individual (I think), I merely would turn my emotions around by realizing that I was not the patient. Or I would compare my situation with others. Believe me, you always will be able to find someone with bigger problems.

The key was not to let this new experience rule my life. "What will be, will be." "Don't worry until it's time to worry." These clichés, corny as they may sound, have helped me keep my head about matters.

The loss of a kidney patient, even if not known personally, was, and still is, somewhat depressing. Knowing the patient, of course, is more devastating and takes more time to get over. I know I speak for most spouses in these situations. We go through the hurt and silent periods that kidney patients experience.

I could not write this article without mentioning the great help and support of the KT/DA. When Jo and I first learned of this organization, I

was all for joining. Jo was nervous about it and didn't make any bones about it. She did not want to be around kidney patients. I certainly understood her feelings, and I'm sure many patients feel the same way. But here's where I will take some credit. It was my nagging—now that's a switch!—that got us to join the KT/DA (I might add, with the help of our good friend and patient, George Arena, who assisted us with getting involved).

The KT/DA members have supported me in so many ways. Ironically, some of the sickest patients have been inspirations to me. Incredible as it may sound, it's true.

Over fourteen years, we have had some memorable times with our fellow members. These times have helped me cope and always look ahead, as I'm sure they have for my wife.

And one other most important fact to mention is the birth of our son, Stephen (now eighteen). Not quite two years after my wife's transplant, our only child was born. What more can I say?

Fortunately, what I've worried about has not come to pass. However, I must thank God for all the wonderful things that have come our way. I can best sum up my feelings by quoting another good friend and kidney patient for over 25 years, Rick Faber, who wrote in the *RenalGram* several years ago, "...some type of activity is necessary to prevent dialysis from becoming the focus of your life. If you spend 15 hours a week on dialysis, you have 153 other hours during the week when you're not. Make the best of these."

Whether it's dialysis, a transplant, or any other problem that you may encounter through life, these are certainly fruitful words to live by. Enjoy life to its fullest.

PSYCHOLOGICAL ADJUSTMENT

Benjamin J. Murawski, Ph.D.

There is no sure or easy way to provide a person with information or skills which will allow him to cope with a treatment and a changed life style he has not yet experienced. This is particularly true with kidney disease, since it is not like the usual medical illness which can be treated by a doctor with perhaps only minimal participation by the patient. In the case of an infection, which can be treated by antibiotics, all the patient need do is take the medication as prescribed. Even though taking medicines on a rigidly prescribed schedule should be relatively simple, people do forget to take their pills with them when they leave the house, for example.

The reason kidney disease is different is because it is *chronic* and *progressive*. Except for prescribing dietary restrictions, the doctor is relatively helpless. The doctor has no cure to offer; only at a certain point can he offer dialysis to imperfectly substitute the washing of the blood which the kidneys, when healthy, do so easily and perfectly.

The job of coping with and living with kidney disease is almost totally in the hands of the patient. The role of *doctor-patient* is reversed to *patient-doctor* in the sense that the patient is really in charge of the treatment; he or she must take an active role for it to be successful. The patient has to reorganize his/her life to accommodate the dietary and fluid restriction and the change in daily activities to go to the center for treatment. No longer is the patient totally free to plan his/her life; the medical condition comes first, all other activities have to take second place. This is why kidney disease is different, why it is called a *chronic* condition; it is life-long and requires changes in the patient's life style to accommodate the demands of the treatment. It also means a long and continuing partnership between patient and doctor. This cannot be emphasized enough. The usual doctor-patient contact and contract are different in many ways, and how well things go depends on what the patient does, how *actively* he participates in treatment, how well his family and marriage hold together, and how well he can deal with the stresses of life on an artificial kidney.

Since most patients are treated at a center, this discussion will deal mainly with the tasks of a patient undergoing treatment at a center. The patients on home dialysis have to deal with similar psychological problems, but there are differences.

It will be important to remember that one's feelings and outlook will change as treatment goes on. After the first few dialyses, which will clean the blood of many poisons, you will feel much more yourself, more alert, less fatigued. This has been called by some the "honeymoon" phase. As time goes on, however, the full impact of the many changes you had to make in your life will hit home. You will not necessarily feel progressively better, your spirits may drop, and discouragement and depression may set in. This is quite normal, and the staff, family, or friends will help you if you let them know how you feel; others have been down that road before.

While the tendency is to withdraw from others when depressed, just the opposite needs to be done. If you let people know how you feel, they will try to help. Your doctor may prescribe medications to lift your spirits.

In time, and this will vary from person to person, you must resume work or other activities on a full-time basis. It will mean pushing yourself, extending your efforts even though it seems like your energy is drained. If you know you cannot return to your previous work, you should very early seek job retraining by asking to see a social worker. We have found that those who adjust best to dialysis are those who continue to work; in the case of a homemaker, she resumes her housework on a full-time basis.

FAMILY AND MARRIAGES

It is a rare marriage and family that avoids stress, conflict, anxiety, and unsettlement while a member is making the psychological, emotional, and financial adjustments which are bound to occur while coming to grips with dialysis treatment. Disruption, discomfort, disillusionment are inevitable at some point. Friends rush to help the sick, but they don't intend to stay; neighbors and friends extend themselves in emergencies, but it is the family that is expected to deal with the long haul.

Every effort has to be made to keep the marriage and family intact, since the presence or absence of support provided by family members affects health and recovery from illness. How this works is unknown but it does work. The same is true for religious beliefs. In our experience, practicing one's religion is more important than the type of church one attends.

The tendency, however, is for the patient on dialysis to withdraw from social activities outside the home and rely heavily and exclusively on the family. We do not know why this happens, but it certainly is not necessary and unwise psychologically and emotionally. The larger the number of friends, the greater the diversity, the more likely a solid network of support is available to the patient. For example, if one has maintained contact with friends or relatives in another part of the country where dialysis facilities are available, quite inexpensive vacations can be taken which otherwise might be too expensive or difficult to arrange. With the facilities now available, vacations, that important restoring change of scene and pace, need not be denied to patients undergoing dialysis treatment. With the likelihood of a change in income either because of inability to work or the expense of the treatment, only inexpensive vacations are likely to be possible and only possible if contact is maintained with friends and relatives. The practical aspect is far less important than the support a network of friendships provides. The people around us need not be seen; letters maintain contact, and that important invention the telephone is even better. However the way, keep in touch, do not rely exclusively on the immediate family for support.

One of the stresses dialysis places on the marriage is what we call *role reversal*, which happens if the patient-husband was the primary bread winner and can no longer work at his former occupation. It can be very stressful to accept the change from being the person on whom others depend to become the dependent one. This is a particularly difficult change for patients on home dialysis if the husband has to give up control and depend on his wife's skill in inserting needles and regulating the equipment—in our culture typically male activities. It is difficult enough to be dependent on the machine for one's life; to be dependent on the person who was formerly dependent does not come easily and may be fought

vigorously by the husband if, in fact, or in his eyes, his wife was of the “weaker sex.”

SEXUAL ACTIVITY

A very wise physician predicted some time ago when dialysis was first available that the emotional problems of dialysis patients would not be fully appreciated for some time to come. He correctly reasoned that the concern with keeping the patient alive would be uppermost in everyone’s mind, and not until the treatment was refined and became routine would anyone have the time to look at patients and ask what was going on inside them and in their lives. He knew that there would be an emotional and psychological cost, and time has proven him right.

It was not until 1973 that a survey was done on a large group of patients to find out what the disease and the treatment does to sexual desire and drive. Man’s sexual interest and activity has deep biological roots; how else would man have survived as a species? Yet we all know that sexual urges and expression are highly sensitive to how we feel emotionally and physically, the situation, the receptivity of our partners, the recency of the last sexual activity, etc., etc. A man may be satisfied with twice weekly intercourse with his wife, for example, yet find himself having intercourse twice in an evening with his lover. His hormonal levels have not changed, the intensity of his sexual stimulation has.

Just as we stress the importance of the relationship with the doctor, of equal importance is open communication between the patient on dialysis and his/her loved ones. While dialysis reverses many unpleasant feelings and states it does not necessarily restore sexual energy and may in fact produce less interest and desire. Patients typically report they can “take it or leave it” when asked about sexual desire. We do not know why this happens but fortunately studies are being conducted to search for the cause or causes and if hormones are being washed out in dialysis. There are ways to correct and restore this vital part of life and living.

In the meantime the partner should realize that loss of interest in sexual activity *does not* mean loss of love or that he/she is no longer desirable.

Except in relatively rare cases, the male patient on dialysis can perform the sexual act; he only feels the desire less intensely and therefore performs less frequently. The sexual partner obviously has to make adjustments, but there is no reason why he or she could not provide the setting and stimulation to arouse the partner to a level of excitement for both of them to obtain the needed pleasure and release that sexual activity produces.

What we are saying is that sexual appetite may change in patients on dialysis, and as such, adjustment must be made. It is a problem which can be worked on, however, and needs to be openly discussed and jointly tackled. For some couples, intercourse is the chief form of expressing love and affection; for them alternate ways of filling these needs and finding these pleasures will have to be developed lest each feels undesirable and unloved. These feelings rapidly lead to depression.

Probably the single most difficult psychological adjustment is an internal one and involves using *denial* as a protection against facing the reality of one's illness and its treatment. This is not unique to kidney disease. Some patients in the early stages of a heart attack will attribute the crushing pain of damaged heart muscle to "indigestion." This is an unconscious reaction and protects against the intense anxiety that would accompany realization that death may be imminent. This goes on even though another part of the individual knows that delaying emergency medical attention increases the risk of death.

Denial is part of everyone's method of coping with life. In measured doses it is healthy, when excessive it is dangerous. Ignoring dietary and fluid restrictions is the way excessive use of denial shows itself in patients on dialysis. Without some use of denial who would fly in an airplane or drive a car on a holiday weekend when statisticians can accurately predict the number of automobile deaths that will occur?

Striking the right balance between denial and recognition may not be possible without professional help. A person using denial excessively is most unlikely to recognize this and ask for help. Family members may recognize it, and certainly the doctor and dialysis technicians will recognize it because deniers will not follow instructions. In the extreme case they may miss

treatments because they convince themselves that either they don't need dialysis or feel well, so why bother. Professional help is available and should be used.

One thing is clear with dialysis, in fact any long term disease: support from the family is critical. This includes children. While the sight of blood moving through tubes into a whirling machine may be frightening on first exposure, the unknown is equally frightening. With repeated exposure and information, fear diminishes. Anxiety about dental procedures, for example, is greatly diminished if a child sees dental procedures on specially prepared television tapes before visiting the dentist. This is not true of the unknown; it remains frightening because knowledge or familiarity cannot take place when dealing with an unknown fear. For patients on home dialysis there should be no locked doors, and for children the ideal arrangement would be to have the area in which dialysis occurs also be suitable for children's play. The association of pleasurable activities with a medical procedure quickly crowds out fears and worries. While hooked up to the machine, physical participation with the children in play is not possible, but verbal participation and involvement in children's play is definitely possible. Children are flexible and can adapt surprisingly well if they are aware what has changed in their lives. Dialysis cannot be kept secret, the treatment is just too time consuming, and the access is visible for all to see. As in most disfigurements, others are less shocked than we fear they are or might be.

Family involvement in treatment, whether in center or at home, is not without stress, and weak points will be exposed. Asking for professional help early can prevent serious rupture in the family life. Anything that weakens the support felt by the patient is very likely to affect treatment. Sticking with diet restrictions, for example, is very difficult if we are upset or in an atmosphere of quarreling, or if irritation pervades family life. Not eating enough is as bad as eating the wrong foods. Everyone has to be aware that their lives will be affected some way, and that adjustments will be necessary; some of these are major. Being aware that we will have to make changes allows us to identify the problem and then to cope with it.

COMMUNICATION IN MARRIAGE

Mary Jo Peterson, ACSW

Married couples involved in home dialysis must deal not only with the technical procedures for the treatment of kidney failure, but also with the “emotional aspects of living with a chronic disease in a marital relationship.”¹ How do partners in a successful marriage handle this? They talk to each other.

Sounds easy, doesn't it? It's not. Meaningful conversation is not a few monosyllables during dinner or comments during TV commercials or a discussion about a new technical problem with the equipment. Meaningful conversation is telling your spouse where you are—intellectually, emotionally, and physically. When couples come to me for counseling, and begin to voice their complaints, they are astonished by their revelations. This astonishment signifies how very little they communicated. Just because two people live together doesn't guarantee that they'll be omniscient about each other's feelings—they must talk!

Spouses stop talking to each other about things that really bother them, and yet they can discuss “everything” with their counselor. What does the professional counselor do that encourages people to talk? Firstly, they can offer an objective outside opinion, and secondly, they are able to feel and communicate genuine acceptance of the other person. According to Dr. Thomas Gordon, “It is one of the simple but beautiful paradoxes of life: when a person feels that he is truly accepted by another, as he is, then he is freed to move from there and to begin to think about how he wants to change, how he wants to grow, how he can become different, how he can become more of what he is capable of being.”²

Unfortunately, most people believe that, if you accept the other person as he is, nothing will change. They believe that only through immediate confrontation and immediate change will the problem be resolved. The fact is

¹. Campbell, Jim & Campbell, Ann, “When It's All Got You Down, Some Problems You Were Afraid to Ask About,” *Renal News*, v. 7, Fall, 1975.

². Gordon, Thomas, *P.E.T.*, New American Library, N.Y., 1975, p. 31.

without acceptance there can be no communication, and without communication there can be no resolution of problems.

Husband comes home from work and wants to sleep. Wife wants him to do some work around the house. Husband avoids the confrontation by asking, "What's for dinner?" Wife's face is beet red as she walks out of the room.

Conveying nonacceptance turns people off, they stop talking. They learn it is more comfortable to keep their feelings and problems to themselves.³

Later husband and wife again try to resolve their differences. By this time, the wife is more relaxed. She has had the insight to see that she was not really angry about his not helping around the house at that particular moment. She was angry because sometimes she had to carry more than her share of the responsibilities. She tells her husband that she's especially tired, working alone makes her feel that their life style really has changed. She recognizes that his illness has imposed some limitations on them despite their concerted effort not to let it. She feels more responsible for the management of the household, and occasionally she feels overwhelmed!

Husband says he too feels overwhelmed. He is frequently tired and can't get to things as soon as he would like. He feels angry and frustrated. Perhaps instead of making a general statement about her husband's character the wife could give him a specific task to do. If he needs to get some rest before he can get started, he should tell her.

Acceptance opens people up. It frees them to share their feelings. "But of all the effects of acceptance," Dr. Gordon believes, "none is as important as the inner feeling of the person that he is loved. And in psychology we have only begun to realize the tremendous power of feeling loved. It can promote the growth of mind and body, and is probably the most effective therapeutic force we know for repairing both psychological and physical damage."⁴ But, just because you accept the other person, that doesn't mean

³ Op. Cit., Gordon.

⁴ Ibid., p. 33

that issues should go unresolved. Communication is the instrument used to solve the problems, but to communicate effectively you need special skills.

(1) Be aware of your communication style. How do you let your spouse know your feelings? Avoiding confrontations, complaining, blaming, accusing or ridiculing⁵ the other person is not going to help you get what you want from the relationship.

Just before husband leaves for work one morning, he sees a note on the kitchen table telling him that he has a doctor's appointment at 10:30 A.M. He is furious because today he must also attend several very important conferences at work. He awakens his wife to tell her that she was dumb to schedule an appointment without letting him know sooner. Wife answers that she's got better things to do than be his secretary, and from now on he can make his own appointments!

Another way the husband could have expressed his feelings might begin with: "This might seem like a low priority to you, but it's something that really bothers me. I know you're often busy, but when you make a doctor's appointment for me, please let me know at least two days in advance so I can plan my other activities to accommodate it."

In this response the wife's competence wasn't questioned. Consequently, she doesn't need to channel her energy to defend her ego against an onslaught of complaints and condemnations. Instead she can put her energy toward solving the problem with her husband.

(2) Determine an appropriate time for discussion.⁶ Husband comes home from work, obviously frazzled and says, "Boy, have I had a terrible day!" Wife answers, "If you think you had a bad day, wait till you hear about mine!"

An alternative response from wife might begin, "Gee, I'd really like to hear about your day, but let's wait until after dinner when things should be a little more relaxed around here."

⁵. Sherod, Miller, et al., *Alive and Aware: Improving Communication in Relationships*, Interpersonal Communications, 1975.

⁶. Ibid.

(3) Be alert to the non-verbal clues. We send messages by what we say and by what we don't say. Non-verbal messages are communicated through gestures, postures, facial expressions or by other behaviors.⁷ To understand them you must learn to read the unspoken language of the eyes, the articulation of the body, and the message beneath the words. Listen to learn when a hearty "I'm fine" is really expressing "I'm low now and need some encouragement." Learn to sense the pride of accomplishment or the pain of failure behind the seemingly casual description of some event.

Wife is sitting in the living room reading the evening paper. Husband has just come from an appointment with the doctor and proceeds to tell her that he has put his name on the cadaver list. He notices that his wife hasn't lifted her eyes from the newspaper. "Hey, are you listening to me or reading the paper?" he asks.

Guiltily, the wife looks up from the paper, "Don't be silly, of course I heard every word." "Forget it," answers the husband, "the paper is more important to you than I am. Go back to it."

The husband was right. His wife had not really heard what he said. He wanted to do more than just to let her know what he decided. He was looking for some reassurance that he had done the right thing, that someone cared about him and was really on his side.

(4) The importance of touch. Touching the other person—nothing erotic—just plain touching can express acceptance. Sitting close enough to feel each other's body, taking his/her hand, or holding each other during times of stress are all ways of communicating that you are really with the other person.

Finally, be sure you really understand what your spouse is saying before the discussion gets too far along. To check your understanding of what is being said repeat what you think you're hearing in your own words. At this point, it is important for the person sending the message to clarify any misunderstanding before the conversation goes on too far. Remember: you're merely trying to reiterate your partner's message. Don't send back a message of your own. Often times, what goes wrong in the communication

⁷ Op. Cit., Gordon.

process is that the person receiving the message misunderstands it, but no one is aware that a misunderstanding exists.⁸

I'd like to close by briefly summarizing the specific skills needed to foster meaningful conversation in a marital relationship.

- (1) Accept the other person as he/she is and convey that acceptance.
- (2) Be aware of your communication style and make appropriate changes when necessary.
- (3) Determine a suitable time to discuss the issue.
- (4) Don't forget the importance of touch. And finally, be sure that both you and your spouse are hearing the same message before the conversation gets too far along.

Remember: Solving problems requires meaningful talk between open people, and the key to fostering openness is acceptance.

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⁸. Op. Cit., Sherod

RESOURCES FOR KIDNEY PATIENTS

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(Revised by Debbie Flashman, MSW)

When a patient is told that his kidneys are failing and that he will soon need dialysis treatments or a kidney transplant, there are many concerns for him and his family. First and foremost are the questions about his health and what life will be like. Patients and families are worried also about questions like, “How much will this cost?”, “Where will I get some help if I am unable to work?”, “Whom can I talk with about my feelings about this?” There are often so many questions and frequently too few answers. However, there really are many different resources available to kidney patients and their families. Hopefully, if you share your concerns with the doctor, social worker, nurses, or other members of the kidney team that is caring for you, they will be able to direct you to the proper resources. Patients may want to explore these resources on their own as they plan for the future. The following directory has been prepared as a guide to the various services available.

I. PAYMENT OF MEDICAL TREATMENT: The high cost of medical care is well publicized, and most people are naturally concerned about how the cost of their treatment will be met. Many people already have good medical coverage. Others do not know what kind of coverage they have. In most dialysis programs, there will be someone to help you investigate what kind of medical coverage you have and also help you apply for additional help for which you might qualify. In many hospitals, a social worker will help you with this. In other hospitals, there are special funding secretaries or credit officers who help you with financial problems. You may also want to investigate your situation on your own. The following program list serves as a guide to the major sources of help for medical expenses.

A. *Medicare:* Almost all dialysis or transplant patients are eligible for Medicare. There are two parts to Medicare: Part A (or Hospital Insurance) and Part B (or Medical Insurance). Part A pays for most costs of being in the hospital. Part B pays 80% of dialysis costs, doctor bills, and other outpatient services.

To qualify for Medicare, a person has to be either fully or currently insured under Social Security or be a dependent (husband, wife, child) of someone who is fully or currently insured. Anyone who has worked 40 quarters under Social Security is fully insured, and anyone who has worked 6 out of the last 13 quarters is currently insured. Only a few people have not qualified, so it is important to apply for Medicare even if you think you might not be covered.

Medicare becomes effective on the first day of the third month after the month in which you start dialysis. However, coverage can start in the first month of dialysis for a patient who begins home training if this begins before the third month after dialysis begins. If you have a transplant before three months of dialysis, Medicare will cover you on the day you enter the hospital for transplantation. Therefore, you really can't apply for it until you have a starting date for dialysis; but you may want to check with Social Security to see if you have enough quarters. You are covered by Medicare for as long as you are on dialysis. Medicare covers you through a transplant and will remain in effect until 36 months after the date of a successful transplant. In addition, Medicare will pay 80% of FDA approved immunosuppressive medications for 365 days following hospital discharge after a transplant.

If you are already 65 years old or have been receiving Social Security disability for 24 months, you are eligible for Medicare and will not need to reapply. The benefits are the same.

Medicare is also referred to by such terms as "the federal government," "HR-1" and "Public Law 92-603," which can be confusing. It is all Medicare.

B. *Blue Cross/Blue Shield*: You may be insured in a group plan through your job or someone else's job by Blue Cross/Blue Shield, which is a semi-public insurance plan. The benefits under these plans vary greatly from rather basic coverage to extensive Master Medical or Master Health Plus coverage. Almost all group plans in Massachusetts now cover dialysis at 100% under the basic policy. Only a few groups do not have this coverage. You can check with Blue Cross and/or your employer to find out

exactly what kind of coverage you have for dialysis and in hospital benefits. Some plans pay for meds after a deductible.

Non-group plans from Blue Cross cover families and individuals. In Massachusetts all of these plans pay for dialysis at 100%. Coverage for hospitalization varies according to the individual policy. Blue Cross will supply you with a written explanation of coverage on request.

C. *Medex*: Medex I, II, and III are supplementary plans for Medicare. Blue Cross offers these plans to people over 65 or on Social Security (SSA) Disability for more than two years.¹ Medex pays the 20% of dialysis costs that Medicare does not pay. It also provides extra coverage for hospital and doctors bills. These plans have not been easily available to people who have already started dialysis, but there have been a few exceptions. Blue Cross can tell you if you are eligible for coverage.

D. *Other Insurance Plans*: Some companies have group insurance plans through commercial insurers such as Travelers, John Hancock, Liberty Mutual, Metropolitan, etc. These plans vary widely in their coverage. Some cover all expenses and others cover only the basics. Families and individuals may also purchase commercial policies on their own with a great variety of coverage. The insurance company or your employer should be able to explain the nature of your policy.

E. *Medicaid (Medical Assistance)*: Medicaid is a program whereby the federal and state government pay the medical expenses of people who do not have adequate income or resources to pay their medical bills. Medicaid is administered by the Department of Public Welfare. You can apply for Medicaid in the local office of your town. Eligibility is based on income and resources—strict guidelines are followed. If your medical bills are very high, you may be able to get some help even if you have income above the guidelines. If you are receiving Supplemental Security Income (SSI), Aid to Families with Dependent Children (AFDC), or General Relief, you are already covered by Medicaid.

F. *Veterans Administration*: If you are a Veteran and if your kidney disease is service connected, you are eligible for treatment at a VA Hospital.

If you do not have service connected kidney disease you may still be eligible for treatment at a VA Hospital *if* the VA Hospital has room in its program and chooses to provide treatment. There is also some coverage for prescription drugs for Veterans.

If you think you might be eligible for some help as a veteran, contact the Veterans Administration or the VA Contact Officer in your local community.

II. RESOURCES FOR INCOME: Sometimes people are too ill to return to work immediately after starting dialysis. Some people receive adequate sick benefits from their employers, but many people have used up their sick leave or never had any to begin with. There are numerous programs which help patients and families supplement their income while they are unable to work.

A. *Social Security Disability Insurance:* Social Security Disability Insurance provides a source of income for those who qualify for benefits. Qualifications include two factors: how old one is in relation to how long and how much one has worked, and the extent of one's physical limitations. Local Social Security offices can determine if one meets the first qualification. To meet the second qualification one must also be unable to participate in "substantial gainful activity" for a period expected to last at least 12 months. Social Security intends this phrase to mean that an individual is completely unable to work and this must be documented by a physician's statement or via information from a medical facility. The first five months are not covered by disability insurance. Insurance payments begin the sixth month from the date of onset of the disability.

A widow, age 50 or older, may qualify for a disabled widow's pension. Your local Social Security office has information about this.

B. *Supplemental Security Income (SSI):* If you are disabled, blind, or over 65, and you have only a small income, you may be able to receive SSI benefits. Many people apply for SSI while they are waiting for their Social Security Disability. You should apply for SSI at your Social Security Office. Unfortunately, it often takes several months for SSI benefits to be approved.

C. *Emergency Aid for Elderly, Disabled and Children (EAEDC)*: provides limited assistance for people who have very low income or no income. It is often helpful to people who are waiting for SSI benefits, as this assistance can be given quickly. General Relief is available through your local welfare office.

D. *Aid to Families with Dependent Children (AFDC)*: Families where one parent is either disabled or unemployed, and families where there is only one parent, may be eligible for help from AFDC, which is a federal and state sponsored program. The amount of income from other sources and the number of people in the family determine the amount of help given. AFDC may be received also while one is waiting to be approved for disability payments. Application should be made to the local welfare office.

E. *Veterans Pensions*: If you are a veteran, you may be eligible for a pension from the Veterans Administration if your income is low. Contact the VA or your local veterans contact officer.

F. *Private Disability Plans*: If you are working, your company or union may have a disability plan whereby you receive all or partial pay while you are out of work. Although most people know when they are covered by such a plan, occasionally people have failed to sign up for benefits of which they were not fully aware. Check with your personnel department or union representative to be sure.

III. OTHER SOURCES OF FINANCIAL AID:

A. *The Patient Assistance Committee (PAC)*: The Patient Assistance Committee is part of the Kidney Transplant/Dialysis Association. KT/DA has set aside funds for helping kidney patients with special individual needs. Applications may be obtained by contacting KT/DA directly, or through your kidney team social worker.

B. *National Kidney Foundation (NKF)*: The National Kidney Foundation devotes most of its resources to research programs, political lobbying efforts, and public education. NKF occasionally funds some community projects, but does not provide funds directly to individuals.

C. *National Kidney Foundation Affiliate Organizations*: Affiliates of the NKF are typically state organizations, such as the National Kidney Foundation of Massachusetts and Rhode Island. The NKF does not provide funds directly to patients, but many affiliates provide medications that are related to kidney disease at significantly reduced rates. Applications for the reduced rate drugs can be obtained from the affiliate organization directly. Affiliate organizations also provide literature about kidney disease, organ donation, etc., and engage in various public education efforts. Some affiliates, such as the National Kidney Foundation of Massachusetts and Rhode Island and the National Kidney Foundation of Maine, donate funds to KT/DA for its Patient Assistance Committee.

D. *The American Kidney Fund (AKF)*: The American Kidney Fund provides funds directly to individuals. Applications can be obtained from your kidney team social worker.

E. *Indigent Programs*: There are a number of “Drug Cost Share Programs” which can cover all or part of a patient’s cost of certain medications. These programs are administered through the drug companies directly and are designed to be resources of last resort. For more information about these programs, please contact your kidney team social worker.

F. *Other Funding Organizations*: Other sources of funds include various religious organizations and civic clubs. These groups sometimes provide help, but their funds are not specifically allocated for kidney patients and so may be more limited.

IV. SPECIAL SERVICES:

A. *Transportation*: Transportation is often a significant problem for kidney patients. Getting to and from dialysis treatments or transplant clinic appointments can be a major concern. The voluntary agencies that are most likely to help with transportation, and that are most widely located are the following:

1. American National Red Cross.
2. FISH is a church based community group located in a number of cities and towns in many states.

3. Salvation Army.
4. Councils on Aging: Many local community governments in Massachusetts have Councils on Aging. Some provide a variety of services including transportation. Some offer services to people with health related problems who are not elderly.
5. Home Care Corporations are private, non-profit agencies designed to meet the needs of elderly people in Massachusetts. They were organized in recent years with urging and help of the Massachusetts state government. Some Home Care Corporations provide transportation to medical facilities, and this service is sometimes available to non-elderly people with special needs. Income guidelines may apply.
6. Medicaid will pay for taxi or chair car to and from medical appointments. There must be medical disability that prevents the patient from using public transportation.
7. "The Ride," run by the MBTA (Boston area and some satellite areas), helps disabled people get around.
8. Senior Shuttle, run by City of Boston Elderly Commission, for medical appointments.

B. *Home Services:* Some dialysis or transplant patients may occasionally need help at home. A mother may need a baby-sitter; someone recently discharged from the hospital may need some help with personal care needs or household chores. The following services meet home care needs:

1. Voluntary – At this time there are few voluntary groups that provide help in the home. FISH does often provide babysitting services. Another helpful contact is the Women's Educational and Industrial Union, located in Brookline, MA.
2. Professional – This includes homemakers and home health aids. Homemakers help to organize and maintain a household. They do household errands and chores such as shopping, laundry, preparation of meals and help with care of children. Home health aids primarily provide personal care such as bathing. They also do some light housekeeping and meal preparation if this is needed. For professional homemakers and home health aid services, contact your doctor or social worker.

C. *Counseling:* At times some kidney patients and their families may feel the need to talk with a professional person about emotional difficulties they are experiencing. These difficulties may or may not stem from the

problems kidney failure presents. For whatever reason people are experiencing difficulties, there are many people available to help. The kidney team social worker is trained to provide counseling. There may be psychiatric personnel at the kidney center's "backup hospital." If the kidney center or hospital is an uncomfortable distance from home, there are many community mental health clinics, and family service agencies scattered around most states. The kidney team social worker can help arrange referral to community agencies.

V. PATIENT ORGANIZATIONS: There are many local and national patient organizations for kidney patients. They have various purposes, but in general they exist to provide a place for kidney patients to share experiences, find mutual support, and exchange information.

A. *Kidney Transplant/Dialysis Association, Inc. (KT/DA)*, P.O. Box 1362 GMF, Boston, Ma. 02205, (617) 267-3747. KT/DA is a nationwide, Boston-based group of kidney dialysis and transplant patients whose motto is "Patients Helping Patients." They have a regular publication (the **RenalGram**), regular meetings, occasional social events, and provide funds for individual patient assistance (see III A above) and for various projects that directly benefit patients. They consistently seek to expand their membership, which consists primarily of patients, but includes relatives, friends, and members of the medical team as well.

B. *American Association of Kidney Patients (AAKP)*, 1 Davis Blvd., Suite LL-1, Tampa, FL 33606. AAKP is a non-profit, national patient organization. AAKP has a quarterly publication, local chapters, and regional meetings which provide patient fellowship and an opportunity to share information. They are active in legislative matters affecting patients.

C. *Other Patient Organizations:* Many kidney centers have their own patient groups that have organized to meet their own goals and needs.

Chapter 17

FOOD — WHAT DOES IT MEAN TO YOU?

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Before you started dialysis, or maybe even after you were transplanted, you may not have thought much about your food choices and how they affected your health. Maybe you read a magazine or newspaper article once in a while about cholesterol and heart disease or weight control. You don't see much in the news about potassium and phosphorus. The thought of how sodium affects blood pressure and fluid gains for folks on dialysis probably never crossed your mind.

As a renal patient, you probably have experienced numerous changes in your eating patterns. Some of these changes may have occurred because your physician and dietitian felt that a special meal plan would be helpful to you for medical reasons. Other changes may have been "self-induced" when you found that certain foods didn't taste quite right or just didn't agree with you. Perhaps it was never clear to you why certain diet modifications were necessary at one time and not necessary at another time, or why your diet was so much different from that of a friend who also had renal disease..

At any rate, after reviewing your diet with your dietitian, you probably had many questions such as—WHAT CAN I EAT? What must be avoided? How will I live without salt? Are POTASSIUM and PHOSPHOROUS the same thing? or Will my diet change after I get a transplant? These questions, and many others, are good questions and should be asked. Don't ever feel embarrassed or uncomfortable about asking questions, since that is the best way to get all the answers.

YOUR DIET AND EATING HABITS

The word "diet" is not intended to be synonymous with restriction. Your *DIET* is whatever foods you eat. Food—a necessity of *all* life—has probably become more meaningful to you now than ever before, or at least now you probably realize how important it was to you before. We all establish our eating habits in our very early years, and changing these

habits is quite often very difficult. Your dietitian, the doctors, nurses, social workers and all other members of the “renal team” realize that to modify one’s diet is no easy task. Therefore, when you do follow your recommended meal plan, we are proud of you and pleased as can be. When you don’t follow it, we usually become concerned or even upset. We feel our concern is justified since a diet modification is recommend *only* when we feel it will be in your best medical interest. Your diet can and should change as your medical/nutritional needs change. It is important to note that your nutritional needs will differ from those of someone else, even though that someone else may also have kidney disease and/or require dialysis. This is because no two people have the same blood pressure, weigh the same, and drink and eat the same. We feel that *your diet can* offer you better general health.

What follows is an explanation of the nutritional aspects of your care in relation to kidney disease. It is hoped that this chapter will help to answer some of your questions and clarify other points of interest for you.

Let’s start with what might be your first question if you are on dialysis: *Why do I have a bad taste in my mouth?* or *Why do foods I used to like taste different?*

The kidneys, when functioning normally, play a major role in getting rid of many of the “toxic wastes” which come from the digestion of food. When the kidneys are unable to function normally and the “toxic wastes” which come from the digestion of food begin to build up in the body, many patients develop a bad taste in their mouth. This is referred to as uremic or ammonia taste. It is difficult to prevent, but effective dialysis and certain diet modifications usually improve this bothersome problem.

Many patients have reported that sucking on a piece of hard candy or iced lemon wedge is helpful in temporarily relieving the bad taste. Others have found that tart beverages (in quantities permitted for your meal plan) such as lemonade and limeade are effective. Still others suggest that frequent brushing of teeth and tongue helps. If this is a problem for you, do mention it to your doctor and dietitian. They will probably have some suggestions for you. It is especially important for you to mention any change

in your routine eating pattern such as during bouts of the flue or dental work, to your dietitian. She will try to advise you of ways you can manipulate foods to allow for well-balanced, nourishing meals. Good nutritional practices are extremely important to you in sickness and in health.

How can I ever be expected to follow this diet?

At first all the various diet limitations may be confusing and seem impossible to balance, leaving nothing to eat at all. A slow, methodic learning of each aspect of your diet may best enhance your knowledge. Meal plans from your dietitian with breakfast, lunch and dinner ideas already developed will also be of benefit in demonstrating how the whole diet order is worked into balanced meals. Soon the renal diet will be second nature to you and be part of your daily routine.

It is up to you to control your diet and not let the diet control you. Following a “special” diet is sometimes easier if you, as well as your family and friends, fully understand WHY your diet is necessary so that they can add to your support. It is hoped that the following information, in conjunction with information you receive from your dietitian and other members of the renal team, will help you to understand the why’s of your particular nutritional needs. This in turn will make your new meal plan a bit easier to follow.

SODIUM

What is sodium and what does it do?

Sodium is *part* of salt. It is a mineral we all need *in very limited quantities* for fluid balance. It is found naturally in many foods, but is frequently added to foods (as salt or other sodium-containing ingredients, e.g., sodium glutamate, sodium caseinate) for flavor or as a preservative. As a result, most of us have acquired a taste, through the years, for much more salt (sodium) in our diets than our bodies actually need.

The normal kidneys eliminate almost all of the sodium we get from our diets. Kidneys which aren’t functioning properly, however, may not be able to efficiently perform this function. They may either retain most of the

dietary sodium, *or*, in some cases, they may cause too much sodium (more sodium than we get from food) to be eliminated in the urine.

Logically then, if your kidneys are not producing much urine, you are not losing much sodium. If your kidneys hold onto too much sodium the extra sodium in your body attracts fluid, and also causes thirst and falsely leads one to drink even more fluid. This excess sodium and fluid can cause high blood pressure and/or swelling of your ankles, or other extremities. This swelling is called *edema*. These symptoms, if not controlled, can lead to other more severe problems, such as congestive heart failure or pulmonary edema, which can require hospitalization. As a means of preventing these problems, if your kidneys are unable to eliminate this mineral, you will be asked to limit the amount of sodium in your diet.

There are many possible levels of modified sodium intakes—from very, very low (requiring special “salt-free” diet foods) to fairly liberal. The “average” dialysis patient, for example, who needs a sodium restricted diet, doesn’t usually need a very low intake of sodium but rather a moderate intake. In this case, the purchase of many special food products is unnecessary. In most instances regular breads and margarine are permitted (in specific amounts), while table salt and very salty foods are to be avoided. Be careful reading food labels. A food may be “salt-free” but rarely are foods “sodium-free” since *most foods contain their own natural sodium*. Your dietitian will give you specific guidelines about *your* particular needs.

Frankly, many people who are accustomed to a high sodium diet have some difficulty adjusting to a low sodium diet because foods cooked or prepared without salt seem very bland or tasteless. This acquired taste for sodium can and will change in time, especially if attempts are made to flavor foods by other means. This can be done by experimenting with various herbs and spices, most of which are low in sodium. Ask your dietitian for a list of herbs and spices and their food complements. Here are a few to get you started:

Rosemary is good on beef roasts and beef stew.

Thyme is good on chicken.

Dill Weed is good on fish.

Remember not every renal patient needs to limit his or her intake of dietary sodium. The level of sodium you need in your diet will depend upon your own particular needs and may be different from the needs of someone else. The above information about sodium is true for the pre-dialysis, dialysis and transplanted patient.

ARE PHOSPHORUS AND POTASSIUM THE SAME THING? No, No, No!

PHOSPHORUS is a mineral which is closely associated with CALCIUM in the body. Phosphorus and calcium work together to help build bones and keep nerves and muscles in working order. To perform these functions effectively, these two minerals need to be present in the blood stream in a definite ratio to one another.

Normally the kidneys are responsible for excreting any excess phosphorus taken into the body from food. This keeps the calcium and phosphorus in balance, which allows for efficient use of both minerals. In kidney disease, however, the kidneys frequently are unable to excrete any extra dietary phosphorus. When the kidneys cannot eliminate dietary phosphorus, the phosphorus content of the blood begins to rise! The extra phosphorus usually binds with calcium and then deposits in joints, blood vessels, and muscle tissue. More calcium is often released from bone to bind with phosphorus, and this weakens bones. Calcium levels may become low due to this binding and deposition action. Calcium blood levels may also become low because oral calcium absorption is impaired. Usually the kidney activates *Vitamin D*, which helps in the calcium absorption process. Renal failure typically inhibits Vitamin D activation and therefore sufficient calcium is not well absorbed from oral intake. Calcium and Vitamin D supplements may be prescribed in such cases. When the calcium-phosphate ratio is altered, the body tries to remedy the situation by secreting *parathormone*.

In the neck area, we all have four, very small parathyroid glands that produce parathormone. Parathormone draws calcium from the bones in an attempt to increase the serum calcium level and restore the calcium-phosphate balance, thereby weakening the bone structure. Without strong, healthy bones it becomes difficult to sit or walk because of severe bone pain and fractures may occur with little or no trauma. If the parathyroid glands

become hyperactive and enlarged from non-compliance with diet and medications, then surgery may be required to remove some of the enlarged glands.

All this may seem quite complicated, but with your cooperation, your doctor and dietitian will work with you to try to prevent these side effects from occurring by:

1. Keeping your dietary phosphorus intake to about 1 gram per day.
2. Prescribing Vitamin D and supplemental calcium if necessary.
3. Prescribing specific antacids containing aluminum or calcium which you are to take with EVERY MEAL OR LARGE SNACK.

It is important to know that these antacids are NOT prescribed for indigestion: They are to be taken to BIND PHOSPHORUS from your diet in your gastrointestinal tract. This decreases the amount of dietary phosphorus absorbed into your blood stream. USE ONLY THOSE ANTACIDS PRESCRIBED FOR YOU. NEVER TAKE ANY MEDICATION WITHOUT YOUR PHYSICIAN'S APPROVAL OR RECOMMENDATION! If you become constipated from the phosphorus binders, please ask your physician to prescribe a stool softener.

Unfortunately the best food sources of calcium are also the best food sources of phosphorus! THERE IS NO EFFECTIVE WAY OF INCREASING THE CALCIUM IN YOUR DIET WITHOUT INCREASING YOUR PHOSPHORUS INTAKE TOO, AND LIMITING PHOSPHORUS IS OUR PRIMARY CONCERN!

Your dietitian will advise you which specific foods you should adjust in your meal plan to keep your phosphate level within normal limits. Generally, however, dairy products (milk and all milk products, except butter or margarine) are your highest sources of phosphorus. Eggs, certain cereals or grains and many high *potassium* foods (dried fruits, dried peas and beans, nuts, cocoa, and whole grains) are also very high in phosphorus. (This is probably why many people think potassium and phosphorus are the same thing, but you will see that they are distinctly different.) As a rule, if

you are eating a moderate amount of protein, and limiting your potassium intake, your intake of dietary phosphorus should automatically be reduced.

Restriction of dietary phosphorus is usually necessary long before you ever need dialysis. The abnormality in phosphate excretion will continue while you are being dialyzed. People on peritoneal dialysis typically continue to require phosphate binders too, as phosphorus is not well dialyzed. After transplantation, however, if the new kidney works effectively, there usually is no need for you to limit the phosphorus in your diet. In fact, quite frequently transplanted patients are encouraged to *increase* their dietary intake of phosphorus, and even then, some require additional phosphorus supplement.

POTASSIUM

POTASSIUM does not have anything to do with bones or calcium or phosphorus. Potassium is a mineral which we all need for muscle tone. Rarely do we have problems supplying our bodies with sufficient potassium since most all foods contain potassium. This being the case, even a potassium-restricted meal plan will not be potassium-free. It will be somewhat on the low side of a “normal” potassium intake.

Normal kidneys are able to excrete in urine any extra dietary potassium which the body does not need. Therefore, if you are unable to produce sufficient urine (1-2 quarts or more per day) you will be unable to eliminate the potassium your body does not need. Potassium is unique because the build-up of potassium in the blood usually occurs without any detectable warning signals except for maybe weakness. When potassium builds up in the body too rapidly or to too high a level, *it can cause the heart (the most important muscle) to beat irregularly and in some cases to stop.*

Because of the very undesirable side effects of a high blood potassium level, it is in your best interest to follow the guidelines your dietitian gives you. She will try to include as many of your favorite foods as possible to allow for a flexible, well-balanced, lower potassium meal plan.

Limiting intake of potassium is frequently necessary before dialysis, as well as after hemodialysis is initiated. Hemodialysis does remove potassium from your blood, but it does not take very long for potassium to

re-accumulate after a dialysis treatment is over. This is why a potassium restricted diet is needed even when you are receiving effective dialysis. People on continuous ambulatory peritoneal dialysis (CAPD) or continuous cycling peritoneal dialysis (CCPD) may find that their potassium intake may be liberalized somewhat since they are constantly being dialyzed. After transplantation, potassium will be liberalized somewhat if the transplanted kidney is able to produce sufficient urine to eliminate extra dietary potassium. However, in many instances you may be asked to limit your intake of potassium in order to maintain normal blood levels of this mineral because one of the medications (cyclosporine) can cause an increase of potassium in the blood.

PROTEIN

PROTEIN is supposed to be good for everyone—why is it “bad” for people with kidney disease?

Protein is not really “bad” for people with kidney disease. However, if too much protein is eaten, and if the wrong type of protein is eaten at certain stages of renal disease, it can literally make a person sick.

The truth of the matter is that, as with so many other types of foods, most of us eat much more protein than our bodies need. Certainly, we all need protein for growth, maintenance and repair of our body tissues. However, when we eat dietary protein, that protein is “broken down” during digestion so that it can be used effectively and efficiently by our bodies. When protein is broken down, nitrogen and other wastes, which are found in all protein-containing foods, becomes available for the kidneys to eliminate. When the kidneys cannot rid the body of these wastes of protein break-down, these wastes build up in the body and can be measured in the blood. Blood urea nitrogen (BUN) is one blood test which can determine the kidney’s ability to remove protein wastes. If a person with advanced kidney disease eats TOO MUCH protein, the BUN will rise rapidly to a very high level. At the same time, a decreased appetite, nausea, and vomiting, as well as the impaired taste mentioned earlier, may occur.

There are *two types* of protein in food: high quality and low quality. The high quality protein is found in eggs, milk, meat, fish and poultry. The

low quality protein is found in “starchy” foods (breads, cereals, pasta, etc.) and most vegetables.

When your dietitian talks to you about the protein in your meal plan, he or she will advise you to choose most of your total protein allowance from the high quality protein sources. The reason high quality protein is stressed is that even though our bodies need both kinds of protein to function efficiently, the high quality proteins *must* come from the food we eat, but our bodies are capable of making the proteins of low quality.

To complicate matters a bit, in addition to the nitrogen and wastes produced in protein breakdown, foods of high quality protein also tend to contain a great deal of potassium, phosphorus and natural sodium. Perhaps now you can see that there is more than one good reason for you to limit your intake of dietary protein.

If you are not yet being dialyzed, you might be asked to reduce your total protein intake to a fairly low level. If you are being dialyzed, the quantity of protein suggested for you will depend on your body size and general well-being. People on CAPD and CCPD typically need more protein than persons on hemodialysis. Rarely does the protein intake of a person receiving dialysis need to be restricted to an amount less than that recommended for a person without kidney disease. Remember: most of us eat much more protein than our bodies need.

After transplantation, your protein intake will be liberalized. In fact, for the first month after your transplant, you will need to eat a fairly large amount of protein—more than when you were on dialysis. There are two reasons for this. The first is that the transplant surgery itself requires extra protein for healing, and the second is that a medication (prednisone) you will take increases your protein needs.

It will always be very important for you to eat ALL of the protein you are permitted each day. Follow your suggested meal plan closely and enjoy better nutrition!

FLUIDS

Why should I limit my fluid intake — I thought that lots of fluid was good for “flushing out” my kidneys?

FLUIDS are good for your kidneys (and your body) only if your kidneys are capable of producing enough urine to almost equal (or better) the amount of fluid you take in.

As the kidneys fail, they frequently (but not always) lose their ability to produce urine. When this happens, the body loses its main method of eliminating extra fluid. Therefore, if you were to drink “lots” of fluid when unable to produce “lots” of urine, that fluid you drank (or ate since many foods have a high fluid content) *would not* “flush out the kidneys.” It would have nowhere to go and therefore would stay in your body.

The first thing that happens when you drink more fluid than your kidneys can turn into urine, is that you gain weight — FLUID WEIGHT! Sixteen ounces of water weighs one pound. Fluid weight gains can occur very rapidly, while solid (muscle and fat) weight gains—which depend on your intake of calories—occur very slowly.

Although our bodies normally contain (and need) a significant amount of fluid, *extra* fluid can destroy normal fluid balance and can cause high blood pressure, edema, shortness of breath or other more severe complications which can require hospitalization. This situation, of excess fluid in the body, is often called “fluid overload.”

“Fluid overload” is an undesirable condition which can usually be prevented—by restricting your intake of fluids. Now, this sounds fairly simple and clear cut until you realize that fluid means more than just water. FLUID IS EVERYTHING WHICH IS LIQUID AT ROOM TEMPERATURE. This includes jello, ice cream, popsicles, sherbert, soups, gravies, sauces, tea, coffee, milk, and other beverages. It also includes *ICE*, *all liquid medications* (including intravenous solutions and blood transfusions), as well as all liquid used to take your pills!

In sickness and in health there are two main reasons for our taking in fluids—*habit* and *thirst*. If you are advised to decrease your intake of fluids,

you may have to change a long-standing habit. As before, this is no easy task, but with some effort this habit can and will change.

Thirst, also can usually be controlled. One of the most frequent causes of increased thirst for all of us is a high intake of sodium. Most of us can relate to the fact that after a meal of corned beef or ham (both very high in sodium) we become thirsty. As a result we drink large quantities of water or other fluid. This occurs because our bodies are telling us—by making us thirsty—to dilute the extra sodium in our bodies with extra fluid. Logically then, decreasing your sodium intake should help to decrease your thirst! A high blood glucose level will also make diabetics thirsty. Thirst will also occur if and when we lose too much fluid. This is frequently the case with excess perspiration, diarrhea and/or vomiting.

In addition to all this, patients with renal disease may develop a “false thirst.” This occurs when the nitrogen and other wastes are allowed to build up in your blood. If this seems to be the cause of your excessive thirst, you may be asked to reduce your intake of certain foods, especially high protein foods.

Fluid manipulations may be necessary prior to the initiation of dialysis, during chronic dialysis, or after transplantation. Your physician and/or dietitian will advise you of exactly how much fluid is best for you. The amount of your urine output will govern how much fluid you can drink. If you are receiving dialysis treatments, you will probably be advised to take in enough fluid to gain about 2 kilograms which equals 4.4 pounds (or an amount specified by your doctor) of FLUID WEIGHT between dialysis treatments. The reason some fluid weight gain is desired is that the artificial kidney does remove some fluid during your treatment. If you gain this recommended amount of weight between treatments — you should have a fairly comfortable treatment.

At the end of your treatment, you should have all extra fluid removed. You will be weighed post treatment to see how close you are to your target or DRY WEIGHT. Just before your next dialysis treatment, you will be weighed again to see how much fluid you have retained between treatments. Your weight at the beginning of your treatment is called your WET WEIGHT.

Wet Weight — Dry Weight = Available Weight

Your machine will then be set to remove your available weight. If the machine was not able to remove all of your available weight, you will “leave a little heavy” and need to be careful of your fluid intake until your next chance for the dialyzer to remove your accumulated fluid.

Signs of nausea, vomiting, cramps, dizziness, sweating, and low blood pressure *may* indicate that you have lost too much fluid. Dialysis personnel may recline your chair, turn the machine pressure down, or infuse some saline (salt water) into your venous blood line. It is important to finish your treatment so that the wastes may continue to be removed from your blood. If these symptoms persist, then you may have gained dry weight and your target dry weight may be increased.

Conversely if you persistently are short of breath, sleep with your head elevated, have swollen ankles and hands or puffy eyes, or have a high blood pressure or headaches, then you are accumulating too much fluid and perhaps your dry weight needs to be lowered.

Ideally, the renal team will be able to maintain you at an appropriate weight, but please report any of the above symptoms immediately so that you may feel your best.

CALORIES

Do I have to count calories too?

CALORIES come from carbohydrates (sugars and starches), proteins and fats. Calories are the body’s main source of energy or fuel and are responsible for changes in your dry weight.

- If you eat *less calories* than your body burns as fuel, you will *lose dry weight*.
- If you eat *more calories* than you burn, over a prolonged period of time, you will *gain dry weight*.
- If you eat the *same number of calories* as your body burns for energy, your *dry weight will remain the same*.

As a rule you don't really have to count calories, but your meal plan, as determined by you and your dietitian, will include suggestions for manipulating your caloric intake primarily from *non-protein* sources to meet your daily energy needs.

Non-protein caloric sources are, obviously, carbohydrates and fats. The reason these caloric sources will be emphasized is that, if you burn protein for energy, the protein cannot and will not be used as it should be for growth, maintenance, and repair of body tissue (muscle, blood cells, etc.).

Solid weight gains and fluid weight gains are frequently confused, but very simply, *fluid weight gains can occur rapidly* in a day or two) and *solid weight changes* (losses or gains) occur *very, very slowly*. One pound of dry weight = 3500 calories, but one pound of fluid weight = 2 cups of fluid. For this reason, we can be certain that most all of the weight you gain between dialysis treatments is *always* fluid weight!

After transplantation, it is not uncommon to gain weight, especially within the first six months. As your kidney begins to remove waste products, you will probably notice that food tastes better and your appetite increases. Also one of the medications (prednisone) you will take can actually stimulate your appetite. As a result, you may overeat and ultimately gain an undesirable amount of weight.

One of the culprits in this weight gain is fat. Fat is a concentrated source of calories and can add unwanted pounds quickly. Therefore, your intake of fat should be limited (to less than 30% of total calories consumed), and your cholesterol and saturated fat intake should be restricted, especially since the medication prednisone can elevate your blood cholesterol to higher than normal levels. Some of the foods that typically add a great deal of cholesterol and saturated fat to the diet are whole-fat dairy products, red meats, fried foods, and commercially prepared cakes and cookies.

Furthermore, if you're watching your weight after your transplant, you will want to limit your intake of sugar. Sugar and concentrated sweets are usually high in calories and low in vitamins and minerals. A large sugar

intake is of concern to transplant patients because prednisone can raise the sugar in your blood higher than normal. Eating a diet high in sugar, along with taking prednisone, can contribute to blood sugar control problems.

If you are concerned about your current weight, for whatever reason, please mention this to a renal team member. The dietitian can then guide you in proper meal planning for weight gain, loss, or maintenance.

VITAMINS AND MINERALS

If my meal plan is balanced, why do I need to take a vitamin every day?

Your meal plan is as balanced as possible, given the guidelines of your diet prescription. A vitamin supplement replaces the water soluble vitamins (the B and C vitamins) that are washed away in the dialysate. Boiling vegetables in large amounts of water to reduce their potassium content also destroys some vitamins. Folic acid is given to enhance red blood cell production.

In renal failure, red blood cell counts generally are low because the kidney's ability to secrete *erythropoietin* (a hormone which stimulates red blood cell production) is depressed. Iron, erythropoietin, Vitamin D and calcium supplementation is individualized. Please take only the vitamins and minerals prescribed by your doctor.

IN BRIEF

- Your diet is an important part of your overall medical care. Therefore, it is very important for you to follow the meal planning suggestions you receive, just as you would follow all other suggestions from your doctor or other team members. When you meet your dietitian, he or she will probably ask you about your eating habits and will keep you informed about your nutritional status.
- Your meal plan is designed especially for you and may be entirely different from the diet of other patients with kidney disease. In fact, their diets could be harmful to you and vice-versa!
- You are responsible for your food and fluid regulation. Your dietitian and other members of the renal team can give you the how's and why's of diet manipulation, but they cannot follow the diet for you. You are in control!

- Be sure you have a full understanding of your nutritional needs. Your dietitian has many informational sources to share with you including nutrition handbooks, cookbooks, menu ideas, suggestions for dining out and fact sheets. Take full advantage of these resources that are available to you.
- If you do not understand certain aspects of your diet, speak up! Continue to ask questions! No question is ever too small or unimportant.

Good luck, Good Eating, and Good Health!!

Appendix

This information is being included to help you more clearly understand some of the diet-related terms you might hear or read.

ABBREVIATIONS

(Metric system)

Na	= Sodium	tsp	= teaspoon	l	= liter
K	= Potassium	tbl.	= tablespoon	cc	= cubic centimeter
P	= Phosphorus	C.	= cup	Kg	= kilogram
Ca	= Calcium	oz.	= ounce	gm	= gram
CHO	= Carbohydrate	lb. or #	= pound	mg	= milligram
Pro	= Protein	mEq	= millequivalent		
Al	= Aluminum	EDW	= est. dry weight		
Kcal	= Calories	AW	= available weight		

WEIGHTS AND MEASURES

1 ounce = 30 cc = 2 tablespoons
 1 tablespoon = 15 cc = 3 teaspoons
 1 teaspoon = 5 cc

1 cup = 8 oz. = 240 cc
 3/4 cup = 6 oz. = 180 cc
 1/2 cup = 4 oz. = 120 cc
 1/4 cup = 2 oz. = 60 cc
 1/8 cup = 1 oz. = 30 cc

4 cups = 32 oz. = 1 quart (qt.) = 960 cc
 1 liter = 1000 cc (40 cc more than a quart)
 1 pound = 16 ounces (= 2 cups = 480 cc)
 3/4 pound = 12 ounces (= 360 cc)

1/2 pound = 8 ounces (= 240 cc)

1/4 pound = 4 ounces (=120 cc)

1/8 pound = 2 ounces (= 60 cc)

2.2 pounds = 1 kilogram = 1000 cc = 1 liter

Chapter 18

HYPERTENSION

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What is hypertension? Hypertension, or high blood pressure, is defined as an elevation in either the systolic or (and) diastolic blood pressure. The systolic blood pressure, which is the higher number reported for your blood pressure, and the diastolic blood pressure, which is the lower number, are normally a function of the force with which blood is pumped from the heart and the resistance in the blood vessels to its forward flow. The numerical definition of hypertension is influenced by the individual's weight, sex and age. However, for adults it is generally accepted that a blood pressure of greater than 150/90 is excessive and fulfills the definition of hypertension. Interestingly, elevation of the diastolic blood pressure is the value which is most often associated with the long term complications of heart failure, heart attacks, poor circulation, strokes, and eye disease.

What are the causes of hypertension? In adults, hypertension is usually without a well-defined, and therefore reversible etiology. Uncommon diseases, such as hormone producing tumors in the adrenal gland or constriction of blood flow to one or both arteries of the kidney, are treatable causes of hypertension. However, in most cases of hypertension, no such abnormalities are found. These individuals are described as having "essential" hypertension. Obviously, this description is a misnomer. Although there is a genetic predisposition to hypertension, hypertension is not a constitutive or essential disorder.

Vigorous research to define the causal factors in essential hypertension have suggested two general abnormalities which are particularly relevant to the patient with hypertension and kidney disease. The first of these factors is the amount of fluid contained within the body. In the patient with kidney insufficiency, the capacity of the kidneys to excrete the daily dietary load of salt and water is compromised. These fluids accumulate in the body, including the blood vessels. Like a garden hose which is turned on, but is knotted and therefore the water entering it cannot escape, the pressure inside increases.

A second factor which contributes to the elevation of blood pressure is that diseased kidneys release a hormone which indirectly causes the kidneys to retain salt and water, and causes the blood vessels to narrow. This hormone, which is called renin, may also contribute to the progression of kidney failure. Therefore, reducing the effects of renin are the target of many

Newer medications used to treat high blood pressure in kidney disease. For the patient with a kidney transplant, an additional factor which contributes to the development of hypertension is the use of steroids, such as prednisone, to prevent transplant rejection. This group of medications causes the inappropriate retention of salt and water. Less commonly, hypertension may develop in a transplant patient because of too great a dose of cyclosporine A, which constrict the blood vessels, or because the blood flow to the transplant is blocked. In any form of hypertension, environmental stresses and anxiety augment the increase in blood pressure.

The clinical presentation of hypertension is highly varied. Essential hypertension is typically a disease of middle age, but the presentation in blacks is often at an earlier age than in whites. Most patients with essential hypertension have no symptoms until the heart, kidneys, eyes, blood vessels, or brain have been damaged. In its most extreme presentation, hypertension is associated with heart failure, kidney failure, visual impairment, and (or) confusion, strokes, and seizures. Because of its fatal course if the patient is not treated immediately, this presentation for high blood pressure is described as malignant hypertension. Most patients with malignant hypertension have a background medical history of underlying kidney disease or hypertension which is inadequately treated. It is also more common in blacks than whites.

How is hypertension treated? Therapy for hypertension is directed at the cause. For example, in those patients who have a adrenal tumor or inadequate blood flow to the kidneys as the cause of their hypertension, the treatment is to remove the tumor or to restore normal kidney blood flow, respectively. For the majority of patients with essential hypertension and normal kidney function, blood pressure control is initially directed at limiting the dietary intake of salt, with or without the use of diuretics ("fluid pills") to accelerate the excretion of salt and fluids in the urine. Additional strategies for

blood pressure control include weight loss in patients who are overweight and the institution of an exercise regimen for sedentary patients.

For patients with more severe hypertension which is unresponsive to these initial maneuvers, or for patients with kidney disease not yet on dialysis, medications which reduce the blood level of renin (such as captopril, enalapril, and lisinopril), relax the blood vessels (such as hydralazine, clonidine, minoxidil, methyldopa, and nifedipine), or decrease the force with which blood is pumped from the heart (such as propranolol, atenolol, and labetalol) may be used alone or in combination. Once renal failure requiring dialysis is necessary, approximately 75% of the previously hypertensive patients can have their blood pressure controlled by the aggressive removal of fluid with dialysis. Thus, for the patient on dialysis, the amount of fluid in the body is a critical determinant of blood pressure.

A frequent complaint of dialysis patients is that “too much fluid is [being] removed.” This perception relates to the imprecision of the patient’s sense of well-being as an indicator of the appropriate fluid status. Most patients feel less well when fluid is removed at dialysis, especially when large amounts are removed in a short interval of time. Further, many dialysis patients feel improved when their blood pressure is moderately elevated. However, the chronic consequences of inadequate fluid removal at hemodialysis are grave. They are the same severe and often irreversible injuries to the heart (congestive heart failure, heart attacks), brain (strokes), blood vessels (swollen legs, leg cramps, poor circulation), and eyes (loss of vision) that occur in untreated essential hypertension.

The determination of the appropriate amount of fluid to be removed at dialysis is imprecise. This is because the estimated dry weight (EDW), which is the optimal weight for a normal blood pressure with no fluid excesses, is not static. For example, if the patient has been ill and eating poorly, the amount of solid weight (muscle, fat, and bone) will decrease, and the EDW must fall as well. If the EDW is not appropriately decreased, the additional weight is composed of fluid, which has deleterious consequences. You can facilitate your sense of well being at dialysis, and your blood pressure control between dialysis session, by limiting the intake of fluids such that a weight gain of 2 – 4

pounds per 48 hours is not exceeded. Adherence to a 2 gram per day sodium diet will greatly ease excessive thirst.

Strict adherence to the prescribed schedule for the administration of blood pressure control medications (antihypertensives) is an equally important adjunct to the control of hypertension. A helpful strategy to assess the adequacy of blood pressure control between the dialysis session is to monitor it at home. Typically, blood pressures obtained in the dialysis unit are higher than the values measured at home. The role of contributory factors, such as anxiety in the dialysis unit or withholding antihypertensive medications before dialysis, can be eliminated by checking the blood pressure at home. These values obtained at home provide your physician with more accurate blood pressure determinations in a realistic setting that is representative of most of your time.

In the hypertensive patient with a well functioning kidney transplant, salt and water restriction, with or without the use of antihypertensives, may be used. Hypertension in transplant patients which is secondary to cyclosporin toxicity or to steroid side-effects may be treated by reducing the doses of these medications.

ANEMIA IN PATIENTS WITH CHRONIC RENAL FAILURE AND IN PATIENTS UNDERGOING CHRONIC HEMODIALYSIS

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Anemia is defined as a reduction in the oxygen carrying capacity of blood, measured in the laboratory as a low *hemoglobin* concentration, or a low *hematocrit* (the percentage of the blood volume that is occupied by red blood cells or *erythrocytes*). In a normal person, the hemoglobin is approximately 13 grams per deciliter and the hematocrit is approximately 40%.

Anemia is not a disease per se, but a reflection of some other problem. It occurs when the balance between the normal rates of blood loss and blood production is disturbed. There are three basic mechanisms by which this occurs: (1) blood loss, (2) excessive destruction of red blood cells (*hemolysis*), and (3) abnormally low production of red blood cells by the bone marrow.

In a person with normal renal function, the finding of anemia on routine blood analysis would prompt a work-up to determine the ultimate cause. In chronic renal failure, anemia is almost always present, and can be a result of any of the mechanisms listed above. However, the typical “anemia of chronic renal insufficiency” is a result of a decreased production of red blood cells by the bone marrow.

This defect in red blood cell production is largely explained by the inability of the failing kidneys to secrete the hormone *erythropoietin*. This hormone is a necessary stimulus for normal bone marrow to produce red blood cells. In addition, other factors associated with renal failure, including the accumulation of so-called uremic toxins, may play a role in depressing bone marrow function. Excess stores of aluminum may accumulate in the bone marrow of long term dialysis patients and can contribute to anemia as well.

Blood loss and red blood cell destruction also frequently contribute to the anemia in patients with renal failure. Platelets, which are small constituents of blood which aid in blood clotting, do not work normally in uremia. The defective blood clotting seen in uremia makes bleeding more common. Rapid bleeding—from an ulcer in the gastrointestinal tract, for example—causes a rapid decrease in the hematocrit and is a medical emergency. Very slow loss of blood can also cause anemia by depleting the body's stores of iron, which the bone marrow uses to produce blood cells.

Excessive destruction of red blood cells is also seen in advanced renal failure. Normally, red blood cells survive for about four months before being destroyed. This life span is reduced in renal failure, probably because of chemical effects of uremia and decreased flexibility of the red blood cells. This hemolysis is usually mild and a person with a normal bone marrow could easily compensate for it by increasing red blood cell production. However, in renal failure, the bone marrow's capacity to compensate is diminished.

What is the role of hemodialysis in the anemia of chronic renal failure? The effectiveness of dialysis in reversing any complication of uremia depends on the nature of that complication. Those disturbances which are due to accumulation of a uremic toxin may be reversible if that toxin is dialyzable and if the removal rate by dialysis outstrips its generation rate. Some improvement in red blood production is seen with initiation of dialysis, probably by decreasing the toxic effect of uremia on the marrow. Dialysis, however, does not replace the hormone producing functions of the kidney and therefore does not by itself correct the main cause of anemia, namely deficient production of erythropoietin. Dialysis does correct the bleeding tendency seen in uremia, but not to normal.

Dialysis itself may also contribute to the anemia. Iron deficiency can result from unavoidable dialyzer blood loss, clotted dialysis membranes, and frequent blood sampling. Hemolysis may occur if there are problems with the dialysate (temperature problems, contamination with aluminum, fluoride, copper, chlorine, or chloramine). Folate, a water soluble vitamin necessary for normal red blood cell production, is dialyzable. Generally, dialysis patients are given oral supplementation with folic acid in case their

normal diet does not supply them with sufficient folate to keep up with its loss through dialysis.

Most patients tolerate chronic anemia fairly well. In an otherwise healthy patient with chronic renal failure, a hematocrit of approximately 25% is typical. The presence of other medical problems, particularly heart and lung disease, can decrease a patient's ability to tolerate a lower blood count. Patients who have undergone bilateral kidney removal (nephrectomies) often have hematocrits which are significantly lower, probably because they cannot make any erythropoietin at all. Patients whose kidney failure is a result of polycystic kidney disease generally do not have anemia.

The treatment of the anemia of chronic renal failure has changed dramatically in recent years. Until recently, the principal treatments were transfusion of red blood cells and administration of the hormone testosterone. Although transfusions will rapidly correct a low blood count, repeated transfusions are associated with some problems, including iron overload, the development of certain antibodies, and the possibility of viral infections. Testosterone may stimulate red blood cell production by the bone marrow, but the effect is generally small, and its use is often associated with virilizing side effects

In 1983, the gene for erythropoietin was isolated, then cloned. Subsequently this led to the mass production of erythropoietin and finally to its use in renal failure patients in 1990 (see Chapter 20). It is administered either intravenously at dialysis or subcutaneously. In anemic patients with chronic renal failure, treatment with erythropoietin is now standard practice and has dramatically reduced the need for blood transfusions. The increase in hematocrit seen with patients treated with erythropoietin has generally resulted in improvement in exercise tolerance and overall sense of well-being. It is important to monitor the iron status of treated patients, as iron deficient patients will not respond appropriately to administration of erythropoietin. The use of erythropoietin is constrained by the extremely high cost of this hormone and the reimbursement policies of insurance companies and Medicare.

To summarize, anemia is a universal complication of chronic renal failure. It has multiple causes, the most important of which is decreased production of erythropoietin by the kidney. The availability of the recombinant form of this hormone is revolutionizing treatment of this form of anemia.

Chapter 20

EPO: TREATING ANEMIA IN CHRONIC RENAL FAILURE

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What is erythropoietin? Why is it important?

Erythropoietin (EPO) is a hormone that prevents anemia (low blood count) by helping you make red blood cells. Anemia causes fatigue and low energy levels. It occurs when there are not enough red blood cells to carry oxygen from the lungs to supply all the body's needs.

Why do patients with kidney disease develop anemia?

Almost all the body's EPO is made in the kidneys. *Kidney disease may damage the cells that make EPO, leading to anemia.* Before EPO was synthesized and made available for injection, many patients with kidney disease had to receive blood transfusions to treat anemia. Now that EPO can be made, people with kidney disease can be given this form of EPO to correct anemia. The injectable form is called recombinant human erythropoietin and is almost identical to what a normal kidney makes.

How is EPO used? Who will give it to me?

EPO is *given by injection*. It may be injected directly into a vein (intravenous) during dialysis or under the skin (subcutaneous). It may be given by a dialysis nurse or by the patients themselves.

How long will I need EPO?

Probably for *as long as you are on dialysis*. EPO should be given regularly to maintain your red blood cell count (hematocrit) at a stable level, usually between 30 and 36 percent. If you have a successful kidney transplant, your new kidney will produce EPO and you will no longer need recombinant human erythropoietin.

Where can I get EPO?

Most patients get EPO at their dialysis unit. Starting July 1, 1991, home dialysis patients became able to get EPO from a *dialysis center*, *physician's office*, or through their *dialysis supplier*.

How much does EPO cost?

The cost *will depend on how much EPO you need*. It is estimated that the annual cost of EPO will be about \$5,000.

How can I afford EPO?

For the dialysis patient, *Medicare will pay for part of the cost* of EPO. You should also check with your insurance company to find out if they will pay for the rest of the cost. The social worker at your dialysis unit may know other resources that can help you.

Do all kidney patients need EPO?

No. EPO is needed only by those patients whose *hematocrit is less than 30 percent*.

What is the lowest dose that will work?

The dose of EPO needed *varies among individual patients*. Most patients require between 25 to 125 Units of EPO per kilogram of body weight, three times a week. (A kilogram is 2.2 lbs.) In order for EPO to be effective, the body must have enough iron. Many dialysis patients need to take iron supplements once EPO therapy is started.

Will I always take the same dose of EPO?

The initial dose needed to increase your hematocrit can be reduced when the blood count is stable. Sometimes, *the dose will need to be adjusted* again, depending on your response to the treatment. An increase in the dose may become necessary if you develop an infection or other complication.

If I am receiving peritoneal dialysis, can I still take EPO?

Yes. Peritoneal dialysis patients can receive EPO. Usually, it is given by subcutaneous injections.

How long before I notice a difference in how I feel?

Often, there is a period of several weeks before your hematocrit begins to rise. Most patients will begin to feel better when the hematocrit has risen by five or more points. This *may take from one to two months*. Some patients may be started on EPO before their hematocrit falls below 29 or 30 percent. In this case, EPO will prevent the feeling of fatigue and low energy levels caused by anemia.

Does treatment with EPO have side effects?

Rarely, patients develop *flu-like symptoms*, such as muscular aches, from 60 to 90 minutes after the intravenous injection. These symptoms usually are not serious and generally go away with continued use of EPO. The increase in hematocrit can cause an *increase in blood pressure*. This occurs in about a third of patients as the hematocrit level rises toward 30 or above. In general, increases in blood pressure can be handled by the doctor. Be sure to take your blood pressure medication as your doctor tells you.

Can I do anything to prevent my blood pressure from increasing on EPO therapy?

Your blood pressure must be checked at each dialysis treatment. You can help prevent a rise by *watching your salt and water intake* and by *taking all your medications*. If your blood pressure does go up on EPO therapy, your doctor may increase your blood pressure medication or order a new blood pressure medication. If you are overweight, losing weight can help reduce high blood pressure.

Why must my iron count be checked all the time?

If your body does not have enough iron, EPO is wasted. If your iron count shows that you need extra iron, it can be given to you by injection or pills.

I hear some patients clot their fistulas. Will this happen to me?

This is *not likely to occur*. Studies have not shown an increase in fistula clotting related to EPO therapy or to a higher hematocrit.

I have had a seizure in the past. Am I likely to have more seizures from EPO?

No. *EPO does not cause an increase in seizures.* If you have had seizures, you should be taking anti-seizure medication. If high blood pressure develops suddenly, it could lead to a seizure. So, the best way to prevent a seizure is to make sure that your blood pressure stays under control.

I am on a special diet to control my potassium level. Can I take EPO and still control my potassium?

Yes. However, you may become more hungry when your hematocrit goes up from EPO therapy. If you eat more foods containing potassium, you may have problems with high potassium. Your doctor may recommend the following measures to prevent your potassium level from becoming too high: a special diet low in potassium; increasing the hours of dialysis; changing the dialysis bath; or sometimes, the use of a special medication to remove potassium from the body.

What happens if my hematocrit gets too high?

A hematocrit above 50 percent *may cause clotting of blood* in the arteries and veins and other complications such as strokes. That is why your hematocrit should be checked on a regular basis.

Do I need to take EPO if I am hospitalized?

Continuing your EPO injection schedule while you are in the hospital *may prevent a further decrease in your hematocrit* as a result of hospitalization.

How can I take EPO if I go on a trip?

The social worker at your dialysis unit may be able to help you arrange to *receive your EPO at a dialysis unit you visit* during your trip. It also may be possible for you to *arrange to take the EPO with you (in a cooler)* and inject it yourself. However, you should check with the health care team at your dialysis unit about this.

If I feel better, will I need to dialyze as long?

Absolutely. In fact, *some patients need to dialyze for more hours* to clear their bodies of the wastes from increased food as their appetites improve.

Will EPO cure or improve my kidney failure?

No. EPO is not a substitute for dialysis or for other therapy. However, it should make you feel much better.

Will I ever need blood transfusions again?

EPO should eliminate the need for blood transfusions unless you have a severe loss of blood such as that caused by bleeding ulcers or some surgical procedures. In these situations, a transfusion may be necessary since EPO acts slowly to increase the hematocrit.

Are there other uses for EPO besides kidney failure?

Yes. EPO seems to work in some bone marrow diseases. EPO also has been used to increase the number of units of blood for patients who are saving their own blood for elective surgery. However, its main use seems to be for patients with kidney failure.

Does EPO need to be refrigerated?

Yes. However, a temporary loss of electricity will not cause EPO to “go bad.” Please do not let EPO freeze or get too warm. If you inject EPO yourself, always inspect your EPO vial before using it for your injection. Never use any EPO that is cloudy or discolored or has particles in it. If you have any questions about this, ask your doctor or nurse.

Do any other medications interfere with EPO, and does EPO interfere with any medications?

In general, EPO *does not interfere with any other medications*. At the present time, other medications do not seem to affect the action of EPO.

What else do I need to know?

You will feel better with EPO treatment. You may become interested in an exercise program or returning to paid employment. For more information on these topics, see National Kidney Foundation brochures: *Fitness After Kidney Failure: Building Strength Through Exercise* and *Working With Kidney Disease: Rehabilitation and Employment*. If you are still employed, you may find that EPO therapy will enable you to keep working.

Rehabilitation and adjustment to kidney failure require hard work, determination and cooperation with your doctor. However, the continuous effort you make to adjust can be well worth the effort.

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β_2 -MICROGLOBULIN AMYLOIDOSIS

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β_2 -microglobulin amyloidosis is a disabling disease that affects patients with long-term chronic renal failure but not individuals with normal renal function. The term *amyloid* refers to a specific conformation of proteins that deposits in tissues of various organs. There are many different types of amyloid, each defined by its unique subunit protein. The form of amyloid depositing in patients with long-term chronic renal failure contains the subunit protein β_2 -*microglobulin amyloid* (abbreviated β_2 M).

β_2 M is a small protein that is present on the surface of all cells that contain nuclei. Because of its molecular weight of 11,800 daltons, it has been classified as a “middle molecule.” As such, it is not cleared by certain dialysis membranes, such as cuprophane membranes, while it is cleared to some extent by more permeable membranes, such as polysulfone and polyacrylonitrile, that are found in most modern dialyzers. β_2 M is normally broken down and excreted by the functioning kidney. Thus, β_2 M levels increase in patients with chronic renal failure.

β_2 M amyloid deposits preferentially in bone, joint cartilage, synovium (joint lining), muscle, and ligaments. Patients with β_2 M amyloidosis commonly display signs and symptoms of joint pain and swelling. Deposits of β_2 M amyloid in internal organs usually do not cause symptoms, although they may be present. Deposits of β_2 M amyloid in the gastrointestinal tract may lead to bleeding from blood vessels, the walls of which have been weakened by amyloid deposits, or to decreased absorption of nutrients from the intestine, with resulting diarrhea and weight loss.

β_2 M amyloidosis tends to occur more often in older patients receiving long-term hemodialysis for the treatment of chronic renal failure. The condition appears to manifest itself earlier, the older that the patient is. For example, an 84 year-old patient may develop

signs and symptoms of λ_2 M amyloidosis 3 to 4 years after beginning hemodialysis, whereas a 30 year old patient may not demonstrate signs of symptoms of λ_2 M amyloidosis, even after 20 years of dialysis treatment.

Patients with λ_2 M amyloidosis often have a characteristic triad of shoulder pain, carpal tunnel syndrome, and flexor tendon deposits in the hands on presentation. Shoulder pain is often exacerbated by dialysis treatments and may be accompanied by limitation of shoulder motion. The shoulder may appear enlarged with a “shoulder pad sign,” such that the shoulder resembles that of a well-trained athlete.

Carpal tunnel syndrome occurs when the median nerve is compressed as it passes through the wrist. Symptoms of this condition include numbness and tingling, predominantly in the thumb, index, and middle fingers, and pain in the fingertips. The symptoms of carpal tunnel syndrome are also often more prominent during hemodialysis treatments, resolving one to two hours after the treatment has concluded. As the condition progresses, the symptoms may become more constant.

Deposits of λ_2 M amyloid on the palm of the hand may lead to contractures of the fingers, preventing full extension of the fingers. The amyloid on the palm may appear as a small mound of tissue. The amyloid deposits cause the flexor tendons of the fingers to adhere to one another, thus preventing full mobility of the fingers.

λ_2 M amyloid also deposits within bone, usually in the wrist and at the ends of long bones, near the joints. These deposits appear as cysts on X-rays. When cysts enlarge, they may compromise the structural integrity of bone and predispose to fracture of bone. The hip is the most common site of fracture occurring through amyloid deposits within bone.

λ_2 M amyloid may also deposit within the vertebrae of the spine and in the disks between the vertebrae. These deposits usually do not cause symptoms or neurologic problems. However, neck pain

(and rarely weakness or paralysis), may result from λ_2 M amyloid deposits involving the spine.

λ_2 M amyloidosis can be diagnosed by a physician who is familiar with this condition and can recognize its clinical appearance. X-rays may confirm the diagnosis, when characteristic findings are present. Diagnostic ultrasound may identify amyloid deposits within the shoulder. Ultrasound is painless, takes very little time for the examination, and exposes the patient to no radiation. Computerized tomography (CT) and magnetic resonance imaging (MRI) may also be useful in defining the presence of λ_2 M amyloid deposits.

Presently, no treatment is available to reverse λ_2 M amyloid deposition. Medical therapy of patients with λ_2 M amyloidosis is symptomatic. Surgery may be necessary for patients with large deposits of λ_2 M amyloid. Successful renal transplantation can halt the progression of some manifestations of λ_2 M amyloidosis.

Physical and occupational therapy may lessen the disability associated with manifestations of λ_2 M amyloidosis in the muscles, bones, and joints. Wrist splints for carpal tunnel syndrome and adaptive devices to assist with activities of daily living are useful. Heat and range of motion exercises for the shoulder increase mobility. Immobilization of the neck in a cervical collar may be useful when amyloid deposits compromise the integrity of the cervical spine. Injection of corticosteroids into the shoulder may greatly decrease the pain associated with deposits of λ_2 M amyloid in the shoulder and permit increased shoulder function.

Nonsteroidal anti-inflammatory drugs are useful in treating symptoms of pain involving multiple joints. However, the increased risk of bleeding in patients undergoing dialysis dictates that caution should be observed in the prescription of these medications.

Surgical release of the carpal tunnel is indicated for patients who have symptoms of carpal tunnel syndrome unresponsive to conservative management; however, symptoms may recur after surgery has been performed, requiring repeat surgery. Carpal tunnel

release may be performed using an arthroscope, and arthroscopic surgery of the shoulder may also provide symptomatic relief of shoulder pain related to deposits of λ_2 M amyloid.

Pathologic (spontaneous) fractures through λ_2 M amyloid deposits in the hip should be treated by total hip arthroplasty (hip replacement) because of the compromised structural integrity of the involved bone. When bone cysts are present in the femoral neck of the hip, prophylactic hip replacement or curettage (scraping out the amyloid from the bone) and bone grafting may be performed.

It is not clear that dialysis with membranes that are more permeable to λ_2 M will prevent the development of λ_2 M amyloidosis. Patients with λ_2 M amyloidosis who undergo successful renal transplantation exhibit a marked reduction in joint pain and stiffness following transplantation. Symptoms usually resolve over a period of several days to six months. Joint pain recurs rapidly in patients who resume hemodialysis because of graft rejection. However, λ_2 M amyloidosis does not resolve completely following renal transplantation. Early renal transplantation in appropriate candidates, before significant deposition of λ_2 M amyloid has occurred, may be the most effective preventative measure that is presently available for this condition without a definitive cure.

Laboratory studies have shown that λ_2 M is modified with what are called *advanced glycation end products (AGE)* in λ_2 M amyloid deposits. AGE-modification of proteins is involved in processes such as the development of complications of diabetes mellitus and of Alzheimer's disease. Aminoguanidine (pimagedine) is a medication that is presently undergoing clinical trials in patients with diabetes mellitus to see if it may delay or prevent the development of diabetic kidney failure. If this medication is successful in treating diabetic patients, further study of this medication may be appropriate to determine whether it may delay or prevent the development of λ_2 M amyloidosis.