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.
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
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.
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.
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.
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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.
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
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.