Mount Sinai Dialysis Admission Booklet

- Welcome To Mount Sinai Kidney Center
- Welcome Letters
- Mount Sinai Hospital Patient Bill Of Rights
- Dialysis Patients Bill Of Rights and Responsibilities
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- Patient Emergency Preparedness (At Home and In Center)
- Mount Sinai Hospital Resources For ESRD Patients
- National Dialysis Resources/Organizations/Agencies
- International Dialysis Resources And Websites

- Forms Attached (Enclosure)

Educational Material On All Dialysis Modality Including But Not Limited To Home Hemodialysis, Hemodialysis And Peritoneal Dialysis
Welcome to the Mount Sinai Kidney Center

The staff at our units are committed to providing quality dialysis treatment with a team approach. We maintain a high degree of collaboration and use each other’s experience to optimize your healthcare. You are the most important member of the team. Therefore, your active participation makes you a key factor in attaining your treatment goals.

Each patient is cared for by doctors, nurses, social workers, and dietitians. These staff members see patients on a regular basis and are also available for further assistance by telephone.

My Doctor is: ______________________________, M.D.

My Clinical Coordinator is: ____________________________, R.N.

My Primary Nurse is: ____________________________, R.N.

My Social Worker is: ________________________________, LCSW

My Dietitian is: ________________________________, RD

My Vascular Access Liaison is: _________________________, MPH

My Patient Representative: ___________________________
Dear Patient

Welcome to Mount Sinai Hospital’s Peritoneal Dialysis center. We are glad that you have chosen us to care for you. Our program aims to give you the best of care and to help you in doing your dialysis at home.

To support you in dialyzing at home we will work with Baxter, a medical vendor, to provide you with the necessary supplies, a Homechoice Pro Cycler machine and other materials. For your convenience all your materials will be delivered to your home.

Our PD staff will work with you as a team. Mutual cooperation and understanding is necessary.

We would ask that you:

1. **Maintain Monthly Clinic Visits.** It is important that you come to the clinic on a monthly basis to make sure you are doing your dialysis correctly at home. At these appointments you will be examined by Dr. Uribarri and the PD nurses. Blood will be drawn monthly you will be given the opportunity to express any concerns or issues.

2. **Call in your monthly orders in a timely fashion.** It is your responsibility to check your supplies and put in your monthly orders 2 weeks before your delivery date. If you do not place an order and run out of supplies, rush orders will cost $75 dollars.

3. **Someone must be present to receive your home delivery.** Home delivery will be scheduled at your convenience. If you know that nobody is going to be home on the day and time agreed to, you must call Baxter to reschedule the delivery.

We look forward to seeing you at your monthly visits. If you have any questions or trouble we ask that you please call the unit 212 241-5537.
Patients' Bill of Rights

As a patient in a hospital in New York State,

you have the right, consistent with law, to :

(1) Understand and use these rights. If for any reason you do not understand or you need help, the hospital MUST provide assistance, including an interpreter.

(2) Receive treatment without discrimination as to race, color, religion, sex, national origin, disability, sexual orientation, source of payment, or age.

(3) Receive considerate and respectful care in a clean and safe environment free of unnecessary restraints.

(4) Receive emergency care if you need it.

(5) Be informed of the name and position of the doctor who will be in charge of your care in the hospital.

(6) Know the names, positions and functions of any hospital staff involved in your care and refuse their treatment, examination or observation.

(7) A no smoking room.

(8) Receive complete information about your diagnosis, treatment and prognosis.

(9) Receive all the information that you need to give informed consent for any proposed procedure or treatment. This information shall include the possible risks and benefits of the procedure or treatment.

(10) Receive all the information you need to give informed consent for an order not to resuscitate. You also have the right to designate an individual to give this consent for you if you are too ill to do so. If you would like additional information, please ask for a copy of the pamphlet “Deciding About Health Care — A Guide for Patients and Families.”

(11) Refuse treatment and be told what effect this may have on your health.

(12) Refuse to take part in research. In deciding whether or not to participate, you have the right to a full explanation.

(13) Privacy while in the hospital and confidentiality of all information and records regarding your care.
(14) Participate in all decisions about your treatment and discharge from the hospital. The hospital must provide you with a written discharge plan and written description of how you can appeal your discharge.

(15) Review your medical record without charge. Obtain a copy of your medical record for which the hospital can charge a reasonable fee. You cannot be denied a copy solely because you cannot afford to pay.

(16) Receive an itemized bill and explanation of all charges.

(17) Complain without fear of reprisals about the care and services you are receiving and to have the hospital respond to you and if you request it, a written response. If you are not satisfied with the hospital’s response, you can complain to the New York State Health Department. The hospital must provide you with the State Health Department telephone number.

(18) Authorize those family members and other adults who will be given priority to visit consistent with your ability to receive visitors.

(19) Make known your wishes in regard to anatomical gifts. You may document your wishes in your health care proxy or on a donor card, available from the hospital.
Dialysis Patients' Bill of Rights and Responsibilities
PATIENTS’ Rights
- Quality Care
- Information
- Individual Treatment
- Privacy and Confidentiality
- Services Without Discrimination
- Treatment Options
- Kidney Transplantation
- Home Care
- Self-Care Treatment
- Emergency Care
- Dietary Counseling
- Social Work Services
- Facility Management
- Formal Complaint Process
- Refusal and Advance Directives
- Medical Consultation
- Research Programs
- Treatment Costs

PATIENTS’ Responsibilities
- Be Informed
- Plan and Follow a Treatment Program
- Be on Time
- Follow Facility Policies
- Be Considerate
- Fulfill Financial Obligations
Your Responsibilities as a Patient

**Be on Time** - You must be on time for your treatments. Please call if you will be late. If you are late this affects your fellow patients.

**Keep to the Treatment Ordered By Your Doctor** - For your health it is important that you come to dialysis every time you have a treatment scheduled. You may get sick if you miss an appointment. Your doctor orders the length of time for your treatment.

**Eating and Drinking** - This is not permitted once you are seated in the dialysis chair. Please eat or drink only in the patient waiting area.

**Visitors** - Visitors are not usually permitted in the dialysis unit. If there is a special reason the nurse in charge will decide if this is allowable.

**Holiday/Vacations** - Traveling is possible and encouraged if proper arrangements have been made. You must let your social worker know at least one month in advance that you are planning a vacation.

**Making a Complaint** - It is our goal to provide the best quality care for you. If you have a problem with your care please discuss your concerns with any staff member or call the numbers listed in this packet or posted in the center.

**In Case of Fire** - In the event of fire or disaster, the staff is trained to take care of you and assist you safely. Remain calm. Your dialysis treatment will be discontinued and you will be escorted out of the unit.

**Transportation** - If you are eligible to receive transportation assistance it is your ongoing responsibility to arrange pick-up time and to be ready as scheduled.

**Respect for Fellow Patients and Staff** - Disruptive behavior in the unit including offensive language, shouting, or physical fighting will not be tolerated.

**Financial Payment** - You are responsible for making sure your insurance stays active and in obtaining any authorizations needed from your primary care physician. Your social worker in the unit is available to advise with applying for primary and secondary insurance coverage. If you do not have complete insurance coverage you may be billed for some of your care.

**Please provide the dialysis unit with your correct and up-to-date insurance information. In addition, please notify us immediately of any changes in your insurance coverage.**
Mount Sinai recognizes that there are times when patients in need of care will have difficulty paying for the services provided. The Mount Sinai Financial Assistance Policy provides discounts to qualifying individuals based on your income. In addition, we can help you apply for free or low-cost insurance if you qualify. Just contact:

- Financial Counseling Department at
  - Main office: (212) 241 4851 located at Annenberg B2 Level room B-62 or
  - B1 Office: (212) 241 5676 located on the B1 level in the Annenberg building Room 220 or,
  - CAM Office: (212) 824-7274

- REAP (212) 423 2800 located at 1450 Madison Ave or,
- Customer Services at (212) 731 3100 for free, confidential assistance.

Who qualifies for a discount?

Financial Assistance is available for patients with limited incomes and no health insurance. Everyone in New York State who needs emergency services can receive care and get a discount if they meet the income limits. Everyone who lives in the City of New York can get a discount on non-emergency, medically necessary services at Mount Sinai if they meet the income limits. You cannot be denied medically necessary care because you need financial assistance. You may apply for a discount regardless of immigration status.

What are the income limits?

The amount of the discount varies based on your income and the size of your family. If you have no health insurance, these are the income limits:

<table>
<thead>
<tr>
<th>Family size</th>
<th>Annual Family Income</th>
<th>Monthly Family Income</th>
<th>Weekly Family Income</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Up to $32,671</td>
<td>Up to $2,723</td>
<td>Up to $628</td>
</tr>
<tr>
<td>2</td>
<td>Up to $44,131</td>
<td>Up to $3,678</td>
<td>Up to $849</td>
</tr>
<tr>
<td>3</td>
<td>Up to $55,591</td>
<td>Up to $4,633</td>
<td>Up to $1069</td>
</tr>
<tr>
<td>4</td>
<td>Up to $67,051</td>
<td>Up to $5,588</td>
<td>Up to $1,289</td>
</tr>
<tr>
<td>5</td>
<td>Up to $78,511</td>
<td>Up to $6,543</td>
<td>Up to $1,510</td>
</tr>
<tr>
<td>6</td>
<td>Up to $89,971</td>
<td>Up to $7,498</td>
<td>Up to $1,730</td>
</tr>
</tbody>
</table>

* Based on the 2011 Federal Poverty Guidelines

What if I do not meet the income limits?

If you cannot pay your bill, Mount Sinai offers a payment plan to those patients that meet the income limits. The amount you pay depends on the amount of your income.

Can someone explain the discount? Can someone help me apply?
Yes, free, confidential help is available. Call any one of the numbers listed above. If you do not speak English, someone will help you in your own language. The Staff can tell you if you qualify for free or low-cost insurance, such as Medicaid, Child Health Plus and Family Health Plus. If the Staff finds that you don’t qualify for low-cost insurance, they will help you apply for a discount. The Staff will help you fill out all the forms and tell you what documents you need to bring.

What do I need to apply for a discount?

Documentation requirements vary depending on your situation. Normally an application would have to prove who they are, where they live (utility bills, rent receipt) and how they support themselves (pay stubs, checks etc).

If you cannot provide any of these, you may still be able to apply for financial assistance.

What services are covered?

All medically necessary services provided by Mount Sinai are covered by the discount. This includes outpatient services, emergency care, and inpatient admissions. Charges from private doctors who provide services in the hospital may not be covered. You should talk to private doctors to see if they offer a discount or payment plan.

How much do I have to pay?

The amount for an outpatient service or the emergency room starts from $0 for children and pregnant women, depending on your income. The amount for outpatient service or the emergency room starts from $15 for adults, depending on your income. Our Financial Counselor will give you the details about your specific discount(s) once your application is processed.

How do I get the discount?

You have to fill out the application form. As soon as we have proof of your income, we can process your application for a discount according to your income level. You can apply for a discount before you have an appointment, when you come to the hospital to get care, or when the bill comes in the mail. Send the completed form to your place of application or bring it to any one of the locations above. You have up to 90 days after receiving services to submit the application.

How will I know if I was approved for the discount?

Mount Sinai will send you a letter within 30 days after completion and submission of documentation, telling you if you have been approved and the level of discount received.

What if I receive a bill while I’m waiting to hear if I can get a discount?

You cannot be required to pay a hospital bill while your application for a discount is being considered. If your application is turned down, the hospital must tell you why in writing and must provide you with a way to appeal this decision to a higher level within the hospital.

What if I have a problem I cannot resolve with the hospital?

You may call the New York State Department of Health complaint hotline at 1-800-804-5447.
MOUNT SINAI KIDNEY CENTER

We strive to provide excellence in patient care. It is the policy of the Mount Sinai Kidney Center to encourage patients to bring complaints and/or recommendations to any member of the Center without restraint and without fear of recrimination or reprisal.

If you have any Concerns, Questions or Complaints about the care you receive, a complaint form will be made available to you at the Front Desk. The form should be given to the Program Coordinator. If you need assistance, any dialysis staff member can assist to describe your complaint on the form. Each issue will be addressed.

If the grievance cannot be resolved, it may be brought before the facility’s GRIEVANCE COMMITTEE. Formal minutes are taken at these meetings and are available to all participants. You and/or your representative may attend the meeting.

Our Grievance Committee is composed of:

Medical Director: Dr. Brian Radbill
Administrative Director: Edward Gelfand
Associate Director, Nursing: Yvette Cummings, RN
Social Worker: Yvette Braunstein, LCSW

A formal letter of issue resolution will be sent to you by the Mount Sinai Hospital Patient Service Center within 30 days of the meeting.

If your issue is not resolved in a timely manner or you are not satisfied with the resolution, you have the right to bring the matter to the attention of the following agencies either by writing a letter or calling as follows:

Mount Sinai Hospital Patient Services Center
One Gustave L. Levy Place, Box 1515
New York, NY 10029
Guggenheim Pavilion, 1st Floor
Tel: 1-212-659-8990

Other agencies:

IPRO-ESRD Network of New York
1979 Marcus Avenue
Lake Success, NY 11042-1002
Tel: 1-800-804-5447
E-mail: info@nw2.esrd.net

Department of Health
Centralized Hospital Intake Department
Hedley park place
433 River Street, 6th floor
Troy, NY 12180-229
Tel: 1-800-804-5447
E-mail: hospinfo@health.state.ny.us

The Joint Commission
Office Quality of Monitoring
One Renaissance Blvd
Oakbrook Terrance IL 60181
Tel: 1-800-949-6610
E-mail: complaint@jointcommission.org
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- Medical Director: Dr. Vijay Lapsia
- Administrative Director: Edward Gelfand
- Associate Director, Nursing: Yvette Cummings, RN
- Clinical Coordinator: Tonya Peartree, RN
- Social Worker: Lynette Ortiz, LCSW
  Dana Kane, LCSW

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Lake Success, NY 11042-1002
Tel: 1-800-804-5447
E-mail: info@nw2.esrd.net

The Joint Commission
Office Quality of Monitoring
One Renaissance Blvd
Oakbrook Terrance IL 60181
Tel: 1-800-949-6610
E-mail: complaint@jointcommission.org

Department of Health
Centralized Hospital Intake Department
Hedley park place
433 River Street, 6th floor
Troy, NY 12180-229
Tel: 1-800-804-5447
E-mail: hospinfo@health.state.ny.us
Welcome to the Mount Sinai Kidney Center
We strive to provide a standard of excellence in patient care.

If you have any Concerns, Questions or Complaints about the care you receive in our units:

For B1Hemodialysis, Peritoneal Dialysis and 94th Street
Please contact:

Associate Director, Nursing: 212-241-8084
Clinical Coordinator: 212-987-7397
Administrator Director: 212-241-3715

Or call any of the Following Numbers:

Mount Sinai Hospital Patient Service Center
212-659-8990

End Stage Renal Disease Network
1-800-238-ESRD (3773)

For patient complaints please call:
The Department of Health
1-800-804-5447

The Joint Commission
Office Quality of Monitoring
1-800-944-6610
People You Will Meet

Nephrologist
The Nephrologist is a physician with advanced training who specializes in the care of individuals with kidney problems. Your nephrologist has the ultimate responsibility for your dialysis treatments, writing your medical and dietary orders and coordinating care with other specialists.

Associate Director / Nurse Manager
The nurse manager supervises the nurses, technicians and administrative staff and oversees clinical operations. The nurse manager is available to work with you and your primary nurse to coordinate your plan of care.

The nurse manager can help you with any questions related to your treatment, dialysis schedule and other concerns you might have about the dialysis unit.

Primary Nurse
You will be assigned a primary nurse within the first two weeks. The primary nurse will assist with the following:

- Help you and your family and significant other learn about kidney disease, the dialysis regimen, and other treatment options.
- Work with your doctor, nutritionist, and social worker to formulate your plan of care.
- Implement the care plan; evaluate effectiveness of interventions and revise as needed.
- Review home medications with you every month.
- Review blood test results with you every month as needed.
- Help you with adhering to your treatment plan

Vascular Access Liaison
The Vascular Access Liaison is a member of your healthcare team. In order to receive dialysis you must have an access created. The Vascular Access liaison is specially trained to talk with you about your options such as getting an Arterial Venous Fistula, or Arterial Venous Graft.

The Vascular Access Liaison will:

- Counsel you on the different ways you can receive dialysis.
- Provide education and review information to clarify the type of access that is best for you.
- Help you identify other Mount Sinai services, make referrals, and schedule appointments for follow up for vascular access.
- Work closely with you and your healthcare team to make sure you get the best treatment and care possible.
- Continue to work with you for ongoing progress or changes.
**Dietitian**
Hemodialysis is a lifestyle change which includes changing what you eat. You will be assigned a dietitian who will give you the tools needed to follow a renal diet. The dietitian will:

- Review your monthly lab reports with you and counsel you on your food intake.
- Work with your physician behind the scenes to ensure you are receiving adequate dialysis and appropriate bone care.
- Assess the need for you to have nutrition supplements and consults with your doctor to choose the most medically appropriate one for you.
- Meet with your family, friend or home aid to review the renal diet if you are not shopping and cooking for yourself.

**Social Worker**
As a dialysis patient in our program, you can expect to speak regularly to your social worker. The renal social workers are specially trained to help patients and their families cope with chronic kidney disease. Some of the areas in which the social workers can help include:

- Identifying certain feelings that you may be experiencing including; anxiety, fear, sadness and depression due to the constraints of dialysis and abrupt lifestyle changes.
- Helping you to understand your feelings in order to enhance your coping with chronic hemodialysis.
- Providing supportive counseling to you individually or with a family member to address the following; sadness and depression, dealing with stress, adjusting to changes, living with uncertainty; and learning and understanding the dialysis treatment
- Meeting with team members to optimize your care
- Providing you with the resources or directing you to appropriate community resources that will help you to adjust to the various aspects associated with your illness. Some of the areas may include: adequate insurance coverage for dialysis and medications, home care safety and medical equipment, lack of transportation arrangements to and from dialysis, changes in employment status or income, community referrals i.e. (mental health, National Kidney Foundation, REAP and Social Security)

**Dialysis Technician/Patient Care Technician**
The dialysis technician is an individual trained by the dialysis facility to service and maintain machinery and/or provide direct patient care under supervision of a nephrology nurse and nephrologists.

**Your Patient Representative**
There are patient representatives from the Mount Sinai Dialysis Unit and the End Stage Renal Disease Network here to assist with your concerns. The names and numbers of the representatives are posted in the waiting area. Refer to Grievance Committee list.
IMPORTANT INFORMATION YOU SHOULD KNOW

Medications
Medications are reviewed with you by your doctor and nurse. Please ask them any questions you may have. Please let your nurse or doctor know of any problems you have taking your medications.

Please have your medications refilled one week before you run out.

Bring in any new medications that were ordered by any doctor other than your kidney doctor. It is important that we know about all medications you are taking.

You will be asked to bring in all prescription and over the counter medications once a month for review by your nurse.

Blood Work
Blood will be drawn monthly or more often if needed. The blood work results indicate whether or not you are following your diet and getting enough dialysis. Our dialysis team will discuss results with you each month. If there are any problems with your blood work, the nurse, doctor and/or dietitian will discuss with you ways to make it better.

Diagnostic Testing
Chest X-rays, bone scans, EKG’s eye exams or other tests may be ordered by the kidney doctors. The staff will help you to schedule appointments and explain the purpose of the tests. The results will be discussed with you. Please ask any questions you may have.

Food and Fluids
If you have diabetes please eat prior to your treatment.

Seating
Seating is determined by the Clinical Nurse Manager. Every effort will be made to dialyze you in the same seat and section of the Dialysis Center each treatment.
Hemodialysis ..... diet guidelines for the beginner.

Hemodialysis involves changes in lifestyles, including your diet. Below is an outline of the diet you may need to follow, even if you are only on hemodialysis temporarily. Please check with your healthcare provider which guidelines you need to follow now.

**Fluids** – limit intake to 1 liter *(approximately 32 fluid ounces)* daily. You may be permitted more fluids if you still have a significant urine output.

**Sodium** – you can have up to 2,000 milligrams daily. Following this restriction is important to regulate your blood pressure and control your thirst. Avoid using salt while cooking, and do not add it to your meals. Read food labels. Limit your intake of processed foods such as canned, cured and fast foods which are highest in sodium. Freshly prepared foods are lowest in sodium.

**Potassium** – you can have up to 2,000 milligrams daily. Following this restriction is important so that the potassium level in your blood does not become dangerously high. Many foods are high in potassium especially fruits and vegetables.

**Avoid:** bananas, broccoli, collard greens, melon, oranges, plantains, potatoes, spinach and tomatoes.

**Acceptable:** apples, carrots, cucumbers, grapes, green beans, pears, and pineapple

**Protein** – your body needs more protein when you begin hemodialysis compared to when you weren’t on dialysis. Before you started dialysis you may have been told to reduce your protein intake. Now, it’s OK to eat lots of protein. So, enjoy plenty of chicken, fish, turkey, lean pork and lean red meat. You can have up to 3 whole eggs a week and unlimited egg whites. However, you may need to limit milk and milk products. *(see below)*

**Phosphorous** – Patients with renal failure often have a high phosphorous level in the blood. When this occurs, a phosphate binder will be prescribed. This is generally calcium carbonate, or a pill called PhosLo®. It is important that you take your phosphate binder with your meals.

Limiting your intake of high phosphorus foods is helpful too. It is best to limit your intake of milk and milk products *(such as cheese and yogurt)*, because they are extremely high in phosphorus. Other foods that should be limited include legumes *(such as black beans and pigeon peas)* and most nuts.

Be sure to speak with the nutritionist at the outpatient facility where you will be dialyzed. Don’t be shy. Ask all the questions you want; the more you understand about your diet, the better you will be able to take care of yourself.
Shortened Treatment Policy

If a patient asks a staff member to shorten their dialysis treatment time because they are in pain or are feeling too sick to continue their prescribed dialysis treatment, treatment will be stopped and a doctor will be notified.

If a patient asks a staff member to shorten their dialysis treatment time because they simply refuse to stay for their entire treatment, treatment will be stopped and the patient will be asked to sign a “Shortened Treatment form”.

If a patient arrives late for their treatment and the staff is unable to provide full treatment because there is not enough time left on the shift, the dialysis staff may cut the treatment time as follows:

- If patient is late because of a transportation issue that is no fault of their own, treatment will be cut short by a maximum of 30 minutes as needed to best accommodate patients on later shifts

- If a patient is late because they simply did not arrive in a timely fashion, treatment will be cut short by a maximum of 2 hours as needed to best accommodate patients on later shifts

If there is any concern about a patient getting adequate dialysis, a physician will be contacted and arrangements will be made to make sure every patient gets the treatment they need. This may include sending a patient to the Emergency Department or rescheduling a patient for another day or time.

If you have any questions about this policy, please contact your primary nurse or call (212) 241-4060 and I will return your call.
Travel Information for Dialysis Patients

We encourage patients to travel whenever possible. However there are many arrangements to be made and advance notice of 4-6 weeks is needed.

Once you have decided where you would like to travel, you can obtain a list of area units from the social worker. **It is the patient’s responsibility to locate a center with an available slot.**

Allow enough time to make your arrangements. The 4-6 week time period guarantee that the paperwork and any needed medical tests are completed before you travel. Many units routinely require results of an HIV blood test. These results often take two weeks to process.

Many units accept travel (also known as transient) patients on "First Come, First Serve" basis. The earlier you contact the unit, the better your chances of finding an open spot, especially during holiday periods.

Once you have found a unit, tell your social worker the name of the unit, telephone number and contact person. The social worker will then contact the unit and finalize arrangements.

**Emergency Travel** – Speak with your social worker if a situation arises where emergency travel is required and there is no time for confirm arrangements.

Please feel free to ask questions and to consult any of the websites listed in this packet.
In order to obtain authorization for transportation services, patients must meet medical and insurance eligibility for a particular type of transportation.

Once authorized, to schedule transportation to a medical appointment or dialysis treatment, please call 212.659.8900. You will be asked in English and Spanish to “Press 1” to talk to the transportation staff.

Please call the Transportation Office 2 days before your appointment to arrange the service.

**Hemodialysis patients:** When you first begin your dialysis regimen, your social worker will set up a “standing order”. A standing order includes the specific days and time of your dialysis schedule. If you are running late or need assistance, please call the number above.

**Peritoneal dialysis patients:** For the monthly clinic appointments or any other dialysis related visits, please call the above number to arrange your transportation.

**For all other medical appointments, it is your responsibility to call the transportation office and arrange your own transportation!**
The Telephone Number for the Transportation Office

(212) 659-8900

When you call (212) 659-8900, you will be asked in English and Spanish to “Press 1” to talk to the transportation staff.

Please call the Transportation Office 2 days before your appointment to arrange for service.

Thank you for your cooperation.
Mount Sinai Kidney Center
Patient Emergency Preparedness

When at home

It is important to be prepared for emergencies that come without warning, such as severe weather, disaster, loss of power or transportation in the city. Some emergency situations may make it impossible for you to get to your dialysis facility or give yourself dialysis. It is important to be prepared so you can feel better and stay healthier.

Helpful Tips in an Emergency:

1. Prepare an **Emergency Bag** that has all the following necessary items that you will need:

   - Have a fanny pack or backpack stocked with:
     - Emergency supplies
     - Some food
     - Medication
     - Batteries and flashlight

   - Medications- At least 2-4 pills of each medication that you are currently taking for 5 -7 days

   - Copy of your current medication list with dosage and frequency

   - Have a document with the following information:
     - Medical History
     - Insurance Information
     - Medical Information including Allergies
     - Your prescribed diet

   - Make sure to have your medical bracelet alert on.

   - Take your portable glucometer
Mount Sinai Kidney Center
Patient Emergency Preparedness

- Emergency address and phone numbers
  - Dialysis facility phone number
  - Nephrologist phone number
  - Your local pharmacy number
  - Other dialysis facilities in your area and Emergency Room

**Note:**

*Emergency bag should be reviewed and maintained every 6 months*

*Emergency bag should be kept by the door for easy access in the event of an emergency*

*Under no circumstances should any medical personnel unfamiliar with your dialysis status place or inject anything into your vascular access.*

Keep your medical information with you at all times. You may also want to give a copy to a caregiver or family member.

If you must go to a shelter, tell the person in charge about your special needs.

In addition to the list above, **Peritoneal Dialysis Patient** needs to have the following items in the Emergency Bag.

- 4 mini caps
- Foam or a small bottle of Purrell
- 2 masks
- 2 Clamps
Mount Sinai Kidney Center
Patient Emergency Preparedness

a. Know how to disconnect yourself quickly in the event of an emergency

✓ Wear mask
✓ Close Clamps
✓ Foam hands
✓ Disconnect

b. Always keep a week worth of Peritoneal supplies reserved for emergencies

c. Cycler patients:

- Be aware that your cycler has a 30 minute back-up battery. Your treatment can be interrupted and you should quickly disconnect yourself from the machine.

- Switch from CCPD to manual CAPD exchanges.

- Ask you Dialysis Social Worker to provide you with a letter notifying Con Edison of the life sustaining machine you use daily. This will alert Con Edison of your urgent need for power.

If unable to perform your dialysis treatments go to the nearest Emergency Room. If you are unable to come to the hospital right away maintain a low potassium diet with fluid restrictions.

If there is an emergency while receiving treatment, your dialysis nurse or dialysis technician will give you instruction to self disconnect. The following items will be provided: scissors, tape, clamps.

If no staff person is available to help you or give you directions, here is what to do. Remember, these directions are for emergency evacuation situations only.

**Your access needles should be left in place until you get to a safe place. Never cut your access needle lines.**

**How to Clamp and Disconnect**
- Clamp both access needle lines.
- Clamp both of the thicker blood lines. If the lines have pinch clamps, pinch all four clamps closed. Cut or unscrew the lines between the closed clamps. If you must cut your lines, cut ONLY the thicker blood lines.

NEVER, NEVER cut your access needle lines. NEVER cut the line between the clamp and your access.

- If you have CATHETER, your professional staff should assist you. Do not try to disconnect yourself.

**Care of Your Access in an Emergency:**

After you have been disconnected from your dialysis machine, go to the designated safe area. Wait for directions from the person in charge. This person could be a dialysis facility staff member, or emergency personnel such as a paramedic, policy officer, or firefighter. Do not remove your access needles until you have been checked by medical personnel, or until you are sure that you are in an area out of immediate danger.

Under no circumstances should any medical personnel unfamiliar with your dialysis status place or inject anything into your vascular access.

Mount Sinai Hospital Resources for ESRD Patients

B1 Dialysis Unit
Hemodialysis 212.241.8081
Peritoneal Dialysis 212.241.5537

Mount Sinai 94th St. Dialysis Center 212.987.7208

Mount Sinai Kidney Transplant Program 212.241.8086

Mount Sinai Transportation Department 212.659.8900

REAP 212.423.2800
(Resource, Advocacy, Entitlement Program)

Patient Financial Services 212.241.5676
# National Dialysis Resources/ Organization/ Agencies

These organizations can provide general information about kidney disease, finding hemodialysis units, benefits, and travel.

<table>
<thead>
<tr>
<th>Organization</th>
<th>Phone</th>
<th>Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>End Stage Renal Disease Network (ESRD)</td>
<td>800.238.3773</td>
<td></td>
</tr>
<tr>
<td>National Kidney Foundation (NKF)</td>
<td>800.622.9010</td>
<td><a href="http://www.kidney.org">www.kidney.org</a></td>
</tr>
<tr>
<td>American Association of Kidney Patients (AAKP)</td>
<td>800.749.2257</td>
<td><a href="http://www.aakp.org">www.aakp.org</a></td>
</tr>
<tr>
<td>American Kidney Fund (AKF)</td>
<td>800.638.8299</td>
<td><a href="http://www.akfinc.org">www.akfinc.org</a></td>
</tr>
<tr>
<td>Polycystic Kidney Research Foundation</td>
<td>800.753.2873</td>
<td><a href="http://www.pkdcure.org">www.pkdcure.org</a></td>
</tr>
<tr>
<td>RenalNet</td>
<td></td>
<td><a href="http://www.renalnet.org">www.renalnet.org</a></td>
</tr>
<tr>
<td>The Nephron Information Site</td>
<td></td>
<td><a href="http://www.nephron.com">www.nephron.com</a></td>
</tr>
<tr>
<td>The Whole World of Nephrology</td>
<td></td>
<td><a href="http://www.nephroworld.com">www.nephroworld.com</a></td>
</tr>
<tr>
<td>Social Security Administration</td>
<td>800.772.1213</td>
<td><a href="http://www.ssa.gov">www.ssa.gov</a></td>
</tr>
</tbody>
</table>
International Dialysis Resources and Websites

What if I need to dialyze outside of my local area?

- **www.nephron.com/usacgi.html** Offers free information about dialysis units in the United States. The site includes maps and driving instructions.
- **www.dialysisfinder.com** Locates dialysis units in the United States by entering an address, zip code, city or state.
- **www.medicare.gov/dialysis/home.asp** When you enter the name of a specific dialysis facility, this site will give you information about the facility’s ownership, location, size, and clinical outcomes. Some of the information is based on older data, so you should always check with the facility for the most current information.

What if I want to travel?

- **www.dialysisatsea.com** Dialysis at sea cruises*
- **www.medicaltravel.org** Medical Travel, Inc. has cruises and land vacations for adults and children on all forms of dialysis. Dialysis while in port is offered by the Renal Association of Boca Raton, FL*
- **www.globaldialysis.com** This web site can help you locate a dialysis unit both in and outside of the United States. The searchable directory lists 10,200 facilities in 115 countries. The site includes links to lodgings, travel agents, and tours that accommodate people on dialysis. There are also stories and tips from fellow dialysis “world travelers.”
- **www.renalworld.com** This web site has international listings of dialysis centers around the world.

*Medicare pays 80% of the transient dialysis treatments in the U.S. and the U.S. territories, including Puerto Rico, U.S. Virgin Islands, and Guam. Medicare does not pay for dialysis on cruises, even if the cruise originates in the U.S. Medicare also does not pay for dialysis at clinics outside the U.S. or its territories.
UNDERSTANDING YOUR HEMODIALYSIS OPTIONS

aakp
American Association of Kidney Patients
HEMODIALYSIS is a medical procedure designed to remove wastes, toxins and fluids from the blood when the kidneys have failed. It is the most common treatment for end-stage renal disease (ESRD), more commonly known as kidney failure. Doctors may recommend hemodialysis if your kidneys have failed and can no longer perform the function of removing waste and extra water from the blood to form urine.

Before beginning dialysis, doctors create an “access.” The access serves as a site, usually in the arm, where blood can be safely removed and returned to the body. The access site is often referred to as the “lifeline.” There are four access options: a fistula, a graft, a subcutaneous device or a catheter. Fistulas and grafts are permanent accesses. A permanent access involves the creation of a connection between an artery and a vein under the skin. These are used for patients with renal failure who are expected to need long-term dialysis treatment. The other types of access, catheters and subcutaneous devices, involve direct placement of a tube into a large vein in the neck, chest or groin. These are used for those who need short-term dialysis or those who are on long-term dialysis and no longer have a place to insert a fistula or graft. (Please refer to “Understanding Your Hemodialysis Access Options” brochure, which is available by calling AAKP at 800-749-2257.)

During each dialysis treatment, two needles are inserted into your access. Each needle is connected to a hollow plastic tube. The dialysis machine pumps blood from the body to the hemodialysis machine by way of a flexible, plastic tube. The blood is cleaned and returned to your body through a second tube and needle. (See picture below.)

During the procedure, fluids and waste products are removed from the blood before being returned to the body. The blood is cleaned by a part of the hemodialysis machine known as an artificial kidney or dialyzer, which filters the blood after it has entered the machine. The dialyzer does not completely replace your original kidney’s function.
Remember, your kidneys worked 24 hours a day, seven days a week.

It might look like there is a lot of blood outside your body. Actually, there is only about one cup of blood in the tubing and dialyzer at any time during the treatment. Just as people are not normally aware of blood moving through the body, you cannot feel blood being pumped out to the machine.

Dialysis machines have many gauges and alarms. You may find this overwhelming at first. The machine makes sure your treatment is safe by monitoring your venous pressure, how quickly your blood moves through the tubing and how much water is removed during the treatment.

Hemodialysis is a process that can be performed in a dialysis unit or at home. You will begin dialysis treatment in a center so your doctor can monitor your status and wait for your access to mature. There are three types of hemodialysis treatment: conventional hemodialysis, short daily hemodialysis and nocturnal (nightly) hemodialysis.

Conventional hemodialysis is usually performed at a dialysis facility or a hospital outpatient unit three or four times a week. This is the most common and available type of hemodialysis and what most people think of when they hear the term hemodialysis.

Another option for hemodialysis treatment is short daily hemodialysis. As the name implies, this type of treatment is used five to six times per week for a short amount of time, and is usually done at home.

The third type of hemodialysis is called nocturnal or nightly hemodialysis. This form of hemodialysis is performed during the night while you sleep, and is available in the home and in select centers.

Home therapies, including short daily and nocturnal, may not be available in all areas. You may have to do some research to locate a facility in which these treatments are available.

For all treatment options, if you are not being dialyzed well you might experience side effects such as headaches, nausea, vomiting or fatigue. AAKP offers a brochure, entitled “AAKP Hemodialysis Advisory.” This brochure discusses the importance of adequate dialysis and how to know if you are receiving enough dialysis. For more information or to request a free copy, call AAKP 800-749-2257.

This brochure was created to explain your hemodialysis treatment options. It features a brief description of each kind of treatment, how you can find more information, common questions associated with each treatment and the benefits and drawbacks to each.
Conventional hemodialysis is usually done three times per week. Each treatment is on average four hours in length. Your nephrologist prescribes the length of your treatment. The time you spend during each treatment depends on your body size, laboratory results and medical condition.

IN-CENTER
In-center conventional hemodialysis or clinic hemodialysis is performed in an outpatient dialysis unit, usually three times a week. Many healthcare specialists will be involved or are in the facility during these treatments. These include dialysis technicians, doctors, dialysis nurses and a few others. Nurses and technicians who have special training place the access needles and tubing and monitor the machines. Most dialysis centers have technicians who help begin and end the dialysis treatment, monitor vital signs during the treatment, clean the equipment after each use, maintain the machine and order supplies. You also have the opportunity to interact with other patients experiencing the same treatment.

Every dialysis unit looks and runs differently, but there are some common elements you will find in almost every unit. For many people, it is helpful to tour a dialysis unit to see how it looks and sounds before beginning treatment. Most dialysis centers are designed as an open area with reclining chairs along the wall and a dialysis machine beside each chair. There are usually televisions in the center of the room or a small television at each chair.

An example of a fixed conventional hemodialysis schedule is, Monday, Wednesday and Friday from 9:00 a.m. to 1:00 p.m.

<table>
<thead>
<tr>
<th>PROS</th>
<th>CONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Facilities are widely available</td>
<td>• Staff who are not familiar with you may be working with you</td>
</tr>
<tr>
<td>• Trained professionals perform treatment for you</td>
<td>• You must follow the rules of the dialysis center, such as number of visitors or eating restrictions</td>
</tr>
<tr>
<td>• You can interact with people who are on dialysis at the same time as you</td>
<td>• You must travel to a center three times per week on a fixed schedule</td>
</tr>
<tr>
<td>• Treatments are a standardized three treatments per week, four days off</td>
<td>• Treatment times are scheduled by the dialysis center</td>
</tr>
<tr>
<td>• You do not have to care for and store a machine or supplies</td>
<td>• Medical help is available quickly in an emergency</td>
</tr>
</tbody>
</table>
HOME
Conventional hemodialysis may also be performed in your home. This treatment option requires help from a partner. In this setting, nurses and technicians train you and a partner on how to use a hemodialysis machine. Training generally lasts four to 12 weeks and is done while you are receiving treatments at the center. Each time you are treated during the training process, you and your partner will gradually take on more responsibility with the treatment. Once you, your partner and the training staff are confident in your abilities to manage dialysis at home, you can begin home hemodialysis.

You will need to choose a dependable partner. This person will need to be with you and assist you each time you dialyze. It is important for you to choose someone with whom you can work well. It needs to be someone who can stay calm and help you to solve problems when issues arise.

When you dialyze at home, you are in charge of many things the people in the dialysis center would do. You are responsible for setting up and preparing your machine for treatment. You will also have to clean the machine afterwards. You must make sure you have the needed equipment and supplies. After the treatment is finished, you are also responsible for cleaning up and disposing of the used supplies.

When dialysis is performed at home, your equipment and supplies are delivered to you. Sometimes the volume of supplies is quite large. You must have a home with adequate space for the equipment and storage of supplies. You will pay for the additional electricity and water required for dialysis. There must be suitable electrical outlets and plumbing to make the dialysis solution and to drain the machine. The home hemodialysis training program will check for these requirements. In some cases, changes may be made to your home’s existing plumbing and electricity.

You and/or your partner will be trained to insert needles into your access for dialysis. You will be expected to give your own erythropoietin (EPO) injections, but you will go to the center for other IV injections and for a monthly check-up.

Even if you dialyze at home, you still have access to the same professional team as someone who dialyzes in a facility. There will be a training nurse available by telephone at all times who can answer questions, assist you in dealing with problems, arrange for technical support of the machine and advise you. It is also likely that a training nurse will visit you at home once a year to advise and observe hemodialysis sessions.
This treatment option may cause extra stress for your family members and/or helper who must be present during and sometimes assist with treatments. To prevent “burn out” of the family member or helper, it is important to focus on taking care of yourself. The home program can also arrange for you to dialyze in-center to allow time-off or vacation for your helper.

<table>
<thead>
<tr>
<th>PROS</th>
<th>CONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Same person always helps you</td>
<td>• Not all facilities offer home hemodialysis</td>
</tr>
<tr>
<td>• You decide if you want to have visitors or if you want to eat during dialysis</td>
<td>• You and your partner will need to be trained for several weeks for home hemodialysis</td>
</tr>
<tr>
<td>• More control over times to dialyze, within the number of hours and days ordered by your doctor</td>
<td>• Need room for storage of equipment and supplies</td>
</tr>
<tr>
<td>• No travel to dialysis clinic for treatment</td>
<td>• Need to call paramedic for help in an emergency</td>
</tr>
<tr>
<td>• You have more control over your treatment and life, which allows you more independence</td>
<td>• Trained helper or family member must be present to assist with treatments and emergencies</td>
</tr>
<tr>
<td>• You have access via the phone (or clinic appointment) to a nurse, <strong>dietitian</strong> and <strong>social worker</strong> to answer questions or to solve problems you may have with the hemodialysis treatment</td>
<td>• Home must have required plumbing and electrical capabilities</td>
</tr>
</tbody>
</table>

“**Home hemodialysis allows me to continue working, since I dialyze after I get home and on Saturdays.**”

*Tom*
*Home Hemodialysis Patient*
Short daily hemodialysis is a term used to describe more frequent hemodialysis five or six days each week, leaving one or two off days when you do not dialyze. Since you will be receiving more frequent dialysis, your dialysis time per treatment will be less. For example, if you dialyzed three times per week for four hours each time on conventional hemodialysis, you might dialyze six times per week for two hours each time on short daily hemodialysis. Your doctor and healthcare team will determine how many days and the length of treatment that is best for you.

More frequent hemodialysis lessens the amount of fluid that gathers in the body between treatments. Therefore, less fluid needs to be removed during the next treatment. This usually decreases symptoms often experienced both during and after conventional hemodialysis treatments, such as headache, nausea and vomiting, cramping, hypotension and post-dialysis fatigue. Since short daily hemodialysis matches normal kidney function more closely than conventional hemodialysis three times a week, you may feel and look better.

### PROS
- No travel to dialysis clinic for treatment
- Same person always helps you
- Shorter dialysis session
- More control over times to dialyze, within the number of hours and days ordered by your doctor
- You have more control over your treatment and life, which allow you more independence
- You may have fewer fluid and diet restrictions than conventional hemodialysis
- Closely resembles normal kidney function
- Better blood pressure control

### CONS
- You and your partner will need to be trained for several weeks for home hemodialysis
- Need room for storage of equipment and supplies
- Need to call paramedic for help in an emergency
- Trained helper or family member must be present to assist with treatments and emergencies
- Home must have required plumbing and electrical capabilities
- May have to use conventional hemodialysis when traveling
Fistulas, grafts and central venous catheters have all been used successfully in short daily hemodialysis patients. To date, it appears that problems such as access failure or infections do not occur more often than they do with dialysis three times a week.

When traveling, you may temporarily have to switch to conventional hemodialysis three times a week in a center. This allows you to travel in the same manner as if you were always on a conventional hemodialysis schedule. When you return home from your trip, you go back to your short daily hemodialysis schedule.

Short daily hemodialysis is generally offered as a home treatment option. If you are an in-center patient, you have the option to switch to short daily hemodialysis if it is available and with your doctor’s approval. There are certain requirements for people who choose short daily hemodialysis. You will need a home helper (preferably a family member or close friend). The dialysis unit will help you get set up at home with your own dialysis machine and train you and your partner.

“I like dialyzing daily because my diet is more flexible than when I only dialyzed three times per week.”

Cindy
Short Daily Hemodialysis Patient
Nocturnal hemodialysis is a form of hemodialysis that is performed while you sleep. It can be done in-center three times per week or at home five to seven times a week. Nocturnal or nightly hemodialysis can offer a very high dose of dialysis because it lasts for a long period of time. When it comes to toxins such as urea, it can offer results as effective as normal kidneys. Patients have reported feeling more energetic, having increased stamina, improved appetites and fewer spells of nausea. There are fewer complaints of itchy, dry skin or “restless leg syndrome.” Since dialysis takes place at night during sleeping hours, you can spend more of the daytime at work, leisure or recreation.

To prevent accidental disconnection of the dialysis tubing from the access during the night, the connections are reinforced with locking boxes and other safety devices.

When traveling, you may temporarily have to switch to conventional hemodialysis three times a week in-center. This allows you to travel in the same manner as if you were always on a conventional hemodialysis schedule. When you return home from your trip, you go back to your nocturnal hemodialysis schedule.

**IN-CENTER**
Nocturnal hemodialysis can be performed in a dialysis center or hospital unit. Most treatments are three nights a week and last about eight hours. Your doctor will determine the length of treatment that is right for you.

During the dialysis time, you will be in a bed. The unit is in “sleep mode” with the lights off. Nurses and technicians start and end your treatment and observe you.

<table>
<thead>
<tr>
<th><strong>PROS</strong></th>
<th><strong>CONS</strong></th>
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<tbody>
<tr>
<td>Trained professionals perform treatment for you</td>
<td>Potential for accidental disconnection of the dialysis tubing during the night</td>
</tr>
<tr>
<td>You can interact with other people on dialysis at the same time as you</td>
<td>You must follow the rules of the dialysis center such as number of visitors or eating restrictions during treatment</td>
</tr>
<tr>
<td>Treatments are a standardized three treatments per week, four days off</td>
<td>Travel to center on a fixed schedule</td>
</tr>
<tr>
<td>Medical help is available quickly in an emergency</td>
<td>Treatments are scheduled by the dialysis center</td>
</tr>
<tr>
<td>Better blood pressure control</td>
<td>May have to use conventional hemodialysis when traveling</td>
</tr>
<tr>
<td>You may have fewer dietary and fluid restrictions than conventional hemodialysis</td>
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while you sleep. Dialysis technicians look after the machine and service aides help in the unit. The dialysis technicians connect your access to the dialysis machine with a secure line that sounds an alarm if it senses any wetness around your access.

It may take time for you to get used to the noises made by the dialysis machine, the nurses walking around and sleeping in the dialysis center.

HOME
This treatment is performed five to seven nights a week. The length of the dialysis varies. It can last as long as you want to sleep, anywhere from five to 12 hours, with eight hours being the average. The dialysis treatments take place in your home, eliminating the need to travel to a center to dialyze. All requirements of other home options apply as well.

In some locations trained hospital staff monitors the dialysis machine by telephone modem or the Internet. A member of the dialysis team can observe each stage of your dialysis treatment and is able to evaluate pressures, flows, fluid removal and alarms. The machine will occasionally alert you to any problems. If you do not respond within a reasonable period, the hospital monitor will contact you by phone. You have access via the phone (or clinic appointment) to a nurse, dietitian and social worker to answer questions or to solve problems you may have with the dialysis treatment.

For more information on training you and your partner for nocturnal home hemodialysis, refer to the conventional home hemodialysis section.

<table>
<thead>
<tr>
<th>PROS</th>
<th>CONS</th>
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<tbody>
<tr>
<td>• No travel to clinic for treatment</td>
<td>• Some modifications to plumbing and electrical supply in the home may be required</td>
</tr>
<tr>
<td>• You have more control over your treatment and life, which allows you more independence</td>
<td>• May have to use conventional hemodialysis when traveling</td>
</tr>
<tr>
<td>• Same person always helps you</td>
<td>• Requires training and you must have trained partner to help you</td>
</tr>
<tr>
<td>• More frequent dialysis closely resembles normal kidney function</td>
<td>• Need room for storage of equipment and supplies</td>
</tr>
<tr>
<td>• You may have fewer dietary and fluid restrictions than conventional hemodialysis</td>
<td>• Need to call paramedic for help in an emergency</td>
</tr>
<tr>
<td>• Better blood pressure control</td>
<td>• Trained helper or family member must be present to assist with treatments and emergencies</td>
</tr>
<tr>
<td></td>
<td>• Potential for disconnection</td>
</tr>
</tbody>
</table>
In conclusion, this brochure was developed by the American Association of Kidney Patients (AAKP) to help patients and their family members with their physicians make educated and informed decisions about the type of treatment available. If you are interested in changing your present treatment, talk to your nephrologist and/or dialysis unit staff.

In evaluating hemodialysis options, please keep in mind:

1. Every patient is unique.
2. Each will have different outcomes and experiences with treatments.
3. Almost all new patients start on conventional in-center hemodialysis.
4. Not all treatment types may be available in all areas; and
5. Some treatment types may not be an option for you.

With the recent introductions of short daily and nocturnal hemodialysis in the United States, patients have more treatment choices than ever. We hope you found this brochure helpful in explaining your hemodialysis treatment options and remember to talk to your doctor if you have additional questions.
Glossary

Access: General term used to describe the site where the needles for the hemodialysis process are connected to your body.

Dialysis: The process of cleaning wastes from the blood artificially. See also hemodialysis.

Dialyzer: A part of the hemodialysis machine that removes wastes and extra fluid from the blood.

Dietitian: The renal dietitian can help you make good food choices and understand your blood chemistry results.

End-stage renal disease (ESRD): Total chronic kidney failure. When the kidneys fail, the body retains fluid and harmful wastes build up. A person with ESRD needs treatment to replace the work of the failed kidneys.

Erythropoietin (EPO): A hormone that working kidneys produce that tells the body to make red blood cells. Lack of EPO leads to anemia.

Hemodialysis: The use of a machine to clean wastes from the blood after the kidneys have failed. The blood travels through tubes to a dialyzer, which removes wastes and extra fluid. The cleaned blood then flows through another set of tubes back into the body.

Kidneys: The two-bean shaped organs that filter waste from the blood. The kidneys are located near the middle of the back.

Nephrologist: A doctor who treats for kidney problems and related hypertension.

Nurses: A registered nurse (RN), a licensed practical nurse (LPN) or a nursing assistant (NA) are often the people who perform dialysis treatments or supervise technicians performing dialysis.

Renal: Relating to the kidneys.

Social Worker: A trained professional who can provide you with a great deal of information, from financial resources to emotional coping and support systems.

Surgeon: The doctor who creates your access.

Technician: A trained professional who helps begin and end your dialysis treatment, monitor your vital signs during treatment, maintain the machine, order supplies and clean the dialyzer after each use.

Urea: A waste product that the body makes when protein is broken down. Levels of urea in the blood are a measure of how well the dialysis treatment is working.

Uremia: When waste products that are normally removed by the kidneys build up in the blood, leading to symptoms such as poor appetite, nausea, vomiting, fatigue and inability to concentrate.
UNDERSTANDING YOUR HEMODIALYSIS ACCESS OPTIONS
Hemodialysis, is the most often used treatment for end-stage renal disease (ESRD), more commonly known as kidney failure. During a hemodialysis treatment, a machine pumps blood from your body by way of a flexible, plastic tube, cleans it and then returns it to your body through a separate tube. In order to perform hemodialysis, an access must be created. An access is a site from which blood can be safely removed and returned to your body. The access site is often referred to as your “lifeline.”

There are two types of dialysis accesses. The first kind involves the creation of a permanent connection between an artery and a vein under the skin. The two kinds of permanent accesses, fistulas and grafts, are used for patients with renal failure who are expected to need long-term dialysis treatment. Fistulas and grafts are usually placed in the arm, but they may also be placed in the leg. They are surgically placed a few months before dialysis is scheduled to begin in order to allow for the site to heal and develop properly.

The other type of access involves the direct placement of a tube into a large vein in the neck, chest or groin. As described in this brochure, catheters are most appropriately reserved for patients needing short-term dialysis or patients on long-term dialysis who no longer have a place to insert a fistula or graft.
This brochure contains a brief description of the most common types of accesses. It is divided into two sections covering permanent and temporary access options and provides information on how each type of access is placed, when they are used and the limitations of each.

The following guidelines can help keep all types of vascular accesses in good health:

- Wear a Medical Alert bracelet to notify healthcare providers that you are on dialysis and the location and type of your vascular access. Also state that no blood pressures or vein punctures are to be done on your access limb.

- Pay attention to the machine during dialysis. Possible signs of access problems include: a) trouble maintaining good blood flow (above 300-350 ml/min), b) excessively negative pre-pump arterial pressure (greater than -200 to -250), or c) high venous pressure (causing the alarm to go off often).

“I was looking for something when I originally started dialysis that would be as pain-free as possible and easy to take care of.”

Jamie – Ottawa, Canada
The arteriovenous or AV fistula is a type of vascular access involving a direct connection between an artery and a vein. This connection is made underneath the skin with a surgical procedure that can often be performed on an outpatient basis. The connection between a vein and artery allows for adequate blood flow during dialysis. This increased blood flow leads to larger and stronger veins and makes repeated needle insertions easier. Fistulas are the preferred vascular access for long-term dialysis patients because they last longer than any other vascular access and are less prone to infection and clotting.

The fistula is usually placed in the forearm. AV fistulas may also be placed in the upper arm if an access in the forearm fails or if the arteries or veins in the forearm are unsuitable for the creation of a fistula. It is preferred that the fistula be placed on the “non-dominant” arm or the arm that you do not use as frequently.

A few months are usually needed to allow the fistula to properly develop, although it may take longer in some cases. Once the fistula has developed, you are ready for hemodialysis. A healthcare professional will insert two needles into the fistula, one for withdrawing blood from the body and the other to return dialyzed or filtered blood to the body.

The connection between a vein and artery allows for proper blood flow during dialysis.
Not everyone is eligible for an AV fistula. They can be difficult to create in some patients due to small veins and other conditions. Your surgeon may order a test of the blood flow in your arms or legs to determine if you are eligible for a fistula. The most common problem with the AV fistula after it has been successfully placed is a condition known as *stenosis*, which is a narrowing in the width of a blood vessel. In the case of fistulas, this narrowing involves either the vein or artery leading to the access. This may lead to a decrease in blood flow or clotting.

<table>
<thead>
<tr>
<th><strong>PROS</strong></th>
<th><strong>CONS</strong></th>
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</thead>
<tbody>
<tr>
<td>• Best overall performance</td>
<td>• Visible on the forearm</td>
</tr>
<tr>
<td>• Considered the best vascular access</td>
<td>• May take a while to develop</td>
</tr>
<tr>
<td>• Less chance of infection than other types of accesses</td>
<td>• May require temporary access while fistula matures</td>
</tr>
<tr>
<td>• Tend to last many years</td>
<td>• Not feasible for all patients due to other medical conditions</td>
</tr>
<tr>
<td>• Predictable performance</td>
<td>• Bleeding after the needles are removed</td>
</tr>
<tr>
<td>• Increased blood flow</td>
<td>• Fistulas may fail to mature</td>
</tr>
</tbody>
</table>

“I’ve had my fistula for 22 years, the entire time I’ve been on dialysis. I make sure to take care of it because it’s my lifeline and allows me to receive dialysis. I have learned to put my own needles in because I like to be involved in my own care.”

*Tom – Dallas, TX*

22-year hemodialysis patient
GRAFTS
Grafts are similar to AV fistulas. Unlike the fistula which is created by the direct connection of the artery to the vein, the graft is formed through the indirect connection of the artery to a vein by a synthetic tube. Therefore, grafts are typically used when patients have small or weak veins that will not properly develop into a suitable fistula. Like a fistula, this type of access is usually implanted under the skin in your arm. A surgeon performs a brief procedure in order to properly place the graft.

The graft is usually a soft, synthetic tube that connects to an artery at one end and a vein at the other. The tube acts like a natural vein, allowing blood to flow through it.

Following the surgery, you may experience pain and swelling in the area over the graft for three or four weeks. The arm should be kept elevated. After the swelling goes down, a graft can be used for hemodialysis. Grafts can be used repeatedly for needle insertion during dialysis treatment.

<table>
<thead>
<tr>
<th>PROS</th>
<th>CONS</th>
</tr>
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<tbody>
<tr>
<td>• CAN BE READILY IMPLANTED</td>
<td>• INCREASED POTENTIAL FOR CLOTTING</td>
</tr>
<tr>
<td>• PREDICTABLE PERFORMANCE</td>
<td>• INCREASED POTENTIAL FOR INFECTION</td>
</tr>
<tr>
<td>• CAN BE USED FASTER THAN AN AV FISTULA (WITHIN 3 OR 4 WEEKS)</td>
<td>• DOES NOT USUALLY LAST AS LONG AS A FISTULA</td>
</tr>
</tbody>
</table>
**Care for Fistula and Grafts**

**Find out** if your vascular access is a *native fistula*, moved vessel fistula or a synthetic graft. You need to know which way the blood is flowing within your access and which area is used for the *arterial* (red) and *venous* (blue) segments. You need to ensure the dialysis staff person inserts the needles in the proper orientation to the blood flow and then connects the bloodlines red to red and blue to blue.

**Learn how** to properly hold the patches after the dialysis needles are removed. Also learn how to hold pressure to a needle site in case it bleeds after dialysis. Have in your purse or pocket an emergency supply of gauze dressings and tape to reapply a clean dressing if the needle sites bleed on the way home from dialysis.

**Wash** the skin over the access with soap and water daily and before dialysis.

**Make certain** the staff is using proper techniques in preparing your skin before inserting the needles into the access. Ask what these techniques are for your particular unit.

**Watch for signs** of infection. These may include redness, tenderness or pus. Cleanliness is one of the most important ways to prevent infection. Any signs of infection should be reported to your doctor or nurse immediately.

**Feel** your access and check for a *thrill* (vibration) or pulse every day. Check also if you have experienced low blood pressure, dizziness or lightheadedness. If you cannot feel a pulse, listen to your access for a *bruit* (swishing sound). If you do not think your access is working, contact your dialysis unit or physician immediately. They can arrange to have the surgeon or radiology specialist examine you.

**Try not to carry** heavy items draped over the access arm or wear tight fitting clothing over the access arm or leg.

**It is important** to try not to sleep on the access arm or leg.

**If your fistula** or graft develops an *aneurysm* (looks like a small balloon), notify your doctor or nurse immediately. It may need surgery or simply to be closely monitored. Better rotation on needle sites must be used to prevent aneurysm formation or enlargement.

**Develop** a close relationship with your patient care technician and nurse. You can help remind them to rotate needle sites for each treatment. You can also learn a lot about caring for your access from them. You may even want to learn to put your own needles in for each treatment.
CATHETERS

Catheters are flexible, hollow tubes which allow blood to flow in and out of your body. They are most commonly used as a temporary access for up to three weeks. This is often done when a patient needs dialysis immediately and is waiting for a fistula or graft to mature. They are also used when a permanent access fails and a patient is too unstable to delay treatment. Several different types of catheters exist.

Internal jugular catheters are inserted into the jugular vein on the side of your neck. Subclavian catheters are placed into the subclavian vein under the collarbone on the chest. Femoral catheters are placed in the large femoral vein in the leg near the groin.

Catheters are flexible, hollow tubes which allow blood to flow in and out of your body. They are most commonly used as a temporary access for up to three weeks.
After a catheter has been placed, needle insertion is not necessary to receive hemodialysis treatment. Catheters contain an exit site, which is covered with bandages or other types of dressing. These dressings need to be changed and kept dry at all times. Many physicians recommend mupirocin ointment treatment at the exit site.

<table>
<thead>
<tr>
<th>PROS</th>
<th>CONS</th>
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<tbody>
<tr>
<td>• Dialysis can be performed immediately</td>
<td>• Not ideal as a permanent access</td>
</tr>
<tr>
<td>• Readily inserted with an outpatient procedure</td>
<td>• High infection rates</td>
</tr>
<tr>
<td>• Easy removal and replacement</td>
<td>• Difficult to obtain sufficient blood flow to allow for adequate toxin removal</td>
</tr>
<tr>
<td>• Avoi ds needlesticks</td>
<td>• May cause narrowed veins</td>
</tr>
<tr>
<td></td>
<td>• Swimming and bathing is not recommended</td>
</tr>
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</table>

“I was told I needed to begin dialysis immediately after being rushed to the emergency room. Of course, I was really scared but the doctor assured me that he could begin dialysis immediately with a catheter. I was only required to keep the catheter in for a few weeks until my fistula was ready, but I was so glad to have it as an option during the emergency.”

Margaret – Ashville, NC
1-year hemodialysis patient
**Care of Catheters**

*Your catheter exit site* should be cleaned with each dialysis treatment and clean dry gauze applied. You must wear a mask for the dressing change, on and off procedures for dialysis or anytime your dialysis catheter is opened for use. Ask your dialysis staff what the unit specific dressing procedure is and how you are to care for the catheter at home. Specifically ask about mupirocin ointment.

*For non-cuffed catheters,* the sutures must remain in place for as long as you have the catheter. For tunneled cuffed catheters, the sutures should be removed once the catheter is healed into place to prevent infection from the sutures.

*Your catheter caps must remain* on the catheter and only removed by the dialysis staff. The clamps must remain closed at all times. Your dialysis catheter must only be used by the dialysis staff unless authorized by your nephrologist. If the clamp comes undone, close the clamp immediately. If a catheter cap becomes loose and falls off, make sure the catheter remains clamped and report to your dialysis center or emergency room for you are at risk for an infection or air entering your bloodstream and need urgent care. If any portion of the catheter develops a hole, leak or part separation, then you must ensure the catheter is clamped off above the problem area. The catheter clamp may be movable and can be slid up on the body of the catheter to close off the catheter, or you may need to kink the catheter with your fingers to **occlude** the catheter and then call 911. If blood leaks out, air can enter and cause an air embolism. You need immediate help to prevent serious injury.
Aneurysm - An abnormal enlargement of a blood vessel. Aneurysms may occur around an access site in the form of what appears to be a small balloon.

Arterial - Characterized or related to the function of the arteries.

Arteriovenous - Term used in dialysis to refer to a connection between an artery and a vein. An arteriovenous connection is used to create fistulas for hemodialysis treatment.

Bruit - Any of several abnormal sounds produced by an artery.

Exit Site - The site where the catheter emerges.

Jugular - Related to the jugular vein, located in the region of the neck or throat.

Native Fistula - A type of vascular access created by connecting a patient’s own artery to his own vein using no artificial parts.

Occlude - To close or obstruct.

Stenosis - A narrowing in the width of a blood vessel.

Subclavian - Related to the subclavian artery or vein, located beneath the clavicle.

Suture - Material used to surgically close a wound or join tissues.

Thrill - A tremor or vibration in the circulatory system.

Tunneled Catheter - A specialized type of catheter that is “tunneled” or placed under the skin.

Vascular - Related to the arteries or veins.

Venous - Characterized or related to the function of the veins.
MEMBERSHIP FORM

Please include my membership in AAKP at the following:

☐ Patient/Family Member ($25)
☐ Professional Member ($35)
☐ Sustaining/Physician Member ($100)
☐ Institutional Member ($150)
☐ Life Member ($1000)

For memberships outside the USA, please add an additional $30 for foreign postage.

Please return completed form and payment to:

American Association of Kidney Patients
3505 E. Frontage Rd., Suite 315
Tampa, Florida 33607
(800) 749-2257

Name

Street Address

City    State    Zip

Telephone

Enclosed in an additional contribution of $__________
 to assist AAKP with its many patient programs.

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            AmEx or Discover

Account #: __________________________

Expiration Date: _____________________

Signature: __________________________

MEMBERSHIP BENEFITS

• A subscription to AAKP’s magazine, aakpRENA\LIFE.

• An opportunity to subscribe to the AAKP Renal Flash, Kidney Transplant Today, Kidney Beginnings: The Electronic Newsletter and AAKP Public Policy Briefing, electronic newsletters transmitted once a month via e-mail.

• Access to the AAKP Web site (www.aakp.org) which displays useful healthcare information and provides links to other renal related sites.

• A membership packet filled with a wide range of informational brochures on issues affecting the care and treatment of kidney patients.

• Access to special interest brochures that address changing medical technology.

• Local chapters in your community (if available) that provide social and educational support to you and your family with meetings, newsletters and group activities.

• An opportunity to attend our annual convention, a four-day event featuring seminars addressing treatment options, rehabilitation, and psychological and social concerns of renal disease patients.

HOW AAKP HELPS YOU AND YOUR FAMILY

• Assuring that your voice is heard and your interests are represented through actively defending the rights of kidney patients in Washington, D.C. and the renal community.

• Focusing on issues such as treatment options, adequacy of care, access to rehabilitation and employment and many other issues that address the needs of patients and their families.

• Encouraging the development of local patient and family support groups.

• Conducting patient conferences and seminars that help patients and their families deal with the medical, psychological and social concerns associated with kidney disease.
UNDERSTANDING YOUR PERITONEAL DIALYSIS OPTIONS

Healthy kidneys clean your blood by removing excess fluid, minerals and toxins. They also make hormones that keep your bones strong and your blood healthy. As your kidneys fail, harmful toxins build up in your body, your blood pressure may rise, and your body may not make enough red blood cells. When this happens, you need treatment to replace the work of your failed kidneys.

Peritoneal dialysis (PD) is one of the available treatment options to remove waste products and excess fluid from the blood when the kidneys are no longer properly functioning. There are many forms of dialysis available to patients. PD uses your own peritoneum – a natural membrane that covers the abdominal organs and lines the abdominal wall. This membrane acts as a filter. The peritoneum is a porous membrane that allows toxins and fluid to be filtered from the blood.

In order to perform this treatment, a permanent PD access to the peritoneal cavity will need to be created. In general, this will require a surgical procedure to insert a small, soft tube, known as a catheter. Usually, this will be an outpatient procedure that will include local anesthesia and an intravenous (IV) sedative. A sterile dressing will remain in place about five to seven days. Your PD nurse will change your dressing throughout your PD training program. The healing process will take approximately two to three weeks.

“ When my father went on PD, it gave him his life back.”

Mrs. S. Reilly
During your procedure, a catheter is inserted through the abdominal wall and into the peritoneal cavity. The area where the catheter extends from the abdomen is called the exit site. A portion of the catheter remains outside the abdomen and under your clothing, providing a means for attaching the bags of dialysis fluid (dialysate). Your PD nurse will teach you a simple routine for cleaning and looking after the catheter exit site.

When receiving a PD treatment, dialysate will flow into the peritoneal cavity through the catheter. The solution will remain in the cavity for several hours. During this time, waste products and excess fluid pass from the blood into the peritoneal cavity. After the completed dwell time (period the dialysis solution is in your abdomen), the solution will be drained from the cavity. You will then fill the cavity with fresh solution and the process begins again. This process is called an **exchange**. Each time you perform a treatment you will use a new disposable set. Keep in mind, there is potential for infection with any surgical or invasive procedure; therefore you will need to follow proper techniques for performing your treatments. Different types of PD have different schedules of exchanges. Some PD treatments are done during the day while others are at night.

Your doctor will prescribe how many exchanges you will do each day, as well as the amount and type of dialysis fluid you will use. It is important to follow your PD prescription and do all of the exchanges as instructed.

Storage space is needed at home for PD supplies. Delivery of solution bags is typically scheduled once each month. These supplies must be stored in a clean, dry area.

Since you don’t have to go to a dialysis center for treatment, PD gives you more control. You can do treatments at home, at work or on trips. This independence makes it especially important that you
work closely with your health care team: your nephrologist, dialysis nurse, dietitian and social worker. The most important member of your health care team is you.

There are two types of PD. One is continuous ambulatory peritoneal dialysis (CAPD) and the other is continuous cycling peritoneal dialysis (CCPD). The type of PD you choose will depend on the schedule of exchanges you would like to follow, as well as other medical factors particular to you. You may start with one type of PD and switch to another, or a combination of automated and manual exchanges may work best for you. Work with your health care team to find the best schedule and techniques to meet your lifestyle and health needs. Your doctor will look at your body size, lifestyle, lab tests, and your ability to do the dialysis steps. Both types of PD are continuous, meaning you receive around-the-clock treatment, usually with PD fluid in your abdomen 24 hours a day, seven days a week – similar to the way healthy kidneys work.

Most people with kidney failure can be treated by PD, but there are exceptions. Some people who have had major abdominal operations or scarring of the peritoneal membrane may not be good candidates. However, it is important to consult with your health care professional as even some of these cases may allow you to be treated with PD.

**Continuous Ambulatory Peritoneal Dialysis (CAPD)**

CAPD does not require a machine. It can be done in any place that is clean and well lit. The only equipment you need is a bag full of dialysate fluid and the plastic tubing that comes attached to the
As the word ambulatory suggests, you can walk around with the dialysis solution in your abdomen. CAPD is performed manually and can be done almost anywhere.

With CAPD, dialysis takes place 24 hours a day, seven days a week. The peritoneal membrane acts as a filter, removing toxins and excess fluid from the blood. The toxins and excess fluid cross the membrane into the dialysis solution. They are removed from the body when the dialysis solution is drained during an exchange into a pre-attached drainage bag.

CAPD requires that you have dialysis solution in your abdomen. The amount of dialysate will vary depending on your specific needs. Exchanges are usually performed every four to six hours during the day. After a specified time, the solution, which now contains toxins, is drained into the drainage bag. You then repeat the cycle with a fresh bag of solution.

An exchange of dialysis fluid in CAPD is simple. You will be able to do it yourself once you have been trained by a specialized CAPD nurse. This training usually takes one to two weeks.

The solution bag is hung on an IV pole, using gravity to allow dialysate to flow into the peritoneal cavity. First, empty the abdomen of the fluid, then add fresh solution. Once you have filled your peritoneal cavity with the clean dialysate solution, you can detach the tubing and empty the used dialysate into the toilet. The clean fluid then sits in the peritoneal cavity until your next exchange. During this time, you are free to go about your regular activities. Each exchange takes about 30 minutes to complete. Your doctor will prescribe the number of exchanges you’ll need, typically three or four exchanges during the day and one evening exchange with a long overnight dwell time while you sleep.

“I was fascinated by the possibilities. I could control everything myself, make myself more or less dependent, travel for several days, and continue to work. My nurse was never more than a telephone call away. I like the thought of being able to live as normal a life as possible, and went for CAPD.”

Ms. A. Norway
CONTINUOUS CYCLING PERITONEAL DIALYSIS (CCPD)

The other form of PD requires a machine, called a **cycler**. This type of cycler-assisted PD is called CCPD. Sometimes called **automated peritoneal dialysis (APD)**, this treatment is done at home with your catheter connected to the cycler machine.

CCPD is a simple procedure. The machine automatically controls the timing of exchanges, drains the used solution, and fills the peritoneal cavity with new solution. The machines are easy to operate and have built-in safety devices. They are portable and

<table>
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<tr>
<th>PROS</th>
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<tr>
<td>• CAN BE DONE IN MANY LOCATIONS, MAKING IT EASIER TO TRAVEL AND WORK.</td>
<td>• TREATMENTS ARE USUALLY PERFORMED FOUR TIMES PER DAY.</td>
</tr>
<tr>
<td>• NO NEEDLES.</td>
<td>• NOT ALL DIALYSIS FACILITIES OFFER CAPD.</td>
</tr>
<tr>
<td>• FLEXIBLE SCHEDULE AND INCREASED INDEPENDENCE.</td>
<td>• YOUR ABDOMEN IS ALWAYS FULL OF FLUID, WHICH MAY INCREASE THE SIZE OF YOUR WAIST.</td>
</tr>
<tr>
<td>• FEWER FLUID AND DIET RESTRICTIONS THAN HEMODIALYSIS.</td>
<td>• REQUIRES THE INSERTION OF A PERMANENT CATHETER.</td>
</tr>
<tr>
<td>• NO MACHINE IS NECESSARY.</td>
<td>• PROCEDURES MUST BE CLOSELY FOLLOWED TO REDUCE THE RISK OF INFECTION IN THE PERITONEAL CAVITY OR AT THE EXIT SITE.</td>
</tr>
<tr>
<td>• TRAINING IS EASIER THAN HOME HEMODIALYSIS.</td>
<td>• STORAGE SPACE NEEDED IN YOUR HOME FOR SUPPLIES.</td>
</tr>
<tr>
<td>• ONGOING (CONTINUOUS) DIALYSIS SIMULATES NORMAL KIDNEY FUNCTION.</td>
<td>• REQUIRES THE INSERTION OF A PERMANENT CATHETER.</td>
</tr>
<tr>
<td>• OFTEN PROVIDES BETTER BLOOD PRESSURE CONTROL.</td>
<td>• PROCEDURES MUST BE CLOSELY FOLLOWED TO REDUCE THE RISK OF INFECTION IN THE PERITONEAL CAVITY OR AT THE EXIT SITE.</td>
</tr>
<tr>
<td>• PROLONGS REMAINING KIDNEY FUNCTION.</td>
<td>• STORAGE SPACE NEEDED IN YOUR HOME FOR SUPPLIES.</td>
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about the size of a small suitcase. They can be used wherever there is an electricity supply.

Patients on either type of PD are relatively independent and can manage their own care at home. However, PD is not always trouble free. The following are some things to consider when making a treatment choice.

**Responsibility:** Some patients get tired of doing dialysis every day. If this is a problem, talk to your PD nurse who may be able to help you incorporate more flexibility into your routine, including a “holiday from PD” using hemodialysis.
**Body Image:** Some PD patients find it difficult to accept a permanent PD catheter. They worry the catheter may affect their sexual activity and their relationship with their partner. PD nurses and social workers can help with tips on how to disguise the PD catheter. PD also tends to stretch the abdomen, giving it a rounded appearance. Keeping fit and doing exercises will help.

**Fluid Overload:** When there is too much fluid in the body, it can cause a sudden increase in body weight, swollen ankles and/or shortness of breath. Generally, dialysis patients need to restrict their fluid intake to prevent fluid overload. PD patients, however, have more flexible fluid allowances than hemodialysis patients.

**Discomfort:** Some PD patients find having dialysis fluid in their abdomen uncomfortable. They feel full, bloated or experience back pain.

**Peritonitis:** This is an infection of the peritoneum, usually caused by bacteria entering through or around the catheter. This can happen when patients touch the open ends of the connections between the bag of dialysis fluid and the catheter. Sometimes, contamination around the catheter at the exit site can lead to peritonitis. Peritonitis is greatly reduced by following correct dialysis techniques. On average, patients can expect to get less than one episode of peritonitis every year. Some patients never get one. Peritonitis is easy to recognize because it makes your dialysis fluid cloudy. Some patients also experience abdominal pain and fever. Most germs and infections can be treated with antibiotics, but some are very hard to treat. Prompt medical attention is necessary. For more information on peritonitis, please speak with your physician.
IN CONCLUSION

This brochure was developed by the American Association of Kidney Patients (AAKP) to help patients make educated and informed decisions about the type of treatment available. If you are interested in changing your present treatment, talk to your nephrologist.

In evaluating the different PD options, please keep in mind:

1. EVERY PATIENT IS UNIQUE.
2. EACH WILL HAVE DIFFERENT OUTCOMES AND EXPERIENCES WITH TREATMENTS.
3. NOT ALL TREATMENT TYPES MAY BE AVAILABLE IN ALL AREAS.
4. SOME TREATMENT TYPES MAY NOT BE AN OPTION FOR YOU.

To assess whether you may be a good candidate for PD, see the Self-Assessment Tool on page 11.

We hope you found this brochure helpful in explaining your PD options. Remember to talk with your physician if you have additional questions.
GLOSSARY

Adequacy: This is a general term that refers to how well dialysis is working. It measures the amount of toxins removed from the blood. Your doctor will test for adequacy. The results of the adequacy test determine the amount of dialysis needed. As a result of this test, patients may need a change in their dialysis prescription. For more information, refer to the “AAKP Peritoneal Dialysis Advisory” available by calling AAKP at (800) 749-2257.


Catheter: Sterile tubing surgically placed in the abdomen that allows for the exchanges in peritoneal dialysis.

Continuous Ambulatory Peritoneal Dialysis (CAPD): A form of peritoneal dialysis in which the blood is always being cleaned using a system of bags and tubing. No machine is required.

Continuous Cycling Peritoneal Dialysis (CCPD): A form of peritoneal dialysis that uses a machine. The machine automatically performs the exchanges while the person sleeps. This is sometimes called APD.

Cycler: Machine used to perform CCPD.

Dialysis: The process of artificially cleaning toxins from the blood through a medical procedure. See also CAPD and CCPD.

Exchange: Term used to describe each time the dialysis fluid (dialysate) used in peritoneal dialysis is drained and refilled.
**Peritoneal Cavity:** The space in the abdomen that holds the major organs. The inside of this space is lined with the peritoneum.

**Peritoneal Dialysis:** Cleaning the blood by using the lining of the abdomen as a filter.

**Peritoneal Membrane:** A sac, resembling cellophane with tiny holes, which serves as a lining of the abdominal cavity and holds organs in place within the peritoneal cavity.

**Peritoneum:** The lining of the peritoneal cavity.

**Peritonitis:** An inflammation of the peritoneal membrane. This inflammation causes an infection in the peritoneal membrane. Peritonitis is treated with antibiotics that are included in a special type of peritoneal dialysate.

**Urea:** A toxin the body makes when protein is broken down. Levels of urea in the blood are a measure of how well the dialysis treatment is working.

**Uremia:** When toxins that are normally removed by the kidneys build up in the blood, leading to symptoms such as poor appetite, nausea, vomiting, fatigue and inability to concentrate.
SELF-ASSESSMENT TOOL

If you think peritoneal dialysis (PD) may be a good treatment option for you, take a look at the questions below. Your answers to these questions can help your physician assess how PD may fit your health and lifestyle needs.

1. Do you work outside of the home? If you do, PD may be an ideal option since you are able to maintain your normal work balance with minimal interruption from your therapy.

2. Do you live in a rural area making traveling to a dialysis center difficult? PD may be appropriate for you since it gives you the freedom to dialyze and manage your disease primarily from home.

3. Do you have impaired vision? Since you are managing your own treatments, you may need assist devices or family support to allow you to perform PD at home.

4. Is your hand strength or dexterity impaired? If you live alone, you will need to see if assist devices can allow you to perform PD at home.

5. If you are diabetic, is your diabetes well-controlled? Many diabetic patients do very well on PD, but it is important that you work with your physician to find the best treatment for you.

6. Do you have adequate storage space for dialysis supplies? Each month, you will have many boxes (approximately 30-40) that will be stored. The supply company can sometimes deliver more frequently if space is limited.

7. Have you had multiple abdominal surgeries? Some people with major abdominal surgeries or scarring of the peritoneal membrane may not be good candidates for PD.

8. Will you and a possible support person be able to devote time for proper training? A support person is not required, but may prove to be very helpful in administering treatment.

9. Do you have a phone? This is essential for contact between the patient and a designated nearby dialysis unit, as well as ordering supplies.

10. Do you think you would be comfortable accepting the responsibilities associated with PD? With the independence PD offers, it also requires responsibility on the patient’s part.

Now that you have answered these questions, take them to your physician and discuss whether PD may be right for you.
Membership Form
Please include my membership in AAKP at the following level:

- Patient/Family Member ($25)
- Professional Member ($35)
- Sustaining/Physician Member ($100)
- Institutional Member ($150)
- Life Member ($1,000)

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Tampa, Florida 33607
(800) 749-2257

Name

Street Address

City State Zip

Telephone

Enclosed is an additional contribution of $___________________ to assist AAKP with its many patient programs.

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Account #: ____________________________________
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Signature: ____________________________________

Membership Benefits
- A subscription to AAKP’s magazines, aakpRENAFlFE and Kidney Beginnings: The Magazine.
- An opportunity to subscribe to AAKP’s electronic newsletters; AAKP Renal Flash, Kidney Beginnings: The Electronic Newsletter, Kidney Transplant Today and AAKP Public Policy Briefing.
- Access to the AAKP Web site (www.aakp.org), which displays useful health care information and provides links to other renal-related sites.
- A membership packet filled with an array of informational brochures on issues affecting the care and treatment of kidney patients.
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How AAKP Helps You and Your Family
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