

**Release date**

November 18, 2005

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# *FACTS ABOUT KIDNEY TRANSPLANTATION*

Pediatric Patient Education Brochure



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# *FACTS ABOUT KIDNEY TRANSPLANTATION*

## *PEDIATRIC PATIENT EDUCATION BROCHURE*

### **1. WHAT IS KIDNEY (RENAL) FAILURE?**

For information, please go to <http://www.kidney.org/general/atoz/index.html>.

### **2. SIGNS OF CHRONIC KIDNEY DISEASE AND KIDNEY FAILURE IN CHILDREN**

- Chronic kidney disease in children is when the kidney filtration falls below 60 (mL/minute/1.73m<sup>2</sup>).
- Chronic kidney failure in children is when this number falls below 15. Signs and symptoms of renal failure in children are much like those of adults. An added problem is delayed growth (<http://www.kidney.org/general/atoz/index.html>). This delay in growth often happens in children when their kidney filtration falls below 50.

Most children with kidney filtration of less than 15 will need help to sustain life and replace the failed kidney. This is done by dialysis or through a transplant. There are 2 kinds of dialysis:

- Hemodialysis. Most of the time this is done with the help of a machine in a special center, 3 or 4 times a week.
- Peritoneal dialysis. This is done at home, mostly at night with the help of a machine.

Kidney transplantation is the best treatment for kidney failure in children. Some children go for a transplant after being on either kind of dialysis for a period of time. Other children, whose kidney function is slowly getting worse, will have enough time to plan for a transplant without going on dialysis. This is called *preemptive kidney transplant*.

### **3. EVALUATION OF THE CHILD FOR KIDNEY TRANSPLANTATION**

Kidney transplant is the preferred treatment for kidney failure in children. It provides the best way for the child to lead a normal and healthy life. Many, but not all, of the steps to assess the child for kidney transplant are the same as those for adults.

[http://www.a-s-t.org/patient\\_education/navpatcare.htm](http://www.a-s-t.org/patient_education/navpatcare.htm).

Most children with kidney failure are referred for transplantation by their pediatric nephrologists. Most children are eligible for kidney transplants. Some are not because of medical reasons. Examples of medical reasons are severe heart or lung disease or a bad infection such as HIV. Children will qualify for transplants when their kidney function falls below 20. They may not need to go on dialysis before the transplant. About 55% of children get their kidney from one of their parents. Either parent is already half matched for a special protein on white blood cells that can tell the risk of rejection. (This protein is called *HLA*.) The better the match, the less likely the body will reject the transplant. The other 45% of children will be placed on the deceased donor waiting list at their transplant center.

### **4. GETTING A KIDNEY TRANSPLANT**

For information, please go to [http://www.a-s-t.org/patient\\_education/navpatcare.htm](http://www.a-s-t.org/patient_education/navpatcare.htm).

## 5. AFTER KIDNEY TRANSPLANT

Your child's care will be managed by a health-care team. It will consist of your pediatric nephrologist, the rest of the transplant team, and your child's local family doctor. Many of the principles of renal transplant care are the same for children and adults. There are, however, some special needs for the child with a transplant. For more information, go to [http://www.a-s-t.org/patient\\_education/navpatcare.htm](http://www.a-s-t.org/patient_education/navpatcare.htm).

### I. Side Effects of Immunosuppression Medications

The immunosuppression medications used in children after transplant are the same as the ones used in adults, and the side effects are similar. Other side effects for steroids (prednisone) that are common in children are slow growth, hyperactivity, mood swings, and depression. For more information, go to [http://www.a-s-t.org/patient\\_education/navpatcare.htm](http://www.a-s-t.org/patient_education/navpatcare.htm).

### II. School After Renal Transplantation

#### *When can my child go back to school?*

Most children may return to school 6 weeks after transplantation. It is best to check with your child's kidney doctor, as there may be special reasons to delay your child's return to school. If family members are ill, it is always best to keep the sick person away from the child with a renal transplant. Perhaps the child with a transplant should wear a mask at home at this time. Please check with your kidney doctors about the need to isolate any sick person in the house from your transplanted child.

#### *What about home schooling?*

You might use a tutor for your child during extended times of missed school. But regular attendance at school is an important part of your child's overall development. If you do not feel good about sending your child to school for health or other reasons, please call and talk to your transplant team and your kidney doctor.

#### *Can my child participate in school activities?*

Once in school, children with renal transplants should take part as fully as possible in school activities. There are very few limits on physical activities. Please refer to the section on sports.

### III. Sports and Activities

#### *What sports can my child take part in after kidney transplantation?*

Use good common sense when choosing activities for your child. The list below can be used as a guide. In general, aerobic exercises are good for children with kidney transplants. Of course, no one can guarantee that any of these activities are totally safe and will not injure the new kidney. Please discuss this with your transplant team. It is a good idea to wear a kidney protector if there is a chance that the transplant could be injured.

#### **Sports to be avoided:**

Rugby football	American football
Karate, judo, Asian martial arts	Ice hockey
Trampoline	Wrestling
Boxing	Wall ball/dodge ball
Jumping from heights	Skiing (downhill)
Gymnastics	Snowboarding
-Uneven parallel bars	
-Balance beam	
-Tumbling	

#### **Sports that are encouraged:**

Field hockey	Running
Jump rope	Basketball (except one-on-one)
Swimming, canoeing, rowing	Weight lifting
Volleyball	Jazzercise
Aerobics	Cross-country skiing
Sledding	Skating
Tennis	Cycling
Horseback riding	Soccer
Badminton	Table tennis
Golf	

## IV. Immunizations

### *Why does my child need immunization?*

Getting immunization shots helps protect children from serious diseases. Some children with kidney disease may have missed some of their shots. They could have been ill at the time or on medications that lower the immune system. Your child should be up to date on his or her shots before getting a kidney transplant. Please check with your child's doctor and the transplant team on which ones your child needs before the transplant.

### *When should we start immunization after transplant?*

After the transplant, your child will be on drugs that will lower his or her immune system. As a result, he or she will not be able to respond to the immunizations. Ask your child's kidney doctor about the best time to restart these shots after the transplant. This can vary between 3 to 9 months after getting the kidney. It will depend on the transplant medications used for your child.

### *What immunizations can my child get after transplant?*

Your child should **NOT** receive live vaccines such as the following:

- Smallpox
- Measles
- Mumps
- Rubella
- Oral polio
- Varicella/chickenpox (Some medical centers give this vaccine after transplant, so please check with your child's kidney doctors.)

Immunizations your child may receive are the following killed vaccines:

- Injectable polio
- Hepatitis B
- Tetanus/diphtheria booster
- Flu shot
- Pneumovax
- Hepatitis A
- TB skin test (which is actually not an immunization but a test to see if your child was exposed to tuberculosis [TB] before)

Please call the children's transplant office before getting any shots.

### *What if we plan a trip outside the United States?*

If you plan a trip to a foreign country that requires any of these immunizations or other live viruses, please contact the transplant office. They will give you a letter for the Passport Bureau to explain your child's situation.

For more details about immunization in renal disease, link to <http://www.kidney.org/general/news/factsheet.cfm?id=29>. A few examples of what is in the link are listed below:

### *What about immunization for the other children in my household?*

Other household members should not get the oral polio vaccine. Only the inactive vaccine or IPV should be used. At this time, only the IPV is used in the United States. Talk with your doctor before giving chickenpox vaccine to other household members, as it is made from live viruses. It is safe for other children in the household to get the measles, mumps, and rubella vaccines.

### *What should I do if my child is in day care with other children who may have received live vaccine?*

Talk with your day-care provider about your child's condition. If your child has had an organ transplant, talk with your doctor. Ask if your child can be around children who have had oral polio or other live vaccines.

## Recommended immunization schedule for kidney transplant recipients ages 0–18 years according to the American Academy of Pediatrics 2003

This is the schedule for immunizations that need to be done before a kidney transplant. After transplant, live vaccines should not be given, as mentioned above. Please check with your child's kidney doctor for the shots that can be given to your child after the transplant. It is suggested that teens get shots for meningitis before they go to college. Please check with the kidney doctors about the need to give this vaccine to your teenager.

Vaccine	Age	Total Doses	Catch-up Vaccination
Hepatitis B	Birth, 1–4, 6–18 months	3	2–18 years (hepatitis series)
DTaP (Diphtheria, tetanus, acellular pertussis)	2, 4, 6, 15–18 months, 4–6 years, DTaP not approved over age 7	5	
Td (Tetanus and diphtheria toxoid)	11–16 years	1	
<i>H. influenzae</i> B	2, 4, 6, 12–15 months	4	
IPV (Inactivated poliovirus)	2, 4, 6–18 months, 4–6 years	4	
MMR (Measles, mumps, and rubella)	12–15 months (#1) 4–6 years (#2)	2	11–18 years (#2)
Varicella	12–18 months	1	2–18 years, >13 years 2 doses, 4 weeks apart
Pneumococcal	2, 4, 6, 12–18 months (PCV) 2–18 years (PPV)	5	2–4 years (PCV + PPV) >5 years (PPV)
Hepatitis A	2–18 years (2 doses, 6 months apart)	2 (Efficacy in pediatric renal transplant recipients is not established yet)	
Influenza	6 months–18 years (yearly)	Every year	

## V. Dental Care

### *Why does my child need dental care before and after kidney transplant?*

The mouth has a large number of bacteria in it. The use of transplant medications after transplantation makes it harder for the body to fight infection. A bad dental cavity may turn into a tooth abscess if the immune system is low. Some of the drugs used after transplant, such as Neoral® (cyclosporine) and Norvasc® (amlodipine), may cause gum swelling. This, in turn, leads to bad gum disease. It is important for your child to go to the dentist before transplant. Have your child's teeth cleaned and all cavities filled.

### *What can I do at home to keep my child's teeth healthy?*

Have your child brush and floss his or her teeth regularly. Your child should have a dental checkup every 6 months after transplant. Wait 3 months after transplant to have any dental care done, unless it is an emergency.

### *What should I do if my child has a dental appointment?*

Your child should have antibiotics before any dental work. They will help lower the chance of an infection in the mouth or gum during the dental work. It will protect your child. It will help your child have good dental care and prevent infections.

Remember that the following steps are recommended for any dental care:

1. Make an appointment with your dentist.
2. Tell your dentist that your child has a kidney transplant and is on transplant medicine.
3. Your child will need to take a dose of antibiotic **before** any dental work is done. This includes cleaning and polishing. It includes orthodontic work as well. The antibiotic is usually given by mouth 1 hour before dental work. You may call your child's doctor or kidney doctor for a prescription.

### *What about the use of braces after kidney transplant?*

Many children and teens get braces after transplant without problem. If a lot of cleaning or dental work needs to be done, your child should have antibiotics before the dental work starts.

## **VI. Ophthalmologic (Eye) Care**

One of the side effects of prednisone is that cataracts can form on the eyes. Therefore, all children should have dilated eye examinations **once a year** while they are on prednisone. If your child complains of blurry vision, take him or her to the ophthalmologist sooner.

## **VII. Skin Care**

Transplant patients have a higher risk of developing skin cancer as adults. The transplant medications that allow your child's kidney to work and survive increase the risk of skin cancer. This is mostly true in areas that are very sunny. It is very important that children with kidney transplants and their families know about how to protect themselves from the sun. This should be done both before and after the transplant. Children with a lot of moles or unusual moles need to be checked by a dermatologist before transplant.

Prevention of skin cancer means daily use of a sunscreen with a sun protection factor (SPF) of 30 or more. Clothing with long sleeves and a tight fabric weave should be worn outdoors as well as a broad-brimmed hat. Stay out of the direct sun between 10 AM and 4 PM as much as possible. Tanning beds should not be used.

Transplant patients could have problems with warts. They may have more and larger warts that last longer and are harder to treat. The transplant medications may make it harder for your child to fight off the virus that causes warts. If your child has too many large or painful warts before transplant, he or she should be checked by a dermatologist who has skill in dealing with warts in children.

Useful Web sites:

<http://www.itscc.org>

<http://www.scopnetwork.com>

## **VIII. Nutrition and Diet After Kidney Transplant**

Diet plays a very important role in promoting good health and well-being after a kidney transplant. This is done by eating a well-balanced, varied, and heart-healthy diet. Your child's diet will change after a kidney transplant.

### **General Recommendations**

**Protein Intake.** In the first 6 months after transplant, your child should eat more protein. It will help your child heal from the surgery and offset the side effects of prednisone. (Prednisone in high doses can cause breakdown of muscle protein.) The best sources of protein:

- Meats, fish, poultry
- Low-fat dairy products (milk, yogurt, cheese)
- Eggs
- Nuts
- Dried beans, lentils, peas
- Soybeans, soy milk, tofu

**Bone Health.** Long-term use of prednisone may place your child at increased risk for osteoporosis (weakening of bones) and bone fractures. It is therefore very important to get enough vitamin D and calcium from food. Some good sources of calcium:

- Milk
- Cheese
- Yogurt
- Canned salmon or sardines with bones
- Calcium-fortified orange juice

(When possible choose lower-fat milk products. This will help control weight gain and promote a heart-healthy diet.)

You will need to increase the phosphorus in your child's diet. The best sources:

- Dairy products
- Nuts and nut butters
- Dried beans, lentils, peas
- Seeds

**Potassium Intake.** Your child will be able to have normal amounts of potassium-containing foods.

**Sodium.** In general, salt does not have to be restricted after transplant. But in some children, it may be a good thing to do. One of the medications, prednisone, can cause fluid to build up in the body. Limiting the salt in some children can help control bloating, fluid buildup, and high blood pressure. These foods are high in sodium:

- Salt
- Cured meats (bacon, ham)
- Luncheon meats
- Canned or dried soups
- Ethnic foods: Chinese, Japanese, Mexican, Italian
- Sauces: Worcestershire, chile, soy
- Prepared casseroles
- Macaroni and cheese mixes

Ask your doctor if you need to restrict the salt in your child's diet. The dietitian will meet with you if this is needed. For babies with kidney transplants, extra salt may be needed to keep a good blood flow to the new kidney.

**Heart-Healthy Diet.** Some transplant medications will raise your child's cholesterol levels. This in turn is known to increase the risk of getting heart disease. To help lower cholesterol levels:

- Limit the total amount of fat in the diet as well as the saturated fat (fat from animals). Choose low-fat dairy products (skim or 1% milk, low-fat cheese, yogurt, ice milk) and lean meats.
- Avoid fat listed as animal or vegetable shortening, lard, palm, and coconut oil.
- Choose olive and canola oil and nonhydrogenated margarines.
- Increase high-fiber foods. Fiber helps to keep cholesterol from being absorbed. Fresh fruits, vegetables, and whole-grain products are high-fiber foods.

**Food Safety.** Transplant medications place your child at a higher risk for infections, so it is very important to prevent illness that comes from food.

*Safe food handling is a must!*

- Wash hands often. Always wash before handling food.
- Wash fruits and vegetables under running water.
- Separate foods to be eaten raw from raw meats. Use separate cutting boards.
- Sanitize sinks and chopping boards with ½ teaspoon bleach in 2 cups water.
- Use a fast check thermometer to check the temperature of cooked meats.
- Hot dogs, hamburger, and sausage must be well cooked (160 degrees) even if they are irradiated.

Do not share utensils or food.

Do not eat these foods raw: eggs, milk (unpasteurized), seafood, and poultry.

## COMMON QUESTIONS ABOUT THE DIET AFTER KIDNEY TRANSPLANT

### *My child is gaining a lot of weight after transplantation. Is this healthy?*

A common problem with transplant patients is gaining too much weight. Babies, children, and teens are expected to gain weight as they get older. It is needed for growth. But a large weight gain can easily happen:

- Your child can eat his or her favorite foods again.
- Your child has a much better appetite.
- Prednisone can increase his or her appetite.
- Food tastes better!

Eating too much and lack of exercise lead to obesity. This leads to high blood pressure and diabetes and may lead to heart attack and stroke. Even at normal weights, transplant patients are at higher risk for diabetes, high cholesterol, and heart disease for many reasons. Obesity adds to his or her risk. It can also hurt your child's self-image, especially in teenage years.

A healthy life style is the key to controlling your child's weight gain and reducing his or her risk for heart disease. It includes regular exercise and a healthy, well-balanced, low-fat diet. You can learn more about this by linking to <http://www.niddk.nih.gov/health/nutrit/pubs/helpchld.htm>.

### *What shall I do to prevent excessive weight gain?*

Excessive weight gain can be prevented. Try these strategies to help your child keep from gaining too much weight.

- Limit high-fat foods: fast food, fried foods, chips and other high-fat snacks, cakes, donuts, pastries.
- Avoid “simple” sugars: sugar, sweets, soda pop, and drinking too much juice. This will become even more important if your child gets high blood sugar, a possible side effect of prednisone and other transplant medications.
- Let your child eat 3 meals a day with average helpings. Serve many different kinds of food. Avoid too much snacking.
- Have many kinds of healthy low-fat snacks on hand for when your child cannot control the “munchies”. Some of these are raw vegetables, fruits, and unsalted, unbuttered popcorn.
- Regular exercise is a very important part of keeping a healthy body weight. Any exercise should be discussed with your transplant nurse and doctor. In general, it is suggested that children have some physical activity 3 times per week for at least 30 minutes.

### *My doctor tells me that my child's transplant kidney is still slow to start. What diet is good for my child?*

If your child's new kidney is slow to start, your child may need to remain on his or her kidney diet. This means limits on sodium, potassium, phosphorus, and fluid. But, as the kidney begins to work, your child will be able to have many more kinds of food.

### *My child was on fluid restriction before transplantation. Should my child drink more fluids now that the kidney is working well?*

Once your child has normal kidney function, your child will need to drink more fluid, preferably water, each day. The amount of fluid will depend on his or her weight. The more he or she weighs, the more he or she will need to drink: possibly up to 8 glasses of fluid a day. The transplant team will make sure you are clear about your child's new fluid goals at the time of transplant. In general, it is very important for your child to keep from getting dehydrated. This means drinking a generous amount of fluid each day.

### *My child had been on tube feeding for a long time. Should I stop the tube feeding after transplantation?*

Some children, mostly those under the age of 5 years, have been on tube feedings before their transplants. Those children may have not eaten solid foods at all. Or they may have only nibbled food now and then in the months or years before their transplants. The good news is that most children who have been on tube feedings are able to stop the tube feedings and go on to eat a normal diet after transplantation.

Some children can begin to eat right away. But most children will take a few weeks or months to slowly decrease their tube feeding and slowly increase eating. The formula used for the tube feeding will most likely change right after transplantation. The new formula will have normal amounts of potassium and phosphorus. It will have higher amounts of protein as well. Some children may need to work with a feeding specialist to help them eat normally again. At times after transplant, the feeding tube is used at night to give more fluids.

## IX. Growth After Kidney Transplant

Children with kidney failure have problems with growth and are shorter than their peers. One of the main causes of poor growth in kidney failure is that the body does not respond to its own growth hormone. Children with kidney disease can grow if they are given growth hormone.

### *Will my child grow normally after kidney transplant with good kidney function?*

After transplant, growth can still be slow in children, even if the new kidney works well, because of the transplant medication, prednisone. Younger children tend to have the best growth rates after transplantation. If your child is not growing well, your doctor may discuss changing the prednisone dosage. He or she may even want to start treatment with growth hormone.

### *My child was on growth-hormone treatment before kidney transplant. Can he or she continue on it?*

Some children grow very well after transplantation, especially if the kidney works well. Your child may or may not need growth hormone after transplantation. If your child is not growing enough, please talk with your transplant doctor about the growth hormone. Your child should have stable kidney function with no rejection under way before going back on the growth hormone.

### *What is a good time to start growth-hormone therapy in my child after kidney transplantation?*

- It is best to start the growth hormone when kidney function is stable and when prednisone dose is low. This can vary from center to center. Most of the time it is started 6 months after the transplantation. Sometimes a kidney biopsy is done before starting this treatment.
- It is best to give growth hormone to children before they go through puberty. Bone x-rays are done before starting growth-hormone treatment to see how much the child might be able to grow.

### *What are the side effects of growth-hormone therapy in children after transplantation?*

Growth hormone can do the following:

- Excite the immune system. This means your child's kidney function must be closely checked while on the growth hormone.
- Increase serum creatinine suddenly for no known reason. This is a blood test used to measure kidney function.
- Found in some studies to increase acute rejection in children who had more than one rejection in the past. This does not seem to happen in stable patients.
- Can make kidney function worse. It could do this by increasing the body's attempts to reject the kidney.
- Treatment might require changes of some medications (such as prednisone).
- May cause high blood sugar, diabetes, and headache after transplant.
- Cancer has been reported in patients receiving growth-hormone treatment.

## X. Importance of Adherence With Medical Care

Kidney transplant is a major procedure. It can be very challenging at times and hard to manage. It means you have to take a number of medications. You will have to change your life style as well. It can be overwhelming at times, especially for a teenager. It is very important to keep working closely with the transplant team to keep your kidney healthy. The team is there to help you during the hard times.

Nonadherence means failure to follow up or to stick to a treatment plan suggested by your transplant team. It happens most often in children and teens between 11 and 15 years of age. It can cause loss of the kidney transplant. The teen years are times when feelings about independence, body image, and acceptance by peers are very strong. Some of the transplant drugs cause changes in how a person looks and will create a problem with body image. Taking medicine throughout the day may become socially awkward as well. It can all be very frustrating for a teen.

Nonadherence can happen in different ways:

- Not taking medicine on time or as instructed
- Not keeping up with medical appointments
- Not getting needed blood tests
- Not taking medical advice about diet, activity, or other issues

Tips and facts to help you keep your kidney healthy as long as possible:

- Keeping a kidney transplant healthy means a change in life style. It will take some discipline.
- Keeping a kidney healthy can sometimes be very stressful. Please talk to your transplant team about your concerns.
- If you have crises in your life, please contact your transplant team at once for help.
- Taking your medications regularly every day and on time is very important. It is the only way to keep your body from rejecting your kidney. This can happen even after many years of having a stable transplant if you stop taking your transplant drugs suddenly or if you do not take them as instructed.
- If the medications get in the way of your daily activity, or you are having bad side effects, please talk to the transplant team. There may be changes in your medications that can be made to help you. Do not stop or change medication on your own.
- If your insurance coverage is running out, please talk to your transplant team. They will help you find a way to get you the medications without a break in your treatment.
- Keep your regular doctors' appointments.
- If you are close to 18 years of age and worry about being switched to adult nephrology care, please discuss your concerns with your regular transplant doctor. Sometimes this transfer can be delayed or done slowly until you get to know your new adult nephrologist.
- Always remember that if you lose your kidney because of nonadherence you will go back on dialysis. You may be on it for a long period of time before you can get another kidney. Dialysis is not a good alternative to transplant. You will still need to take a lot of medications for your kidney failure.

## **XI. Life of the Kidney and the Need for Future Transplants**

The use of new transplant drugs to keep the body from rejecting the kidney has made it possible to keep a new kidney for a long time. A key point in keeping the kidney working well is staying on a strict medication schedule and following medical advice. Some kidneys can work for many years. The average life of a kidney transplant is about 10 years. Some can keep working for a longer time. Children can get a second or a third kidney transplant if the first one fails. Remember that many new advances and new medications are being introduced every day. We expect transplanted kidneys to keep working longer in the future. These days, children with kidney transplants can live normal lives. They can look to a bright future like all other children.

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# *SEXUALITY AND REPRODUCTIVE HEALTH FOR TEENAGERS AND YOUNG ADULTS WITH KIDNEY TRANSPLANTS*

In this section of the brochure, we discuss the following:

- Common questions about sexuality and the transplant recipient
  - Including safe sex, birth control, sexually transmitted diseases (STDs), and pregnancy
- Some myths and facts
- Regular sexual health checkups

Questions that often arise with teenagers who have had kidney transplants include the following:

- What if I don't want to have sex and my partner is pushing me? How can I say no?
- What is safe sex?
- Can I get pregnant?
- Can I father a child?
- Will the medications I take affect my baby?
- Will the disease that affected my kidney be passed on to my children?
- Will I lose my graft if I get pregnant?
- What about sexually transmitted diseases (STDs)? Do they mean the same for me as for others?
- I know safe sex is important, but my partner doesn't agree. What should I do?

## *DECIDING TO HAVE SEX*

Sex is a loving experience between 2 people: something to cherish. The first time should be particularly special. Decide ahead of time when and what is right for you.

There's plenty of pressure on young people to have sex. TV and movies might make you think there's a lot you're missing. Remember, most TV shows and movies exaggerate. Don't feel pressured. Your sex life is your own business. When, with whom, and how you make love are your choices. You have the right to say no any time you want. If you want to put it off until later, it's up to you to say what you want.

If the decisions are troubling you, take time to talk to an adult you trust: your parents, a friend, your nurse, your doctor, a school counselor, or religious leader. These things can usually be discussed privately. You have the right to ask in advance if your conversation will stay private. All health professionals must keep talks with patients confidential. They can't tell your parents what you've been talking about unless you give them permission.

Even if you're not yet ready to start having sex, it's important to know about safe sex. That way you'll be prepared to make good choices when the time is right.

### **Safe Sex**

Important things to think about before deciding to have sex are the possibilities of pregnancy and of STDs. Hugging, kissing, caressing, massaging: They're all part of safer sex and not complicated. If you decide to do more, you and your partner need protection. This and more are discussed below.

## Myths

- I can't get pregnant now that I've had a transplant.
- I look younger than my friends, so I can't get pregnant.
- The disease I had before transplant affected my fertility. I don't need to worry.
- I'm tired of being treated like a child because I'm small. If I have a baby or have sex, people will start to treat me like an adult.
- I want to be accepted by my friends, and the only way is to have sex.
- STDs affect others, not people like me.

## Facts

- Almost any young woman can get pregnant. Never assume you can't!
- Almost any young man can make a girl pregnant. Never assume you can't!
- Fertility isn't an "all or none" thing. Some medical conditions may reduce fertility, but all that is needed for pregnancy to occur is one egg and one sperm.
- Having a baby before you're ready can make your life very difficult. Think about it carefully.
- Real friends don't pressure you to do things you don't feel right about.
- Even if someone looks great, you can't be sure they don't have an STD or even HIV. Anyone can get an STD if they don't protect themselves, whether they're gay or straight, fertile or infertile.

## Prevention of Pregnancy

If you're thinking about having sex, you probably want to know about preventing an unplanned pregnancy. Here we discuss the types of birth control teenagers use most often. Even if most methods depend on the girl to do or take something, it's really important for guys to understand and support their girlfriends. Don't forget; only the condom can prevent STDs.

No method of birth control works perfectly! There is always some risk of pregnancy. However, the risk can be quite small with correct use of the birth control methods described. However, many sexual activities are almost always safe without any special precautions. These include holding hands, hugging, touching, and kissing.

## ***BIRTH CONTROL METHODS USED MOST OFTEN BY YOUNG PEOPLE***

### Overview

- Hormonal Methods

These include birth control pills and Depo-Provera® shots. The hormones stop the egg from leaving the ovary. They also make the mucus in the vagina too thick for sperm to move in. They prevent pregnancy between 70% and 99% of the time.

All medicines have side effects. You need to speak to your doctor to find out which pill is best for you. A specialist in gynecology or adolescent (teen) medicine can be very helpful.

Important things to tell your doctor:

- The other medications you take for your transplant
- If you have migraines: in particular, the kind with flashing lights or that make parts of your body numb or weak
- If you have had problems with clots; these can be clots in your dialysis fistula or catheter, in your legs or lungs, after surgery, or at any other time.

If anyone in your family has had clots and became very sick or died from them (especially if they were young when it happened). Most women taking birth control pills have no problems at all. If you have a problem, your doctor might be able to switch your pill to a slightly different one. That often takes care of it.

- Barrier Methods

These include the condom and the intrauterine device (IUD). The condom is a popular method. It blocks the sperm from getting to the egg. Used the right way, condoms prevent pregnancy 60% to 85% of the time. Condoms are the only good protection against STDs. Transplant recipients should never use the IUD. The risk for infection is too high. Along with using a condom each time, many young women and their male partners want more protection from pregnancy. The condom is very good at preventing STDs. The hormonal methods are better for preventing pregnancy.

#### Birth Control Methods *That Don't Work Well*

- The “Withdrawal” Method
- The “Rhythm” Method

#### Emergency Contraception (“Morning-After Pill”)

This may be used in an emergency. It can't prevent all pregnancies, but it can help a lot. The doctor gives you a few special hormone pills to take right away and some more to take 12 hours later.

The morning-after pill must be started within 72 hours (less than 3 days) after having sex, and the sooner the better. If you can't reach your own doctor, call your local emergency clinic. Remember to tell the doctor about the other medications you take for your transplant. You may find it helpful to tell an adult you trust that you're worried about being pregnant and what happened. Then you need to decide what birth control method will work best for you in the future.

Call your doctor if

- You have questions about sex.
- Your period is more than a week late and you had sex with someone.
- You know the condom broke, or you didn't use one, and no other method of birth control is being used.
- You think you might need emergency contraception (the morning-after pill).

Useful Web sites:

[http://www.plannedparenthood.org/bc/030205\\_bc4teens.htm](http://www.plannedparenthood.org/bc/030205_bc4teens.htm). Accessed July 27, 2005.

[http://kidshealth.org/teen/sexual\\_health/contraception/contraception.html](http://kidshealth.org/teen/sexual_health/contraception/contraception.html). Accessed July 27, 2005.

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[http://kidshealth.org/teen/sexual\\_health/contraception/contraception\\_condom.html](http://kidshealth.org/teen/sexual_health/contraception/contraception_condom.html). Accessed July 27, 2005.

## ***SEXUALLY TRANSMITTED DISEASES***

### **About STDs**

It is especially important for transplant patients to keep from getting STDs. The transplant drugs they take make the risk of infection and of serious problems higher. There are heaps of different STDs, but they all have one thing in common: They are spread from one person to another during some type of sexual activity.

- Well-known STDs include chlamydia, gonorrhea, herpes, crab lice, syphilis, condylomata (genital warts), trichomoniasis, HIV (the virus that causes AIDS), and hepatitis B (a liver disease).
- Some STDs are much more dangerous than others and can make you very sick.
- Some can be deadly.
- There are treatments for some STDs, but not for all of them. Prevention is very important.
- Often a person can have an STD and not know it because they have no symptoms and don't feel sick. (This is especially true for chlamydia.) They can spread the disease to their sexual partners if they are not careful.

## Prevention of STDs

### Safer Sex

- Many activities are almost always safe without any need for precautions. These include holding hands, hugging, kissing, and touching.
- If you choose to have intercourse, you can protect yourself against almost all of the STDs. You do this by using condoms each and every time.

### Other STD Facts

- You're more likely to get an STD if you have more than one sexual partner or if your partner has had other partners before you.
- You can get the same STD more than once, even if you've been treated.
- You can get an STD even if you have sex just one time.
- The "withdrawal method" does not prevent STDs.
- If you think you may have an STD, you must get treated as soon as possible.

### Call your doctor if

- You have any symptoms you think might be from an STD; don't wait! You can also go to an STD clinic or community health center.
  - Examples of STD symptoms:
    - > Burning or pain when urinating
    - > Strange or weird-smelling discharge from the vagina or penis
    - > Itching, burning, or pain around the vagina, penis, or anus (bottom)
    - > Rashes, sores, blisters, or growths around the vagina, penis, or anus.
- You think you might have had sex with someone who had an STD.

### *So, you don't feel like using a condom anymore?*

If you're in a stable relationship, and both have only one partner, or if you're married or living together, maybe you're thinking of not using condoms. Before you make that decision, both you and your partner should be tested for HIV and other STDs. The same goes if you're trying to get pregnant. If the results of the tests are negative, you can stop using condoms for as long as you both stay faithful to each other.

## Pelvic Inflammatory Disease

### *What is it?*

Pelvic inflammatory disease (PID) is an infection that starts in the uterus and moves into one or both fallopian tubes. (These are the tubes that connect the uterus to the ovaries.) From there it can move to the ovaries and can spread into the abdomen as well. The organisms that cause STDs can cause PID. (Gonorrhea and chlamydia are common causes of PID.) Symptoms may include the following:

- Lower stomach pain
- Thick, creamy, yellow, or clear vaginal discharge
- Bleeding or spotting between periods
- Fever or chills
- Pain during sex
- Pain or burning when you go to the bathroom

A doctor must always check you to see if you have PID.

PID is a very serious infection. It increases your risk of pregnancy outside the uterus and of not being able to have children. The outcome depends on the following:

- How long you have been infected and how much the PID has spread
- Proper and early treatment
- The number of PID infections you have had

### How do you treat PID?

1. **Antibiotics.** It is very important to take all the medicine prescribed. Don't forget to tell your doctor about your other transplant drugs. Some antibiotics can change your drug levels and affect your kidney function.
2. **Contacts.** Everyone you've had sex with in the last 3 months must also be treated, even if they have no symptoms. Don't have sex until both you and your partner have finished all the medicine.
3. **Follow-up.** See your doctor again 2 to 3 days after you start your treatment to make sure the infection is under control. See the doctor again 1 week after you finish all the medicine. You need to make sure that it is gone.
4. **Prevention.** See the section on STD prevention. STDs can cause PID.

Call your doctor immediately if

- Your pain gets worse
- You vomit and cannot keep your medication down
- You have a fever higher than 101°F (38.4°C)
- You feel you are getting sicker

## OTHER HEALTH ISSUES RELATED TO SEXUAL ACTIVITY

### Urinary Tract Infections

Many women get urinary tract infections (UTIs) after sex, even if they've never had them before. Some women with kidney transplants may have had problems with UTIs before. These may get worse or more frequent after sex.

These UTIs happen because the tube that drains the bladder is right in front of the vagina. This tube is called the urethra. During sex, the movement of the penis in the vagina rubs the wall of the urethra next to it. This can push bacteria from the urethra up into the bladder.

For women with a kidney transplant, UTIs may be quite serious because of the transplant drugs they take. Sometimes the infection can invade the bloodstream. This can make you very, very sick. Another concern with UTIs for transplant patients is that they can lead to damage of the kidney graft.

Symptoms of a UTI may include the following:

- Pain or burning during urination
- Pain in the lower abdomen
- Fever or chills
- Foul-smelling urine

If you think you have a UTI, call your transplant team or regular doctor at once. It is important to get your urine tested as soon as you have symptoms. You need to have both a urinalysis (rapid test) and a urine culture. Remember that the urinalysis may not always show an infection in a transplant patient. This is due to the transplant drugs. If you have UTI symptoms, ask your doctor if you can start treatment while you wait for the results of the urine culture, even if the urinalysis is normal. Medicine can be changed if needed when the culture results come in.

Don't forget that some antibiotics may react with your transplant drugs. Always discuss this with the doctor.

If you get a lot of UTIs after having sex, talk with your doctor about ways to prevent them. Some women need to take an antibiotic, either after sex or every night. Your doctor and transplant nurse can help you find the method that works best for you.

### Yeast Infections (Thrush)

Many women have problems with yeast infections. These are most often caused by an organism called *Candida*. Yeast normally live in the bowel. They can grow out of control when antibiotics upset the balance between the "good" bowel bacteria and the yeast. Yeast infections may be more of a problem after puberty. They are also a problem for people who take a lot of antibiotics or who are on transplant drugs. Men may get yeast infections as well, but they tend to be less frequent.

Yeast (thrush) shows up most often in the mouth and vagina. In the mouth, there may be redness with white spots. In a vaginal yeast infection, women may have itching, burning, and a white “cheesy” discharge. Thrush is easy to treat with antifungal creams or oral medicines. It is important to see your health-care provider to be sure it is a yeast infection before starting treatment.

Once in a while, yeast infections can be more serious. This happens when they invade the bloodstream or the kidney. That's why it is important to find and treat them early.

People sometimes use natural remedies to treat thrush. Always discuss this with your transplant doctor or nurse first. Some of these remedies may interact with your transplant drugs. This can cause serious side effects. Others can sometimes be harmful to kidneys.

*Above all, don't stop your transplant drugs.*

## ***DECIDING TO HAVE A BABY***

This is a very big decision for anyone. As a patient with a kidney transplant, you have extra things to think about, such as the impact on your own health.

If you decide it's the right time for you to have a baby, there are many things to think about. You need to talk to your transplant doctor and nurse before you start trying to become pregnant. You should also see an obstetrician (specialist in pregnancy) who has taken care of other transplant patients.

- For women, it's best to wait until 2 years after transplant to become pregnant. By that time, you are taking a lower dose of your transplant medicine, and your graft function is stable.
- Pregnancy is generally safe if you have the following:
  - Good graft function
  - No protein in the urine
  - Normal blood pressure
  - No ongoing rejection
  - A normal ultrasound of your kidney graft
- Pregnancy after a transplant is seen as a high-risk pregnancy and should be watched closely by both your transplant doctor and obstetrician. You will have a higher risk of the following:
  - Kidney infection
  - High blood pressure
  - Anemia (low blood count)
  - Protein in the urine
  - Premature birth
  - Perhaps an increased chance of a rejection event

### *Can your baby get the same disease that affected your native kidneys?*

This is a very important question. It is something you need to discuss with your transplant specialist. Some diseases that lead to kidney failure in children may be inherited, but not all are. Your doctor will be able to help you sort this out. If there is a chance that your condition was inherited, you can ask to talk to a genetic counselor. The best time to do this is before you get pregnant. Genetic testing may be possible. This can be done before you decide to have a baby or early in your pregnancy. You need to discuss these issues, as early as possible, with your transplant doctor and obstetrician.

This is a list of drugs for transplant patients that must be changed to something else if you're pregnant:

- Mycophenolate mofetil (MMF or CellCept®)
- Sirolimus (Rapamycin®)
- Angiotensin-converting enzyme (ACE) inhibitors
- Angiotensin II receptor blockers (ARBs)

This is a list of drugs that are thought to be low risk during pregnancy:

- Cyclosporine
- Tacrolimus
- Azathioprine
- Prednisone

## ***SEXUAL HEALTH CHECKUPS***

Even if you're not having sex, you should have regular checks of your sexual and reproductive health. This is definitely the case once you become sexually active.

For women, this means breast checks and, once you're having sex, Pap smears. Pap smears are done to look for cancer of the cervix. If it is found early, cancer of the cervix is easy to treat. If found late, it can be very serious. You can also discuss your periods and whether you have problems with a large amount of blood loss or bad menstrual cramps. There are ways to help these problems.

For men, regular testicular exams are important. Cancer of the testis is the most common cancer found in teens and young men.

Your family doctor can show you how to do breast or testicular self-exams as well.

Transplant patients need to be on the lookout for early signs of cancer before it spreads. The medicine you take to keep your kidney healthy lowers your body's defenses to certain types of cancer. But the good news is that finding cancer early makes the chance of successful treatment much, much higher.

*You're in control. You need to schedule your regular checkups.*

## ***CERVICAL CANCER***

*What is it, and how does it occur?*

The cervix is where the uterus joins the vagina. Cervical cancer is one of the most common cancers found in women. It affects women with transplants more than 3 times as often. The most common type, squamous cervical cancer, may be caused by an STD, the human papillomavirus (HPV). This virus causes genital warts as well. A Pap smear may find cervical cancer at an early stage.

You are at greater risk for cervical cancer under the following circumstances:

- You have had an organ transplant.
- You have an abnormal Pap smear.
- You or your sexual partner has or had genital warts.
- You have many sexual partners.
- Your partner has had many partners in the past.
- You don't use condoms.
- Your sexual partner's previous partner had cervical cancer or abnormal cells on the cervix.
- Your sexual partner has or had cancer of the penis.
- You smoke cigarettes.
- Your mother took the hormone DES while pregnant with you.

### *What are the symptoms of cervical cancer?*

- Early on, there are no symptoms. It is usually found by a Pap smear and pelvic exam. Young women should start having Pap smears and pelvic exams as soon as they start to have sex.
- Later, symptoms may include the following:
  - Abnormal vaginal bleeding
  - A bloodstained discharge at unexpected times, such as between menstrual periods or after sex
  - An abnormal vaginal discharge: cloudy or bloody, or mucus with a bad odor

### *How is cervical cancer diagnosed?*

Your doctor will take a Pap smear. During this test, a small spatula (like a Popsicle stick) and tiny brush are used to gently scrape cells from the cervix. The cells are spread on a glass slide and sent to a lab. The earlier this cancer is found and treated, the better the chance that you will be able to have children.

### *What can you do to help prevent cervical cancer?*

- Avoid having a lot of different sexual partners.
- To reduce your risk, your partner should also have as few partners as possible.
- Use latex condoms every time you have sex, especially if you or your partner have had many partners in the past.
- Have regular gynecology checkups, with a Pap smear, once you begin to have sex.
- Women with a transplant should have a Pap smear every 6 to 12 months.
- If you have an abnormal vaginal discharge, bleeding between periods or with sex, or painful intercourse, see your doctor as soon as possible.
- Don't smoke.

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