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Getting A New Pancreas: Facts About Pancreas Transplants

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Getting a New Pancreas

FACTS ABOUT A NEW PANCREAS

Getting a new pancreas involves placing a healthy pancreas that produces insulin into a patient whose old pancreas does not make insulin.

The potential benefits are:

- You may be able to have normal sugar levels in your blood without taking insulin
- improved quality of life
- prevention of complications from diabetes.

The tradeoffs are:

- the need to take anti-rejection medicines for the rest of your life
- to have the operation to get the new pancreas that has risks of complications

When you get a new pancreas there is a lot of planning and work to do before and after the operation. Before the operation, you will work with the transplant team to complete an evaluation that requires many studies and many visits to the doctor. These may take a long time to complete. After the operation, you will need to make frequent visits to the clinic to see your transplant team. These visits are to make sure your pancreas is working well and that you stay in good health.

You, the transplant team, and your family and caregivers will work together to keep you and your new pancreas healthy.

WHAT DOES A PANCREAS DO?

The pancreas is an organ near your stomach that makes insulin. Insulin helps the cells in your body process sugar. The reason you are receiving a new pancreas is to obtain healthy insulin-producing cells. The pancreas also has cells that make digestive juices. When you receive a new pancreas, the juices from the new pancreas will empty into a small section of the donor's intestine that also is transplanted along with the pancreas. During surgery, the surgeons will connect this small piece of intestine attached to the new pancreas to your intestine so the digestive juices can drain. Sometimes this small piece of intestine is connected to your bladder.

WHAT IS DIABETES?

Diabetes affects millions of people worldwide. When a person has diabetes, his or her body either cannot make enough insulin or

is unable to use insulin in the right way to control the amount of sugar in the blood.

Insulin is a hormone. This hormone changes sugar, starches, and other foods into energy. Your body needs this energy every day to function. If a family member has diabetes, you may have a higher chance of getting it.

HOW INSULIN WORKS

Insulin is a hormone that regulates absorption of sugar (glucose) into your cells. Once inside the cell, glucose turns into energy. When the body does not make enough insulin, this creates a lot of sugar in the blood. This condition is called high blood sugar. When too much sugar ends up in the blood, instead of in the cells, it can cause two problems:

1. Right away, your cells will not have any energy.
2. After some time, high blood sugar can harm your eyes, kidneys, nerves, or heart.

The two main types of diabetes are type 1 and type 2.

- **Type 1 diabetes**

About 1 million people have type 1 diabetes in the United States today. This is also called juvenile diabetes, because it is the type that affects children and young adults. With type 1 diabetes, the pancreas does not make insulin. People with type 1 diabetes must take insulin shots every day.

- **Type 2 diabetes**

About 18 million Americans have type 2 diabetes. This type of diabetes happens when the body cannot use insulin the right way, or does not make enough insulin. People can often control type 2 diabetes with lifestyle changes, such as having a healthy diet, and exercising regularly. It is important to maintain a healthy weight. Some people may need to take pills, insulin injections, or both to control their diabetes.

Note: Your transplant team will work with you to see if a new pancreas will allow you not to have to take insulin every day.

HOW DOES A NEW PANCREAS HELP SOMEONE WITH DIABETES?

- You will no longer need insulin shots.
- You will be able to eat a regular diet.
- You will have fewer or no reactions from low blood sugar or insulin.
- You will not need to monitor blood sugar as often.

- The risk of secondary complications from diabetes, such as kidney disease and nerve damage, may remain the same or decrease.

WHAT ARE THE DIFFERENT TYPES OF PANCREAS TRANSPLANTS?

There are three types of pancreas transplants:

- **Pancreas and kidney transplant at the same time**
This transplant is for patients who have diabetes and kidney failure. This is the kind of transplant a patient has when there is no living kidney donor.
- **Pancreas transplant after a kidney transplant**
This transplant is for patients with diabetes who have already had a kidney transplant (from a living or a deceased donor).
- **Pancreas transplant only**
This transplant is for patients with diabetes who have major complications, such as dangerously low blood sugar or severe eye problems. This transplant is also for patients with diabetes who do not have kidney disease.

Your transplant team will help you decide which type of transplant is best for you.

WHAT HAPPENS WHEN YOU GET A NEW PANCREAS?

There are four steps involved in getting a new pancreas. Your transplant team will:

1. Decide if you qualify for a new pancreas and are healthy enough for the operation.
2. Help you to prepare for your operation.
3. Perform the pancreas transplant operation.
4. Help you stay healthy after the transplant.

Step 1: Decide if you qualify for a new pancreas and are healthy enough for the operation

Before you get a new pancreas, you need to know that getting a pancreas depends on your physical and mental health. It depends on the people who give you social support. It also depends on your ability to get the medicines you need.

In order to be considered for a new pancreas, your diabetes specialist needs to refer you to a transplant center. You will receive an invitation from the center for an educational session and an appointment to complete a multidisciplinary pre-transplant evaluation.

There are four parts to this step.

1. First, you will visit a transplant center.

You, your doctor, a nurse, or a social worker can schedule this visit. Your doctor's office will send your medical records to the transplant center before your appointment. Your medical records will help determine if you are a possible candidate to receive a new pancreas. Your medical records will also help to confirm that you follow all the instructions and recommendations made by your endocrinologist and other member of your healthcare team.

2. Your physical health will be evaluated.

While transplants are life-saving, they are also complicated, risky operations.

The four main concerns that need to be addressed about your health include:

- Is your heart in good enough shape to tolerate the operation and recovery?
- Are you free of cancer and is your risk to get cancer low?
- Are you free of infection and is the risk to get infections low?
- Is your body in good enough shape to 'fit an organ in' safely?

The reasons for these concerns are the following:

- Heart disease is the main reason people have life-threatening complications in the operating room and after surgery. Heart disease is the leading reason people die after transplant.
- After receiving a new organ, the medicines you take to help prevent your body from rejecting the new organ slightly increase your risk of getting cancer. Any existing cancer can grow very rapidly if it is not found before surgery. Skin cancer is the most common cancer, so wear sunscreen, wear a hat, and stay in the shade.
- After receiving a new organ, the medicines you take to help prevent your body from rejecting the new organ increase your risk of getting infections or allowing 'old' infections to 'wakeup' in your body. These include infections like CMV, tuberculosis, or shingles.
- A operation to receive a new organ may be too risky for some people. For example, some people's blood vessels become old and plugged up with calcium making a transplant impossible. Others have had too many

operations in the belly causing scarring which may make it hard to perform the transplant. Others may be at high risk for infections in their wounds due to significant obesity.

The specific tests you need depends on your age, sex, and past history. The decision is made by the transplant team that evaluates you. The following tests may be required: a sample of your blood, X-rays, CT scans, dental exam, prostate evaluation, mammogram, PAP smear, EKG, cardiac stress test, echocardiogram, heart catheterization, or colonoscopy. You may be referred to other specialists.

On the day of the evaluation, you will meet with a group of specialists trained to help you reach the goal of receiving a new organ. The team includes: transplant surgeons, transplant nephrologist, transplant coordinators (nurses), dieticians, social workers, financial coordinators, nurses, psychologists or psychiatrists and transplant pharmacists.

3. Why do I need to see a social worker and a mental health specialists like a psychologist or psychiatrist?

You may need to see a social worker, psychologist or psychiatrist to confirm you are not abusing alcohol or recreational drugs. Your mental health must be assessed to identify emotional conditions that could affect your recovery or jeopardize the good outcome of your transplant.

You will need to see an insurance specialist.

- An insurance specialist will review your insurance to make sure your policy covers the transplant operation, clinic visits, and your anti-rejection medicines needed to keep your new organ healthy and to prevent rejection and infections. Without proper medications, your transplant is likely to fail.

4. Identify the type of pancreas transplant.

Depending on the health of your kidney, you may qualify for a pancreas transplant alone (PTA), or a simultaneous kidney pancreas transplant (SPK), or a pancreas after kidney transplant (PAK). You should discuss which option is best for you with your transplant team.

If the transplant selection committee decides that you are a good candidate for the operation, the team will add you to the United Network for Organ Sharing (UNOS) list and will work with you to keep you active and healthy while you wait for your new kidney.

How can you help? Be sure to send in your monthly blood samples. These samples are use by transplant centers to keep your "matching" up to date and helps centers find the

best pancreas for you. Be sure to let your transplant center know of any recent hospitalizations, surgeries, or transfusions.

Step 2: Preparing for your pancreas operation

Step 2 involves finding a pancreas for you. This can sometimes take a long time.

Your transplant center may give you some handouts to read about your operation. This information will help you get ready for the operation. It will also tell you about your care after the operation. If you are waiting for a kidney and pancreas, consider finding a living donor kidney transplant first, if possible. A kidney transplant before a pancreas transplant can minimize the risks of illness and dying from kidney failure. For more information on how to find a living donor for a kidney transplant, please see the American Society of Transplant (AST) brochure, Getting a New Kidney, Step 2.

While you are waiting for your pancreas operation, it is important to keep in touch with your transplant center. If your health condition changes, be sure to let the transplant center know. If you change medical insurance, you also need to call the center. It is very important that you notify your center immediately if you have address or phone number changes. The transplant center always needs to know how to contact you when an organ becomes available.

It is very important to stay healthy while you wait for your new pancreas.

- If you smoke, you should quit. If you need help quitting, talk to your regular doctor. Patients who smoke after receiving a new pancreas do worse than those who do not smoke. Many transplant centers will not perform pancreas transplants on people who continue to smoke.
- Be careful not to gain too much weight. Some centers may delay your transplant if you gain too much weight. If you need to lose weight, ask your regular doctor to help you with a weight loss plan.
- Keep all your appointments, including any important regular testing, such as having a mammogram or a colonoscopy.
- Do your best to control your blood sugar.
- It is important that you remain healthy while waiting for a new pancreas. If your health changes, your pancreas operation may be delayed or you may no longer be considered a candidate for a new pancreas.

Step 3: Perform the pancreas transplant operation

During this surgery, a healthy pancreas (and kidney if you are getting them together) is placed inside your body. Surgeons will connect the pancreas to your blood vessels. They will also connect the pancreas to either your small intestine or your bladder so the pancreatic juices can drain. The operation will last three to six hours, depending on whether you are getting one or two organs.

Your own kidneys and pancreas will stay in your body. You will have a tube (catheter) inserted into your bladder. You will also have an IV (intravenous line) inserted into a vein in your arm and/or neck. You might also have a tube in your nose that drains to your stomach.

You will stay in the hospital until your doctor feels you are ready to go home. How long you stay in the hospital depends on your health and how well the new organ(s) is/are working. How long you stay in the hospital also depends on how quickly you learn to take care of your new organ/s. The average stay in the hospital is seven to twelve days.

Transplant Medicines

After your operation, you will take strong medicines every day to help your body accept the new organ. Your body is smart and can detect that the organ comes from another person. These medicines will keep your body from rejecting the new pancreas. These medicines are called anti-rejection medicines.

You will need to take these every day for as long as the transplanted organ is in your body.

These medications are also called immunosuppressive medicines. If you stop taking these medicines, even for a short period of time, your body will destroy your new pancreas. You must tell your transplant center if you miss taking your medicine or if you run out of your medicines.

Some Tests You Might Need to Have

- **Transplant ultrasound**

With an ultrasound, doctors can see your pancreas, kidney, and blood stream on a screen. This shows them if there are any problems.

- **Transplant biopsy**

Your doctors will take a small sample of your new organ. They use a needle to remove a tiny piece of kidney or pancreas. This piece is then looked at under a microscope. By looking at the cells, your doctors can find problems like rejection. This test also provides important information that will help the transplant team decide the best treatment for you.

- **CT Scan or Magnetic Resonance Scan**

This test is used to see if you have a leak of digestive juices or an infection after a pancreas transplant. It can also be used to check the blood vessels going to your new pancreas.

Step 4: Keeping you and your pancreas healthy after the transplant operation

The most important part of the pancreas transplant operation is staying healthy after the operation.

Here is what you will need to do after you leave the hospital:

- After you leave the hospital, you will be seen at the transplant center 2–3 times per week for the next few weeks.
- Take your medicines as instructed. This is very important. Also, do not take any other medicines (prescription or over-the-counter) or supplements of any kind without first checking with your transplant team.
- Give a sample of your blood when requested by your transplant center.
- Tell the staff at the transplant center about any problems you are having. Be sure to let them know if you have trouble keeping an appointment or taking your medicines. Call immediately if you are having trouble getting or taking your medicines. This include difficulties in paying for your medicines and side effects you are having. Your transplant center can help!
- Call your transplant center if you have any of these symptoms:
 - Fever or chills
 - Stomach pain
 - Burning sensation when you urinate
 - High or low blood sugar
 - Trouble breathing
 - Bad cough
 - Trouble taking your medicines
 - High blood pressure
 - Diarrhea, nausea, vomiting, or constipation
 - Weight loss or weight gain

Your Appointments

If your body begins to reject your new pancreas, **you may not know it**. Some patients may have signs, but most patients do not recognize them. If your body is rejecting the new pancreas or kidney, your doctors and nurses will know it. **This is why it is so important to go to all your medical appointments**. Your health care providers watch closely for signs of rejection and side effects from the medicines.

Your doctors will only be able to tell if you are rejecting the new organ by examining you. The doctor can detect rejection through blood tests or by looking at a small piece of your organ.

Your doctor and transplant staff will be watching for the following:

1. Rejection

The risk of rejection never goes away. You will always need to take anti-rejection medicines. Your doctor may adjust how much medicine you are taking, but you should never skip or stop taking the medicines.

2. Infections

Anti-rejection medicines can increase the chance of getting infections. These infections can be treated. However, always tell your doctor if you have a fever, unusual pain, or any other new feelings. The risk of infection may decrease when your doctor lowers the strength of these medicines you are taking.

3. High Blood Pressure

High blood pressure is a common problem after transplant. Most patients require medicines to keep the blood pressure at a safe number. If your blood pressure is not kept in a safe range, this can damage your kidneys. It can also cause strokes and heart attacks.

4. High Cholesterol

You may develop high cholesterol after transplant. This can put you at risk for a heart attack or stroke. Your health history, diet, and some of your anti-rejection medicines may also contribute to this increased risk. There are some medicines called statins that help keep cholesterol in a safe range.

5. Cancer

Patients who receive a new organ are at a greater risk for skin and certain other cancers. The anti-rejection medicines can increase this risk. It is important that you use sunscreen lotions and wear long sleeve clothing to protect your skin from the sun. It is also important for you to have tests that can detect whether you may have cancer. These tests that check for cancer include pap smears and mammograms for women, and prostate tests for men. All patients should have their colon checked as recommended by their primary care physician.

6. Other health issues

Be sure to see your eye doctor for regular check-ups. You may also need to see other specialists, depending upon what other health problems you may have. Be sure to visit your primary care doctor often.

7. Pregnancy

It is possible to get pregnant after transplant. However, you must talk with your transplant team to find out if pregnancy is safe for you. If you want to get pregnant, tell the transplant team before you stop using birth control. This is because some of your anti-rejection medicines may need to be changed before you get pregnant. If you find out you are pregnant, tell the transplant team right away.

If your pancreas drains into your bladder, and you use a urine pregnancy test bought at a pharmacy, the results of the test may indicate that you are not pregnant even though you are pregnant.

You need a blood test to be sure.

Step 5: Enjoy your pancreas

By following directions given to you and taking your medicines, the pancreas transplant will allow you to enjoy a better quality of life without diabetes.