Pancreas Transplant Education

For the Pretransplant Patient
Welcome
Welcome to Indiana University Health Transplant. We are partnered with the Indiana University School of Medicine to provide you with outstanding, comprehensive transplant care.

The information in this booklet has been prepared by members of the transplant team to tell you about our Pancreas Transplant Program. We hope this information will answer many of your questions and ease some of the fears that you may have regarding transplantation. However, its purpose is to serve only as an introduction and basis for further discussions with your doctor about the option of transplantation. The information presented deals in general terms and addresses those questions common to most potential pancreas transplant patients. It is not meant to cover all the specific medical and social issues that each patient may have, since this must be done on an individual basis.

We suggest as you read through this material, you discuss it with your family and write down any questions that come to mind. Then, please discuss your questions with any member of our transplant team. Our pretransplant coordinators are available Monday through Friday, 8 am to 4 pm, and can be reached at 800.382.4602 or 317.944.4370.

Pancreas Transplant Team
Our multidisciplinary team is comprised of staff members to provide you with comprehensive care. The team includes skilled transplant surgeons, nephrologists, nurse coordinators, anesthesiologists and surgical team members, pharmacists, interventional radiologists, pathologists, dietitians, social workers, psychologists, nursing staff, chaplains and administrative staff, as well as financial counselors and coordinators.

Transplant coordinators work closely with each patient, helping him or her throughout the entire transplantation process, from evaluation through follow-up care. Our dedicated transplant nursing staff provides excellent care in a specialized unit created just for transplant patients.

About the Pancreas and Pancreas Transplants
The pancreas is a gland (organ) about five to six inches long that is located horizontally in the back of the abdomen. It makes digestive enzymes that are delivered to the small intestine. It also makes hormones that go into the bloodstream. One of the most important hormones the pancreas makes is insulin, which regulates blood sugar levels. This regulation of blood sugar levels is a critical function.

Many individuals successfully manage their diabetes with diet, exercise and medications. If your diabetes treatment plan is working, a pancreas transplant isn’t likely a better option. But if your diabetes can’t be controlled or you have serious diabetes-related complications, a pancreas transplant may be worthwhile.

The option of pancreas transplantation is for individuals with Type I diabetes and may prevent, stop or even reverse some of the negative health consequences of long-term diabetes. Your medical team will help determine if a pancreas transplant could be of benefit to you.

Pancreas transplants can be performed alone, but in many cases are combined with other organ transplants. Most frequently the pancreas is combined with a kidney transplant because diabetes can cause permanent damage to the kidneys and lead to end-stage kidney disease. Pancreas transplantation may also occur after a previous kidney transplant. This frequently happens when a recipient needs a kidney transplant and a living kidney donor is available.
Transplant Costs

Before moving forward with your evaluation and surgery, our financial counselors and coordinators review your insurance carefully and advise you if they find anything of concern. Many insurance companies have special rules when it comes to transplant benefits. Our finance team will help you to understand these.

One of the main concerns is the cost of the medications that are needed after transplant. If problems are anticipated, our finance team can help give suggestions for other options.

If your insurance changes in any way (changes in coverage, open enrollment with an employer, loss of coverage, etc.) you must tell the financial team.

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Recipient Evaluation Process

To be considered for a pancreas transplant, the medical team must determine if there are any conditions that may affect normal recovery.* Selection criteria for pancreas transplant recipients include:

- Type I diabetes
- Existing or impending end-stage renal disease (only with combined kidney/pancreas transplant or pancreas after kidney)
- Free of malignancies (history is evaluated individually)
- Free of active infection
- Intact or correctable urological system (if combined with a kidney transplant)
- No active abuse of alcohol or drugs
- Heart and lung status consistent with being able to tolerate the surgery and consistent with a long-term outcome
- Ability to follow transplant protocols and medication regimens
- An acceptable body weight

*Every potential candidate is considered on an individual basis.

The basic evaluation includes the following tests:

- Pelvic exam and Pap smear (females only)
- Heart testing (ECG)
- Chest X-ray
- Gastric emptying study
- Hepatitis, syphilis and AIDS blood tests
- Mammogram (females over age 40)
- Tuberculosis test
- Prostate blood test (males over age 50)
- Blood and HLA tissue typing (more details in next section)
- Colon screening (age 50 and over)
- Dental exam and treatment if necessary
- Other tests/consults as needed if first tests are abnormal, or if a medical or psycho/social condition suggests more evaluation should be done (determined by the transplant team)

Blood and Tissue Types

Blood types are either A, B, AB or O. Type O is the most common (50 percent of the U.S. population has this type), followed by A (40 percent in the U.S.). Types B and AB are more rare. A table of compatible blood types is listed below. In addition to blood type, tissue typing (white blood cell/lymphocyte or HLA type) is tested. For pancreas transplantation, the donor must have compatible blood and tissue types to you. This is determined by doing a crossmatch with blood cells from you and the donor. Crossmatching will be discussed in more detail later.

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<tr>
<th>Blood Type</th>
<th>Can receive from:</th>
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<tbody>
<tr>
<td>A</td>
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Wait List Activation

Once you have completed all necessary testing and all the results have been reviewed and approved by your transplant team, your information must be sent to your insurance company for medical review and approval. Most insurance plans take an average of two to four weeks to approve you for a transplant.

Please note—you are not a transplant candidate until you have completed the evaluation, completed any necessary corrective procedures AND received prior approval from your insurance plan.

Your transplant coordinator will tell you when the approval process is finished. You will then be added to the United Network for Organ Sharing (UNOS) wait list to wait for a deceased donor pancreas transplant. This process is commonly referred to as being “activated” or “listed.”

The National Organ Transplant Act of 1984 required the development of uniform national policies to define how all solid organs from deceased donors are distributed. UNOS was established and oversees organ allocation on a national basis. Balancing fairness with medical usefulness is the intention of this system. Currently deceased donor organs in Indiana are usually offered to recipients on Indiana waiting lists first, but a pancreas can be exported to and imported from anywhere in the United States. Please keep in mind that national policies are constantly reviewed and subject to change. You will receive the most current information on pancreas distribution once you are activated.

Things to Consider Before Activation

The decision to have a transplant is an important one. Before you decide if a transplant is right for you, you need to think about the lifestyle changes that are required and the risks. Some of the issues to consider are:

- Different diabetic treatment options versus transplantation
- The need to take medications that have side-effects and are expensive for the life of the pancreas
- Frequent outpatient clinic visits for the life of the pancreas

[Image]
While you wait for a deceased donor pancreas transplant, you will have a monthly blood sample sent to us for panel-reactive antibody (PRA) testing. If you are waiting for a kidney/pancreas and on dialysis, the dialysis staff will draw this sample and send it to us. If you are not on dialysis, you will be sent orders and supplies to have this done monthly. This blood sample is tested to determine if you have, or have developed, anti-HLA antibody since your initial tissue typing tests were done. As you recall, the HLA type is another compatibility test that is looked at along with the ABO blood type. Recipients can develop antibodies against specific HLA markers that can make them incompatible with a deceased donor who has those specific markers. These antibodies can develop or change over time and need to be monitored carefully to predict the likelihood of there being incompatibility. Things that can possibly change a recipient’s PRA are blood transfusions, pregnancy and previous transplants. Testing called a final crossmatch is always done just prior to a transplant to make sure that there are no incompatibility issues. A negative crossmatch means that you can possibly change a recipient’s PRA are blood transfusions, pregnancy and previous transplants. Testing called a final crossmatch is always done just prior to a transplant to make sure that there are no incompatibility issues. A negative crossmatch will decide if it is safe to proceed with the transplant.

On the Waiting List
No one can predict how long it will take before a deceased donor organ will become available for you. Many potential recipients find this to be one of the most frustrating parts of waiting for a pancreas transplant. Wait times can vary widely depending on your ABO blood type and other specific immune factors. The waiting phase can last from a few days to years with the current allocation policies.

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General Health Tips When Waiting For Your Transplant Waiting for a donor organ can be a stressful experience, especially because the amount of time you’ll have to wait is unknown. Regardless, there are important steps transplant candidates can take to ensure they are ready for surgery when the important call comes.

- **Take care of your health.** Try to stay as healthy as possible and take your medicines as they are prescribed. Notify your transplant coordinator if any additional medicines are prescribed or altered, or if you are hospitalized for any reason.
- **Keep scheduled appointments with your physicians.** Until your transplant, you will need to see your physician(s) to continue to evaluate your overall health.
- **Follow dietary guidelines.** Weight management is very important while waiting for your transplant. A dietician can work with you to plan and develop a diet program that will give you the greatest benefit before and after transplantation.
- **Occupy yourself by staying involved.** Spend time doing what you enjoy and stay as active as your physical condition will permit. Keep up with your work, studies and/or leisure activities, or start a project or hobby that can help distract you.
- **Maintain contact with family and friends.** Good company will take your mind off of waiting and enrich your life.
- **Just relax.** Reading or listening to music or relaxation CDs can be helpful in taking your mind off your transplant and avoiding negative thoughts.

Getting the Call
‘The call’ can come for a deceased donor pancreas transplant at any time, day or night, and it is your responsibility to make sure you are always available to receive this call. When you are activated, your transplant coordinator will ask you to give us multiple phone numbers for the best ways to reach you. Please be sure to update your coordinator with any changes in your contact information.

For pancreas transplants, the transplant coordinators have one hour to reach you for the potential transplant. If the coordinator cannot find you in one hour, then you will be passed by and the next patient on the list is called. Please be assured that the coordinator will do everything possible to find you, but ultimately, it is your responsibility to make sure that the coordinator can locate you. Once the coordinator reaches you, they will give you specific information about the admission process. The donor pancreas can only be preserved for 12 to 18 hours outside the body. You will need to leave for the hospital within 1.5 to 30 minutes after you have been notified that a donor pancreas is available. Do not eat or drink anything after you have been called in for your transplant.

Tips for the Call – When you get “the call,” it can be an overwhelming experience. We suggest the following to help make this process less stressful for you.

- **Make sure you are available.** It is important for your transplant team to know how to get in touch with you at all times. Cell phones and/or pagers allow you to be away from home and still able to be reached. If you will be out of town and still want to be called, you can call your coordinator with other ways to reach you. Or, if you are gone and know it would be difficult to get back for a transplant, you can be placed “on hold” temporarily and your name will not come up during that time. This will not affect your ranking for future calls. You must remember to update us if any of your contact information changes.
- **Be prepared by having a list of things you need to bring with you.** This list should include insurance information, driver’s license and medications. Other things to bring if you have them are your pager, blood pressure cuff, glucometer, loose fitting clothing and any other necessities.
- **Be prepared with transportation.** When you are placed on the waiting list, your first responsibility is to plan how to get to the transplant center. Prepare yourself for this call by making the necessary arrangements for transportation well in advance.

There can be times that a patient is called in and does not receive a transplant. Examples include:

- More than one potential recipient is called even though only one pancreas is available for transplant. This usually happens when the first patient has a high PRA and might have a positive crossmatch. A positive crossmatch means that the new pancreas would probably be rejected, so the transplant is not done. Since crossmatches take several hours to do, a “backup patient” is called in so the pancreas can then be transplanted quicker than having to try to locate another recipient. The sooner a pancreas is transplanted, the better chance of it working properly.
- Occasionally, after a recipient is called in, a problem is discovered with the donor or the donor’s pancreas. Obviously, the transplant team only wants to use organs that are safe and will be of benefit to you. In these cases, the transplant recipient would be sent home to wait for the next call.
- If a health problem for the recipient is found and the transplant team believes it would be unwise to proceed with the transplant at that time, the recipient will be sent home and placed on-hold temporarily until the issue is resolved.
Your Transplant Surgery and Hospitalization

When you come to the hospital, you will have preoperative evaluation and testing done before your pancreas transplant. Blood will be drawn for routine lab tests and final donor/recipient crossmatching, in addition to heart testing and a chest X-ray. If this final evaluation confirms that you have no new medical problems and the crossmatch is acceptable, then the transplant surgery will proceed.

The surgery usually begins within 6 to 12 hours after you arrive at the hospital. The combined kidney/pancreas transplant generally takes approximately 5 to 8 hours. A pancreas alone transplant takes approximately 2 to 4 hours. During the operation, an incision from the sternum (chest bone) to the pubic bone is made in the middle of your abdomen. The pancreas is attached to the bowel, allowing pancreatic juices to drain into the gastrointestinal tract. If a combined pancreas/kidney transplant is being done, both organs are placed through the same incision. Your own kidneys and pancreas will stay in place in most cases. Throughout the surgery, the operating room staff will update your family members frequently.

Risks and Complications

As with any surgery, there can be complications. Generally the complication rate after a pancreas transplant is low. Some of these complications are:

- **Technical complications**
  - Clotting of the blood vessels to the pancreas
  - Bleeding
  - Pancreatitis (inflammation of the pancreas)
  - Bowel leak
- **Other complications related to general anesthesia and abdominal surgery**
  - Heart attack
  - Stroke
  - Hernia
  - Anesthetic reaction
  - Bowel problems
  - Pulmonary embolus (blood clot to the lungs)
  - Poor healing of the surgical incision
  - Death

- **Rejection** – Rejection occurs when the body recognizes the transplanted pancreas as not belonging and tries to destroy it. There are different types of rejection, but most can be treated and reversed. The highest risk for rejection is within the first 3 months after the transplant, so close monitoring is critical. But, it is important to remember that rejection can happen at any time, even years later. Therefore, it is critical that you follow all medical guidelines that the transplant team gives you.

- **Infection** – The drugs taken to prevent rejection can decrease your body's ability to fight infections. Infections in a transplant patient can be serious and even life threatening. Your medications will be closely monitored and adjusted as needed to keep the risk of infection as low as possible.

- **Malignancy** – Transplant patients have a slightly higher risk of cancer than the general population. Skin cancers are the most common, but the risk can be decreased by avoiding prolonged exposure to the sun and wearing sunscreen.

- **Donor risk factors** – Although deceased donors are screened very carefully, there are diseases that can go undetected. It is then possible for these diseases to be transmitted to you.

It is important that you consider your treatment options carefully and discuss your choice with your family and/or support person(s). The transplant team is available to answer your questions.

You have the right to refuse transplant at any time up to the time of surgery.

After Surgery

Once the surgery is finished, you will be sent directly to the Intensive Care Unit (ICU). The ICU provides a specialized environment where you can be monitored closely.

Your length of stay in the ICU will depend on your rate of recovery. Your transplant team will determine when it is time for you to be discharged from the ICU to the specialized Organ Transplant Unit (OTU). The typical length of stay in the hospital after a pancreas transplant is 7 to 10 days.

- **Catheter** – During surgery you will have a catheter inserted in your bladder so your urine can drain and the output can be carefully measured and monitored. It is usually in place about five days.

- **Pain control** – Your nurse will provide you with medicine for pain control. Taking pain medication before doing any activity will help you move about more easily.

- **Activity** – You will be encouraged to do deep breathing and coughing exercises to prevent lung complications. Activity will advance as your doctor sees fit.

- **Monitoring vital signs and fluids** – You will have an IV (intravenous) line placed in surgery so IV fluids and medicines can be given to you. There will be frequent checks of your vital signs and measurements of your fluid intake and output.

- **Lab testing** – After the transplant, you will have many blood and urine tests. Blood sugar levels are carefully monitored to ensure that your new pancreas is functioning properly.

- **Nutrition** – You will be started on a liquid diet once your bowel function has returned to normal. Your diet will then be advanced as tolerated.

There is a waiting room for your visitors outside the ICU. Visiting will be restricted and the ICU staff will inform you and your family of visiting times. Staff members understand the importance of spending time with those you love, so we will work closely to maximize visiting time wherever possible.

Family members who have any type of infection should not enter your room. Children under 14 years old generally are not allowed in the ICU. Children are welcome on the Organ Transplant Unit once you are transferred, but they should receive a health clearance at the information desk.

Cut flowers are not allowed in your room because of harmful bacteria that may grow in the water, but potted plants, Mylar balloons and cards are welcome.
Diet

In addition to careful daily monitoring, you’ll need
– Correct dosage, time and frequency
– All your medications by name and appearance,

To demonstrate your understanding of the following:

1. Current medications. It is a good idea to keep the
booklet to record medical information and your
resources when needed. You will be using this
visits. Add questions you may have and consult
the transplant team when needed.

You will receive a transplant handbook which
you should bring with you to all your follow-up
visits. Add questions you may have and consult
the transplant team when needed. You will be using this
booklet to record medical information and your
current medications. It is a good idea to keep the
book with you at all times in case of emergency.

Before you are discharged from the hospital, you
and/or your support person will be expected to
demonstrate your understanding of the following:

- How to prepare and take your prescribed
medicines correctly. You must know:
  - All your medications by name and appearance,
    and their purpose
  - Correct dosage, time and frequency
  - Any major side effects and special precautions
  - How to check and record your vital signs
    twice daily
  - Signs and symptoms of infection
  - Signs and symptoms of transplant rejection
  - Your prescribed diet and exercise regimen
  - Procedure for returning for follow-up care
  - How to contact the transplant coordinator
  - How to promote good general health

In addition to careful daily monitoring, you’ll need
to follow these guidelines:

Diet – While you are in the hospital, the dietitian
will instruct you on a proper diet.

Activity – For approximately six weeks after your
surgery, you will be limited in certain activities such as
driving, lifting heavy objects, or anything that
causes pain or pulling across your abdomen.
However, it is important that you exercise. Sexual
activity may be resumed after your discharge as
long as it does not cause pain or pulling across your
incision. Most patients may return to work once
they no longer require pain medications, as long as
the job does not require heavy lifting. Your doctors
will help you decide when you are ready.

Avoid Illness – The risk of organ rejection is greatest
during the first few months after transplant, so your
anti-rejection medicines are at their highest levels,
making your risk for infection higher. Because of
this, it is advised to avoid people who are known to
be ill and crowds for several weeks when possible.
Frequent hand washing is also one of the best things
you can do to protect yourself.

Clinic and Ongoing Monitoring

The transplant team will continue to monitor all
patients closely after discharge. This post-transplant
follow-up care is individualized, but most patients
will initially need frequent clinic visits and lab testing.
As time goes on, the frequency of clinic visits and
lab tests will decrease, but remember that rejection
can occur years after receiving a transplant, so it
is very important that clinic appointments and lab
work continue as directed by your transplant team
for the life of the transplant.

Immunosuppressives and Other Medicines

You will take immunosuppressive (anti-rejection)
medication for as long as you have your transplanted
organ. You will probably be taking two or three
immunosuppressive medicines that work in different
ways to prevent rejection. All are equally important.

To receive the maximum benefit, they should be
taken exactly as directed. Your doctor will choose
the best drug regimen for you.

All immunosuppressives, while preventing rejection,
also lower your resistance to infection. For this
reason, it is especially important to review the
measures for preventing infection. If you experience
any symptoms of illness, contact your transplant
coordinator.

Please remember that your transplant will fail without
immunosuppressive medicines. The most common
reason that a transplanted pancreas is rejected
is that the recipient fails to take their medicine
properly. It is your responsibility to make certain
that you have an adequate supply of medicine and
that you take it every day as directed. We strongly
suggest you keep a two-week supply of all your
medicines on hand, should weather or illness prevent
you from traveling to obtain prescription refills.

Most patients take other medicines in addition to
their immunosuppressive drugs. These may include
medicines to prevent infection, anti-hypertensives
(for high blood pressure), vitamins, antacids, etc.
Some of these medicines may only need to be
taken for a short time, while others may be continued
for other medical conditions you have. If another
doctor prescribes medication for you, it is wise to
let the transplant team know to make sure that
they do not interfere with your immunosuppressive
medicines.

After Pancreas Transplant

Some pancreas recipients find their immediate
post-operative course to be challenging. After
receiving a pancreas transplant, recipients have said
of their experience “it got worse before it got better.”
After the transplant, there may be multiple
readmissions for certain symptoms such as vomiting,
constipation and/or diarrhea. This can be discouraging
in the immediate post-operative period, however,
these symptoms typically subside and your long-term
quality of life improves.

It is also important to remember that some patients
experience a sense of loss when they no longer have
diabetes. With a new pancreas, your life as you have
known it for many years is now different. Your
responsibilities change from treating your diabetes
to caring for your new organ. It is important that
you prepare for this psychological adjustment.

Most pancreas transplant patients have a much
improved quality of life. They are able to enjoy new
dietary freedoms, can exercise without taking in
extra carbohydrates and usually have excellent blood
sugar control. Instead of checking their sugars
numerous times a day, they may only check them
once or twice daily. There is no further need for
insulin injections since the new pancreas will
supply the body with necessary insulin.

To make sure things stay that way, you will need to
keep focused on the guidelines the transplant team
sets for you and on the things that can impact
long-term health. We look forward to working with
you to achieve this goal!

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