



The Emotional Ride OF THE TRANSPLANT PROCESS

Jody L Jones, PhD
Licensed Clinical Psychologist
University of Iowa Organ Transplant Center

DEVELOPED AND BROUGHT TO YOU BY:



AMERICAN
PSYCHOLOGICAL
ASSOCIATION



TOPICS

We will be discussing coping with the wait for a transplant, which includes:

- Fears about the process
- Managing expectations
- Mental preparation for the surgery



IT'S A MARATHON...



... NOT A SPRINT.



PACE YOURSELF



FEAR: WHAT WILL HAPPEN?

- One of the first concerns patients express is the fear of the unknown: what will happen during a transplant evaluation? What will happen after?
- This can seem like a mysterious process but I am going to explain the evaluation experience to you, so you know what to expect and how decisions are made.



THE GOAL IS TRANSPLANTATION

- Transplant centers are in the business of doing transplants. They are NOT looking for reasons to NOT transplant you.
- Most patients worry they will say something wrong or do something that will prevent them from getting listed for a transplant. This is a normal concern, but remember that the center's goal is to work with you, not turn you away.



BE HONEST

- The best thing you can do is be honest with the team when you are asked questions about your health, your feelings, your support, your finances, and your compliance with medical guidelines.
- If there is a problem, the team will talk with you about how to solve it.
- Trying to hide issues just makes it look like you are hiding issues! And that worries the team. They can't help with things they don't know about.



THE WAITING BEGINS

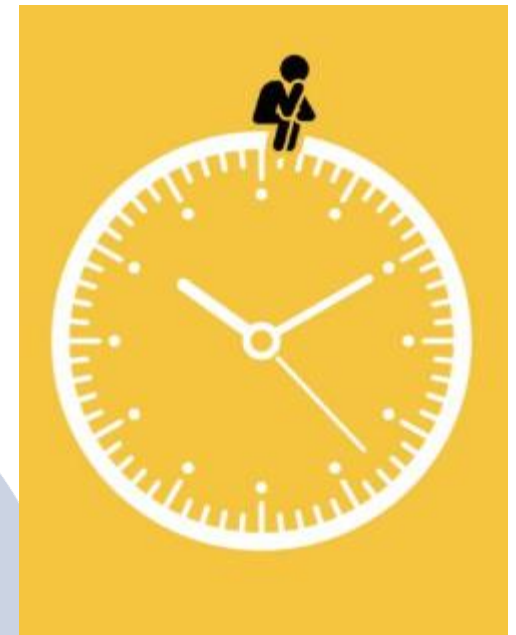
- The process starts with the referral to the transplant center.
- The information sent to the transplant center must first be processed to ensure you have insurance coverage that will allow you to be treated at that center, and then a “transplant episode” will be opened in your file.
- At that point, a scheduler will call to set up your first appointments.



THIS CAN TAKE A WHILE...

Transplant centers do their best to get new patients in as soon as possible, but it can take anywhere from a just few days to a few weeks or even a couple of months before your evaluation starts.

Usually, new patients are sent information about the evaluation as soon as the appointment is set up. Be sure to read the information carefully. It will include important facts about how to prepare for your evaluation.



THINGS YOU NEED TO KNOW

- **Where to stay:** For patients coming in from out of town, you will be given information about local hotels or hospital residences that offer discounts for patients.
- **Instructions for tests:** Some tests require that you not eat or drink anything for several hours before the test starts. Please look carefully at your schedule to see if you have tests that require no food or drink.
- **Who/what to bring:** Most programs want you to bring your caregivers and might ask you to bring other information, such as medical records, insurance cards, or other similar items.



THE EVALUATION

Many centers try to arrange all testing and appointments for one day, whereas others will spread appointments out over two or more days. Schedules at transplant centers are affected by many things, including how many people are being evaluated or whether everyone on the team is available to see you that day; in addition, we know you have to arrange transportation and your caregiver also needs to be available that day.



CAREGIVERS

Most centers will want you to bring someone from your support system to accompany you through your evaluation. Although this can feel like an inconvenience, having that person with you helps for several reasons:

- You have an extra set of eyes and ears to help you remember everything you are being told. (It helps if your support person brings a notebook and pen to take notes.)
- The team can confirm with this person that they are available to assist you before and after the surgery.
- This person can often help provide information the team needs, but that you can't necessarily remember yourself.



HEALTH INFORMATION YOU SHOULD BRING

- A list of medications
- A list of previous surgeries
- Information about other health conditions you have (such as date of diagnosis, treatment, etc.)

Your caregiver might want to bring a file folder with this information in it to help you stay organized.



THE DAY OR (DAYS) OF EVALUATION

- You will meet with several members of the team:
 - Surgeon
 - Nephrologist (transplant kidney doctor)
 - Social worker
 - Financial counselor
 - Pharmacist
 - Dietitian
- You will undergo a number of tests to make sure your heart and lungs are in good shape, and to see what your kidneys look like.



LABS

- You should expect that your blood will be drawn on the day of your evaluation. The team is looking for information about how your kidneys are functioning, whether you seem to be compliant with dialysis (so we look at potassium and phosphorus, for instance), and many centers perform a toxicology screen to look for any substances in your body that should not be there.
- Make sure you have an updated medication list with you so the team knows what medicines you should have in your system and which ones you should not.



NURSE COORDINATOR

- You will be assigned a person called a nurse coordinator. This person is sort of like an air traffic controller sitting up in a tower and watching everything that happens. He or she knows the most at any time about where you are in the listing process.
- Your nurse coordinator is responsible for communicating with you about your “status.” This means she will let you know if more tests need to be completed before you are listed. You will hear from your coordinator when you are on the list.
- If anything changes about your situation, you should call the coordinator. This includes changes in address, if you are hospitalized, if you lose insurance, or anything else that affects your situation.



TEAM MEETING

- After you complete your evaluation appointments and tests, the team has a group meeting to look at all the results together.
- Usually, everyone who has met with you is at the meeting. Your coordinator will bring all the results of your scans.
- Everyone on the team has input. No one single person makes the decision about listing.



WHAT THE TEAM NEEDS TO GET YOU LISTED

- To know that your heart and lungs are healthy enough to get you through surgery
- To know that any other health problems you have are being managed properly
- To know that you have enough social support (meaning people who can help you at home after the surgery, provide transportation, help with taking care of your house and family)
- To know that you have the financial resources to pay for your medicines after transplant



EMOTIONAL STABILITY

- The team also needs to know that you can handle the stress of this process.
- It is completely normal to have feelings of anxiety and depression while undergoing dialysis or going through the transplant evaluation. We do not want you to hide this from us.
- Many people have been diagnosed with depression or anxiety, or more serious psychological problems like PTSD, bipolar disorder, or even schizophrenia.



EMOTIONAL STABILITY, cont.

- The psychologist, psychiatrist, and/or social worker will talk to you about how you manage your symptoms.
- They will ask about the medications you take and whether you see someone for therapy.
- They also want to know who you have in your life to support you and help you. The team will be a lot more comfortable moving forward with listing if they know you have people in your life who care about your wellbeing and can help you if you are struggling.



DEFERRAL

- In most cases, people are not put on the transplant waiting list immediately after they complete the evaluation.
- When we put someone “on hold” for listing, we call that a deferral.
- People are deferred for many reasons. We usually give patients a timeframe for the deferral (3 or 6 months, for instance), so they have time to complete the recommendations that are made.



REASONS FOR DEFERRAL

- Taking care of health maintenance appointments (women might need to see a gynecologist or have a mammogram; a person might need a colonoscopy; you might need some vaccinations)
- Working out financial problems
- Identifying more support (someone with a reliable car, or who can take time off work)
- Addressing mental health issues
- Identifying a primary care physician (PCP) if you do not already have one.



NOT LISTED YET!

During your deferral, you are not on the waitlist yet. This can be an anxious time, because you might worry that something will keep you from being listed. What should you do?

- Make a checklist or use your deferral letter to keep track of what you need to do. Check off items as you complete them.
- Stay in touch with your coordinator. Call or email to make sure test results are being sent to the transplant center.



MAKE A CHECKLIST



RESPONSIBILITY

- One way to mentally prepare for going through a transplant process is to remember that YOU will be responsible for many parts of the process.
- Unlike many other kinds of medical procedures, YOU will be the person setting up appointments and making sure your providers are sending results back to the transplant team.
- Do not be surprised that YOU are going to be asked to do things you might not have done before, such as calling your doctor to set up vaccinations for yourself.



YOU HAVE CONTROL!

It can feel a little overwhelming to make those phone calls and get to those appointments. But this is a good thing! You have control over what happens next. You are the person who can make this happen.



ASK FOR HELP

If you feel overwhelmed or don't understand some of the things you have been asked to do, please ask for help!

- Call the coordinator and explain that you are not sure exactly what is expected of you.
- Ask a family member or a friend to look at your letter with you, and help you make a checklist.
- Write down the steps you need to follow to complete everything on your list.



IDEAS TO TRY

- Get a calendar to keep with your checklist.
- Write down all the phone calls you need to make to set up appointments.
- Look up the phone numbers and put them on your list, so you don't have to keep looking those numbers up. Or program them into your phone.
- As each appointment is made, make sure to put it on your calendar and circle the date to make sure you don't forget it.



MORE IDEAS TO TRY

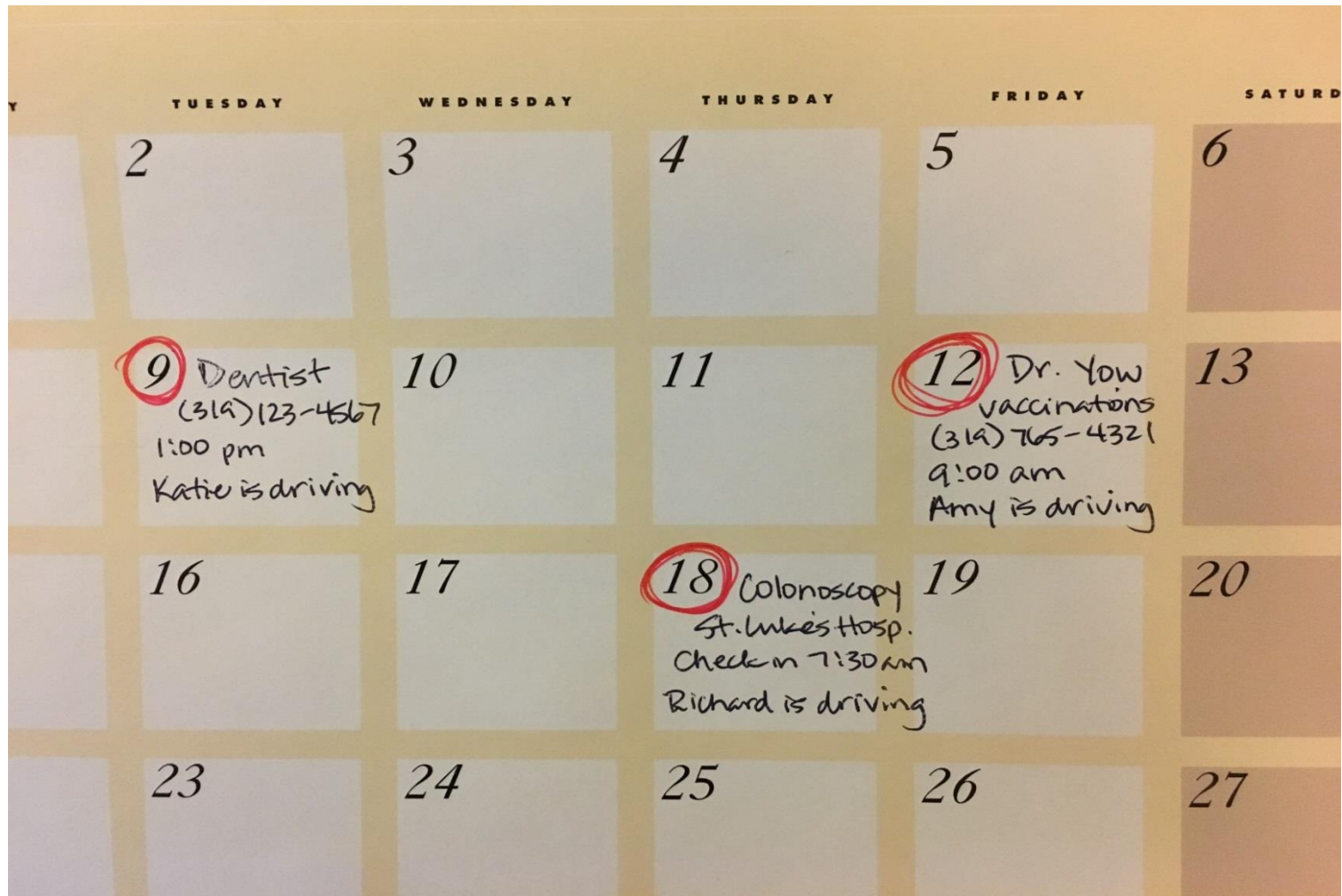
- Be careful not to schedule appointments on your dialysis days. If you don't have any choice, be sure to talk to someone at dialysis to reschedule the session you'll miss.
- If you need transportation to your appointments, talk to the person who usually drives you. If they agree to take you, write that person's name on your calendar with the appointment. (You might have several people helping you, so the calendar will show you who is driving you on what day.)



MORE ON THE CALENDAR

- Keep the calendar out so you are always reminded of what is coming up next.
- It is a good idea to call anyone who is driving you or coming to an appointment with you a couple of days in advance to remind them.





An example of how your calendar might look

CLIMB THAT LADDER ONE RUNG AT A TIME



GETTING LISTED

- Sometimes the transplant team will ask you to come back for more appointments at the end of your deferral so they can be sure you are ready for transplant.
- When you are put on the list, your coordinator should call to tell you. You will also be sent an official letter explaining that you are on the list. You will also receive information about what it means to be on the waitlist.



HURRY UP...AND WAIT!

The wait for a kidney can be several years.
What this means is:

- You need to keep going to dialysis and your doctors' appointments.
- You need to make sure you have reliable transportation and a way the team can contact you. This means keep your phone in working order.
- If you change your phone number, or your address, or you get divorced, or you change dialysis centers, or experience any other major life changes, **CALL YOUR COORDINATOR.**

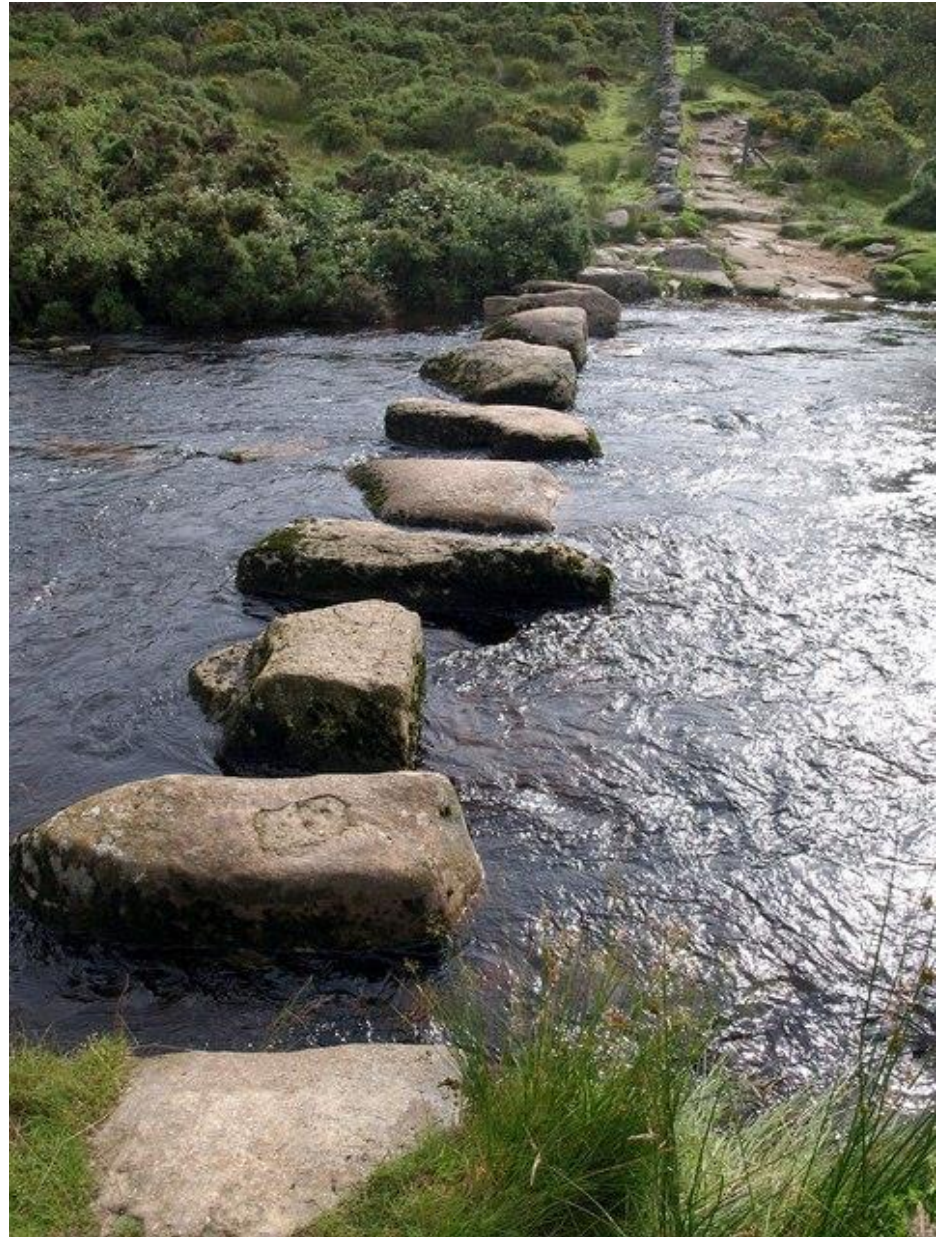


WAITING...

This is the hardest part. People hate waiting. You must remember that your life is not "on hold," although it might feel that way. Your life is meaningful exactly as it is. Find ways of discovering meaning in your life. Do something every day that makes you feel good in some way.



**ONE
STEP AT
A TIME**



WHILE ON THE WAITING LIST...

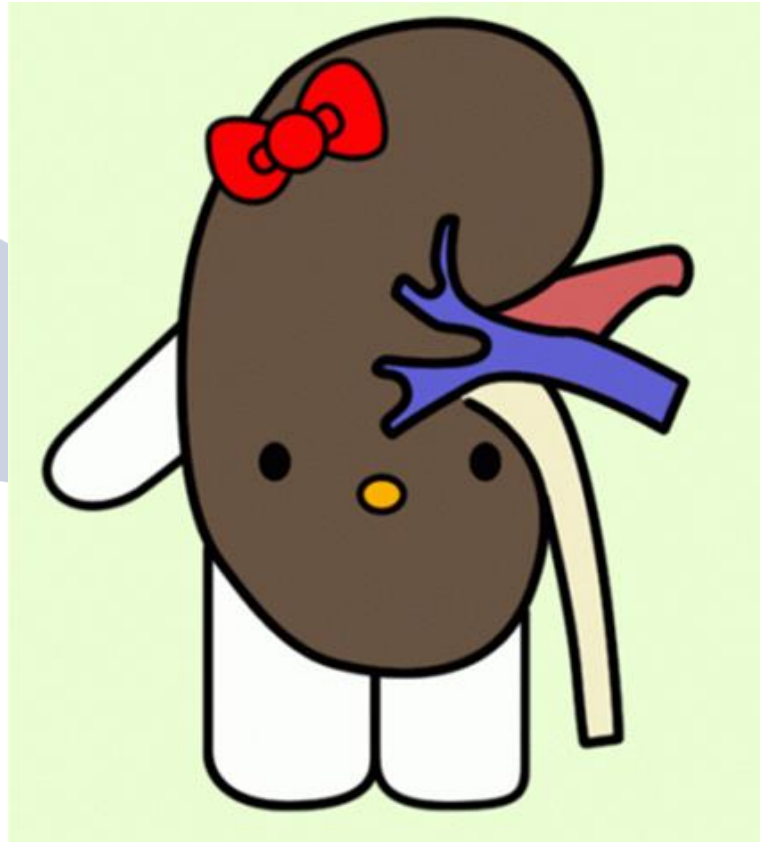
- A whole lot of “nothing” happens with the transplant team. Keep in mind that your coordinator is keeping track of many (sometimes hundreds) of other patients waiting for a transplant.
- Do not be surprised or hurt if you do not hear from your coordinator on a regular basis. They do not usually just “check in” with you once you are listed.



WHILE ON THE WAITING LIST... cont.

- It is normal to be brought in at least once a year to update your testing.
- A social worker or financial counselor might occasionally check in with you on the phone or have you come in to make sure your insurance is still good and that you have the support you need.





Hello Kidney

THE CALL

- When you get a call about a possible kidney for you, the coordinator will explain how soon you need to get to the hospital and where to go to check in.
- Sometimes, we have “false alarms” or “trial runs” and must send the patient back home without a transplant. This can happen for a variety of reasons, including that it turns out the kidney was not as good a match as originally thought, the donor unexpectedly dies before organ procurement, or the recipient comes to the hospital and we discover a fever or some other illness that would make a transplant unsafe.



THE SURGERY

- You will wake up from the surgery sore, but the people caring for you will get you moving as soon as possible. Walking is good for you.
- **DRINK WATER.** This is not as simple as it seems. You have been on fluid restriction for a long time and are used to being thirsty and being careful about what you drink. Now you will be asked to drink A LOT of water. It might feel overwhelming. Use a straw. It goes down faster that way.



DRINK

WATER

WATER!



Sometimes the new kidney is slow to “wake up.” There are a few people who need some dialysis treatments after the transplant while the kidney is getting up to speed. Don’t worry if this happens. Usually, the kidney will be fine and you’ll be peeing like you used to before you know it!



AFTER THE TRANSPLANT

- You will be expected to come back to the transplant center on a regular basis for appointments. These appointments are absolute and will likely require that you get a ride for at least the first one or two.
- **YOU WILL BE ON MEDICATION THE REST OF YOUR LIFE.** This is not negotiable.
- **YOU NEED TO GO TO THE LAB ON A REGULAR BASIS** to determine your drug levels. This is also not negotiable.



A BIG CHANGE

Even though you might not like dialysis or get tired of being there, a big change in your life will occur with a transplant. After years of spending a half-day three days a week at the dialysis center, you will not be going back. You will not see the nurses and technicians and social workers who cared for you, or some of the patients who have become your friends. This can be a sad transition. You can go back to say “hi” as soon as you are healthy again. But be prepared that something that was once a very big part of your life will be gone.



THINGS TO REMEMBER

- Transplant is a lifetime commitment.
- You will be responsible for many parts of your healthcare. It is manageable once you break it down into smaller pieces.
- The wait for an organ can be a long one. Be prepared to keep doing what you're doing during the wait.



LIVE IN THE MOMENT

- Your life is important NOW. Your life is not on hold (even if it feels that way). You are important to your family and friends. You are important to the people who provide your medical care.
- It is important to identify ONE GOOD THING in your life every day. It might be a ray of sunshine coming through the blinds. The smell of honeysuckle. The relief of putting on your favorite pajamas. The joy of a hug. Every day, we have small reminders that life is beautiful.



STAY CONNECTED

- Try to keep up with friends and family, staying involved in your social circle.
- Consider joining groups on Facebook for people on dialysis and/or waiting for transplant.
- Make a point of saying hi to the people at dialysis. A smile goes a long way and can make someone else feel less grumpy or frustrated or alone.





**THINK OF THINGS
THAT
MAKE YOU SMILE...**

Finnegan

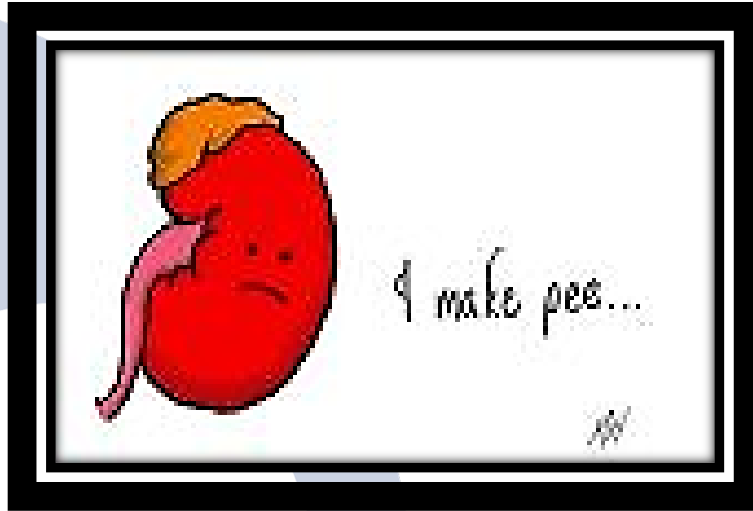


Shandy





Pippa



HAPPY KIDNEY!

Thank you!

