

PROSPECTIVE LIVING ORGAN DONOR QUESTIONS

This document contains a list of questions for a prospective organ donor to ask medical professionals in the course of considering donation. You will probably not want to ask all of these questions, and some of them will probably be answered in the course of conversation with transplant center staff or from their written publications. However, this list may contain questions you haven't thought of and will, hopefully, help you decide what is important for you to know.

If you have questions of your own, you can post them on the Living Donors Online message board: www.livingdonorsonline.org

EVALUATION

- Who will be my coordinator? How long has he/she been a coordinator with the transplant team? What is his or her role?
- If I need to speak with my coordinator and he/she is not available, who would I ask for?
- Please provide me with written information about living donation, including the hospital's policies.
- What tests will be performed during the evaluation?
- What tests will be done to ensure I don't have a disease or condition that could compromise my health after donation?
- How and when are tests scheduled? Will I receive a written schedule?
- Who will I have interviews with?
- When, and by whom, will the results of my evaluation tests be explained to me?
- Will I be able to receive copies of all of the tests performed?
- What health problems would rule me out as a donor?
- Do I need to lose weight before I have the surgery? If so, how many pounds do I need to lose?
- Do I need to stop smoking before I have the surgery? If so, how far in advance do I have to quit?
- In my research I've noticed that I'm a little older than the average donor. Do you think age makes a difference in the outcome for the donor?
- Who will be responsible for my medical care if something adverse happens during my evaluation, e.g., colon perforation during colonoscopy?
- Will I have a donor advocate? Is this person independent of the transplant team and free from conflicts of interest?
- Who will be available to talk with me about doubts I may have about donating?
- Up to what point can I change my mind about donating? How does the hospital handle this? Would a plausible medical excuse be provided so that I would not be embarrassed?
- I have a few more questions of Dr. _____. Who should I speak with to set up an appointment for me to see him or her again?
- How quickly should I expect the transplant coordinator to return my calls (or email)? If I do not receive a timely response, who else may I contact?
- How long does the evaluation process take?
- After being approved as a donor, how long is it until the surgery is performed?
- Is my organ size suitable for donation?
- (For kidney donors) Which of the following tests will you perform?
 - Tissue-type match test
 - Crossmatch testing
 - Hepatic angiogram
 - CT scan
- If I donate, how long should I expect to be in the hospital?
- (For those with domestic partners): I want to be sure that my domestic partner is permitted to visit me anywhere and anytime that family members are permitted. What do I need to do to ensure this happens?
- Please show me the family waiting area, the pre-op area, the I.C.U., and a typical patient room?
- Does the hospital permit my family or friends to take pictures within the hospital? If so, when and where are they allowed to do this?
- I would like to speak with someone who has donated here. Who can arrange this for me?
- Without violating confidentiality, please tell me what you think my recipient's prospects are for a full recovery?
- What can I do to make the process more successful? Less stressful?

Some thoughts from Naomi who posts on LDO - **Evaluating the Transplant Center:**

YOU should be evaluating THEM (the transplant center) -- you will be trusting them totally with your life and health.

- What is their attitude toward you?
- Are they impatient with you?
- Do they act like your questions are stupid or as if you are being too pushy for asking them?
- Do they seem to be looking out for YOUR interests scrupulously, as much as the recipient's?
- Do they treat you like a person and patient, or like an available kidney (or whatever organ you're donating)? (If they are indifferent to you during the initial process, you can't count on them treating you any better afterward.)
- Does the center seem organized with the testing and screening process?
- Is there effective communication among the staff?
- Do things seem to "slip through the cracks"?
- Do they return your calls/emails in a timely manner and respond to your concerns?
- Do they pay attention to details?

TRANSPLANT CENTER PROCEDURES AND HISTORY

- What different types of surgical procedures [for the particular type of donation] does your hospital perform and what are the advantages and disadvantages of each one for a person's particular body type and physiology? Is there a statistical difference in transplant success for the procedures?
- How many of these types of surgeries have been performed at your hospital?
- How often are these types of surgeries performed at your hospital?
- What are the risks associated with this type of surgery?
- If having laparoscopic donor nephrectomy, ask how many times they have had to go to the open nephrectomy during the surgical procedure.
- What is the complication rate of donors who have donated at this hospital? Does the hospital track donor complications and for how long? What are the complications tracked?
- At this hospital, have any donors died as a result of donation? If so, how many? Please explain.
- Who will be responsible for my medical care if something adverse happens during my donor surgery and/or in the days after the surgery during the time I'm in the hospital?
- Have any of the donors who donated at your hospital needed transplants after donation?

FINANCES

- How will my evaluation, surgery, and hospital stay be paid for?
- Does your patient financial office bill my insurance first to get a denial, then bill the recipient's insurance? (Important: your insurance should not be billed first. This is not necessary. If you are asked to provide your personal insurance card or insurance information to the hospital, ask them how it will be used.)
- Who will be responsible for the costs of my care if something adverse happens during my evaluation testing? (If an affirmative answer is given, ask for it in writing.)
- Who will be responsible for the costs of my care, including long-term care, if something adverse happens during surgery and/or in the days after the surgery while I'm in the hospital? (If an affirmative answer is given, ask for it in writing.)
- After discharge, is there any cost to me for routine follow-up care provided to donors?
- How long and for what will I be covered under the recipient's insurance if I have problems after being discharged?
- After discharge, if I have to go to an emergency room (that is not the transplant center's E.R.), obtain outpatient medical care, or obtain prescriptions, what procedure should I use to ensure that the recipient's insurance is billed and that I'm reimbursed for out-of-pocket expenses?
- Does the hospital provide a short- and/or long-term disability insurance policy for donors in case something should go wrong?

- If my recipient dies and I receive counseling at the transplant center (assuming it's provided), will there be a cost to me personally for this service? If so, how much would I pay? Would my or the recipient's insurance company cover some of the cost?
- Will my current insurance be affected by the surgery or will I have difficulty finding another carrier if I decide to change carriers in the future?

PRIOR TO SURGERY

- Will I be staying overnight at the hospital the night before surgery?
- What time do I need to be at the hospital on the day of surgery?
- Where do I go to check in?
- Can I do the pre-admit paperwork prior to checking into the hospital?
- What do I need to bring to the hospital? (Some hospitals have cut costs by not providing the usual admit kit, which includes toothbrush, toothpaste, soap, Kleenex, wash basin etc. You have to ask for anything you need and the charges are outrageous.)
- What medications do I need to stop taking before surgery and, if so, how long before the surgery should I discontinue taking them?
- What physical preparation do I have to do prior to surgery? (e.g., laxative the night before)
- Will my hair in the incision area be trimmed or shaved? May I do this myself in advance in the privacy of my home?
- Are there any dietary restrictions on the day(s) before surgery? If so, what are they?
- May I take a sleeping or anti-anxiety medication the night before surgery? If so, what medications may I take?

SURGERY

- Will I meet with the surgeon well in advance of the surgery so I can ask questions and have my concerns addressed?
- Please describe the process, from the donor's standpoint, of what happens on transplant day and the following few days in the hospital.
- May a loved one(s) be with me in the pre-surgical area until I'm taken into surgery?
- If possible, I would like to be near my recipient in the pre-surgery area. Will you arrange that to happen?
- Will I be assigned my own surgeon in the operating room?
- Who will be doing my surgery? How many of these surgeries has he or she done?
- May a donor request that a certain type of music be played in the O.R.? May the patient furnish the music?
- May a donor take an item, such as a small cross or medal or a "good luck" piece, into the O.R.?
- Do acrylic nails and all nail polish need to be removed prior to surgery?
- Will I be awake when I arrive at the operating room or will I be "out" by then?
- What are the standards for the conversation and decorum in the operating room?
- Will any other organs be removed besides the one I'm donating for transplant (e.g., gall bladder for a liver lobe donor)? If so, how will that affect me?
- Are transfusions usually given to donors? Do I need to bank my own blood in advance of the surgery?
- What will the anesthesia be like? Is local anesthesia an option? Will I be given an epidural anesthetic for pain control?
- How long does the donor's surgery last?
- Will the surgeon who performs my surgery close my incision?
- Will my incision be stapled or sutured or steri-stripped? Can a plastic surgeon be brought in to do the sutures?
- What medical apparatus does a donor wake up with when out of surgery (e.g., catheter, naso-gastric tube)? When are these typically removed?
- How long will I be in the recovery room?
- Will a drain(s) be used? (note: drains can tend to encourage infection)
- What support will my family receive while I'm in surgery? (e.g., social worker, chaplain, etc.) When should my family expect to receive status reports about my surgery?

RECOVERY IN THE HOSPITAL

- When I leave the post-surgical area, where will I be taken? (e.g., I.C.U.) If to I.C.U., how long does the person usually stay in I.C.U.?
- How soon, and where, can my family see me?
- What is the level of experience of the staff that will be taking care of me while I recover in the hospital?
- What is the nurse-to-patient ratio on the unit? (RN's, LPN's, CNAs, Student Nurses)
- Does the facility staff the unit with its own trained nurses or does it use floaters and agency nurses?
- How often will the staff check on me?
- Who gives the post-surgical medical orders after surgery until a donor leaves the hospital?
- What can you tell me about infection control in your hospital?
- How soon after surgery will I be expected to start getting up and walking?
- What pain control methods are used after surgery? Do I have choices?
- Will I have a pain medication pump? How long will I have it?
- I know that some doctors have definite opinions about giving potentially addictive pain medication and might skimp on the amounts given. What is the hospital's practice, typically, for providing potentially addictive pain medication to patients both in the hospital and upon discharge?
- Does your hospital have a pain management department, and if so, when will they be available to me?
- Will pain medications be scheduled? Or will they be given only if I ask for them?
- What medications, other than pain medications, will be given to me in the hospital?
- If I can't sleep, can I request and be given a sleeping medication?
- How soon after surgery will I be able to start taking my regular medications?
- What can I expect in terms of the function of my digestive tract? When will I be able to eat solid food?
- May I have a friend or family member with me during nonvisiting hours while I am in the hospital?
- May my young children visit me, assuming they are healthy? Are there any age restrictions?
- How does the hospital handle "off-hours" problems?
- Can I contact my surgeon (or other hospital doctors if applicable) easily during my hospital stay and how would I do that?
- Will I receive physician visits daily while in the hospital? Who will be seeing me during these visits?
- If I'm in the hospital over the weekend, will there be a change (i.e., a reduction) in my care, doctor visits, etc.?
- Will I receive any physical therapy while in the hospital?
- (For liver lobe donors): What are bile duct leaks? What does the patient experience? How are they detected? What is done about them?
- A day or so prior to my discharge, I would like to try the pain medication that I'll be taking at home to make sure it agrees with me and is effective for me. Also, I want to be sure that I will be in a safe environment in case I have an adverse reaction to it. Will you arrange this?
- A day or so prior to my discharge, will you give any written prescription(s) to my caregiver so that s/he can fill them before taking me home? Who is responsible to pay for the prescriptions?
- Are live plants and/or flowers permitted in the donor's room? (If not, let your friends and relatives know.)
- How will my diet be modified after the surgery? For how long?
- Will my room be on the same floor as my recipient?
- How soon after my surgery may I see my recipient?
- Can I obtain a copy of my hospital record upon discharge? Can that be arranged before my discharge?

RECOVERY POST-DISCHARGE

- What kind of clothing works best for going home in?
- May I take a bath or shower as soon as I get home?
- (For those who live far away from the transplant center): How long do I need to stay close to the transplant center after discharge before going home?
- If I encounter problems with moving my bowels, what OTC medications should I purchase to relieve the problem?
- Will I be able to travel after the surgery? How soon after discharge may I travel?
- Is there any problem with flying home? How soon can I do so?

- In addition to pain medication, are there other methods to manage pain when I'm at home? (e.g., ice, heat)
- What symptoms indicate trouble and the need to call the doctor at the hospital? What phone and/or pager numbers should I use?
- Which doctor will be responsible for responding to any complications I might suffer?
- What symptoms indicate an emergency for which I should go to the emergency room?
- (For those who live far away from the transplant center): For outpatient care, what type of physician should I see? (e.g., primary care, hepatologist, etc.)
- What is normal for the stages of an incision as it heals?
- Should I expect numbness around the incision or are any nerves affected in the surrounding area? Will the numbness go away or will it be permanent?
- What will the scar look like? How big will it be? Where will it be? Can you show me a picture of a typical scar? Are there methods to minimize the scar's appearance? (e.g., creams, silicone patches)
- Will I be able to stoop over to pick up things, tie shoes, etc.?
- When will I be able to drive?
- What physical activity limitations will there be? What about stairs? How much walking can I do or do you recommend?
- Kidney donors: What are the best ways to relieve the pressure from the CO2 post surgery?
- How long will the effects of the general anesthetic last?
- What lifting restrictions will I have?
- When can I start exercising and what exercises may I do?
- When are patients typically able to return to work?

LONG-TERM ISSUES

- Do you have a living donor coordinator for people who have already donated? (different from the coordinator you have during the evaluation phase) What is his/her role?
- When will my first follow-up visit be? How do I schedule it?
- What is the transplant center's follow-up plan? How many follow-up exams will I receive? Will procedures such as labs, CT scans, or x-rays be included? Will I have an annual exam? If so, will the exam be only at the end of the first year? Or will exams be provided for more than one year? If so, for how many years will annual exams be performed?
- What should I expect during the first year after surgery?
- Do I have any individual risk factors that might need follow-up?
- If I have a question related to my donation, who should I call?
- Long-term, how does a donor's body function differently after healing? Will my body feel different?
- Are there any prescription or over-the-counter medications that I should avoid?
- Should I wear a medic-alert bracelet to indicate to emergency workers that I've had this surgery?
- Do you recommend a schedule to my primary care physician for follow-up blood work or blood pressure checks?
- What are the organ donation-related long-term problems that donors might experience?
- What symptoms would I have if there were problems?
- Long-term, is there additional stress placed on the (remaining) (organ) if a donor becomes ill with a nondonation-related illness?
- If I have another surgery in the future, will my (remaining organ, e.g., kidney, remaining liver lobe) have trouble with the anesthesia?
- Would I be able to donate (another organ, tissue, blood, bone marrow) if the need arose within my family or circle of friends, or if I wanted to be a nondirected donor?
- If the recipient dies within the first year, what emotional support, if any, can I expect from the hospital (e.g., grief support group, individual counseling)?