Living Liver Donor Manual
If you’re thinking about being a donor
Welcome
To the Living Liver Donor Manual

This manual is for people who want to learn about living liver donation. It explains why some people choose to donate an organ while they are alive. It tells what to expect during the assessment process, what is involved in the operation, and what care is needed after surgery. Benefits, risks, and complications for both the donor and the transplant recipient are included.

Please read this material carefully and completely. Be sure to call the Transplant Care Team at 206.598.8881 if you have any questions or want to learn more about any part of the donation process.

Thank you for choosing University of Washington Medical Center for your healthcare needs.

Contents
Overview of the Living Donor Process
Questions to Ask Yourself
Benefits and Risks for the Transplant Recipient
Living Donor Assessment Process
Living Donor Surgery
Risks and Complications
Self-care After Donor Surgery

Questions?
Your questions are important. Call your doctor or health care provider if you have questions or concerns.

Transplant Services:
206.598.8881
Who can be a living donor?

Healthy people between the ages of 18 and 55 years may be donor candidates. Living donation must be a voluntary choice, with no pressure from others or desire for material gain.

The donor’s primary goal should be to help the recipient. Donors must:

• Be able to read, understand, and sign a consent form
• Have a healthy liver
• Have no major physical or psychological health issues
• Have a stable home and ongoing family support

What is the first step?

First, the recipient must agree to living donation. The recipient usually must be listed for cadaveric donation before a living donor assessment (work-up) starts. The recipient for a living donor liver transplant (LDLT) stays on the cadaveric donor waiting list while the living donor work-up is in progress.

What should a potential donor know?

If you want to be a living donor:

• All information you provide during your work-up is confidential. It will not be shared.
• You have a responsibility to honestly and fully report any and all health concerns, issues, and behaviors that might either affect your ability to be a donor or pose health risks to the recipient.
• If our screening shows that you have major health issues, we may ask you to give consent for us to get reports from your doctor before we start your work-up.

• It is your responsibility to tell the donor team about any homeopathic or herbal remedies you are taking. These supplements may interfere with liver function.

• The length of the work-up depends on your schedule and how complex your health issues are. It may take days, weeks, or even months to complete all the tests that are needed.

• If you wish to talk with someone who has had liver donor surgery, please tell us. We will set up a time for you to talk with a liver donor.

Who decides the results of the donor assessment?
The final decision to do the living donor transplant rests with the donor healthcare team. We will not do a living donation if the medical and/or surgical team believes that potential for harm outweighs the benefits.

If we decide not to accept the live donation, we will offer referrals to other programs for another opinion.

What happens when the donor is approved?
Once the donor is approved, the recipient must wait while the transplant surgery is arranged. It usually is scheduled within 1 to 2 weeks.

For the Donor: About the Assessment Process
The process of assessing a living donor takes time. **Donor safety is our first priority. We will not rush or compromise the donor assessment process even if the recipient is very sick.**

Your assessment will be guided by a Donor Advocate Team. This team is led by a special social worker and an anesthesiologist.

As part of the assessment process, you will also see a medical liver specialist consultant who is not part of the donation and recipient teams. This specialist can act as your advocate if you have any concerns.

The assessment process is designed to protect and advocate for the donor’s best interests. Our teams will:

• Make sure you understand the assessment process and the medical, psychological, social, and financial effects of being a living donor

• Assess your suitability (whether the medical risk to you is acceptable)

• Make sure that you give your consent freely and that you have all the information you need to make your decision
• Talk with you about the results of the work-up
• Provide emotional support, follow-up, and continuity of care throughout the donation process

The Donor Advocate Team will support you during the work-up process, but as the donor, you must also advocate for yourself. **If, at any point in the assessment process, you, your family members, or your friends have any reservations about donation, you must share this information with the donor advocate team.**

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**Questions?**

Your questions are important. Call your doctor or health care provider if you have questions or concerns.

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Questions to Ask Yourself
For potential living liver donors

It is important to ask yourself many questions as you think about becoming a living donor. Please talk about any or all of these issues with a member of the Donor Advocate Team.

Motivation

• Have I been totally honest with myself about why I want to donate part of my body to the recipient?

• Am I making this decision of my own free will because I believe it is the right choice for me and the intended recipient? Or am I considering this surgery because I feel pressured or influenced by others? (This would be a poor reason to be a donor.)

• Am I expecting anything in return for my donation, such as gratitude, publicity, other kinds of attention, or a better relationship with the recipient?

Pain and Discomfort

• Do I feel adequately prepared to deal with the pain and discomfort that I will have with this surgery?

• Will I be able to tell hospital staff and/or my family about what I need, both physically and emotionally?

• Can I manage the recovery period without running into problems such as boredom, anxiety, or nervousness?

Financial Concerns

• Am I prepared financially to be out of work for the time it will take for assessment, the surgery, and my recovery?

• At what point will I become anxious about my lack of income?
Questions?

Your questions are important. Call your doctor or health care provider if you have questions or concerns.

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- Do I have a backup plan in case I have to be off work longer than expected?

**Concerns After the Surgery**

- What do I expect about what this experience will do for me? Am I being realistic?
- Have I thought about how I would feel if the recipient does not take care of the portion of liver I donated?
- Have I thought about how I would feel if the recipient has serious complications or does not survive the transplant surgery?
- Is my family, personal, and professional life mostly stable and secure? If not, are there things that I can do now to improve my situation?
- Is there anything I can do now that will improve my recovery? Do I need to lose weight, exercise more, stop smoking, or take other self-care steps?
- Do any of my close friends and family disapprove of my wanting to make this donation?
- Will I be able to handle the reactions of family and friends when I am feeling weak and/or emotionally exhausted?

**Family Concerns**

- Have I talked with my family about how they will cope if I should have serious, unexpected complications from being a liver donor?
- Do I have a plan in place for my children or other dependents if I should have an unexpected outcome?
- Do I have an advance health directive? Does my healthcare proxy know what treatments I want to have if my condition worsens, so that I need advanced medical technology to survive?
- Does my family know who my healthcare proxy is? Do they understand that I have chosen that person to make medical decisions for me if I were not able to communicate with the medical team?
Livers that are donated for transplant can come from someone who is deceased or from a living donor. Both types of transplant surgery involve benefits and risks.

**What are the benefits of having a living donor?**

**Less Waiting Time**

There are not enough deceased donor organs to meet the needs of listed liver recipients. The waiting time for deceased donor (cadaveric) liver transplant ranges from days to months to years, depending on the health of the recipient. Being able to receive a liver from a living donor reduces the risk of declining health and death for the person who needs the liver transplant.

**Better Organ Quality**

Live donation provides the recipient with a high-quality organ. In comparison, about 35% of deceased donor organs are less than ideal. This is because the deceased donor may have been older, had mild to moderate liver abnormalities, or have died from health problems that may have weakened the liver. Often, doctors do not know the full health history of a deceased donor.

**What are the risks of having a living donor?**

**Survival Rates**

Survival rates for liver recipients after transplant do not depend on where their new liver came from. These numbers are the same for people who received a living liver and for people who received a cadaveric liver.
• 1 year after liver transplant, more than 90% of all recipients (90 out of 100 recipients) are still living.

• 5 years after transplant, 80 to 85% of all recipients (80 to 85 out of 100 recipients) are still living.

**Risk of Complications**

Liver function is usually excellent after a living donor liver transplant (LDLT). But, there is a slightly higher risk of complications during surgery with LDLT:

• Risk of leaks or narrowing of the bile duct connection:
  - 25% with LDLT (25 out of 100 patients) have this complication
  - 5 to 10% with deceased donors (5 to 10 out of 100 recipients) have this complication

• Risk of clotting of the hepatic artery is slightly higher with LDLT.

These complications can lead to loss of the liver or may require more surgery. But, they can often be managed without needing more surgery and without affecting how the liver works long-term.
Living Donor Assessment Process
For liver transplant

What You Should Know

As a living donor candidate, you will be having many medical tests as part of the assessment process. During your health assessment, we may discover health issues that you did not know about, or that had not yet been diagnosed. A new diagnosis could affect your ability to get health insurance or a job, and may cause emotional distress.

You can withdraw from the assessment process at any time. The recipient will not be told the reason, only that the donor was found to be medically unsuitable.

If More than One Donor Voluntees

Sometimes, more than one person volunteers to be a donor. If this occurs, we will contact the most suitable donor to start assessment, unless the intended donors meet, jointly make a decision, and together tell us otherwise. Other donors will be placed on hold and will only be contacted if the first donor being assessed is not accepted.

Getting Started

To be a candidate for living liver donation, you must:

- First provide us with your blood type and full health history.
- Be in excellent physical and emotional health. If you have a history of cancer or an active infection, you cannot donate.
- Have normal liver function. Your liver must have certain qualities that make it suitable for transplant.
- Have a stable home and family or friends who will support you before, during, and after surgery.
- Have a primary healthcare provider.
Reducing Risks

- Smoking and birth control pills are avoidable risk factors for blood clots after surgery. Before donation:
  - We ask donors to stop smoking.
  - We also ask women using any form of hormonal birth control or replacement therapy to stop this medicine.
- If you use alcohol, marijuana, or any illicit drugs, you cannot be a living donor at University of Washington Medical Center (UWMC).
- While you are waiting for donor surgery, you have a responsibility to avoid all behaviors that would put you at risk for infection (such as HIV, hepatitis C, or syphilis) that could be passed on to the recipient. We advise that you:
  - Abstain from any high-risk behaviors such as unprotected sex and intravenous drugs
  - Use condoms to avoid disease transmission through sexual contact

Screening Tests

You will have these screening tests as part of the assessment process:

- An electrocardiogram (EKG) and chest X-ray to make sure your heart and lungs are working well.
- A CT scan, ultrasound exam, and MRI scan to look more closely at your liver veins, arteries, and bile ducts. The results will help us plan your donor surgery.
- Blood tests to confirm normal organ function and check for the presence of several viral diseases. These diseases include hepatitis B and C, HIV, syphilis, and others.

Blood tests are done because there is a risk of transmitting infections via organ donation. Please note that we are required by law to report some viruses to the Public Health Department. You may be contacted by Public Health if you have a positive test for these viruses.

During the assessment, call the Living Donor Coordinator right away if you have a fever, flu-like illness, or neurological symptoms (changes in vision or balance, or a feeling of weakness in your arms or legs). If you have an active infection, you should not donate part of your liver because the donated organ will infect the recipient.

The surgeons will review the results of your screening tests to make sure your liver is healthy and suitable for transplant surgery. Sometimes, more studies are needed, such as a liver biopsy.
Keeping Your Appointments

If you do not keep your appointment for a required test:

- The test will be re-booked. We will call you with a new test date.
- If you do not keep this new appointment, and we do not hear back from you within 2 weeks, we will assume that you do not wish to go ahead with the work-up. We will tell the recipient team that you are no longer a donor candidate and that a work-up on a different donor may begin.

Test Results

- If the results of your scans and blood tests meet our requirements, we will offer you a possible surgery date. This date will be based on when you are available.
- If we find that you are not a good donor candidate for any reason:
  - We will tell you right away and the work-up will stop.
  - We will send the results of your screening tests to your primary healthcare provider and request that your provider do follow-up tests. If a condition (such as obesity) is corrected, the work-up can be restarted.

Stopping the Assessment Process

At any stage in the assessment, either the potential donor or the healthcare team may decide not to proceed with liver donation.

The donor team may decide it is not possible for a donor to proceed for a variety of reasons. If this occurs, the team will talk with you in detail about those reasons. Only about 20 to 30% of potential donors (20 to 30 out of 100) who indicate an interest in liver donation actually become donors.

Some of the most common reasons for candidates not becoming donors are:

- The blood vessel structure in their livers will not work for transplant.
- They have abnormal blood tests.
- They are overweight (obese).
- They have health issues that were found during the assessment.

We always protect the donor’s confidentiality. If there is any reason you cannot be a living liver donor, we will not tell the recipient why, unless you tell us to share that information.
Next Steps

If we believe you are a good donor candidate after reviewing your test results, you will next meet with at least one of the transplant surgeons to talk about the donor surgery in detail. The surgeons will talk with you about the benefits, risks, and other options to doing this surgery. If you agree to proceed, we will ask you to sign an informed consent form.

Potential donors must talk directly with the Living Donor Coordinator about any questions or concerns. For your privacy and protection, we will not talk with other parties such as family members, friends, or the recipient about your donor assessment process.

Questions?

Your questions are important. Call your doctor or health care provider if you have questions or concerns.

Transplant Services:
206.598.8881
Living Donor Surgery
What to expect

Surgery Date
The target surgery date is always subject to change. The date may change because:

• As the donor, you may decide not to donate at any time. Your reasons for doing this are kept confidential.

• The liver transplant program may decide that other live donor surgeries need to take priority because of the donor’s health issues.

• The recipient has a cold, pneumonia, or other illness and is too sick to have the transplant surgery.

If your donor surgery is cancelled or delayed, we will reschedule the surgery as soon as possible.

Getting Ready for Surgery

Traveling
Sitting still for a long time right before donor surgery increases your risk of blood clots during and after the surgery. Because of this, if you:

• Travel by air to have the donor surgery, you must complete your air travel at least 2 days before the surgery.

• Are taking a long car trip to have the donor surgery, stop often to walk and stretch your legs.

Night Before Surgery
• Do not take anything by mouth after midnight.

Day of Surgery
• Do not take anything by mouth the morning of your surgery.
• Bring your usual medicines with you to the hospital.

• Follow the other instructions your nurse gave you in your pre-surgery visit.

**At the Hospital**

• You will be admitted to the hospital at 5:30 a.m. on the day of surgery.

• You will change into a hospital gown.

• Compression stockings will be placed on your legs to help prevent blood clots.

• An *intravenous* (IV) line will be inserted into your arm. You will receive fluids and medicines through this line during the surgery.

• We will check your blood pressure, heart rate, and temperature.

• You will meet with:
  - The anesthesiologist to talk about plans to manage pain during and after the surgery.
  - The operating room (OR) nurse to talk about your home medicines and any allergies you have.
  - Your surgeon to talk about the surgery and to answer any last-minute questions you might have.

• You will then be moved to the OR. You will receive general anesthesia to make you sleep, antibiotics, and a blood thinner to prevent blood clots.

• After you are asleep, tubes will be inserted into your body. These tubes will drain the contents of your stomach and bladder, provide fluids, and monitor your blood pressure.

**The Surgery**

• Your surgeons will first carefully examine your internal organs. This exam will include an ultrasound and an X-ray of your *bile ducts* (the tubes that carry bile from your liver to your intestine).

• Your gallbladder will then be removed.

• Your surgeons will clean the blood vessels and bile ducts to the part of the liver that is going to be removed.

  Sometimes at this point, even with normal screening tests results, we find that the donor’s blood vessels or bile ducts would make the transplant very risky for the donor or the recipient. If this occurs, we stop the donor surgery and close the incision. This happens in 3 to 5% of donor surgeries (3 to 5 out of 100 surgeries).

• If the donor’s blood vessels and bile ducts support transplant, we will start surgery on the recipient.
• The donor liver will be split in half. The part to be donated will be removed.

• Donor surgery lasts 6 to 8 hours.

**After Surgery**

After surgery, you will be taken to the intensive care unit (ICU). Your care team will include surgeons, intensive care unit specialists, nurses, physician assistants, and pharmacists.

UWMC is a teaching facility. This means that your care team will also include medical students and nurses and doctors who are in training. But, all decisions about your care will be made by your surgeons and intensivist (a doctor who specializes in caring for critically ill patients).

**Pain Control**

You will control your own pain medicines using a *patient-controlled analgesia* (PCA) machine. This machine allows you to push a button when you begin to feel pain or discomfort.

You will also have a *regional anesthesia block* that keeps the nerves in the surgery area from sending pain signals to your brain.

After 2 to 3 days, your doctor will prescribe pain medicine for you to take by mouth. This pain medicine may be acetaminophen (Tylenol), oxycodone, or hydromorphone (Dilaudid).

**Medical Equipment**

During surgery, many tubes are inserted into your body. These include:

• A *nasogastric* (NG) tube that goes through your nose and down to your stomach for feeding.

• *Intravenous* (IV) tubes that go directly into a vein to provide medicines and nutrients.

• A *bladder catheter* inserted into your urethra to drain urine from your bladder.

These tubes are removed when they are no longer needed, usually during the first few days after surgery.

**Eating**

Most patients are able to start eating and drinking about the 3rd day after donor surgery. Until then, you will receive nutrients and fluids through the NG and IV tubes.

**Exercise**

• On the first day after your surgery, we will encourage you to get out of bed and start walking, with the help of your nurse or physical therapist.
• You will be given an incentive spirometer (blowing balloon) right after surgery. The nurse will teach you how to use it. Using the spirometer will help prevent pneumonia.

Tests
• You will have blood tests to check how your liver is working, both during your hospital stay and after you leave the hospital.
• An ultrasound will also be done to check your liver.

Preventing Blood Clots
To lower your risk of getting blood clots, you will receive blood-thinning medicine (anticoagulants) after surgery and during your hospital stay. Blood thinners carry a small risk of bleeding and stroke, but we believe the benefits outweigh these risks.

Walking often after surgery will also help lower your risk of getting blood clots.

Going Home
Most donors are discharged from the hospital about 5 to 7 days after the operation.

Healing
Within a few weeks after surgery, the portion of your liver that remains in your body will grow and start to work normally again.

Travel
Because of the risk of blood clots, we advise that donors:
• Stay in the Seattle area for 1 week after you are discharged from the hospital. After 1 week, you can travel within the U.S.
• When you travel, it is important to:
  - Drink fluids
  - Extend and flex your legs at least 10 times every hour
  - Get up every hour to walk around and move your legs for at least 10 to 15 minutes
• Do not travel outside of the U.S. for 8 weeks after your donor surgery.

When to Call
Most complications occur soon after surgery. But, some complications can occur after you leave the hospital. During your discharge teaching, we will review symptoms to watch for.
Call the donor office right away if you have:

- New abdominal pain
- Redness or swelling around your incision, or pus coming from your incision
- Yellow eyes or skin
- Fever higher than 101°F (38.3°C)
- A cough or you feel short of breath
- New pain, or strong pain that your pain medicines do not ease

If the donor office is closed, go to the nearest Emergency Department right away.

**Follow-up**

Follow-up clinic visits are set up before you leave the hospital. The surgery team will meet with you at these visits. You will also get weekly phone calls from our patient care coordinator to make sure you are doing well.

We will follow you closely during the first year after your donor surgery. You will receive a survey in the mail at 6 months and 1 year after your surgery. This survey will ask you questions about your recovery and quality of life.

**Returning to Normal Life**

It is common to feel a “let-down” or mild depression about 4 to 6 weeks after surgery. These feelings usually go away quickly, but please let us know if they become a concern. We want to support you throughout your recovery process.

It usually takes 3 to 4 months before donors are able to return to all of their normal activities with their usual level of energy.

See “Self-care After Donor Surgery” for more details.

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**Questions?**

Your questions are important. Call your doctor or health care provider if you have questions or concerns.

Transplant Services: 206.598.8881
Liver donation is linked with major health risks, no matter how carefully the donor surgery is done. If you are thinking about donating an organ, you need to have a good understanding of what the surgery involves, the benefits and risks, and the other choices you can make.

During your assessment process, you will hear a lot about the risks of donor surgery. Your surgeons will also carefully review these risks during your pre-surgery visits. Feel free to ask any questions you may have.

Here are some of the known risks of live donation:

**Donor Death**

Liver donation is a challenging operation. Donor deaths and/or major complications can occur even when the very best care is provided.

The risk of death from donor surgery is:

- About 0.1% with the left lateral segment and left lobe donation (1 out of 1,000 donors die)
- 0.3 to 0.4% with right lobe donation (3 to 4 out of 1,000 donors die)

In comparison, the risk of death after live donation is higher than the risk of death after routine heart bypass surgery.

**Health Changes**

To remove the donor liver, the surgeon makes a large incision in the donor’s upper abdomen. This results in mild, permanent weakness in the abdominal wall. The donor will also have a small area of numbness beneath the incision, just above the navel (belly button).
Other Health Risks

Up to 40% of liver donors (40 out of 100) have some complications. Most of these are mild and short-term. But, some can be very serious and life-threatening.

Health risks of liver donation surgery include:

- Bad reaction to anesthesia
- Stroke or heart attack
- Blood clots in the legs or lung (*pulmonary embolism*)
- Fluid around the lung
- Fluid retention (*edema*)
- Mild or serious infections
- Infection or other bad effects of having a blood transfusion (transfusions are needed in about 5% of donor surgeries, or 5 out of 100 surgeries)
- Bleeding that requires another operation
- Bile leakage or bile duct damage that needs surgery to repair
- Injury to nearby organs such as the spleen, stomach, or intestine
- Injury to the blood vessels leading to the remaining liver segment, causing liver failure
- Severe depression
- Ugly scar
- Injuries from the use of a retractor, causing short-term or permanent nerve damage
- Ongoing pain in the incision

Some donors in the U.S. and Japan have needed liver transplants to treat liver failure that developed after they donated part of their liver.

Job Security and Health Insurance

If complications occur during or after your donor surgery, they could affect your ability to get health insurance or life insurance. They could also affect your way of living or your ability to keep or get a job. And, even if there are no complications, the surgery itself might affect your job security or your ability to get insurance.

If you are thinking about being a live donor, talk with an insurance agent and with your employer. Find out what their policies are for someone who has donated an organ, with or without complications. Staff from the donor program can help provide any information that is needed.
Recipient Death

No matter how carefully the transplant surgery is done, it is possible that the liver recipient will die during or after the transplant surgery. If this happens, donors will know that they have done everything possible to help a loved one.

If you are thinking about being a liver donor, think carefully about how the stress of dealing with the recipient’s death might affect you.

Other Rare Issues

It is very unlikely that your intended recipient will have issues that make transplant surgery impossible after your liver segment has been removed. If this does occur, we will try to place your liver segment (called an orphan graft) into another recipient. Worldwide, this problem has happened only a few times.

Every transplant recipient is unique, and every living donor is unique. This means that other issues may arise that we are not yet aware of.

Questions?

Your questions are important. Call your doctor or health care provider if you have questions or concerns.

Transplant Services: 206.598.8881
Self-care After Donor Surgery
For living liver donors

When to Call
The living donor liver team is available to talk with you about any issues or concerns that you have. If you have questions:

• Weekdays from 8 a.m. to 5 p.m., call 206.598.3873.
• After hours and on weekends and holidays, call 206.598.6190 and ask for the Liver Transplant Fellow on call to be paged.

Call the doctor right away if you have:

• Fever higher than 101°F (38.3°C)
• Yellow eyes or skin
• Shortness of breath or a cough
• New pain or a strong pain that your pain medicines do not ease
• Redness or swelling around an incision, or pus coming from an incision

Activity

• For 6 weeks after surgery:
  - Do not lift anything heavier than 15 pounds (1 gallon of water weighs a little more than 8 pounds).
  - Do not do any exercise that makes you breathe hard.

• In the first 6 weeks after surgery, you can:
  - Go for daily walks
  - Do light exercise
  - Have normal sexual activity, if it is comfortable

• After 6 weeks, you can slowly resume full activities.

Go for daily walks to help your recovery after donor surgery.
Return to Work
You can return to work within 6 to 8 weeks if your work does not require heavy lifting or exertion. If you must do physical labor in your work, you may not be able to return to your job for 12 weeks after surgery.

Diet
- Do not drink alcohol for 12 weeks after surgery.
- Eat a normal, healthy diet. Eat low-fat foods and foods with fiber such as fresh fruits and vegetables to keep your weight at an ideal level.

Travel
Because of the risk of blood clots, we advise that donors:
- Stay in the Seattle area for 1 week after you are discharged from the hospital. After 1 week, you can travel within the U.S.
- When you travel, it is important to:
  - Drink fluids
  - Extend and flex your legs at least 10 times every hour
  - Get up every hour to walk around and move your legs for at least 10 to 15 minutes
- Do not travel outside of the U.S. for 8 weeks after your donor surgery.

Medicines
When you leave the hospital, you will be given prescriptions for:
- Pain medicine, usually oxycodone (Oxycontin) or hydromorphone (Dilaudid)
- Anti-nausea medicine, usually metoclopramide (Reglan) and ondansetron hydrochloride (Zofran)
- A stool softener, usually Docusate, senna, or MiraLAX
Take acetaminophen (Tylenol) and your prescription pain medicines as needed to relieve pain during your recovery. **Do not take more than the recommended dose.**
You should be able to stop taking your prescription pain medicines about 3 to 4 weeks after surgery. If your pain lasts longer than 4 weeks, please call the Living Donor Office at 206.598.3873.
Prescription pain medicine can cause constipation (hard stools). To ease constipation:
- Be sure to drink 3 to 4 liters (12 to 17 cups) of fluid every day.
- Take the stool softener as needed.