

In their own words

The Experiences of Living Liver Donors



“Trust your instincts and lastly, if it is right for you to donate, you will know it in your heart!”

“Be informed, ask questions, even if they seem like stupid questions.”

“You become a better person, meet amazing people, encounter great experiences, see life in a new light, save an individual’s life.”

“The journey of becoming a donor never ends, it’s full of amazing things.”

“Every decision is personal...get as much information as possible and speak to other donors.”

About This Booklet



This booklet is different from other materials you may have received about living liver donation. The information is from individuals who have donated a portion of their liver to a loved one.

For the past twelve years, we have surveyed individuals who donated in New York State about life after living donation. The 224 respondents included spouses, siblings or children of the recipients. Parents, friends and other relatives also gave information.

In their own words, here is what these donors said about:

- The Surgery
- Recovery After Donation
- Costs of Donation
- Employment Issues
- Life After Donation

As you read this booklet, you may be surprised at how open the donors are in describing their experiences. We have included both positive and negative feedback. Most of the feedback was good, and almost all of the donors agreed that donating has affected their lives in a positive way—95% of the donors said that they would do it again.

This booklet will help answer some of your questions about the experience of living liver donation. While this isn't an easy decision, we believe that hearing from other living liver donors will help you make the right decision for you and your family.

We thank the living liver donors who shared their experiences and helped create this booklet.

The Surgery



“Prep by my team was very thorough. My living donor coordinator was instrumental in the process.”

All potential living donors are assigned a donor advocacy team that includes a physician, psychiatrist, social worker and donor nurse coordinator. This team ensures that you have the information you need to make an informed choice.

Donors were asked how satisfied they were with the quality of care they received in the hospital. Eighty-two percent (82%) were very satisfied with the quality of care they received in the hospital, and almost all of the others were somewhat satisfied (15%).

More than 80% of the donors also reported being very satisfied with the quality of care they received from the nursing and physician staff.

One donor said, *“Prep by my team was very thorough. My living donor coordinator was instrumental in the process. Please stress the importance of this key figure’s interpersonal skills, medical knowledge and compassion.”*

“Don't underestimate the recovery process and pain involved.”

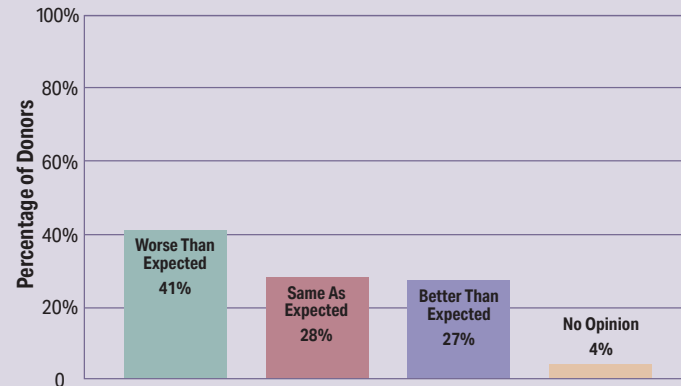


The donor advocate team at the transplant center describes the surgery in detail to a donor prior to the surgery. However, even with this information, in the days after the surgery, donors reported that they felt worse than they expected more often than feeling better. As with any major surgery, recovery can be difficult and the experience varies with each person.

One donor wrote, *“Don't underestimate the recovery process and pain involved.”*

“Don't be afraid to stand up for yourself if you don't like something in the hospital. It is very easy to feel defenseless after surgery; you are reliant upon the nurses and so is the recipient.”

Figure 1: How Donors Felt After Donation



Recovery After Donation

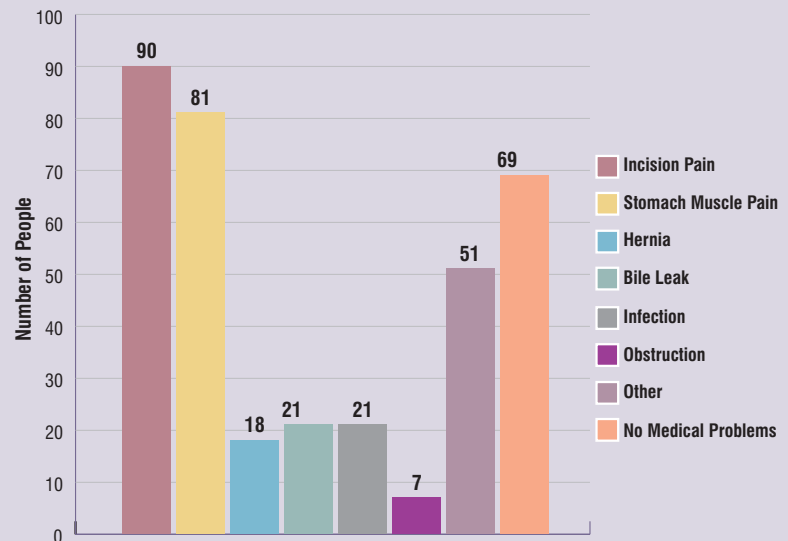


Currently, about 7 in 10 of the donors felt as well after the surgery as they felt before the surgery and almost all have returned to normal daily activities such as driving, shopping and exercising. In fact, 82% of the donors rate their own health as very good or excellent.

However, people considering living liver donation should know that it takes time to return to everyday activities. Within the first three months after surgery, 69% of donors report some problem, most common is incision or muscle pain. Hernia, bile leak, obstruction and infection were reported less frequently, while some donors did not report any medical problems.

When asked approximately one year after the surgery, 65% of donors report no *current* medical problems (see Figure 3). Of those that continued to report problems, stomach muscle pain was the most common. Other problems include indigestion, discomfort and fluid retention.

Figure 2: Medical Problems Following Surgery



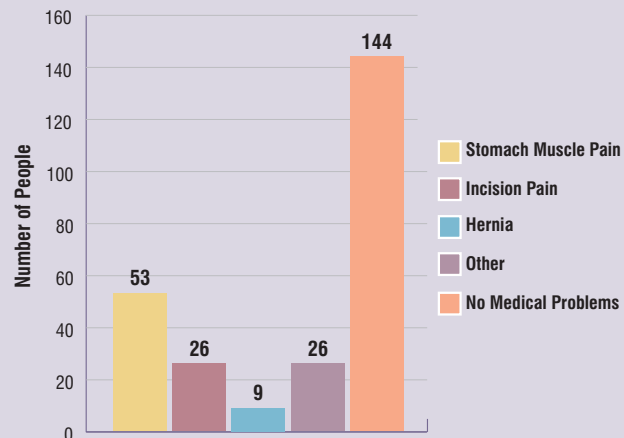
“It was extremely beneficial to have family help out in the hospital and after discharge.”



In addition, living donors may experience anxiety and depression during recovery. A third of the donors felt anxious and/or depressed right after the surgery. Less than one quarter of donors continued to have emotional problems related to the surgery after three months. A small number of donors reported ongoing emotional problems due to concern for the recipient's health. It is important to remember that living donation is a treatment—not a cure—for the recipient.

Family and friends play an important role during recovery. One donor commented, “Immediate post-op period was difficult. It was extremely beneficial to have a supportive family to help out, both in the hospital and after discharge.” However, some donors reported strained relationships with the recipient (5%) or other family members (5%) after donation.

Figure 3: Medical Problems Now



Costs Associated With Donation



There are some costs for living liver donors that should be considered. For example, potential donors must be evaluated for living liver donation to determine if they can be a donor – are they healthy, do they understand the process, are they a good match? To be evaluated, potential donors must travel to the transplant center where their loved one is waiting for a liver transplant.

Donors were asked how much they spent for medical and non-medical expenses such as travel, lodging and meals.

Approximately 63% of the donors spent less than \$1,000 for expenses such as travel, lodging and meals. While 70% felt donating was not a financial hardship, 1 in 5 donors reported minor financial hardship from these expenses.

When asked if there was anything they would tell future donors about the expenses of donating, the respondents said:

- Inquire about short or long term disability
- Prepare for out-of-pocket expenses
- Prepare for loss of income

One donor suggested, *“Plan ahead for help at home. Contact all your utility, cable and phone companies and explain what’s going on. Our cable company gave us two months free under the circumstances. Some companies will help.”*



Health Insurance

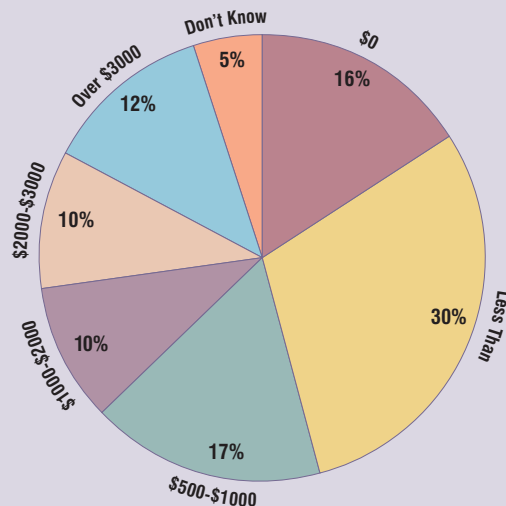
All but ten of the donors have health insurance or a health plan. Two of the donors reported being aware of an increase in their premiums or denial of health insurance coverage. Some of this information was collected prior to the implementation of the Affordable Care Act.

Life Insurance

Two-thirds of the donors currently have life insurance; three donors reported premium increases or denial of life insurance.

“Plan ahead for help at home. Contact all your utilities, cable, and phone companies and explain what’s going on.”

**Figure 4:
Money Spent by Living Liver Donors
On Medical and Non-Medical Expenses**



“The majority of donors said that their employers were very supportive.”

Employment Issues



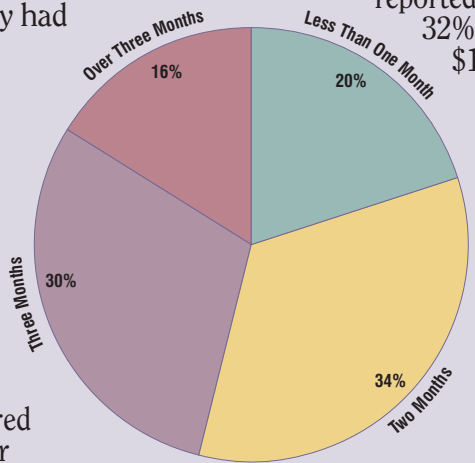
Returning to work can be a major concern to potential donors. Donation did not result in donors losing their jobs. Almost all of the donors who were employed at the time of their donation returned to work; over 90% in the same job they had when they donated.

Most donors were back to work within 3 months of donating. About 84% of the donors are currently working full-time, 2 donors are not currently working, and all the others are working part-time.

Of the donors who responded to the survey, 85% worked at the time of their donation and most worked full-time. Almost half had jobs that required them to be physically active; the other

half had a desk job or were seated most of the time.

The largest number of donors reported their average household income above \$100,000 (35%), nearly 9% reported income below \$25,000 per year and about 32% reported income within the \$50,000-\$100,000 range.



The majority of donors reported that their employers were *very supportive* of the donation (81%) or somewhat supportive (12%), providing paid time off, flexible work schedules, or holding the donor’s current job. A little over half of the employed donors used personal, sick, or vacation time to cover time off following surgery.

Figure 5: Time Out of Work for the Donation Surgery

Life After Donation: Would they do it again?



Almost all (97%) of the donors say that they would choose to donate again. Over 80% of donors reported they are very satisfied with their experiences as living liver donors, although two donors reported being dissatisfied with the experience.

1 in four donors report some negative impact from donation—ranging from dislike of the scar to continuing abdominal discomfort, or difficulty getting back in shape.

The majority of donors agree that donating has affected their lives in a positive way; they feel good about donating. Six in 10 agree that they appreciate life more and three-quarters of donors report no negative impacts from donation.

*“Ask questions...
take notes. Speak
to at least one
former donor.”*

NYCLT is a non-profit organization comprised of the liver transplant programs in New York State. It has brought together liver transplant professionals dedicated to enhancing the quality of liver transplant services. Through public and professional outreach, the Center strives to provide accurate and current information about liver transplantation to NYS transplant professionals, recipients, donors and families.

Additional Resources

Donate Life America
www.donatelife.net

Organdonor.gov
www.organdonor.gov

The Organ Procurement and Transplantation
Network (OPTN)
www.optn.org

Transplant Living
www.transplantliving.org

The United Network for Organ Sharing (UNOS)
www.unos.org



The New York Center for Liver Transplantation, Inc. (NYCLT)
250 Jordan Road, Troy, NY 12180 • (518) 533-7877 • www.nyclt.org

Transplant programs in New York State have regulatory requirements under Section 405.22 of part 405 of Title 10 of The Official Compilation of Codes, Rules and Regulations of The State of New York to track living liver donors after donation. The information presented in this brochure is based upon the survey responses of living liver donors. Two-hundred-twenty-five donors responded to the survey, response rate=44%.

These materials were developed through the support of the State of New York. The opinions, results, findings and/or interpretations of data contained herein are the responsibility of the New York Center for Liver Transplantation and do not necessarily represent the opinions, interpretations or policy of the State.

This material is not intended to be a substitute for professional medical advice, diagnosis or treatment. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition. Never disregard professional medical advice or delay in seeking it because of something you have read in these materials.

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