



# Living Liver Donation: Medical Toolkit

## CHAPTER • 16

## Liver donation and your social and emotional health

### What symptoms could I have right after liver donation?

Everyone's experience with social and emotional health is different and can change over time, positive and at times negative. Some donors feel gratitude and higher self-esteem right after their surgery. However, some donors feel frustrated about:

- Physical symptoms:
  - Fatigue (tiredness)
  - Pain from the incision (cut)
  - Changes in taste and digestion, or nausea
- Emotional symptoms:
  - Adjusting to the way their scar looks
  - Taking longer than their recipient to recover and return to their pre-surgery health
  - Realizing returning to work and family may take longer than they expected

### What changes could happen after liver donation?

#### Emotional changes

After donation, most living liver donors say they feel:

- Less worried about future stress or health issues
- Closer to family and their recipient (person they donated to)
- A sense of well-being and purpose in life

Yet some donors may:

- Feel very tired
- Have family or relationship problems

- Have short term depression or anxiety symptoms – donors with a history of depression or anxiety may feel symptoms get worse and require outside support such as therapy
- Feel grief, sadness, or guilt if their recipient dies, especially within the first 2 years or if they were a close relative or friend

If any of these emotional changes happen, a liver donor should consider reaching out to the psychosocial team (social worker, psychologist, or psychiatrist) that they met as part of their Evaluation Process (chapter 1) and make a plan for how to cope with changes to mental health.

#### Physical and behavior changes

After donation, some donors struggle because:

- They have ongoing health problems after the surgery that make recovery take longer (see chapter 4 for the types of problems that can happen after surgery)
- They worry about body image or appearance
- They have ongoing pain or discomfort within the first year after donation – this can lead to sleep problems, ongoing fatigue, depression, and anxiety
- For those with a history alcohol, drugs, or tobacco misuse, they may use it again (relapse)

#### Financial changes

After donation, donors may struggle with financial changes such as:

- Health costs: Donating may cause out-of-pocket healthcare costs. Donors may not expect costs because Medicare and the recipient's private insurance pay for the donor's:
- Evaluation lab testing and imaging scans
- Surgery and follow-up visits and tests



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- Any transplant problems from donor surgery throughout the recovery period. This varies by the recipient's insurance at the time of transplant

As recommended, all living donors should have their own health insurance to cover costs not covered by Medicare or the recipient's insurance.

- Other costs: Most donors have other costs, such as from:
  - Lost wages, such as unpaid time away from work
  - Transportation and lodging for themselves or their caregivers

Financial burden can significantly affect a living donor's physical and mental recovery and quality of life post donation.

### Get financial help:

- Many donors will qualify for help paying for travel, lost wages, or dependent care through the National Living Donor Assistance Centers
- New laws offering state specific and federal tax adjustments for living donors may help. Living donors can refer to the AST living donor financial toolkit for help

## Will being a living liver donor change my relationship with my recipient?

Possibly, in the years after donation – some people say their relationship got better, and others say it got worse.

Donors and recipients are uniquely connected and may not always think of the relationship in the same way. Talk about your wishes for the relationship with your team during your evaluation process.

## How can I protect my emotional health as a donor?

During the evaluation process, be fully honest and share your full medical, financial, and mental health history with the transplant team. This can help you avoid any possible emotional struggles after surgery. Also talk with all your current medical providers about who will help you during recovery so that you get the support you need.

## REFERENCES

1. Butt Z, Dew MA, Liu Q, et al. Psychological Outcomes of Living Liver Donors from a Multicenter Prospective Study: Results from the Adult-to-Adult Living Donor Liver Transplantation Cohort Study 2 (A2ALL-2). *Am J Transplant.* 2017; 17: 1267-1277.
2. DiMartini A, Dew MA, Liu Q, et al. Social and Financial Outcomes of Living Liver Donation: A Prospective Investigation Within the Adult-to-Adult Living Donor Liver Transplantation Cohort Study 2 (A2ALL-2). *Am J Transplant.* 2017 Apr;17(4):1081-1096.
3. Dew MA, DiMartini AF, DeVito Dabbs AJ, et al. Preventive intervention for living donor psychosocial outcomes: feasibility and efficacy in a randomized controlled trial. *Am J Transplant.* 2013 Oct;13(10):2672-84.
4. Dew MA, Butt Z, Humar A, DiMartini AF. Long-Term Medical and Psychosocial Outcomes in Living Liver Donors. *Am J Transplant.* 2017 Apr;17(4):880-892.
5. Dew MA, DiMartini AF, Ladner DP, et al. Psychosocial outcomes 3 to 10 years after donation in the Adult to Adult Living Donor Liver Transplantation Cohort Study. *Transplantation* 2016; 100: 1257-1269.
6. Holtzman S, Clarke HA, McCluskey SA, Turcotte K, Grant D, Katz J. Acute and chronic postsurgical pain after living liver donation: Incidence and predictors. *Liver Transpl.* 2014 Nov;20(11):1336-46.
7. Hong SK, Choe S, Yi NJ, et al. Long-term Survival of 10,116 Korean Live Liver Donors [published online ahead of print, 2019 Dec 16]. *Ann Surg.* 2019;10.1097.
8. Dew MA, Butt Z, Liu Q, et al. Prevalence and Predictors of Patient-Reported Long-term Mental and Physical Health After Donation in the Adult-to-Adult Living-Donor Liver Transplantation Cohort Study. *Transplantation.* 2018;102(1):105-118.
9. Rudow DL, DeLair S, Feeley T, et al. Longterm Impact of Living Liver Donation: A Self-Report of the Donation Experience. *Liver Transpl.* 2019 May;25(5):724-733.
10. Parikh ND, Ladner D, Abecassis M, Butt Z. Quality of life for donors after living donor liver transplantation: a review of the literature. *Liver Transpl.* 2010 Dec;16(12):1352-8.
11. <https://www.livingdonorassistance.org/How-to-Apply/How-NLDAC-Helps>.
12. <http://www.livedonortoolkit.com/>.

*Note: This information is the opinion of the Living Donor Community of Practice (LDCOP) of the American Society of Transplantation. The LDCOP is a group of health care professionals and researchers who specialize in living donation. The LDCOP's recommendations are meant to offer you helpful information, but you may find opinions from other groups or organizations that are helpful to you, too.*