

# Post-Operative Psychosocial Needs of Living Liver Donors

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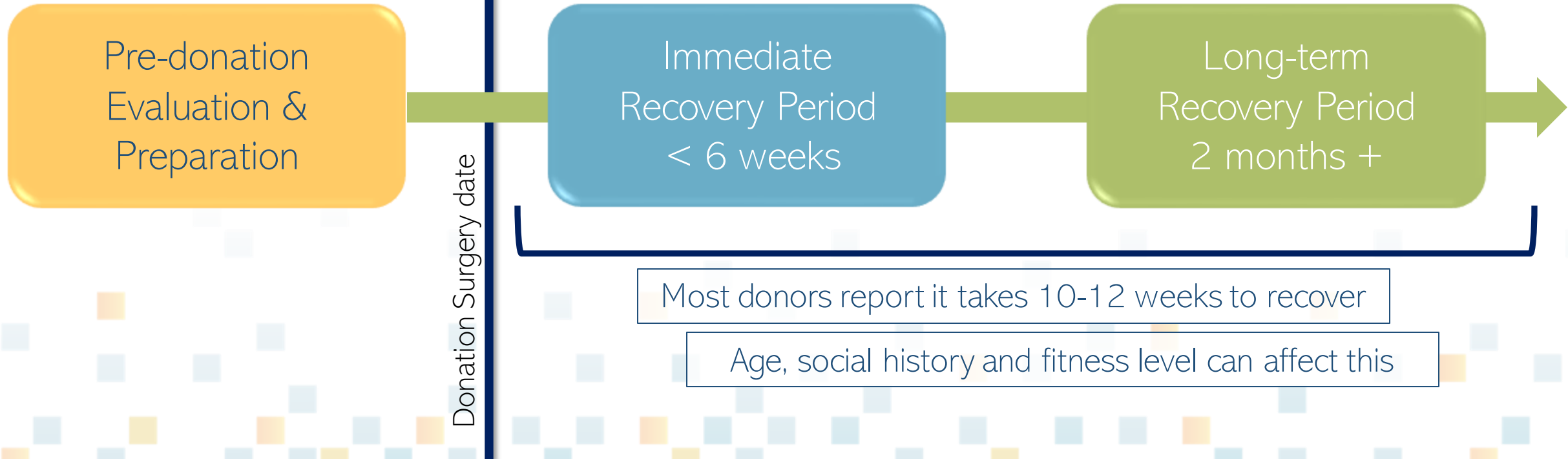
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# Timeline of Donor Experience



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# Pre-donation Evaluation & Preparation

Psychosocial impacts begin as soon as a potential donor is considering being a donor.

Feelings often include:

- Ambivalence
- Fear
- Obligation
- Worry/anxiety
- Excitement
- Anticipation



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# Pre-donation Evaluation & Preparation

Dynamics include:

- A magnifying glass on family system dysfunction and functioning
  - Intensified reflection and evaluation on familial relationships
- Potential fear that they will not be medically able to donate
- Worrying about financial impact of donation
- Underestimating surgery/recovery complexity and risks
- Planning for relocation causing disruptions in work/family obligations

“My uncle did this to himself, why should I put myself at risk?”

“It’s like a tummy tuck, right?”



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# Unique to Liver Donation Recovery:

Donors have:

- Longer time out of work and for recovery
  - Open hepatectomy vs laparoscopic
- More intensive medical follow up
  - More frequent, etc



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# Living Liver Donor Recovery

- What does back to baseline actually mean?
  - Able to perform ADLs without fatigue?
  - Back to baseline fitness level?

Work leave depends on type of work:

- Work-from-home or administrative roles:
  - 6-8 weeks
- Labor intensive roles:
  - 10-12 weeks



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# Recovery is impacted by:

- Fatigue:
  - Regeneration starts almost immediately, and the body uses a lot of energy to regenerate the liver
- Pain: Abdominal, back & referred
- Nutrition:
  - Oral intake is less in first few weeks, food may taste different, and they may have constipation
  - Food tolerance: intermittent nausea, effects of gallbladder removal
- Sleep: requires a comfortable position, may have night sweats



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# Immediate Recovery Period < 6 weeks

## Positive/comfortable feelings:

- Gratitude
- Higher self-esteem
- Satisfaction
- Connection
- Relief

## Challenging feelings:

- Adjustment
- Distress
- Anxiety/worry/fear
- Frustration
- Discomfort
- Disappointment



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# Immediate Recovery Period < 6 weeks

Dynamics include:

- Recovery is taking longer than expected
- Recovery is linked to recipient outcome
- Adjusting to the look of the scar and donation side effects
- Role change in the family: now needing care/support
- Concern about their physical abilities
  - e.g. preventing a hernia
- Returning to work may take longer than expected

“I feel like I was hit by a Mack truck.”



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# Long-term Recovery Period 2 months +

## Positive/comfortable feelings:

- Increased connection
- Self-esteem
- Satisfaction
- Relief

Case: 49 year-old two organ non-directed donor within three years sees the donations as being transformative and meaningful, especially after meeting the kidney recipient.

## Dynamics:

- Lessening worry and stress about their health, work and financial concerns
- Lessening concern about caregiving and managing health needs for the recipient
- Increasing sense of wellbeing & purpose

“I’m getting a tattoo to honor what I’ve done!”



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# Long-term Recovery Period 2 months +

## Challenges:

- Managing long term effects including fatigue, discomfort, soreness and pain
- Impacts on body image
- Depression and anxiety
- Impact of lost wages
- Family system relationship/role adjustments
- Grief/sadness/guilt if recipient dies, especially in the first 1-2 years



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# How we can support donors:

- Educate Educate Educate
- Validate/normalize their experience
- Referrals for psychotherapy
- Linking with financial resources
- Connect with a mentor



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# Case Study 1

- 27-year-old woman, former college athlete, employee of a group home
- Donated liver to 30-year-old sister
- Recipient did not leave the hospital, died a few weeks after donation
- Donor became the legal guardian of recipient's son
- Donor had exceptional physical recovery, though significant emotional impact, and the stress caused weight loss
- Donor utilized ILD social worker for supportive/grief counseling for several months. Recipient team referred recipient's son to supportive services.
- ILD SW referred donor to a psychiatrist, and she started anti-depressant meds
- Donor was out of work for 4 months. Significant financial impact on family system

Emotional

Psychiatric

Financial

Family system



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# Case Study 2

- 41-year-old woman, donor to her mother
- No concerns on evaluation nor complications with surgery
- Developed a hernia 3 months post-op
- Hernia incision became infected and required a wound vac
- Wound did not heal properly with vac, admitted for IV antibiotics
- Underwent four subsequent operations for wound debridement including one for removal of infected mesh
- Total of 6 surgeries over the course of her first-year post-op, requiring considerable amount of time off from work

Emotional

Financial

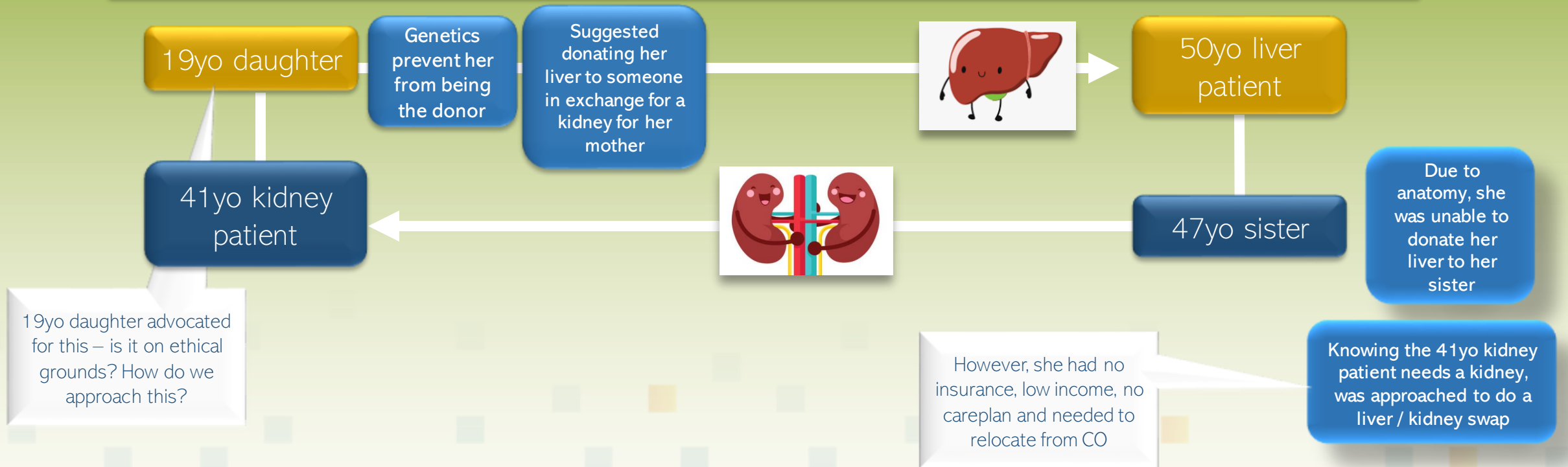
Family system



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# Case Study 3



Multiple in-depth assessments

Ethics

Psychiatry

Financial Resourcing



# References:

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Thank you!



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# Session Survey

Jaime Cisek RN, BSN, and Sandy Weinberg, LCSW | April 19<sup>th</sup> 2:45 PM-3:30 PM



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