

**LIVING WITH
LIVER DISEASE
AND AS A
LIVER TRANSPLANT
RECIPIENT:**

MANAGING YOUR MENTAL HEALTH



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AUTHORS' NOTE

This document has been prepared in collaboration with representatives of Royal Victoria Hospital (RVH) Liver Support Group and Liver Ireland Support Group (LISN), both not-for-profit organisations for the support and education of, and information provision to liver transplant recipients and those with liver disease on the island of Ireland.

It has been informed by data findings from PhD research undertaken by Dr. Sharon Millen on the psychological wellbeing of liver transplant patients in a population of 18 participants (11 men and seven women), with ages ranging from 29 to 70, who were treated at the National Liver Unit of St. Vincent's Hospital, Dublin, over a one-year period.

The authors, Dr. Sharon Millen and Dr. Karol Donnelly are both two-time liver transplant recipients who, between them, have more than 45 years' life experience of managing liver disease and liver transplantation, and all that those events entail.



Dr. Sharon Millen



Dr. Karol Donnelly

INTRODUCTION

This guide is designed for people who have had chronic liver disease¹ and who are either waiting for, or have already received, a liver transplant. Its aim is to provide you, the patient, with information and practical advice for managing your mental health when you are ill with liver disease, or you are preparing to have a liver transplant.

It is intended as a guide for patients only and does not purport to be exhaustive in its description of emotional and psychological responses to illness and / or the liver transplantation process. For information about more specific psychological issues and concerns, you are strongly advised to consult your GP, liver transplant co-ordinator or an accredited psychologist or psychotherapist.

IMPACT OF LIVER DISEASE ON QUALITY OF LIFE

As you might already be aware, having liver disease negatively affects your quality of life. There are many physical symptoms associated with liver disease which can and will affect various parts of your body. These symptoms can include nutritional impairment, loss of appetite, loss of body hair, weight loss, opportunistic infections and various gastrointestinal symptoms such as nausea, diarrhoea, heartburn and intolerance of fatty foods. In addition, dulling of the senses, severe itch, swollen legs and abdomen, dilated abdominal veins, jaundice, dark urine, pale stools, vomiting or passing blood, extreme lethargy, poor memory, disorientation and sleep disorders are other classic symptoms of the progression of a liver condition. Some also experience a reduced libido.

While these symptoms might be temporary, and disappear following your transplant, they are distressing and can impact on mood and/or your emotional wellbeing.

Often a person's daily functioning becomes compromised due to the debilitating effects of having liver disease. In reality, many people have to be admitted to hospital as an inpatient at various stages throughout their illness and this can cause a major disruption to normal daily activities. However, disruption can also be a typical occurrence in day-to-day life as a consequence of fatigue, nausea and loss of appetite.

¹ Or a chronic or acute disease which has resulted in severe liver damage or failure.

Emotional reactions to having liver disease

Along with the physical symptoms, your psychological state can be significantly affected by the experience of having liver disease. For example, when your doctor initially informs you that you have liver disease this can come as a shock and lead to a depressed mood. Many patients quite naturally feel scared and anxious about what is going to happen to them. They might fear death, pain, the unknown, or worry about their families. They might also feel sadness about their physical decline and becoming increasingly dependent on family and friends. Uncertainty about the future is also a typical emotion.



End-stage liver disease (ESLD), when your liver is damaged beyond repair, is characterised by jaundice, extreme itching, abdominal pain and nausea, among other symptoms. At this point, your doctor will likely have discussed a liver transplant as your only viable option of recovery. Mixed emotions to this news are very normal and might include distress and disbelief, as well as relief and joy. Other emotions might include self-blame, forward planning and mental preparation for the transplant surgery.

Coping with the prospect of becoming a liver transplant recipient

Liver transplant surgery can vastly improve both the life expectancy and quality of life for many patients with liver disease, but it is still a complicated surgery with a, sometimes, lengthy recovery.

Each patient must go through an individual assessment for suitability for surgery, and this process might be both useful and daunting. You will have the option to meet with the liver transplant co-ordinators to discuss any concerns you have regarding the procedure, but it might also be advisable to discuss your fears and other emotions with a psychologist, psychotherapist or indeed other liver transplant recipients with lived experience.

Learning about the liver transplant process

Learning more about the procedure, donor process and life as a liver transplant patient should help to ease your concerns and mentally

prepare you for surgery and for the complex medical regimen involved in becoming a liver transplant recipient.

Pre-transplant mental preparation has proven to be very beneficial, helping patients cope psychologically after surgery. Useful sources of information include your patient information booklet (provided by the hospital). Again, it might also be beneficial to have a chat with a liver transplant recipient who shares your illness or disease to learn about their particular journey. There are peer support groups with personal experiences of liver disease and the transplant process including RVH Liver Support Group and LISN (*details in Appendix III*). Remember, though, everybody's experience is different, and recovery might be more or less challenging for you than others.

Waiting for a donor liver



Waiting for a donor liver can generally take place in your own home, if you are adequately stable to do so. Whatever your team decides is for your own welfare and this may mean waiting in the hospital for weeks or even months. This brings its additional challenges such as worries or concerns about those at home, particularly if there are young children involved. Be mindful that there is generally no alternative to being admitted, but that this is a temporary arrangement.

While waiting for your donor liver, you may experience a false alarm – when you are prepared for your transplant, but the surgery does not proceed. While this is very disappointing, and may lead to increased fear and anxiety, it might be helpful to acknowledge that this donor liver was not considered the best option for you by the transplant team and waiting for a more suitable liver is preferable.

Though less common, a super urgent transplant experience - when a patient has to undergo an emergency liver transplant due to an acute liver illness or injury - may leave no time or opportunity to prepare for a transplant. In this case, emotions following a liver transplant can be of shock, denial, trauma, fear and anxiety. (*Paslakis et al., 2018*). There may also be feelings of guilt and disbelief.

Receiving a donor organ

It is common for patients to have questions or concerns about receiving a donor organ and it is very important to talk about these issues with the hospital team before surgery. It may help to remember that many families find comfort in the act of donation as the donor may have made a conscious decision to donate his / her organs after death and the family often see this as fulfilling a wish. It often helps grieving families to cope with their loss. Nevertheless, guilt may often feature as an emotion when you think of the deceased donor and their family.

Setting recovery goals



The wait for a suitable organ to become available can be quite distressing for patients. While it is essential that you are aware of the potential risks involved with the procedure, it is also important to try to maintain a positive outlook and think about what you are looking forward to doing after surgery. Do remember, the potential benefits of receiving a liver transplant are a significantly improved life expectancy and a better quality of life.



Some people find it useful at this stage to set themselves goals which they can look forward to achieving after their operation, for example, returning to a hobby or sport, attending Church, going on holiday or resuming work. Learning new skills might also be an exciting prospect!

Be patient and kind to yourself and remember that not every day will be a good day.

Support

As well as providing you with vital information, the hospital team and other patients can also provide you with much needed psychological support at this stage.

Other sources of social and emotional support might include friends and peer support groups such as Liver Ireland Support Network (LISN) and RVH Liver Support Group.

IMPACT OF LIVER TRANSPLANT SURGERY ON QUALITY OF LIFE

Recovery - a gradual process

The majority of patients who receive a transplant for a chronic liver disease have a relatively smooth post-operative course and can expect to go home in two to three weeks. Almost all patients' quality of life significantly improves after receiving a liver transplant. However, liver transplant surgery is a major operation, and it is important to accept that every person will have different experiences of the surgery itself and of the recovery process.

It is advisable to limit the amount of physical activity that you do within the first few months after your transplant and to set yourself realistic goals. This can sometimes cause frustration as you might be feeling better, but your body needs time to heal properly after your illness and transplant. Acknowledgement of your progress rather than dwelling on your lack thereof is very important!

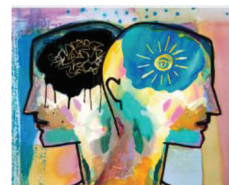
Regaining your independence



It is important for patients to regain their independence as soon as practical after liver transplant surgery as this can greatly enhance quality of life. You can perhaps begin this process by going for short walks to facilitate your recovery. As time progresses, it might be helpful to gradually reintegrate yourself back into society by visiting friends, going shopping, returning to hobbies and/or attending social and (if appropriate) religious events. This should only be undertaken with medical advice and when deemed safe to do so. Even in this post-covid-19 era, there are always viruses and infection-causing bacteria circulating in areas where people congregate. Your immune system will be less effective in the days and weeks post-transplant so be sensible and carry sanitizer and a face mask. Eventually many patients are able to return to work, even on a part-time basis at first, as a balance is struck between your immunosuppressant dose and protecting your new liver from rejection.

LIFE AS A LIVER TRANSPLANT RECIPIENT

Immediate post-transplant phase



The immediate post-transplant phase is often characterised by a range of mixed emotions including fear, anger, frustration and guilt. Indeed, during the first few weeks after surgery it is quite common to feel more anxious than you did before your surgery. This is likely to be due to the fact that you are adjusting to the many changes and medical regimen in your life as a result of receiving a liver transplant. However, it might also be possible that you will feel elated, optimistic and grateful for your 'second chance'. Whatever your emotions, neither suppress nor criticise them – they are your feelings; allow yourself to experience them and accept them.

Being discharged from hospital



You will probably have mixed feelings about returning home for the first time after your transplant. Many patients are anxious about the fact that they will no longer have the 'safety net' of the ward staff should anything go wrong. It is important to remember at this stage that the hospital team must consider you well enough to leave hospital otherwise you would not have been discharged. Your health will still be closely monitored on a regular basis when you attend the outpatients' clinic.



Often when patients return home from hospital, they have more time to think about their illness experience, transplant surgery and their new life as a liver transplant patient. It is completely normal and understandable that you may have some queries and concerns regarding the transplant process, and it is very important to discuss these concerns with a health professional. In addition, this 'thinking time' might also bring up new or unexpected emotions. Should you feel less positive as time goes on, it is important to seek psychological support.

COMMON AREAS OF CONCERN POST-TRANSPLANT

Coping with the self-medicating regime

The vast majority of patients establish their own routine of taking their medications at allocated times throughout the day. Over time this usually becomes easier.

Establishing a proactive approach to taking your medication will help you to feel more in control of your life. You might want to set timers at first to remind you to take your medication, for example. Additionally, many people find using a pillbox or organiser to dispense their daily tablets is an effective way of keeping track of different pills. By putting your daily dose of medication in each section, you can check whether you have taken your required dose of medication, without the worry of missing a dose. It is likely that the number and volume of medication will reduce as time goes on.

The ongoing risk of rejection



It is important to be aware of any changes in your well-being. Always consult a doctor if you are feeling unwell. The hospital team will be closely monitoring you for any signs of rejection at your outpatients' appointment.

Remember, whilst the threat of rejection is ongoing, the risk of a rejection episode occurring lessens over time. In order to minimise the risk of rejection in the longer term, it is vital that you take the correct dosage of your medication at the proper times and also follow any additional advice given by the hospital team.

Increased risk of infection



Due to your recent surgery, and the fact that your immune system is suppressed by anti-rejection or immuno-suppression medication, it is important to take extra care to avoid infection. It is common for patients to experience at least one episode of infection post-transplant with the greatest period of risk being the first few months following surgery.

Always seek medical advice if you have any cuts or broken skin and try to avoid contact with people who are ill, particularly those with vomiting or diarrhoea.



Despite the increased risk of infection due to immunosuppression therapy, it is necessary for patients to take this medication for life as it lowers the immune system response, thereby preventing it from rejecting your new liver. Taking control of your health and making efforts to avoid infection will be enabling, and likely will reduce stress and anxiety.

Coping with the donor issue

Post-transplant, patients often try to avoid thinking about the fact that they have someone else's liver. After a suitable period of time has elapsed (approx. six months to one year) some patients write a letter of thanks to the donor family; this might help them cope better with this issue. However, patients are under no obligation to do this and might decide to never contact the donor family. This choice is entirely up to the individual. Refer to Appendix II for advice on contacting the donor family.

Thoughts and feelings about the donor usually lessen with time, but again, it is very important to discuss any issues you have with a member of the hospital team, or possibly a mental health professional such as a psychologist or psychotherapist.

Some emotional responses in the months following your liver transplant

As time progresses, you will not only experience positive physical changes but also psychological and emotional transformations. In a study undertaken by Millen (2007) as part of her PhD research, the early post-operative stage or one month following patients' liver transplant demonstrated an array of feelings including concerns relating to side effects of some medication, the complexity of the medical regimen and fear of post-operative complications.

After three months, some patients' typical emotional reactions included both relief and feelings of gratitude towards the donor,

family members and hospital staff to fear of donor liver rejection, and anxiety about not recognising its typical symptoms.



After nine months, patients' emotions ranged from an improved mood and a genuine hunger for life to developing coping mechanisms including self-distraction by undertaking pleasant or new tasks and hobbies.

Body image and self-esteem



There will inevitably be a large scar on your abdomen and, depending on how your surgery and recovery proceeded, there may be other physical reminders post-transplant. These might include sagging skin from weight loss or other scars from cannula and drain use. Such scarring might inadvertently impact on your body image and result in low self-esteem. Body image and organ integration concerns have been reported as main themes in the psychological adaptation to transplantation, with the former becoming a significant component of measuring the quality of life in transplant patients (*Zimbrea, 2015*). While this is understandable, it is beneficial to accept what you cannot change. Many people feel that scars are physical reminders of their illness and subsequent transplant and wear them with pride. They signify a battle fought and won - embrace your scars!

Relationships and intimacy



While loved ones, family and carers generally aim to be supportive, feelings of isolation and aloneness are commonplace. In truth, despite listening and being informed, no one quite understands the liver illness and transplant journey except those who have experienced it. Changes in relationships are inevitable following a transplant as spouses' or partners' roles are shifted. A partner who may have been a carer pre-transplant may now feel reluctant to let go of this protective role which, in turn, may suffocate the recovering transplantee who is yearning for independence and control. This may place pressure on a marriage or relationship, and so couple's counselling might be considered, and effective communication between a couple encouraged.

In addition, intimacy and the resumption of a sexual relationship post-transplant should only occur when you feel not just physically ready but also emotionally and psychologically prepared or receptive. Your body will feel different to both you and your partner and physical needs might also change. Be communicative, as your transplant might impact libido, intimacy, or just having a close connection with your partner (*Knox-Rice, 2021*). If not in a relationship post-transplant, remember to practise safe sex and use protection, both to avoid infections but also to avoid an unplanned pregnancy until it is deemed safe to become pregnant.

Support

During your recovery post-transplant, it is vital that you have people to help and support you both physically and emotionally. Common sources of support include family members, friends, the hospital team and other liver transplant recipients.



Despite all of the concerns listed previously and the additional burden of feeling alone and isolated, the vast majority of recipients will feel optimistic and positive about their future. Almost all patients feel that their lifestyle has significantly improved post-transplant but adjustment to life post-transplant can take time. Do not be afraid to admit you need mental health support. Be patient with yourself and your body; listen to yourself and become accustomed to monitoring how you are, physically and mentally, on an ongoing basis. It is perfectly okay if not every day is a good one - but not okay if every day is a bad one!

There appears to be a public perception that life post-transplant is 'as normal', and immediate gratitude is obligatory. Your feelings about your illness and liver transplant are valid, and no one can tell you how to feel or what emotions you should have. This is your experience; no other story will be the exact same as yours, and your own emotions and feelings, however mixed or confusing, are perfectly understandable.

SUMMARY

Pre-transplant

- Actively seek sources of information to gain a better understanding of your condition and of the transplant process.
- Discuss any concerns you have regarding your condition and the transplant process with a member of the hospital team.
- Try to maintain a positive outlook. It may be helpful to set yourself recovery goals which you can look forward to achieving after surgery.
- Ensure that you have adequate support to help you emotionally and physically throughout your illness.

Post-transplant

- Do not overexert yourself during the first few months after surgery; accept that your recovery is a gradual process.
- Gradually try to regain your independence.
- It is normal to experience mixed emotions, particularly during the immediate post-transplant phase.
- It is normal to have queries and concerns regarding your illness experience, transplant surgery and life as a liver transplant patient. Always discuss these concerns with a health professional.
- Always consult a doctor if you are feeling unwell - no question is too basic
- Ensure you have adequate support, especially during the early stages of your recovery.
- Remember - liver transplant surgery is generally associated with a significant improvement in quality of life and life expectancy of patients, but it can take time to adjust.

References

Knox-Rice, T., April 17 to 23, 2021. *For Better or Worse: Changing Relationships After Transplant*. [Conference Presentation] BMTInfonet.org Symposio Virtual 2021 (<https://www.youtube.com/watch?v=pvbmp5E1P9g>)

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Paslakis, G., Beckmann, M., Beckebaum, S., Klein, C., Gräf, J. and Erim, Y., 2018. Posttraumatic stress disorder, quality of life, and the subjective experience in liver transplant recipients. *Progress in Transplantation*, 28(1), pp.70-76.

UHN, 2022. *Coping with a Transplant D-8779*. Transplant Psychosocial Team, University Health Network.

Zimbrea, P.C., 2015. Body image in transplant recipients and living organ donors. *Current opinion in organ transplantation*, 20(2), pp.198-210

Appendix I Tips to reduce stress

While we are all unique and have different liver disease experiences and transplant journeys, there are some general 'tips' to manage transplant-related stress.

Balance your perspective

While it may feel like you have no control over your life, particularly your health, you have the power to choose your attitude or response to your circumstances.

- Try to challenge negative thoughts and worries with realistic ones. Instead of fearing for the future and the 'what ifs' post-transplant, concentrate on the present and the progress you have already made.
- Guilt that a person dies so you could receive a liver might be replaced with joy, and acknowledgement that your donor's family might have some comfort and solace that their loved one saved lives.
- Try journalling or keeping a diary - writing feelings down may reduce the stress of mixed thoughts and emotions.
- Try to keep a sense of humour - even through the difficult times!

Assume control of your health

A feeling that you are only alive because of your transplant may be a heavy burden to carry. But receiving your new liver is only the first step of your recovery.

- Try to explore ways to improve your health by taking exercise you know you will enjoy and be able to maintain.
- Educate yourself on your medication and their side effects; keep a record of any changes you identify and discuss these with your consultant.
- Keep to a healthy diet and maintain a healthy weight; be aware of food safety and infection risks from foods you haven't prepared yourself.
- Get a good night's sleep – every night!
- Always remember to drink enough water to stay hydrated.

Self-care

Love yourself and ensure you feel loved and cared for.

- Engage in a hobby that you really enjoy; try something new following your transplant! Remember being fit is vital to keeping well. You might even consider joining a transplant sport team and taking part in the Transplant Games!
- Try some yoga and mindfulness to help calm your mind and encourage relaxation.
- Make time for yourself to enjoy an afternoon coffee or tea. Two cups of coffee per day are optimum for liver health!
- Pamper yourself with a bubble bath, a visit to your hairdressers, barbers, a facial or a manicure.

Connect with Others

If you are lucky to have supportive and understanding family and friends, spend time with them and share your feelings, both positive and challenging. While they may be empathetic, connecting with other liver transplant recipients may be even more advantageous.

- Make a conscious effort to meet some other transplant recipients for coffee, walks and talks, or just someone to share your story with at your outpatient's clinic.

- Join peer support groups specifically for transplant recipients via Facebook, Instagram, LinkedIn, X or through support group websites.
- Listen to other transplant stories without comparing them to your own; we all have our own unique story but 'we just get each other'.

Pay it forward

Your life has been saved by a generous brave person who gave consent to donate their loved one's liver. While you cannot thank them personally, consider helping others.

- When you're up to it, volunteer with a local charity, involve yourself in fundraising or visit a lonely neighbour.
- Write your anonymous letter to your donor family, expressing how you feel (*Appendix II*).
- Express your gratitude to your hospital health care team; send a card, write a letter, send chocolates or flowers.
- Make a donation to a registered liver charity, host an event, participate in a mini marathon or encourage friends and family to sponsor you to undertake a challenge.

Appendix II Writing to your donor family

Everyone expresses their thanks to the donor family in their own way. In nearly all cases, transplant recipients say that this is the most difficult letter they have ever written and that they had to re-write it many times before getting it 'right'. Below is some helpful advice to help guide you through this very difficult and emotionally challenging task.

Transplant co-ordinators generally recommend that you allow at least 6 months to elapse after receiving your transplant before attempting to write a letter of thanks to your donor family.

- The letter should not identify you (except your first name if you wish). Your address or telephone number should not be included.
- It is best not to date the letter as often it can be some time before it can be forwarded to the donor family.
- Do not seal the envelope as the donor co-ordinator, who knows the family, will need to check the letter for confidentiality before passing it on.

- The letter usually starts with 'Dear Donor Family' or 'Dear Friends'.

The following is an outline of the details you might like to include: Gender, age, family, length of illness. Most people describe how their lifestyle was prior to the transplant and outline the contrasting quality of life they are experiencing since transplant surgery.

Some of you may have become suddenly or unexpectedly unwell and underwent transplant surgery with little or no warning. If this is the case, you could describe this in your letter and acknowledge that your life was saved due to receiving an urgent transplant.

Once you have written your letter you should give it your transplant co-ordinator who will forward it to the donor co-ordinator. They will in turn, send it directly to the donor family. Generally, there will likely be no further contact between you and the donor family

Appendix III Useful websites

www.RVHLiverSupportGroup.org

RVH Liver Support Group
(offering support to those in Northern Ireland)

www.lisn.ie

Liver Ireland Support Network
(offering support to those in the Republic of Ireland)

www.kch.nhs.uk/services/services-a-to-z/liver-transplantation/
Kings College Hospital - Liver Transplantation

<https://www.stvincents.ie/departments/hepatology/>
St. Vincent's University Hospital Hepatology Department

<https://www.facebook.com/p/Transplant-Sport-Northern-Ireland-100081507747546/>
Transplant Sport NI

www.transplantsport.org.uk
Transplant Sport UK

<https://www.transplantsportireland.ie/>
Team Ireland - Transplant & Dialysis Sports

www.uktransplant.org.uk
UK Transplant

www.britishlivertrust.org.uk
The British Liver Trust

www.liverfoundation.ie
Irish Liver Foundation

<https://pscpartners.libsyn.com/>
PSC Partners Seeking a Cure

www.transplantsupportnetwork.org.uk/
Transplant Support Network

