



Patient & Family Guide

2022

Advanced Liver Disease

Changes in Your Quality of Life



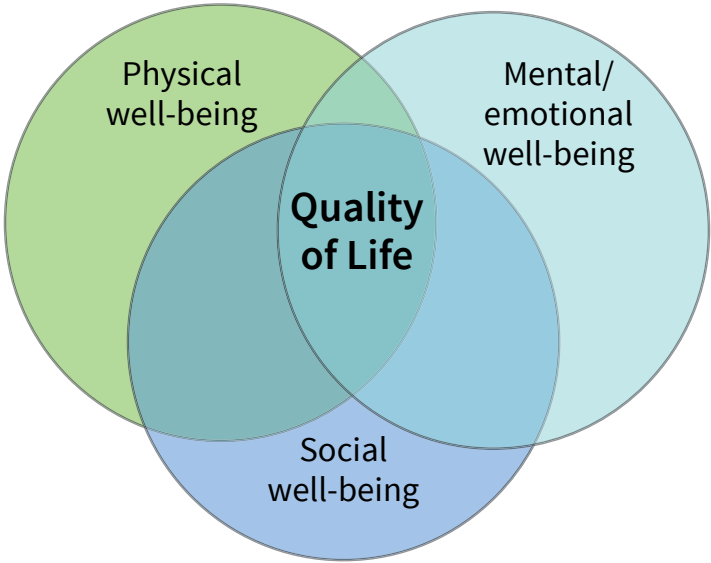
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Advanced Liver Disease - Changes in Your Quality of Life

Being diagnosed with advanced liver disease can be confusing and scary. You will need to make changes in your life and think about difficult treatment options. You and your loved ones may have many emotions during this time. For example, you may feel scared, upset, or anxious. This is normal.

Quality of life

While your health care team is focused on your medical care (understanding and treating your liver disease), they also care about your quality of life. **Quality of life is your overall sense of physical, social, and emotional/mental well-being.**



Advanced liver disease can cause changes to your physical health, relationships, and emotional well-being. This can have a negative impact on your quality of life.

Common physical changes include:

- Ascites (fluid build-up in your stomach area)
- Encephalopathy (confusion)
- Trouble sleeping
- Fatigue (feeling tired)
- Muscle weakness
- Changes to your diet
- Itchy skin
- Pain or discomfort
- Sexual problems

These physical changes can affect how you think and feel. They can also affect your relationships. For example, people with fatigue and muscle weakness may not be able to do their usual activities, or may need help from their loved ones to do everyday activities.

It can be challenging when your independence and ability to do things for yourself is limited by your physical health.

Common social changes include:

- Changes in your roles (as a partner, parent, daughter or son, etc.)
- Changes in your responsibilities
- Changes in how your loved ones respond to you
- Changes in your romantic and/or sex life

Many couples find that coping with advanced liver disease changes the way they relate to one another. For example, they may relate as the “ill partner” and the “caregiver,” instead of as spouses.

It can be hard to cope with changes to your relationships, especially since the impacts of advanced liver disease can last for a long time.

Common mental changes include:

- **Hepatic encephalopathy** (confusion, brain fog, or delirium). This is caused by a buildup of toxins (poisons) in your body, which can affect your thinking. Symptoms include:
 - › Feeling irritable, anxious, or depressed
 - › Drowsiness
 - › Confusion
 - › Memory problems
 - › Trouble relating to the things around you

Hepatic encephalopathy can be unsettling for you and your loved ones. Your health care team can help you manage these symptoms.

Common emotional changes include:

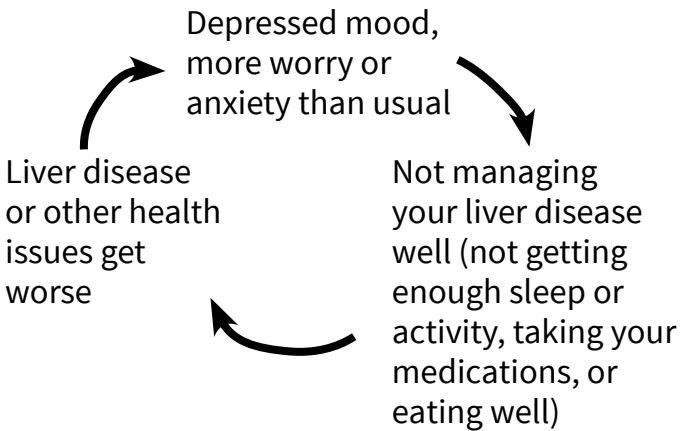
- Sadness
- Anger
- Helplessness
- Guilt
- Shame
- Disappointment
- Frustration
- Feeling overwhelmed
- Feeling discouraged
- Regret
- Anxiety

Common worries include:

- “How will this disease or a liver transplant affect my loved ones?”
- “What if my symptoms become more serious?”
- “What if I never get better?”
- “Will I be put on the wait list for a liver transplant?”
- “Will a liver become available for me?”

Why should I get help?

It is normal to have negative feelings and worries when you are living with advanced liver disease. Everyone will have some bad days. Your physical health and mental health can affect one another. Sometimes, feeling low, depressed, or full of worry can make it hard to take care of yourself. This can cause your symptoms of advanced liver disease to get worse. If your symptoms get worse, you will feel more physically unwell. And feeling physically unwell can make feelings of depression or worry worse, too.



When should I get help?

There are a few important questions that can help you decide if you or your loved one(s) may need further support.

1. Is the mental stress **persistent (does not go away)**? For example, is it happening nearly every day, and for much of each day?
2. Does the emotional distress **affect my ability to function**? For example, does it make it hard for me to do my usual activities or socialize?
3. **Can I cope** with this level of emotional distress? For example, does it bother me so much that I feel like I cannot manage it on my own?

How do I get help?

You will be asked to meet with the liver transplant social worker and liver transplant psychologist. These appointments are part of the assessment for a liver transplant.

The goals are:

- To understand any challenges you have
- To provide the supports you need to improve your quality of life
- To get you ready for a transplant

You can get ready for these appointments by thinking about the information in this guide. If you have any questions, please ask them at these appointments.

What other supports are available?

If you are being tested for, or are waiting for, a liver transplant, you may be able to talk with the liver transplant psychologist. Please ask your Transplant Coordinator for more information:

- › Phone: 902-473-6016

There are many online, self-guided programs available. Visit the Nova Scotia Health Mental Health and Addictions website for free tools:

- › <https://mha.nshealth.ca/en/tools>

If you need mental health help right away:

- Call the Provincial Mental Health and Addictions Crisis Line.

- › Phone (toll-free): 1-888-429-8167

OR

- Call your primary health care provider (family doctor or nurse practitioner).

OR

- Call 911 or go to the nearest Emergency Department.

Looking for more health information?

Find this pamphlet and all our patient resources here: <https://library.nshealth.ca/PatientEducation>

Contact your local public library for books, videos, magazines, and other resources.

For more information, go to <http://library.novascotia.ca>

Connect with a registered nurse in Nova Scotia any time: call 811 or visit <https://811.novascotia.ca>

Learn about other programs and services in your community: call 211 or visit <http://ns.211.ca>

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The information is not intended to be and does not constitute health care or medical advice.

If you have any questions, please ask your health care provider.

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The information in this pamphlet is to be updated every 3 years or as needed.