

End-Stage Liver Disease and Palliative Care

What is End-stage Liver Disease (ESLD)?

ESLD is used to describe advanced liver disease, liver failure, and decompensated cirrhosis (advanced stage of cirrhosis). ESLD develops after an inflammation of the liver, which then leads to fibrosis (scarring), and loss of regular liver function. While the only cure is liver transplantation, a large number of ESLD patients do not always receive one due to wait times or other health issues that make them too sick to survive surgery.

What are Common Symptoms of ESLD?

The severity of symptoms may be worse in decompensated liver disease and therefore addressing symptom management should be done in combination with the interdisciplinary health care team.

Common physical symptoms include:

- Abdominal pain
- Fatigue
- Confusion
- Pruritis (itchiness)
- Jaundice - a yellowing of the skin and eyes due to the buildup of bile
- Muscle cramps
- Edema (swelling) in the legs
- Dyspnea - shortness of breath
- Nausea and vomiting
- Constipation
- Diarrhea
- Malnutrition

What are some Complications associated with ESLD?

Specific complications of ESLD are related to *portal hypertension* or increased difficulty of blood flow through the liver due to permanent changes in the liver cells.

- **Ascites** - swelling of the abdomen due to fluid build-up
- **Spontaneous bacterial peritonitis** - infection of the fluid from ascites. The symptoms can include fever, abdominal pain and low blood pressure, but it can also be present without any symptoms at all
- **Esophageal and gastric varices** - blood flow through the liver is impaired which results in the blood flow being re-routed around the liver into small veins in the passageway between the throat, stomach and abdomen. These small veins become enlarged and can burst and cause bleeding

- **Hepatic encephalopathy (HE)** - deterioration of brain function that can be experienced as:
 - Trouble sleeping at night
 - Difficulty thinking clearly
 - Disorientation
 - Poor concentration or shortened attention span
 - Mild to severe confusion
 - Forgetfulness
 - Shortened attention span
 - Poor judgement
 - Personality or mood changes
 - Slow reaction time
 - Anxiety
 - Depression
 - Worsening of handwriting or fine motor movements
 - Unusual movements (shaking of hands or arms)
 - Slurred speech
 - Slowed movement
 - Decreased alertness and responsiveness
- **Hepatorenal syndrome (HRS)**- impaired kidney function
- **Coagulopathy** – prolonged bleeding
- **Spontaneous bruising**
- **Bleeding inside the stomach or intestine**
- **Bloating**

How are Symptoms for ESLD Managed?

Pain: Medications may be used for pain management at the end of life; however the best therapies to use can vary for each person with ESLD. Therefore, please talk to your doctor about the right type of medication and dosage for you. Alternative methods for managing pain can include acupuncture and mindfulness.

Ascites: A low-salt diet and oral diuretics (medication to help remove fluids from the body; ex: *spironolactone* or *furosemide [Lasix®]*), are usually prescribed. If these treatments begin to lose effect, more invasive options such as using a needle to remove fluid from the abdomen or surgery may be considered.

Hepatic encephalopathy: Laxatives and antibiotics are most commonly used to help preserve brain function as they can reduce the build-up of certain toxins in the blood which are harmful to the brain.



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Itchiness: A common medication called *cholestyramine* is used to help with the itchiness. The exact mechanism by which this medication helps with itchiness is not fully understood, but it is believed that *cholestyramine* helps the body excrete the chemicals in the stool.

Malnutrition: Ensuring sufficient calorie intake, especially protein, as well as vitamin replacement, is recommended.

What is My Life Expectancy with ESLD?

It is hard to predict the life expectancy for someone with ESLD because it is influenced by many factors such as the degree of liver disease or complications and the presence of other diseases. While it is difficult to gauge a precise timeline for ESLD, certain symptoms have been associated with worsening disease and shorter life expectancy, such as ascites that does not respond to treatment, kidney failure, and bleeding from the gastrointestinal tract. Also, those with advanced stage of cirrhosis have a life expectancy on average of around two years. A model has been developed that predicts long-term outcomes for ESLD called the *Model for End Stage Liver Disease* (MELD). The MELD score is based on lab values and is used for prioritizing patients waiting for a liver transplant. Your doctor would be able to provide you with a more accurate assessment of your current situation.

What Should I Know About Advance Care Planning (ACP)?

Advance Care Planning (ACP) is a process of thinking about and sharing wishes for future health and personal care. It can help prepare everyone when a person becomes ill and unable to communicate. ACP takes into account goals, values and beliefs with regards to a person's end of life decisions. The process of this planning involves the patient, their family, and their health care team and can help guide future health care decisions. The discussion should begin early in the disease process to ensure a plan is in place for managing the patient when their health declines. ACP directives should be reviewed, especially during hospital admissions.

Some topics to think about can include:

- What is important to you?
- Do you have beliefs that influence your health care wishes?
- Are there conditions under which you do or do not want a certain treatment?
- Where would you want to be cared for?
- Have you had experiences with family or friends where health care decisions had to be made?
- Have you considered Organ and Tissue Donation?

Some documents that should be considered:

Power of Attorney: Legal document that gives another person the right to make medical decisions on the patient's behalf.

Living will: Document that has the patient's preferences for future medical care. The document usually consists of resuscitation and life support preferences and can address specific interventions like enteral feeding or ventilator (breathing tube) support.



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What is Palliative Care?

The goal of palliative care is to improve the quality of life for individuals suffering from an advanced illness, provide comfort and dignity and relieve suffering. Palliative care addresses medical, emotional and spiritual needs. Early access to palliative care for those living with a chronic disease is associated with an improved quality of life. Instead of prolonging life with medical treatment, palliative care focuses on quality of life. Symptom management is an important aspect of palliative care.

The course of ESLD is less predictable due to the periods of recovery and worsening symptoms; therefore, early palliative care referrals should be sought.

When Should I seek Palliative Care?

Possible triggers that could prompt one to seek palliative care are:

- Swelling of the abdomen due to fluid build-up (ascites) that does not resolve with treatment
- Infection of the ascitic fluid (accumulated fluid in the abdominal cavity)
- Kidney failure
- Impaired cognitive or worsening brain function

What is Hospice Care?

Hospice care is a branch of palliative care that is directed towards individuals that are in their last 6 months of life.

Where Do I Access Palliative Care in Canada?

You may wish to speak to your doctor, home care nurse or social worker to find out about palliative care services available near you, or to obtain a referral.

The websites and phone numbers for each province below can also be useful:



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Alberta:

Palliative coverage is available to Albertans who have been diagnosed as palliative by a doctor or nurse practitioner.

You can apply for the program by having your health care provider complete the form provided on this website and faxing it to Alberta Health:

<http://www.health.alberta.ca/services/drugs-palliative-care.html>

To find where palliative care services are offered, visit this link:

<https://www.albertahealthservices.ca/info/Page14778.aspx>

Pilgrims Hospice can be used to complement palliative services. They are a non-profit organization that provides community-based hospice and bereavement care in a homelike environment.

<http://pilgrimshospice.com>

British Columbia:

Palliative care benefits are available to BC residents who want palliative care. They can receive coverage of medications, medical supplies and equipment where they are living. The doctor or nurse practitioner has to confirm that you meet the criteria and then fax the information to Health Insurance BC and The Home and Community Care office in your regional health authority locality.

This website outlines how to arrange for palliative care in British Columbia:

<https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/how-to-arrange-for-care>

This website describes the eligibility criteria:

<https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/are-you-eligible>

This is the contact information for the regional health authorities:

<https://www2.gov.bc.ca/gov/content/health/about-bc-s-health-care-system/partners/health-authorities/regional-health-authorities>

Manitoba:

The Palliative Care Drug Access Program offered by the provincial government covers the cost of drugs during the end stages of one's illness. Your doctor or nurse practitioner has to complete the form and then submit it to the palliative care coordinator at the regional health authority. Visit this website for more information:

<http://www.gov.mb.ca/health/pcdap/index.html>

The Winnipeg Regional Health Authority coordinates palliative care services and ensures your doctor or nurse practitioner makes a referral. Their information can be found here:



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<http://www.wrha.mb.ca/prog/palliative/access.php>

Grace Hospice is a palliative care facility at Grace Hospital in Winnipeg and their contact information can be found here: <http://www.gracehospital.ca/hospice.html>

Jocelyn House is a hospice house in Winnipeg and their contact information can be found at the bottom of their website:

http://www.jocelynhouse.ca/providing_care

Bereavement services can be found here:

<http://palliativemanitoba.ca/programs-and-services/bereavement-services/>

New Brunswick:

New Brunswick Extra-Mural Programs Home care program can be found at:

http://www2.gnb.ca/content/gnb/en/services/services_renderer.8975.Extra-Mural_Program.html

Horizon Health Network Palliative Care's regional palliative care program is at:

<http://en.horizonnb.ca/facilities-and-services/services/clinical-services/palliative-care.aspx>

Tantramar Hospice Palliative Care Organization's regional palliative care program is listed here:

<http://www.thpco.ca/>

Nova Scotia:

Palliative Care Drug Program can be found on this website:

<https://novascotia.ca/dhw/pharmacare/palliative-drug-program.asp>

Nova Scotia Continuing Care's home care program is listed here:

<http://www.novascotia.ca/dhw/ccs/>

Antigonish Town and County Palliative Care Society local palliative care program can be found here:

<http://antigonishpalliativecaresociety.com>

Eastern Memorial Hospital Palliative Care's local palliative care program can be found at:

<http://www.cdha.nshealth.ca/about-us/our-facilities/eastern-shore-memorial-hospital>

North West Territories:

Home care palliative care service

<http://www.hrhssa.org/ServicesandPrograms/HomeCare/tabid/84/Default.aspx>



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Nunavut:

There is a residential long-term care unit in the Kitikmeot Regional Health Centre with one palliative care bed

Ontario:

Hospice Palliative Care Ontario – to search for Providers and Services visit:

<http://www.hpco.ca/search/>

Home Care Ontario – Home Care Services can be found here:

<http://www.homecareontario.ca/home-care-services/search-for-home-care/find-home-and-community-services>

University Health Network – Inpatient Hospice Palliative Care Directory is listed here:

http://www.uhn.ca/PrincessMargaret/PatientsFamilies/Specialized_Program_Services/Pages/inpatient_hospice_palliative_care_directory.aspx

The Careguide – Hospice and Palliative Care Providers in Ontario can be found at:

<https://www.thecareguide.com/providerLists/setProvinceList/ON/hospice-and-palliative-care>

Hospice Palliative Care Information Line: 1-877-203-INFO (toll-free)

Prince Edward Island:

Prince Edward Island Palliative Care’s homecare program can be found on this website:

<https://www.princeedwardisland.ca/en/information/health-pei/palliative-care-program>

P.E.I. Palliative Care Program’s website is: <http://www.healthpei.ca/palliativecare>

The Gardens of Hope Respite Cottage’s local palliative care program is listed here:

<http://preservecompany.com/blogs/gardens-of-hope/13840329-the-gardens-of-hope-respite-cottage>

Quebec:

Bien chez soi offers palliative services, you can fill their assessment form here:

<http://www.bienchezsoi.ca/en/home-healthcare/palliative>

Palliative home care is offered by the Centre de santé et de services sociaux. You can contact the care team here:

<https://www.csssdelamontagne.qc.ca/en/care-and-services/persons-with-loss-of-autonomy/palliative-home-care/>

West Island Palliative Care Residence Admission form can be filled out here:

<http://residencesoinspalliatifs.com/en/admissions/>



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A list of inpatient hospitals that provide palliative care can be found here:

<http://www.santemonteregie.qc.ca/vaudreuil-soulanges/services/ser/fiche/etablissement.en.html%3Bjsessionid=5A9D308426F838D91C6D512C58A417CB#.Wh5BGniBVFI>

Saskatchewan:

The provincial government has a program that helps pay for prescription drugs for palliative care patients. To register for this program your doctor must complete a “Palliative Care Coverage Form” request. Prescription drugs, dietary supplements and other basic supplies are covered by this program. Visit this website for more information: <http://www.saskatchewan.ca/residents/health/accessing-health-care-services/palliative-care-programs>

You may also be eligible for home care funding:

<https://www.saskatchewan.ca/residents/health/accessing-health-care-services/care-at-home-and-outside-the-hospital/individualized-funding-for-home-care#step-1>

Cypress Health Region offers Palliative services, their phone number can be found on this website:

<https://cypresshealth.ca/programs-services/home-care/palliative-care-program/>

All Saskatchewan centres that offer palliative services can be found here:

http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Support/Resources/Programs+and+Services/Provincial/Saskatchewan.aspx#id_f1d32a13893869fed9f9a06585bf3d6

Yukon Territory:

Home care program

<http://www.hss.gov.yk.ca/homecare.php>

Hospice Yukon

<http://www.hospiceyukon.net>

Palliative care resource team

<http://www.hospiceyukon.net>

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