Kindred at Home

Physician to Physician:

Hospice Care for Patients with End-Stage Liver Disease

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Despite recent advancements in treatment, liver disease remains a leading cause of death in the US. Within developed countries end-stage liver disease (ESLD) with cirrhosis is the final common pathophysiologic pathway for a variety of underlying etiologies, ranging from alcoholic liver disease or fatty liver disease to chronic hepatitis B or C or hemochromatosis, as well as others. ESLD with cirrhosis can be effectively cured with liver transplant; however, an insufficient pool of available livers for transplant, plus some individual's contraindications for the procedure, means there are still over 40,000 deaths per year from ESLD in our country.

With cirrhosis, one or more secondary conditions are typically present at its final stage. Principal among these are refractory ascites, esophageal varices with hemorrhage, and hepatic encephalopathy. Infections and malnutrition are other common complications. Each of these is usually associated with significant symptoms that negatively impact a person's quality of life.

When persons with ESLD are candidates for potential transplant, they generally have a likely prognosis for a life expectancy of six months or less - this means they are usually also eligible for hospice care. In fact, Medicare beneficiaries with ESLD awaiting transplant can receive hospice care until they are admitted for the actual procedure. Patients who meet transplant criteria but who have a medical or other disqualification are also usually eligible for hospice. These patients greatly benefit from such care, helping them better manage symptoms, avoid unwanted hospitalizations, and prepare them and their families for the end of life.

Pain is a symptom commonly seen in ESLD, often associated with abdominal distention from ascites. Aggressive diuretic management, supplemented by periodic paracentesis, can provide significant relief. Additionally, opioid pain management may also be needed, though care is taken to ensure safe dosing because of impaired hepatic clearance of these medications. Dyspnea is also often seen as a result of ascites with similar palliative management as for pain. Fatigue is common, both from the underlying disease process, as well as from anemia associated with gastrointestinal blood loss.

While medications are less helpful for this, the supportive care provided by nursing and hospice aid services help mitigate the effects of such fatigue. Careful in-home management and monitoring by the hospice nurse, in consultation with the attending and/or hospice physician, offers opportunities to quickly detect and adjust medications to manage exacerbations of hepatic encephalopathy, helping to avoid unnecessary hospitalizations.

The psychosocial support provided by social worker and chaplain members of the hospice team assist with anxiety, depression, and other symptoms. This is especially helpful when the patient has guilt regarding the underlying etiology of their ESLD, such as when it is associated with alcohol use or hepatitis contracted from intravenous drug use. The interdisciplinary hospice team also provides support for the patient's family, which continues after death through the hospice's bereavement services.

When treating someone with ESLD, especially when transplant is not an option, consider requesting a hospice evaluation. Medicare contractor guidelines for ESLD hospice admission can seem complex, but the hospice team is skilled in both applying these guidelines and in having discussions with the patient and family regarding goals of care and how hospice may help them achieve those goals.

We are here. Let us know how we can assist with patients with end-stage liver disease.