Hospice Case Study: HIV (Human Immunodeficiency Virus)

For patients with HIV who are at end-of-life, our hospice provides customized plans of care and palliation for optimal outcomes, with focus on clinical interventions for patient comfort, education and support for caregivers, and hospitalization reduction.

Mrs. A is a 36-year-old female with a diagnosis of End Stage AIDS and a secondary diagnosis of Disseminated Histoplasmosis. She has comorbid conditions of Osteomyelitis of her Mandible, Chronic Pain, Nonalcoholic Fatty Liver Disease, and Rheumatoid Arthritis. She was diagnosed HIV positive with AIDS since the age of 16 following blood transfusion. She describes herself as "a strong person who chooses to remain positive."

Mrs. A resides with her husband and two children ages 17 and 12. Her 17-year-old is aware of her diagnosis, disease progression, and terminal prognosis; the 12-year-old is not. Mrs. A requests to remain a Full Code as she does not want her children to feel like she gave up on them. Although she does want to retain a Full Code status, she did request assistance in completing a Living Will so that her family doesn't have to make future decisions regarding her care without her guidance. This was completed within a week of admission to service. Her primary stated goal upon admission is to maintain normalcy in her daily life for as long as possible.

Prior to admission Mrs. A had been unable to tolerate her HIV medications for almost five (5) months. Her most recent CD4 count was 54; a normal CD4 count should be between 500 and 1500. On admission she was alert and oriented, appeared pale and her abdomen was distended. She often changed position from leaning forward to reclining but continually bracing her abdomen with her left arm. She reported an unintentional weight loss of 10 pounds over the last five (5) weeks, ongoing nausea, vomiting, diarrhea, headache and low grade fevers.

Mrs. A reported that she consistently has mild flu-like symptoms but reported new onset of increased mouth pain with sores present under the tongue and right eye. The Attending Physician was contacted by the admitting nurse resulting in an appointment, biopsy, and diagnosis of Disseminated Histoplasmosis. Mrs. A had previously been treated for Disseminated Histoplasmosis in 2020 and now required hospitalization for treatment again.

Upon return home Mrs. A's ability to tolerate food significantly decreased and she is relying primarily on chocolate protein drinks for nourishment. As a result, she has experienced further weight loss, now down to 115 pounds, nausea and vomiting, and chronic diarrhea resulting in bowel incontinence. She is embarrassed by the bowel incontinence and tries very hard to keep that change in condition from her family, specifically requesting that her husband not be told. This presents a bit of a challenge the hospice staff must work through as although Mr. A is the primary caregiver, Mrs. A remains alert, oriented and competent to make her own decisions.

In the couple months since Mrs. A's admission, she has experienced a significant physical decline requiring multiple medication adjustments for pain, nausea and vomiting, anxiety, diarrhea, and an onset of seizure activity. She has been treated for pneumonia and a recent MRI revealed several lesions on her brain. Her mid arm circumference has decreased from 29 cm to 26 cm, her Palliative Performance Scale decreased from 70% to 50% and she is now dependent on 5 of 6 Activities of Daily Living. She now ambulates slowly, experiences dyspnea with minimal exertion, and has begun to experience gaps in memory.

Mrs. A and her family are receiving services from the Hospice nurse, social worker, and chaplain - all of whom are working hard to meet Mrs. A's physical needs and both her and the family's emotional and spiritual needs.

Our Care Matters

- Mrs. A's hospice care occurs in the home, where she lives with her husband and children.
- The hospice care team respects Mrs. A's wishes for her care and her family's knowledge of her decline.
- Her individualized plan of care is adjusted for nourishment needs and increased assistance with ADLs.
- Social Work and Chaplain resources assist the patient and her family with emotional and spiritual needs.

When Life Matters Most

- Clinical interventions were adjusted specific to the patient needs for comfort for improved outcomes.
- The hospice care team works to support the patient's desire for "normalcy in her daily life for as long as possible."
- The patient's plan of care includes her request to remain a Full Code.
- Counseling and support will continue for the family.

Contact us to begin the hospice conversation or to address specific questions regarding hospice care for patients with HIV who are at end-of-life. We Are Here.