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Hospice. It is a scary word. Does that mean that my loved one is going to die? Is my loved one going to die in the next 6 months? Is there nothing more that can be done? Those can be just some of the thoughts that enter your mind when you hear hospice.

As a clinical social worker, and having worked in hospice prior to joining the HDSA, I hear hospice and I hear: comfort, companionship, and support. The goal of hospice is to help the patient retain the best quality of life possible and to offer much needed emotional support to the entire family. While on hospice, the patient and family will be surrounded by an interdisciplinary team consisting of a physician, nurse, social worker, chaplain, bereavement specialist, and home health aides who will work on a daily basis to provide physical care and emotional support to the entire family. Even after death the hospice team can remain involved.

Hospice is an approved Medicare service and is often covered in full by Medicare. To be eligible for hospice an individual must be entitled to Part A of Medicare, be certified as being terminally ill by a physician, and have a prognosis of 6 months or less if the disease runs its normal course. Can you be on hospice for more than 6 months? Yes. Can you be on hospice for less than 6 months? Yes. Every 6 months eligibility for hospice will be reviewed for signs of decline. If there is decline, hospice can continue. If there are no signs of decline during the previous 6 months then hospice must stop.

According to the HDSA’s publication of the Caregiver Guide for Mid to Late State Huntington’s Disease, in general, a person with HD who is no longer able to walk or talk is likely in the late stage of his or her disease. It is possible for a person to be stable in the late stage of HD. Clues that the person might be in a state of terminal decline include weight loss, recurrent aspiration pneumonias, or a serious hospitalization. In the terminal stages, hospice care can be very helpful for the family who is managing HD at home or in the long-term care facility.

To get hospice started, your physician will write an order for hospice. Much like how a physician writes an order for medication or lab work, a doctor has to order hospice. The family including the patient, if possible, has to be in agreement for hospice care to start. Once the order is written, the family gives consent for hospice to start, then a nurse from the hospice team will assess the patient eligibility for hospice wherever the patient is living. If approved, hospice services will start the day the assessment is complete. That day. Not tomorrow. Not in three weeks. That day.

Hearing hospice can be scary. It forces us to talk about, think about, and consider difficult things. But imagine, that you have a social worker and a chaplain to help navigate difficult conservations. Imagine that care was brought to your loved one in their residence. Imagine that when hospice starts, life gets a little easier.

In my personal opinion, hospice is often started too late and the family does not get the benefit of being fully supported during such a difficult time. Hospice does not equal death. Hospice does not mean that you will die today, or tomorrow, in a month, or in six months. Hospice allows for life with less worry and time to enjoy family while receiving quality care and support at home. Hospice is an option when times are tough. Hospice allows the family to be together when minutes, moments, and time is precious.

If you have any questions about hospice care please call me. I’d love to help you navigate your options.

Until next month,

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