

Is There Really No Place Like Home When It Comes to Dying?

By Jeanette Stehr-Green, Volunteer for Volunteer Hospice of Clallam County

While not everyone has the chance to decide where they will die, most Americans say that given the choice, they would prefer to die at home. For most people, home is familiar and comfortable. It is more private than a room in a hospital or nursing facility, and more likely to allow intimate gatherings with family and friends. In the home, the dying person and their caregivers are more in control, deciding when to have visitors, eat, drink, or take medications.

Providing support for a dying loved one at home can also be rewarding. Talking, holding hands, or simply being present can create a sense of closeness and a shared experience for both the caregiver and the dying person.

Caring for a person who is dying, however, can present challenges. People who are dying generally need help with physical comfort, emotional support, and spiritual needs. As death draws near, the dying person may need help with a growing list of practical tasks such as eating and drinking, personal hygiene, toileting, and taking medications. Caregiving also takes time away from just being with the dying person.

Things to consider

Planning, realistic expectations, and adequate support are key to keeping a dying person at home. Consider the following steps.

Consult the dying person's health care provider. The level of care needed by the patient, the availability of caregivers, and the layout of the home can impact how well this setting serves as a final place of care. Open discussions between the dying person, their health care provider, and potential caregivers will help determine if home is the best place for a person to die.

Locate the patient in a convenient spot in the home. A large downstairs room often can be arranged to accommodate the necessary equipment and will save the caregiver trips up and down stairs. A place near family activity, such as a living room or family room, will allow the dying person to feel more connected with those they love. If the dying person is still mobile, the distance to a bathroom can also be a factor.

Have the right equipment and supplies to ease caregiving. A hospital bed, handrails, transfer pole, or trapeze bar can make it easier to help the patient get in and out of bed. Once the patient is bedridden, lots of pillows and specially designed foam wedges and air pressure mattresses can help with repositioning the patient and the prevention of bed sores.

A bedside commode, bed pan, or urine bottle can make going to the toilet easier. Incontinence supplies such as disposable briefs, absorbent pads placed underneath the patient, or urinary catheters, can help with episodes of incontinence or when the person becomes bedbound.

Enlist the help of hospice. Hospice services vary by the provider but usually include pain and symptom management, medical care, counseling for patients and families, spiritual support, education, and the provision of equipment and supplies (such as incontinence products).

Primary care of the dying person, however, still rests with family; thus, it is important to have a good understanding of the level of care that hospice will provide so that expectations are realistic.

Welcome the help of family and friends. The caregiver can benefit greatly from the assistance of others, even with simple tasks such as shopping, laundry, picking up prescriptions, cleaning, cooking, minding children, walking dogs, or sitting with the patient.

Consider asking a close friend or loved one to coordinate support from others. You can bring family, friends, and neighbors together in one “gathering” to identify needs and organize who will do what and when. Online scheduling tools (such as SignUpGenius or MealTrain) can help coordinate the support from others.

When dying at home might not be right

Although home is where the heart is, it might not be the best place for some to die. Distressing symptoms such as severe pain, agitation, and shortness of breath can increase the burden on caregivers substantially. Intractable pain and other symptoms sometimes require care – such as intravenous medications and constant monitoring – that is not easily managed in a home setting

Potential caregivers may not be available. Family members or close friends may not be able to take time off work or will have to neglect other responsibilities to take on the role. Some potential caregivers may find these tasks too frightening, daunting, or physically demanding.

Some home settings will not accommodate equipment that could ease the provision of care. Stairs, a split-level layout, and narrow doorways can preclude wheelchair access in and around the home. Traditional showers, especially those with a tub, can pose fall risks for weak or unstable patients.

Change course if needed

If the decision is made for a person to die at home, regular review of the situation is critical. It is normal for caregivers to experience stress when caring for a dying loved one at home. If, however, the caregiver becomes totally overwhelmed or the patient’s comfort and dignity cannot be assured, other alternatives should be considered.

Jeanette Stehr-Green volunteers at Volunteer Hospice of Clallam County along with a host of other community members who provide respite care, grief and bereavement support, and access to free medical equipment.