



"The simple act of caring is heroic."

Edward Albert



Hospice Caregiving Tips for Patients and Their Families

1. We are your first call for help at (800) 200-2345 available 24/7.

- In case of an emergency, or anytime you need help, please make us your first call.
- We are the experts at helping you stay safe, comfortable and at home. We can help you manage things like pain and shortness of breath.
- VNAHG Hospice will help you avoid the unnecessary stress, and uncomfortable tests, that can come with an emergency room visit.

2. Cherish the time with your loved one.

- Research suggests that touch and hearing are the last senses a person loses, so your loved one will probably feel comfort and safety just hearing your voice, even if he/she can't talk. If you're not sure what to say, just read the newspaper aloud, talk about the weather, or about happenings in your life.
- Play music or pray together, if that is part of your family tradition. If you want spiritual support, counselors are available to support your family on this journey.
- It may be an opportunity to express your love and remember special experiences and relationships.

3. Check your home for safety.

- Your hospice team will assist with home safety recommendations and some items to consider.
- Create a clear pathway for a walker or wheelchair. Remove area rugs and any other obstacles.
- Handrails or grab bars in hallways and bathrooms are recommended.
- We can help you with the medical equipment you may need to ensure comfort and safety.
- If possible, put a monitor in your loved one's room so you can hear if he/she falls or needs help.

4. People wonder, 'Am I doing this right?'

- Remember, you know the patient better than anyone, and you are doing the best you can. Your care is the most valuable thing you can provide.
- Family relationships and emotions commonly intensify during this period. Well-meaning advice can add to your stress and create doubt.
- Remember, this is normal and you are not alone. Your VNAHG team is here to help and only a phone call away.

5. Take care of yourself.

- Make sure to take your own medications. Try to eat healthy food and drink water when possible.
- Know your own limitations, including when it is time for YOU to take a break. If you can, talk to a friend, join a support group, or take a walk.
- There is always time to pause, close your eyes, and take some deep breaths.

6. Eating and drinking may slow down.

- Your loved one's body may not need (or be able to process) food and drink anymore. The body is changing.
- Caregivers often worry that their loved one's refusal to eat will cause starvation. In fact, loss of appetite is common and is a natural progression of the disease.
- Follow your hospice team's advice on nutrition and take your loved one's cues on what feels good to eat or drink.
- Please discuss your concerns with your hospice team.

7. How much longer?

- The truth is that everyone's experience will be different. Try and stay in the present moment.
- In general, increased sleeping and refusal to eat or drink are the two most common signs that death may be near. Your VNAHG Hospice team will provide individual guidance on end-of-life signs and symptoms.
- For more information, review the orange flyer, "Supportive Care for Patient & Caregivers" in your folder.

8. Try to stay organized.

- Check off when medications were given on the enclosed tracking list.
- Keeping a notebook of things that have happened each day can help. Jot down any changes in your loved one's health or behavior, as well as household chores that were completed or still need attention.
- Making notes will also improve communication with other family members and with your hospice team.

9. Helpful resources are available.

- Crossing the Creek is a helpful book for the dying, their caregivers, clinicians, family members and friends that helps people understand the dying process and some of the things to expect physically, mentally, spiritually, and emotionally.
- It can be downloaded for free at <http://www.crossingthecreek.com>

10. Comfort Kits can bring relief.

- You will receive a comfort kit when the patient starts hospice services. Some think of it as a "mini pharmacy" at home. It includes important medicines and instructions that can treat pain and other conditions quickly, especially after hours when the pharmacy is closed.
- Your hospice team will provide instructions about how and when to use the medications in the comfort kit to help manage pain.
- Keep it in your refrigerator, as this is a safe place and also easy to find.

11. Attend a VNA Caregiver Hospice Support Group.

- If you can, sign up for the VNAHG Caregiver Hospice Support Group.
- This online weekly meeting - led by a trained VNAHG counselor - provides an opportunity to share ideas and discuss common challenges. Pre-registration is required. Please call (800) 200-2345.

12. We appreciate you.

- Caregiving can be hard. People wonder if their fear, sadness, guilt or even resentment are normal. It is normal to go through highs and lows.
- Some days you may feel good. Other days, it is fine to just keep up and do the best you can do.
- *Whatever your situation, always remember that you are doing important work. Thank you for allowing us to be a part of your journey.*

For More Information

For an electronic version of this material, download the **VNA Connect App** in the Apple Store, Google Play, or scan the QR code.

National Partnership for Healthcare and Hospice Innovation - This website provides detailed information for patients and their families on a wide variety of end-of-life care issues www.hospiceinnovations.org.

Caregiver Volunteers of New Jersey caregivervolunteers.org/get-help/respice-care/
Volunteers are available to offer a few hours of relief for family caregivers.



YOUR HOSPICE TEAM

Your hospice team is dedicated to making your time at home comfortable, safe and peaceful. During this period, several key people will be visiting your home. Others will be working behind the scenes on your behalf.

For 24-hour support, call (800) 200-2345



Nurse Case Manager

The nurse case manager is the main nurse who will support your physical and medical needs. They will visit at least once every 14 days, but will set a schedule based on your care needs. They are there to perform your physical assessment, assess medication needs, help with equipment and supply needs, and act as a support system.



Social Worker

The social worker can provide emotional support and help you navigate any long-term planning needs. They are a good resource for connecting with support groups, life reflection and discussion, assistance programs, advanced care planning, and more.



Spiritual Support

A spiritual counselor can come to your home to support your spiritual needs. They will only come at your request and will support all religious practices and beliefs, regardless of whether you participate in an organized religion or not. Spiritual counselors are non-denominational and adapt a generalized approach to spirituality in hospice care.



Home Health Aide

The home health aide can help with preparing meals, feeding, light cleaning, bathing, or hygiene. The frequency of visits depends on your care needs and is supplemental to already established care in the home.

Team Leaders



Medical Director

The Medical Director is the hospice physician who reviews your care on a regular basis to maximize comfort and symptom management. They typically do not visit the home but are always available to team members to consult on your care.



Clinical Manager

The Clinical Manager is the leader of your Hospice team. They oversee your team and are available for any troubleshooting or to address special needs that may arise.

Additional Support