

# Patient and Family Handbook



**HOSPICE CARE**



## HOSPICE CARE

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VNS Health is committed to culturally sensitive care to meet the diverse needs of New York's communities. We provide welcoming, safe home health services to all individuals—regardless of race, religion, color, national origin, age, disability, sex, sexual orientation, gender identity, or gender expression. VNS Health is proud to be accredited by the Community Health Accreditation Program (CHAP), The National Institute for Jewish Hospice, as well as by SAGECare with platinum-level LGBT cultural competency credential.



### Making the most of each day together.

Thank you for choosing VNS Health Hospice Care at this important time in your life. We're here to help you live with advanced illness by combining sensitivity and compassion with expert knowledge and skill, all within the familiar comforts of home.

Our specially-trained hospice team, which is comprised of nurses, social workers, spiritual care counselors and doctors, works with you and your loved ones so you can better understand, plan and navigate the physical, emotional and spiritual paths ahead. Our goal is to help you feel confident and comfortable, so you can make the most of each day together.

## Your VNS Health Hospice Care team

Your **VNS Health Care Hospice team** works with you and your family to enhance the quality of your life together.

Our team of highly-trained professionals is dedicated to working together with you to support you through each day. Every member of our team has chosen to practice in this specialty and takes great care in helping people live with advanced illness.

The care team is available **24 hours a day, 7 days a week** and will consist of:

- **An RN Nurse Coordinator of Care** who is responsible for assessing needs, and for planning and coordinating all of your services. The RN works with you and your physician to provide recommendations for your care. Your Coordinator of Care has professional training in managing the symptoms of advanced illness and will be directly involved in providing care to you.
- **Hospice physicians** are specifically certified in advanced illness palliative care and end-of-life care and consult with your primary physician to determine the best possible plan of care. See the next page for more information about hospice physicians.
- **Social workers** help you and your family members work through the emotions that can accompany advanced illness as well as help you with personal, legal and financial matters. This includes understanding your family's culture, values and communication style.
- **Home Health Aides** provide personal care for people living with advanced illness as well as assist with meals and moving around your home.
- **Spiritual care counselors** provide care focused on emotional and spiritual needs during times of suffering, stress and grief. Our team members have backgrounds in multiple denominations and can work with your faith community as needed.
- **Volunteers** provide support to patients and families through companionship, often reading, talking, journaling or participating in a favorite activity with you. All volunteers complete a specialized training program.

## How can a physician who specializes in hospice and palliative care medicine help you and your family?

Physicians who specialize in hospice and palliative care medicine are committed to treating the distressing symptoms that can result from advanced illnesses. Working together with a team of experienced health care professionals, these physicians can help you and your family members regain comfort, dignity and control by providing:

- Expertise at relieving pain
- Treatment for a broad spectrum of other symptoms, such as fatigue, breathlessness, nausea and anxiety
- Help setting goals for care
- Guidance making complex treatment choices
- Coordination with other health care providers, including the primary physician and specialists, such as oncologists, surgeons and cardiologists
- Hospice services to improve quality of life at home or in the nursing home, assisted living facility, hospital or hospice facility



**Your hospice and palliative medicine physician can work as a consultant to your primary physician. Upon request, he or she may also assume primary responsibility for your care.**

For more information about hospice and palliative care medicine and for links to other organizations that can be helpful to patients and families living with life-limiting illness, visit: [www.AAHPM.org](http://www.AAHPM.org), [www.NHPCO.org](http://www.NHPCO.org) and [vnshealth.org](http://vnshealth.org).

## Getting started

Here are **the steps** to be aware of as your plan of care is developed:



### Step 1: Your admission visit

A VNS Health Hospice Care admission nurse will come to your home or other location to discuss important information about your care. He or she will:

- Assess any symptoms that you may be experiencing at that time
- Review medications and order any necessary supplies
- Review important paperwork and ask you to sign consent forms that will allow us to begin providing care
- Answer any of your questions so you feel confident and comfortable about the care you will receive

### Step 2: Registering for care

After you are admitted to receive advanced illness care from VNS Health, you are automatically registered in our electronic database. If you need to contact us at any time, your information will be available to everyone on the VNS Health Hospice Care team, 24 hours a day, 7 days a week. This access to information helps us to provide excellent care to you.

### Step 3: Creating your personal plan of care

Usually within two days of the admission visit, your nurse coordinator of care will schedule a visit to review your plan of care. A schedule that includes all of the members of your care team will be established. The number of times that your nurse visits you each week varies depending on your needs and medical conditions.

### Step 4: Contact from other care team members

Within the first five days of admission, you may expect phone calls or visits from a social worker, spiritual care counselor, volunteer or a home health aide.

## Programs and services to enhance your care

Over the course of your care, there may be situations when you need and want additional support. Receiving advanced illness care from VNS Health allows you to take part in a number of exceptional programs and services that can help you feel confident about your care and ensure you make the most of each day.

Program/Service	What is it?	Where to find more information
<b>Patient and Family Support Services</b>	Comfort and support provided through volunteers, spiritual counseling, social work and bereavement services.	<b>Page 6</b>
<b>Veterans Program</b>	Specialized hospice program for Veterans.	<b>Page 8</b>
<b>Short-Term Additional Clinical Care</b>	Short-term additional skilled nursing care in the home for a serious health situation.	<b>Page 9</b>
<b>Ethics Consultations</b>	Extra support provided when deciding which care choices best honor your values and beliefs.	<b>Page 9</b>
<b>The Comfort Pack</b>	Medications the patient can have on hand to provide relief from common symptoms.	<b>Page 10</b>
<b>Optional Supplemental Services</b>	Additional home care services from a home health aide or other professionals that are paid for out-of-pocket are available from VNS Health.	<b>Page 11</b>

## Patient and family support services

### How can a **social worker** help you?

Social workers are licensed, expert counselors skilled in helping people manage the many emotional, psychological and financial changes that result from serious illness.

#### These new challenges include:

- Coping with life limiting illness and its emotional toll
- Coping with increased need for care
- Coping with caregiving
- Coping with anticipated loss
- Coping with financial obligations

Our mission is to support you and your loved ones during this difficult time and advocate for your hopes and wishes. We achieve this by focusing on your individual and familial needs and strengths, learning about your history, determining your goals, helping you solve current problems, providing supportive counseling, and providing assistance with benefits.

### How can a **spiritual care counselor** help you?

Spiritual care counselors are trained clinicians who provide compassionate care which nourishes and affirms your personal connections to meaning, purpose, and transcendence. Our counselors are non-denominational and serve all patients and families who are interested in support.

#### Here are some of the ways we can help:

- Listening and providing support as you identify questions and emotions
- Helping to access and reaffirm your sources of strength, hope, and joy
- Supporting you and loved ones through anticipatory grief process
- Facilitating healing conversations with families
- Offering prayers, readings, and songs that align with your belief system
- Connecting you with community clergy, faith leaders

Our hope is that you will feel supported at all levels and know that you are not alone. We are available to help at any time in your journey.

### How can a **volunteer** help you?

Our specially trained and dedicated volunteers are ready to provide you with the extra help you might need at this important time.

#### VNS Health Hospice Care volunteers provide:

- Companionship and socialization
- Friendly phone calls and visits
- Empathetic listening & compassionate presence
- Life review assistance (oral/memoirs/letters)
- Help with organizing
- Music & art at the bedside
- Mindfulness practice
- Relief so that a caregiver can take a break



### How can our **bereavement program** help you?

VNS Health provides specialized services designed to help families cope with the loss of a loved one. Our bereavement counselors are available to help families and loved ones, including children, through this difficult time.

The VNS Health bereavement team offers a thirteen-month program for families and loved ones, following the loss of the patient. These services include counseling, support groups in English, Spanish and Chinese, grief and loss presentations, both lecture and experiential workshops, a quarterly newsletter, and an annual non-denominational memorial service. Our bereavement services are offered to family members and friends. We recognize that grief is a normal response and while we are available as needed, we allow for some time to pass before we make our initial contact to begin bereavement services.

**To request any of these Family Support Services or to find out more information, please ask any member of your hospice care team.**



## Veterans program

The **VNS Health Veterans Program** is designed to meet the unique needs of veterans and their families.

**Veterans** receive care provided by a team of experts, many of whom are veterans themselves.

### Care is provided to address:

- Service-connected injuries and illnesses
- Post-traumatic stress disorder (PTSD)
- Survivor's guilt
- Depression
- Substance abuse

### We can also:

- Help identify veteran-specific benefits and connect veterans to additional community services
- Assist with recovery of military discharge papers
- Conduct special recognition ceremonies
- Provide assistance with planning of military memorials



**We are proud to have been granted the *We Honor Veterans* Level Five status by the National Hospice and Palliative Care Organization.**

## Short-term additional clinical care

Hospice Continuous Care (Crisis Care) is a short-term additional level of care that includes pain and symptom management. It is provided in the home setting during a serious health situation and helps you or your loved one avoid an unwanted hospitalization. This special level of care is ordered by your physician and supervised by your hospice RN.

After a careful evaluation of your needs, this extra care is usually provided for a period of one to three days and is a combination of care provided by LPN nurses and home health aides working periods of support shifts. These members of the hospice team stay with you in the home to assist you in caring for your loved and teach you how to provide comfort measures before they leave your home, so that you feel confident that he or she is receiving the best possible care.

## Ethics consultations

Making decisions about health care can be difficult, especially when it involves end-of-life care for yourself or a loved one. Our hospice team works hard to help you make compassionate and informed choices, but sometimes patients and families need even more support when deciding which course of action to take. When this happens, VNS Health Hospice Care draws on the expertise of people who are experienced in this area.

Our ethics consultants are trained to help everyone understand and talk about their values, beliefs, and feelings. This may make it easier to hear what everyone is saying and to reach agreement about which choices are taken for your situation.

To find out more about how the Ethics Committee might be able to help, please ask anyone on your VNS Health Hospice Care team, or contact the committee directly by emailing [hospice.ethicscommittee@vnsny.org](mailto:hospice.ethicscommittee@vnsny.org). Please include your name and a phone number. We will call you within two (2) business days.

You have a right to take part in choices about your own or your loved one's care. For more information, look at the NYS Department of Health brochure, ***Deciding About Health Care***, available at [www.health.ny.gov/publications/1503](http://www.health.ny.gov/publications/1503).



## The Comfort Pack

There may be times when the patient experiences symptoms that can be relieved by **medication**.

The Comfort Pack contains a small supply of medications that you can have on hand for use right away without waiting for delivery.

### The Comfort Pack:

- Is delivered to your home
- Should be placed in the refrigerator when it arrives
- Has a seal/packaging that should not be opened until directed
- Contains medication that should never be used without instructions from a hospice nurse or physician
- **Is for the patient only; do not let others use the medications**



### Medications in the Comfort Pack can help with a range of symptoms:

- Pain
- Excessive secretions
- Fever
- Shortness of breath
- Restlessness
- Nausea
- Anxiety
- Constipation
- Insomnia



**If you are experiencing pain or symptoms, call your hospice team.**

## Optional supplemental services

If your situation changes or more supportive assistance could benefit you or your loved one, it's reassuring to know supplemental private home care services are available for an additional cost.

Services are available **24 hours a day, 7 days a week** and may include:

- Help with day-to-day activities such as personal care, grooming, grocery shopping, meal preparation and light housework
- Supportive care and companionship for family caregivers who need a break
- Assistance getting to and from medical or social appointments
- Additional skilled nursing care, as needed

Customized services that fit your needs can be purchased out-of-pocket or with long term care insurance. **Special discounted rates apply for patients receiving advanced illness care from VNS Health and no assessment fees required.**


**To learn more about how additional private home care services from VNS Health Personal Care can help you, call 1-888-735-8913 or visit [vnshealth.org](https://vnshealth.org).**



## How to reach us when we are not with you

We are always available to help answer questions and concerns you have regardless of the day and time. Based on your particular need or concern, we will help you determine the best course of action so you can feel confident that you and your loved one are receiving the best possible care.

Please call the hospice team phone number on the contact card given to you during your first nursing visit. It is always best to place this card where it can be easily found, like your refrigerator.



VNS HEALTH HOSPICE CARE

### How to reach us when we're not with you

**We're always available — 7 days a week, 24 hours a day to help answer questions or concerns.**

Your VNS Health Hospice Care team manager's name is:

**212-609-1920 (TTY 711)**

## Call us at 212-609-1920



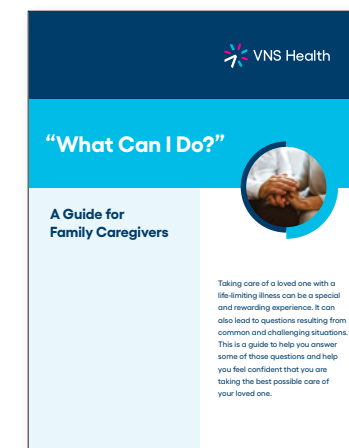
### Call Monday through Friday, 8:30 am to 4:30 pm if you:

- Need more equipment, supplies or medication refills
- Have questions about scheduled team visits
- Would like to request a change in home health aides

### Call seven days a week, any time of the day or night if you:

- Are unsure about a change in condition, whether or not it feels like an emergency

## For situations that feel urgent



Sometimes you or your loved one may experience a serious, uncomfortable situation that requires urgent attention. Please call us right away at **212-609-1920 or Toll Free 888-870-0535 (TTY 711)**. If a care team member needs to make an urgent visit to your home, we will let you know how long it will take for that person to arrive. Please know that you are not alone during this time and feel confident that we are here to support you. We are here with extra phone support and you can and review the **“What Can I Do?”** Guide for tips that can help with symptoms until someone from the care team arrives.

In these situations, we may implement our **Community Paramedicine Program** to provide urgent-level care by a specially-trained paramedic who will work with hospice physicians to help alleviate extreme symptoms in the home. This program is designed to help you maintain your goals of care and avoid an unwanted hospitalization.



## Language interpretation services

Language interpretation service is available via Optimal Phone Interpretation **24 hours a day, 7 days a week** for any questions about your care. For more information about how to access this service, ask any member of your VNS Health care team.



<b>Español</b>	Un servicio de intrerpretación lingüística está disponible a través de (Optimal Phone Interpretation) las 24 horas del día, 7 días a la semana para cualquier pregunta acerca de su atención. Para obtener más información acerca de como acceder a este servicio, pregúntele a cualquier miembro de su equipo de atención de VNS Health.
<b>中文(繁體)</b>	我們透過最佳電話翻譯服務 (Optimal Phone Interpretation) 每週7天，每天24小時，隨時為您提供語言翻譯服務，回答您有關照護的任何疑問。欲了解更多有關如何利用這項服務的資訊，請詢問您的富康醫療照護團隊的任一成員。
<b>العربية</b>	خدمة الترجمة الفورية اللغوية متاحة من خلال الترجمة الفورية المثلى عبر الهاتف على مدار ٢٤ ساعة في اليوم، و٧ أيام في الأسبوع لأية أسئلة تطرحها حول خدمة الرعاية التي تحصل عليها. ولمزيد من المعلومات حول كيفية حصولك على هذه الخدمة، اسأل أي عضو بفريق الرعاية لدى VNS Health.
<b>Русский</b>	Телефонная служба перевода по любым вопросам о вашем уходе обеспечивается компанией (Optimal Phone Interpretation) и работает круглосуточно каждый день. Более подробную информацию о получении данной услуги вы можете уточнить у любого из специалистов VNS Health, ухаживающих за вами.
<b>Kreyòl Ayisyen</b>	Wap trouve sou (Optimal Phone Interpretation) yon sèvis kote ou ka mande enfòmasyon sou sante-w chak jou Bon Dye mete epi nenpòt kilè. Pou ou ka konnen plis koze sou sèvis sila, poze kesyon bay nenpòt ki moun nan ekip VNS Health ou a.
<b>한국어</b>	통역 서비스는 최적전화통역 (Optimal Phone Interpretation) 을 통해 연중무휴 하루 24시간 제공해드리며 귀하의 관리에 대한 어떤 질문도 가능합니다. 본 서비스 이용 방법은 담당 VNS Health 관리팀에 문의해 주십시오.

## “What Can I Do?”



### A Guide for Family Caregivers

Taking care of a loved one with a life-limiting illness can be a special and rewarding experience. It can also lead to questions resulting from common and challenging situations. This is a guide to help you answer some of those questions and help you feel confident that you are taking the best possible care of your loved one.

# End of Life Caregiving

What you might be feeling	Rest assured; VNS Health is here
<b>My loved one wants to stay home and I am not sure I can take care of him/her.</b>	It is completely normal to feel unsure when you are doing something for the first time. VNS Health Hospice Care is here to help you. We teach you what you need to know to take care of your loved one at home in order to avoid unexpected trips to the hospital.
<b>I am tired, scared and alone.</b>	Many caregivers feel like you do, but you are not alone. Our social workers and spiritual care counselors listen to you and help you make sense of the physical and emotional stress you are experiencing. We can help you to navigate all the practical, legal and financial issues.
<b>I am willing to do all I can, but don't know if I'm able.</b>	Remember, your presence and companionship is the most important thing you can do. Our nurses, social workers, spiritual care counselors, physicians and volunteers help you learn, plan and carry out the best care possible. We visit you regularly and we are available to support you 24/7.
<b>How will I manage when my loved one is gone?</b>	VNS Health Hospice Care stays connected and supports you after the death of your loved one with our bereavement program. It includes telephone support, support groups and a range of events and activities.

# What should a hospice patient do in an emergency?

## Can a hospice patient go to the hospital?

It is important to call VNS Health Hospice Care right away if you, or your loved one, is experiencing a change in condition requiring emergent or urgent management. VNS Health Hospice Care is designed to improve a patient's quality of life by managing pain and other symptoms related to their terminal illness without invasive treatments or unwanted trips to the hospital. There are many things that you and your VNS Health Hospice Care team can do together, in most situations, to help your loved one to remain at home.

**For urgently needed Hospice Care support call 212-609-1920 or Toll Free 888-870-0535 (TTY 711)**

**VNS Health Hospice Care** is available to you 24/7. If you or your loved one has an urgent clinical need, your call will be escalated to a Registered Nurse (RN) who will assess your needs and provide one of the following types of support, as clinically appropriate:

- Verbal support, teaching, and interventions provided or directed by an RN or other clinical staff over the phone;
- A non-urgent visit to your home by a VNS Health Hospice Care nurse;
- An urgent visit to your home by community paramedicine services (at no additional charge);
- In-Home Continuous Care which provides a home hospice nurse for a minimum of 8 hours up to 24 hours a day;
- Short-Term Inpatient Hospital Care at a VNS Health Hospice Care contracted hospital facility; or
- **Call to 911 - if the RN or patient/caregiver determines the patient is experiencing a clinical emergency that cannot be managed in the home, such as for a fall causing a broken bone, uncontrolled bleeding, a stroke, or a heart attack.**




**Important Insurance Information:** If you, or your loved one, needs to get care at a hospital for your terminal illness and/or related conditions, VNS Health Hospice Care should make the arrangements in order for your hospice benefit to cover the cost.

**Questions? Call 212-609-1920 or Toll Free 888-870-0535 (TTY 711)**

## What can you do while you are waiting to talk to our nurse?

If you are feeling anxious, the first thing you need to do is take a few slow, deep breaths and make an effort to feel more calm and centered. Count to ten to help focus on what you will do to help your loved one. Remember that if you remain calm, your loved one will remain calm. Tell yourself: **“I am part of an expert Hospice program, I can do this.”**

### What can I do for pain and comfort issues?

Common Situations	Things You Can Do
<p><b>Constant fidgeting and moaning</b></p> 	<ul style="list-style-type: none"> <li>• Ask your loved one if he/she is comfortable. Speak slowly and directly</li> <li>• Prop up head and upper body with 3 or 4 pillows</li> <li>• Change the position in bed (side to back to other side; arrange pillows to support back and legs)</li> <li>• Rub back</li> <li>• Massage hands</li> <li>• Add a blanket if cold or remove blanket if hot</li> <li>• Play soothing music</li> </ul>
<p><b>Complaints of pain</b> (pain medications not working or the effect is very short)</p> <p><b>Becomes cranky or moody</b> (general change in temperament)</p>	<p>Breakthrough pain is an abrupt and intense pain that occurs even when the regular pain medication has been working.</p> <ul style="list-style-type: none"> <li>• Ask them to describe the pain and rate it on a scale of 0-10. Use the pain and comfort scales in this guide (page 22) and write down what he/she says</li> <li>• Check to see the last time a dose of pain medication was given. If it is close to time, give another dose. It should help in 30 minutes to 1 hour. Call Hospice if the medication is not reducing the pain</li> <li>• Decrease stimulation in a room (lower music/TV; calm family members)</li> <li>• Provide distraction (offer something enjoyable – play favorite or soft music, readings, comfort foods)</li> </ul>
<p><b>Running low on pain medication</b></p>	<ul style="list-style-type: none"> <li>• Call us if you think you’ll need medicine before the next nurse visit</li> <li>• Be ready with a list of all medications in front of you in order to be able to tell us exactly what is needed</li> </ul>

### What can I do for breathing issues?

Common Situations	Things You Can Do
<p><b>Appearance of difficult breathing</b> (shortness of breath, gasping, breathing very fast)</p> <p><b>Complaints that clothes are too tight or hot</b></p> <p><b>Strange breathing noises</b> (gurgling)</p>	<p>Breathing noises and other breathing changes are common.</p> <ul style="list-style-type: none"> <li>• Try changing his/her position by sitting up a bit higher or by turning on the side</li> <li>• Coach to take slow, deep breaths and focus on relaxing</li> <li>• Keep the room cool (open window or turn on air conditioning)</li> <li>• Turn on a fan aimed at the face and upper body</li> <li>• Loosen clothing that might appear tight (collar/bra)</li> <li>• If using oxygen, check mask and the tank to ensure flow rate is correct and that tubes are not kinked</li> <li>• Give medication for shortness of breath, as ordered</li> <li>• Decrease stimulation in the room (lower music/TV; calm family members)</li> <li>• Provide distraction (favorite music, readings, comfort foods)</li> <li>• Arrange bed to improve patient’s ability to see out a window, if possible</li> </ul>

### What can I do for stomach, bladder, or bowel issues?

Common Situations	Things You Can Do
<p><b>Decreased appetite</b></p> <p><b>Refusing to eat</b></p> 	<p>This is expected. As the body slowly shuts down, there is a gradual loss of interest in food. His/her feelings of thirst and hunger will go away. It is a natural part of the process.</p> <ul style="list-style-type: none"> <li>• Offer very small amounts of appealing foods; try ice cream, milk shakes, pudding, cream soup, applesauce, Pastina, Jello, soft boiled egg</li> <li>• Do not force food or water when he/she is refusing to eat or drink</li> <li>• Focus on other comfort issues or give good, clean mouth care by using a soft toothbrush or foam swab and applying lip balm</li> </ul>
<p><b>Nausea and/or vomiting</b></p>	<ul style="list-style-type: none"> <li>• Try circulating fresh air by opening a window or turning on a fan</li> <li>• Offer small sips of seltzer or ginger ale</li> <li>• Apply cool compress on the forehead</li> <li>• Offer prescribed anti-nausea medication before meals</li> </ul>
<p><b>Decrease in urination or bowel movements</b></p> <p><b>Urine looks very dark</b></p> <p><b>Blood in the urine or stool</b></p>	<p>This can happen.</p> <ul style="list-style-type: none"> <li>• Create a log of activity (day/time, color, consistency)</li> <li>• Ask if there was discomfort when passing urine or during bowel movement</li> <li>• Write down results and have log handy for when the nurse calls</li> </ul>



## What can I do for changes in **behavior**?

Common Situations	Things You Can Do
<p><b>Anxiety, confusion and agitation</b></p> <p><b>Restlessness; keeps talking about needing to go somewhere: “got to leave”</b></p> <p><b>Angry; he/she is saying hurtful things</b></p>	<p>Sometimes your loved one will say things that sound irrational. “Nonsense” may represent a deeper, symbolic communication. For example, many dying people talk about travel with statements such as “I have to get on the train.” Consider the possibility that a meaningful need or wish is being expressed.</p> <ul style="list-style-type: none"> <li>• Try to respond respectfully to questions and comments even when talk is nonsensical</li> <li>• Remain loving and don’t take it personally if he/she says hurtful things. Remember that it is a confused mind talking</li> <li>• Always talk as if he/she can understand everything even when there is no apparent response</li> <li>• Explain actions before doing (e.g., “I’m going turn you now.”)</li> <li>• Reposition to try a more comfortable one</li> <li>• Coach to take slower and deeper breaths</li> <li>• Open a window; turn on a fan</li> <li>• Ask if he/she has to go to the bathroom</li> <li>• Decrease stimulation in the room (lower music/TV; calm family members)</li> <li>• Reassure your loved one that everything is okay</li> <li>• Give medication as ordered</li> <li>• Massage hands and rub back</li> <li>• Play soft, relaxing music</li> <li>• Use aromatherapy (a scented lavender soap under pillow; potpourri near the bedside)</li> <li>• Call family or a friend to come be with you</li> </ul>
<p><b>Hallucinations:</b> saying they are seeing things and people that aren’t there</p> <p><b>Acts like they are living in a dream world</b></p>	<p>When someone is dying, they are beginning the transition physically and mentally. A person’s past can seem real. Listening to, rather than contradicting, these ‘stories’ can be very affirming for your loved one.</p> <ul style="list-style-type: none"> <li>• Acknowledge the experience. Try not to argue. Avoid insisting that it is not really happening</li> <li>• Take safety measures; avoid and prevent situations where a fall could occur</li> </ul>



## What can I do for **fatigue** and **sleeping issues**?

Common Situations	Things You Can Do
<p><b>Acts more tired today than yesterday</b></p> <p><b>Sleeping for a long time; difficulty waking up and remaining alert</b></p>	<p>This can happen as he/she continues to decline.</p> <ul style="list-style-type: none"> <li>• Check the last time they had medication that could be causing drowsiness</li> <li>• Plan activities for when he/she has the most energy. Plan to rest in between activities</li> </ul>
<p><b>Sleeping a couple of hours at a time</b></p> <p><b>Awake all night</b></p>	<p>This can happen.</p> <ul style="list-style-type: none"> <li>• Do something for your loved one that he/she normally finds soothing (make tea with honey, dim the lights, play soft music or make the room quiet if it is noisy)</li> <li>• Get help from family and friends so you can rest</li> </ul>



## What can I do for **final days** and **the last hours**?

Common Situations	Things You Can Do
<p><b>No appetite; urine output decreases</b></p> <p><b>Arms, legs, face are cool, pale or discolored as circulation decreases</b></p> <p><b>She/he cannot be aroused</b></p> <p><b>Breathing can be noisy due to mucus collecting in his/her throat</b></p> <p><b>Altered patterns of breathing – unusually slow or unusually fast or a combination of both</b></p> <p><b>Depth and frequency of breathing becomes less and less until heartbeat stops</b></p> <p><b>Eyes and mouth may be open</b></p>	<p>This is a time of transition. Your calm companionship supports and honors your loved one in this process.</p> <p>Unusual patterns or noisy breathing is expected and does not mean your loved one is suffering – he/she is often not aware of breathing changes.</p> <ul style="list-style-type: none"> <li>• Call Hospice and family and friends</li> <li>• Hold your loved one’s hand continue to talk reassuringly by letting him/her know it is okay</li> <li>• Always speak as if he/she can understand everything</li> </ul>

**Call the VNS Health Hospice Care dedicated caregiver help line at 212-609-1920 or Toll Free 888-870-0535 (TTY 711).**









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For more information about our services,  
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