



# TAKING CARE OF LOVED ONES

YOUR GUIDE TO  
AT-HOME CARE



Hudson Valley  
Hospice



SERVING DUTCHESS AND ULSTER COUNTIES



**If you are concerned about your loved one's condition, call Hudson Valley Hospice immediately at 845-240-7510 and ask to speak to a nurse.**

**You are not alone. Taking care of a loved one with a life-limiting illness can be a challenge and often raises many concerns. Hudson Valley Hospice is here to support and guide you through the various situations that may occur, so that you may feel confident in the care you provide.**

# ABOUT CARING FOR A LOVED ONE AT THE END OF LIFE

We created this booklet as a guide to help you understand and feel confident in caring for your loved one.

A trip to the ER can be a long, uncomfortable and unnecessary experience that can unsettle your loved one – so keep this booklet as a guide to deteriorating symptoms, so that you know how to handle a change in circumstances and when to call for help. Discuss any questions you have with the Hospice nurse in order to keep the patient as comfortable as possible.

HOW YOU MAY FEEL	HOW HUDSON VALLEY HOSPICE CAN HELP
I feel uncertain and lack confidence.	Your loved one wants to stay home and you are not sure you can take care of him/her. Hudson Valley Hospice can help. Our specially trained nurses will teach you how to care for your loved one at home and help avoid unnecessary trips to the hospital.
I feel tired, scared and overwhelmed.	You are facing a very challenging period, but you don't have to do it alone. Our chaplains and social workers can help guide you. Our specially trained care team offers you personalized attention and support, and helps you and your family manage physically, emotionally and spiritually.
I don't think I can do this.	Remember that your companionship means everything to your loved one. Know that your loved one can expect a better quality of life during this period of hospice care, since many symptoms that might otherwise require a hospitalization can be successfully managed by the hospice team at home. No one can provide the loving care that you can provide.
How will I manage when my loved one is gone?	The experience of grief can be very stressful. We offer grief support ranging from mailings to one on one counseling to support groups and memorials.

## IF THERE IS A SUDDEN CHANGE IN YOUR LOVED ONE'S CIRCUMSTANCES, CALL HUDSON VALLEY HOSPICE IMMEDIATELY.

The hospice nurse will discuss the patient's symptoms and make recommendations over the phone. If needed, they will make a visit. While you are waiting for the nurse to arrive, try to stay calm by taking a few deep breaths, expert help is on the way. Hudson Valley Hospice's specially trained hospice care teams have over 40 years of experience in just this type of situation.

### IF YOUR LOVED ONE HAS PAIN AND COMFORT ISSUES

SITUATION	HOW YOU CAN HELP
Constant fidgeting and moaning	<ul style="list-style-type: none"><li>■ Make sure your loved one is comfortable</li><li>■ Prop up your loved one's upper body and head with additional pillows</li><li>■ Massage hands or feet</li><li>■ Rub his or her back</li><li>■ Add or remove extra blankets</li><li>■ Play his or her favorite music</li></ul>
Complaining of pain	<ul style="list-style-type: none"><li>■ Breakthrough pain can occur even when regular pain medication is working</li><li>■ Do not automatically give more medication</li><li>■ If it is almost time for more medication, dispense as prescribed</li><li>■ Ask your loved one to rate the pain using the chart in this booklet</li><li>■ Decrease the amount of stimulation in the room</li><li>■ Encourage family members to stay calm or leave the room</li><li>■ Provide a snack, drink, heated blanket, ice water or other distraction for your loved one</li><li>■ You can always call hospice and speak to a nurse regarding your loved one's pain</li></ul>
Low supply of pain medication	<ul style="list-style-type: none"><li>■ Call Hudson Valley Hospice as soon as you realize your loved one needs additional medicine</li><li>■ Be ready with a list of medications in front of you in order to tell us exactly what is needed</li></ul>

## IF YOUR LOVED ONE HAS BREATHING ISSUES

SITUATION	HOW YOU CAN HELP
Shortness of breath or gasping for air	<p>It is normal for the patient to experience changes in breathing patterns. This is not painful for the patient.</p> <ul style="list-style-type: none"> <li>Try changing his or her position to sit up a bit higher or by turning on the side</li> <li>Adjust your loved one's pillows and blankets</li> <li>Coach him or her to take deep breaths</li> <li>Loosen or remove any clothing that may feel restricting</li> <li>Keep the room cool</li> <li>Decrease the amount of stimulation in the room by lowering the TV or radio, encourage visitors to remain calm and speak softly</li> <li>Provide a reassuring presence by playing your loved one's favorite music or reading to them</li> </ul>
Complaining of feeling hot or of having trouble breathing	
Making strange breathing noises, such as gurgling	

## IF YOUR LOVED ONE HAS STOMACH, BLADDER, OR BOWEL ISSUES

SITUATION	HOW YOU CAN HELP
Decreased appetite	<ul style="list-style-type: none"> <li>This is a natural part of the process</li> <li>Offer small amounts of his or her favorite foods</li> <li>Do not force your loved one to eat</li> <li>Keep his or her mouth clean, with teeth gently brushed and lips moisturized</li> </ul>
Nausea or vomiting	<ul style="list-style-type: none"> <li>Circulate fresh air by opening a window or turning on a fan</li> <li>Offer small sips of ginger ale or water</li> <li>Apply a cool compress to the forehead</li> <li>Check medication labels for any possible side effects</li> </ul>
<p>Not passed urine for many hours or not moving bowels for 3 days</p> <p>Urine looks dark</p> <p>Blood in the urine or stool</p>	<ul style="list-style-type: none"> <li>Keep a log listing date, time, color and consistency of bowel movements and urine passing</li> <li>Keep the written log handy for when the nurse calls</li> <li>Determine if your loved one experiences discomfort</li> </ul>

## IF YOUR LOVED ONE HAS TROUBLE SLEEPING OR REMAINING AWAKE

SITUATION	HOW YOU CAN HELP
<p>Acts more tired than normal</p> <p>Sleeps a long time</p> <p>Has trouble remaining alert</p>	<ul style="list-style-type: none"> <li>■ This can happen as he/she continues to decline</li> <li>■ Check the last time they had medication that may cause drowsiness</li> </ul>
<p>Not sleeping more than a couple of hours</p> <p>Awake all night</p>	<ul style="list-style-type: none"> <li>■ Make an herbal tea</li> <li>■ Dim the lights</li> <li>■ Play soft music</li> <li>■ Offer a hand or foot massage</li> <li>■ Make sure he or she is comfortable in bed</li> <li>■ Provide aromatherapy (lavender sachet, etc.)</li> <li>■ Ask family and friends for help so that you can rest</li> </ul>

## HELP US HELP YOU. HOW DOES YOUR LOVED ONE FEEL?

Where possible, determine the condition of your loved one and give us this information over the phone when you call.

1) How long has he/she been feeling this particular pain?

2) Where in the body is the discomfort located?

3) At what number would you or your loved one rate the discomfort level?



**NO PAIN**

0



1-2



3-4



**DISTRESSING PAIN**

5-6



7-8



**UNBEARABLE PAIN**

9-10

4) Which word best describes the discomfort?

\_\_\_ shooting

\_\_\_ stabbing

\_\_\_ burning

\_\_\_ aching

\_\_\_ choose another word

## IF YOUR LOVED ONE HAS A SUDDEN CHANGE IN BEHAVIOR

SITUATION	HOW YOU CAN HELP
<p>Anxiety, confusion, agitation</p> <p>Restlessness</p> <p>Hurtful comments, anger</p> <p>Hallucinating, or living in a dream world</p>	<p>Although your loved one may seem confused or irrational, he or she may be trying to express a meaningful need or wish.</p> <ul style="list-style-type: none"> <li>■ Listen and try to respond respectfully to questions and comments</li> <li>■ Do not take it personally if hurtful things are said</li> <li>■ Do not contradict his or her stories or dreams</li> <li>■ Reassure your loved one that they are not alone</li> <li>■ Talk to your loved one as if he or she can understand everything, even if there is no response</li> <li>■ Take appropriate precautions to prevent falls and keep your loved one safe</li> <li>■ Keep the room cool, by opening a window or turning on a fan</li> <li>■ Decrease the amount of stimulation in the room by lowering the volume of music, radio or TV. Reduce the number of people in the room</li> <li>■ Provide reassurance through aromatherapy, soft relaxing music or by massaging hands or back</li> <li>■ Ask a family member or friend to sit with you or take over for a while</li> <li>■ Notify the nurse of the changes</li> </ul>

## WHAT TO EXPECT FROM THE FINAL DAYS AND LAST HOURS

SITUATION	HOW YOU CAN HELP
<p>No appetite</p> <p>Urine output decreases</p> <p>Extremities feel cold or appear pale or discolored</p> <p>Breathing may be noisy or rattling due to mucus collecting in throat</p> <p>Breathing may be unusually fast or slow</p> <p>Eyes and mouth may remain open</p>	<p>This is a time of transition. Your calm presence will support and honor your loved one during this process.</p> <ul style="list-style-type: none"> <li>■ Call Hudson Valley Hospice to inform the nurse</li> <li>■ Call family and friends to join you at your loved one's bedside</li> <li>■ Speak reassuringly to your loved one while holding their hand. Let them know it is okay</li> <li>■ Continue to speak as if he or she can understand you, even if they cannot respond</li> </ul>

**FOR IMMEDIATE PATIENT CARE HELP,  
CALL HUDSON VALLEY HOSPICE AT 845-240-7510**

*Our mission is to enhance the  
quality of living for those at the  
end of life.*



Hudson Valley  
Hospice

DUTCHESS

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[hvospice.org](http://hvospice.org)