

Family's Guide to Hospice Services

Your Hospice Team

The hospice staff assigned to your family member's care include a nurse, social worker and physician. Other services, including pastoral care, volunteer companionship, music therapy, and hospice aide care, may be added to your family member's care. The hospice team will develop a plan of care with your family that is tailored to your family member's specific needs. The team members will always keep you informed about when they will be visiting and will be providing care for your family member.

After-Hours Expert Hospice Support: Evenings, Weekends and Holidays

Help from our expert hospice nurses in consultation with our physicians is always available by phone. A nursing visit will be provided when necessary. If a nurse is dispatched to your family member at night or on a weekend, our triage nursing staff will guide you in the care of your family member via phone and will address any discomfort until a nurse arrives. We urge you to call us when you have a concern, at any hour. Our triage nursing staff is available at all hours. Our 24-hour number is: 718-472-1999.

Our commitments to you:

- Responsiveness
- Clear Communication
- Keeping You Informed
- Dignity and Respect
- Caring
- Listening to Your Concerns

Responsiveness

We are committed to getting you the help that your family member needs as soon as you let us know that you need it. We ask that you let us know about your concerns. Part of your family member's disease process will be changes in appearance, condition and behavior. Please let us know when you notice these changes. A change in condition can be addressed best when it is first noticed. Your regular nurse will answer your call during normal business hours, and a triage nurse will respond to your call after hours.

Clear Communication

The hospice team assigned to your family member has received special training in explaining things in a way that is easy to understand. It is our responsibility to always explain things clearly so that you have the understanding you need to be a strong and prepared caregiver. Your hospice nurse will always end any explanation with time for your questions and concerns. It is our goal to make sure that you never feel confused by what we say. If something explained is not perfectly clear, we ask that you please let us know. We will find another way to explain it and will take the time to help you to understand all that you need to know to care for your family member.

Keeping You Informed

It is crucial that you have the information you need to support your family member through this stage of illness. It is our responsibility to always keep you informed about your family member's condition. If you are not present at the time of a visit from the nurse, social worker, or physician, that team member will call you with an update.

Dignity and Respect

The hospice team is committed to always treating your family member with dignity and respect. Illnesses often affect the body in ways that challenge a person's dignity. We want the care we provide to support your family member's sense of dignity, especially when the body is experiencing the challenges of illness.

Caring

You care deeply for your family member. You want the best of medical care for them. It is important to our hospice team that you know that we do this work because it is the work that we want to do. Each of us feels a strong commitment to caring for your family member. We strive to show you a side of healthcare where you feel that the hospice team consistently really cares about your family member. It is what your family member deserves, and we will strive to deliver healthcare with true caring.

Listening to Your Concerns

The hospice team is committed always listening carefully to you. Sometimes you may have a concern about the care your family member is receiving. Successful end-of-life care requires that the hospice team members coordinate their efforts and that deliveries of medications and supplies go smoothly. On a rare occasion, you may have a concern with one of these many services and supplies. Should this occur, it is essential that the hospice team members always listen carefully to you when you talk with them about any concerns you have with your family member's hospice care.

Supporting You

In doing the hard work of caring for your family member, you deserve the support of our hospice team. Our social workers are expert in providing you and your loved one with emotional support at this difficult time. In addition, all hospice team members are specially trained to provide expert care that supports your family member emotionally, as well as physically. It is crucial that our hospice team provide you with the right amount of emotional support. Please let us know if you would like more support from our team. We want to be present with you during this difficult time.

Our hospice team is also committed to supporting your religious and spiritual beliefs. The entire hospice team is aware of the importance of spirituality and belief in facing serious illness, and any team member would be honored to talk with you about your beliefs or concerns. Our hospice pastoral care coordinators are available to support you, either by joining you in prayer or by reaching out to a religious leader from your religious community to provide spiritual support in accordance with your beliefs. Please allow us to support your beliefs. We strive to provide the right amount of spiritual support to you and your family member.

Very importantly, we wish to support you by providing you with the information that you need as your family member's illness continues. We want to help you to understand the changes in the body, including changes in behavior and function, that occur as the body becomes weaker. We will share information with you about what to expect in your family member's disease process. Your hospice nurse will communicate with you about the signs of decline, so that you can understand the changes that you see in your family member as the body becomes weaker.

Physical Care of Your Family Member

Serious illness causes changes in a person's ability to move and function. One of the most challenging parts of caring for a person with a serious illness can be providing the physical care that is needed as the body needs more and more help. At Hospice of New York, we want to help you always: when our staff are in your home visiting and during those times when our staff are not physically in your home. We will give you the training to care for your family member's physical needs. Your hospice nurse will work with you so that you can learn how to do things like safely move your family member, whether this means helping him or her turn over in bed, or safely getting him or her in and out of a bed or chair. It is important you feel confident that you can provide this help to your family member, and we will work with you so that you can be confident in the physical care you provide.

Help with pain and discomfort

Pain

It is crucial that a person facing a serious illness get quick and thorough attention to any kind of discomfort. We will respond to any report of pain quickly and with a plan to relieve it. Your family member will get the help that he or she needs with pain. Even before pain is reported, we will have a plan ready to manage pain with medications on hand for the quickest possible responsiveness.

You may be concerned giving strong pain medicine because of its possible side effects. The most common of these side effects are sleepiness and constipation. Your hospice nurse will help you to be ready for the possible side effects, by teaching you what to watch for and by responding with any needed intervention.

Another concern that people have about pain medicine is knowing when to give it. We recommend giving the scheduled pain medications on a regular basis in accordance with the plan that your hospice nurse and physician craft for your family member. In addition to any scheduled pain medications, you will also have pain medication ready to be given "as needed" to respond to any increases in pain. The hospice nurse will provide you with training in recognizing the signs of pain so that you can give the medication when it is first needed and most effective.

Trouble Breathing

If ever your family member should have trouble breathing, we will be ready to give them the help he or she needs to alleviate that discomfort. Even before any trouble breathing is reported, we will have medications on hand, ready to alleviate this discomfort in the quickest way possible. Your hospice nurse will give you training in recognizing the early signs of trouble breathing so that you can give the medication when it is first needed and most effective.

Constipation

Constipation is a source of discomfort that may result from decreased activity, changes in diet and use of pain medications. Your hospice nurse and physician will craft a plan specific to your loved one's needs to prevent constipation before it occurs. Often, stool softeners and/or laxatives will be ordered by the physician to prevent and manage constipation. If your family member goes more than two days without a bowel movement, please contact your nurse immediately, so that we can provide your family member with relief before the discomfort develops any further. We are committed to promoting the utmost comfort to your family member.

Anxiety and Sadness

Feelings of anxiety or sadness can accompany serious illness. Our hospice team will respond quickly to any feelings of anxiety or sadness that your family experiences. Please contact us as soon as you notice any hint of these feelings. We will work together as a team to help your family member with the physical, emotional and spiritual challenges that may be contributing to these feelings. In addition, our hospice staff will be checking to see if we can see any signs of these feelings so that we can help without delay. Our help is ready for you and on its way as soon as we hear from you.

Restlessness and Agitation

Behavior changes, including restlessness and agitation, can appear in the late stages of serious illness. It is often very difficult to care for someone who is restless and agitated. Please know that we will work with you to care for your family member should changes in behavior occur. We ask that you keep us up to date on any changes that you notice so that we can act quickly to provide the help that is needed. In advance of any such changes, your hospice nurse will make sure you are prepared, by giving you training in what to watch for, and by arranging for delivery of medication that can alleviate the agitation. This way you will know what to do should a change in behavior occur.

Common Hospice Medications

Morphine Sulfate (Roxanol, Liquid Morphine, Morphine)

- Morphine sulfate is used to reduce pain and can also be used to minimize shortness of breath.
- It is most effective when taken before pain or shortness of breath become severe.
- Morphine is generally started at the lowest dose and increased if needed to treat symptoms.
- The most common side effects are sedation, mild nausea and constipation. Oftentimes sedation and nausea will resolve after a few days of use as the body becomes accustomed to the medication.
- Because morphine slows the bowel, constipation can be an ongoing problem. Stool softeners are recommended when taking morphine to prevent constipation.
- Liquid morphine and immediate release morphine tablets can be administered under the tongue or in the cheek if a person cannot swallow (excludes long-acting formulations: MS Contin or Morphine ER).

Lorazepam (Ativan)

- Lorazepam is used to reduce anxiety and/or restlessness. It may also be used for shortness of breath and insomnia.
- It is most effective when taken before symptoms become severe.
- Lorazepam is generally started at the lowest dose and increased if needed to treat symptoms.
- The most common side effect of Lorazepam is sedation.
- Lorazepam tablets can be placed under the tongue or in the cheek if a person cannot swallow. The tablets can also be dissolved in a small amount of warm water and placed under the tongue or in the cheek.
- It is acceptable to give both Lorazepam and Morphine at the same time if needed for comfort.

Haloperidol (Haldol)

- Haloperidol is used to relieve agitation and restlessness.
- Haloperidol can be taken as a tablet by mouth or can be administered under the tongue.
- Haloperidol may also be used to manage nausea and vomiting.
- The most common side effect of Haloperidol is sedation.

Prochlorperazine (Compazine)

- Prochlorperazine is used to reduce nausea/vomiting
- Prochlorperazine can be taken as a tablet by mouth or can be administered under the tongue if a person is too nauseated to swallow.
- Prochlorperazine is most effective when taken before nausea/vomiting becomes severe.
- The most common side effect of Prochlorperazine is mild sedation.

Hyoscyamine (Levsin)

- Hyoscyamine is used to reduce oral secretions and relieve wet breathing.
- It may be administered in the mouth or under the tongue.
- The most common side effect of Hyoscyamine is dry mouth.
- Providing sips of water or swabbing your loved one's mouth can reduce mouth dryness caused by Hyoscyamine.

Acetaminophen (Tylenol)

- Acetaminophen is used to reduce discomfort and treat fevers.
- Acetaminophen can be administered in a tablet by mouth or by a suppository rectally.
- Fevers can be uncomfortable, and Acetaminophen can be very helpful.
- The maximum daily dose of Acetaminophen is 4,000mg.

Nursing home

For nursing home residents who choose hospice care, nursing home staff and the hospice team work together to provide care. If your family member lives in a nursing home, it is important to understand that the nursing home is considered the patient's residence and the nursing home staff continues to provide daily care. Hospice provides additional supportive services, just as would be provided in a private house or apartment. Hospice nurses offer their expertise in pain and symptom management. Home health aides supplement the personal care already offered by the nursing home. Counselors and volunteers provide additional support to families, residents, and nursing home staff.

We work on coordinating as seamlessly as possible with the nursing home. The information that our hospice team provides to you about your family member should match the information provided by the nursing home staff. If you ever feel that you are receiving different information from different providers, please contact us immediately so that we can help you to understand the information with clarity. We are committed to providing you with the information that you need to support your family member. It is our job to make sure that this important information is communicated in a way that makes sense.

Our goal is to provide your family member with the best care possible. Please let us know if there is anything we can do to help you and your family through this difficult time. We are available to you any time, day or night. During normal business hours, your hospice nurse is the person that will be best able to help answer your questions or concerns. Please do not hesitate to call us (718) 472-1999.