

Questions for your Social Worker

Your hospice social worker is a great resource to help you and your loved ones negotiate your way through this difficult time. Many of your common questions and concerns are addressed here. Use them as a springboard for conversations with your hospice social worker.

How are we going to manage?

While every patient and their support system is unique, there are a number of patterns that we see when hospice care is elected and the end of life is anticipated. In spite of the shock and sadness at the thought of losing life or the life of a loved one, family and caregivers might also feel relief—relief that the suffering is winding down, relief that the burdens of care-giving are time-limited and relief that there will be far fewer medical appointments and treatments. Responses like these are perfectly normal. Your hospice social worker and the entire hospice team is available to support everyone affected by this experience.

Keep in mind that just as you may be short on sleep, not have time to yourself or are dealing with untold stress and grief, those closest to you are struggling as well. Everyone needs a little “extra”—extra compassion, extra TLC, extra freedom to process grief and loss, and the space to bear it all with extra grace. Quirks become annoyances and what was in the past “just Sally” becomes a source of consternation. Just when everyone needs a little more, there is simply no one with anything extra to give. Your social worker will help you work out the adjustment issues you are facing as an individual and as a group of family and friends. It is important to be honest about what is happening so that we can work with you and help to bring some stability back into your situation. A calmer support system allows each family member and friend to focus on being their best for the patient and

for each other, which in turn opens space to create special memories and momentary blessings during a very difficult time.

Are there benefits for which I am eligible?

Your hospice social worker is a good go-to person for some very practical questions that often come up when a person elects to live the last season of their lives in the care of a hospice program.

Every state and local community has a myriad of resources that might be helpful during this time. Libraries have home delivery and pick-up services for books, music and movies. Grocery stores, Meals on Wheels and other social service agencies can help a patient get the nutrition they need. There are handicapped parking placards available for those still able to leave their home. There are airlines that collect mileage rewards for donation to terminally ill patients, special discounts on Lifeline systems and ramps to make living at home safer. Whatever your unique circumstance, your hospice social worker will do everything possible to make this season in your life comfortable and to help meet not only your medical needs but your very real psychosocial needs.

How will I sort out financial resource information?

While your social worker is not a financial expert, there are many documents that they will be willing to sort through with you. Long-term care insurance policies, public aid applications and human resource documents are among the items that a social worker might help you navigate. There are also certain state and local entitlement programs for which some low-income patients might qualify.

What discomfort does a social worker monitor?

Your NorthShore Hospice social worker is specifically trained and certified in hospice and palliative care work. While our expertise should in no way be considered a substitute for your nurse's care, your social worker will be monitoring aspects of your medical condition at every visit. Your potential pain, shortness of breath and anxiety levels will be discussed and noted. Any changes in your sleeping, eating, memory or troubling sensation will be of interest to the social worker who may determine that your nurse be notified of new, worsening or otherwise troubling symptoms. Of course, it is hoped that if a patient, family member or caregiver notices anything unusual, NorthShore will be called regardless of the time of day at (847) 475-3002 so that your needs are addressed as quickly as possible.

Do I need short-term therapy?

You don't need anyone to tell you that this experience is extraordinarily stressful. You may feel flooded with new and unwelcomed realities. Your hospice social worker is available to stand in the chaos and help you sort through it. Your Hospice social worker will listen, answer your questions and help you find ways to cope.

On the really bad days, your hospice social worker will be available to help steady and reassure you by normalizing your experience and providing a much needed perspective. You will not be alone. If your struggles are more complicated issues, your social worker can teach you and your loved ones various coping strategies. These include, but are not limited to, deep breathing, meditation and new self care strategies. Your social worker can also serve as referral source to counselors in your area. Both your social worker and the Hospice grief counselor are available to support you through this time of transition. If you find yourself stuck, just call us and we

will make sure you get the support that you need.

What if I just want someone to talk with?

Some days when your social worker visits, you will be doing well and enjoying your day. Knowing that life is limited makes many patients and their families eager to retell old stories. Life review is a very important part of the hospice experience. For all the things that are difficult and not what you would have chosen in this experience, this time also provides everyone with an opportunity to remember, share and to record your personal history. Talk to your social worker about our *Life Stories and Lessons* program if you are interested in leaving a recorded message for future generations. Social workers, as well as chaplains, volunteers and your nurse, love hearing about how you met your spouse, what you did for a living and what you enjoy doing in your free time.

What if my living arrangements don't work out?

Especially if you have been living independently before your admission to Hospice or if you live with someone with their own health issues and physical limitations, changes in your condition may require some additional support. This does not mean that Hospice requires a particular household arrangement or that one will be dictated to you. Your Hospice social worker, in conversation with your nurse, will assist you in transitioning to and from various care settings. If you have been living independently there may come a time when you will need to hire a caregiver for some portion of the day or full time, 24/7. These services are usually paid privately by the patient and family, but there are some options for low income households. Your social worker has a list of agencies with which we have worked in the past and whose caregivers are bonded and insured.

If your pain and other symptoms cannot be managed at home, your Hospice team, in consultation with your physicians, may recommend that you be admitted temporarily to the *NorthShore Palliative Care Unit* located at Evanston Hospital to stabilize your condition. Although the Palliative Care Unit is typically not designed for long-term hospitalization, each case is assessed individually. A *five-day respite stay* in a skilled nursing facility may be another option. Respite care allows you to be professionally cared for while your regular caregiver(s) attend to their own needs. Caregivers may need to attending an out of town wedding or simply feel overwhelmed by the responsibility of keeping you comfortable. Placement in a long-term skilled nursing facility may be necessary if a home environment becomes unsafe. Situations like these are determined in consultation with your Hospice team and are executed by your Hospice social worker. The costs are paid by patients or their families. The only exception is that public aid does cover the costs in a few designated skilled nursing facilities for those who qualify for that benefit and the five day respite stay is covered fully by the hospice benefit.

How will I get to medical appointments or get errands run?

For many hospice patients and their families, a network of friends, co-workers, neighbors, faith community members or the extended family rallies to help with whatever needs arise. When such a network is not available, NorthShore has a cadre of volunteers who provide companionship by watching TV with people, playing cards or simply being present and sitting vigil. Some patients have volunteers drive them or their loved ones to necessary appointments or even for a treat like a lunch out. Volunteers also do light household tasks like meal preparation and laundry. If you have a unique need, let us know and we will attempt to match you with a hospice trained volunteer in our program.

What if things get out of control?

Self care is an important part of maintaining the role of a caregiver. **If you are not getting enough sleep or are eating poorly and denying yourself little pleasures like an occasional lunch with a friend, you will compromise the care we are able to provide.** Because your Hospice team will be with you so routinely, it is unusual for tensions and anxieties to spin totally out of control. But if that does happen, your team will come around you and make whatever adjustments in the treatment plan are appropriate.

Thankfully, it is very rare, but there are times when either hired caregivers or family do not follow the Hospice team's plan of care, neglect the personal care and needs of a patient, and/or leave the patient unattended for inappropriately long periods of time. Cases of abuse and neglect will be reported to the appropriate authorities.

What about Advanced Directives and making a will?

As the term suggests, Advanced Directives are documents prepared in advance of their need to be used. They include the group of documents needed in order for you to be assured that your desires for end of life decisions around both your health care and your property be carried out by those who are charged with that responsibility. In many cases family and friends do indeed "know what you want" but it is important to reinforce these wishes in a legal document. Here are two main documents that you should prepare with or without the help of your hospice social worker:

- 1. Healthcare Power of Attorney**
- 2. Legal Will for Property**

1. The healthcare power of attorney (HCPOA) is a person you designate to make medical decisions for you in the event

that you are not able to make these decisions for yourself. The person you choose should not only be informed of your medical care preferences but also be capable of making these hard decisions on your behalf, especially when confronted by other family members with conflicting points of view. For example, if your first-born child would want “everything” done to keep you alive and you prefer only comfort care, another person might be better able to act in your stead. Of more pragmatic help is the general decision to have “everything” done to prolong life, comfort measures only, or “everything” done under certain circumstances like no more than two weeks or if recovery is expected by two physicians familiar with the case.

Along with choosing the healthcare power of attorney, some people like to get very specific about other important preferences, like what sort of music they would like played at their bedside or how caregivers are to attend to hair and makeup. These are obviously intensely personal and virtually limitless in their options.

Your hospice medical team will also ask you about your willingness to sign a Do Not Resuscitate (DNR) form. This is an election not to have CPR or intubation or other invasive attempts to revive you should your heart or lungs stop functioning. Technically, this is a medical order since it must be signed not only by the patient or their selected surrogate decision-maker but also by a physician to be valid. It is included here simply because most hospice patients are ready to forgo aggressive curative treatments in favor of palliative or comfort care and want a DNR on file to make this clear.

2. Your Hospice social worker is not directly involved in the preparation of a legal will for property since this is outside their scope of practice. You will generally need to consult with an attorney to accomplish this task. Wills vary in complexity. Forms are

available on line to help in the preparation of simple wills. At the very least, you should consider naming an executor for your estate to handle the paperwork after your death. There should also be a plan in place for the custodial care of any minor children. Currently, NorthShore Hospice has social workers who are *notary publics* and can authenticate and verify signatures of legal documents that are prepared during your illness.

When is it appropriate to start planning a funeral or memorial service?

Timing regarding planning a funeral or memorial service is sometimes dictated by culture or religion but is basically a matter of personal preference. You should not be surprised if some family members may not agree on this matter or have varying abilities to tolerate discussions around end-of-life issues. Minimally, within the first week of admission to hospice you will want to select a funeral home or cremation service. This allows everyone involved to feel a sense of direction when death occurs. It also gives your Hospice team the information they need to assist you at this most stressful time. Your Hospice social worker and chaplain maintain a full listing of area funeral homes and cremation services. They are also experienced at helping you tailor planning to reflect the family budget. Today, the cost of services ranges from \$1,000 for direct cremation to tens of thousands of dollars for more elaborate services.

What can social workers do if family and close friends are far away?

If you or someone close to you needs to make or change travel plans because of a terminal illness, the Hospice social worker can usually secure either reduced fares or have change fees waived by writing a letter on official letterhead. These identify those who are traveling and verify the patient to be in the NorthShore Hospice program.

These letters are addressed to the relevant airline or other transportation office.

In the event of an emergency and you need to contact someone deployed in the U.S. military service, the Red Cross is the agency to contact. Military case workers are available 24/7 and can be reached for reporting and communication services at (214) 678-4800. Your social worker will be happy to help out with this after you provide as much information as you have available about the military personnel.

In the event that family and/or friends are in foreign countries or if a hospice patient is to be buried abroad, you will likely benefit from help working through some potentially complicated systems.

If you would like relatives who live outside of the country to be able to gather in the U.S., they will need passports and/or visas. Details of what this entails varies from country to country, so details and potential expediting processes will need to be

ascertained through the appropriate consulate or embassy. If your loved ones will be traveling abroad for burial, funeral homes know the procedures and requirements and can give you price ranges. Please note that this can be very expensive unless the body is cremated and it is only the cremains that are taken for burial. Also, note that everyone traveling will need a passport. These may take weeks to procure, so be proactive.

While the aforementioned questions are common, you will possibly have many more. In addition to your social worker, the entire NorthShore Hospice interdisciplinary team remains attentive to support you and your loved ones through this difficult time. In many ways your social worker acts as a vital bridge to connect you to other support services. Take advantage of this resource. As questions arise, please feel free to contact your social worker for direction and support.