Tip Sheet #35

End of Life

There may be a time when your loved one's health is declining. He or she may be nearing end of life. Since no one can ever know for sure when end of life will come, it is often better to begin talking about it early.

End of life is a difficult time for the stroke survivor, as well as for family and friends. Should you continue to pursue all available treatments? Should you shift to focus on comfort? How does a caregiver or survivor deal with making such difficult decisions? What about the survivor's spiritual needs? What about their cultural preferences? What resources are available? What is hospice and when is it appropriate? This tip sheet will help to explore what can be done during this difficult time.

What are things to consider during this difficult time?

There are many emotions that both the survivor and family caregiver may have when the survivor's health is declining. Emotions may be different for each person. Some of these emotions may include:

- **Fear** – It is helpful to figure out what the fear is about. Is the fear about suffering or pain? Is the fear about the possibility the survivor will die? Is the fear about what will happen after death? Is the fear about how the death will affect others? Is there fear of the unknown? Talking about fear is important to correct any wrong ideas, and to gain support from others.

- **Anger** – It is normal to be angry, and it is natural to express anger. Ignoring anger or keeping it inside does not work. Try to direct the anger at the disease and not to loved ones. Try to direct the anger toward solving problems or toward meaningful, positive things.

- **Guilt and regret** – Stroke survivors may feel guilty for being a burden on others, or may feel regret for things they were not able to do. Caregivers may feel guilty about not being able to make things better, or they may have unrealistic expectations. Sometimes it is better to get these feelings out in the open, forgive yourself and others, fix what you can, and let go of what you can't change.

- **Grief –** Survivors, caregivers, and others are likely to feel intense loss or grief when the survivor's health is declining. There are both physical and emotional losses, lost dreams for the future, and also the loss of life itself. Talking with someone about these feelings can help you process them so you can move beyond them. This process is not easy and may take several attempts. Coming to terms with losses is one of the most painful parts of end of life. Share your feelings with someone you trust so that you are not trying to work through these feelings alone.

- **Anxiety and depression** – These emotions are very common, and there may be a time when it is important to seek treatment. Anti-anxiety and anti-depressant medications can help. Counseling can also help. Seeking treatment for these emotions can make a big difference in how you or the survivor feels during this difficult time.

- **Finding meaning –** There can also be positive emotions during end of life. Helping the survivor to find meaning in their life can lead to a sense of joy and accomplishment. It is helpful to review and remember positive events and experiences. Write down funny events, meaningful experiences, and positive things that have happened. Sharing these things is a gift that family and friends can cherish for many years to come.

There are many questions that stroke survivors and their caregivers may have when they realize that the survivor may be nearing end of life.

___Will the survivor's wishes about their care be followed?
___How much pain and suffering will there be?
___What happens when the survivor dies?
___How will this affect the family?
___Other? (Please specify) _____
___Other? (Please specify) _____

Advance directives – It is important to let the health care team know about the survivor's treatment wishes. You as a caregiver may have to act on the survivor's behalf. Advance directives are legal documents that put all of this in writing. **See Tip Sheet #24 Legal Health Care Issues and Social Security** for more information about living wills. There is also information there about Durable Power of Attorney, Guardianship, Conservatorship, as well as how to seek legal counsel if you or the survivor feel you need it.

Hospice - Many stroke survivors and their family caregivers consider "hospice" care when the survivor's health is declining. Hospice care focuses on reducing symptoms, relieving suffering, and on improving quality of life.

The main focus of hospice care is comfort, rather than providing a cure for an illness. Hospice does not shorten life, nor does it include treatments designed specifically to prolong life. Hospice care helps the survivor live out the rest of their life, while also providing support for the family.

Hospice care includes experts (e.g., doctors, nurses, social workers, counselors, clergy, therapists, volunteers) that can help you and the survivor. Below are some examples of hospice services:

- Team of professionals to help plan care and support for the survivor

- Home care and inpatient care – Hospice care is usually provided in the home, in a familiar environment. Family members work with the hospice team to care for the survivor. If this is not possible, inpatient care can be provided in a nursing home or inpatient hospice.

- Coverage includes such things as medication, physical care, counseling, equipment, and supplies for the terminal illness and related conditions.

- Pain and symptom control, including dealing with side effects of treatment, and additional therapy to make the survivor comfortable.

- Emotional care for the survivor and their family (e.g., managing fear, anger, guilt or regret, grief, anxiety, depression, or finding meaning).

- Spiritual care for the survivor and their family, including what death means to you, helping to say goodbye, and helping with a certain religious ceremony or ritual if desired.

- Respite care for family caregivers to have some time away if needed

- Family conferences

How are costs for Hospice covered? Hospice care is covered by private pay, private insurance, Medicaid (in most states), and Medicare. In order for Medicare to pay for hospice care, the following conditions must be met:

- The survivor must be eligible for Medicare Part A

- The doctor and hospice medical director must certify that the survivor is terminally ill with less than 6 months to live if the illness runs its normal course.

- The survivor (or designee) must sign a statement choosing hospice care rather than other care for the terminal illness (Medicare will still cover other illnesses that are not related to the terminal illness).

- The survivor must receive care from a Medicare-approved hospice program.

If the survivor's condition improves and they no longer need hospice care, it can be stopped, and they will receive the same treatments they had before beginning hospice. If eligible, the survivor can go back on hospice care again at any time.

How do I find Hospice care?

- Ask the survivor's physician or the hospital where the survivor was treated. Ask to speak with a social worker.

- Ask trusted family members or friends. Clergy may also be able to suggest quality programs.

- Ask state hospice organizations.
    - LeadingAge Ohio, (614-444-2882 or http://www.leadingageohio.org/aws/LAO/pt/sp/home_page)
    - Indiana Association for Home and Hospice Care, Inc. (317-775-6675 or www.iahhc.org)
    - Indiana Hospice and Palliative Care Organization, Inc. (317-464-5145, or Toll free 866-254-1910 or www.ihpco.org)
    - Kentucky Association of Hospice and Palliative Care (888) 322-7317, or http://www.kahpc.org/

See **Tip Sheet #8 Where to Find Resources** for a variety of resources, such as aging and disability resource centers in your area:

- Eldercare Locator (800) 677-1116 or https://eldercare.acl.gov)
- United Way 211 (dial 211 or https://www.211.org/about-us/your-local-211).

- Keep in mind… The hospice program you choose must be "Medicare-approved" if you want Medicare to cover it.

What can I do as a caregiver to help with end of life for my loved one?

- Help the survivor with their emotions that they are experiencing as his or her health declines. Listen to their feelings. Help them find meaning from their life. Explore some of the tip sheets in this notebook for ideas on how to help the survivor with their emotions.
    - See **Tip Sheets #9 through #16** for ideas on how to manage the stroke survivor's emotions and behaviors.
    - See **Skill-Building Tip Sheet #SB6. Stress management workbook for caregivers and survivors.**

- Seek help for your own emotions. You should not go through this experience alone. Check out some of these tip sheets to help with your own emotions.

    - See **Tip Sheet #27 Dealing with my own emotions while providing care.**

    - See **Skill-Building Tip Sheet #SB6. Stress management workbook for caregivers and survivors.**

    - See **Tip Sheets #28 through #33** for other ideas about how to take care of yourself during this difficult time.

- Consider advance directives for the survivor. **See Tip Sheet #24 Legal Health Care Issues and Social Security** for more information about advance directives.

- **Consider hospice care** if you think that the survivor is nearing end of life. Talk with a trusted family member or friend. Ask the survivor's health care providers.

When do I need to call a health care professional?

- Any time you feel the need to discuss the survivor's declining health or the need to change treatment goals. Most people wait too long to begin hospice care. It is never too early to consider hospice care if you think the survivor may be better off with a focus on comfort, rather than cure.

Where do I find more information?

Contact organizations that deal with hospice. For example,

- **National Hospice & Palliative Care Organization (NHPCO)** 1700 Diagonal Road, Suite 625 Alexandria, VA 22314 1-703-837-1500 www.nhpco.org

- **Hospice Association of America** 228 7th Street, SEWashington, DC 200031- 202-547-7424 www.nahc.org

Contact Medicare for a booklet on hospice services.

- Centers for Medicare & Medicaid Services (2010): Medicare Hospice Benefits. Official government booklet, Department of Health and Human Services. To get a free copy, call 1-800-MEDICARE (1-800-633-4227). TTY users should call 1-877-486-2048 or visit www.medicare.gov.

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