

A VISION FOR *Better Care at the End of Life*

Death and dying are not easy to deal with. Perhaps you or someone you love is facing an illness that cannot be cured. Few of us are really ready for the hard choices that may have to be made at the end of life. It can be hard for everyone involved — the dying person, their family and loved ones, and health care providers, too.

*But there are ways to ease pain and make life better for people who are dying and for their loved ones. It is called **palliative care**.*

Palliative care means taking care of the whole person — body, mind, spirit — heart and soul. It looks at dying as something natural and personal. The goal of palliative care is that you have the best quality of life you can have during this time.

Some health care providers — doctors, nurses, social workers, pharmacists, clergy, and others — have learned how to give this special kind of care. But all health care providers should know how to give good palliative care or to help you find someone who can.

Five Principles of Palliative Care

The following Five Principles of Palliative Care describe what care can and should be like for everyone facing the end of life. Some of

these ideas may seem simple or just common sense. But all together they give a new and more complete way to look at end-of-life care.

1 Palliative care respects the goals, likes, and choices of the dying person. It...

- Respects your needs and wants as well as those of your family and other loved ones.
- Finds out from you who you want to help plan and give you care.
- Helps you understand your illness and what you can expect in the future.
- Helps you figure out what is important.
- Tries to meet your likes and dislikes: where you get health care, where you want to live, and the kinds of services you want.
- Helps you work together with your health care provider and health plan to solve problems.

2 Palliative care looks after the medical, emotional, social, and spiritual needs of the dying person. It...

- Knows that dying is an important time for you and your family.
- Offers ways for you to be comfortable and ease pain and other physical discomfort.
- Helps you and your family make needed changes if the illness gets worse.
- Makes sure you are not alone.
- Understands there may be difficulties, fears and painful feelings.
- Gives you the chance to say and do what matters most to you.
- Helps you look back on your life and make peace, even giving you a chance to grow.

3 Palliative care supports the needs of the family members. It...

- Understands that families and loved ones need help, too.
- Offers support services to family caregivers, such as time off for rest, and advice and support by telephone.
- Knows that caregiving may put some family members at risk of getting sick themselves. It plans for their special needs.
- Finds ways for family members to cope with the costs of caregiving, like loss of income, and other expenses.
- Helps family and loved ones as they grieve.

4 Palliative care helps gain access to needed health care providers and appropriate care settings. It...

- Uses many kinds of trained care providers—doctors, nurses, pharmacists, clergy, social workers, and personal care givers.
- Makes sure, if necessary, someone is in charge of seeing that your needs are met.
- Helps you use hospitals, home care, hospice, and other services, if needed.
- Tailors options to the needs of you and your family.

5 Palliative care builds ways to provide excellent care at the end of life. It...

- Helps care providers learn about the best ways to care for dying people. It gives them the education and support they need.
- Works to make sure there are good policies and laws in place.
- Seeks funding by private health insurers, health plans and government agencies.

The Five Principles are

a vision for better care at the end of life. They were developed for people who are dying, their families, and their loved ones by the *Last Acts* Task Forces on Palliative Care and the Family. *Last Acts* is a coalition of more than 400 organizations representing health care providers and consumers nationwide.

The organizations involved in *Last Acts* believe that everyone can make a difference in the care given to dying people and their families. We need to work together toward a health care system that

offers all Americans, when they are dying:

- the services that meet their individual needs
- health plans that cover that care
- health care providers well trained in palliative care

That would make the Five Principles of Palliative Care a reality.

What you can do

You and your family should expect to get good care at the end of life. You can improve the likelihood that you and your family will get the care you want if you:

- Share this document. Discuss the care you want with your family, friends, physician and other health care professionals, and spiritual advisor. Don't wait until you are seriously ill!
- Learn about your options for care. Make a list of questions to ask your doctor, to find out whether s/he can provide the care you want at the end of life. Visit the Last Acts Web site, www.lastacts.org, for a list of sample questions.
- Check with your local hospitals, nursing homes, and home health agencies about the special services (palliative care) they offer for dying patients and their families. Examples: Are there physicians, nurses, social workers and spiritual counselors trained in end-of-life care who can talk to you and your family about your concerns? Do they have experts who can manage pain and other physical discomforts? Do they offer bereavement services?
- Find out about local hospice services.
- Think about important decisions now. Prepare a living will and appoint someone to make decisions for you if you are not able (health care proxy).
- Look into community support groups and educational programs for seriously ill patients and their families (often offered by church groups, community centers, libraries and others).



For more information about **Last Acts**, visit our Web site at www.lastacts.org.

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