

[TRACK 6: SURVIVOR STORIES: HOSPICE]

Arlene, in her 60s: Part I

[Arlene]

I know that my cancer is not curable and more treatment to try to control it is not very likely to do me any good. Still, as long as I take my pain medicine, I can stay pretty active. I enjoy being with my daughter and son, my grandchildren, and my dog. It has been getting harder to pay for the services I have been using... and for the medicines that keep my pain and other symptoms controlled. I heard about "hospice" but thought that is just where people go to die. I want to live for as long as I can, and I want what is left of my lifetime to be meaningful. I'd like to stay at home too. Still, I worry about being a burden to my family... about the costs of the care I need now, and the care I will need as time goes on. It is not easy for me to talk to anyone about this phase of my illness. My doctor seems to avoid the topic of my eventual death, too. I was afraid that stopping treatment would mean an end to seeing the doctors and nurses I've come to know and trust. But... finally, I mentioned my worries about costs to the nurse in the doctor's office, who suggested that we look into what is offered by Medicare's hospice program - called "The Medicare Hospice Benefit." I found out that admission criteria require that the doctor and the medical director of the hospice say, in writing, that I am "terminally ill" - meaning that if nature runs its course, I can expect to live for several months yet. I needed to give informed consent that simply says that it is my choice to receive the hospice benefit. My care has to be provided by a hospice that is certified by Medicare. The certified hospice uses a team approach, that lets me and my family be part of planning my care. The other team members are a registered nurse, a doctor, a social worker, and my pastor. I can have help from a dietician, a physical therapist, an occupational therapist, and even a speech therapist. There is 24-hour access to services, home care when and if I need it, home health aide assistance, medical equipment and supplies, prescription medicines for pain and other symptoms, and even bereavement care for my family members. Most care is provided in my own home, but I am also eligible for periodic respite care - short term care given by someone other than my daughter and son so that they can have a break - a respite - from care giving. Once I had all the information, and understood what hospice care really means, it was fairly easy to make the decision to use the hospice benefit. It was not a problem to find a hospice program in my town. Many of the services I now have with hospice were not open to me before, and my out-of-pocket expenses have dropped a lot. That's good for me, but it's also good for my family: I don't worry so much now about being a burden. My daughter and her husband, and my son and his wife, and I have worked out a plan that combines some of their time with the time of the home-health aide to help me at home. I know that I will go through the last stage of my life with dignity and in my own home. I definitely don't want to be subjected to all those fancy high-tech measures, surrounded by strangers, or cooped up in an impersonal hospital room. These things are very important to me.

[Narrator]

There are nearly 3,000 hospice programs - they exist in all 50 states, the District of Columbia, and Puerto Rico. Nearly ninety percent of these hospices are Medicare-certified. Many private insurance policies have copied the Medicare Hospice benefit, so hospice benefits are often available to people who do not have Medicare, but have private insurance. Arlene and her family, like the other cancer survivors you've heard already, used the basic skills covered in other programs of the Cancer Survival Toolbox to create a plan of care that would add to her quality of life. They found information about the options available, and talked with the doctor and other members of the health-care team about her wishes. They made decisions and solved problems linked to paying for care, and negotiated with family members and the health-care team about the plans for care. Arlene created her own plan of care that fit with her needs and her wishes.