



California Hospice Foundation



CHOICES

Empowering People

Spring 2013

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Caring for the Caregivers

The patient and their family have traditionally been at the center of the hospice philosophy of care. Under the Medicare Hospice Benefit, hospices must provide bereavement support for at least one year to families, partners and close friends of patients who have been in their care. However, caregiver support extends beyond the Medicare requirements and beyond the hospice walls.

“You are not alone, there is help.”

Social workers, chaplains and other hospice staff and volunteers have traditionally provided support and counseling to those caring for loved ones in hospice care, but hospices saw a greater need. “We recognized the increase in the number of people in our community providing daily support to aging parents and spouses,” said Christine Ramsey, Public Relations Manager at Community Hospice in Modesto.

“Many people look after parents while working full-time and taking care of their children. These overburdened caregivers didn’t know where to turn for resources,” she said. “We want them to know: you are not alone, there is help.” In response, the hospice launched Caregiver College where 100 people each month attend seminars on Alzheimer’s and dementia, advanced healthcare directives, estate planning and other topics.

Attendees also receive the Caregiver Toolkit, a resource guide that helps caregivers organize and manage financial, legal and insurance information, medications and more. A regular attendee said the seminars helped her successfully negotiate her father’s Veterans benefits, and better understand her mother’s Alzheimer’s symptoms.

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If you or anyone you know has a need for Hospice Information and Referral services please call the California Hospice Foundation’s toll free number: 888-252-1010

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Because of the toolkit, her brother could step in to relieve her and have all the information he needs in one place.

Hospices provide caregivers many types of support.

“As a non-profit community hospice, we see ourselves as providers of support to the community, whether that’s bereavement counseling or crisis intervention,” said Lauren Kenney, LCSW, Bereavement Services Manager at Hospice by the Bay in Larkspur. She said hospices feel a responsibility to educate their community about grief, loss and end-of-life issues. “Our society doesn’t feel comfortable talking about these issues, so we feel we have to lead the way. There’s so much need for education. Who better to do it than hospice?”

Grief is a normal and natural process. Many people think, “I can handle this on my own” and some can. However, Lauren said, most people will benefit from support. “We hear people say, ‘Is this normal? This is not how I usually am. I feel like I’m going crazy.’ There’s a wide range of normal. Counseling and education normalizes and validates the grieving process, provides answers to questions and helps to relieve stress.”

Lauren said, “Caregivers who have the opportunity to get hospice support for a longer period of time seem more prepared to deal with death, emotionally and practically. Early hospice referrals help prevent some of the complications of grief.” When loved ones are last-minute referrals and die shortly after entering hospice care, families don’t have time to prepare themselves and often experience more chaos and distress. Their grieving process is more complex.

Hospices offer a range of individual and group counseling for spouses and partners in early/mid-life or late life, children, young adults, and adults who lost siblings, parents or other loved ones. A unique program at Hospice by the Bay, Integrative Restoration (iRest), uses mindfulness and guided meditation to help people cope with emotions arising from grief and stress. Because it’s a meditation group rather than a traditional process-oriented group, both caregivers of ill loved ones and those mourning a death participate.

“Even after counseling, some people are stuck in their grief,” said Lauren. “iRest helps them get to a place of emotional balance.” Participants are taught to notice and accept what’s going on within them, gain validating and non-judgmental insight, and find the peace needed to simply relax and sleep. “People need support in all kinds of ways. Each time we offer iRest, we have full groups,” said Lauren.

Hospices help children who feel isolated in grief.

Hospice social workers and chaplains help family members of all ages deal with grief. Community Hospice provides booklets and support groups for children at different developmental stages. Christine said, “Our social workers help parents understand how their children’s feelings might be expressed and how to communicate with them about death in age-appropriate language.”

“Adults often don’t know how to talk to children about a parent or sibling dying,” said Lauren. “We educate them and facilitate those conversations, in addition to providing support to the parent so they’re able to help their children.”

This summer, Hospice by the Bay will host the sixth season of Camp Erin, a free bereavement camp for children and teens who have experienced the death of a loved one. The usual camp activities, like arts and crafts, hiking and swimming, are offered in addition to therapy groups and rituals honoring loved ones. “If you dropped in, you’d never know it was a bereavement camp,” said Lauren. “It’s a unique and healing experience to be around other kids who have also lost someone. So often these kids feel isolated in their grief because other kids can’t understand their pain.”

Hospices also reach out to grieving children in the community. Counselors from Hospice by the Bay and Community Hospice help relieve over-burdened public school counselors by facilitating support groups for students who have lost family members.

Whether someone wants to learn about caring for an aging parent or needs support to help cope with a loss, hospices are there to serve their communities.

Written by Deirdre Reid. Deirdre is a freelance writer in North Carolina.



How to Support Someone Caring for Another

Many of us know someone who is a caregiver. Do you know someone who spends time providing physical, emotional or practical support to a family member or friend? Many caregivers feel alone, helpless, confused, unprepared, tired and unable to provide for the needs of their family member or friend. Often, people caring for another need help and do not know how to ask for it.

There are many ways to help support a caregiver.

Ask the caregiver how they are doing:

Let them know you respect their privacy, but care about them and want to offer support and a listening ear.

Reach out to caregivers with a touch, a hug, or other physical expression of support:

Supportive human contact is important and can be very meaningful to someone who is caregiving and experiencing the many losses that accompany being a caregiver. However it is always important to check with the caregiver to make sure they are okay with being touched.

Spend time with the person who is sick or injured:

Family caregivers are often the only link the care receiver has with the outside world. Offering to spend time with the person can be a gift to both the care receiver and caregiver. Bring a book or newspaper to read aloud, a game to play, photos to share or just a friendly ear for a conversation.

Offer specific help:

Saying “call me if you need me” is vague and may not appear to be a sincere offer for help. Often caregivers do not want to be a bother or may not feel they have the time to make a call, as it is one more thing for them to do. Be specific, ask the caregiver if you can go shopping, make a phone call, cook a meal or sit with the person who is ill. By offering to do something specific, you are communicating that you are really willing to help the caregiver.

Tell the caregiver it is okay to take a break from their caregiving role:

You can let them know that it is okay to take time to renew themselves; they deserve it and need to care for themselves in order to continue providing care.

Acknowledging You Need Assistance

As caregivers, we sometimes become so involved in the day-to-day efforts to keep things going we may forget to let others know we need additional assistance with providing care, or just need a break from the work of caring for someone.

Some ways to make your needs known include:

- **Work Options.** If you are a working caregiver, it is important to discuss your needs with your employer. Telecommuting, flextime, job sharing or rearranging your schedule can help to minimize stress. Increasingly, companies are offering resource materials, counseling, and training programs to help caregivers.
- **Involve older children.** Older children living at home may be able to assist you and/or your loved one. Such responsibility can help young people become more empathic, responsible, and self-confident and give you needed support.
- **Ask others to help.** You can and should ask other family members to share in caregiving. A family conference can help sort out everyone’s tasks and schedules. Friends and neighbors also may be willing to provide transportation, respite care, and help with shopping, household chores or repairs.
- **Create a list of things that need to be done,** such as grocery shopping, laundry, errands, lawn care, housecleaning, or spending time with your loved one or friend, and put it on the refrigerator or near the front door. If someone says, “let me know if there is anything I can do to help” you can point to the list.
- **Take a break from caregiving.** Even if it is only 15 or 20 minutes a day, make sure you do something just for you.
- **Exercise.** Whether it is a 20 minute walk outside or taking a yoga class, exercising is a great way to take a break, decrease stress and enhance your energy.
- **Eat healthy.** Your health and nutrition is just as important as your loved one’s, so take the time to eat well. If you are having difficulty doing that, ask for help and get others to fix meals for you.
- **Subscribe to caregiving newsletters or list serves** for support.
- **Attend a support group for caregivers.** Check with your doctor, hospice or local Area Agency on Aging for groups that meet for this purpose.
- **Seek professional help.** Many caregivers have times when they feel lonely, anxious, guilty, angry, scared, frustrated, confused, lost and tired. If you feel like these feelings are overwhelming you, call your doctor, hospice or another community resource for help.

Information provided by Caring Connections, a program of the National Hospice and Palliative Care Organization. For more information about caregiving or caring for the caregiver, please call Caring Connections at 1-800-658-8898 or visit www.caringinfo.org.



Donate Your Vehicle



If you have a vehicle that you are thinking of trading in or selling, please consider donating it to the California Hospice Foundation's Donate a Car Program.

When your vehicle is sold, the proceeds will go to the California Hospice Foundation (CHF). You may also be able to deduct the fair market value of your vehicle as a charitable contribution for

income tax purposes.

We have partnered with Car Program, which accepts most vehicles, including cars, trucks, trailers, boats and RVs. The donation process is easy by fax or by phone.

If you have questions or would like to learn more, please visit our website at www.cahospicefoundation.com or call us at (888) 252-1010

Editor's Note

The California Hospice Foundation would like to hear from you. Are there subjects you want us to cover in future issues? Do you have questions you want answered? Please submit ideas and suggestions to Laura Fisher at lfisher@calhospice.org or call toll free 888-252-1010.