

Pastoral Care *Newsletter*

*For Overseers, Ministry and Counsel,
and others who provide pastoral care in
unprogrammed Friends meetings*

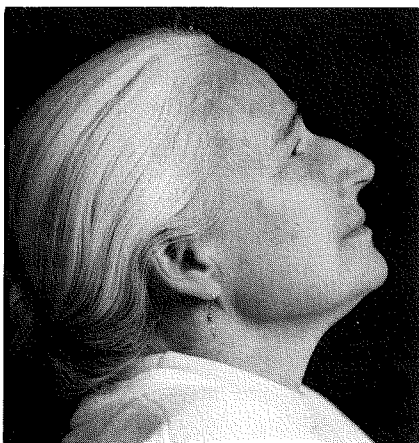
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Caring for the Terminally Ill and Their Caregivers

By Lucy McIver

Responding to the needs of someone who is dying can seem like an overwhelming task. Most of us are not experts, only human beings who carry our own fears about facing death. Mostly we learn how to do as we go along by listening to one another. But we need not face these times unprepared if we are aware and respect the gifts of those within our spiritual communities. Responding to the terminally ill and their caregivers can be an opportunity to grow together.

Like many meetings, my meeting in Eugene, Oregon, has many elders who are getting closer to their time of dying. And we knew that not only these cherished souls but any one of us could immanently face death. We recognized that many of our responses to the dying and bereaved were unorganized. Many felt a growing concern to respond in a more intentional way. What follows is a report on what we have learned along the way.



Lucy McIver

Eugene Meeting's Story

A concern for supporting one another came to the surface through our social concerns committee which requested that the meeting look into long-term care insurance. Several people came forward to consider how we might address this concern. Through several discussions and research into insurance availability, we came to feel that the insurance issue was more an individual one. But underlying was the larger concern of how we can respond and help one another in times of health crises, including death and dying.

This resulted in the formation of Friends' Care Co-op within Eugene Friends Meeting. The co-op, an outreach arm of the meeting's Oversight Committee, responds to the needs of those within the meeting facing end-of-life and health needs and makes a monthly report to Oversight. Our goal is to develop an organized way of responding to health crises.

A survey was developed to determine who within our meeting community could provide practical support. From the responses we created a skills bank of volunteers within the meeting who could be called upon to provide meals, transportation, personal care, companionship, house cleaning and lawn care, clearness committee and support committee involvement, and financial support.

The original committee members became the "care team." Their responsibility is to take the initial call for help and assess what needs are apparent. Two members of the care team visit with the individual and family to determine what support is needed, what the family can provide for themselves,

and how the meeting can best respond to their request. From here a plan of response is developed. The team then turns to the skills bank to organize volunteers.

We have recognized that not everyone who volunteers has the experience or skills to be with the terminally ill person. Some training is needed to help those "compassionate hearts" do their work with sensitivity. To meet this need we offer verbal suggestions in our initial contact with each volunteer as we organize the contact schedule. We stress becoming aware of our body language and to show that we are attentively listening by making eye contact. We remind each volunteer that our greatest gift is offering a time of silence or worship out of which often comes space for people to speak of their concerns. In other words, we stress compassionate listening skills.

Secondly, we initiated quarterly training sessions for volunteers. The first one was centered on the topic of the rights of the terminally ill. We identified

these rights as:

- The right to be in control
- The right to have a sense of purpose
- The right to be touched if they wanted
- The right for individuals to live their spiritual beliefs as they are dying
- The right to hear the truth
- The right to reminisce
- The right to laugh

We encouraged dialogue among our volunteers as we discussed these rights through sharing personal stories and experiences. Those who participated in this discussion found commonality in their fears, positive reinforcement for their gifts, and an eagerness to work together.

We rely on the professionals from within our group or invited from outside the meeting to educate us in matters of pain and symptom relief as we educate our volunteers. We support our families and caregivers through education about the final rights of

One Meeting's Experience: A Care Committee in Salem Quarter

Salem Monthly Meeting is a small meeting nestled in the farmlands and wetlands of rural southern New Jersey. It has held meetings for worship and business continuously since its beginnings in 1676. When Bill, one of its elderly members, was stricken with a massive, paralyzing stroke, his family knew the meeting would be there for them. His one request was that he be discharged from the hospital to his home rather than to a nursing home. Forming a care committee made this possible. Other members from the quarterly meeting eagerly joined in – he had been a quarterly meeting clerk for 25 years.

The circumstances of Bill's condition were such that although mentally alert, he could not speak or move, and swallowing was both difficult and dangerous. The committee had met and their tasks had been identified and assigned by the day of Bill's discharge. A telephone tree message was sent to meeting members stating he was home and that his care committee was ready to receive volunteers.

Since Bill's body had to be turned every two hours, four-hour shifts of two persons each were created. One committee member who works at home took phone calls, filled shifts, and coordinated visits. Another organized food donations. Another took responsibility for errands and chores. Yet another created a log book into which each shift worker recorded the time and position of body turnings, fluid intake and output, and

medications given. The log included a section for journaling observations, ideas, feelings, and thoughts.

A peace settled over Bill once he was home and surrounded by loved ones. It was then that he quietly refused all offers of food and water. He was lucid and receptive, clearly spiritually prepared for his transition, and his decision was honored. He lived another ten days without food or water. These final days were a series of centered, mindful interactions among a meeting community that tenderly upheld one another. Anyone who wished had private time at bedside, and this sharing was intimate and often profound. Bill's spirit transitioned effortlessly. Each gift along the way, offered so generously by so many, had been an act of love.

One year later Bill's widow Mabel was diagnosed with terminal cancer. The care committee claimed it had never officially laid itself down and so was in place for Mabel when she was discharged to her daughter's home for her final four months. Again, food and visits were coordinated, bedside meetings for worship were organized, respite for the family was provided. Bill's care had been intense whereas Mabel's was protracted, but the level of commitment was the same. To this day the care committee remains attentive to the family.

In Salem Meeting, and in Salem Quarter, if ye ask, ye shall receive.

Mary Waddington
Salem, NJ

the dying including information on advance directives, do-not-resuscitate directives, and practical matters. We do not make recommendations about medical care but attempt to strengthen communication between the family and the medical community. And we know that there is often a certain chaos for those facing death and those providing care. To address the needs that arise out of this time our goal is to develop open lines of communication, friendships, and a close ability to work together. From that foundation we offer our prayer that peace will enter and create the sacredness that we all seek.

Spiritual Aspects

We continually address the spiritual aspects of our work by deepening our own spiritual life. We encourage our volunteers to read Quaker literature available to them on the subject of death and dying. (See the reading list, page 6.) Included in those readings is my Pendle Hill Pamphlet on research into seventeenth-century Quaker attitudes towards death and dying. The stories of early Friends' deaths remind us that their attitude toward life and death did not so concretely separate living from dying as we do today. Seventeenth-century Friends shared the belief that they were to live every day as if it were their last. Living their faith daily was understood to strengthen their personal relationship with the Divine. Early Friends regarded death to be the climax of their spiritual journey, a final goal for which they needed to spiritually prepare.

In other words, life was not separate from death only a part of the greater journey. Because of this belief, when someone finally came to their time of dying, early Friends saw that person to possess a spiritual authority that no other person had. At death's door a person was seen to be firmly in God's Light but still among the living. One was expected to minister or witness from that liminal place. Often, the whole family along with visitors from the meeting, including children, would gather around the dying person who, in this time of close relationship to God, would preach to them.

Such an attitude toward death as a spiritual experience can create a sacred attitude towards life. Friends and family within the support circle thus can witness and affirm the one who is dying. Holding one who is dying in a sacred manner can gather us together with the Divine. We might say this experience is like birthing into the divine love of

FRIENDS COUNSELING SERVICE

Counseling needs of members and attenders may, at times, exceed what the meeting can provide. Within Philadelphia Yearly Meeting, the Friends Counseling Service is a resource available for consultation with the meeting or for referral. The counselors are active Friends whose spiritual lives are integral to their counseling. Service is not denied because of a person's lack of means.

Friends may call a counselor directly or phone Deborah Cooper, Counseling Service Coordinator, at 215-249-0489, for a referral.

Henry Beck, Ph.D.
Bala Cynwyd & Lansdale, PA
610-664-5443

Ray Bentman, M.Ed.
Philadelphia, PA
215-985-1314

Terence Carroll, ACSW
Philadelphia, PA
215-473-2600

Deborah Cooper, M.Ed.
Philadelphia, PA
215-248-0489

John L. Hall, Ph.D.
Downingtown & Mt. Airy, PA
610-458-9060

Harriet Heath, Ph.D.
(parenting issues only)
Haverford, PA
610-649-7037

Gary M. Johnson, Ph.D.
Wilmington, DE
302-656-1295

**Beth Resko, ACSW,
LSW**
State College, PA
814-238-1880, #16

**Karin M. Sannwald,
ACSW, LCSW**
Lumberton, NJ
609-518-1057

James J. Saxon, Ph.D.
Swarthmore, PA
610-544-7583

John Scardina, Ed.M.
West Chester, PA
610-696-2153

Fran Van Allen, M.A.
Philadelphia & Media, PA
610-358-3212

**Lindley M. Winston,
M.D.**
West Chester, PA
610-431-3955

**Elaine P. Zickler, MSW,
LCSW**
Cherry Hill, NJ
856-482-2477

God. Death can be experienced as a spiritual birth. The physical pains along with the emotional surrender in dying are the labor of that sacred transition.

Four Friends Who Have Received Our Care

Eugene Friends' Care Co-op (FCC) has now responded to four elders within the meeting as they faced terminal illness. In each response we have found differing needs of the dying persons and their caregivers. Families vary in their structures. We try to remain open to these differences. Our aim is to fit each scenario and respect individual needs. We begin by offering simple practical suggestions that are not

invasive to their family relationships. We present several options to their questions leaving the decision-making to them. Truly common among caregivers is a reluctance to ask for help. We try to empower the caregivers to acknowledge their own needs and ask when they need help.

Visiting Friends Who are Very Ill

1. Check in advance to see if the patient wishes to see you at this time.
2. Plan to stay just a few minutes; longer if you are sure the patient wants you to stay.
3. If others are already visiting, return some other time.
4. Your friend may be shockingly changed in appearance. It is good to be aware of your reaction, but it is generally not helpful to comment on it.
5. What you talk about is less important than the way you listen. Allow the patient to choose the subject. You might start with a non-committal statement such as "How goes it?"
6. If the patient wants to tell you about the illness, be receptive even if it makes you feel uncomfortable. Be careful about quizzing for details or matching the account with tales of your own. Suffering is not a contest. Avoid false reassurance.
7. If you are left with choosing the subject, try to connect with what you know of the patient's interest. Some may welcome talk about the world outside: your trip to the city, or some world event. Others may find that distressing. Take your cues from the patient's response.
8. Some people enjoy hearing a poem, story, or article read aloud. Let the patient help choose what is to be read.
9. Others may find that reminiscing makes for good conversation.
10. When death is imminent, it is likely to be in both your minds even if neither of you can speak of it. If the patient wants to talk about it, be receptive in your listening. Just let your friend talk, if you can.
11. With some, sharing deep silence is most is the best way to communicate caring.
12. Be sensitive to how touch is received by the patient. Some people do not like to touch or be touched, while others crave direct contact. Be aware that for some touch, though desired, is physically painful.
13. "Anything I can do to help" is often meaningless, but a concrete offer like "Could I water your garden?" or "Can I fill your bird feeder?" may be really appreciated.
14. Some would-be visitors are so worried about the visit that the patient has to do the reassuring. If that includes you, perhaps a card would be more helpful.

Based on guidelines prepared by the Mental Health Committee at Medford Leas Retirement Community

One family needed companionship for their mother as she learned to live with congestive heart failure. At the time of our involvement she was quite weak and the family unprepared for the amount of care she required. Her primary caregiver was her elderly husband. Volunteers stayed with her while family members found professional in-home care. Friends provided food and helped with its serving. We worshipped with her twice a week. Others went to read to her and/or helped with correspondence. Over the last few months this woman has gained strength and is now able to attend women's meeting and sometimes attends worship.

Another elder was dying from cancer. FCC provided support and clearness as she attempted to deal with the material accumulation of her life. Over the winter it became apparent she could no longer live alone. The FCC team worked with her family in finding 24-hour care by providing contacts and phone numbers for several eldercare agencies. Her son made the decision as to which one was best for his mother and workable for his budget. Volunteers continued to visit and monitor the care since the son lived out of town. When she neared death the son was called and supported as he witnessed his mother's dying. Because of FCC's involvement with the family, the planning for the memorial felt easier and more natural for members of Oversight.

A third elder has been experiencing a slow physical decline. His wife has congestive heart failure. They very much want to remain in their home. Oversight organized a clearness/support committee that has met with this family for over a year. How to empower this loving wife to ask for help and to take care of her own needs has been the primary clearness task. Individuals from this committee visit regularly, and the committee meets with the couple once a month. We also keep lines of communication open with children who live away from Eugene. Close spiritual friendships have grown from this long-term commitment.

A fourth elder came to the attention of FCC from concerned members within the meeting. When the initial contact was made no additional help was being requested. Nonetheless we stressed what we could offer in specific things, like shopping, picking up prescriptions, etc. We ended the contact with letting that individual know he could call us anytime with small needs. A week later it became apparent that this elder's time of death was close when he was moved to a nursing home. Only then

Celebrate the New Year!

December 29-January 1

Theater for a Change

Steve Gulick

Act out! Express your self in creative ways that make an impact!

The Liberation Poetry of Ernesto Cardenal

Aurora Camacho de Schmidt

World class Nicaraguan poet

Re-Turning to the Light

Marcelle Martin

Create an opening to turn anew to God

A New Year's Sojourn

Relax at Pendle Hill for the New Year



PENDLE HILL

A QUAKER CENTER FOR STUDY AND CONTEMPLATION

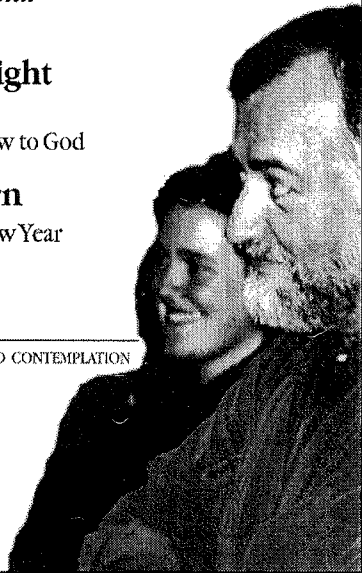
338 Plush Mill Rd

Wallingford, PA 19086

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registrar@pendlehill.org

www.pendlehill.org



did he ask FCC to invite a few long-time friends to come and visit. He also asked that his wife be contacted to help with practical matters. She had not lived with him for some time, and we thought of him as divorced. Our job was to respect her coming and connect her with his children. We supported the family lines of communication as they learned to trust one another.

Always at the center of our work is the spiritual care of individuals and families. We want to strengthen the ties of meeting friendships, offer times of worship and worship sharing, and pray together for those who come to us. Volunteers are coached in ways of listening and how to open opportunities for personal sharing and worship. When our fourth elder was dying such an opportunity came to one of our FCC volunteers. As only grace can provide, minutes after this elder died our volunteer arrived to play the harp at his bedside. She felt called to stay with his spirit and play while the family gathered around him. This time grounded their family as it began to work together again.

Each volunteer is encouraged to report back to the FCC care team any concerns, joys, or needs that might have come from their work. These

Of Interest...

HOW DOES YOUR MEETING ORIENT NEW MEMBERS TO QUAKERISM ?

PCN has planned an issue for early 2001 on orienting new members to Quakerism. We would like to devote the issue to brief stories of several meetings' approaches: Quakerism 101, having seasoned Friends serve as mentors to new members, providing scholarships to inquirers' weekends, etc.. We would like to hear from small meetings as well as large ones about how you are helping new members mature as Friends.

Could you share your story with us? We are not expecting to find the meeting that has it all figured out. In fact, we are finding that most meetings feel that they have a lot to learn. We are hoping that with your help we can help meetings to share with one another on this important topic.

To share your meeting's story with *PCN*, please send a brief paragraph to editor, Patricia McBee. She will get back to you with specifics of what we are hoping for. You can reach her by e-mail at <pmcbee@juno.com> or by postal service, at Pastoral Care Newsletter, Philadelphia Yearly Meeting, 1515 Cherry Street, Philadelphia, PA 19102.

Thanks.

conversations help us to learn from one another. Volunteers are always thanked for their gifts of friendship and support. And in the sharing of these times we grow closer together in community.

In the greater meeting picture, we have come to recognize our responsibility for education of our volunteers and the community as a whole. To meet those needs, we have offered quarterly evening gatherings for anyone in the meeting to explore specific topics. Such topics include discussion around needs in senior housing, developing conversations around financial needs and support, and bringing in an attorney to speak of end-of-life topics of advance directives, wills, and estate planing.

A second method of education is currently being initiated to reach more people within the meeting. We are asking individuals to write personal essays from their own experience of facing the transitions in life, health issues, etc. These essays will be printed and circulated in the monthly newsletter. It is hoped that these essays will bring into the open issues that are commonly shared but not often talked about.

Reflecting on Our Experience

As we reflect on the work that FCC is doing within Eugene Meeting, we realize that there are

many kinds of situations we have not had to deal with in the short time we have been organized. We have not faced a sudden or traumatic death nor the death of a young person. We pray that if that these situations arise we will have the spiritual foundation to respond together. We know there are resources within the wider professional community to help us and perhaps that will be the topic of another quarterly training session.

As a Care Team we regularly must ask, "Are we meeting the needs of the terminally ill and their caregivers?" We recognize that we are learning as we go along this path. Sometimes we may bumble and fall short, only because of human weakness not from lack of love. We try to let our organization help us to evaluate each response individually rather than shape it into a patterned response. We aim to give fully and wholly to all within the meeting whether the call comes from a beloved elder or a sometimes attender. We know that as we respond we will come closer

together, grow into new friendships, and see one another's strengths. Most of all, we know we are not alone and that others will walk with us as we face death ourselves or within our families.

In helping others who are facing death we have come to know that we must prepare for our own death by living our faith each day. When we are then called to be with one who is dying we can support them by opening ourselves to the commonality of death and assuring the dying one of their final human rights. To prepare the sacred ground where the greatest spiritual work can be done by all within the circle, we must do this work worshipfully. We must move beyond "self" allowing all to become gathered into a larger purpose, beyond time. In those moments we feel God's presence working upon us. We truly come to know the fullness of living – the whole cycle of life and death and life.

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Lucy McIver currently serves on the Worship and Ministry Committee of Eugene (Oregon) Friends Meeting. She and her partner, Karen Lundblad, are supported by EFM in their ministry to lead workshops in opening our spirits as we face death.

Readings on Terminal Illness

Dear Gift of Life, by Bradford Smith. Pendle Hill Pamphlet #142.#

Facing Death, Diana Lampen, (1979), Quaker Home Service.#

Meetings at the Edge: Dialogues with the Grieving and the Dying, the Healing and the Healed, by Stephen Levine. Anchor-Doubleday, 1984.#

Planning Ahead: Meeting Our Responsibilities When Death Occurs. Final Affairs Committee. Honolulu Friends Meeting. 1990?#

A Quaker Look at Living with Death and Dying, by Phyllis Taylor, PYM, Family Relations Committee 1984.#

Share the Care: How to Organize a Group to Care for Someone Who Is Dying, by Cappy Capossela & Sheila Warnock, Simon & Schuster 1995.

A Song of Death, Our Spiritual Birth: A Quaker Way of Dying, by Lucy McIver. Pendle Hill Pamphlet # 340.#

Without Nightfall Upon the Spirit, by Mary Morrison. Pendle Hill Pamphlet #311.#

#Available from Philadelphia Yearly Meeting Library, 215-241-7220. Friends outside PYM can subscribe to the library.

Questions for Reflection

1. How can we help members of the meeting reflect together on the challenges that will face each of us at the end of life?
2. What plans do we have in place for responding to the needs of members with terminal illness?
3. Who in our meeting has a particular gift for being with those who are sick or dying? Who has professional experience?
4. Who among the meeting might be willing to provide simple, practical help for families caring for a person who is near death?
5. What resources are available in the yearly meeting or our community to help us respond sensitively and knowledgeably?

Pastoral Care Newsletter is published quarterly by the Care and Counsel for Meetings and Members of Philadelphia Yearly Meeting. Annette Bennert, clerk. Patricia McBee, editor. We are located at 1515 Cherry St., Philadelphia, PA 19102. Comments are welcome. **Please do not duplicate without permission.** To obtain additional copies or to subscribe, contact Steve Gulick, at 215-241-7068 or steveg@pym.org.