

# Science Editing and Caregiving: Experience and Guidance

**Elizabeth Whalen and  
Barbara Gastel**

*On becoming editor of CBE Views, the fore-runner of Science Editor, I knew that some invited pieces would arrive late. After all, the authors were busy, and they were contributing as volunteers. I expected a common reason for the delays to be heavy professional demands.*

*I did not, however, expect another frequent reason for delay: serious illness of a parent or other family member. Yet several times per year I have found myself revising plans for CBE Views or Science Editor when contributors interrupted or restructured their professional activities to help care for adult kin. Reflecting on the demographics of the Council of Science Editors, I recognized that the frequency of such delays should not have surprised me.*

*Because many CSE members occupy caregiver roles or have recently done so, and many others might soon enter such roles, I thought it worthwhile for Science Editor to publish an article on maintaining a science editing career while being a caregiver. Questions that I envisioned the article addressing included the following: What kinds of professional adjustments have science editors made to accommodate caregiver roles? What can one do to minimize disruption of one's work yet maximize time, energy, and attention available for caregiving? What advice is there for colleagues*

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*who may be caregivers in the future?*

*A different sort of caregiving—that of serving as interim head of a university department—left me with little time to work on the article I envisioned. Therefore, I thought about finding a coauthor. When Elizabeth Whalen, who has written many fine pieces on science editing, mentioned returning to her home region to help her mother in her last years, I told Elizabeth about my idea. The current article is the product of the resulting collaboration.*

*We hope many of you will find this article useful, interesting, or both. If you have perspectives to add, please write to me at b-gastel@tamu.edu or the postal address listed in the information for contributors (page 144). With permission, items received may be run as letters to the editor or excerpts may be compiled into a follow-up piece.*

Barbara Gastel

Science editors, like others in the United States and elsewhere, live and work in an aging population. In a 1998 survey, 54% of Americans said they probably would be responsible for the care of an older relative or friend within the next 10 years.<sup>1</sup> Moreover, in 1996, more than 22.4 million American families were already providing care for older relatives or friends—and about 64% of the caregivers were employed either full-time or part-time.<sup>2</sup> According to a recent guide: “One out of every four employees has some level of eldercare responsibility. Half of these caregivers say their involvement is equivalent to another full-time job.”<sup>3</sup>

Sources of stress for employed caregivers include difficulty in finding and managing care, reductions in work effectiveness because of worry, and trouble in balancing time and energy for work and caregiving.<sup>4</sup> Also, as noted by one researcher, “permanent or temporary job exit creates salary and benefit losses. Workers who must rearrange schedules or reduce hours

at work may be seen as less worthy of training or promotion by their supervisors. Some caregivers also may refuse additional responsibility, training opportunities, or a shift in position that would advance their prospects in the firm, and thereby increase their incomes.”<sup>5</sup> Although these concerns are related primarily to full-time staff, both employees and freelancers face challenges posed by combining caregiving and career, as evidenced by research literature and day-to-day observation.

What about science editing and caregiving? Some common features of science editors may affect how they function as caregivers and how they experience such roles. Science editors' ability to read technical materials and talk effectively with technical experts may help them to deal with health professionals but also may add the stress of having knowledge but little power. Many science editors truly love their work; work can prove a distraction or a stabilizing influence during stressful periods of caregiving, but suspending work to fulfill caregiving duties may be particularly painful. If there are siblings, the science editor may face heavier pressures than them to help because of technical knowledge, ability to deal with financial and legal forms, and the tendency to focus on the quality (goodness) of their work. Science editors may tend to care especially about being “good”—at their work and as people; wanting to be a “good” child is one trait of those who give care to elderly parents.<sup>6</sup>

To learn more about how science editors can—and do—mix caregiving and career, we looked at the growing body of research on caregiving, interviewed fellow science editors who have been caregivers, reflected on our own experience, and otherwise explored the subject. The following are highlights of what we found. Not surprisingly, they support the conclusion that no “one right way” exists but that financial

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and other planning, systematic exploration of options, willingness to accept help from others, and remembering to care for oneself serve the best interests of all involved.

**Science Editors as Caregivers**

Caregiving Options and Professional Adjustments Science editors, like others, have effectively pursued a variety of caregiving options. For example, some with aging parents in distant cities have helped find suitable in-home care for them. Others have had parents move in with them or have helped place parents in facilities nearby. Still others have moved close to, or temporarily moved in with, parents. As well as caring for parents, science editors have cared for terminally ill spouses and others. Depending on various factors, professional adjustments to accommodate a caregiving role have ranged from slight to sweeping.

Ellen Chu is editorial director at Northwest Environmental Watch in Seattle, and her 96-year-old father resides in Los Angeles. A live-in caregiver keeps house for him and provides other help. The caregiver, who is like a relative, has been with the family for more than a decade, including the 7 years before the death of Chu's mother, who had an Alzheimer's-like illness. The caregiver's devotion, Chu notes, allows Chu to maintain her professional life and care for her growing children.

Chu, who was widowed in 1997, came to put her work second during her husband's terminal illness, which lasted 9 months. The changes in her situation were gradual, so Chu, then in a different job, was able to adjust. For the last 3 weeks of her husband's life, she essentially took a leave of absence. She kept in touch with the office by e-mail and phone, however, and continued to edit a book on a freelance basis. She considered the editing project a lifeline, providing a tie to the past and the future. Research supports the notion that caregivers may find respite in work.<sup>7</sup>

Miriam Bloom, of Jackson, Mississippi, and Renee Cohen, of White Plains, New York, are among those who have moved aging or ailing parents to their communi-

## Some Resources for Caregivers

Many resources exist for current and potential caregivers; the following are some of the most prominent. Particularly featured are resources that can aid in identifying other resources.

**Printed Materials**

Caregiver's Handbook: A Complete Guide to Home Healthcare. Visiting Nurse Associations of America. Deni Bown. New York: DK Publishing Inc; 1998.

The Caregiver Helpbook: Powerful Tools for Caregiving. Vicki L Schmall, Marilyn Cleland, and Marilynn Sturdevant. Portland, Oregon: Legacy Caregiver Services; 2000.

The Caregiver's Manual: A Guide to Helping the Elderly and Infirm. Gene B Williams and Patie Kay. New York: Carol Publishing Group; 1995.

Caregiving: The Spiritual Journey of Love, Loss, and Renewal. Beth Witrogen McLeod. New York: John Wiley; 1999.

Caring for Those You Care About: Helping Mom & Dad. (Set of tip sheets available from AARP, 601 E Street NW, Washington DC 20049, [www.aarp.org](http://www.aarp.org); includes a sheet on balancing work and caregiving.)

Caring for Yourself While Caring for Your Aging Parents: How to Help, How to Survive. Claire Berman. New York: Henry Holt; 1997.

The Complete Idiot's Guide to Caring for Aging Parents. Linda C Rhodes. Indianapolis: Alpha Books; 2001.

The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer's Disease, Related Dementing Illness and Memory Loss in Later Life. (Third edition.) Nancy L Mace and Peter V Rabins. Baltimore: Johns Hopkins University Press; 1999.

**Web Sites**

[www.caregivers.com](http://www.caregivers.com)

[www.CaregiverZone.com](http://www.CaregiverZone.com)

[www.caregiving.org](http://www.caregiving.org)

[www.medlineplus.nlm.nih.gov/medlineplus/caregivers.html](http://www.medlineplus.nlm.nih.gov/medlineplus/caregivers.html)

[www.NFIVC.org](http://www.NFIVC.org) (National Federation of Interfaith Volunteer Caregivers)

[www.seniorlaw.com](http://www.seniorlaw.com)

**Organizations and Government Agencies**

AARP

[www.aarp.org/caregive](http://www.aarp.org/caregive)

Administration on Aging

[www.aoa.gov](http://www.aoa.gov)

Children of Aging Parents

800-227-7294

[www.careguide.net](http://www.careguide.net)

Family Caregiver Alliance

415-434-3388

[www.caregiver.org](http://www.caregiver.org)

Well Spouse Foundation:

An Association of Spousal Caregivers

800-838-0879

[www.wellspouse.org](http://www.wellspouse.org)

ties or into their own homes. For the last 11 years, Bloom's mother, now 96, has lived in a nursing home a 5-minute drive away. Bloom talks with her daily and visits her often, helping her cope with nursing-home life. Earlier, when her father was terminally ill, Bloom arranged for her parents to live in a rented house near her own; the arrangement worked out well.

For 5 years, Cohen and her husband have shared their condominium with her now 89-year-old mother, who is in good health but not well suited to living alone. Bloom and Cohen say that they have had to make very few professional adjustments. Both are freelance editors and writers, and both can adjust their schedules when necessary. Cohen does mention that she had to "train" her mother not to walk into her office talking in case she is on the phone with a client. But she feels confident that she remains able to manage even complicated freelance projects from her home office. And her mother doesn't seem to mind sharing her bedroom with the fax machine and copier!

During his parents' final years, Seth Beckerman, freelance writer and editor in Pittsburgh, helped his parents move from independent living quarters through increasing-care facilities progressively closer to him; he was there to ensure care during health crises, to provide emotional and physical support, and to help them deal with financial matters. Beckerman indicated that helping his parents did take some time and energy away from work. His wife and his aunt filled in when he had to travel, but he was always aware of the possibility of midnight calls and unexpected crises: "In the back of your mind, you know that you're responsible for another couple of people."

Lynn Dirk, editor for the institutional review board at the University of Florida, recently cared for her widowed mother during an 8-month terminal illness. Dirk made substantial adjustments to aid her mother in activities of daily living. Her mother lived a 3-hour drive away, and Dirk continued to work while staying at her mother's home and took accumulated

leave time to help. She says that although her supervisors were very accommodating, she was disappointed to find that in her absence a portion of her work that she had enjoyed was routed in a different direction.

From 1996 to 2000, one of us (Elizabeth

***"The respondents who liked their jobs, had a good relationship with their supervisors, and thought their work organizations were responsive to the demands of their families reported fewer health complaints."***

Whalen) provided mainly long-distance help to her parents, whose health was declining. During these years, she held full-time jobs and did freelance work. At one job, a colleague helped Whalen find information important to her father's care; but at another, her supervisor showed little sensitivity to her situation. As a freelance in San Diego, Whalen changed business-travel arrangements and rescheduled classes she was teaching so that she could visit her parents. In June 2000, she and her husband moved from San Diego to South Dakota largely to help care for her mother, who by then was widowed and in an assisted-living center. She is substantially curtailing her career until she is no longer primary caregiver for her mother.

Whalen left an opportunity-filled location where she had established a strong professional network and reputation to move to a much less populated area where she lacked a network. Fortunately, she and her husband had saved enough money to live on, if necessary, while her mother

needs care. After that, they may be starting careers anew, although Whalen hopes that her 20 years of experience will help her re-enter the job market when the time comes. In the meantime, she still works on short-term writing and editing jobs.

### Balancing Career and Caregiving

Many caregivers, including science editors, face the difficult question of whether to stay employed as before or to suspend or cut back paid work. Authors of guidebooks, benefits counselors, and researchers have commented on the dilemmas involved.

Mace and Rabins,<sup>8</sup> authors of a well-established guide for caregivers of family members with dementing illnesses, say to consider options carefully when thinking of giving up a job to serve as a caregiver. They note that many caregivers feel more stressed after giving up a job; reasons include "putting up" with the elder full-time, dealing with the loss of income, and placing a desired career on hold. Often employed caregivers can discuss options with their employers; alternatives sometimes include flex time, job sharing, and leaves of absence.

Supervisors and benefit counselors have been finding ways to retain productive employees who have caregiving responsibilities; many employers recognize that providing good benefits for caregivers improves a company's productivity and profit in the long run. Recent research<sup>5,9-13</sup> shows that many companies are now providing caregiving resources and referrals to their employees.

Although research findings are mixed as to whether employed caregivers feel more or less stress than caregivers who are not employed,<sup>10,12,14</sup> it appears that a supportive work environment can help caregivers avoid stress-related health problems. Having studied workers who were caring for aging parents, one researcher concluded that "responsive work environments emerged as an important mediator on serious long-lasting and costly (financial, emotional, and social) unwanted changes in health. The respondents who liked their jobs, had a good relationship

## Science Editing and Caregiving *continued*

with their supervisors, and thought their work organizations were responsive to the demands of their families reported fewer health complaints.”<sup>12</sup>

### Communication Technology: A Possibly Mixed Blessing for Caregiver-Editors

When asked about using communication technologies to help maintain one's career while caregiving, Dirk responded, “Thank God (maybe!) for the laptop and e-mail. I wouldn't have been able to continue working without the laptop.” Chu found that continuing to do science editing was a stabilizing factor—an Ariadne's thread, she called it—but others may find continuing such work too stressful. With communication technologies, caregivers may feel pressured to keep working wherever they are—even if, for instance, they prefer to focus on family priorities at the time. “I think it would have been better to have suspended work, and I would have preferred to do that”, Dirk said, “but I chose to balance both responsibilities as best I could.”

Computer technologies can help freelance science editors retain clients when changing locations for purposes of caregiving. Whalen, for example, could keep working for one client after her move to South Dakota because all the work was done online. Having initially resisted the switch to electronic editing, she laughs that it has now become her main option for editing work.

Old and new communication technologies can aid science editors serving as caregivers long-distance, on a short-term basis, or both. Cohen, who arranged for her father's care in another state, recommends obtaining telephone directories for areas where ailing relatives or friends live. Today the Internet likewise can aid in identifying remote resources.

Laptop computers, e-mail, voice mail, fax machines, and the like can help science editors keep in contact with their offices and meet deadlines while they are out of town because of a family member's surgery or illness. They also can help in staying in touch with recipients of care and with

others involved in the caregiving or the associated paperwork. In the early 1980s, Barbara Gastel (second author of this article), then in a different academic position, bought her first telephone-answering machine after her parents had trouble reaching her to ask about an imminent medical decision. And she worried about the often slow and unreliable communication links when soon thereafter she left to teach for 2 years in China. These days she can call on more varied and dependable technologies to help ensure that she is rapidly reachable almost anywhere if family medical problems arise. She hopes, though, that those same technologies will not allow workday pressures to intrude unduly on time that would perhaps be better devoted to caregiving.

### Advice for Caregivers

#### Caring for a Parent, Partner, or Other

Although caregiving situations differ, science editors' experience as caregivers and the literature support some general guidelines. Among them: Try to plan, financially and otherwise, for possible caregiving. Be ready to substitute satisfactions gained from caregiving for some professional satisfactions. Recognize that no solution is right for all caregivers or all recipients of care. If possible, gain support from others. Be ready to serve as an advocate for the person receiving care.

Financial and other planning can ease the caregiving role. For offspring, caregiving tends to be easier if parents help them take over their finances and provide such legal items as power-of-attorney and living wills. Beckerman noted that it is best to take care of these items while parents are still clear-headed and legally competent but that bringing up the topic is not always easy. Tact may be needed to broach the idea that parents might soon need their children's help with their daily lives.

Availability of savings or insurance means that formal caregiving can more readily be purchased, for example, via services of professional home-based caregivers, assisted-living centers, and nursing

homes. Bloom observed that many science editors enjoy what they're doing so much that they tend to ignore the financial aspect; however, as she noted, it can be important to prepare financially for one's old age—and possibly for the need to provide caregiving for others.

In addition to considering financial aspects, coping effectively as a caregiver can include recognizing nonmonetary rewards. For example, Whalen has come to redefine “work”. She now finds herself for the first time in 32 years without regular income from a full- or part-time job. Whalen's work now is mostly not for pay but for the rewards of helping her mother. Among the possible emotional rewards of caring for a parent are feeling closer to the parent and enjoying being with the parent; taking responsibility for the parent, which boosts the caregiver's self-esteem; and receiving the parent's appreciation and watching the parent enjoy something, sources of pleasure to the caregiver.<sup>15</sup> Noting the support his parents had provided as his career evolved, Beckerman said, “I am glad that when the tables turned, I was able to help.”

Echoing points in the literature and in other interviews, Cohen noted: “Be true to yourself. There is no one right thing to do, no one path to take as a caregiver.”

Cohen also raised the point of doing what's best for the relative: “My mother would not thrive in assisted living or in a small apartment near us.” But Whalen's mother is happiest in an assisted-living center; she would be uncomfortable living with either of her daughters, because she “wouldn't feel right”. And, whereas Beckerman, Bloom, and Cohen moved their parents closer to them, Whalen and Dirk found the ailing parent unwilling to be moved, and they made caregiving provisions accordingly. Often, it seems, what is best for the relative is best for the caregiver too: a home aide works out well for Chu and her father, nearby nursing homes have worked best for Beckerman and Bloom and their parents, and Dirk said that despite her own initial reservations, her mother's preference to stay in her own home prob-

ably worked best for both of them in the long run.

A stress-management guide for caregivers notes the importance of carefully making any decision about relocation: “You may face the tough decision of whether to move your relative closer to you. . . . Carefully weigh the advantages and disadvantages for your relative, yourself, and your family. . . . A move can separate your family member from long-established roots that are not easily replaced.”<sup>16</sup>

Assistance from other family members can be important for successful caregiving. Cohen said, “I know I can only do this [share her home with her mother] because my husband has agreed to the situation.” Bloom notes that her husband joins her and her mother for lunch every Sunday and “pretends he enjoys it. . . . A strong family helps in so many ways.” And Whalen’s husband is a delight to her mother (“my only son!”). However, research shows that although spousal support can help, conflicting or competing roles can also add stress. Brody, who has done much research on caregiving for the elderly, tells the following anecdote: “One married woman, when asked who she thought has the hardest time among women [caregivers] whose marital status differed, replied ‘Married women.’ When asked who she thought had the easiest time, she laughed and again replied ‘Married women.’”<sup>15</sup>

Gerontology specialist Judith Warren, of the Texas Agricultural Extension Service, recommends bringing family members together, if feasible, to plan ways to share caregiving responsibilities. Sometimes, she notes, a professional outside the family, such as a social worker or member of the clergy, can facilitate discussion and help the family explore possibilities. Although many science editors seem to like being self-reliant, sharing the tasks of caregiving can prove beneficial both personally and professionally.

All the help need not come from family. When Chu’s husband was dying, a hospice provided substantial help. So did friends and colleagues who spent time with her husband, provided child care and

chauffeuering, and brought over food and favorite books. “Don’t hesitate to ask for help”, Chu said.

No situation will be perfect for the person being cared for; after all, typically the person is ill and has lost some control over his or her life. So providing support remains important after the decision is made as to what is best for all concerned. In providing such support science editors can often draw on their particular strengths by helping to read medical documents, discussing medical matters with health professionals, and being advocates when needed.

Bloom notes that patients in nursing homes and hospitals need advocates—people who can speak up for the patients’ interests. Warren observes that family members can be especially good advocates

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because they know the patients’ personal histories and usual modes of functioning. Whalen’s experiences with her father in a nursing home and her mother in a hospital support the value of advocacy. As stated in one recent guide, “Staff take notice of those residents who have family looking in on them, so visit your parent often. . . . Be sure to let staff know you appreciate them.”<sup>17</sup> Bloom mentioned that “the [nursing home] staff needs care, too—praise, tips, cookies, whatever moves them to perform their jobs a little better.”

### Caring for the Caregiver

Caregivers themselves are at risk for health problems. One small study<sup>10</sup> showed the following to be the most common coping mechanisms among caregiving daughters: talk with someone, pray, busy self with other things, cry, hide feelings, ask for

help, get away, busy self with job, and yell or scream or slam. Less common mechanisms included exercise, smoke more, take more alcohol or drugs, and ignore or try to forget. Obviously some of these mechanisms are healthier than others.

One general observation from the current interviews and from the published research is that caregivers tend to minimize the problems and sacrifices they face because of their role. Two of our interviewees wondered whether they should be interviewed—their experiences were “too good”; another feared that she was making the experience sound “harder than it really was”. However, outsiders looking at the situations described might well conclude that all three faced difficult challenges. All the caregivers seemed to believe that devoting some part of their lives to providing care was the right thing to do; concentrating on the positive, rewarding aspects may make that experience easier. However, caregivers may find that it sometimes helps to recognize and acknowledge the difficulties and negative feelings also.

Like others, caregivers need to take care of themselves. Cohen, for example, hasn’t stopped participating in the activities she enjoys most, like hiking and yoga, and she would cut back on work before giving those up. Likewise, during her husband’s final months, Chu and her children went away twice—once to a close friend’s wedding, another time to spend a weekend with friends. Chu compares taking time for oneself with donning one’s own oxygen mask first in an airplane: Only by taking care of oneself can one care well for others.

Support, informal or formal, can be crucial to a caregiver’s well-being—and perhaps to the ability of the caregiving science editor to maintain a career effectively. As mentioned above, some companies now provide resources for employees who are caregivers. When science editors seek jobs, they may want to consider employers’ policies and attitudes toward caregiving responsibilities. Although freelance workers have less access to benefits, they may wish to consider such factors as clients’ flexibility about deadlines.

## Science Editing and Caregiving continued

There are many resources, both commercial and nonprofit, for those who, regardless of employment status, seek help with caregiving. Among means of caregiver support are paid or volunteer companions or friendly visitors (who can provide a safety check as well as companionship), telephone reassurance systems, in-home medical-alert programs, chore services, homemaker services, home health aides and nurses, home-delivered meals, congregate meals, transportation services, adult day care, and day treatment.<sup>16</sup> For some “metaresources”, please see the accompanying sidebar.

It might be said that a contemporary phenomenon is salient if a *Complete Idiot’s Guide* to it has been published. The challenges and rewards of caring for aging parents are now addressed in such a guide. The book cites problems of caregiving: “The National Family Caregivers Association’s national profile of caregivers found that 67 percent of caregivers felt frustration while nearly 40 percent felt sad and anxious. Half of all caregivers experienced back pain, sleeplessness, and depression.”<sup>18</sup> It also provides advice in the form of a “Caregiver’s Creed”, which includes

- Laugh. And laugh some more!
- Forgive yourself; it’s okay to be angry and resentful sometimes.
- Don’t dwell on your shortcomings; move on. Take joy in the good work you are doing.

Many science editors have cared for or will soon care for ill or aging parents, partners, or others. Various characteristics of the effective science editor may facilitate successful adaptation, both professionally

and personally, to a caregiving role. These characteristics include communication skills; science literacy; proficiency in information-gathering, planning, and organization; adeptness with paperwork; flexibility; internal motivation; and ability to identify small changes that can make big improvements. Some of those interviewed for this article said they found it helpful to discuss their situations. We hope you found it worthwhile to read about some of the relevant research and about some science editors’ experiences and insights. 

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