

## SCENARIO/ROLE PLAY IDEAS FOR CARING FOR CAREGIVERS

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### CARING FOR CAREGIVERS

#### INFORMAL FAMILY CAREGIVERS:

The family of a baby, Sam, who has been identified as having a congenital condition that will probably end his life before age three. The baby is now 18 months old, and the mother has two other children, a girl, Anna, aged five and very bright, who recently displays anger problems, and a healthy son born three months ago.

#### Identified Problems:

- Anna's anger against the sick toddler, Sam, the new baby, and her distracted mother.
- The parents' stress in working and taking care of the three children, one terminally ill.
- The parents' wish to build happy memories as a family that include their terminally ill toddler.
- The parents' guilt at giving birth to a second son, whom they know they think of as a "replacement" for Sam (and maybe Anna wonders if they will "replace" her soon too?)

**TO HELP:** This family has access to psychiatric care for Anna, and a children's research hospital program for Sam. Design programs to include arts, humanities, and/or expressive arts therapies, each program to help at least one member of the family. (Don't forget they can stay in or go out, and some programs can be at home.) Since there are multiple agencies involved, the family may be able to get more services than most – so let your imagination run wild.

### INFORMAL FAMILY CAREGIVERS

The family of a male resident, Calvin, who has just been moved to the Pleasant Nursing Home, diagnosed with Alzheimer's Disease. The family, his daughter Loretta, and son-in-law Eddie, both aged 67, have been taking care of Calvin for three years at home, but feel they can no longer do so. Calvin has always liked sports and working in his vegetable garden, and he used to sing in the church Gospel choir.

#### Identified Problems:

- Calvin seems depressed, and needs help to adjust to life in the nursing home and needs encouragement to attend activities, as he often refuses to leave his room.
- The family wants to continue to be a part of Calvin's life, and would like to participate in a project with him at the nursing home.

TO HELP: You are the Activities Director. Design a program for Calvin and his family. Calvin is prescribed physical therapy, occupational therapy, and recreational activities at the nursing home, and his family visits often. Arts specialists and interns sometimes appear for short period of times at Pleasant Nursing Home. Don't forget Calvin's interests and the family's desire to be involved.

## INFORMAL CAREGIVERS AND FORMAL CAREGIVER

Friends and neighbors were caregivers for Rob, a dancer in a small city, who died of complications of HIV/AIDS two weeks ago. Rob became very ill about six months after the death of his longtime partner, Joe. Rob's informal caregivers are two women and two men, not related, all neighbors and friends, who took care of him 24/7 for past 5 months (including a long stay at the hospital). A formal caregiver, an aide from a Hospice program, has helped intensively, but only for the past month. Rob's father, who never acknowledged that Rob was gay, and his brother, a football coach with whom he was not close, arrived in town shortly before Rob's death, stayed for the funeral and to clean out his apartment, then left. At no point did the family acknowledge Rob's relationship with Joe or talk about HIV/AIDS.

### Identified Problems

- The caregivers feel grief but only one of them, identified as "primary caregiver," is eligible to attend the grief programs at the only local AIDS program.
- The caregivers try not to be as depressed as they feel. They were just friends and neighbors, after all, and his family was his family. Nonetheless, they feel anger at the Dad and brother.
- The family has cleared out the apartment leaving very little for the caregivers to have as "keepsakes." The primary caregiver has a few photos and items from Rob and his partner that the family did not want.
- The aide also became fond of Rob and his caregivers, and also wants to be able to express grief in some way.

TO HELP: Design an arts project through which the caregivers (informal and formal) who are not eligible for grief programs, can express their sadness and work through their grief. Remember that this program is not funded, and it has to be a "do it yourself" project by the caregivers for the caregivers. What resources can they access? What can they do?

### INFORMAL FAMILY CAREGIVERS

Mrs. Barton and Mr. Barton are farmers who have been married for 56 years and they live on a farm about 25 miles from the town where the hospital and hospice programs are located. Mr. Barton has been seriously ill with cancer for about two years. The Bartons are devoted to each other, and fiercely independent. (For example: Mr. Barton wants to keep driving the truck down to the barn to take care of the animals, even though he now uses morphine to control pain.). Mr. and Mrs. Barton's three children, all married with children of their own and jobs in cities at least two hours away, try to take turns visiting every weekend.

### Identified Problems

- Three of the members of the family (two of them grandchildren) want to do "something," a project to share memories of their Dad's life with their Dad before he passes away, but also something their Mom could have, and they could have a part of, too.
- Mrs. Barton would like to interest Mr. Barton in something where he would be safer, more willing to stay in the house, not want to work on the farm, drive the truck, etc.

TO HELP: You are the volunteer coordinator of a home hospice program in the City 25 miles away. You have worked with Barton Family for some time, and would like to help them with the "Project." Recently you have had an offer of help from some art, music, drama, photography, and creative writing students at the local College. Can you design a program for one or more of them to work with the Bartons? You have \$300 for supplies and materials.

## HOSPITAL PHYSICIANS

The medical director of the cancer center where you head up the arts and cultural services programs has been reading books about “wounded healers” and would like to establish a retreat program for oncologists. You know that such programs have been developed and run by Commonweal near San Francisco and Smith Farm in Washington, DC, but she wants your ideas by the end of the day, so you don’t have much time for research.

### Identified Problems

- You remember reading something in one of Rachel Naomi Remen’s books, something like “Doctors burn out not because they don’t care but because they don’t take time to grieve.” (idea if not exact wording from *Kitchen Table Wisdom*)
- The oncologists work under a great deal of stress and the hospital social worker you contact says they need stress reduction activities.

### TO HELP

Come up with some ideas to provide a three-day retreat program to include stress reduction and expression activities for the oncologists. Who will lead activities? How will each day be structured, and how will the whole retreat “flow.”? What do you think the goals should be? The budget?

## MEDICAL STUDENTS

The medical students have several sets of problems and their professors think you might be able to help. You are Director of cultural services at the university medical center.

### Identified Problems

- One problem is that many students are apprehensive about doing a dissection of a cadaver, but don't want to admit it.
- The second problem is that several of the students do not relate in a positive manner with patients. In fact they can be downright rude!
- The third problem is that many of the students have worked so hard for so long on the sciences that they have not kept up with interests in arts and humanities activities that might help them with the stresses involved in being a physician.

### TO HELP

You are asked to develop medical school elective classes in the arts and humanities that might help any of the above problems. You are also asked to suggest ways in which each problem area could be addressed using arts, arts therapies, humanities, etc.

## HOSPITAL NURSES

Nurses at the hospital where you are employed as interior designer (your job also includes being in charge of purchases of art) have been leaving at a very high rate. The hospital has received a major grant for upgrading the environment and the CEO has asked you to present a design for the nurses' "break room" and rest area.

### Identified Problems:

- Nurses are asked to work long shifts and are often called in to work extra shifts.
- Nurses feel they are not getting the respect that their job responsibilities And the excellent job they do with patients deserve.

TO HELP: Design a break room and rest area that will provide stress reduction possibilities of at least three different types. Suggest some "Caring for Caregiver" activities that could take place in the break room to make the nurses feel that the hospital cares about and respects their work. There is no specific budget for this project, so let your imagination run wild.

### FORMAL PARAPROFESSIONAL CAREGIVER

Mrs. Fletcher works as a paraprofessional caregiver for Mrs. Brown, an extremely angry patient with dementia, sometimes violent, who lives at home. Mrs. Fletcher lives with her husband, two children aged 15 and 13, and her mother, who recently suffered a stroke and had to retire from her job as a homemaker. Mrs. Fletcher's mother can't help much with housework or looking after the kids since her stroke, now uses a walker, and has dizziness and balance problems.

#### Identified Problems:

- Mrs. Fletcher is under an incredible amount of stress, dealing with Mrs. Brown at work and her own mother and family at home, in addition to having her own house to clean.
- Mrs. Fletcher wishes she had had more training in how to take care of Mrs. Brown, who is angry and violent (although small and skinny she has hurt Mrs. Fletcher with her fingernails), and whose dementia makes her to put herself at risk by doing dangerous things.
- Mr. and Mrs. Fletcher are beginning to have trouble in their relationship. While their adolescent children no longer need a babysitter, they are at an age where the Fletchers worry about their hanging out on the street with neighborhood kids. And Mrs. Fletcher worries about her Mom falling if they go out....so they stay at home all the time.

TO HELP: You are Mrs. Fletcher's employer at a large home health agency (or at a Union like healthworkers' union #1199) in a very large City. What can you do to help Mrs. Fletcher and the many women like her who work at your agency? Are there in-service and peer support activities you can build into the program? Can you provide afterschool teen programs for workers' children? Day care for Mrs. Fletcher's Mom? Peer support? Social programs for Mrs. Fletcher and her husband? Respite care....Don't forget you need to think of fundraising sources for most of these programs, since they don't exist now.

### INFORMAL FAMILY CAREGIVER

Widow Rita Ramirez has been looking after her son, José, who returned from Iraq with serious head and limb injuries, for the past 18 months. Rita sits by his bed and eats all day, watching television. She is not getting any exercise and has put on 50 pounds. Now the doctor at the clinic says her blood sugar is up. Her blood pressure isn't so good either. Rita says she wouldn't feel right about leaving José alone and going out to a gym or to walk around. When she is pushing his wheelchair she can't go very fast. Besides, José is very depressed, he doesn't get to go out and he has been having these rages this year, or else he withdraws completely and doesn't want to talk. Rita is afraid to say too much to the doctor because she thinks they will take José away again.

#### Identified Problems

- Pre-Diabetes and high blood sugar for Rita, overweight, lack of exercise.
- Depression for José, and perhaps for Rita as well.
- Possible PTSD for José.
- No socialization for either José or Rita except with each other.

To Help: You work at the Veterans Administration and your job includes responsibility for arts in healthcare programs serving vets with or at risk for PTSD and their caregivers. Develop an arts or humanities program that will serve Rita and Jose and other families with similar problems. You have a budget of \$20,000, a grant from a corporation, to serve 20 families for one year.