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Discussion Guide

for the film

My Mother, My Father

(Caring for Aging Parents)



Dear Friend,

This study guide is designed to accompany the film, My Mother, My Father (Caring for Aging Parents).

What this film shows are four real-life families each struggling in their own way with the stresses and changes involved in caring for a frail older parent.

The Honel family chooses to care for their Alzheimer's afflicted father in their own home and deal with strong emotional stresses that accompany that choice.

The Hagwoods make use of Adult Day Care as they gradually face the need to place their mother in a nursing home.

The Tjeerdemas struggle with a history of emotional conflict in the family when Mrs. Tjeerdema can no longer live alone and a decision needs to be made where she will live.

The Geralis support the decision of their eighty-seven-year-old mother, who is in poor health but highly independent in spirit, to live with one of her widowed daughters.

Each family is refreshingly honest as they talk about the stresses and rewards of their caregiving situations. What this does is help the viewer open up as well to the deep and often conflicting feelings involved in caregiving and decisions about caregiving.

Because of this, ample time and competent facilitating need to be given for discussion after this film is seen.

This study guide is designed to help explore and discuss the many and varied issues that come up as people view the film. We hope you find it both extensive and flexible so that you can use it in a variety of to meet the needs of your group.

If we can be of any further help to you as you design and implement programs around the issues of caregiving, please feel free to contact us.

Sincerely,

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P.S. Quantity copies of this study guide can be ordered at a nominal cost. Just use the order form on the back page or call Terra Nova Films.

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Who Should See This Film?

- · Adult Children of Frail Parents
- Caregiver Support Groups
- Caregiver Support Group Leaders
- Health Care Professionals, including:
 Adult Day Care Personnel
 Nursing Home Personnel
 Respite Care Providers
 Home Health Care Workers
 Hospital Personnel, especially social workers,
 nurses and discharge planners
- Clergy
- Church Groups
- Community Groups
- Senior Center Staff
- Mental Health Professionals
- Family Counselors
- Social Workers
- Gerontology Students
- Medical and Nursing Students

Some Facts on Aging and Caregiving

- For every person now in an institution, at least two with similar disabilities are being cared for in the community. One-third of these need constant rather than intermittent care. Caregiving concerns like those shown in the film are increasing as the numbers of elderly continue to increase.
- \bullet Persons 65 and older comprise 11% of the total population 24 million persons (compared to 3.1 million at the turn of the century). By the year 2030, the total population will grow 40%. The elderly population will almost double. The population over 85 will almost triple!
- It is a myth that families abandon their elders. A recent study revealed that more than half of the older persons surveyed saw at least one of their children on the day of the interview or the day before, that three-quarters of them had seen their children within a week, and that only 10% had not seen any of their children within a month preceding the interview.
- Family, friends, neighbors, and other non-professionals are the care-providers most preferred by the elderly. In general, a flow of give and take exists between older and younger relatives throughout an individual's lifetime. But as elderly family members become more dependent financially or socially, they may receive more of some kinds of assistance than they give. Families provide many kinds of direct physical assistance, as well as financial assistance and emotional support.

Some Thoughts on Family Caregiving

Although many families wish to provide care for elderly members, their ability to do so is influenced by many trends in contemporary life.

Among these are:

- Increased employment of women, the traditional caregivers
- Lowered birth rates (fewer children to provide care)
- Increased divorced and single-parent families
- Increased longevity (both parents and grandparents may need care)
- Increased mobility (children may live across country)
- Lack of community support services for home-bound elderly

Various supportive services and resources for families caring for an older person are available. Reputable health care agencies and institutions in the community will readily provide this information to caregiver families who seek it.

In addition, many hospitals, colleges and churches now provide (or will provide, if asked) educational programs and caregiver support groups for families caring for a frail older person.

These kinds of supportive services help a family to continue to care for an elder, and thus delay or prevent placement in a long-term care facility.

However, nursing home placement may be the long-term care plan of choice for some elderly and their families. When loneliness, safety and health needs make a home a less desirable place, it may be a relief to choose a nursing home or a retirement home over home care. Cost of services for extensive care from community agencies may also be a factor in the decision for placement.

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Some Ways to Use the Film, "MY MOTHER, MY FATHER"

One 2-4 Hour Session:

A brief session starting with the film and followed by discussion in small groups of 4-6, using a professional from the community or a seasoned caregiver to facilitate each small group. These facilitators may have been included in the planning and promotion of the program and may wish to preview the film and have copies of this discussion guide ahead of time. The program coordinator may wish to wind up the program with brief reports from each group, sharing highlights of the group's experiences.

A Day Long Workshop:

In addition to the above, you may wish to begin the day with an exercise in which paired participants share 1) their own caregiving experiences and 2) what they expect from the workshop. This pair could then choose another pair after the film to form a group of four for the post-film discussion. The discussion could continue until the lunch break.

After lunch you could present a panel of service providers from your community (or program directors from your own agency) who could talk about the services available to home-bound older persons and their families.

You may want to offer a number of mini-sessions where some of the following topics could be presented and discussed in more detail:

- Myths and Stereotypes of Aging
- When is Guardianship an Option?
- Deciding Who Does What--The Family Conference
- Feelings of Caregivers
- Managing Difficult Behaviors
- The Normal Aging Process
- Accessing and Utilizing Community Resources
- How to Start a Self-Help Support Group for Caregivers
- Skills and Conditions for Home Care
- Alternative Living Arrangements
- Taking Care of the Caregiver
- Helping the Elder Cope with Grief and Loss
- Death and Dying and Home Care
- Time Management for the Caregiver
- Communication with Someone Who Has a Dementing Illness
- The Finances of Caregiving

6-8 Sessions:

You may wish to plan a series of sessions for caregivers choosing from the topics previously listed. Some people may prefer to use the film in four segments, showing one family each week for four weeks, discussing the issues and concerns of that family as they apply to the caregiver's own situation. These groups of participants may choose to spin off from this experience into a self-help, mutual support and problem solving group, inviting professionals in to lecture as skills and information are identified and needed.

Considerations For Facilitating Your Discussion Group

The adult participant has experiences and information of value to others in the group. This experience can be organized around discussion points or topics. Remember that adults as learners:

- Are self-directing
- Are responsible for themselves and their learning
- Learn more if they participate actively/share
- Have much to contribute
- Apply learning to current life situations
- Require practical application/results

There are a number of facilitator qualities and skills which help to create a positive climate for risking and sharing. Warmth, sincerity, patience, understanding, flexibility and perseverence are all human qualities which help to create a climate of openness and trust. Skills in interpersonal communication, listening, and empathizing are also important. In creating a positive learning climate, a facilitator should do the following:

- Provide a non-threatening atmosphere which encourages participants to express their ideas, opinions, feelings and experiences.
- Arrange to meet in a comfortable setting where there are a minimum of outside noises or distractions.
- Design discussion groups of 4-6 participants. It is easier to speak in a smaller group.
- Sit in a circle so everyone can see and hear each other.
- Ask questions to stimulate discussion.
- Encourage sharing of resources, ideas, feelings and solutions.
- Challenge without attacking self-worth, confidence or integrity.
- Provide positive and constructive feedback.
- Allow for clarification and discussion of issues.
- Don't be afraid of silence! Participants need time to think.
- Emphasize that conclusion or resolution need not always be reached.
 There is no one right answer!
- Promote mutual support and networking.

1. Old is...

2. Successful Aging is...

3. Decisions about Caregiving and Living Arrangements

Anna Gerali says, "...I feel old... because I can't do what I want to do!" "You know when you're old? When you're six feet under! When do you throw something away? When you can't wear it no more, right? It's old, you don't want it, throw it away! You don't throw a good garment away."

Anna says, "My poor eyesight...won't hold me down. I still like to be with people, I like to work, I like to do things..." I don't worry about the future...who knows if I'll wake up!...I said, 'Lord, you have to give me strength to take care of myself.'

Julia Hagwood's daughter says, "My minister brother said to me, 'Where is it written that you have to be a martyr for mother?"

One of Jennie Tjeerdema's daughters recalls that Jennie used to say, "I'll spend a little time with each of you when I grow older..." But now Jennie says, "I don't want to be by the kids, and the kids don't want me."

Jennie's son-in-law says, "Basically she's a very independent person and very hard to live with and very dominating. No matter who would have her, it would upset (their) family."

When is one old? (Many older persons think that only those older than they are really old.)

Has anyone ever died of old age?

What changes occur as we grow older?

What happens to memory and intelligence as we grow older?

How do our emotional needs change as we grow older?

True or False: "We are, when we are old, what we have always been, only more so."

Many elderly say they never expected to live so long and are unprepared to fill the time in a meaningful way.

Who do you know who has aged well? Someone who could be a model for how you'd like to grow old. List some characteristics of that person.

What can you begin to do now to ensure your own successful aging?

How might the need to make decisions about living arrangements cause stress? What might be stressful about making changes in family routines as caregiving responsibilities increase?

List the options for living arrangements for older persons unable to completely care for themselves.

What kinds of relationships exist between the older person and other members of the family and how do they affect choices concerning caregiving?

Are decisions about caregiving based on love? Guilt? Responsiblity?

It is very important to be in communication with the older family member whenever difficult caregiving decisions are made such as: Who will provide "respite" (rest, a break) for the adult child? Who will be hired to do the homemaking chores? And when it is no longer possible to provide adequate care in the home, what nursing home will be chosen? It is important for the older family member to be involved as much as possible in any decisions that are made concerning him or her. The amount of involvement will, of course, depend on his or her degree of impairment.

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4. Sharing the Caregiving

5. Feelings of Caregivers

Grandpa Honel's daughter-in-law says, "I was proud that I was good at handling him but what I wanted was everybody else to watch me and learn how to do it; instead, they let me do it." And, "This was his father, and he was still, you know, with the elbow at night! We came to a change on that. He decided he could take over night duty and still work at his job during the day. That meant a lot to me. I could see that he wanted to do his part."

One of the Gerali daughters says, "Each one of us (daughters) plays a different role in this..."

Grandpa Honel's daughter-in-law says, "The hardest thing for me was my anger. Anger that I had never experienced before...hard to know how to handle that...you just want to go away and not have to put up with this." His granddaughter says, "I felt I was above him because this was my house and he didn't belong here. He was telling me what to do...I resented it a lot!"

Julie Hagwood says, "I knew I had reached the saturation point. I feel like I'm being strangled or suffocated and you keep thinking, if I could just get some air, if I didn't have to live with this dread of if the phone rings late at night, what might have happened."

Then she continues, "The spiritual things that...I believe in...are there because of what she taught me...by precept and example...Why can't I apply these things and make them work so that I am actually able to take care of her?"

Whose responsibility is the caregiving?

How can the duties be divided and shared?

What gets in the way of sharing the caregiving responsibilities?

How is the primary caregiver chosen?

What might be stressful about the role of caregiver?

How would you as the caregiver divide your time to reduce the stress you feel from competing demands?

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r, if the List and talk about some positive feelings common to caregiving such as: love, respect, laughter, joy, happiness, warmth, closeness, affection and the appreciation for the opportunity to return or repay all that has been given to you.

List and talk about some negative feelings common to caregiving such as: fear of the unknown future, trapped, loneliness, missing friends and normal activities, prisoner in your own home, guilt for things done and those not done, embarrassment over a parent's behavior; anger, vulnerability, grieving for the person she or he used to be, the grief of watching a loved one suffer through illness and dependency, the disappointment that you can't make everything better.

5. Feelings of Caregivers (cont'd)

6. Caregivers
Need Support

One of Jennie's daughters says, "She's hurt me from the time I was a little kid... She would never be kind to me or do anything for me. I have a bitterness that says 'No way! No way!" The grand daughter adds that Jennie had said, "My mother once told me that I was a stupid person. I'll never forgive her for that." The grand daughter says, "It went from me to my mother, to herself, to her mother. The hurts are lifetimes long."

Julie Hagwood tells how her husband had once said to her, "Were you just about ready to give her a good swift kick?" and that she had responded, "Yes! And that's when I just walked out the door. If I had stayed there one second longer...oh yes, honey, she would really have been slugged."

A support group member says, "If you get it up to here you lose your mind, and you actually want to kill them."

Grandpa Honel's daughter-in-law says, "People come up to me and say, I know what you're going through."

Julie Hagwood says, "When (you) come to support group and you mention some of the experiences you're having and looking for ways to cope with them, everybody there understands what you're saying and you don't have to try to explain the frustration or make them believe that what you're saying is true!"

In some situations the severity and amount of stress on the caregiver can lead to abuse or neglect of the older person. Passive neglect includes leaving the person alone, isolated, or forgotten. Such things as withholding food, medicine, companionship and bathroom assistance are active neglect.

Abusive treatment may be physical, verbal or emotional. While this is not the norm, it does occur in instances where people have reached their limit and have acted in frustration or rage. These caregivers need to find and accept 1) their limitations, 2) their need to take care of themselves and 3) their need for support from family, friends, church, neighbors, and community service agencies.

Why is support important?

Everyone needs support! It's a basic human need. It may include physical, emotional, financial, or spiritual elements.

A person involved in long-term, stressful situations runs a high risk of illness unless a planned support system is available. The older person's well-being depends on the caregiver's well-being. The caregiver needs to let others know how they can be helpful. It is necessary to ask for help!

How may family members provide support? What kind of support can each of these provide? Friends. Neighbors. Churches. Professionals. Peer support groups .

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7 Unmet Needs of Caregivers

8. Home is Best...

9. Community Services

Milt Honel reports, "My dad was aware that he was deteriorating. Here-to-fore he had never told me that he loved me or cared about me. At this point, a half-a-dozen times, maybe, he said to me that he loved me. If he had been in a nursing home, he would have gone through that phase and we would not have had that opportunity."

Jennie Tjeerdema's daughter says, "She's never given anything back to me. I'm still looking for it. I hope that when I come to see her, she'll say something nice to me, but generally she doesn't."

Julie Hagwood told her mother, "I'm doing everything I possibly can do to see to it that you don't go any place but stay right here where you want to stay, in your own home!"

Jennie tells her daughter, "You'll find out later-- you want to stay in your own house!"

Julie Hagwood's daughter says, "What the Adult Day Care Center does for us is to preserve our sanity. I know that when my mother is there, she is in a secure environment. She's also involved in meaningful activities. We feel that the Day Care program has slowed the deterioration process down considerably. If she stayed in her home, living alone, she never would have lasted as long as she has."

Anna Gerali's daughter asks, "What services can we get (when mother can't see anymore and I'm at work)?"

What are some emotional responses a caregiver might expect to receive from an older family member?

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Do adult children still need expressions of love and approval from their parents? If so, how can these needs be met?

What are some barriers to good communication between the older person and a caregiver?

How might role shifts cause stress for a frail older person? For the caregiver? Can negative feelings between the caregiver and the frail older person be ignored if the need for care requires that they now spend more time together? What can be done? Is assertive confrontation with an elderly parent realistic? Are there other options?

When there has been a good relationship between the older parent and the child, can the relationship grow even closer through the caregiving experience?

Do older people who are frail prefer staying in their own home if they can get the help they need? Why?

What considerations need to be made regarding conditions, equipment, safety, and services?

Community services and agencies are intended to supplement family care. An older person can retain independence and continue to live in the community by allowing dependence on some community resources and services that reduce the burden of the family's caregiving.

When and why should we consider services from formal support systems? What are some limitations of formal supports?

What kind of feelings might you have as you relate to community agencies? What are some things caregivers should know when they communicate with service providers?

10. Nursing Home Placement

Julie's daughter says, "Mother would turn to me and say, generally almost with tears, 'You wouldn't put me in a nursing home would you?'... If I know that next week she's actually going to go...I know that it's going to be difficult.

Anna Gerali's daughter says, "The last thing I would do is to see her go into a nursing home! The last thing! That would be the last resort! The three of us would try to pitch in, share days or share evenings and do what we could as long as we could."

Why is nursing home placement so hard to consider? List situations when nursing home care may be the care of choice; the responsible thing to do.

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Bibliography: Caring For Aging Parents

- Bonjean, Marilyn J. In Support Of Caregivers: Guidebook for Planning and Conducting Educational Workshops for Caregivers of the Elderly. Vocational Studies Center, School of Education, University of Wisconsin-Madison, 1983.
- Bressler, Dawn S. Understanding Your Aging Parents: A Community Based Education and Support Program for Adult Children. AARP, 1909 K St. N.W., Washington, D.C. 20049, 1985.
- Bumagin, Victoria E. and Kathryn P. Hirn. **Aging is a Family Affair.** N.Y.: Lippincott and Crowell Book, 1979.
- Cicirelli, Victor G. **Helping Elderly Parents: The Role of Adult Children.** Boston: Auburn House Publishing Company, 1981.
- Gilles, John. A Guide to Caring for and Coping with Aging Parents. Nashville, Tenn.: Thomas Nelson Publishers, 1981.
- Goodman, Jane G. Aging Parents: Whose Responsibility? Family Service Association of America, 44 East 23rd Street, N.Y., N.Y., 1980.
- Mace, Nancy and Rabins, Peter. The 36-Hour Day: A Family Guide to Caring for Persons with Alzeimer's Disease, Related Dementing Illnesses and Memory Losses in Later Life. Baltimore: John Hopkins University, Press, 1981.
- Rzetelny, Harriet and Joanna Mellor. Support Groups for Caregivers of the Aged. Community Service Society, 105 E. 22 St. N.Y., N.Y., 10010, 1981.
- Schwartz, Arthur N. Survival Handbook for Children of Aging Parents. Chicago: Follet, 1977.
- Silverman, Alida G., Carl I. Brahce and Carol Zielinski. **As Parents Grow Older.** Child and Family Services of Michigan, 9880 East Grand River, P.O. Box 548, Brighton, Michigan, 48116, 1981.
- Silverstone, Barbara, and Helen Handel Hyman. You and Your Aging Parent. N.Y.: Pantheon, 1982.
- Springer, Dianne and Timothy H. Brubaker. Family Caregivers and Dependent Elderly:
 Minimizing Stress and Maximizing Independence. Beverly Hills, CA: Sage Publications Inc., 1984.
- White, Diana and Margaret Neal. A Guidebook for the Family and Friends of Older Adults. Portland, Oregon: Institute on Aging, Portland State University, 1981.

Newsletters and Pamphlets:

- Cohen, Stephen Z. Bridging the Other Generation Gap. Philadelphia, PA: Colonial Penn Group, Inc. 19181, 1980.
- Your Aging Relatives: How You and Your Family Can Help Them. Spring House, Pennsylvania 19477, 1980.
- **Change,** Newsletter of the National Support Center for Families of the Aging. P.O. Box 245, Swarthmore, PA 19081.

Compiled by Connelly Consultants On Aging, 1985:

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TERRA NOVA FILMS

Terra Nova Films is a growing not-for-profit organization specializing in the production and distribution of films that explore social and personal issues.

Since its inception in 1979 by its present director, James Vanden Bosch, the hallmarks of our films have been to show the dignity of all people, challenge stereotypes and encourage caring attitudes.

Several other films on aging are available from Terra Nova Films. Write for our free catalogue.

Terra Nova welcomes input and ideas from agencies or individuals wishing to work cooperatively with us on new films on socially relevant issues.

Terra Nova Films is also available to produce films, videotapes or slide programs for clients who want artistic excellence and social purpose in their visual productions.

For more information contact James Vanden Bosch at (312) 881-8491.

MY MOTHER, MY FATHER

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BLUE RIBBON

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FIRST PLACE

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CHRIS BRONZE PLAQUE

Columbus International Film Festival

FIRST PRIZE

American Journal of Nursing Media Festival