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A Teenager's Guide to



Care
giving

NEW YORK STATE OFFICE FOR THE AGING

Facilitator's Guide

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Guide
to
Caregiving

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Facilitator's Guide

About the Teenager's Guide to Caregiving

The Teenager's Guide to Caregiving is designed to break down barriers and offer support to the adolescent's affected by aging relatives in need of care. It is written in terms that young people will understand and find interesting. The New York State Office for the Aging recognizes that families provide an enormous amount of care to their frail and dependent elderly. Such care is provided in the community and allows the elderly person to maintain independence and avoid institutionalization.

The Guide was developed by the Madison County Office for the Aging and the New York State Office for the Aging. A technical work group comprised of teenagers and representatives from the Madison County Mental Health Dept, Madison County Council on Alcoholism and Substance Abuse, Retired Senior Volunteer Program of Madison County, Central New York Association for the Blind and Visually Impaired and State University of New York at Morrisville, all participated in its development.

Field testing of the Guide was conducted in Westchester, Ontario, Orleans and Madison counties by the local Offices for the Aging in those counties. The Guide was tested in a variety of settings: junior/senior high classroom, after school program, support groups and at a senior day program.

Introduction

While children are sometimes seen as a stressful responsibility to caregivers, junior and senior high students can be a resource. Their contributions can reduce stress on parents and are integral to the care provided in the household. In fact, teenagers often have caregiving responsibilities for elderly adults, and for younger siblings which enable parents to devote attention to the frail adult.

Teenagers may be influenced positively or negatively by family caregiving and may feel isolated, angry and confused. Some may see their parent's attention to grandma or grandpap as somehow depriving them of parental guidance, love and time. They may encounter "stressed out" parents who are short on patience. Teenagers may witness strange behavior, or physical

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violence by older relatives whom they love. Often children are more sensitive to a deterioration in their parent(s) relationships with the care-receiver than the parents themselves. Traditionally, research and attention has focused on the adult primary caregiver's emotional and physical needs. Now, support groups, training, and resources such as this Guide positively address the caregiving experiences for adolescents.

Providing care for a functionally impaired older person is not a new issue. Over 80% of the frail elderly are cared for by family members. The phrase "Sandwich Generation" refers to adults who are caring for an elderly relative (usually a parent) as well as caring for their own children. For the older person and the adult caregiver there are many resources. For the teenager who lives in the home with an elderly relative there are few resources. This Guide will create an awareness that teenagers, too, may feel the same or similar stresses their parent(s) feel in the role of caregiver. Creating an awareness and identifying the possibility that teenagers feel "caregiver burn-out" is the first step towards helping them to cope.

Teenagers made valuable contributions to this Guide. They shared their stories, emotions and experiences of living with a frail and dependent older relative. The most important message they wanted to give to other teenagers is "You Are Not Alone." There are ways to cope, survive and to make the caregiving experience a rewarding one.

Your Role as Facilitator

Teenager's must be treated as persons with their own needs. They want to understand what is going on in the family, what is happening to the older person physically, mentally, and emotionally, and the techniques to assist in caregiving. They want to be able to communicate with their parent(s) about this issue. They must learn how to overcome embarrassment and cope with their altered lifestyle when home becomes hospital — when they become home health care aides, home chore workers, and respite providers.

The Teenager's Guide to Caregiving is designed to address these issues for the 12-18 year old.

Your role as facilitator is important. Participants in the group must feel safe and respected with an atmosphere of trust in the group situation.

Achieving this is a gradual process. Some of the teenage participants may purposely express negative feelings to test the waters to determine if all feelings are acceptable. If there are periods of awkwardness and silence, participants may be deciding who they can trust, how much information to disclose, how safe the group is, who they like or dislike and how much to get involved. The participants will be learning to build trust.

The facilitator must be empathetic. Put yourself in the shoes of the teenager. For example, remember when you were fifteen years old:

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*** You have a wonderful relationship with your grandparent. All your life you have shared experiences, baked cookies together, played cards, fished. Remember those magical moments? Suddenly your grandparent accuses you of stealing money. How does that make you feel?**

*** Your grandparent may call you by another name or not recognize you. How does that make you feel? Your grandparent may be in the early stages of Alzheimer's Disease, but you don't know that! All you know and feel is hurt. "Why is Grandma saying this?"**

*** Your grandparent lived far away, your only relationship was occasional phone calls, a brief vacation together, birthday and holiday cards. Then your grandparent is unable to live alone and moves in with you. Are you supposed to love and care for this person who is practically a stranger to you?**

*** If you live in a small apartment, does livingroom become Grandma's bedroom or hospital room? How does that make you feel when you bring your friends home? Do you bring your friends home or do you choose to stay away because you are embarrassed of your living situation? Why does this old person demand so much time and attention from your parents(s)?**

These are all real situations and thoughts that teenagers who are living in caregiving families have expressed. Fear, grief, confusion, resentment, love, hate, guilt, and compassion have been expressed by teens. Caregiving can be very rewarding but with it comes a mixed bag of feelings and it is OK to feel all of these emotions.

The facilitator must be sensitive to diverse populations. Culturally different populations have their own ethnic values and beliefs passed from generation to generation. The way families react to a dependent older person is not determined by race but is influenced by the family's religious beliefs, social class, national origin, and even the geographical area in which they live.

As a worker, be aware of your own prejudices and beliefs.

All families need to be looked at in terms of cultural and environmental contexts. Strive towards sensitivity and objectivity in working with families of diverse ethnic heritage.

Work with your local Office for the Aging and learn all you can about the caregiving experience. The greater the awareness of caregiver issues that you have, the greater will be your ability to help those in caregiving environments. Take a wholistic approach to helping caregiving families by giving support to the entire family, including adolescents.

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Communicate with your local Mental Health Agency and Department of Social Services. Make them aware and encourage them to be involved in your program. You will need their support and expertise. Suggest monthly meetings with these professionals to keep them informed of your group's progress.

Teenagers who are in caregiving environments must try to maintain a positive self-image. Finding resources, listening and sharing feelings with others will help them cope with the caregiving experience.

Do not compare or assume that every teenager will be experiencing the same feelings. Treat them and respect them as individuals.

Encourage caregivers who may be experiencing any of the warning signals for caregiver burnout to contact their local Office for the Aging, county social services, public health department or mental health department to find help to assist them as caregivers.

Warning Signs of Caregiver Burnout

- **shortness of temper**
- **sleeplessness**
- **physical problems** *such as: loss of appetite, headaches, fatigue, shortness of breath and dizziness*
- **withdrawal from people close to you**
- **financial problems**
- **disinterest in normal leisure activities**
- **inability to accept help from others**

Program Design

The Teenager's Guide to caregiving is designed for teenagers who assist older relatives in need of care. It was written to be used in a group setting or individually.

The curriculum is divided into eight sessions or chapters to help the teenage participant:

- *Understand his/her role in a caregiving family*
- *Understand normal aging and attitudes*
- *Understand what is happening when their older relative becomes frail*
- *Maintain a positive self-image*

- *Understand and cope with special concerns and feelings he/she may experience in a caregiving family*
- *Realize the importance of communicating — talking to someone about feelings and concerns*
- *Understand their parent(s) regarding caregiving issues*
- *Understand memory loss (dementia)*
- *Learn about supports available to the teenager*

Outreach and Recruitment

To recruit participants, give presentations to groups of adults using the *Teenager's Guide to Caregiving*, NYS Office for the Aging video *You Are Not Alone*, and the video *Just For the Summer*. These will help create an awareness that teenagers are affected in caregiving families.

Encourage adult participants to refer teenagers to you for the workshops. Many adults are involved in caregiving themselves and have children of their own or they may know of teens who would benefit from this involvement.

Approach groups by letter and a follow-up telephone call. Local school districts may be able to provide you with a list of organizations in your area. Mailing and telephone lists may also be obtained from your local Office for the Aging, clergy, Chamber of Commerce, and Employee Assistance Programs.

Make presentations to:

- school faculty and staff (target school nurses, Jr/Sr High School teachers of health, home economics, human development, etc.)
- Parent Teacher Associations
- Business Groups, Service Organizations
- Church groups
- Support groups and Caregiver Workshops (your local Office for the Aging can help reach the informal caregiver)

Approach teenagers by offering to give a presentation to groups they are involved in. Follow-up with telephone calls. Publicize workshop schedules by displaying information at youth centers, libraries, YM and YWCA's and other places teenagers "hang out". You must have a lot of patience — establishing a teen group will take time.

Make presentations to teenagers in:

- schools • church groups • Boy Scouts/Girl Scouts • 4-H clubs
- other teen groups

Use Media:

- Radio • Television • Newspapers, including school newspapers • Caregiver, Office for the Aging Newsletters • Church bulletins

Sample Press Release

For Immediate Release

Today's Date

Contact:

Your Name

Agency

Address

Phone Number

Attention Teen Caregivers!

Do you help care for an elderly relative? If you do, you know that providing care for an older relative can be very rewarding, and sometimes extremely difficult. Caregiving can produce a mixed bag of emotions for teens that is difficult to deal with.

Now there's help specifically for teenagers who are living in this type of situation. The Teenager's Guide to Caregiving workshop uses a fun workbook designed in part by teenagers who have helped in caregiving situations. They share their experiences and ideas to create a better understanding of caring for an older relative along with tips for success in dealing with the problems that come along.

Get the help you need! For information on the Teenager's Guide to Caregiving contact (*Name*) at (*Phone Number*), at (*your local Office for the Aging, etc.*)

Teenagers who have elderly relatives living with them do not jump out of the woodwork and announce "Here I am!". You must do a lot of ground work to reach them. Be persistent and patient.

Options for presenting the curriculum:

- This eight session open workshop can be offered as an after school program, at a local YMCA, Youth Center, school or church

- Overviews can be delivered to community teen groups, health, marriage & family, home economics, psychology, junior/senior high classes, as a preliminary outreach method
- The Guide may be used by teenagers individually

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Group Sessions:

The sessions must be interesting and fun! You want your group to look forward to additional sessions.

Determine how often and when the sessions will be held.

- weekly or bi-weekly are recommended
- be flexible, sessions are designed for approximately 1 1/2 hours
- no more than 15 participants per group is recommended
- be aware of conflict with other after school activities
- end each session on a positive note, with discussion

The Teenagers Guide to Caregiving has been designed to be flexible. Whenever a teenager expresses an interest to participate in the open workshop, welcome them, even if it is the final session.

Guidelines:

1. **Meet in a comfortable, casual setting.** If you are sitting around a table, place paper and pencils around for doodling and notes.
2. **Allow teenagers to become comfortable with you.** Show them you care, that you understand how challenging it is for them. Be empathetic.
3. **Try to know each teen's individual caregiving situation.**
4. **Give permission to say what they really feel.** Some feelings may shock you, "I wish she were dead". Without the confidence that they can talk freely, a young person may not share any true feelings with you and that would defeat the purpose of the workshop.
5. **Help the teenager confront and deal with their worst fears.** "Grandpa is dying" or "Maybe I'll catch Grandma's cancer".
6. **Encourage family communication.** Confidence gained in a support group may result in a long avoided talk between the teen and family members.
7. **Keep trying, gently, gradually,** to involve a reluctant teenager in the group's activities. A teen who sits back may join when emotionally ready. Remember, the important thing is that they are there.
8. **Reinforce the importance and validity of their lives.** They may feel guilty for being young and strong when their elderly relative is frail. Encourage them to discuss their futures, college, careers, relationships.
9. **Point out that most older persons lead active and healthy lives.** As with anyone of any age, health concerns may cause an older person to need help.

10. Work out problems and conflicts with them. You may want to recommend a counselor in some situations.
11. Hold meetings regularly, be consistent and dependable.
12. While some teenagers feel comfortable in group situations, others may need individual attention to share their feelings.
13. Provide refreshments at each meeting.

First Session:

Participant Registration Form *(use sample form in Appendix or similar)*

- Distribute registration forms to participants
- Allow (up to 10 minutes) time for completion. Ask for name, address, telephone number (in case of cancellation), name of parent/guardian, and a brief sentence of what they hope to get from the sessions
- Explain the Open Workshop — Anyone can join the group at any-time

Icebreaker/Getting to Know One Another

A group activity to "break the ice" helps everyone to get to know one another (*New Games and More New Games* by Andrew Fluegelman, Doubleday Publishing, is used as a resource here and is worth consulting for further suggestions)

Examples:

- Have the group (*including facilitator*) stand in a circle and toss a ball around quickly. The ball must never touch the floor. The purpose of this exercise is to develop trust among the participants and instill good feelings.
- Have the group walk around as quickly as possible shaking hands and introducing themselves. It may be helpful to put a time limit of 3 - 5 minutes depending on size of group. "Hi, my name is" and go on to the next person. Ask them how many names they remember.
- Have teenagers participate in a trust walk. Teenager' choose a partner (*preferably someone they do not know very well*). One is blindfolded while the other guides them around the room. After a few minutes they switch.

Encourage teenagers to bring family photo to first session

Facilitator must understand that it is unlikely teenagers will just open up and start discussing the family caregiving situation. Allow time to develop a trusting relationship.

- Before introducing the **Teenagers Guide to Caregiving**, have the group view the SOFA video *You Are Not Alone* or *Just For The Summer*.

Introduce the Teenagers Guide to Caregiving

- Say to your group, "This book belongs to you and only you. The feelings that you express are yours and you have the right to express them. You can write, doodle, draw or just turn the page anytime you want."
- "Caring for a grandparent or older relative is both rewarding and at times can be very difficult. The purpose of this manual is to better understand the feelings that you may have and the feelings of your older relative."
- "Many teenagers participated in the writing of this manual. They shared their feelings and experiences of caring for an elderly relative. Most importantly the message they want to share with you is that You Are Not Alone."
- "Have fun using this guide. The activities are intended to be fun and educational."

Encourage members of the group to share family photo's

Include in every session:

Session Steps:

1. Opening Remarks

- extend cordial welcome to group
- Introduce yourself
- Explain your role — to provide information and to guide participants in discussion
- Encourage participants to ask questions, comment, share concerns, be courteous about time

2. At end of each session, summarize the session, using Key Points.

- Ask for additional questions or points to be raised for further discussion.
- Thank teenagers for participating and give a brief preview of the next session topic areas. End sessions with discussion, and on a positive note.

3. Getting Started

- Explain seating arrangements (arrange group to face each other in order to facilitate conversation)
- Point out stairs, elevators, entrances, exits, rest rooms etc.
- Explain length of sessions, breaks, refreshment possibilities

Materials:

1. pens, pencils, erasers, magic markers
2. tape

3. extra copies of each activity page
4. a box of tissues
5. 3x5" cards

Preparation for Facilitator:

1. Read all information before each session
2. Preview videos

Program Content:

Session 1 - A Caregiver Provides Care

This chapter seeks to give the teenager a sense of belonging within their family network and to answer the question, "Who is a caregiver and why?". The following activities can encourage creativity, stimulate communication and discussion, identify roles in the household, and help identify where each person "fits in".

Heather's Story (p.1)

Heather wrote this story when she was a senior in high school. This story recalls one evening Heather spent with her grandmother. Ask for a volunteer to read this story and discuss using the following questions.

1. Who is a Caregiver and Why? (p.1)

This is a brief narrative which defines caregiving. Read it to your group and discuss.

2. The Family Tree (p.3)

The Family Tree activity helps a teen to visualize and have a sense of belonging in their family. If the relationship of the care-receiver is not included on the Family Tree, have the teenager create a line. *For example, if your Uncle is living with you and he is your mother's brother, under the line for your mother draw another line and write in your uncle's name.*

- If a teen is caring for an unrelated older person, have him or her create their own special spot for that person.
- Including step-parents is a personal decision the teenager needs to make. Whether or not they include them is OK.
- Teenagers may have difficulty completing the Family Tree in the group. Encourage them to complete as much as they can. Suggest they have family members help them at home.

Remember, a teenager may choose not to do this activity. That is OK. Suggest that they try to complete the Family Tree at another time. If they choose not to complete this or any other activity, reinforce the fact that they are and always will be a welcome member of the group.

3. You and Your Family (p.2)

It may be easier for the teenager to use a photograph for this fun activity. Encourage teenagers to take turns to introduce their family to others in the group. Again, if they choose not to participate in this activity it is OK.

4. Remember a Fun Moment (p.4)

Read Jesse's Story out loud before beginning activity

Remembering a fun moment helps identify positive feelings about the older relative in the teenager. Remembering a Fun Moment could be something that happened years ago, or just yesterday.

After completing this activity, encourage teenagers to share their fun moment with the group. Again, it is OK if they choose not to participate.

5. Is Your Parent Sandwiched In? (p.5)

This activity helps create awareness and understanding of what teen's parents may be experiencing as members of the Sandwich Generation. Be aware that this may be a very sensitive activity to some group members. Anger, rejection and resentment may be expressed here. Suggest someone volunteer to read their response out loud. If negative feelings are expressed, encourage the teenager to talk to someone they trust, i.e., sibling, parent, teacher, counselor, friend, minister, etc. Be ready to listen!

Reinforce the following statement:

Your parent(s) may not intend to spend less time with you, they're probably just "sandwiched" in between you and your elderly relative.

6. Get to know your older relative in need of care (p.6)

Interviewing an older relative may prove to be a cherished moment and the teenager may want to record the interview. Encourage teens to think of questions in addition to those suggested in the Guide.

In some cases the older relative may be unable to remember or to verbalize. When this occurs, encourage the teenager to interview a parent or someone who knew the older person well.

Be aware that the interview may bring up family secrets. If this happens, encourage the teenager to discuss them with an adult they trust.

Session 2 - Aging Happens to All of Us

This session deals with the normal aging process and examines myths and stereotypes with the objectives to better understand normal aging; to understand attitudes and to identify life roles. Point out that most older persons lead active and healthy lives. You may choose to make a list of famous older celebrities to demonstrate, *for example*; Chuck Berry, George Burns, Lena Horne, Jessica Tandy, Nelson Mandela, Minnie Pearl, Bob Hope, Ronald

Reagan, Ella Fitzgerald etc. Use community resources for this session. Invite a doctor, nurse, or gerontologist to be a guest speaker.

There are many diseases that affect the elderly. Encourage teenagers to use libraries to get more extensive information. Reproduce and distribute the list of helpful toll-free telephone numbers provided in the Appendix to this Facilitator's Guide.

1. Read The Normal Aging Process... (p.7)

You may provide photographs demonstrating the life span beginning at birth to old age. Say to your group *"the one thing we all have in common in this world, is that for every second, minute, hour, day and year, we are all aging. It's a fact of life!"*

2. Age and Attitude... (p.8)

This fun activity demonstrates the difference between chronological age and the age we feel inside.

You may choose to start out this activity by asking members of the group to identify their actual age, the age they wish they were, and why. Now ask them what the age they feel inside. It is expected that the ages they wish or feel will be quite different then the age they actually are.

Have group members share their findings at the next session

3. Age Simulation (p.9)

For this activity, you may choose to have an assisant help you. A large spacious room is recommended.

Age Simulation materials (per person):

two elastic bandages (3 or 4 inches wide)

coat	earmuffs
bulky gloves	Swim goggles or old glasses
shirt with buttons	petroleum jelly
pencils and paper	newspaper or book
marshmallows	apple or snack food
needle and thread	sandwich bags
yardstick	radio or tape player
masking tape	music tapes
cotton balls	television

This is a fun and stimulating demonstration to help create awareness of physical impairments that may affect some of the elderly. It is important to

point out that while this activity is a lot of fun, most older persons lead active and healthy lives. As with anyone of any age, health concerns may create physical impairments.

Ask group members to pair up. Have them take turns assisting each other with simulation techniques.

You may want to videotape this activity.

Ask teenagers to describe how they felt while doing this exercise. How easy was it for them to move around? Communicate? See? Hear? Walk? Button a shirt? Was it frustrating for them? If so, have them explain.

4. You're Still Yourself As You Age (p.10)

Say to your group "Let's look into the future. It's hard to imagine what you will be like when you are much older. This exercise is intended to make you think about what you will be like." Read aloud *You're Still Yourself As You Age*.

5. We play many different roles - life spectrum (p. 10-11)

This activity demonstrates the different roles we hold in life. Many roles will overlap, for example your group members are a son/daughter, student, babysitter, athlete, and caregiver, right now!

Encourage teenagers to complete the Life Spectrum for themselves and if possible for a parent and older relative. They may need to complete their spectrum with a relative's help. An example of a Life Spectrum has been completed in the *Teenager's Guide to Caregiving*.

Session 3 - You The Caregiver (p. 12)

Negative and confusing feelings are often felt by a teenager due to caregiving experience. Isolation, anger, love, fear, guilt, confusion and resentment are a few of the feelings which may magnify a negative self-image and put teenagers at-risk.

This session seeks to reinforce a positive self-image, identify the importance of communication, the importance of a sense of humor and to focus on positive emotions.

1. Caring for yourself and another person... (p.13)

Providing care to another individual is a big responsibility regardless of age. Caregiving is assisting someone with things like bathing, grooming, feeding, household tasks, shopping, meal preparation, and companionship.

Teenagers may feel as if their life has been disrupted by the caregiving situation. They may feel as if they are asked to do too much or as if they are not contributing enough to helping their older relative.

Making a list helps identify how the teenager does contribute. It is important that the teenager recognize the "little things" as valuable contributions to caregiving. Just spending time talking with an older relative is as important as assisting with a bath.

After teenagers make a list of contributions they give to the care of an older relative, write the contributions on a blackboard or large paper. This will help the teenagers to actually visualize their accomplishments and instill a sense of pride.

2. Mirror Mirror... (p.14)

Materials: Hand held mirrors

Teenagers may be embarrassed and view this activity as silly. Positive affirmations are often difficult to accept from others and equally difficult to give to ourselves.

For this fun activity pass a mirror around or have them face a partner and say aloud some of the statements on page 14.

3. Sharing Experiences (p. 14)

Read Sharing Experiences and Tammy's Story. Use the questions following to stimulate discussion.

4. Humor is the Best Medicine (p.16)

Say to your group *"we all know that when we see or hear something funny we laugh and it makes us feel good. We have experienced laughter already in the group."* Suggest that someone volunteer to read **Humor is the best medicine**. Ask your group members to share a funny experience with others.

5. Remember the good times (p.16)

Remembering good times will ease negative feelings. A great moment may have happened years ago or just yesterday.

6. Keep a Journal (p.17)

Encourage group members to record their experiences and emotions as caregivers in a notebook or journal. This can not only provide cherished memories in future, but can also provide insight into each person's growth and progress, and can be a way of "talking" to someone when that activity is not possible.

Session 4 - Dear George (p. 19)

Dear George examines the impact on peer relationships and caregiving when dealing with the problems of caring for an older person. The purpose is to share experiences and to demonstrate the concept that "You Are Not Alone." Allow teenagers to express themselves, share ideas and special concerns.

Activities:

1. Read and discuss
2. Suggest teenagers write on 3 X 5" cards how they would answer if they were George and discuss. What advice or comments would your group give to others?

3. Suggest teenagers role play using the Questions & answers. Create a scenario for discussion. 15

4. Desiree's question (p. 23) **Reinforce:** say no, get away and tell someone! Be aware that unwanted sexual advances is not gender specific, either sex can make advances. Regardless, the same procedure must be followed. Stress the point that personal safety must always come first.

Session 5 - Dementia Can Be A Major Problem for Older People (p. 25)

This session addresses the difficult issue of caring for someone with memory loss, the most common being Alzheimer's Disease. A guest speaker from your local Alzheimer's Association can help present accurate information and training on communicating with a dementia patient.

Memory loss or dementia is not a part of the normal aging process. Older people do not get "senile," this is a myth!

Recommended Resources:

The 36 Hour Day, Mace & Rabins

Just For the Summer, video, Alzheimer's Disease and Related Disorder Association

1. Read Coping with dementia (p. 25)

2. Steven's Story (p. 29)

Encourage a volunteer to read Steven's Story to the group. Ask the questions which follow Steven's Story in the Guide to stimulate discussion.

3. Support groups help you to cope (p. 31)

- How does your group feel about sharing information and their own experiences with each other?
- Encourage group members to continue their support network with each other after sessions are completed. They may want to form their own support group.

Session 6 - Coping Skills (p. 32)

This session seeks to identify feelings and reactions to situations. Teenagers will learn to identify defense mechanisms in themselves and learn about the grieving process.

Reinforce the idea that You Count! It's ok to feel sorry for ourselves once in a while. The facilitator must be ready to listen.

We use defense mechanisms to protect us as a group. Ask Teenagers if they can identify defense mechanisms in themselves. Again, encourage them to

express themselves either by verbally sharing with the group or writing their thoughts down.

Activities:

Understand that a young person with an elderly or sick relative will experience a range of mixed feelings. Coping with them by using defense mechanisms works in the short run, but in the long run ends up making problems worse.

1. Read and discuss pages 32 - 35.

2. Talk to Someone (p. 35)

One of the overall messages throughout this Guide is the importance of communication. Talking to someone, a friend, sibling, parent, teacher, clergy, is a way of coping. Suggest to your group that they talk with their older relative and share their feelings.

Communication, is the first step to understanding and coping with a difficult situation.

3. Hanna's Story (p. 36)

Hanna was a sophomore in college who participated in the writing of this Teenager's Guide. She realized the importance of communication. Read her story and use the questions following to stimulate discussion.

4. Dealing with Grief (p.38)

It is difficult, at any age, to accept the fact that caregivers may be experiencing feelings of grief while their elderly relative is still alive. It may be useful to turn to your community resources such as the county Mental Health Department or Hospice volunteers for speakers to address this difficult issue. Most importantly you need to accept whatever the teenagers express.

Recognize the possibility that while teenagers may have feelings of grief, so too may their older relative.

Dying Process (Facilitator's Guide Only)

An optional topic for discussion, included in the Appendix for your information. There may be teenagers in your group whose older relative is dying (see Hanna's Story, p. 36). Understanding the dying process and what their older relative is going through may help them to cope. Understandably, this is a very sensitive issue. If you choose to broach this topic, it is recommended that a trained counselor be present.

5. Use your support network, (p. 38)

One way of understanding and dealing with the caregiving situation is to talk. By talking and listening to others you will find that you're not crazy, alone, selfish or an awful person if you feel angry, guilty or upset.

Suggest to the group they make a list of people who they can talk to and help with the care of their aging relative. For example: a friend, neighbor, parent, brother, sister, cousin, aunt, uncle, minister, etc. 17

6. Physical exercise relieves stress (p. 39)

The topics in this session can be very emotional and depressing. Have your group spread out and start jumping jacks. See how long it takes before they start laughing and feeling better.

Other simple exercises may be appropriate for your group. Try tossing a ball around, dancing, or running in place. Be sensitive to group members who may be physically impaired. Try to choose an exercise everyone can participate in.

Session 7 - Practical Ways You Can Help (p. 40)

This session gives information on skills for the direct care of an older person. It will help teenagers to assist their older relative who need extra help. Invite a nurse to demonstrate practical help methods such as communicating with persons who have visual and/or hearing impairments and understanding sleep patterns and activities for the bedridden.

Reinforce maintaining respect for an older relative. Treat them as you would like to be treated. For example, no one wants to be talked to in "baby talk". Talk to your older relative like an adult.

1. Learn to communicate with the hearing impaired (p.40)

Read and discuss. Suggestions are given on how to communicate with someone who has difficulty hearing. Your local school district is an excellent resource for a guest speaker on hearing impairments.

2. You can help someone who has vision loss (p.41)

Read and discuss. Suggestions are given on how to communicate with someone who has a visual impairment. Your local Association for the Blind and Visually Impaired is a good resource for a guest speaker.

3. Don't ignore a person confined to bed (p. 42)

No one likes to be sick and stuck in bed all day. Again, this is a situation that can happen to all of us at any age. Remind teenagers that they may have been sick and had to stay home in bed from school. We may laugh and say "*Gee wouldn't that be nice*" but in fact it can be difficult to be bedridden. Read and discuss. If appropriate, ask your local Fire Department to donate special window labels to distribute to your group members.

Session 8 - Things to Try - Things to Do (p. 43)

This session explores fun activities a teenager can do with an older relative. One of the greatest gifts a teenager and older relative can give to each other

is shared quality time. No one, young or old, likes to have their leisure time planned for them. Plan activities together.

1. Share Activities (p. 43)

Read and discuss. What are some of their favorite recipes or cooking projects? Encourage your group to share their favorite recipes. As a suggested activity, create a simple dish during this session to demonstrate a cooking activity appropriate for all ages. Your local library is an excellent resource for cook-books.

2. Talk about the past (p. 44)

Read and discuss. Reminiscence can bring about good feelings at any age. Suggest to your group that they recall and share a favorite memory. You may start the discussion by giving an example of one of your favorite memories. Urge your group to encourage the older person to remember positive experiences.

3. The greatest gift is your time (p. 45)

Read and discuss. Ask your group to remember times that would have been considered a "gift of their time".

Conclusion

Together we have discussed how caring for an older relative is rewarding and at times difficult. The intent of these sessions was to understand the many different feelings you and your older relative experience.

You have learned about feelings, family, your older relative and practical ways to help. You now have a greater understanding of how to cope with a variety of emotions.

Remember that every caregiving family is unique, yet they all share similarities. The teenagers who participated in the writing of the Teenager's Guide to Caregiving shared their feelings and experiences of caring for an elderly relative. The most important message Jesse, Steve, Hanna, Heather, and Tammy wanted to share with you is that You Are Not Alone.

The majority of older people are very independent and active even in their 70's and 80's. Health problems at any age may require assistance from others. Your parent(s) and you are now providing care to an older person(s). Assistance provided by family members does not require special training.

Evaluation Forms & Certificates

Ask your group members to complete the evaluation form (*Use form in Appendix, or similar*)

Distribute completed certificates of participation (*Use certificate in Appendix, or similar*) to group members.

Helpful Toll Free Telephone Numbers:

Call for further information on a specific topic.

New York State Office for the Aging
1-800-342-9871 in NY or • 518 474-7252

Eldercare Locator A service of the
National Association of Area Agencies on
Aging • (800) 677-1116

**Alzheimer's Disease & Related
Disorders Association**
(800) 283-7800 • (800) 572-6037 in Illinois

**Arthritis Foundation Information
Line**
(800) 283-7800

American Cancer Society
Cancer Response Line (800) ACS-2345

American Diabetes Association
(800) ADA-DISC • (703) 549-1500 in VA &
DC metro area

Grief Recovery Institute
(800) 445-4808

**Library of Congress National
Library Services for the Blind &
Physically Handicapped**
(800) 424-8567 • (202) 707-5100 in DC

National Headache Foundation
(800) 843-2256 • (800) 523-8858 in Illinois

Dial A Hearing Screening Test
(800) 222-EARS • (800) 345-EARS in PA

Hearing Helpline
(800) 327-9355 • (800) EAR-WELL • (703)
642-0580 in VA

American Liver Foundation
(800) 223-0179 • (201) 256-2550 in NJ

**Lung Line National Asthma Cen-
ter**
(800) 222-5864 • (303) 355-LUNG (Den-
ver Metro Hotline)

**National Foundation for Depres-
sive Illness**
(800) 248-4344

**National Mental Health Associa-
tion**
(800) 969-6642

National Kidney Foundation
(800) 622-9010

National Stroke Association
(800) 367-1990

National Parkinson Foundation
(800) 327-4545 • (800) 433-7022 in FL
(800) 547-6666 in Miami

Simon Foundation *Information on
Incontinence*
(800) 23-SIMON • (708) 864-3913 in IL

**American Foundation for the
Blind**
(800) 232-5463 • (212) 620-2147 in NY

American Council of the Blind
(800) 424-8666 • (202) 467-5081 in DC

**The Lighthouse National Center
for Vision and Aging**
(800) 334-5497

20 BIBLIOGRAPHY

- The Age Wave*, Ken Dychtwald PHD and Joe Flowers 1990 Bantam Books, NY
- The 36 Hour Day*, Nancy Mace M.A., and Peter Rabins MD, MPA John Hopkins University Press 1981, 1991 Baltimore, Maryland
- The Vanishing Mind*, Leonard Heston, June White, W.H. Freeman & Co 1983, 1991, NY
- Caregivers Practical Help*, New York State Office for the Aging
- Communicating with the Alzheimer Patient*, Alzheimer's Association
- What's Wrong With Daddy?*, A.E. Young Willowisp Press 1986 Worthington, Ohio
- Grandpa Doesn't Know It's Me*, D. Guthrie Human Sciences Press, Inc 1986 NY (Available through ADRDA)
- "Put Yourself In Their Place," K.W. Sehnert *Family Health* April 1976
- On Death and Dying*, Elizabeth Kubler-Ross MacMillan Publishing Co., NY 1969
- Going Backwards*, Norma Klein Scholastic, Inc. 1986
- Alzheimer's Disease: The Silent Epidemic* Lerner Publications Co., Minneapolis, MN 1985
- New Games*, Andrew Fluegelman, Doubleday 1981
- More New Games*, Andrew Fluegelman, Doubleday 1981
- Just for the Summer*, Churchill Films, 12210 Nebraska, Los Angeles, California, 90025 (A film made for the Alzheimer's Association, Los Angeles Chapter)
- Psychology For You*, Sol Gordon, Oxford Book Company, 1972
- Our Aging Parents, A Practical Guide to Eldercare*, edited by Colette Browne and Roberta Onzuka-Anderson, University of Hawaii Press, 1985
- Facts About Aging and Blindness*, American Foundation for the Blind, NY
- Handbook for the Hearing Impaired Older Adult-An Individual Program*, Joan M. Sayre, Danville, 1980
- The Senior Handbook*, New York State Office for the Aging

The survivors are not the only ones who must deal with loss. The ultimate loss is sustained by the dying individual. Elizabeth Kubler-Ross has done some pioneering work leading to an understanding of the process of death. This kind of understanding may enable caregivers to offer support at what has come to be known as another stage in the life cycle.

In an effort to rediscover and to explain to the public and professional what dying is like, Kubler-Ross has talked widely with people near death and those who have clinically experienced it. In her book, *On Death and Dying*, she attempts to sensitize the public to the needs of chronically ill patients who in many instances are treated as though they are already dead.

Kubler-Ross hypothesized that the dying go through five psychological stages prior to death. The dying do not necessarily have to progress through these stages in this order; some may skip one stage or vacillate between stages. Thus, the stages should not be looked at as absolute or distinct, but rather, seen as levels of experience during the course of dying.

1. Denial

The individual simply refuses to believe that they are going to die.

2. Anger

The individual fights against the injustice of life ending.

3. Bargaining

The person tries to make a deal with God or fate in return for life. Promises may be made to be a better person, to show more concern for others, and so on.

4. Depression

When bargaining seems futile, the individual enters a period of depression over the loss of life and loved ones.

5. Acceptance

The individual may not approve of their impending death, but approach death with a feeling of quiet contemplation. With this can come a lessening of interest in the material world and one's loved ones.

Kubler-Ross has found that for several reasons persons are very often left to cope with their dying alone in anguish, not knowing what to expect. They are avoided, never touched nor looked in the eye. Decisions are made for them, and they are openly discussed by others as if they were already dead.

Often, family and friends are trying to spare the dying individual. Parents may be trying to protect their children and themselves from hurt by avoiding the issue of impending death. Very often, they simply do not know how to deal with death and what is expected of the living. Encouraged to maintain open communication, family members can aid their own grieving process as well as aid the dying member.

Teenager's Guide to Caregiving

Registration Form

Name _____

Address _____

Parent(s)/Guardian Name _____

Telephone Number: Home _____

Work _____

1. What is your age? _____ grade level? _____
2. What are the names and ages of the elderly relatives/friends for whom your family provides some kind of care?

Name, Age, Relationship: _____

3. Who lives in your household? _____

Name, Age, Relationship: _____

4. If your older relative/friend does not live with you, where do they live?

-
5. Is your older relative physically disabled, frail (*for example, is it difficult for them to walk unaided, etc*)?

yes, please explain no

6. Does your relative experience memory loss, confusion, forgetfulness?

yes, please explain no

7. Do you have a good relationship with your older relative/friend?

yes no

8. At times, do you take care of your older relative?

yes no

9. Do you sometimes babysit for your brothers/sisters because your parent(s) must care for your older relative?

yes no

10. Has providing care for your older relative affected your school work and/or after school activities?

yes no

11. When you experience pressure, confusion or need help in handling your fears, concerns, problems in regards to your older relative, where do you find help?

-
12. Do any of your friends live with older relatives or provide some care to an older relative?

yes no

13. What do you hope to get out of these sessions?

Thank you for completing this Registration Form

Teenager's Guide to Caregiving

EVALUATION • Please complete the following questions. **Thank you!**

1. What is the relationship of the older person your family cares for? _____

2. How old is this older person? _____

3. Where does this older person live?

my home nursing home his/her own home other (specify)

4. These following statements are about how the training might have affected you. (Please check all that apply)

Information I learned at the training session helped me understand my elderly relative better

The information helped me understand my parent(s) better

The information helped me understand the Aging Process better

The information helped me understand myself better

The information helped me to better communicate with my older relative

The information helped me to better define my role as a caregiver.

5. The information that helped me the most was:

6. The information that helped me the least was:

7. Overall, I would rate this program: (Circle number)

1	2	3	4	5
excellent				poor

Your Name (optional) _____

Address _____

Age _____

Please mail completed evaluation forms to: New York State Office for the Aging, 2 Empire State Plaza, Albany, NY 12223-0003

Has successfully completed a special workshop
on
Caregiving for Teenagers

CARING MATTERS

facilitator

Date

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Dear Reader,

Caring for a grandparent or older relative can be both rewarding and difficult. This book will help you better understand your own feelings and the feelings of your older relative. It offers guidance and practical suggestions.

A time may come when an older relative suffers a serious health problem and your life changes. An older person who may have been very independent now requires care. You may be involved in that care.

This book is especially for you if you:

- have older relatives, neighbors, or friends
- have friends whose lives are affected by older relatives who need care
- want to learn more about what it means to grow old.

Family members who aid older relatives in need of help are called caregivers. This means that your family must help your grandparents do what they used to do for themselves.

Although you may be willing to help and take on added responsibilities, these extra demands can sometimes be stressful for your family and you.

Many teenagers find themselves in similar situations. Some of them have shared their feelings and experiences in this book. Heather, Jesse, Steve, Hanna, and Tammy talk about their situations hoping that you will understand that you are not alone.

I wish you well as you deal with the issue of caregiving in your family.

George E. Pataki, Governor
Walter G. Hoefler, Director

HEATHER'S STORY

Heather, a high school student, spent a great deal of time helping her parents care for her grandparents who live next door. She wrote this story which recalls one evening Heather spent with her grandmother.

She used to be able to walk sturdy by herself without the guidance of my hand or her walker. I remember the nights she helped me into bed, covered and tucked me in. Now, I do this for her. Her hands are so fragile, like her feelings. It's hard to get old, this I know.

She feels that nobody cares about her. She thinks we think she is crazy, but we know she is not. She's just sad. All she does is sit in her lounge, the kind you push the button and it will bring you up to a standing position. She just stays there all day until around 9:30 -10:00 pm then she goes to bed. She often falls. Sometimes it's serious but most of the time it just "shakes her up" One time she fell she separated her shoulder. About two months ago she broke her wrist. I remember one night I stayed at my grandparents house. I was helping Grandma get ready for bed. Her dress was at her ankles and I was about six feet away from her. I saw her start to lift her foot, attempting to get out of the dress, but it clung to her ankle and she started to fall backwards. I was paralyzed. My body wouldn't move to catch her or comfort her fall. She hit the floor.

I ran to her, she was in pain. I checked carefully to see if she had any broken bones. None were broken from what I could tell. She complained that her shoulder hurt so I was careful when I helped her up. It was difficult helping her because I had to be very cautious not to hurt her. She was weak and had to rely on my strength. It seemed impossible, the farthest I could get her was on her knees. I could see she was feeling sick. Her face was so pale, an off-white color. She was cold and clammy. I told her to lay down and I would get her a pillow and blanket. I told her to rest a little till she felt stronger. I was going to call Mom and Dad but she said no. All I kept thinking was "How am I going

to be able to get her up myself? I need my dad's help", but she said no and I didn't want to upset her.

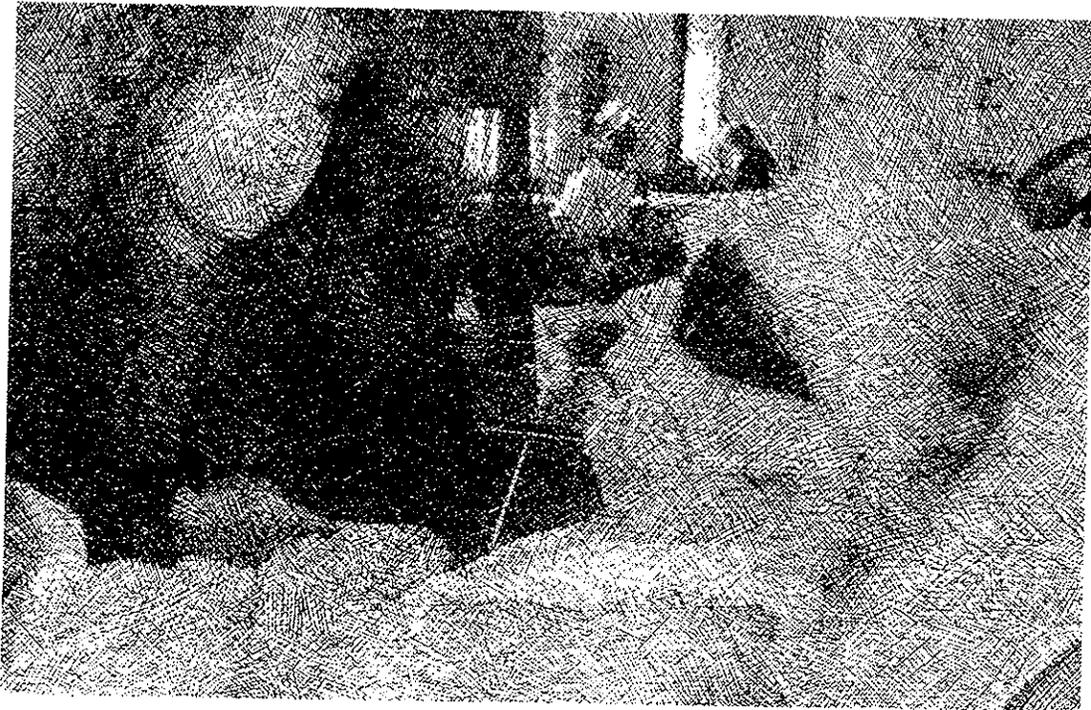
After about five minutes her face was a little bit darker. She wanted to attempt getting up and so we went ahead. We got to the end of the bed. She pulled herself up. I helped by supporting her and lifting. Finally, on her feet, I guided her over to the bed. She sat and then put her head down on the pillow. I picked up her feet and put them on the bed. I got the blanket and covered her up. I asked if she was alright, bent down gave her a kiss and hug and said, "I love you Grandma!"

What adult decisions did Heather have to make?

Would you have handled it as Heather did?

Can you relate to Heather's story? How is it similar to your own situation?

There may be times when you have to make adult decisions as Heather did. You may remember your older relative as active and independent. It is difficult coping with the fact that your older relative has changed and is no longer the way they used to be. This book will help you to understand the different emotions you may feel when caring for an older person.



Chapter One

A CAREGIVER PROVIDES CARE.

A caregiver is someone who provides different types of care to another. Giving care to another person is not new. It starts the minute a baby is born. A baby is totally dependent on family. As a child grows to be more independent less care is required. When people age, and if their health declines, they can become less independent and more dependent on family to provide care.

Caregiving is helping someone out, assisting someone, nurturing them. It can range from Saturday grocery shopping for a grandparent to providing total care, such as transporting, bathing, feeding and dressing. The person you take care of doesn't have to live with you for you to be a caregiver. Assisting someone who does not live with you is also caregiving. So you see, if you help someone you are providing care, you are a caregiver.

Love and responsibility help your family care.

Generally a caregiver takes on this role out of love and sense of responsibility. As rewarding as it can be, it can also be extremely stressful.

Caring for an older relative is a family experience. Whether your family is large or small, members of your family may participate in different ways in the care of your older relative.

The caregiving experience can produce negative and confusing feelings. Isolation, anger, love, fear, guilt, confusion and resentment are a few feelings that you may encounter. This "mixed bag" of emotions will only magnify confusing thoughts.^{1,2,3}

A Family Tree is a record of people who are related to you.

To show how you are related to your family, talk to your parent(s) or grandparent(s) and ask them to help you complete the Family Tree.

If there isn't a branch on the tree for a member of your household, create one. For example, if "Uncle Bill" is living with you and he is your mother's brother, under the line for your mother draw another line and write in your Uncle's name. When possible include date of birth next to your relative's name.

You and your family

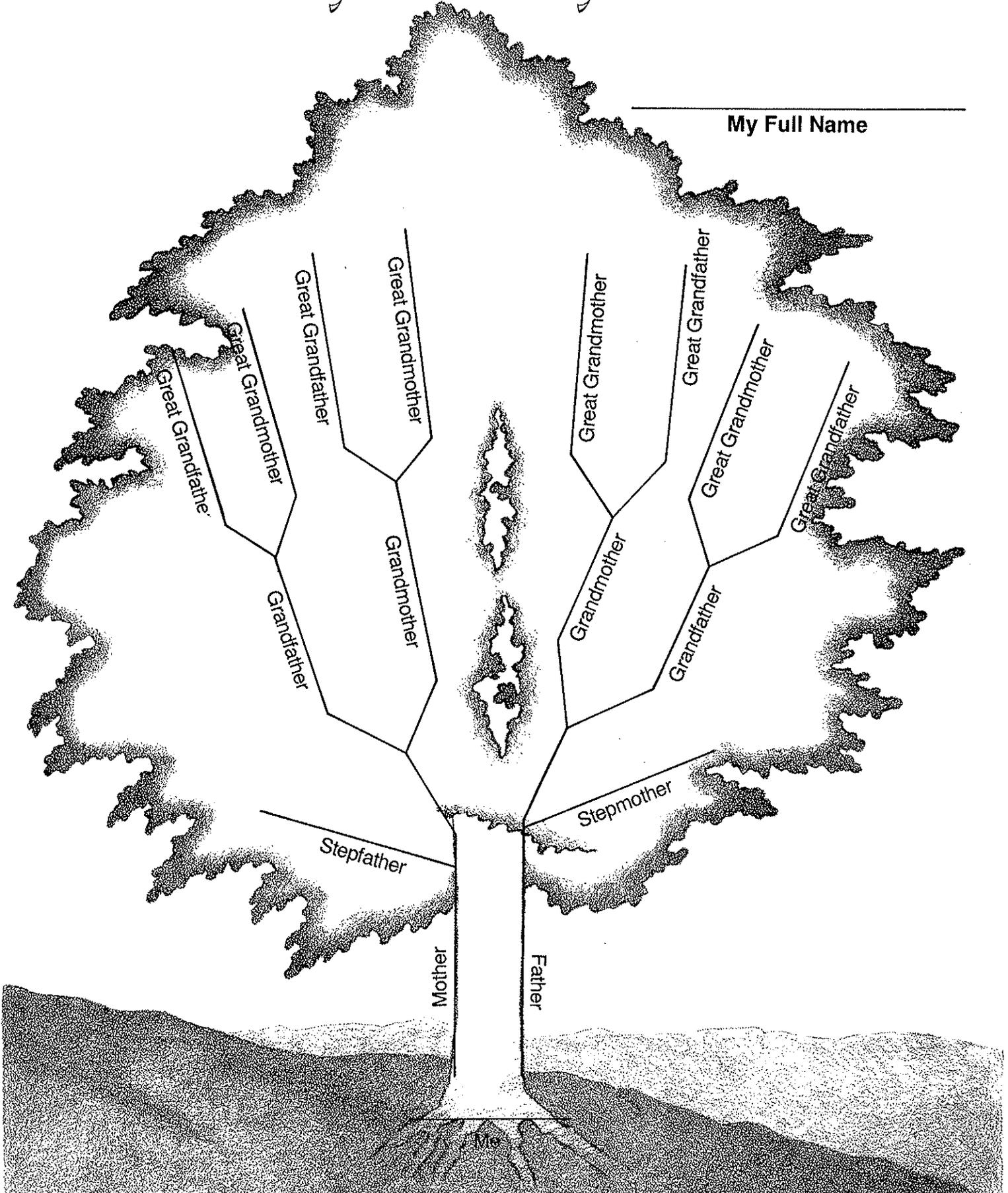
Write about or place a photograph of your family in the space provided below:

List the people in your picture and how you are related:

Relationships often determine the 'role' each relative plays in your family.

My Family Tree

My Full Name _____

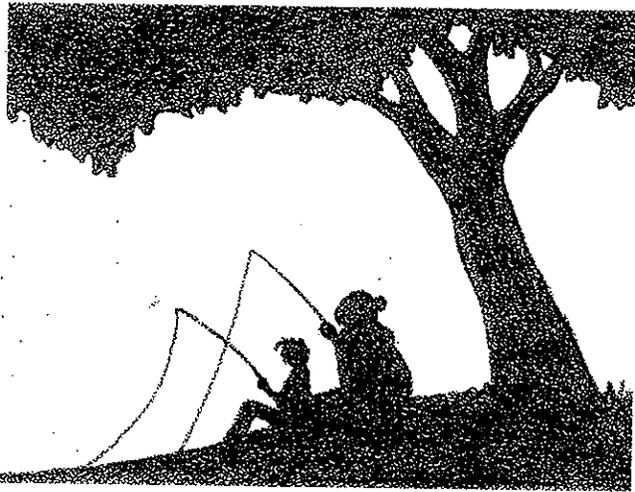


Laugh and remember fun times.

Remembering a fun moment or favorite time spent with an older relative can make you feel good inside and relieve stress. You have already completed the Family Tree exercise. Next, remember a fun moment with your older relative. It could have happened years ago or yesterday.

For example, Jesse is a teenager who wrote about a special time with Great-Gram. He said it made him feel better to remember good times shared with his older relative:

Jesse's Story



I remember when both of my great-grandparents were in excellent health. We spent a lot of time together. I especially loved fishing and cooking with Great Gram. When we went fishing we would sit on a dock and she would put the worms on my hook and even take the fish off for me. One time we filled two buckets and brought them up to camp and she helped me clean the fish and cook them for dinner. Other times she would let me cook breakfast, I would flip the pancakes and set the table. Great-Gram would praise me for helping her and give me special attention, I was glad I could help out.

In the space below, write about, make a list, or paste a photo of a favorite or fun moment you have had with your older relative.

Caregiving is rewarding and challenging.

Providing care to an older person is very rewarding. Sometimes you learn from or develop a special relationship with the person you are helping. Sometimes caring may become a challenge, especially if the person who needs care becomes increasingly dependent.

Parent(s) may feel “sandwiched” in . . .

Parents often become caregivers because they love and feel responsible for the older person. Parents care for you at the same time. This can cause them to feel caught in the middle, or “sandwiched.” They want to give you all the attention you deserve. However, it may seem like they are overlooking your needs because grandma or grandpa requires more care. You may feel left out or that your older relative is more important. Your parent(s) are referred to as the “Sandwich Generation”.

Try to recognize and be sensitive to the possibility your parent(s) may feel “sandwiched in”.

*Is Your Parent Sandwiched In?
Explain below...*

Your parents may not intend to spend less time with you. They're probably just “sandwiched” between responsibilities for you and your older relative.

Get to know your older relative in need of care.

Pretend you are a television reporter. Your job is to learn all you can about your older relative. Interview your older relative or someone that knows them well. Use the following questions to assist you. Then make up your own questions.

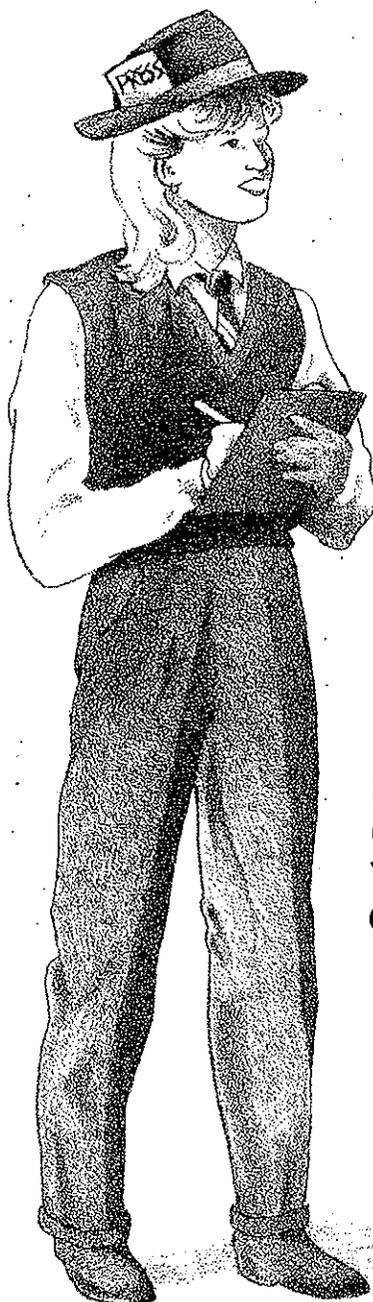
- 1. What year were you born?*
- 2. Where were you born?*
- 3. What were some of your favorite things to do as a teenager?*
- 4. What were some of your goals in life as a kid?*
- 5. When did you get married? How many children did you have?*
- 6. What was my parent like as a teenager?*
- 7. What are some of your favorite things to do now?*
- 8. What is the funniest thing that ever happened to you?*
- 9. Make up your own questions here.....*

Be aware that the interview may bring up family secrets. You may want to discuss them with an adult you trust.

Chapter 1

KEY POINTS:

- A caregiver provides care.
- Love and responsibility help your family care.
- A Family Tree is a record of people who are related to you.
- Laugh and remember fun times.
- Caregiving is rewarding and challenging.
- Your parent(s) may feel "sandwiched in".
- Get to know your older relative in need of care.



Chapter Two

AGING HAPPENS TO ALL OF US.

As people age many changes occur. Look at some of your baby pictures and look into a mirror. Have you changed? Of course you have. You have aged.

The normal aging process can include graying hair, diminished eyesight and hearing

Aging is a process of growth. As we grow our skin changes and becomes more wrinkled and our hair may become gray. Eyesight and hearing may diminish and glasses or hearing devices may be needed.

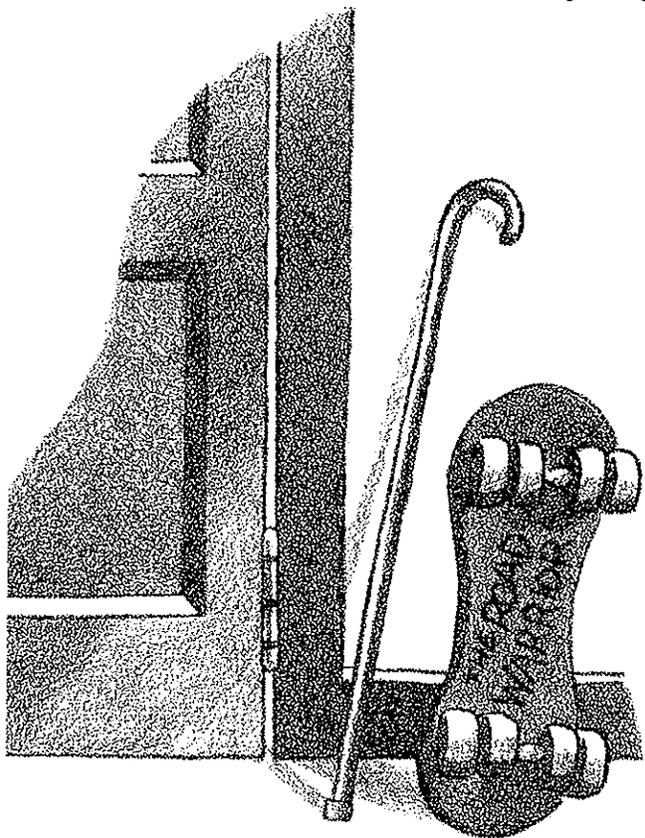
Aging bones may become weakened due to loss of calcium.

Aging bones gradually lose their calcium, become weakened, and fracture easily. This loss is inevitable. It may be slowed by increasing physical activity and eating foods rich in calcium (for example, dairy products, sardines, salmon, and raw vegetables) but it can't be stopped.

Older people may be sensitive to temperature.

Frequently, an older person may be very sensitive to temperature because of circulation problems, loss of body fat and other changes. For example, your older relative may ask for a sweater because they are cold and you could be roasting.

Usually, weight generally decreases due to muscle loss. Body fat shifts to the lower body and hips. And, this does affect how an older person functions.⁴



Most people age well

Most older people remain independent in their later years. It is only when a major health event occurs such as a stroke, heart attack, or memory loss that people of any age become more dependent for their care.

Most older persons lead active and healthy lives. You may recognize some famous older celebrities. Write the names of some in the space below and tell why you think they aged well.

Age and age attitude are different

Age and attitude are quite different. Our chronological age (our actual age measured from date of birth to present) is often quite different from the age we feel inside. Has anyone ever said to you "act your age"? What does that mean? You already asked your older relative how old they were. Now ask them how old they feel inside? Do you get a different answer? Do the same with a variety of people. Ask your parents how old they are, then ask them how old they feel. Most likely you'll get two different answers.

Ask five people how old they are and how old they feel. Write down their answers.

Name	Present Age	How old they feel
1. _____		
2. _____		
3. _____		
4. _____		
5. _____		

Physical changes occur gradually

It's hard to imagine what its like to get old when you are young. Aging is a very gradual process. If you are aware of the physical

difficulties some older people have you may be more sensitive to that person's special needs. This activity is a lot of fun while at the same time you'll become aware of what it feels like to age.

Age Simulation Techniques⁵

Arthritis/Stiff Joints

Wrap two elastic bandages around one knee firmly but not too tightly and try walking.

Place elastic bandages around elbows and try to put on a coat, eat or drink something.

Put a pair of bulky gloves on and try to button a shirt.

Stroke or Paralysis

Write with the opposite hand you would normally use. If right handed use left hand, if left handed use right hand.

Place a marshmallow in your mouth.** Now start talking or call a friend on the telephone and see if they recognize your voice.

Tape a yardstick on the outside of one leg. Securely tape it every six inches. Walk around the room or try walking up and down stairs. (Make sure you have a partner to assist you). Feel awkward?

Hearing Impairment

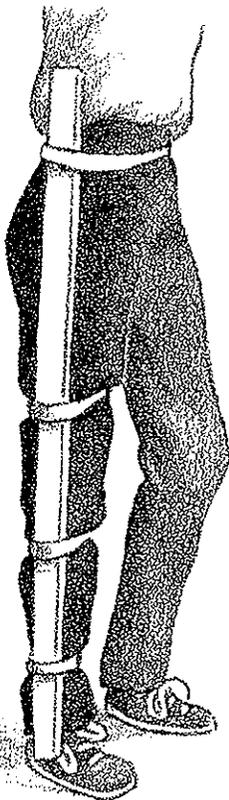
Place a cotton ball in each exterior ear canal and then put on earmuffs. Try talking to someone. Did you ask them to repeat what they were saying?

Turn television volume down to the lowest level. Sit at the opposite end of the room and listen to your favorite program. Hard work isn't it?

Visual Impairments

Smear petroleum jelly over swim goggles or old glasses. Put them on and read a book or watch TV. Do your eyes feel strained?

Adjust your TV so it is slightly out of focus. See how long you can watch before you become irritated.



Loss of Sense of Smell**

Clamp your nose shut between the thumb and index finger. Now eat an apple or snack while holding your nose. How does it taste?

Loss of Sense of Touch**

Put on a pair of bulky gloves or cover your hand with a sandwich bag. Tie a knot in a piece of thread. Or try to tie your shoes. Not very easy is it?⁵

You're Still Yourself As You Age

It's hard to imagine that in 60 years you will be elderly. Your skin will be wrinkled and your hair grey. You may have trouble hearing, your hands may not be as steady, and you may walk slower than you do now. Yet, although you may look older you may not feel old at all.

Throughout your life you will be the same person inside that you are now. If you're a friendly, outgoing person, chances are you'll be that way when you're older. Likewise, if you prefer being alone now, you'll probably like to be alone as you age. If you like rock n' roll music now, chances are you'll like it when you are older.

How old will you be in 60 years? _____

What will you be doing in sixty years?

We play many different roles in our lifetime.

Life Spectrum

As people age they gain many life experiences. Think of all the things you have experienced. Every day brings with it new lessons,

^{**} This activity is not recommended for young children.

expectations, and knowledge. Aging is a very rewarding process because everyday we grow and change.

Throughout life we have many different roles. Each role; brother/sister, student, babysitter, boy/girl scout, athlete, etc., affects your self image. Everything you do contributes to the type of person you are. Fill in your Life Spectrum line and see the different roles you have had.

For example:

child student contractor retired
/-----/-----/-----/-----/

Draw a Life Spectrum for yourself:

/-----/-----/-----/-----/

Ask your parent to fill in their Life Spectrum.

/-----/-----/-----/-----/

Draw a Life Spectrum for your older relative:

/-----/-----/-----/-----/

Look at all the changes you, your parent, and your older relative have been through.

Chapter 2

KEY POINTS:

- Aging happens to all of us.
- Most people age well
- Age and attitude are different
- Physical changes occur gradually
- We play many different roles in our lifetime

Chapter Three

YOU THE CAREGIVER

When you care, you create emotion.

Providing care to another person is a big responsibility regardless of your age. Caregiving is assisting someone with activities like bathing, grooming, feeding, household tasks, shopping, meal preparation, and companionship.

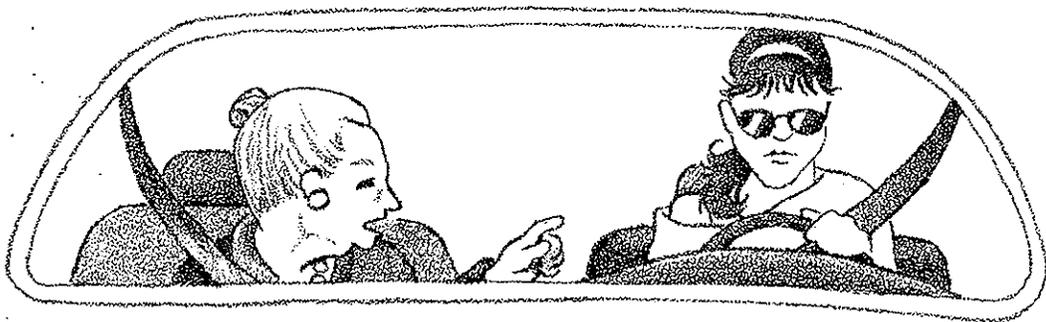
There may be times when you have to give up an activity you enjoy to help your family. You may feel lost in the shuffle or resent your older relative because of the demand on your time.

Negative and confusing feelings may be felt in a caregiving situation. You may have feelings of isolation, anger, love, fear, guilt, confusion and resentment. All of these emotions are normal.

Talking with someone will make you feel better.

Like many others, you may have these negative and confused feelings about caregiving. You may feel alone or guilty or be angry or resentful. All of these emotions are common.

Talking with someone is the best way to release emotions. Remember, there are other teenagers who are experiencing a caregiving situation. Exchanging ideas, feelings and ways to understand what is going on will make your caregiving experience easier. Talk to a friend, parent, teacher, or cleric. Just talk!⁶



Caring for yourself and another person is a balancing act

When you provide care, you may have to give up a planned activity. While it's important to help, it's also important to have time for yourself. When you provide care, it will be a balancing act between responsibilities at home, school, sports, clubs, and activities with friends. You are important! Care for your older relative but also care for yourself.

You may do many things for your older relative. All caregiving responsibilities are important.

List some of the things you do.

Mirror Mirror ...

Isn't it nice to hear a friend say "you look wonderful today" or "you sure are funny?" A compliment can make you feel good about yourself.

Did you know, that saying positive things to yourself can make you feel good too?

Look into a mirror and say:

I like me because.....

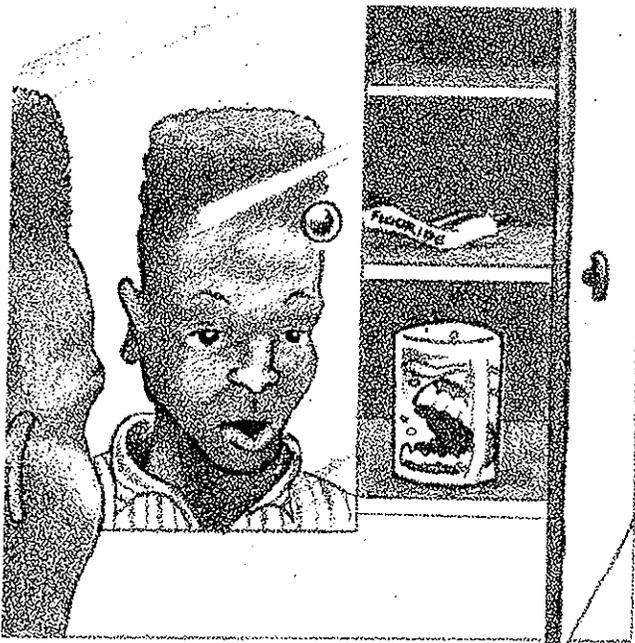
Special things I do for myself are....

Good things I do for others are.....

I am a special person because.....

I am important because.....

It feels wonderful to hear good things about ourselves. And, it's important to tell yourself "I am special"



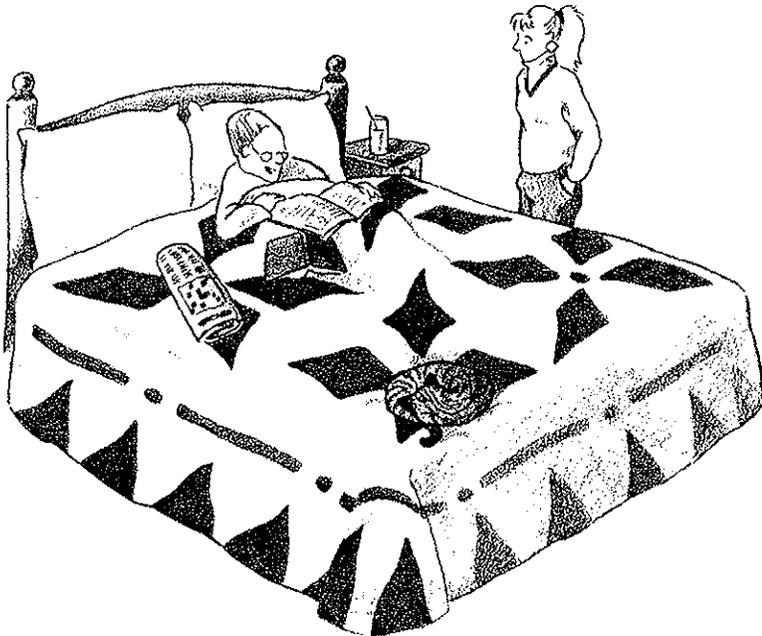
Sharing Experiences

The teenagers who helped write this book want you to know that you are not alone. Tammy is a teenager who wanted to share her story with you.

Tammy's Story

When I was eight years old I met my Step-Great Grandparents and my Step Grandfather. I have to admit, I was scared when I first met them. My Great-Grandfather had a stroke and lost his speech. My Great-Grandmother could walk with a cane only if someone walked behind her for support. She too, had a stroke and later developed cancer. My Grandfather had a crippling disease and was confined to a bed. All three of these people lived in one house where my mother took care of them.

At first, I was afraid to talk to them because I didn't know if they'd understand me. Many times my feelings would be hurt by my great-grandma. Her stroke had changed her personality and sometimes she said things that were mean and insulting. I'd walk through the living room where she sat with my head down, hoping that she wouldn't talk to me. I didn't understand her so I avoided her.



My relationship with Great-Grandpa was much different. I tried to communicate with him as much as I could. When he tried to tell me something he'd use his hands to point. He would smile if I guessed what he was trying to say. At times he'd do things and forget he did them. He would sneak cookies into his room and put them in a drawer for later, and then forget about them.

My Grandpa was my favorite person to visit. At first I was uncomfortable with his confinement to bed. I didn't dare ask

questions about it because I didn't know if it was something that should be talked about. I learned from him that humor is the best medicine, whether they can remember things or not. It doesn't matter if you're sick or well, laughter is great for everyone.

Grandpa would tell me jokes and play the harmonica. He showed me he was determined to overcome obstacles to do what he enjoyed.

I felt helpless when I didn't communicate, so I did little things to improve communication. I smiled when I walked past my Great-Grandma and developed a sense of humor that helped me feel more comfortable. I started asking questions and talked to my family for support, all these things made it easier to help my mother with her caregiving responsibilities.

How can you improve communication with your older relative?

Tammy's grandfather taught her that the best medicine is humor. Remember a time that made you smile.

What can you learn from Tammy's story?

Humor is the best medicine

It is important that you feel good about yourself.

Maintaining a sense of humor can help you cope with the stress of caregiving. Lets face it, laughter and smiles feel good and good feelings are contagious.

At times you may feel down. Humor is an excellent way to take the blues away. It's okay to laugh and have fun!

Caregiving can be a lot of work. However, it can be a rewarding experience. Remembering a funny experience with your older relative can make you smile and feel good.

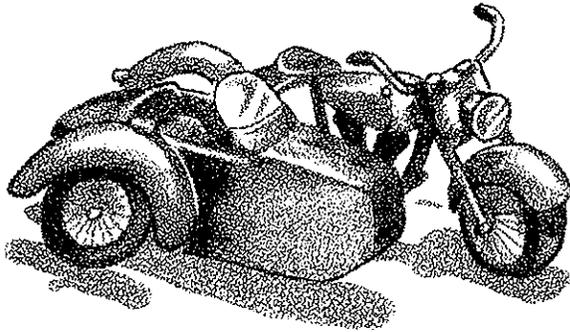
Remember the good times

Ask your older relative about a funny thing that happened to them when they were young, or ask a parent to describe a humorous story that included your older relative.

Here are two incidents as told by teenagers:

"I remember my grandmother telling me that before they were married she and grandfather would drive all over the countryside on a motorcycle with a sidecar. It was fun trying to imagine

her with a leather helmet and goggles on bouncing around all over the country in a sidecar!"



or

"Yesterday a friend came home from school with me. Grandma kept asking him over and over again if he wanted a cookie. My friend understands that she doesn't remember things. When he left to go home for dinner his pockets were full of cookies because he didn't want to hurt her feelings."

Keep a journal.

Record your experiences as a caregiver. It will be fun to look back at this in future years and it will help you better understand your emotions and your work.

*Think of funny moments and write in the space below.
This is a great exercise to do when you are feeling
down.*

*Remember: Humor is the best medicine for taking the
blues away.*

Great Moments with _____!

Chapter 3

Key Points:

When you care you create emotions

Talking to someone will make you feel better

Caring for yourself and another person is a balancing act

Humor is the best medicine

Remember the good times

Keep a journal

Chapter Four

Dear George

This chapter contains questions and comments by teenage caregivers. You see that there are others who have similar situations. You are not alone. The answers given are by "George", a professional teen counselor. Read what other teens had to say and see if you can identify with them.

"Andy"

Age 17 - Many times my siblings, parents, and I cannot go places freely without making arrangements for someone to be with her. We never have activities with just our parents.

Dear Andy,

It may be possible to work out a routine where your family goes out together once a month. However, hiring someone to care for your older relative during this time can be expensive. Check with local agencies to see if they have a Respite Program to provide temporary care. Another way to spend time together is to plan an activity at home, like a special dinner, picnic, or a game which can be played together.

"Jim"

Age 16 - We don't live together. She lives right next door. She makes me mad because she can do things for herself and won't. Then she'll tell us we don't do things for her and puts us down. When people get older they can get meaner.

Dear Jim,

When people get older they often feel lost, lonely, and confused because they can't do as much as they used to do. Set aside a spe-

cial time you can spend with your elderly relative doing things you enjoy doing with her. She may honestly need help doing some things. She probably doesn't want to be mean. She may feel frustration at having lost the ability to do many things she used to do.

"Theresa"

Age 15 - Grandpa is fun. Grandma doesn't like loud noises and gets mad when I have friends stay all night. How do I get Grandma to not be mad at me all the time?

Dear Theresa,

Try to talk to your grandma about how you are feeling and see if you can come to a compromise on the noise. Also try to include her in an activity with you and your friends. You may find she has a lot to offer and share.

"Chris"

Age 14 - My grandfather has Alzheimer's and I sometimes take care of him because I am needed. I enjoy having the chance to spend time with him since he may not be around much longer.

Dear Chris,

The time you've spent with your grandfather has given you rewards and memories - memories that you will never lose. While it is difficult to watch a loved one's health get worse, your positive attitude will do a great deal to make the current situation less stressful for you and your family.

"David"

Age 16 - He can't walk well and can't grab things, or hold up his head. I'm kind of nervous and uncomfortable around him. I feel it would just bring me down if I let his illness affect me more than it already has.

Dear David,

If you learn more about your grandfather's illness, you may feel more comfortable around him. Try to keep in mind, that inside your grandfather is the same man you always knew. Visits with him may be very special to both of you. However, your feelings are important and valid. You may want to have someone else with you during your visits to help steady your grandfather and to make you feel more at ease.





“Pat”

Age 16 - We've semi-switched roles. Gramma used to care for me, now I take care of her. Some things I have to do make me uncomfortable. I don't want to be resentful and bitter towards Gramma, but sometimes I see her as a burden. My good memories are being ruined. Is it selfish to think of my own life and what I want?

Dear Pat,

Thinking of your own life is far from being selfish. Talk to your parents and let them know how you feel. Maybe you could swap some of the things that make you uncomfortable for other activities which you enjoy doing. It may be hard, but try to continue to respect your grandmother. Try to focus on the good times. She is still the same person even if she can't do the things she used to do.

“Tim”

Age 16 - The thing that pains me the most is viewing the effect this is having on my parents. This is ripping Dad apart and I know it just gets worse every day.

Dear Tim,

It sounds like you care a great deal for your parents. Situations like this can be very difficult for a family. It is important that you and your parents talk about what is happening in your family. Letting your dad know you are there for him may be the best thing you could do.

“Anton”

Age 13 - Grandma is 91 and has lived with us for 4 years. She has trouble hearing, is brittle and can't walk fast. She is a nice person, but is hard to understand because of her problems.

Dear Anton,

Continue to be patient with Grandma. Learn all you can about communicating with someone with a hearing impairment. This will make it easier to talk to her. If she will let you, help her up stairs and over carpets that are hard for her to walk on.

“Julie”

Age 17 - Sometimes there is too much commotion at home to study.





Dear Julie,

You're right. Sometimes it can become too hectic at home to do homework or study. You might try getting your family to agree to a quiet time each day. If that doesn't work try doing your studying at school, at the library or at a friend's home.

"Charlie"

Age 14 - My grandmother has lived with my family for a few years yet she only knows my mother and father. When out with us she walks slowly and looks confused. She is usually a friendly person yet can become angry and annoying. I rarely invite friends over to my house anymore. I'm just too embarrassed! Why does she always have to come along to school events when she forgets them anyway?

Dear Charlie,

It's tough when you feel you can't invite your friends over to your home and find it embarrassing to be with your grandmother. This must make you angry sometimes. Because of her physical difficulties it is probably hard for her to keep up. Her physical condition probably contributes to the changes in her moods, too. Are there any of your friends that you would feel okay about telling about what your situation at home is like? Maybe if they knew, you would feel better and might feel okay about inviting them over. Although it may be confusing why your grandmother attends school functions, she may enjoy herself while she's there. Your parents may be happy she can be there or they may have no choice but to bring her along because they don't like to leave her alone.

"Gina"

Age 12 - Once while I was home watching Grandma she had an accident. She wet all over herself. I was shocked and didn't know how to handle it.

Dear Gina,

What happened to your grandmother is called incontinence and can be a problem for people at any age. Your family should consult with a doctor since often incontinence can be helped. Also, I'm sure you've seen the advertisements on television for adult diapers

as an aid for incontinence. Try not to embarrass her anymore than she is. Just ask if you can help her get cleaned up. Offer her towels to clean up, then ask her if you could help her bathe and change into fresh clothes. Stay calm and do not make a big deal about what has happened.

“Sam”

Age 15 - He always says he wants to go home, and this is his home.

Dear Sam,

Grandpa might just be confused or may prefer to have things the way they used to be. Maybe you could sit down with him some evening and go through old photo albums of what his home looked like when he was younger and what his family looked like. A trip down memory lane with photos may help him talk to you about why he wants to go “home”. Maybe he misses a quiet place to read, a garden to work in, or a shop to putter in. Once you pinpoint why he wants to go home, you may be able to help him feel more at home by replacing what he has been missing. Reassure him that you have become his family now and that you want him to live with you now.

Often when a person suffers from memory loss, or has Alzheimer’s disease, they are confused and ask to go home. The important thing to remember is to try not to get angry or frustrated. It may be helpful if you changed the subject and diverted the person’s attention to something else. Suggest a simple game that you can do together.

“Desiree”

Age 17 - I’m very uncomfortable being around my grandfather alone. It’s like he doesn’t remember I’m his granddaughter. There have been times when he has tried to kiss me or touch me. It makes me feel awful.

Dear Desiree,

At no time is it appropriate for someone to make unwanted sexual advances. Do not go into his room alone. If this is impossible, be firm. Say “NO” and try to divert his attention elsewhere. You must tell your parents or someone you trust about his behavior.

It is unfortunate when this happens. However, your personal well being must always come first!

“Ray”

Age 18 - My grandmother has lost the ability to speak or write. It is stressful for her and for us. Because of this, it is hard to know how much she understands and how she feels. Why is she angry? Does she understand? How does she understand the situation?

Dear Ray,

Facial expressions, body language and tone of voice are all important parts of communication for both your grandmother and you. Try to maintain a gentle attitude and eye contact, use gentle hand signals to point or direct, and use friendly facial expressions. As you help your grandmother, this will reassure her that you are trying your best to understand what she want or needs.

Dear Reader,

Respect your elderly relative when you assist in caregiving.

Try not to make your elderly relative feel any more vulnerable than they already do. Don't use "baby talk" or talk to them as if they were children. Be encouraging and positive. Work together and you may even find things to laugh about.

Sincerely,

George

Chapter Four

Key Points:

You are not alone as a caregiver.

There are answers to caregiving problems.