

10. Caregiver Considerations

Preparing for Caregiving

If you have an aging or a physically disabled adult in your family, you may be a caregiver or soon to become one. Planning ahead is a luxury that many caregivers do not have. Most experienced caregivers say they wish they had started to prepare before facing a crisis. A few key questions to answer are:

- ❑ Do I know what the person's wishes would be if he or she were unable to make medical decisions? Are there any legally binding documents stating this?
- ❑ Do I know where important documents, such as insurance, wills, or financial statements are located?
- ❑ Do I have the authority to take over his or her finances if the person can no longer manage money?

CaregiverNJ

The New Jersey Department of Health and Senior Services maintains a website for people providing care to senior citizens and adults with disabilities at **www.caregivernj.gov**. The site includes extensive caregiving resources, educational tools, and self-assessment. It has a searchable database by topic and county and includes short descriptions and contact information for accessing important services for the caregiver and his or her loved ones. The site is also available in Spanish.

Starting the Conversation

If you are the caregiver of a senior or adult with a physical disability, it may be up to you to start a conversation with your loved one regarding your concerns as it relates to their health, safety and overall well-being. Ideally, such conversations should happen before there is a crisis. It can be prompted by a decrease in a person's ability to do certain things she or he has always handled independently. Your loved one may find it difficult to discuss issues or may be relieved to talk about their own concerns once the issues are raised. Don't assume that you are the only one who wants to talk.

You may want to start the conversation by talking about an article you read or something you saw on television about someone in a similar situation. This will assure the person that he or she is not the only person whose life is changing—others are experiencing the same changes and confronting similar issues.

Who Should Be There?

Consider how to make the conversation as caring and productive as possible. If possible, talk together with your family before meeting with the person needing

supportive services. Give everyone the chance to discuss their own needs and concerns, and what role they want to or are willing to play as part of a family caregiving team.

Small Steps

You probably do not want to begin with the big picture. Start with small steps, small decisions, and small changes. It is important to be direct and specific about your concerns, next steps, or even solutions.

Sometimes an assessment by an outside expert can be a good starting point. For instance, if the person has stopped eating or showering, you might suggest bringing in a social worker or occupational therapist to assess the person's ability to do daily tasks and make suggestions about how to make things easier and safer. As stated in the *Getting Started* section, your local ADRC/AAA is an excellent starting point.

What About Denial?

At first, the person may deny that there is a problem at all. This is very common. Concerns such as the person's ability to continue driving is a particularly sensitive topic. (See the **Transportation** section of this handbook). However, a successful conversation does not mean that you both reach complete agreement. You have made progress simply by starting the conversation and beginning the process of planning for the future. Be prepared to have several talks over a period of time. Being supportive and sympathetic about the difficulty of change and the person's fears, as well as his or her loss of independence, will help ease defensiveness and make him or her more receptive to what you are saying.

Listen Carefully

Remember that the person needing support is the expert on his or her situation. Listen thoughtfully to his or her ideas as you present your concerns and suggestions. Rather than telling the person what he or she must do or change, ask the person to help you assess the problem and welcome his or her input on possible solutions. The person must ultimately own the solution. You may be surprised to discover that he or she is also worried or feels unsafe, and is comforted to learn that support is available.

Assessing Care Needs

The first step to assuming a caregiver role is to develop a care plan based on a careful assessment of current needs. The plan will depend in part on whether the person has had a sudden health crisis or physical injury, a medical condition that is progressive, such as dementia or vision deterioration, or has needs due to a normal and gradual process of aging. But a plan is only as good as the information it is based on. Ask yourself:

- How do I assess what kind of care is needed?

- ❑ How can I get help in making this assessment?
- ❑ Once I understand the needs, what kind of services should be put in place?
- ❑ What services will be needed down the road?

For more about assessment of needs, see the **Getting Started** and **Home Care** sections of this handbook.

The Older Driver - Caregiver Considerations

If you are a caregiver of an older driver, riding with or following this person every once in a while is one way to keep track of his or her driving abilities. The following is a guide to assist you with addressing the concerns about your loved one's driving.

- ❑ **Talk to your loved one.** Say that you are concerned about his or her driving safety, but do not bring up your concerns in the car. Give specific reasons for your concerns such as recent fender benders, getting lost, or running stop signs. Realize your loved one may become upset or defensive. Be a good listener, and take your loved one's concerns seriously.
- ❑ **Encourage a visit to the doctor.** The doctor can check your loved one's medical history, list of medicines, and current health to see if any of these may be affecting his or her driving ability. A treatment plan may be recommended, which may improve this ability.
- ❑ **Encourage your loved one to take a driving test.** A driver rehabilitation specialist (DRS) can assess your loved one's driving safety through an office exam and driving test. The DRS can also teach special techniques or suggest special equipment to help him or her drive more safely.
- ❑ **Help make plans for transportation.** When your loved one is ready to talk about his or her driving safety, you can work together to create plans for safety. Your loved one may rely less on driving if he or she has other ways to get around.
- ❑ **Be there for your loved one.** Let your loved one know that he or she has your support. This is a difficult time, and it is important to show that you care.

- ❑ To find a DRS in your area, ask your doctor for a referral or contact the **Association for Driver Rehabilitation Specialists**, telephone: **1-866-672-9466**, website: **www.driver-ed.org**.
- ❑ For concerns about driving, the **MIT Age Lab and the Hartford Insurance Company** have prepared a guide called "Having the Conversation" to help families discuss changing driving skills, risks, and alternatives at **www.thehartford.com/talkwitholderdrivers/driversatrisk.htm**. The site includes useful worksheets and links to other resources.

Finding Services

Here are a few pointers to keep in mind as you begin to navigate the long-term care supportive services system:

- ❑ Talk to a real person. Many phone numbers you call will lead to voicemail. It's important to leave a message, but don't wait for a call back. Some services have backlogs of calls to return. Keep calling numbers until you connect with a human being who can help you.
- ❑ Keep track of your conversations. Write down names, phone numbers, and notes from each call.
- ❑ Most services are ultimately local, and can vary widely from state to state and region to region. If you are caring for someone but not living nearby, make sure you look for resources in the state or neighborhood where the person lives.
- ❑ Be persistent. You may get frustrated trying to find the person and the information you need. You may be told that something cannot be done when in fact it can. Don't give up!
- ❑ Ask for "Information and Referral" (I&R). I&R specialists are trained to answer a wide range of questions and connect you to services, so ask for that first.

Assessing Your Needs

Many caregivers do not think about their own needs, but in order to manage caregiving over time – days, months, or years – you should think about your own needs, not just those of the person you are caring for. Ask yourself:

- ❑ Can I manage these services by myself?
- ❑ How can I get support or take a break?
- ❑ How do I take care of myself?

Why Caregivers Need Care

Caregivers often lose themselves in providing care. If you provide care for a loved one who is aged or disabled, you may not realize that everything you do is part of caregiving. You may say, "This is just what families do for each other," or "This is what friends are for." However true these statements are, you may find yourself masking the value of the care provided and the significant toll this work can take on your physical, emotional and overall well-being. The Caregiver's Bill of Rights (see **Appendix X**) is a reminder that you have rights too.

Learning Caregiving Skills

Once you learn your role as a caregiver, you will be better equipped to face the current and future needs of caring for your loved one. Caregivers need more than information. You may need to learn new healthcare-related skills. As hospitals and rehab facilities shorten the length of patient stays, families are asked to provide more direct care for loved ones. Families may be expected to keep wounds clean, give medications, or monitor heart and blood sugar levels.

Too often they are not given the training they need to provide this care effectively. You may find the following resources helpful:

- ❑ The **National Caregivers Library** at www.caregiverslibrary.org/Default.aspx?tabid=68 provides a comprehensive website of information and tools for caregivers including useful articles, forms and checklists.
- ❑ **Eldercare at Home** at www.healthinaging.org/public_education/eldercare/2.xml, published by the American Geriatrics Society, is written for family caregivers and explains how to communicate effectively with doctors and other professionals as part of a caregiving support team, as well as how to care for you.
- ❑ The **American Red Cross** at www.redcross.org has courses in first aid that give hands-on training on how to recognize and respond to emergencies, how to perform CPR, and how to use automated external defibrillators (AED) to save victims of sudden cardiac arrest. Visit the website and enter your zip code to find classes near you.

Many organizations related to specific diseases (cancer, diabetes, Alzheimer's, etc.) provide education and training on various aspects of caring for loved ones with those conditions. Contact the national or state chapters of these organizations for more information on educational services.

Collecting and Organizing Information

Caregivers need to know how to collect and organize many details about their loved one's health care, home care, medications, safety equipment, and so on. These records are vital but difficult to keep track of.

- ❑ **The Caregiver's Organizer** at www.seniorconnection.org/caregiversupport.htm can be downloaded from the website in ten different languages. Click on "Services and Resources Provided," then "The Caregiver Organizer."
- ❑ See also **Appendix Y and Z** for documents to help you get organized, including a medication list and an important papers checklist.

Family Leave

Caregiving is not without its sacrifices. You may find a constant conflict between job responsibilities and the demands of caring for family at home. Many baby boomers are now part of the sandwich generation – caught between caring for young children and aging parents – and find the demands of both overwhelming. Others are caring for an adult with a disability whose needs change over time. One answer may be family leave.

Family leave is paid or unpaid time away from work to care for someone in your family. Federal and state laws have defined this benefit.

The Family and Medical Leave Act of 1993 (FMLA)

The U.S. Department of Labor's Employment Standards Administration, Wage and Hour Division, administers and enforces the Family and Medical Leave Act (FMLA) for all private, state and local government employees, and some federal employees. FMLA entitles eligible employees to take up to 12 weeks of **unpaid**, job-protected leave in a 12-month period for specified family and medical reasons.

Leave Entitlement

A covered employer must grant an eligible employee up to a total of 12 weeks of **unpaid** leave during any 12-month period for one or more of the following reasons:

- ❑ for the birth and care of the newborn child of the employee;
- ❑ for placement with the employee of a son or daughter for adoption or foster care;
- ❑ to care for an immediate family member (spouse, child or parent) with a serious health condition; or
- ❑ to take medical leave when the employee is unable to work because of a serious health concern.

Spouses employed by the same employer are jointly entitled to a combined total of 12 workweeks of FMLA. Employees may take FMLA in blocks of time or intermittently, i.e., by reducing their normal weekly or daily work schedule.

A covered employer is required to maintain group health insurance coverage for an employee on FMLA leave whenever such insurance was provided before the leave was taken and on the same terms as if the employee had continued to work.

Upon return from FMLA leave, an employee must be restored to the employee's original job, or to an equivalent job with equivalent pay, benefits, and other terms and conditions of employment.

Employee Eligibility

To be eligible for FMLA benefits, an employee must:

- ❑ work for a covered employer;
- ❑ have worked for the employer for a total of 12 months;
- ❑ have worked at least 1,250 hours over the previous 12 months; and
- ❑ work at a location in the US or in any territory or possession of the US where at least 50 employees are employed by the employer within 75 miles.

For additional information contact:

- ❑ **New Jersey Department of Labor** at **609-777-3200** or visit their website at <http://lwd.dol.state.nj.us/labor/index.shtml>; or the
- ❑ **U.S. Department of Labor, Wage and Hour Division** at www.wagehour.dol.gov and/or call the toll-free information and helpline, available 8 a.m. to 5 p.m. in your time zone, **1-866-4USWAGE** (1-866-487-9243), **TTY 1-877-889-5627**.

New Jersey Paid Family Leave Act (NJFLA)

In 2008, New Jersey enacted a paid family leave act (NJFLA). It differed from the federal FMLA in that:

- ❑ the New Jersey FLA does not allow an employee to use leave time for his or her own medical condition;
- ❑ the duration of the leave is within a 24-month period;
- ❑ the New Jersey FLA applies to companies with 50 or more employees nationwide;
- ❑ the New Jersey FLA applies to civil union partners; and
- ❑ employees **are paid** 2/3 of their average weekly wages, up to \$524/week maximum for 6 weeks during any 12-month period or 42 days for intermittent leave.

NJFLA Leave Entitlement

Each eligible employee may take up to 12 weeks of continuous leave during a given 24-month period, which begins on the first day of leave. The NJFLA permits leave to be taken for:

- ❑ the care of a newly born or adopted child, as long as leave begins within one year of the date the child is born to or placed with the employee; or
- ❑ the care of a parent, child under 18, spouse or partner in a civil union who has a serious health condition requiring in-patient care, continuing medical treatment or medical supervision. The FLA considers parents to be: in-laws, stepparents, adoptive parents, or others having a parent-child relationship with an employee.

In certain situations, an employee may take leave that is not continuous, for example, a reduced work schedule. Sometimes an employer's approval is necessary for this type of arrangement.

Employees are generally entitled to the same position held before the leave.

- ❑ **Exception:** If the original position is no longer available when the employee returns, the employer must offer an equivalent position in terms of pay, benefits and status.
- ❑ **Layoff:** If a layoff occurred while the employee was on leave, the employee retains the same rights as if no leave had been taken.

Employee Eligibility

To be eligible for the New Jersey FLA, an employee must:

- ❑ work for an employer who has at least 50 employees working for at least 20 weeks during the current or previous year; and
- ❑ work for an employer for a minimum of one year and worked at least 1000 hours, including paid overtime hours, during the 12 months immediately prior to taking the leave.

An employee may be excluded if his or her salary is within the highest 5% of all employees and their absence would have a substantial negative effect on the business. The same is true for the seven most highly paid employees. The employer must provide proper notice to the employee that they fall into this category.

For more information, consult your employer or contact the **NJ Division on Civil Rights** office closest to where you live or visit their website at www.nj.gov/oag/dcr/index.html.

Caregiver Support

Caregiving may be a very isolating experience, especially for those who have limited help or are the sole caregiver for an individual who cannot be left alone for long periods of time. But you are not alone. There are support systems to help you meet the challenges of providing short or long-term care.

These challenges can result in caregivers ignoring their own physical and emotional health. Caregivers often don't recognize the symptoms of stress that they are experiencing.

- ❑ For a simple self-test, see the **American Medical Association's Self Assessment Questionnaire** at www.ama-assn.org/ama/upload/mm/36/caregivertooleng.pdf.

If you take the test and find you do have a number of symptoms associated with high levels of physical and emotional stress, contact your primary care doctor for an appointment, take the questionnaire with you, and discuss next steps, such as finding a therapist or support group, or taking medication.

Securing support from other family members, friends, and community groups is essential. It may be hard to ask for and/or accept help. But you cannot do it alone. Think in terms of concrete actions that can help. Could a friend pick up groceries for you or your loved one? Could a neighbor do yard work for you or give your loved one a lift to a medical appointment? Could a friend or relative keep your loved one company while you take a break to go to a movie, the gym, take a walk or a drive, or do some shopping for yourself? Perhaps you could set up a regular visit from a friend so that you don't feel isolated or overloaded. The

people who care about you want to help, and you may be able to return the help at a later time.

Some caregivers find support groups helpful. They allow caregivers to share their experiences, exchange information, and point each other toward organizations that have been particularly helpful. Some support groups may be linked to stress management or exercise classes. Many support groups are run by professionals, such as social workers, and can help caregivers devise productive strategies for dealing with intra-family conflicts or tensions that may arise around difficult caregiving decisions.

- ❑ To find or start a support group, contact the **New Jersey Self-Help Group Clearinghouse** toll-free at **1-800-367-6274** or on-line at **www.njgroups.org**. The clearinghouse maintains a database of information on over 4,500 groups within the state and over 1,100 national organizations, including on-line groups.

The Family Caregiver Support Program, through your local ADRC/AAA, primarily serves family caregivers of adults 60 years of age and older, and people of any age with a diagnosis of Alzheimer's disease. There are no income eligibility requirements for information or services. The overall goal of the program is to enhance the caregiver's ability to keep their loved ones at home and in their communities, in a safe and supportive environment. Each program works to provide support in five key areas:

- ❑ Information about valuable services, community resources, and local programs.
- ❑ Assessment of needs and access to services through one-on-one assistance to identify options and gain access to community-based services.
- ❑ Training, support, and counseling, such as caregiver support groups and training classes to assist caregivers in making decisions, solving problems, and managing stress.
- ❑ Respite programs to provide temporary relief through in-home care, or adult day care or emergency respite.
- ❑ Supplemental services, on a limited basis, for home modifications and repair, transportation, and other things it may be for the caregiver to do.

The Family Caregiver Support Program gives priority to caregivers with the greatest social and economic need, but it is also open to middle-income families.

- ❑ Find support groups in your area through the Family Caregiver Support Program in your county. Contact you local **ADRC/AAA** or call **1-877-222-3737**.

Respite Services

Every caregiver needs time off. Respite, or time off from caregiving duties through substitute care, can be provided on a regular basis or can be scheduled in advance when needed for vacations or special occasions. Respite care can be funded privately, or through the NJ Medicaid waivers and NJ Statewide Respite Program.

The NJ Statewide Respite Care Program provides services for the elderly and functionally impaired persons age 18 or older to relieve their unpaid caregivers of physical and emotional stress arising from the responsibility of providing daily care.

Services Offered

Services available under the NJ Statewide Respite Care Program include:

- Companion
- Homemaker/home health aides (on an hourly or overnight basis)
- Medical or social adult day care
- Temporary care in licensed medical facilities
- Private duty nursing service
- Caregiver-Directed option
- Adult Family Care
- Campership

Priority is given to those families where the impaired member is at risk of long-term care institutionalization due to inability of a caregiver to continue in that role.

Eligibility Requirements

The following criteria must be met for participation in the NJ Statewide Respite Care Program:

- Resident of NJ with a chronic physical or mental disability requiring supervision or assistance with basic daily needs from a caregiver;
- Age 18 or older; and
- Income and resource eligible (call for current year limits).

Cost of Services

Respite care services can be provided for those with private pay funding or through the NJ Medicaid waivers and the NJ Statewide Respite Care Program. The individual requiring the care is the only one whose income is considered when establishing eligibility for participation in the program. A cost-share may be required based on the individual's income.

For additional information:

- Contact your local **ADRC/AAA** or call **1-877-222-3737**. Information is also available on-line at **www.nj.gov/health/senior/respites.html**.

- ❑ **National Respite Coalition and National Respite Locator Service** at www.archrespite.org, **703-256-9578**, helps parents, caregivers and professionals get a break using respite services in their local area.

More Caregiver Resources

In addition, the following organizations provide information to help you manage your role as a caregiver:

National Organizations

- ❑ **AARP** at www.aarp.org/family/caregiving/articles/agingparentsintro.html has free on-line seminars for caregivers, such as “Managing Caregiving Details: The Basics” and “Planning for the Care of Aging Parents.” Click on “Learning and Technology,” then “Family Caregivers.”
- ❑ **Caring from a Distance** at www.cfad.org is a nonprofit organization geared specifically to the particular challenges faced by caregivers who live far away from their loved one. It offers information, support and helpful links.
- ❑ **Family Caregiver Alliance**, accessible toll-free at **1-800-445-8106**, is a national network that addresses the need of families and friends providing long-term care at home. Their website, at www.caregiver.org/caregiver/jsp/home.jsp, includes information, free publications, and an on-line caregiver support discussion group.
- ❑ **Well Spouse** at www.wellspouse.org and **1-800-838-0879** is a national organization that gives support to wives, husbands, and partners of the chronically ill and/or disabled.

Faith-based Organizations

Faith-based organizations have a long tradition of providing assistance to those in need, whether they are members of that faith community or not. Faith-based organizations coordinate volunteers to help with individuals who are chronically ill or disabled. Some organizations may sponsor meal programs as well as provide other direct services. The following organizations are just a few examples of the kinds of services provided by faith-based organizations. Check with your religious affiliation for additional resources.

- ❑ The NJ Department of State operates an **Office of Faith-Based Initiatives**. Its website is at www.state.nj.us/state/faith/index.html.
- ❑ **Association of Jewish Family and Children’s Agencies (AJFCA)** at www.ajfca.org/elder.html, **1-800-634-7346 toll-free**, links concerned family members with Jewish Family Services Agencies in that community through its Elder Support Network.
- ❑ **Catholic Charities** at www.catholiccharitiesusa.org, **703-549-1390**, provides social service programs that may include home visiting

programs, adult day health, visiting nurse services, a foster grandparents program, caregiver support programs, and basic needs services (food, fuel, utility, and rental assistance).

- **Lutheran Services in America** at www.lutherservices.org has more than 300 health and human service organizations that provide care, ranging from health care to disaster response.