
Perspective of a Caregiver

Richard Gilmur



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Syllabus

Perspective of a Caregiver

Presenter:

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Description:

The caregiver plays a vital role in the long-term treatment of anyone with a major illness or chronic condition. This role is often bestowed upon a family member who must not only provide appropriate care and treatment team management, but also continue to function in their role of parent, spouse, and/or job holder. There are many challenges faced during the patient's, caregiver's, and other family member's journey through the progression from a diagnosis of transverse myelitis (TM) to an established, viable long-term care and treatment program. Four aspects of this progression (adapt, accommodate, advocate, and accept) will be discussed. The dynamics of the patient's needs and, hence, the caregiver's changing roles and responsibilities will be discussed. The interrelationships and interdependence between the caregiver and the treatment team members will also be discussed. This presentation will not only address the primary functions of the caregiver from a caregiver's perspective and concomitant challenges in this process, but also the considerations necessary to ensure "care for the caregiver."

Objectives / Outcomes:

Understanding the phases or progression of adjustment to a family member's long-term diagnosis.

Understanding the changing dynamics associated with a TM patient's needs and typical challenges that arise for the caregiver and for the family as a whole.

Will identify sources of stressors for caregivers and the need for respite care.

Will identify resources for family caregivers.

Will provide a perspective on the importance for active caregiving and treatment team management inclusive of the development of a partnership/collaboration with treatment team members.

The Common Bonds of Caregiving

What is caregiving and how do you define a family caregiver? What is the common thread that ties together those of us who care for spouses, children, parents, siblings, partners or friends who are chronically ill, frail, or disabled?

It certainly isn't the tasks of caregiving. They vary so much, from helping a developmentally delayed child learn new skills, to taking an aging parent to frequent doctors appointments, or suctioning a spinal chord injured spouse virtually every hour every day.

It surely isn't the number of years involved. Caregiving can last a few short months . It can last three to five years. At times, caregiving is a lifetime commitment.

Location varies from situation to situation. Although most caregiving goes on in the home, and most caregivers and recipients live under the same roof, talk to anyone whose parent is in a nursing home and you'll quickly learn that caregiving doesn't end when someone else is responsible for day to day care, or when caregiving takes place long distance.

If it isn't the responsibilities or tasks, and it is not the length of time, if it isn't the location - what is the essential bond of caregiving? What does caring for a spouse with multiple sclerosis have to do with caring for parents who are losing their independence, or a child with epilepsy.

In 1994, when the National Family Caregivers Association (NFCA) conducted its first caregiver member survey, we were seeking to find that common bond, to define the link between all caregivers. We found in no uncertain terms that the common bond of caregiving is its emotional impact. In 1997 when we surveyed our members again we found the same thing.

The common bond of caregiving is the intense sadness we feel because someone we care about has suffered a brain injury, is losing their mobility, will never achieve normal life functioning. It is the sadness that comes from wanting the miracle of normalcy.

The common bond of caregiving is the upheaval of changing family dynamics that occurs because life has been turned upside down and because there is no set timetable for working through the painful stages of grief which caregivers and care receivers all experience in their own personal and private way.

The common bond of caregiving is the sense of isolation that comes from living outside the norm, from having everyday activities of life - dressing; walking; toileting; breathing, thinking clearly - that everyone else takes for granted, become such a big focus in your own life.

The common bond of caregiving is the frustration we all experience because it is so hard to get things done, because non-caregivers just don't understand, because healthy people park in handicapped parking spots, and because people who are supposed to have the answers often don't.

The common bond of caregiving is the stress we feel because we don't have enough leisure or personal time, and the common bond of caregiving is unfortunately often the severe depression that so many of us suffer.

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These are the common bonds of caregiving that tie us to one another, that develop in us an innate understanding of each other's pain, each other's lost dreams, each other's fears.

These shared emotions, these very difficult emotions, are the common bond of caregiving. But there is another common bond, another shared emotion, that we don't recognize as often as we should. It is the inner strength that most of us never knew we had.

It is the fortitude to go on despite the pain. It is the wellspring of hope we always dip into. It is the power to make a difference. It is the clever way we solve a difficult problem. It is the knowledge that we have been tested by fire, and we have survived.

Our inner strength is the gift we have been given. It is the "pay back" for the pain, and although many of us would gladly trade it in for an easier life and our loved one's health and well being, we nevertheless ought to recognize its extraordinary value.

The problem is I don't think most caregivers do recognize it. I think most caregivers are so caught up in the act of caregiving that they don't step back and look at the extraordinary things they do. I think a great many caregivers don't even identify themselves as caregivers.

This is not surprising. The term caregiving does not exist in most dictionaries. Caregivers have not been counted in a US census and are therefore not officially recognized as a significant minority. Caregiving and caregivers, are invisible.

I wish it weren't so. I wish caregivers were given their just due. I wish caregivers themselves would recognize their value, acknowledge their individual achievements. Empowerment is an overused word, but it is the one that comes to mind when I think of what I want for caregivers.

Empowerment for me means a sense of self confidence, a belief in one's ability to have some control over situations, a sense of pride, a feeling of self respect and self worth. For the most part, we use our inner strength to help our loved ones and to get through difficult caregiving days. We need to begin to use it to take better care of ourselves, to feel proud, to experience the beauty of self love.

I received a letter recently, actually an e-mail, from a member of the National Family Caregivers Association. She said that NFCA had become a great solace to her. She said that we made her proud to be a caregiver.

Proud to be a caregiver. I mulled the phrase over in my mind for quite some time before I realized that the true definition of caregiving is buried in that phrase, in the understanding that caregiving is a role that tests our abilities, our faith, and our character.

What is caregiving? How do you define a family caregiver? I think I have the answer now - you define family caregivers by their emotions and their spirit, by the sadness in their eyes, but also by the determination in their hearts. Caregivers are very special people.

This article first appeared in [Paraplegic News](#).

FAMILY CAREGIVING STATISTICS

Compiled by the National Family Caregivers Association

- **More than one quarter (26.6%) of the adult population has provided care for a chronically ill, disabled or aged family member or friend during the past year. Based on current census data, that translates into more than 54 million people.** Source: National Family Caregivers Association (NFCA) Random Sample Survey of 1000 Adults, Funded by CareThere.com, Summer, 2000.
- **Caregiving is no longer predominantly a women's issue. Men now make up 44% of the caregiving population.** Source: National Family Caregivers Association (NFCA) Random Sample Survey of 1000 Adults, Funded by CareThere.com, Summer, 2000.
- **The value of the services family caregivers provide for "free" is estimated to be \$196 billion a year.** Source: Health Affairs March/April 99 - as above
- **Virtually one half of the US population has a chronic condition. Of these 41 million were limited in their daily activities. Twelve million are unable to go to school, to work, or to live independently.** Source: Chronic Care in America (Institute for Health & Aging, Univ. of CA/SF for the Robert Wood Johnson Foundation) 1996
- **People over 85 years of age are the fastest growing segment of the population. Half of them need some help with personal care.** Source: US Bureau of the Census Statistical Brief, Sixty Five Plus in the United States, May 1995
- **Elderly caregivers with a history of chronic illness themselves who are experiencing caregiving related stress have a 63% higher mortality rate than their non-caregiving peers.** Source: Journal of the American Medical Association, December 15, 1999, Vol. 282, No. 23.
- **The pool of family caregivers is dwindling. In 1990 there were 11 potential caregivers for each person needing care. In 2050 that ratio will be 4:1.** Source: Chronic Care in America - as above
- **Sixty-one percent (61%) of "intense" family caregivers (those providing at least 21 hours of care a week) have suffered from depression. Some studies have shown that caregiver stress inhibits healing.** Source: National Family Caregivers Association/Fortis Long Term Care (Caregiving Across the Life Cycle) 1998; Lancet 1995;346 (Slowing of Wound Healing by Psychological Stress - Kiecolt-Glaser, JK et al)
- **Heavy duty caregivers, especially spousal caregivers, do not get consistent help from other family members. One study has shown that as many as three fourths of these caregivers are "going it alone".** Source: Caregiving Across the Life Cycle - as above
- **Approximately 80% of home care services are provided by family caregivers.** Source: US General Accounting Office (GAO/HEHS 95-26, "Long-Term Care: Diverse, Growing Population Includes Millions of Americans of All Ages") 1994
- **A recent study calculated that American businesses loses between \$11 billion and \$29 billion each year due to employees' need to care for loved ones 50 years of age and older.** Source: National Alliance for Caregiving/Met Life (Met Life Study of Employer Costs for Working Caregivers
- **Fifty nine percent of the adult population either is or expects to be a family caregiver.** Source: National Family Caregivers Association (Random Sample Survey of 1,000 Adults Sponsored by Aleve)

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TIPS FOR
FAMILY
CAREGIVERS

- Choose to **take charge** of your life, and don't let your loved one's illness or disability always take center stage.
- Remember to **be good to yourself**. Love, honor and value yourself. You're doing a very hard job and you deserve some quality time, just for you.
- **Watch out** for signs of depression, and don't delay in getting professional help when you need it.
- When people offer to help, **accept the offer** and suggest specific things that they can do.
- **Educate yourself** about your loved one's condition. Information is empowering.
- There's a difference between caring and doing. **Be open to technologies and ideas** that promote your loved one's independence.
- **Trust your instincts**. Most of the time they'll lead you in the right direction.
- Grieve for your losses, and then allow yourself to **dream new dreams**.
- **Stand up for your rights** as a caregiver and a citizen.
- **Seek support** from other caregivers. There is great strength in knowing you are not alone.

To order copies of NFCA's 10 Tips for Family Caregivers Bookmarks, go to our [Publications & Resource Materials Order Form](#).

Caregiver Self Advocacy

4 Messages to Live By

What does it mean to be a happy person when you are a family caregiver? How can you gain a feeling of confidence in your abilities and have a sense of pride in your achievements? How do you stand up for yourself, take care of yourself and find a balance between your own needs and those of your loved ones? These are heady questions, and ones that we have discussed often at NFCA.

We've looked for answers in our own experiences, in books, from professionals, and from other caregivers. We've struggled with these issues because they are at the core of our search for meaning and our need to have principles to live by as caregivers. We've now given form to the many ideas we have developed, and we want to share them with you. We call them NFCA's Principles of Caregiver Empowerment. They are the fundamental principles by which we try to live, and we hope you will use them as guideposts in your search for a sense of direction and inner peace.

1. Choose to take charge of your life. Don't let your loved one's illness or disability always take center stage.

We fall into caregiving often because of an unexpected event, but somewhere along the line you need to step back and consciously say, "I choose to take on this caregiving role." It goes a long way toward eliminating the feeling of being a victim.

2. Honor, value and love yourself. You're doing a very hard job and you deserve some quality time, just for you. Self care isn't a luxury. It's a necessity.

Self care isn't a luxury. It is your right as a human being. Step back and recognize just how extraordinary you are, and remember your own good health is the very best present you can give your loved one.

3. Seek, accept, and at times demand help. Don't be ashamed to ask for help. When people offer assistance, accept it and suggest specific things that they can do.

Caregiving, especially at its most intense levels, is definitely more than a one person job. Asking for help is a sign of your strength and an acknowledgment of your abilities and your limitations.

4. Stand up and be counted. Stand up for your rights as a caregiver and a citizen.

Recognize that caregiving comes on top of being a parent, a child, a spouse. Honor your caregiving role and speak up for your well-deserved recognition and rights. Become your own advocate, both within your own immediate caregiving sphere and beyond.

To order copies of the Caregiver Self Advocacy 4 Messages to Live By bookmarks, please go to the [Publications and Resource Materials Order Form](#).

A Guide to Improving Doctor/Caregiver Communications:

Suggestions from the

National Family Caregivers Association

There is much to be gained by improving communications between family caregivers and health care professionals, especially physicians. Positive outcomes include: better care for the patient, less stress and illness on the part of the caregiver, more efficient use of doctors' time, reduced costs for the health care system, and more satisfaction for all concerned.

In order to reap these benefits caregivers and physicians need to gain a better understanding of each other's worlds. They need to try, as hard as it is, to "walk in each other's shoes".

The following guide is offered as a path for doing just that.

Tips For Doctors From Family Caregivers

1. Be open and forthright
2. Think about the practicality of the treatments you suggest and consider their effect on the entire family, not just their medical efficacy.
3. When you prescribe medications, be sure caregivers understand potential side effects so they know what to expect.
4. In non life threatening situations, assure caregivers that every decision doesn't have to be made on the spot. Respect the right of the caregiver and the patient to think things over
5. Now and then ask the caregiver: How are you? Let them know you understand that illness and disability are a family affair.
6. Be accessible - especially when a caregiver is opening his or her heart.
7. Reach out to the caregiver - literally. A simple touch can mean a great deal
8. Be sensitive about where you talk to caregivers about difficult subjects - waiting rooms and corridors are not appropriate.
9. Always explain as completely as possible all of the legal ramifications of life-saving actions.
10. Be prepared to tell caregivers about helpful resources. Living with a chronic illness or disability requires more than medicine has to offer.

Tips for Family Caregivers From Physicians and Other Healthcare Professionals

1. Write questions down so you won't forget them.
2. Be clear about what you want to say to the doctor. Try not to ramble.
3. If you have lots of things to talk about, make a consultation appointment, so the doctor can allow enough time to meet with you in an unhurried way.
4. Educate yourself about your loved one's disease or disability. With all the information on the Internet it is easier than ever before.
5. Learn the routine at your doctor's office and/or the hospital so you can make the system work for you, not against you.

6. Recognize that not all questions have answers - especially those beginning with "why".
7. Separate your anger and sense of impotence about not being able to help your loved one as much as you would like, from your feeling about the doctor. Remember, you are both on the same side.
8. Appreciate what the doctor is doing to help and say thank you from time to time.



National Family Caregivers Association

800-896-3650

info@nfcacares.org

Working together we can make a difference!

10 Managed Care Tips for Caregivers

From www.FamilyCareAmerica.com

If you provide care for an elderly, ill, or disabled loved one, you've probably had to deal with his or her insurance company. Filling out the paperwork can be a time consuming and confusing process-especially if the company denies a claim. Luckily, help is available in many states through the office of the managed care ombudsman. These consumer advocates can help you understand your rights under different managed care plans and guide you through the appeals process.

The following tips were provided by The Office of The Managed Care Ombudsman, the Bureau of Insurance, Commonwealth of Virginia. Check with the appropriate office in your loved one's state for information regarding specific regulations.

- 1) It's worth the time and effort to read and understand the documents provided by your loved one's insurance company. This includes evidence of coverage, as well as other documents such as member handbooks, provider directories, newsletters, and other material.
- 2) Understand as much as you can about the plan before your loved one uses it. It's particularly important to know the primary care provider, the plan's policy regarding referrals to specialists, co-payment requirements, and access to emergency care. Be prepared. The plan will probably not cover all of your loved one's medical expenses, and he or she may have to pay part of the cost.
- 3) Ask questions about anything that isn't clear.
- 4) If you need assistance, contact the plan's representatives, your loved one's insurance agent, his or her employer, or the office of the managed care ombudsman.
- 5) If a problem arises, you should first contact your loved one's managed care plan. The evidence of coverage contains a telephone number and mailing address. Be sure to record the day you call, the name of the person you speak with, the title of the person you speak with, and a summary of the conversation.
- 6) If your loved one or his or her physician has difficulty obtaining approval for medical care-or experiences difficulty with a claim-know what your loved one's rights are according his or her particular plan.
- 7) Follow the instructions provided by the plan to appeal any decision. Familiarize yourself with the levels of appeals and grievance procedures that are available through the plan's internal process.
- 8) Carefully document- in writing-the facts that support your case. Keep your letters business-like and clearly state why you believe you are correct. Include copies of documents from your loved one's physician that support the appeal.

9) Follow the time lines and meet the deadlines set up by the plan. Be sure to keep a copy of any letters you send.

10) At any point in the process, feel free to contact your local office of the managed care ombudsman for assistance.

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MOST FREQUENTLY ASKED QUESTIONS

The National Family Caregivers Association (NFCA) receives hundreds of phone calls and emails a week from family caregivers seeking resources, referrals and advice.

The following is a compilation of the most frequently asked questions (FAQs) and our responses.

1. I'm looking for respite services, whom should I contact?

NATIONAL ORGANIZATIONS AND PROGRAMS

Easter Seals

230 West Monroe Street, Suite 1800
Chicago, IL 60606
1-800-221-6827
web: www.easter-seals.org
email: info@easter-seals.org

Provides a variety of services at 400 sites nationwide for children and adults with disabilities, including adult day care, in-home care, camps for special needs children and more. Services vary by site.

Family Friends

National Council on the Aging, Inc.
409 Third Street, SW
Washington, DC 20024
202-479-6675 or 202-479-6672
web: www.ncoa.org
email: miriam.charno@ncoa.org

Provides respite for families of children with special needs by men and women volunteers over the age of 50. Programs located throughout the country - with 47 centers and over 2000 volunteers.

Interfaith Caregivers Alliance (ICA)

One West Armour Street, Suite 202
Kansas City, MO 64111
1-816-931-5442
web: www.NFIVC.org
email: NFIVC@aol.com

Provides respite support and a variety of other services through local congregations working together. Services vary by site. There are currently 1300 programs throughout the country.

Shepherd's Centers of America

One West Armour Street, Suite 201
Kansas City, MO 64111
1-800-547-7073
web: www.shepherdcenters.org
email: staff@shepherdcenters.org

Provides respite care, telephone visitors, in-home visitors, nursing home visitors, home health aides, support groups, adult day care, and information and referrals for accessing other services available in the community. Services vary by center. There are currently 75 centers around the country.

REFERRAL SOURCES

National Association of Adult Day Services

National Council on the Aging
409 3rd Street SW, Suite 200
Washington, DC 20024
202-479-6682
web: www.ncoa.org

Provides information about locating adult day care centers in your local area

National Respite Coalition

4016 Oxford Street
Annandale, VA 22003
703-256-9578
web: www.chtop.com/NRC.htm
email: jbkagan@nrc.com

They provide a list of states that have respite coalitions. These state coalitions then list respite services available in their state for children with special needs.

National Respite Locator Service

800 Eastowne Drive, Suite 105
Chapel Hill, NC 27514
800-773-5433
web: www.chtop.com/locator.htm

Lists over 1900 sites nationwide, all of which focus on respite care for families of special needs children.

2. ARE THERE CAREGIVER RESOURCES ON THE INTERNET?

CAREGIVER WEBSITES

There are a variety of web sites that offer information and support for family caregivers. Many of these sites

offer the ability to type in a zip code and obtain a list of local resources for home care, respite care, assisted living facilities, rehab facilities, hospice and other types of care. To locate other sites, type "FAMILY CAREGIVER" on any of the major search engines for a complete listing. Here are some of our favorites:

www.nfcacares.org

The home page of the National Family Caregivers Association. Explore this web site and find out more about caregiving, what NFCA has to offer, about projects and programs underway and those that are planned for the future.

www.carethere.com

Provides a broad national database of information and services in the areas of health care, finance, insurance, legal products and emotional support – all specifically designed to assist caregivers.

www.caregiver.com

Internet home for Today's Caregiver Magazine. Site includes topic specific newsletters, online discussion lists, back issue articles, chat.

www.familycareamerica.com

Offers varied resources to meet caregivers' specific needs, in their own localities, provides caregiver support, solution sharing, and discussion forums.

www.webofcare.com

Offers advice on disease-specific care situations, caregiver chats, product information, health news and local resource searches.

ELDERCARE WEBSITES

There are a variety of websites that offer information and support about elder care. Type "ELDERCARE" on any of the major search engines for a comprehensive listing. Below are sites that we are familiar with and are good resources:

Each of the sites listed provides general geriatric health information, senior news and information, bulletin boards, etc. Many of these sites offer the ability to type in a zip code and obtain a list of local resources for home care, respite care, assisted living facilities, rehab facilities, hospice and other types of care.

www.caregiving.com

www.careguide.com

www.carescout.com

www.eldercorner.com

www.extendedcare.com

www.ec-online.com (eldercare online)

www.senior-directions.com

3. WHERE CAN I FIND FINANCIAL HELP FOR MY CAREGIVING?

GENERAL RECOMMENDATIONS

Contact county or state Department of Health and Human Services , or area social service agencies, such as Catholic Charities, Association of Jewish Family and Children's Agencies and local chapters of voluntary health agencies to find out if they are offer any financial support programs and how to apply for it.

PRESCRIPTION DRUG AND MEDICAL CARE SUPPORT PROGRAMS

Federal Hill-Burton Free Care Program

1-800-638-0742 (message center).

Offers referrals to agencies that offer free medical care.

Medicine Program

PO Box 520

Doniphan, MO 63935

1-573-996-7300

web: www.themedicineprogram.com

email: help@themedicineprogram.com

A means-tested program for persons who do not have coverage either through insurance or government subsidies for outpatient prescription drugs, and who cannot afford to purchase medications at retail prices.

Pharmaceutical Research and Manufacturers of America (PHRMA)

1100 Fifteenth Street, NW

Washington, DC 20005

1-800-762-4636 (message center)

202-935-3400 to speak directly to someone

web: www.phrma.org

Provides a patient assistance directory that includes a list of pharmaceutical company-run programs to help people without insurance or those with a low income obtain medications

4. I'M LOOKING FOR OVERALL CAREGIVER SUPPORT. WHERE CAN I FIND IT?

GENERAL RECOMMENDATIONS

Contact your local hospital or clinic (social work department); county department of senior services or disability services, area adult day centers, social service agencies and/or the local chapter of the health

agency that focuses on your loved one's condition. It is by no means certain that they will offer caregiver support services, but they are good places to check.

SPECIFIC ORGANIZATIONS

National Family Caregivers Association

10400 Connecticut Avenue Suite 500
Kensington, MD 20895
1-800-896-3650
web: www.nfcacares.org
email: info@nfcacares.org

The National Family Caregivers Association (NFCA) is a grassroots organization created to educate, support, empower and advocate for the millions of Americans who care for chronically ill, aged or disabled loved ones. NFCA is the only constituency organization that reaches across the boundaries of different diagnoses, different relationships and different life stages to address the common needs and concerns of all family caregivers. NFCA is the voice of family caregivers. Members receive the quarterly newsletter, Take Care!, inspirational greeting cards and access to an experienced staff which provides information, referrals and caregiver support counseling.

American Self-Help Clearinghouse

Northwest Covenant Medical Center
25 Pocono Road
Denville, NJ 07834
1-973-625-9565
web: www.selfhelpgroups.org
email: ashc@cybernex.net

Not caregiver specific, but serves as an information clearinghouse for self-help groups of all types and provides information on how to start a support group.

Family Caregiver Alliance (FCA) (in California only)

690 Market Street Suite 600
San Francisco, CA 94104
1-415-434-3388
1-800-445-8106 (CA only)
web: www.caregiver.org
email: info@caregiver.org

FCA is a nationally recognized information center on long-term care and the lead agency in California's system of Caregiver Resource Centers. FCA serves as a public voice for caregivers, illuminating the daily challenges they face, offering them the assistance they so desperately need and deserve, and championing their cause through education, services, research and advocacy.

Friends Health Connection

PO Box 114

New Brunswick, NJ 08903
800-384-7436
web: www.48friend.org
email: FHC@pilot.NJIN.NET

Links persons with illness or disability and their family caregivers with others experiencing the same challenges.

Well Spouse Foundation

30 East 40th Street PH
New York, NY 10016
1-800-838-0879
web: www.wellspouse.org

A national, not for profit membership organization which gives support to husbands, wives and partners of the chronically ill and/or disabled. They offer support group information for spouses.

5. WHERE CAN I FIND INFORMATION ABOUT CARING FOR MY AGING PARENTS, AND RELATED FAMILY ISSUES ?

GENERAL RECOMMENDATIONS

Contact your county department of senior services or elder affairs, area adult day centers, and/or social service agencies providing services to the elderly.

REFERRAL SOURCES

AARP

601 E Street, NW
Washington, DC 20049
1-800-424-3410
web: www.aarp.org

Supplies education and information about caregiving, long-term care, and aging, including publications and audio-visual aids for caregivers.

Children of Aging Parents (CAPS)

1609 Woodbourne Road #302A
Levittown, PA 19057
1-800-227-7294
web: www.experts.com; www.careguide.net

CAPS assists caregivers of the elderly with information and referrals, a network of support groups, and publications and programs that promote public awareness of the value and the needs of caregivers.

Eldercare Locator

National Association of Area Agencies on Aging
 927 15th Street, NW 6th floor
 Washington, DC 20005
 1-800-677-1116
 web: www.n4a.org.

Referrals to Area Agencies on Aging via zip code locations. Offers information about many eldercare issues and services in local communities.

The National Association of Professional Geriatric Care Managers

1604 North Country Club Road
 Tucson, AZ 85716
 1-520-881-8008
 web: www.caremanager.org

Geriatric care managers (GCMs) are health care professionals, most often social workers, who help families in dealing with the problems and challenges associated with caring for the elderly. This national organization will refer you to their state chapters, which in turn can give you the names of GCMs in your area.

6. **HOW DO I GO ABOUT LOCATING HOME CARE HELP OR AN ASSISTED LIVING OR NURSING FACILITY?**

WATCHDOG ORGANIZATIONS**Consumer Consortium on Assisted Living**

PO Box 3375
 Arlington, VA 22203
 1-703-841-2333

CCAL is a national consumer-focused organization that is dedicated to representing the needs of residents in assisted living facilities and educating consumers, professionals, and the general public about assisted living issues. Authored the book "Choosing an Assisted Living Facility, Strategies for Making the Right Decision" which provides helpful information and contains a concise questionnaire.

National Citizens Coalition for Nursing Home Reform

1424 Sixteenth Street, NW Suite 202
 Washington, DC 20036
 1-202-332-2275
 web: www.nccnhr.org
 email: nccnhr@nccnhr.org

Serves as an information clearinghouse; offers referrals nationwide for help with concerns

about long-term care facilities.

REFERRAL SOURCES

New Lifestyles

1-800-869-9549

web: www.NewLifeStyles.com

Publishes regional directories of nursing homes, assisted living and retirement communities. Call for a free copy or visit them on the web.

Senior Alternatives

1-800-350-0770

web: www.senioralternatives.com

Publishes regional directories of nursing homes, assisted living and retirement communities. Call for a free copy or visit them on the web.

Visiting Nurses Association of America

11 Beacon Street Suite 910

Boston, MA 02108

617-523-4042

web: www.vnaa.org

email: vnaa@vnaa.org

Promotes community based home health care. You can contact them to find your local VNA.

ALSO SEE WEBSITE RECOMMENDATIONS ABOVE

7. HOW DO I FIND TRAINING TO IMPROVE MY CAREGIVING SKILLS AND HOW DO I LEARN SKILLS TO HELP ME COPE BETTER WITH THE STRESSES OF CAREGIVING?

GENERAL RECOMMENDATIONS

Community-based organizations periodically offer classes and workshops for family caregivers. Check your local paper for listings. Also check with your local community college, hospital or Red Cross chapter and the local chapter of the voluntary health agency focused on your loved one's illness or disability.

Strength for Caring

1-888-422-7380

web: www.oncolink.upenn.edu/sfc

A national program to train cancer caregivers does exist.

The following is a wonderful article that appeared in the Dear Abby column of the Star Free Press last October. I hope this piece will inspire us all by providing love, patience, and understanding to our special kids...

W e l c o m e t o H o l l a n d by Emily Pearl Kingsley

"I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this :

"When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum, the Michelangelo David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

"After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, 'Welcome to Holland. .

" 'Holland?! ?' you say. What do you mean, Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy. .

"But there's been a change in the flight plan. They've landed in Holland and there you must stay.

"The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, **famine** and disease. It's just a different place.

"so you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

"It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts .

"But everyone you know is busy coming and going from Italy., and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, 'Yes, that's where I was supposed to go. That's what I had planned.'

"The pain of that will never, ever, ever go away, because the loss of that dream is a very significant loss.

"But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland. "

A MOM'S PERSPECTIVE - VICKI ISETT

My husband, David, and I will celebrate our tenth wedding anniversary this May. In spite of a tumultuous beginning to our relationship (or perhaps because of it!) we've had a wonderfully harmonious ten years together.

When Emily, our first child, was born, we worked through a lot of the typical conflicts that arose around traditional male and female *roles* -- who works; who takes care of the baby; who does which household chores: who makes money, who doesn't, etc. To our advantage, we found we were very similar in our attitudes around child rearing. So when Annie was born three years later, we figured we had already done the hard work as a couple. Wrong.

When Annie was diagnosed with a disability at four months of age, we embarked on a whole new set of challenges in our relationship. After years of fairly open communication, we found we couldn't talk about this situation. It was too painful. We had no comfort to offer each other. We protected each other from our deepest, darkest fears. We managed crises together, made medical decision together, but we didn't discuss our feelings about what was happening to Annie, to us, and to our family.

Our male/female roles became more polarized. With the level of care Annie required -- weekly doctor appointments, physical, tests, medications -- I became consumed by my role as her mom. I felt David had the luxury of not dealing with her disability 24 hours a day because he got to go to work. As a result, it didn't seem to impact him to the extent it did me. I was forced to confront her disability daily and so seemed to be much more concerned, devastated, depressed, angry.....In those early days its importance in his life and mine was very different. He thought I was obsessed. I thought he was in denial.

The level of tension in our home became almost tangible. After all, when you take an exceptionally stressful situation that doesn't go away and carefully avoid talking about it, what else could you expect? So how did we survive to celebrate ten years together? I like to think it was (and is) our deep respect for each other that led us to look for the common ground we both knew existed before the current crisis.

We recognized our need for space from the kids -- the opportunity to again be Vicki and David, not mom and dad. In that space we were able to get back to the basics of our shared beliefs. We acknowledged that we had always agreed on two fundamental points: 1) our marriage is very important to us, and 2) we love both our children and want the best for them. That was still true. From there we proceeded very carefully and tentatively. We began to open our conversations to the painful things we were experiencing because of Annie's disability. First we broached relatively "safe" topics such as how we felt about her wearing glasses. But gradually we were able to talk about big issues, such as accepting the permanence of her disability and our fear of losing her. We realized that although we manifested our reactions to Annie's diagnosis differently, our hopes and fears were very similar. We also discovered there can be comfort in sharing even negative thoughts -- we weren't alone in our feelings.

Once that understanding was established, many strategies for coping with daily life became possible. First, we ensured that we had time alone as a couple on a regular (weekly) basis. We call it "date night" and we cherish it. We also made sure we gave each other time away from the family. Both of these strategies have helped us keep the disability and our roles as Annie's parents in perspective. During particularly stressful times, we take turns being "strong." This started unconsciously, but has reached the point where one of us can say "It's your turn" or "I can't do this anymore" and the other steps in.

Through it all, our sense of humor has often saved us. When Annie began wearing glasses at six months of age, total strangers would walk up to us and ask why she wore glasses, what was wrong with her. After a few such encounters, David began replying, "She only wears her glasses to read." The first time we went out in public with her new wheelchair, David put a sign on the back that said, "My other chair is a Porsche." We consciously laugh at the situations in which we find ourselves to break the tension.

Finally, as corny as it sounds, we count our blessings. The truth is we have a lot to be thankful for and we remind each other of that regularly.

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