



UPC Caregiver e-Journal

Issue No. 4 November 2010

CAREGIVING AND CAREGIVERS...

In the United States today there are approximately 50 million people who are caring at home for family members including elderly parents, spouses, and children with disabilities and/or chronic illnesses. Without this home-care, most of these cared for loved ones would require permanent placement in institutions or health care facilities at great cost to society.

Close to 80% of all long-term care is now provided at home by family caregivers to children and adults with serious conditions... Parents and family caregivers are the backbone of the long-term care system and save health-care insurers and governments billions of dollars annually. The value of the services family caregivers provide for "free" is estimated to be \$306 billion a year. That is almost twice as much as is actually spent on homecare and nursing home services combined (\$158 billion).

According to a November, 2007 survey on family caregiving, most family caregivers feel more positive about their experiences than they did just before they took on the responsibility.

The survey also found that:

- Sixty percent of the caregivers called the experience "very or extremely rewarding," a 50% jump over the number of caregivers who thought in advance they would find the experience "very or extremely rewarding." Nearly 80% of the caregivers found the experience to be at least "rewarding," an increase of more than one-third from initial expectation.
- A majority of the caregivers - nearly 54% - formed a stronger bond with the patient during the time they were together.
- Almost 60% of the respondents reported an improvement in the quality of their relationship with the person for whom they cared. Social activities of the caregiver tend to diminish. The diminished social activities are replaced with an increased quality of relationship with the care recipient.
- More than 2/3 of all caregivers (68.7%) said they enjoy the tasks associated with caregiving. Prior to assuming the role, fewer than half (45.5%) thought they would enjoy caregiving.
- More than ¾ of caregivers are female.
- Nearly ¾ range in age from 35 to 59.

Excerpted from:

Study source: <http://www.caringtoday.com/press-releases/national-survey-of-caregivers>

Source: <http://en.wikipedia.org/wiki/Caregiver>

This topical e-journal is part of a series published by the Utah Parent Center.

The Utah Parent Center has been serving families of children, youth and young adults with all disabilities since 1983. We provide many free resources such as publications, workshops and individual assistance to help families make decisions about education, support services, vocational training, employment and other services for their child, young adult and for their family.



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ARE YOU A CAREGIVER?

Like many Americans, you may be caring for a child with a disability, parent, spouse, sibling, or friend. Here are a few questions to identify if you are a caregiver.

Do you:

- Help someone with hygiene, such as showering, toileting or grooming?
- Assist someone with medications and management of that medication?
- Provide financial help, such as paying bills?
- Shop, cook, housekeep and/or feed someone?
- Arrange and coordinate outside help for someone?
- Provide transportation?

If you said, "yes," to one of these questions, you are a caregiver. There are many different definitions of a caregiver, but one common theme is: being a caregiver demands your time, resources, love and energy.

YOU ARE NOT ALONE

You are part of a very diverse group. There are many people within your own neighborhood that are also caregivers, from a parent caring for a child with disabilities to a grandparent providing care to grandchildren, to people assisting a loved one who is aging or has a debilitating disease that requires care. Caregivers can live with their relative or can provide care long distance.

MANY EMOTIONS

Caregivers experience mixed emotions. Love for your family member and the satisfaction you derive from helping may coexist with feelings of resentment about the loss of your privacy and frustration at believing you have no control over what happens. You may find it hard to accept the decline of the special person for whom you are giving care.

Acknowledge your feelings. Your feelings have a lot to do with the way you view and cope with care giving. All feelings are legitimate, even those that may seem disturbing to you (including anger, frustration, and sadness). Recognizing and accepting your emotions are the first step toward resolving problems of guilt and stress. Learn to express your feelings to family members, friends, or professionals.

*Celebrating the Support of
Loved Ones*
**National Family
Caregivers Month
November**



TAKING CARE OF YOURSELF IS ESSENTIAL

To guard against becoming physically and emotionally drained, you must take care of yourself. You need to maintain your health and develop ways to cope with your situation. This publication includes many ideas to help you identify ways to help you take care of yourself as you fulfill this important role.

CAREGIVER STRESS TEST

Rating your responses to the following questions will help you become aware of your feelings, pressures, and stress you are currently experiencing. Choose the rating that most accurately describes your current situation.

**Seldom – Sometimes – Often –
Usually True – Always True**

- I find I can't get enough rest.
- I don't have enough time for myself.
- I don't have time to be with other family members beside the person I care for.
- I feel guilty about my situation.
- I don't get out much anymore.
- I have conflict with the person I care for.
- I have conflicts with other family members.
- I cry every day.
- I worry about having enough money to make ends meet.
- I don't feel I have enough knowledge or experience to give care as well as I'd like.
- My own health is not good.

If the response to one or more of these areas is “usually true” or “often true” it may be time to begin looking for help with caring for the carereceiver and help in taking care of yourself.

CAREGIVER BURNOUT

Even when we identify stressors and do some things to reduce the stress we still can have burnout. Once you burn out, caregiving is no longer a healthy option for either you or the person you're caring for. So it's important to watch for the warning signs of caregiver burnout and take action right away when you recognize the problem.

Common warning signs of caregiver burnout:

- You have much less energy than you used to.
- It seems like you catch every cold or flu that's going around.
- You're constantly exhausted, even after sleeping or taking a break.
- You neglect your own needs, either because you're too busy or you don't care anymore.

Excerpt from PRESIDENTIAL PROCLAMATION

“...Every day, family caregivers assist loved ones with tasks ranging from personal care and homemaking, to transportation and financial assistance. As the foundation of America's long-term care system, these individuals give millions of Americans the peace of mind and security that only family can provide....I encourage all Americans to pay tribute and support those who are caring for their family members, friends, and neighbors in need of assistance...”
- Barack Obama

- Your life revolves around caregiving, but it gives you little satisfaction.
- You have trouble relaxing, even when help is available.
- You're increasingly impatient and irritable with the person you're caring for.
- You feel overwhelmed, helpless, and hopeless.

In everyone's life, at some time, our inner fire goes out. It is then burst into flame by an encounter with another human being. We should all be thankful for those people who rekindle our inner spirit.

-Albert Schweitzer

CAREGIVER STRESS MANAGEMENT STRATEGIES

Stress management starts with identifying the sources of stress in your life. This isn't as easy as it sounds. Your true sources of stress aren't always obvious, and it's all too easy to overlook your own stress-inducing thoughts, feelings, and behaviors. As an example, you may know that you're constantly worried what medical bills will be paid by insurance, but maybe it's your procrastination, rather than the actual bills, that leads to the stress.

There are a number of ways to help you identify and then reduce the stress you are experiencing. Following are seven stress management strategies. Consider which ones might be helpful and doable for you.

To keep a lamp burning, we have to keep putting oil in it.

-Mother Teresa

STRESS MANAGEMENT STRATEGY #1: CREATE A STRESS JOURNAL

A stress journal can help you identify the regular stressors in your life and the way you deal with them. Each time you feel stressed, keep track of it in your journal. Write down your thoughts and feelings. This helps provide perspective on your situation and serves as an important release for your emotions. As you keep a daily log, you will begin to see patterns and common themes. Write down:

- What caused your stress? (Make a guess if you're unsure.)
- How you felt, both physically and emotionally.
- How you acted in response.
- What you did to make yourself feel better.

Identifying patterns and sources of stress can then help you identify and strategies that you can implement to address your individual need.

STRESS MANAGEMENT STRATEGY #2: AVOID UNNECESSARY STRESS

Not all stress can be avoided, and it's not healthy to avoid a situation that needs to be addressed. You may be surprised, however, by the number of stressors in your life that you can eliminate.

- **Pare down your to-do list** – Analyze your schedule, responsibilities, and daily tasks. If you've got too much on your plate, distinguish between the "shoulds" and the "musts." Drop tasks that aren't truly necessary to the bottom of the list or eliminate them entirely.
- **Learn how to say "no"** – Know your limits and stick to them. Taking on more than you can handle is a surefire recipe for stress.
- **Take control of your environment** – If the evening news makes you anxious, turn the TV off. If traffic's got you tense, take a longer but less-traveled route.
- **Avoid people who stress you out** – If someone consistently causes stress in your life and you can't turn the relationship around, limit the amount of time you spend with that person or end the relationship entirely.
- **Avoid hot-button topics** – If you get upset over religion or politics, cross them off your conversation list. If you repeatedly argue about the same subject with the same people, stop bringing it up or excuse yourself when it's the topic of discussion.

STRESS MANAGEMENT STRATEGY #3: ALTER THE SITUATION

If you can't avoid a stressful situation, try to alter it. Figure out what you can do to change things so the problem doesn't present itself in the future. Often, this involves changing the way you communicate and operate in your daily life.

- **Express your feelings instead of bottling them up.** If something or someone is bothering you, communicate your concerns in an open and respectful way. If you don't voice your feelings, resentment will build and the situation will likely remain the same.
- **Be willing to compromise.** When you ask someone to change their behavior, be willing to do the same. If you both are willing to bend at least a little, you'll have a good chance of finding a happy middle ground.
- **Be more assertive.** Don't take a backseat in your own life. Deal with problems head on, doing your best to anticipate and prevent them.
- **Manage your time better.** Poor time management can cause a lot of stress. When you're stretched too thin and running behind, it's hard to stay calm and focused.
- **Recognize the difference between caring and doing.** Be open to technologies and ideas that promote your loved one's independence.

There are two ways of meeting difficulties. You alter the difficulties or you alter yourself to meet them.
- Unknown

STRESS MANAGEMENT STRATEGY #4: ADAPT TO THE STRESSOR

If you can't change the stressor, change yourself. You can adapt to stressful situations and regain your sense of control by changing your expectations and attitude.

- **Reframe problems.** Try to view stressful situations from a more positive perspective. Rather than fuming about a traffic jam, look at it as an opportunity to pause and regroup, listen to your favorite radio station, or enjoy some alone time.
- **Look at the big picture.** Examine your perspective of the stressful situation. Ask yourself how important it will be in the long run. Will it matter in a month? A year? Is it really worth getting upset over? If the answer is no, focus your time and energy elsewhere.
- **Adjust your standards.** Perfectionism is a major source of avoidable stress. Stop setting yourself up for failure by demanding perfection. Set reasonable standards for yourself and others, and learn to be okay with "good enough."
- **Focus on the positive.** When stress is getting you down, take a moment to reflect on all the things you appreciate in your life, including your own positive qualities and gifts. This simple strategy can help you keep things in perspective.

***It's not the load
that breaks you
down, it's the way
you carry it.***

- Lena Horne

STRESS MANAGEMENT STRATEGY #5: ACCEPT THE THINGS YOU CAN'T CHANGE

Some sources of stress are unavoidable. You can't prevent or change stressors such as the death of a loved one, a serious illness, or a national recession. In such cases, the best way to cope with stress is to accept things as they are. Acceptance may be difficult, but in the long run, it's easier than railing against a situation you can't change.

- **Don't try to control the uncontrollable.** Many things in life are beyond our control— particularly the behavior of other people. Rather than stressing out over them, focus on the things you can control such as the way you choose to react to problem or other people's behavior.
- **Look for the upside.** As the saying goes, "What doesn't kill us makes us stronger." When facing major challenges, try to look at them as opportunities for personal growth. If your own poor choices contributed to a stressful situation, reflect on them and learn from your mistakes.
- **Share your feelings.** Talk to a trusted friend or make an appointment with a therapist. Expressing what you're going through can be very cathartic, even if there's nothing you can do to alter the stressful situation.
- **Learn to forgive.** Accept the fact that we live in an imperfect world and that people make mistakes. Let go of anger and resentments. Free yourself from negative energy by forgiving and moving on.

**I cannot even imagine
where I would be today
were it not for the handful
of friends who have given
me a heart full of joy.**

- Charles R. Swindoll

STRESS MANAGEMENT STRATEGY #6:

SET REALISTIC GOALS

Caregiving is probably only one of the many conflicting demands on your time. It is important to set realistic goals. Recognize what you can and cannot do, define your priorities, and act accordingly.

STRESS MANAGEMENT STRATEGY #7: ACCEPT HELP FROM OTHERS

Many of us have other people involved in our lives who are willing to help such as family, friends, and neighbors. Turning to family members or friends for emotional support and help can be a mixed blessing. Their visits may make you feel less alone and better able to deal with caregiving responsibilities. They can give you a break by spending time with your carereceiver. One suggestion would be to prepare a list of tasks for anyone who may offer assistance. The list might include:

- running an errand for you,
- preparing a meal,
- taking your carereceiver for a ride,
- taking your children after school one day.

However, other relatives or friends can be critical of the way you provide care. They may feel the house is not kept clean enough; or they may not like the way your carereceiver is dressed. Recognize that they are responding to what they see at that time and are lacking the benefit of experiencing the whole picture and any gradual changes in your carereceiver's condition. Harsh criticism may be a response to their own guilt about not participating more in the care process. Try to listen politely to what is being said (even though this might not be easy). However, if you and your carereceiver feel comfortable with the way you are managing the situation, continue to do what meets your needs. Schedule a family meeting from time to time to help other family members understand the situation and to involve them in sharing the responsibilities for caregiving.

**We are each of us
angels with only
one wing, and we
can only fly by
embracing one
another.**

- Luciano de Crescenzo

Some information adapted from:

<http://www.acsu.buffalo.edu/~drstall/hndbk3.html#Part3F>
<http://www.ec-online.net/knowledge/articles/caringforthecg.html>

ACHIEVING WELL BEING

There is no doubt that caregiving, even in the best of circumstances, is stressful. Stress, however, in and of itself is not bad. It is how we respond to it that can challenge our well being.

A FOUNDATION FOR WELL BEING

There are many simple things that we can do for ourselves, on a day-to-day basis to form a foundation for well being. Although they may have been heard before, how many of the beneficial activities listed below, which cost little to nothing, and require little time, do you do for yourself? Look over this list, try some of the activities, see how they make you feel, make your own personal list and work at supporting your well being on a daily basis.

- Nurture your biological-psychological-social-spiritual self - know what nurtures you.
- Surround yourself with people who make you feel good.
- Read, visit bookstores or the library, share books among friends.
- Make your home a place you look forward to going to.
- Drink water.
- Eat three balanced meals daily.
- Get enough sleep/rest.
- Bring nature into your home with plants or flowers.
- Consider a pet.
- Aromatherapy, the use of essential oils and perfumes to facilitate healing. Lavender is a good choice.
- Conscious breathing with mediation. Sitting quietly and comfortably, close your eyes, and breathe slowly in and out through your nose to the count of five. Try doing this for a few minutes throughout the day and whenever you are feeling anxious.
- Exercise regularly – daily if possible. Exercise comes in many forms. Finding what fits with one's lifestyle and caregiving responsibilities is critical to making it a part of routine activities.
- Allow yourself leisure time.
- Use humor:
 - read funny books or jokes.
 - listen to funny tape.
 - watch humorous movies or videos that make you laugh.
- Incorporate activities that give you pleasure even when you don't really feel like it. Listen to music, work in the garden, engage in a hobby...whatever it is that you enjoy.
- Pamper yourself.
- Take a warm bath and light candles.
- Find some time for a manicure or a massage.
- Try to set a time for afternoons or evenings out.
- Seek out friends and family to help you so that you can have some time away from the home. If it is difficult to leave, invite friends and family over to visit with you. Share some tea or coffee. It is important that you interact with others.
- Have goals and fulfill them.
- Do kind acts.

*There is no
exercise better for
the heart than
reaching out and
lifting people up.
Unknown*

Some information adapted from:

http://helpguide.org/mental/stress_management_relief_coping.htm

HOW DO WE MANAGE AS A FAMILY?

Caregiving situations impact more than the main caregiver. The circumstances will impact every member of the family. Following are ideas you can think about as you consider your home environment and relationships between family members.

- Help the whole family see the child with a disability as another important member of the family. The child is not a disabled child, but a child with a disability.
- Even though having a child with a disability or a health problem is difficult, it is important to know that there are accomplishments to appreciate, opportunities to grow, and moments to laugh and enjoy.
- Try to lead as normal a life as possible. Try not to allow the sick child or the disease or disability to dominate all phases of family life.
- Your child who has a disability needs to be involved in family activities and to know that he or she has a responsibility for helping with such things as household chores to the degree they are able to do so.
- Talking things over regularly with all members of the family helps prevent the build-up of tensions and fears.



WHAT ARE SOME OF THE FEELINGS THAT PARENTS OF CHILDREN WITH DISABILITIES AND/OR HEALTH PROBLEMS EXPERIENCE?

- Parents of children with disabilities or who are chronically ill often experience periods of shock, disbelief, depression, and adjustment. These are all normal responses.
- You may be surprised at the range of feelings you may have – feelings that might seem abnormal under different circumstances, but are normal now. You may feel:
 - Anger at yourself, at your spouse, at God, at doctors, or even at your child for what has happened to you and your family.
 - Anger at your friends for their good fortune in having healthy children.
 - Guilt that you may be responsible in some way.
 - Anxiety and worry over specific events or the future in general.
 - Grief over the loss of your child's health or the differences in your expectations and reality.
 - Helplessness that you could not prevent what happened and that so much of your child's care may now be provided by others.
 - Resentment because it "happened to me" or "to my child".
 - Guilt over having any kind of fun or happiness.
 - Confusion about the information given to you by your doctors, teachers, or others.
 - Chronic sorrow may be present to varying degrees and may increase greatly at important milestones in your child's development.
- You may feel so determined to manage well that you ignore your own needs for relief, fun and relaxation.
- At times, you may feel the desire to "run away" and escape your situation.

**Caregiving
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caregiver.**

Suggestions for addressing the many different emotions you may experience:

- Grieve for your losses, and then allow yourself to dream new dreams.
- Seek support from other caregivers. There is great strength in knowing you are not alone.
- As your child and family adjust to the health impairment and/or disability, you may feel the satisfaction, comfort and even exhilaration that can come from managing a difficult situation, growing altogether, and seeing your child make gains.
- You may feel that through a growing understanding of your child, you and your family have a greater understanding for other people who are in some way “different,” or who have special needs.
- Trust your instincts. Most of the time they’ll lead you in the right direction.

WHAT ARE THE REACTIONS WHICH SIBLINGS MAY HAVE ABOUT THE BROTHER OR SISTER WHO HAS A CHRONIC ILLNESS OR A DISABILITY?

Children sometimes lack information about a sibling’s disability, possibly because they’re too young and inexperienced to understand. Brothers and sisters who have a sibling with a disability or chronic illness may:

- feel guilty about somehow having “caused” the illness or disability. In play or fantasy, it is not uncommon to wish a brother or sister sick or dead, and when it happens, they may think they are responsible.
- be angry and resent the special attention and the amount of Mom and Dad’s time which the sick or disabled child receives.
- be afraid that they may “catch” it.
- feel embarrassment about their brother or sister’s condition or disability.
- grieve and be depressed.
- show their anxiety by boisterous disturbing behavior, becoming discipline problems, or behaving in nervous, silly ways. Behavior problems or changes in their achievement at school may be signs that a sibling is disturbed by the home situation and may need some help.
- keep all their feelings bottled up inside and withdraw from family activities.
- sacrifice too much of their free time to help you or the sick or disabled child.
- worry because no one has explained the situation to them, and they may be afraid to ask what is going on.

Brothers and sisters want and need to share both the joys and some of the responsibilities of family life when a child has a disability or health problem. Some things that parents can consider to help the siblings of their child with special needs are:

- Provide simple explanations about the diagnosis or disability.
- Take siblings to visit any special programs their brother or sister is in.
- Talk with and listen to them about how they feel. Answer any questions they have.
- Talk to them honestly if they behave in unacceptable ways. Reassure them of your love for them. Show them acceptable methods of expressing their feelings and frustrations.
- Give them room to be children. Sometimes you won't like to hear the feelings they express as part of the process of maturing.
- Look at things from their point of view.
- Teach them how to handle embarrassing situations.
- If possible, introduce your children to other children who have a sibling with a disability.



HOW CAN I HANDLE THE REACTIONS OF MY CHILD'S GRANDPARENTS?



It is often difficult for grandparents to deal with their feelings when their grandchild is ill or has a disability. It is important to remember that grandparents experience many of the same feelings that parents do. Some of these feelings are associated with the process of grieving, such as shock, denial, frustration, sadness, and then finally acceptance. However, accepting the reality can be harder for them because they are

somewhat removed from the immediate situation. For them the bonding process that helps them to see the child as a child first, instead of just seeing the disability may happen more slowly. Or they may think the parents are using their child's problems as an excuse for something else. They may:

- use denial and never talk about the child's illness or disability, but that does not mean they don't care;
- blame "the other side of the family";
- withdraw and not come to visit because it is too painful for them or they are afraid that their pain will burden you;
- feel helpless and inadequate because this sorrow has come into your life, and they cannot control it.

These factors may explain why they sometimes avoid acknowledging or talking about your child's illness or disability. Grandparents may benefit from having access to information about the interventions or treatments for the child in order to understand

the situation and to cope with their feelings. Sometimes it is helpful for them to talk directly with professionals serving the child. Some parents find it helpful to give the grandparents literature on the disability or take them to doctor's appointments with them. Finding a way for them to be involved can be helpful to everyone.

Parents can also share their needs and feelings with the grandparents. The best time to do this is when things are fairly stable, not in the middle of a crisis. Above all else, try to use the unique challenges to strengthen extended family relationships.

It may help if you ask them to do some specific tasks for your child or the family, like reading to a child, helping with homework, cooking or driving. Other relatives and close friends may have feelings similar to grandparents, but they also can be very supportive of you.

CAN OUR MARRIAGE SURVIVE THE STRESSES OF MANAGING THIS DISABILITY OR ILLNESS?



Caring for a child with a health problem or disability does place stress on a marriage, however, it also may strengthen marital relationships. People have different ways of coping with stress. A husband and wife may have different needs and may not always be able to support each other. Some people need to pull back from a close relationship from time to time while they attempt to manage difficult feelings. Talking it out together can help even if you have different feelings and responses. It is important to accept each other's feelings as valid for that person. Each spouse needs someone with whom he or she can relate or talk to, a

person who will listen and give support. Sometimes, a husband and wife need support persons beyond each other. Other mothers or fathers who have a child with a disability are often wonderful, "safe" sources of support; their common experiences can be a unique source of understanding and validation. It is important for a couple to find some time to be alone together and/or to do recreational things together. It might also be helpful to build in time with a therapist, minister, counselor, or other mental health professional. Different kinds of support may be helpful at different times.

HOW CAN I FIND A BABYSITTER I CAN TRUST AND WHO IS COMFORTABLE WITH MY CHILD?

- Talk with the regular sitters in your neighborhood. Explain your child's needs and offer to have them be with your child while you are present so they reach a comfort level with their needs and the things they will need to do.
- Advertise for and hire a person who is interested in a child with special needs and train the person in providing care.
- Contact nursing students at local hospitals or schools of nursing or child development majors at nearby colleges.
- Go to your local college departments, such as special education, psychology, social work, Occupational Therapy, etc. and put up a flyer about needing respite.



- Join a parents group for children with special needs and exchange babysitting services.
- Form a babysitting “co-op” with friends and neighbors and teach them about your child’s special needs.
- Investigate respite or temporary care facilities in your community.

HOW CAN OUR FAMILY TAKE A VACATION?

Vacations are very important to the physical and emotional health of families, but it may be difficult to include your child who is chronically ill or disabled or to be comfortable about leaving that child home. Some considerations when planning a vacation are to:

- Take mini-vacations several times a year may be more helpful than one long vacation.
- Think of the things you will need to address if your child has a health problem.
 - Ask your pediatrician to recommend a specific physician near your vacation spot.
 - Bring a written statement, prepared by your physician, about your child’s condition or disability and current treatment, as well as other pertinent medical records.
 - Contact the hospital and/or emergency room in the area where you will be vacationing in order to know where the facility is and how to use it.
 - Make sure you know what your insurance coverage is and implications when traveling out of town, out of state, or out of the country.
- If you need a “vacation from child care” and need to leave your child or children at home, perhaps you can:
 - Ask a relative or a member of your extended family to stay with your child/children;
 - Inquire about respite care facilities in your community.
- If your child is going to a special camp, plan your vacation to coincide with the camp session.
- Determine if social service or health agencies have trained personnel available to stay with your child.
- Ask a local chapter of a disability or other organization such as Candelighters, United Cerebral Palsy, Muscular Dystrophy Association, or Juvenile Diabetes Foundation whether they have organized a group of parents to share respite care.

HOW CAN I HELP MY CHILD DEAL WITH REACTIONS OF OTHER CHILDREN?

Children can be very compassionate and caring toward children with special needs, but they can also be cruel. Frequently, natural curiosity, lack of understanding, or fear causes children to say or do things that seem unkind. Following are some things to keep in mind:

- A sense of humor can often help you and your child handle difficult situations.
- Explaining your child’s disability or helping your child to explain their special needs to his or her friends/classmates, their parents, and to teachers, usually

helps to prevent unkind statements or actions.

- Parents need to remember that all children are teased sometimes and not just a child with a disability or health problem. Parents should anticipate that a child may be teased and can thus lessen the shock and make it easier for their child to deal with teasing. It is important to teach a child strategies to respond appropriately when teasing or bullying occurs. It is important, too, to spend time alone with your child talking about these things when they do occur. Parents can show understanding of the child's feelings about being teased by saying, "I know it hurts when..." or "It must make you feel angry when..."
- Look for disability awareness programs that can help impact what children think and feel about those with special needs.



HOW CAN I ENCOURAGE MY CHILD'S FRIENDSHIPS?

- Invite children *and* their parents over to your home to play; you can then accept and allay their fears and teach them about your child's condition.
- Model how to start conversations and how to interact with others.

OTHER INFORMATION IS AVAILABLE IN EACH OF THESE AREAS TO HELP YOUR FAMILY.

Contact the Utah Parent Center for additional resources and suggestions.

**How to love a child:
Listen with your heart.
Care with open arms.
Patience! Patience!
Patience!
Stand Firm.
Focus on the positive.
Be prepared for anything.**

- Unknown

UTAH COALITION FOR CAREGIVER SUPPORT

A group of professionals and advocates who have a common interest in issues relating to caregiving began to loosely gather in the Spring of 2002, recognizing that there was no formal mechanism for information, resources, or support for Utah's caregivers. This diverse group became more structured and organized by the Fall of 2002 and officially declared itself as the first statewide coalition for caregiver support. The genesis of the group revolved around issues of caregivers for older individuals. The Coalition has broadened its mission and purpose to include caregivers of individuals across the lifespan whether the carereceiver is aging, has a disability, chronic illness, or other special needs.

Special thanks to Sonnie Yudell and the caregiver resources created for UCares and the Utah Coalition for Caregiver Support. Sections of information in this publication were used with permission or adapted for use with caregivers of children with disabilities and special needs. For more information on the Coalition visit <http://www.caregiver.utah.gov/index.htm>

WHAT A STATEWIDE COALITION FOR CAREGIVER SUPPORT CAN DO:

- Provide advocacy, information, education, community awareness, and networking of the nonprofit sector.
- Provide more information and ways of disseminating information.
- Respond to community needs and provide for needs of caregivers now and in the future.
- Improve public and private nonprofit collaboration.
- Consolidate and share information.
- Minimize overlapping services from agencies with common missions.
- Assist caregivers statewide, including regionally, culturally, and ethnically diverse areas.
- Ease the burden of referring.
- Improve service delivery.
- Reduce barriers to service.
- Provide a forum to exchange issues and information.
- Develop and share advocacy campaigns.
- Create a mechanism for easy access to resources.
- Strengthen and unite existing resources, information, and people.
- Promote awareness of caregiving and its challenges.

***For more information about the Utah Coalition for Caregiver Support, and to access the valuable information available from the Coalition, visit the website at:
<http://www.caregiver.utah.gov/index.htm>***

***GOVERNOR GARY R. HERBERT DECLARED NOVEMBER 2010 TO BE
FAMILY CAREGIVER AWARENESS MONTH.
THE PROCLAMATION FROM THE GOVERNOR FOLLOWS.***



Gary Richard Herbert

Governor

Declaration

Whereas, one in four Americans can expect to provide some level of caregiver assistance - making caregivers a true resource deserving of community support including program development and services;

Whereas, we value the provision of services offered through the Utah Coalition for Caregiver Support, the UCare Caregiver Training Curriculum, the current effort to create a Lifespan Respite program, as well as efforts to partner with the Alzheimer's Association to provide information and services to those suffering with cognitive impairment;

Whereas, family caregivers may be found in all Utah cities and towns and among every ethnic, social and economic background;

Whereas, Utahns are urged to recognize and appreciate the positive contribution of caregivers; and

Whereas, through the National Family Caregiver Support Program, a continuing partnership with state, local area agencies on aging, faith-based, community, and tribal organizations is encouraged to offer family caregivers important information, counseling, training, respite care, and support service;

Now, Therefore, I, Gary R. Herbert, Governor of the State of Utah, do hereby declare November 2010 as

Family Caregiver Awareness Month

Gary R. Herbert

Governor

DISABILITY RESOURCES

Educating yourself about your loved one's disability, health problem, or special needs is an important strategy. Identifying support groups, organizations, agencies, programs, services, and resources online and in the community that are available to assist you, your loved one, and your family is critical to your functioning and success as a family.

For a detailed resource guide, visit the Utah Parent Center website at www.utahparentcenter.org and choose the "Disability Resource Book" option

OR

Contact the Utah Parent Center at 800-468-1160 to speak to a Parent Consultant.

SUPPORT GROUPS

DISABILITY ORGANIZATIONS

OR

FAMILY TO FAMILY NETWORKS

Contact the Utah Parent Center to determine if a group exists in your community. Call 800-468-1160.

ONLINE PARENT SUPPORTS

Parent support

Our-Kids is a support group for parents, caregivers and others who are working with children with physical and/or mental disabilities and delays.

<http://www.our-kids.org/oknoframe.html>

Utah Kids an online parent-to-parent networking and support group. The purpose is to share information, resources and experiences unique to parents and full-time caregivers of children with special health care needs.

<http://groups.yahoo.com/group/utahkids/>

WEBSITES

Following are just a few websites you might find useful:

UCare – If a loved one leans on you lean on us
http://www.ucare.utah.gov/people_with_disabilities.html

Today's Caregiver – For About and By Caregivers
www.caregiver.com

Empowering Caregivers – Choices, Healing, Love
www.care-givers.com

MedlinePlus – A service of the U.S. National Library of Medicine and the National Institutes of Health
www.nlm.nih.gov/medlineplus/caregivers.html

Medicare.gov
Caregiver Information
www.medicare.gov/caregivers/

BOOKS ABOUT CAREGIVING

There are many print or ebooks on topics related to caregiving. Following are just a few that have been recommended by families. Perhaps you can start here and explore others as you identify titles and authors.



THE CAREGIVER'S BOOK: CARING FOR ANOTHER, CARING FOR YOURSELF

[James E. Miller](#)

Here is a compassionate exploration of the caregiver's role, feelings, and experiences, providing practical, affirming suggestions for renewing strength and hope through words of inspiration from the Bible, literature, and great thinkers throughout the ages.

CARING FOR THE CAREGIVER

[Roy W. Harris](#)

Caregivers have been overlooked. Author Roy Harris faithfully stood by his wife of thirty-three years as the two navigated the uncharted waters of breast cancer, ultimately resulting in her death. Roy's sixteen years of experience as a pastor, someone who has been there for countless families going through the death and dying process, adds special insight to the helpful Caregiver.

CARING FOR THE CAREGIVER: THE USE OF MUSIC AND MUSIC THERAPY IN GRIEF AND TRAUMA

[Joanne V. Loewy](#), [Andrea Frisch Hara](#)

Caring for the Caregiver: The Use of Music and Music Therapy in Grief and Trauma A collection of reflections on music therapy interventions provided as a part of the New York City Music Therapy Relief Project, sponsored by AMTA and the Recording Academy after September 11th, 2001.

A CAREGIVER'S SURVIVAL GUIDE: HOW TO STAY HEALTHY WHEN YOUR LOVED ONE IS SICK

[Kay Marshall Strom](#)

"Kay Strom is a caregiver who has invested countless hours in helping her disabled husband. She knows what it's like to plod through the routines, and she has opened up her heart and shared her poignant and powerful account of how she 'found the smile of God' through it all.

THE TWENTY-THIRD PSALM FOR CAREGIVERS

[Carmen Leal](#)

Offers devotional encouragement, hope, and tender affirmation for all caregivers no matter the disease or situation.

CARING FOR YOU, CARING FOR ME: EDUCATION AND SUPPORT FOR CAREGIVERS: PARTICIPANT'S MANUAL

[David H. Haigler](#), Caring for persons with chronic illnesses or disabilities is a rewarding endeavor, but it often places extreme demands on those providing care. Caregivers need both education and support to understand their caregiving roles and to cope with the difficult situations they face. All too often there is a chasm between professionals who are part of the formal caregiving system and family members, friends, and neighbors who provide daily care.

PASSAGES IN CAREGIVING: TURNING CHAOS INTO CONFIDENCE

[Gail Sheehy](#)

Thrust into the daunting and unexpected role of caregiver when her husband, editor Clay Felker, was diagnosed with cancer, Sheehy was dismayed to find herself lost in the labyrinthine, illogical, and often contradictory world of health care. When second opinions gave way to thirds, and innumerable insurance forms were completed only to have the claims rejected, Sheehy realized she needed answers, assistance, and attitude. For a tenacious reporter like Sheehy, getting answers was second nature but finding competent help and learning how to put things into perspective weren't as easy.

CAREGIVER'S REPRIEVE: A GUIDE TO EMOTIONAL SURVIVAL WHEN YOU'RE CARING FOR SOMEONE YOU LOVE

[Avrene L. Brandt](#)

This book highlights the fact that caregiving is a difficult task and that the emotions caregivers feel are common and normal. The book exonerates caregivers who feel guilty for the difficulties that they face and provides the support that we need to carry on.

THE COMPLETE BEDSIDE COMPANION: A NO-NONSENSE GUIDE TO CARING FOR THE SERIOUSLY ILL

[Rodger McFarlane](#), [Philip Bashe](#)

Caring for someone who is seriously ill is a major responsibility. It is both a full-time job that is physically, emotionally, and financially demanding, and a rewarding act of love. This book, written by two experienced caregivers, "walks you down the road from the onset of symptoms through the very end and afterward." It offers practical information, advice, and support for those who undertake this monumental task.

SELF-CARE FOR CAREGIVERS: A TWELVE STEP APPROACH

[Pat Samples](#), [Diane Larsen](#), [Marvin Larsen](#)

Are you one of the growing number of people who serves as a caregiver for an aging or chronically ill friend or family member? If so, you probably struggle to meet both their special needs and still find time and resources for yourself. But now there is reason to take heart. The authors of this down-to-earth, encouraging book can help you make the most of the experience without losing yourself in the process using the Twelve Steps as a guide.

A SPECIAL “THANK YOU” TO JODI HANSEN, PARENT CONSULTANT, UTAH FAMILY VOICES FAMILY TO FAMILY HEALTH INFORMATION CENTER AT THE UTAH PARENT CENTER FOR HER CONTRIBUTIONS TO THIS ISSUE.

Utah Parent Center Information Disclaimer

Utah Parent Center

Serving families since 1983!

Utah Family Voices - Family to Family Health Information Center

Autism Information Resources at the Utah Parent Center

Family to Family Network – A Network Supported by the Utah Parent Center

Phone: (801)272.1051 • Toll Free Utah: (800)468.1160 • Fax: (801)272.8907

Email: autisminfo@utahparentcenter.org • Website: www.utahparentcenter.org

Our Mission: To help parents help their children with disabilities to live included, productive lives as members of the community. We accomplish this through the provision of information, training, and peer support. The Utah Parent Center is a non-profit organization federally funded by the Office of Special Education Programs under grant #H328M020032.

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