

***COPING
WITH
DISABILITY
RELATED
STRESS***

***A Quality of Life
Pamphlet***

BACKGROUND INFORMATION

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**Florida Developmental
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- | | |
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INTRODUCTION

Stress is a state of bodily and mental tension which affects performance. Stress has become part of our hectic everyday lives and is, indeed, a fact of life. It can be an obstacle which makes quality of life difficult to achieve for families affected by disability.

However, there is some good news about stress:

- ✦ Mild to moderate stress helps motivate people to achieve.
- ✦ Each person and family can choose their attitude about stress: to be a survivor or a victim.
- ✦ Each person and family can also choose to cope by understanding themselves and by using a variety of ways to cope.

This educational pamphlet has been written for parents of persons with disabilities, individuals with disabilities, friends and professionals.

The three goals of the pamphlet are to:

- ✦ Increase understanding of signs and sources of stress
- ✦ Provide tips for preventing and coping with stress
- ✦ Suggest support resources to help people cope with stress



PERSKE

SIGNS OF STRESS

Stress challenges a person's and family's coping ability. High and chronic stress can also turn into a crisis.

Signs of stress are warning signals. They show that persons feel dissatisfied, unsafe, or want relief.

Which of the following typical signs of stress reflect a person you care about or yourself?

Physical Stress Signs

- | | |
|-----------------------------|---------------------|
| * absenteeism/
tardiness | * sickness |
| * blushing | * silences |
| * crying | * slamming doors |
| * drinking | * sleeplessness |
| * headaches | * sloppiness |
| * rocking | * smoking |
| * running away | * stammering |
| * scratching | * throwing |
| | * yelling/screaming |

Mental Stress Signs

- | | |
|-----------------|------------------------|
| * arguing | * forgetfulness |
| * confrontation | * mistakes/errors |
| * confusion | * poor logic |
| * depression | * short attention span |
| * disorganized | * sloppy work |
| * disoriented | * slow thinking |
| * distracted | * talkativeness |
| * dullness | * withdrawal |



Stress affects the whole family.



UNDERSTANDING THE DISABILITY EXPERIENCE

Persons and families can cope with stress and have good lives for themselves if they understand and accept their disability experiences. Each experience is unique, yet some features are common to almost everyone.

TECS is an acronym, or memory aid, for eleven dynamics that occur in the everyday lives of most persons and families affected by disability. **TECS** refers to:

T Time,
Transportation

E Energy,
Empowerment

C Control,
Curiosity,
Cost

S Supports,
Stigma,
Stress,
Strengths

Three other challenges frequently create stress: language, isolation, and developmental transitions.

Language: Language must be chosen carefully because words empower or disempower individuals and groups. In particular, there is widespread agreement to use person-first language to avoid defining individuals in terms of disability or disease. For example, use the term “person with a disability” instead of a “disabled person.”

Isolation: Many persons and families experience isolation and loneliness. Primarily this is because of negative attitudes, like fear and hate, and separation from community life.

Developmental Transitions: Because the human experience changes from childhood to old age, challenges and stress vary over time.



PERSAE

RON: AN EXAMPLE

All 14 of these commonplace dynamics interact to challenge the quality of life of individuals and families. For example, imagine a young man named Ron and his family. Ron is 13 years old, has moderate mental retardation and cerebral palsy.

Time: Each day Ron needs more time than his peers for grooming and making decisions.

Transportation: It takes Ron longer to walk places and he depends on others for rides. Transportation is a major daily obstacle for families who live in communities with poor public transportation.

Energy: Hard physical labor and tough mental work, like tests, drain Ron's energy and that of his parents.

Empowerment: Sometimes Ron doesn't feel very influential or important, such as when he feels left out and when kids tease him. Ron and his parents feel resentful when decisions are made without their involvement.

Control: Ron loves his parents, but sometimes wishes his mom would not protect him so much. It would be nice if his dad weren't so strict. Ron's parents struggle daily with decisions to hold on or let go.

Curiosity: Sometimes, Ron and his family wish they had the same privacy as other families. For example, staring and nosy questions make them uncomfortable.

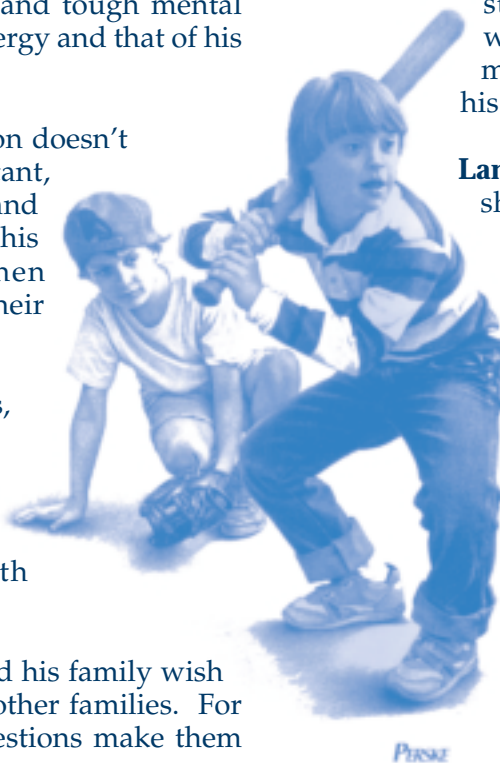
Costs: Ron's parents worry about costs and how to pay the bills. Sometimes Ron feels like a financial burden. They all dream of winning the lottery.

Supports: Ron's education requires more work preparation, where he is learning self-determination and daily living skills. Ron's parents have benefitted from a family education group and respite services. They are forming a circle of support, so family, friends and close professionals can do personal futures planning to help Ron achieve a better life.

Stress & Stigma: Ron and his family get stressed sometimes because of disapproval. At times, it's like fear. Kids who call Ron mean names get them stressed out. They feel real fear when a big school bully tries to make him fight or threatens to take his money.

Language: Ron and his family often shrink or get mad over language that hurts (e.g., "dummy" or "CPkid") or is unnecessary (e.g., physically or developmentally challenged). They get stressed when people cannot understand Ron's speech.

Isolation: Sometimes Ron and his parents choose to stay alone to feel safe, even though the separation from others can feel unpleasant, hurt self-esteem and increase their loneliness.



RON: AN EXAMPLE

Developmental Transitions: Stress often reflects the normal demands of different age periods. When Ron was starting elementary school his family focused on his work habits, trust, and cooperation. As Ron is a teenager interested in dating and paid work, they wish to focus on his social skills so he can get along better with other kids and adults.

Strengths: Many strengths have emerged from the disability experience shared by Ron and his family. These include learning planning skills and discipline to better manage time, energy, and costs.

Other strengths include enjoying being alone, patience, resourcefulness, assertiveness, humility, thrift, and humor. Ron's family and extended family seem to be closer, more positive, and caring because of coping with disability-related challenges.

Parallel Experiences: Ron's closest natural supports, like his immediate family and best friends, have similar experiences to Ron's. For example, Ron's parents feel disability-related stress (e.g., worry about social acceptance) and fear (e.g., Who will help Ron after we die?). Family and friends also get mad at persons who act scared or impatient when Ron is slower to make decisions. Ron's parents feel stress when they disagree or lack the patience for long range solutions.



ADJUSTMENT TO DISABILITY OR LOSS

Being born with or acquiring a disability is almost always upsetting. Disablement seems to reframe hopes and add uncertainty and fear.

Psychologists think that most individuals with disabilities experience different ways of adjusting. These ways are sometimes called stages, states, or dynamics. Common adjustment dynamics include: **shock, partial acknowledgment, depression, anger, and coping.**

Adjustment to disability is a life-span process. A person's adjustment changes with time and circumstances. Over time, there is increasing emphasis on coping skills. Parents, other close family members, and individuals with disabilities have similar ways of adjusting. The adjustment process is shown in the figure below.

* **Shock** is the main feeling upon first learning about disablement or getting discouraging news related to disability. Much of this shock is emotional. People may feel that "this is unreal" or "this can't be happening to me" or ask "why me?" People experiencing shock frequently display some denial, bargaining behavior, and fear related to facing disability realities and implications.

* **Partial Acceptance** is where persons and families accept some of the realities related to disability.

* **Depression and Anger** are parallel ways of emotional hiding. Persons in these stages feel threatened and choose to protect themselves. They turn anger inward on themselves and/or outward on others. Depression and anger are hard on family members, especially persons living together.

Persons who are depressed may have self-pity, be passive, and inefficient. Often, depression is likened to grieving. Very depressed persons feel worthless, helpless, and hopeless.

Angry persons tend to blame other persons and organizations. They may lash out over the unfairness of new limitations and adjustments. Anger is often a secondary emotion used to mask a true emotion like guilt or embarrassment.

* **Coping** is the stage of adjustment where persons recognize and accept certain limitations. Acceptance includes an emotional commitment to make the best possible life for themselves.

Most individuals and families learn to cope effectively with disability and adapt to changes demanded by reality. Individuals and families who regularly practice coping almost always discover important new strengths that improve the quality of life.

Cyclical Stages of Adjustment



DISABILITY AND STRESS

Everyone experiences some stress daily, and intense stress periodically, related to crisis or major loss. The 43 million Americans with disabilities, their families, and friends are most likely to feel anxiety, fear, confusion, apprehension, frustration, anger, and fatigue. In one word: **STRESS**.

Stress can have three kinds of causes or stressors:

- ✧ person-related stressors
- ✧ disability-related stressors
- ✧ environment-related stressors

Psychologists theorize that adjustment to disability is a complex interaction of coping with these three main stressors - person, disability, and environment.

PERSON-RELATED STRESSORS:

- ✧ age
- ✧ coping skills
- ✧ ethnicity
- ✧ gender
- ✧ individuality
- ✧ interests
- ✧ motivation
- ✧ personality
- ✧ relationships
- ✧ self-concept/esteem



DISABILITY-RELATED STRESSORS:

- ✧ age of onset
- ✧ coping skills
- ✧ health
- ✧ mental ability
- ✧ pain and energy
- ✧ psycho-social development
- ✧ stability of disability
- ✧ visibility of disability

ENVIRONMENT-RELATED STRESSORS:

- ✧ comparative values
- ✧ exclusion/isolation
- ✧ inaccessible buildings or events
- ✧ inadequate accommodations
- ✧ inadequate family support
- ✧ inadequate training
- ✧ inadequate transportation
- ✧ lack of services
- ✧ media coverage
- ✧ medications
- ✧ negative attitudes
- ✧ performance demands and time
- ✧ poor economics
- ✧ treatment interventions
- ✧ unaffordable costs
- ✧ unemployment
- ✧ unwanted advice

The interaction of the person, disability, and environmental factors can be illustrated. An example is that an awkward walking style may cause staring and teasing, which may lead to low self-esteem.

WAYS TO COPE WITH STRESS

Individuals and families who cope best with stress master a variety of tactics that work well for them. Some of the following hints fit everyone and some better suit persons affected by disabilities.

Remember, not all of these tactics may be right for you. Try some and repeat those that work best for you. Practice! Don't just tolerate or survive stress. Be active. Take control in reducing your own stress.

Short-Term Stress Reduction Tactics

Short-term stress reduction tactics only take seconds, minutes, hours, or days to do. Following are helpful hints to reduce stress quickly.

What are the top 5 helpful short-term hints listed that help YOU reduce stress?

- * aerobic exercise
- * concentration/focusing
- * cooking
- * craft projects
- * crying
- * dancing
- * daydreaming/fantasizing
- * deep breathing
- * deep muscle relaxation
- * drawing a picture
- * eat/drink something healthy
- * helping others
- * hugging
- * laughter and joking



- * meditation
- * movies and popcorn
- * newspaper therapy
(comics, crosswords, Dear Ann/Abby)
- * physical labor
- * prayer
- * press on your temples
- * reading
- * reframing/reconsideration
- * rehearsal
- * singing
- * smiling
- * story telling
- * talk to a friend
- * talking out conflicts
- * teasing/flirting
- * telephone talks
- * time management
- * travel
- * visualization
- * writing (e.g., poem or postcard)

COPING WITH STRESS

Long-Term Stress Reduction Tactics

Long-term stress reduction tactics are used for weeks, months, or years. Following are helpful hints to reduce stress today and years from now for individuals and their families.

What 5 long-term approaches do you believe best reduce your stress?

- * advocacy & assertiveness
- * assessment of stress & support
- * close relationships
- * counseling (individual/group)
- * credentials (certificates, licenses, degrees)
- * education
- * employment
- * empowerment
- * exercising regularly
- * family & friends
- * future planning
- * healthy life habits (e.g., diet, sleep, moderation)
- * knowledge competencies
- * leisure/hobbies
- * mentoring
- * moving
- * networking with peers
- * new knowledge
- * positive affirmations
- * positive attitudes
- * respite/rest
- * skill mastery
- * socializing
- * support groups
- * training
- * travel/vacations
- * values to live by
- * writing/journaling

Best Practices for Persons with Disabilities

Research has shown that certain activities or services are most likely to help individuals with a disability have a higher quality of life. This includes helping to achieve more independence, happiness, connectedness, and less stress.

Which of the following *best practices* have helped you or someone you know?

- * advocacy
- * counseling
- * early intervention
- * employment
- * empowerment
- * family involvement
- * friendships
- * interagency collaboration
- * peer assistance
- * self-determination skills training (e.g., decision-making, assertiveness)
- * support resource coordination



24 PRACTICAL TIPS TO EASE TENSION

The following information will give you some specific direction a person can do immediately to reduce stress. Many of these tips were first suggested by a panel of nine experts who wrote on stress reduction in *The Doctors Book of Home Remedies*.

Which five tips work best to reduce your

TENSION?

1. Adjust Your Attitude: "... the single most important point you can make about stress is that in most cases it's not what's out there that's the problem, it's how you react to it" (Dr. Paul J. Rosch, M.D., president of the American Institute of Stress). This wisdom is illustrated by experiences like roller coaster rides that are shared by a group, but perceived as wonderful or awful by different individuals. Positive, "can-do," attitudes can change a life of stress and discomfort to a life of challenge and excitement.

2. Think About Something Else: Distract yourself! Break the chain of thought that is producing stress by thinking about almost anything else.

3. Delay Reacting to Tension: Pause and relax for a few seconds before acting. This will help you feel more in control and more confident. For instance, count to five and breathe deeply before responding.

4. Take a Mental Vacation: Fantasizing can ease tension. Visualize yourself lying in warm, fine sand on a beach in the tropics. A cool wind is blowing in off the ocean, and the surf is rolling in quietly in the background.

5. Take a Time-out: Brief time-outs, even seconds or minutes long, can really ease tension by giving you a chance to relax and regroup.

- * One time-out technique is to **look away**. If you feel on the spot to act before you're ready, look out a window at a far distant view and relax before responding.
- * Another effective time-out method is to **get up and leave**, perhaps saying words like "Excuse me, I need a five-minute break" or "Pardon me, while I go to the restroom."

6. Time Someone Else Out: Sometimes brief time-outs help others cool off and get themselves under good control. Sending children to their room for a 5-30 minute time-out is a time-tested behavioral management technique, which also give parents time for respite and regrouping.

7. Talk with a Friend: Heart to heart talk with a friend who truly listens and supports you unconditionally helps you feel understood and valued. Such straight talk can prepare you to talk with persons who are stressor.

24 TIPS CONTINUED

8. Repeat Affirmations: Repeating positive belief statements reduces stress. Effective affirmations or positive self-talk does not have to be complicated. Persons calm down after saying words to themselves, like:

- * "Inch by inch life's a cinch."
- * "I've done this successfully before."
- * "I can handle this."
- * "Cool it. Chill."
- * "I'm prepared and competent."
- * "I know more about this than anyone else."
- * "Change what's changeable and accept the rest."
- * "My mother always loves me."

9. Recite an Anti-Stress Litany: Stress can strike anytime, at work, in the bathroom, in the deli at lunchtime, in the car on the way home. To help yourself when unpleasant thoughts knot the muscles in your neck and tension mounts, recite the following litany, suggested by stress expert, Dr. Emmitt Miller. Try it just before bedtime and evaluate the effect the next morning.

- * "There's no **place** I have to go at this moment in time."
- * "There's no **problem** I have to solve at this moment in time."
- * "There's nothing that I have to **do** at this moment in time."
- * At this moment in time, I need to **relax**.

10. Take Several Deep Breaths: The correct way to breathe is abdominally. Feel your stomach expand as you inhale, and collapse as you exhale. Repeat three times.

11. Yell or Cry: A good yell or cry in a private place can provide a quick release to stored emotions.

12. Creative Projects: Doing something you like that is very practical gets you a tangible product, and takes your mind off of stressors. Water and prune plants, paint a room, mow a lawn, cook a gourmet meal, take care of a pet, etc.

13. Stretching and Massage: Many people respond to stress with muscle tension. It is especially helpful to massage your own target muscles (e.g., neck or upper back) that get most tense under pressure.

14. Press on Your Temples: Massaging nerves in your temples relaxes muscles - chiefly in your neck.

15. Laugh. Use Your Sense of Humor: Children laugh an average of 250 times a day, but adults only 15. Let yourself laugh at the ridiculous, smile at the sublime. Take life seriously, but not yourself. For a lifetime of great free entertainment, learn to laugh at yourself.



PIRELLA

24 TIPS CONTINUED

16. Meditation: Any kind of meditation (Zen, Transcendental, yoga) can produce a relaxation response that reduces tension. Dr. Herbert Benson, M.D., of the Harvard University Medical School suggests the following steps for producing relaxation:

1. Pick a focus word or phrase (e.g., “peace,” “calm,” “balance”) that is firmly rooted in your personal belief system.
2. Sit quietly, close your eyes, and relax.
3. Start repeating your focus word in time with your breathing, each time you exhale. Continue for 10 to 20 minutes.
4. Practice at least once a day, and don’t worry about how you’re doing.

17. Progressive Relaxation: Try this effective exercise. Starting at top or bottom, tense one set of muscles in your body at a time, hold for six seconds, then let them relax. Work your way through all major body parts - feet, legs, chest and arms, neck and forehead (the hardest part to relax). Then enjoy the sense of release you feel.

18. Easy Listening: Relaxing music and tapes that emphasize sounds of nature facilitate relaxation. Browse the music or bookstores, and you’ll find an inexpensive tape you like. Or, check out tapes from your local library.

19. Manage Conflicts: Believe that people who are close are playing on the same team. Be willing to apologize, forgive, and collaborate.

20. Exercise: Body motion builds stamina to reduce tension. The best movement is regular aerobic exercise which increased the heart rate. Perform your preferred choice - run, swim, walk, jazzercise, treadmill - at least three times a week for at least 20 minutes.

21. Take a Hot Soak: Hot water defeats tension by restoring blood circulation. This tells your body that it’s safe and OK to relax.

22. Pets: Enjoy a pet that is relaxing to you, such as a dog, cat, or bird. Even taking care of a pet that really accepts you eases tension and lowers blood pressure.

23. Time Management and Organization: Efficient time management and being organized greatly reduces stress. Inefficiency increases stress. Use inexpensive tools to help you be efficient - watches, lists, calendars, a rolodex, file folders. Discard waste. Read on time management. Develop plans and follow them.

24. Master Skills For Coping With Disability Specific Stress: Each of the 11 factors reflected in the TECS acronym, as well as isolation, language, and developmental transitions, can be managed. Individuals and families need to address those unique dimensions that create stress. For example, If curiosity and stigmatization are problems, it is important that persons gain strong self-determination skills, such as verbal assertiveness, conflict management, self-advocacy, use of humor, and high self-esteem.

A SIMPLE TOOL FOR STRESS MANAGEMENT

When confronted with a stressful situation, try the following simple procedure.

“It will work if you will work as it.”

Step 1: Stop the disturbing thoughts. Identify the thoughts you are using to upset yourself and scream the word **“STOP”**. Scream out loud if you are alone or to yourself if you are in public.

Step 2: Ask yourself: Is there anything that I can do about this **“NOW?”** If the answer is “yes,” do it.

Step 3: Now take charge of your thoughts by controlling your breathing. Breathe in slowly and hold your breath for the count of 3 or 4. Then, breathe out through your mouth to the count of 4 or 5.

Imagine that you are blowing up a balloon. Breathe in through your nose and exhale through your mouth. Your chest and shoulders should remain still.

Repeat the process 3 or 4 times. Practice even when you are not anxious or stressed. In this way, the technique will be there when you need it.

Contributed by Dr. Dan Montgomery of Florida State University



SUGGESTED QUESTIONS TO ASK PROFESSIONALS

Understanding the background of professional providers is a basic right of customers. Unfortunately, many families and individuals have very little choice of professionals who come into their lives. Some professionals even get defensive and angry when questioned. Remind yourself that good customers are assertive self-advocates.

Consider asking professionals questions like these:

1. What **specialized training** have you had in working with persons with disabilities and their families?
2. How much **experience** have you had in working with persons with disabilities and their families?
3. What are your **credentials** (e.g., degrees, certificates, licenses)?
4. How much **experience** have you had with this disability?
5. Can you give me the **names and phone numbers** of two parents or individuals with disabilities that you have served? I would like to call them or have them call me.

**Is this professional
the right one
for our family,
or should we
look further?**



ADDITIONAL RESOURCES

Every resource is part of a network that can link you to other persons or organizations. Listed below are some phone numbers to call. Please use phone books or community service directories to find resources in your own local community.



National Resources	Phone Numbers
ADA/American Disabilities Information Line	(800) 514-0301
The Arc (Association for Retarded Citizens)	(800) 433-5255
Beach Center on Families and Disability, University of Kansas	(913) 864-7600
Center for Education and Training for Employment	(800) 848-4815
Down Syndrome Cngress	(800) 232-NDSC
Exceptional Parent Magazine	(800) 562-1973; Subscriptions, (800) 247-8080
Job Accommodations Network	(800) 526-7234
Muscular Dystrophy Association (Northwest FL/South GA)	(850) 681-6763
National Clearing House on Family Support and Children’s Mental Health	(800) 628-1696
National Information Center for Children and Youth with Disabilites (NICHCY)	(800) 69500285
National Rehabilitation Information Center	(800) 346-2742
Parent Education Advocacy Center	(703) 923-0010
Parent Line (All Children’s Hospital)	(800) 727-3688
United Cerebral Palsy Association	(800) 872-5827
State of Florida Resources	Phone Numbers
Advocacy Center for Persons with Disabilities	(800) 342-0823
Alcohol, Drug Abuse and Mental Health Program Office	(850) 487-2920
Association for Retarded Ciotizens	(850) 921-0460
Bureau of Instructional Support and Community Services	(850) 488-1570
Developmental Services Program Office	(850) 488-4257
Division of Vocational Rehabilitation	(800) 451-4327
Florida Developmental Disabilities Council... TDD (850) 488-0956; (800) 580-7801, (850) 488-4180	
Florida Telecommunication’s Relay Service Inc. Voice (800) 955-8770; TDD (800) 955-8771	
Parent Line (All Children’ Hospital)	(800) 727-3688

ADDITIONAL RESOURCES



Local Resources

Association for Retarded Citizens
Big Brothers/Big Sisters
Centers for Independent Living
Churches and Synagogues
City Hall
Clergy
Colleges and Universities
Department of Children and Families
Division of Vocational Rehabilitation
Easter Seal
Friends and Family
Goodwill Industries
Job Service of Florida
Libraries
Medical Services
Mental Health Agencies
Multiple Sclerosis Association
(physicians, counselors, therapists)
Schools
Service Clubs
Support Groups
Telephone Counseling & Referral Service
United Cerebral Palsy
United Way

Reading

The following reading materials are available in most areas. Browse your bookstores and libraries for other helpful information, including audiovisual materials.

Baroff, G. S. (1991). *Developmental Disabilities: Psychosocial Aspects*. Austin, TX: Pro-Ed/

Brill, M. T. (1993). *Keys to Parenting a Child With Downs Syndrome*. Hauppauge, NY: Barron's Educational Series, Inc.

Davis, M., Eshelman, E. R., and McKay, M. (1995). *The Relaxation and Stress Reducrion Workbook*, (Fourth Edition). Oakland, CA: New Harbinger Publications, Inc.

Exceptional Parent Magazine, P. O. Box 3000, Denville, NJ 07834-9919 (800) 247-8080.

Kushner, H. S. (1981). *When Bad Things Happen to Good People*. New York: Avon Books.

Sander, C. M. (1992). *Surviving Grief and Learning to Live Again*. New York; John Wiley

Tkac, D. (Ed.) (1990). *The Doctors Book of Home Remedies*. New York: Bantam Books.

Turnbull, A., Patterson, J. M., Behr, S. K., Murphy, D. L., Marquis, J. G. and Blue-Banning, M. J. (1993). *Cognitive Coping, Families and Disability*. Baltimore, MD: Paul H. Brookes.

CLOSING COMMENT

Excessive stress is not a choice but a certain reality in our hectic lives. The choice is in how we decide to deal with stress. There are many strategies and tactics that will effectively reduce or prevent stress. Some approaches are immediate, short-term, and long-term.

Different ways will be more successful for some individuals and families than others. Everyone is wise to master several ways that work for them.

In the long term, positive attitudes, good communication skills, and caring family and friends are likely to be the best resources for helping with stress. Most important, be active, and take action to control your stress and not let stress control you.

We hope this pamphlet gives you some immediate help, is encouragement for future effort, and guides you to other resources. Best of luck!



In order to continue to improve this pamphlet, we need your comments and reactions. Please, please return the customer satisfaction postcard!



QUALITY OF LIFE PROJECT

The Coping With Disability Related Stress Pamphlet

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