

Coping Workbook for Care Providers of Children with Batten Disease

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STRESS MANAGEMENT

Stress is an everyday fact of life. You can't avoid it! Stress is defined as any CHANGE that you must adjust to. Stressful events can be positive or negative and can come from three sources.

Three Basic Sources of Stress:

1. The Environment. Examples are work deadlines, weather, crowds, interactions with other people.
2. Your Body. Examples are illnesses, accidents, sleep disturbances, poor diet. When confronted with a stressful situation your body reacts physiologically in order to help you deal with the stress. This reaction is often called the Flight or Fight reaction, although some of us may freeze or faint when stressed! Some stimuli are interpreted by the brain as threatening the body's regulatory center. The brain gives the body information to speed up in preparation to confront or escape the threat (stress). Your body responds by constriction of pupils, hearing becomes more acute, muscles tense, blood flow is increased to your brain and large muscles and reduced to your hands, feet and digestive system, heart rate and breathing increase. This is why many people feel "butterflies" in their stomach or lose their appetite and their hands feel cold and clammy when they are nervous.

We all experience these stages of arousal throughout the day but we usually will have some relief of stress. When there is no relief of stress and/or stressors build on each other, a chronic stress reaction can occur. This is the point at which minor stress can overwhelm you and you become tired and have difficulty coping both emotionally as well as physically. The saying "The straw that broke the camel's back" is an example of how a minor stress can cause a full fledged anxiety reaction if the person has been

experiencing chronic stress. Also your reaction to your body's response may become a source of stress. An example of this is when a person develops a tension headache, the headache becomes a stressor that may interfere with the person's ability to work or focus her attention on taking care of her child.

3. Your Thoughts. How you interpret and label your experience will affect the amount of stress you will experience. If you think something is awful or terrible you will react with greater emotional and physical arousal than if you think something is uncomfortable or inconvenient. It is helpful to try to put things in perspective and when things seem to go wrong decide how you can learn from it. There are few things in life that cannot be worked out. Also when it comes right down to it there are only a few things we really need to survive.

Psychologists have also discovered that a person's belief about how successful they will be is the best predictor of whether or not they will be successful. This is called self-efficacy. If you believe that you can find a positive solution you will. Positive thinking, believing in yourself, helps motivate you and helps you stick to the task. When we think negatively we set ourselves up for failure and increase the chances that we will give up before we even begin.

Another way your thoughts can affect you is by dwelling on worries or negative images and emotions. When you think of negative situations or events your brain reacts as if you are actually experiencing this and will send messages to the other parts of your body to prepare for stress. When we think of negative things, particularly ones that generate anger or anxiety our heart rate and blood pressure increases and all those other responses that were described above occur. By focusing on positive images and emotions we begin to relax, feel better and reduce our stress response.

Problems of Life:

All humans have to deal with negative events and problems. Of course some people may have to deal with more traumatic situations than others but very few people go through life without being challenged. Stress management involves learning to cope with daily hassles as well as major stressors in one's life.

Stress Management:

There are a variety of procedures and techniques that can help you manage stress. Some techniques help you change your environment to reduce stress, some help you reduce your body's response to stress and others help you develop more healthy and positive ways to think about yourself, other people and the future. Below is a list of stress management procedures. Some of these will be discussed in this workbook more specifically. Others you can get information on at most bookstores or the library.

Progressive Muscle Relaxation	Cognitive therapy
Breathing Techniques	Problem Solving Training
Meditation	Time Management
Biofeedback	Assertiveness Training
Self-hypnosis	Nutrition
Autogenic training	Exercise

Stress Management

STRESSOR	STRESS REACTION	COPING RESPONSES
<u>Events</u>	<u>Physiological Response</u>	<u>Ineffective</u>
Could be any specific situation	Cardiovascular	Alcohol or drug use
Often sudden & temporary	Gastrointestinal	Smoking
Wide range of events	Muscular tension	Eating
Specific to each individual	Others (perspiration, change in breathing)	Nervous habits
		Gambling
		Aggression
		Sexual acting out
		Escape
<u>Problems</u>	<u>Emotional Response</u>	<u>Effective</u>
Generally ongoing or longer term condition	Anxiety/Fear	Recognize reaction (Self-awareness)
Wide range of problems (health, financial, employment, family inter-personal, life changes or demands)	Depression/Sadness	Delay overreacting
	Anger/Hostility	Rate degree of stress (1-10)
	Guilt	Relax
		Talk to yourself or others
		Assert yourself appropriately
		Problem solve
		Rational self-analysis
		Evaluate your performance
<u>Cognitions</u>	<u>Cognitive Response</u>	
Any troublesome thought belief, memory or attitude	Worry	
	Confusion	
Mental Stressors	Paranoid	

Learning to Relax

1. Find a quiet, relaxing environment.
As you get better at relaxing you can do it in noisier or less comfortable places.
2. Find a comfortable place where you can lie or sit down for twenty minutes.
3. Begin by tensing your hand for five seconds then relaxing your hand.
Do this twice.
Focus on the feeling of letting go.
After you focus on your hands, tense and relax the following muscle groups:
arms, feet, shoulders, calves, thighs, stomach, buttock, chest, back, neck, eyes, mouth and jaw.
You might find that for you, focusing on certain muscles relaxes you better.
4. Between tensing and relaxing muscles, think pleasant thoughts.
Thoughts of things YOU associate with being relaxed. Focus on sensations of warmth, heaviness and letting go. Examples: being at the beach, listening to music, sitting in front of a fire in the winter, floating on a raft, etc.
5. Do this for 15 to 20 minutes per day.
6. Do daily or least 3 times per week.
7. Some people may want to do it when they think that they may be getting stressed, tense, tired, trying to get to sleep or developing a headache.
8. Try to use certain muscles to help you relax during stressful events.
Example: relax your jaw muscles, relax your hands.
9. As you get better at relaxing you will find that it will only take a few

minutes to relax. And, you may only have to think about something relaxing to achieve the same results.

Time Management

Sharper Not Harder

A young man always wanted to be a lumberjack. He wandered up the logging camp on his eighteenth birthday and enthusiastically asked for a job. Seeing that the boy was large, strong and healthy, the boss agreed. The first day the lad chopped down ten large trees entirely by himself. This was quite an accomplishment and the boss was very please. The next day the boy seemed to work just as hard and just as long, but he only chopped down eight trees. This was still quite respectable. The rest of the week passed and each day the boy worked just as hard and just as long, but each day he produced less. On Friday the boss called the boy into his office noticing that he had only felled one tree. He was ashamed because he had produced so little and tears began to roll down his face.

“Sir”, he said, “I’m working harder and harder, but I’m afraid I’m disappointing you”. “Why do you do so little?” the boss asked. “I’m really trying sir”, was the boy’s response. “Have you taken time to sharpen your axe, boy?” inquired the boss. The boy answered, “No sir, I really haven’t had time because I’ve been so busy working”. The moral: work sharper not harder. *Charlesworth and Nathan* (Adapted from Powell and Enright, 1990)

Time Management Techniques

1. Construct a master list.

II. Set Priorities.

A. The ABC method:

A - At once

B - Best done today

C - Can wait

III. The Daily Do List

A. Select 10 items from the ABC list and attempt 3 or 4 of the A=s,
and later when energy is low, do some of the B=s and C=s.

IV. Strategies of Time Management

A. Consolidate and control - cluster similar tasks together and attempt those tasks in the same time period.

B. Divide and conquer - subdivide large jobs into smaller ones.

C. Swiss Cheese Method - useful on tasks of overwhelming proportions. Select two instant tasks, both of which are high priority but quick and easy to perform, such as a phone call. Performing these easy tasks will generate the momentum to stick with the overwhelming task, and make it appear less demanding.

D. Do not be a perfectionist: a perfectionist is one who has problems setting priorities and spends equal amount of time and effort on tasks regardless of their importance. You may

have to deliberately do some things quickly and poorly in order to get the important things done.

E. Perform your most important jobs during periods of increased productivity, your peak efficiency times.

F. Coping with paperwork- getting rid of clutter will enable you to concentrate on your high priority goals:

Assign all mail to one of these stacks:

1. Things to do
2. Things to be filed
3. Things to be routed to another member of the family
4. Things to be discarded

G. Taking breaks will increase productivity.

1. Take a 10 minute break every 45 minutes to increase concentration and attention, which will increase productivity
2. Schedule relaxing and distracting activities on the weekend; engaging in a pleasurable activity will decrease stress.

The Time Manager: Metacognitive System

I. The Goal Manager - very crucial

- * Set high quality goals
- * Specify the goals in detail; goals which are not specified are

unlikely to be achieved.

- A. Goal Generator: produce a long list of possible goals, which are your desires, everything you know about yourself and the world. This becomes a list of candidate goals.
- B. Goal Prioritizer: Order the goals according to their importance.
- C. Subject Generator: Tackle the subordinate goals in order to achieve the main goals.
- D. Subgoal Prioritizer: Rate the subgoals according to feasibility.

II. Task Planner

- A. Task Generator: Plan ways of accomplishing the subgoals.
- B. Task Prioritizer: Prioritize the tasks, keeping feasibility in mind.
- C. Subtask Generator: Break down the tasks individually into components, starting with the most important ones.
- D. Subtask Prioritizer: The task possibilities are narrowed down by the Subtask Prioritizer to produce a list of performable tasks.

Keep in mind 3 properties of a task:

1. Does the task have a deadline?
2. Time required to complete tasks: short and long tasks should be treated differently.
3. Type of mental resource needed to perform tasks

III. Scheduler

A. Job selector: To Do List

B. Run manager: Performs the To Do List, and decides which jobs to do first.

Relationship Problems

Family roles must change to accommodate for the caring of a chronically ill child. Parents as well as children are called on to help with family needs as well as the sick child's needs. Most family members will feel neglected at times. They may have to sacrifice their desires, dreams or family attention because of the ill child. Parents report financial strain as well as problems having enough time to do for their family and for themselves. Spouses often find it difficult to spend quality time together and when they can find time they may be too tired to enjoy it! These issues can begin to wear down the positive bonds between spouses and family members at a more rapid rate than happens in most marriages over time. Again marriages are at greater risk for problems because of these added stressors.

The first step is to take a preventive approach. This means making a commitment to take some quality time with your spouse on a weekly basis. This means planning and agreeing and finding someone to care for your child so that you can have some quality time together. Many people object and say that they cannot afford to do this either because of finances or lack of time. If you do take the time and money now to spend on each other you might prevent so many other problems and possibly divorce. In the long run you will actually save the family money, quality time and the trauma of experiencing an unsatisfactory marriage.

The second step is to take a look at your communication skills, particularly with your spouse and children. Does positive and assertive communication exist in your family? On the next page is a list of communication Do's and Don'ts. Review them. Do you see some areas for improvements? Some people may need to learn how to communicate more effectively. Brief therapy focused on improving your communication skills

can be very beneficial. There are books and tapes on communication that you can use to help improve these skills. Communication is the key to expressing yourself to others and to help you understand your family. If parents are good communicators their children will learn these skills. Good communication skills will help them be successful in all walks of life.

The third step is to recognize that whether we like to admit it or not the way we behave to others in our family will influence their behaviors towards each other as well as towards us. Ask yourself if you use negative or positive reinforcement with your spouse or children? Do you “nag” or react with punishment? If so, bad feelings will flourish. Try to think how you can reward the behaviors and attitudes that you appreciate from your family. Let your spouse or child know you appreciate the things they do for you and the child that is sick. Tell them you love them as often as you can. Catch your children behaving well and praise and give them positive attention. It is so easy to get in a negative mode of interaction with those who are closest to us. Remember also that we must continually add new things to our relationships or they will become stale and boring. Good relationships take work and commitment.

Take twenty minutes each week to have a family meeting to plan family events, work out problems and provide positive reinforcement for each other. You can try this on your own but if you already have significant problems you might want to consider marital or family therapy. A therapist can help guide a couple or family to discover better ways of interacting.

Communication Skills

Do's

1. Open posture, eye contact, not fooling around with other things such as books, looking at T.V.
2. Reflect back and summarize what the other person says to you.
3. Validate the other person's feelings. You don't always need to offer advice or try to change the way someone feels.
4. Make specific requests - you have the right and are responsible for asking for what you want.
5. Stay on the topic of concern.
6. Express appreciation and consideration for what the other person does or says.
7. Expression of feelings, especially angry and sad emotions.
Use this formula: "I feel (emotion) because (specific behavior)."
8. Offer solutions and alternatives.
9. Set time limits when you don't want to discuss a problem.
10. Positive or constructive criticism.
11. Stay in the present.
12. Plan for future. Contract. Set goals.
13. Clear communications, clarify.
14. Explore what the other person means if you are not sure. When you find yourself reacting emotionally, INVESTIGATE.

Don't

1. Interrupt
2. Become historical, bring up past events.
3. Be vague.
4. Express feelings only.
5. Threaten.
6. Criticize.
7. Name call.
8. Mind read or jump to conclusions.

Exercise

If you don't have a regular exercise program established you might first want to schedule a physical with your physician to determine your health status or any medical problems that must be considered in setting up an exercise program. You may also want to get baseline measurements on your physical fitness level. Most YMCAs or gyms will provide an inexpensive or even free physical fitness test. This often will involve measuring your aerobic capacity, body fat composition, strength, and flexibility. People will often think that they should wait until they get in shape before being tested. This is putting the "horse before the cart". The testing will indicate where you need to focus to develop a well rounded exercise program.

Research studies indicate that in order for a person to maintain cardiovascular fitness they should participate in aerobic activity three to four times a week. Aerobic activity means engaging in a continuous physical activity at 75% of your maximum heart rate for thirty to forty minutes each day. Examples of aerobic activity include walking, running, jump roping, aerobic class and swimming.

In order to maintain muscular fitness a weight training program in which the person works out with weights three times a week is necessary. Weight training strengthens a person's back, stomach, and shoulder muscles to help prevent injury.

Besides the physical benefits of exercise, you will find yourself feeling better about the way you look and feel. Many people enjoy being able to take a long walk and use that time to think about things. Also if you can maintain an exercise program it will improve your self-efficacy or belief that you can really accomplish something that is worthwhile. Exercise helps your body

build its endurance level and will actually give you more energy in the long run. Exercise can also be a good outlet for anger and frustration.

The most difficult thing about an exercise program is making the time and commitment. And it means taking the time for yourself that you might want to spend with your child. It is important though to take this time to work on **your** health. By being physically healthy you will have more to give to your child in the long run.

Nutrition

Psychologists have been studying the effects of a person's emotional functioning and are discovering that what you eat can affect how you feel. Two food culprits that may dramatically affect your mood are sugar and caffeine. Small amounts of these substances may not affect you but if you are adding sugar to your food and drinking or ingesting more than two servings of caffeine daily you may be setting yourself up to feel fatigued, depressed and/or irritable. It is easy to test the effects of caffeine and sugar on your mood by not ingesting these for a week and noting how you feel. You can then add back one and note any changes. Then add the other and note any changes.

Your food intake should be appropriate for your age, height and weight. There are many charts that are available for you to use. A basic guideline is to eat balanced meals that include not more than 30% fat. Not eating enough calories can affect your ability to think well and have the energy you need to care for your child. Eating too many calories will lead to weight gain and the negative health and emotional consequences of being overweight.

As with exercise, a moderate, well planned program can increase the likelihood of success. There are many fad diets available but these lead to only short term success and may actually make it more difficult for you to lose weight in the long run. Some people need more guidance and structure than others in order to be successful in developing a good nutrition plan. You might want to log your food intake for a week then meet with a nutritionist to review your normal food consumption. The nutritionist can use that information to help plan a more effective nutritional plan for you.

Screening for Clinical Emotional Problems

As you continue to handle the problems that will occur in caring for your child you will undoubtedly experience stress. Adjustment reactions to problems are normal and all people will experience varying levels of grief, sadness, anger, and anxiety in response to things that will happen. It may even be more difficult to cope when you have no control over the event or situation. However, care providers of chronically ill children are at greater risk for emotional distress because they must continually adapt and adjust to new developments or conditions that do not resolve themselves. This long term stress may affect you over time and you may begin to experience more significant emotional problems. Emotional and/or psychological problems are considered clinical if the symptoms last more than six months and begin interfering with social, home and work functioning.

It may be helpful to take periodic “check-ups” in terms of your own emotional and psychological functioning. Often times care providers are so busy caring for their children and their child’s problems that they do not stop and consider how they are feeling. There are several brief questionnaires available that screen for emotional and psychological problems, evaluate the impact caring for your child has on your health and schedule, and current perceptions of your family’s functioning. By completing these forms and sending them to be scored you can receive feedback on your emotional and psychological functioning. The feedback will indicate whether the level of severity of problems you may be experiencing are in the clinical range. If you find that your scores are indeed high, you may benefit from meeting with a psychologist or counselor to determine if you might be a good candidate for mental health intervention. Mental health intervention may include a variety of services. These services range from medication, support groups, family or

marital therapy to individual psychotherapy. These interventions may be brief or extensive depending on the severity and complexity of your problems. Many medical insurance companies and health maintenance organizations will reimburse you to some extent for these services. Mental health services may be available in your community for free or at a reduced fee or you may have to seek out private practice services which are likely to be reimbursed by insurance companies. Questionnaires are available from Elise Labbe, Ph.D., telephone 1-334-460-7149.

Mental Health Services: Where to get help?

If you belong to a health maintenance organization or have a special insurance plan you can contact member services and ask what mental health services are available. If you live in an area that has a university or college you can contact the psychology department and find out if they provide any services to the community. Many psychology departments have clinics that are used to train doctoral students. The graduate students are supervised by a licensed clinical psychologist faculty member. The psychologist may also provide services through the clinic or refer you to other services in the community that you may not be aware of. Most communities offer mental health services or provide information on how to get psychological services. You can also look in the Yellow Pages under psychologists for names of clinics and private practitioners. Ask if the person has a license. Most states have fairly high criteria in order for a psychologist to obtain a license. Organizations that can help you to find psychologists in your area: Association for Advancement of Behavior Therapy (212)647-1890 American Psychological Association (202)336-5500; webmaster@apa.org

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For more information about Batten Disease,
BDSRA and its programs and services:

Visit BDSRA's website at
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