

# Role of the Caregiver and Family in Recovery

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## Stress of Being a Caregiver

- Daily life can present many sources of stress. When you couple that with caring for a spouse, child, sibling, or parent who has a chronic medical condition or a disability, the stresses of being a caregiver can become overwhelming
- There are an estimated 25 million family caregivers in the U.S. Their family members often require special care, including around-the-clock supervision and help with daily activities

## Stress of Being a Caregiver (*con't*)

- Caregivers can experience considerable stress from their added responsibilities in caring for a loved one. They can become depressed, anxious, or develop physical ailments as a result of the stress of caregiving
- Caring for someone with a chronic medical condition can be a time consuming responsibility that often requires the caregiver to forgo other activities such as work, time with family and friends, and time for their own leisure activities.

## Stress of Being a Caregiver (*con't*)

- The Challenges of coping with a chronic medical condition reverberates throughout the patient's family. Stress on family members may be as great or greater than that experienced by the patient and increasing emotional pressures can put a strain on close relationships.
- "Role expectations" of family members are often affected when there is a diagnosis of a chronic medical condition. Role expectations are ways of behaving in situations that fit with a person's self-image and the expectations of others. Changes in role expectations within the family as a result of a chronic medical condition can contribute to stress within the family.

## Putting the Illness in its Place

- Coping with a chronic illness such as TM necessitates "putting the illness in its place." This means that the family needs to attend to the demands placed on them by the illness but not allow the illness to dominate the family's schedule or control the family's emotional life. Families should try to maintain day-to-day routines, family rituals, holiday traditions, attend to all family member's needs.

## Ways to Reduce Stress

- Don't take on more responsibility than you can handle. Learn to say no or get someone else to help.
- Use relaxation techniques like meditating, visualizing comforting scenes, or listening to music
- Take one thing at a time. If you have an overwhelming amount of things to do, pick one task and work on it. Once you accomplish that task, move on to the next one.
- Make your lifestyle as healthy as possible by eating nutritious meals, limit caffeine and alcohol, not smoking, getting enough rest, exercising regularly, and balancing work and recreation.

## Ways to Reduce Stress (*con't*)

- Schedule time to take a break and do things that you enjoy.
- Have family and friends you can turn to for love, support, and guidance.
- Educate yourself about your loved one's condition. Information can be empowering.
- Consider joining a support group of other caregivers.
- See your doctor if stress begins to feel overwhelming.
- Your doctor or other health professionals may help you find resources in the community to give you the support you need.

## 10 Signs of Caregiver Burnout

1. Denial
2. Anger
3. Social Withdrawal
4. Anxiety
5. Depression
6. Exhaustion
7. Sleeplessness
8. Irritability
9. Lack of Concentration
10. Physical Symptoms/Health Problems

## Stressors Faced by Families with a Member who has TM

- Too little, too much information
- Decision Making
- Confusing medical jargon
- Fear of the unknown
- Emotional distress, anxiety, depression, guilt
- Altered expectations
- Loss of normalcy
- Lack of control
- Lack of independence
- Pain and discomfort
- Performing home care
- Invasive procedures
- Disrupted sleep patterns
- Change in self-image, identity
- Job, financial worries

## Stressors Faced by Families with a Member who has TM (*con't*)

- Reorganization of family roles
- Lack of support
- Marital strain
- Sibling needs
- Strained, lost relationships
- Unpredictability, unexpected events
- Isolation from family, friends
- Disruption of routines
- Extended family's upset
- School/Work disruptions

## Family Coping Strategies

- Be aware of each other's strengths and weaknesses and be respectful of each other's coping styles
- Delegate, share, and take turns
- Use the "buddy system" to fill in when one member is overtaxed
- Take breaks; family members each have their own needs and should participate in activities unrelated to TM

## Family Coping Strategies (*con't*)

- All family members need ego and energy boosters so they come back refreshed and ready to tackle the next crisis
- Keep everybody informed
- Reassess your goals and expectations often

## Coping Strategies for Mothers

- Don't try to be Super mom; ask for and accept help
- Don't be daunted; you can learn the new skills you need. You will stretch and grow, and your child/spouse will benefit, as will you. You will become stronger
- Stop beating yourself up about what you should have done, what you should be doing better, and matters that are out of your control

## Coping Strategies for Mothers (*con't*)

- Take breaks: take a walk, take a bubble bath, meet a friend for a cup of coffee, listen to music, or take a nap
- Don't wait for anger and resentment to boil over; if something is bothering you say so
- Share your feelings with family members, and listen to their feelings

## Coping Strategies for Fathers

- Be a full participant in the treatment process
- Share your feelings with family members, and listen to their feelings
- Express the impact of illness on your sense of self, your ability to continue to work and provide for the family, and your visions of the future

## Coping Strategies for Fathers (*con't*)

- Be willing and able to ask for help, and accept it
- Explore what you have learned from the experience and how your role in the family has changed for better or worse
- Share your thoughts, feelings, fears, and hopes with others

## Coping Strategies for Spouses

- Together with family members, figure out which coping styles and behaviors meet each other's needs and which do not
- Communicate both ways: Listen as well as talk, and fight "fair"
- Compromise must be a two-way street: Meet each other half way
- Take turns and share duties

## Coping Strategies for Spouses (*con't*)

- Support your partner's style of coping and contributing, even though it's different than your own
- Go together to important medical events and consultations. It provides strength and solidarity for yourself and your child/spouse
- Support rather than undermine each other's relations with children, family, and medical personnel

### Coping Strategies for Spouses (*con't*)

- Allow each other some separate “space.” Spouses need to retain separate identities despite areas of dependence which may be necessitated by TM.

### Coping Strategies for Single Parents

- Cultivate partnerships with trusted friends and family, a competent child care provider, home care or visiting nurses, teachers and school nurses, volunteers and others in the community
- Educate your helpers about your child’s illness, home care duties, procedures, warning signs, and emergency plans. Write these in a notebook, or make up a poster or flyer for handy reference. Make sure they have contact information for you, the doctors, the hospital, siblings, and other helpers

### Coping Strategies for Single Parents (*con't*)

- Work out guidelines with staff to keep you in the loop when you’re not there. Insist that procedures or exams not be done without you, your representative, a social worker, or a child life specialist present; Develop a relationship with the nurse
- Swallow your pride; be willing to accept help, and don’t try to be super-parent
- Join a support group, talk to a therapist, or unload on a friend

### Coping Strategies for Single Parents (*con't*)

- Give your time only to those things that absolutely require it or are worthy of you
- Take time for yourself to recharge
- If you have a relationship with a non-custodial parent, do everything possible to improve it and enlist that person’s help. Bury the hatchet. Get counseling, use a mediator, and agree to shelve old issues

### Sibling Issues

- Worry about sibling’s health and ability to cope
- Fear of catching TM
- Fantasy that they caused the TM
- Guilt at normal sibling rivalry
- Guilt that they’re not the sick one
- Isolation from family: sibling in the hospital, parents not at home, nobody to talk to
- Isolation from peers: fewer social outings, friends don’t understand, living at grandma’s
- Lack of attention; feeling abandoned, rejected, lonely, left out, unimportant
- Resentment and jealousy
- Acute and chronic stress, posttraumatic symptoms

### Sibling Issues (*con't*)

- Sick child gets preferential treatment, rules of discipline change to benefit sick child
- Increased responsibilities, chores
- Anger at parents and sick child
- Ambivalent feelings toward sibling, parents
- Unpredictability of events, lack of control
- Embarrassment, shame
- Family role shifts
- Depression, guilt at negative emotions
- Loss of “normal” childhood
- Disruption of routines
- Confusion, misinformation, lack of information, or limited grasp of information

## Caregiver's Rights

- I have the right to make mistakes and to be imperfect
- I have the right to forgive myself and begin anew
- I have the right to say "No" and not feel guilty or selfish
- I have the right to take a break and relax
- I have the right to let go of yesterday and embrace today
- I have the right to enlist the cooperation of my family

## Caregiver's Rights (*con't*)

- I have the right to laugh and be happy
- I have the right to arrange my own priorities
- I have the right to take care of myself
- I have the right to have my needs considered important to others
- I have the right to do special things for myself
- I have the right to take time off even if it costs money
- I have the right to be self-preserving so that I can care for others