

# MULTITASKING: PARENTING YOUNG CHILDREN WHILE LIVING WITH MS.

Presented by:  
Jessica S. Thomas, MSW, PLCSW

# Agenda:

- Parenting with MS...how is it different?
- What does research say about parents with MS and or other chronic illnesses?
- Possible developmental reactions to illness.
- Becoming organized.
- Develop a action plan to take care of yourself.
- Sleep hygiene and fatigue.
- Mindfulness.
- The silver lining of parenting with MS.
- Addressing MS mommy/daddy guilt.
- Talking about MS with a small child: when and what to say?
- Enjoying the summer, holidays, etc.
- Resources.
- Questions, etc.

# What does research say about parenting with MS?

- “Other studies with older children and mothers with chronic fatigue tell us that because fatigue is so prevalent in women with MS, many children can easily spot the symptom in their mother and, thus, may adjust their behavior to create less hassles for her. It might also be with these women that they have worked out an arrangement of sorts with their children centering on their level of fatigue.” It also appears that adequate sleep plays a critical role in managing parenting stress for mothers with MS”.

source: Family Systems Health. 2009 Dec;27(4):325-345.

- “MS parents reported using more social support (e.g., their partners or their parents), more self-preservation parenting (e.g., letting a child play by herself while the mother rests in the same room), and higher expectations of mature behavior from their children (e.g., explaining to their children that they are too tired to do an activity) to cope with fatigue while parenting.”

source: Chronic Illness. 2009 March;5(1) 33-45.

- “If members of the family’s support system are educated about the fatigue factor of MS and are more actively involved in the co-parenting, they may rise to the need, liberating the mother with MS to rest and refresh.”

source: <http://www.ecu.edu/che/press/fatigue.html>

# Possible developmental reactions to illness

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## 18 months- 3 years:

Think: illness is temporary and reversible, doesn't separate fantasy from reality.

Feel: confused about changes, sad, angry, anxious, cranky.

Do: imitates behaviors observed, asks "why".

# Possible developmental reactions to illness

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## 3-5 years old:

Think: illness is temporary and reversible, finality of illness is not evident.

Feel: confused about changes, sad, angry, anxious, cranky.

Do: cries, fights, shows interest in illness.

# Possible developmental reactions to illness

## 6-9 years old:

Think: about the biological process of illness, about who will care for them if a parent is not there or too sick, their actions or words caused the illness.

Feel: sad, anxious, withdrawn, confused, angry, scared.

Do: behaves aggressively, is withdrawn, experiences nightmares, acts as if illness does not exist, lacks concentration, possible decline in grades.

# Parenting with MS...how is it different?

Parenting with MS is more challenging than usual because of limitations that relate to MS. Limitations may include: loss of balance, loss of movement, weakness in limbs, poor vision, fatigue, unpredictability of disease progression, lack of confidence.

*Perhaps one of the hardest aspects of parenting with MS are the emotional aspects.*

# Parents with MS weigh in.....

- “Having MS does interfere with my parenting. There are many days that I do not have the energy to do the activities I would like to with my kids.”
- “Having MS is hard as a parent. Sometimes I get so tired I have to take a nap and my husband has to be both mommy and daddy.”
- “I am unable to do some of the things like teach my daughters to ski or run next to them. I have found ways to ride bikes with a three wheel recumbent bike. I struggle with fatigue and having not enough energy to keep up with their active days and some days have to remove myself from the family to go to bed early and hope for a better day the next day. The fatigue can lead to low tolerance so I am learning to be more insightful and say this just may have to wait until tomorrow, because I just may be too tired to handle this in a way that is more productive.”
- “ I feel like I take more time to explain what my daughters have to be successful at a task or a problem. Before MS I tried to fix what I could and now I find myself trying to help them reach the best answers to problems and encourage problem solving. I feel sometimes I am intolerant and try to recognize when I need to take care of myself and rest. I would have liked to do more active things with my daughters, but I do what I can.”

# Becoming organized

- Plan ahead.
- Use a calendar.
- Bring your “B” plan with you.....just in case!
- Combine errands.
- Make to do lists.
- Being realistic about the “to do’s” for the day.
- Manage your time.
- Prep several days before big outings with children.

# Taking care of yourself

- Focus on your health.
- Find sources of support.
- Address what stresses you.
- Have fun.
- Learn the right times to say both “yes” and “no”.

# How to reduce fatigue

- Bring strollers when possible.
- Have your child sit in the shopping cart.
- Ask for help. Re-create a sense of extended family.
- Enlist “quiet time” at home for you to rest and the child to rest or have quiet play.
- Know your limits, signs of fatigue, etc.
- Have an age specific entertainment bag.
- Be flexible.

# Sleep hygiene and fatigue

## Sleep Hygiene Tips:

- ❑ Maintain a regular sleep schedule by going to bed and waking up at the same time every day. A calm sleep routine prior to bedtime will help train your brain to fall asleep at the same time every night. Many of my patients find that meditation or taking a hot bath helps relax them before they go to bed.
- ❑ Avoid long naps, if at all possible, especially later in the day.
- ❑ Keep the bedroom a calm, quiet, cool, dark place.
- ❑ Train yourself to keep the bedroom primarily for sleep
- ❑ Avoid exercising close to bed time.
- ❑ Avoid drinking alcohol or caffeine for 4-6 hours prior to sleeping.
- ❑ Have your doctor review your nighttime medications to see if there are any that might cause sleeplessness.
- ❑ If you can't fall asleep within 15-20 minutes, get out of bed and read something calming in a soft light until you are ready to try again.
- ❑ Take a short-well timed nap not too late in the day; this can be wonderfully restorative for those whose schedules allow.

# Developing an Action Plan

## □ **Powerful Tool for Taking Care of Yourself: Create an Action Plan**

An important tool to take care of yourself is developing an action plan. Ask yourself the following question: What are things that you like to do? What could you do to take better care of yourself and feel better?

## □ **4 steps developing an Action Plan**

- What - what are you going to do?
- How - how much are you going to do it?
- When - when are you going to do it?
- How Often - how often are you going to do it?

# Mindfulness

Mindfulness, paying attention to the present moment with awareness, can seem elusive to busy parents. But it's worth exploring!

Three core qualities of mindfulness:

(a) present-centered attention and awareness

(b) intention or purposefulness, which highlights a motivational component to one's attention and behavior

c) attitude, which reflects how we attend, or the qualities that one brings to the act of paying attention, such as interest, curiosity, nonjudgment, acceptance, compassion, and receptiveness

# Mindfulness parenting with MS

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Some examples:

- Cooking.
- Painting or other art projects.
- Eating an ice cream cone.
- Watching traffic.
- Listening to music.

# The silver lining of parenting with MS.

- Opportunity to teach your child empathy.
- The awareness of now. We only have right now. Children love being in the moment with their parents enjoying activities, quality times, etc.
- Being open to the possibility that there is something actually positive in experiencing parenting with multiple sclerosis.

# Silver lining from other parents with MS

- “I love my kids so much!!! Sometimes I push myself so hard but it is worth it to see the smiles on their faces and hear their laughter.”
- “My silver lining would be my kids. I may not be able to do everything with them that I think I should be, but I try to make the best out of the good moments and good days that I have. I try to make the best out of my good days.”
- “ I have so my fun with my child. I make efforts to make almost everyday special to him. I feel that having MS has given me an awareness of how lucky I am to have active time with him.”

# Addressing MS mommy/daddy guilt.

- Some parents feel guilty because their version of what it means to be a parent doesn't match the reality of their situation with MS.
- Connect with other parents with MS through support groups, chapter events, etc.
- Cognitive shift of what a good parents looks like?
- Make sure your child is not your caregiver. This does not mean that they cannot help out or have chores, etc!

# Mommy/Daddy guilt...it's normal

- “My biggest mommy guilt, is that I can not do as many activities with my kids that I would like to some days. Many days, my fatigue interferes with the things that I would like to do. Also, I always worry that my girls will have memories of their "mommy needing to rest" a lot. I feel guilty every time I have to say it to them. They are young and I haven't found a way to really explain MS to them yet”.
- “NOT playing with my kids because I am too tired”.
- “That my daughters will never see me the way I was 2 years ago. I am afraid I will be seen different. I did not want them to worry about taking care of me.”
- “ My biggest guilt is when I am missing out on time with my son when I am napping. My husband tries to tell me that napping is better for me, but at times it is hard to let myself not feel guilty. The truth is that I would rather be playing instead, but I always have so much more energy after my nap”.

# Talking about MS with a small child: when and what to say?

- Talk about MS a little at a time.
- Bring the topic up yourself during natural family times.
- Normalize MS as a part of your family.
- Expose your children to MS Walks, family programs, etc.
- Use your instincts when talking with your child.

# Enjoying the summer, holidays, etc.

- ❑ Create a family “summer to do list” filled with fun, MS safe activities.
- ❑ Beach trips during mild temperatures.
- ❑ Create a theater in the living room.
- ❑ Mason jar memories- great way to track special times and read at a special anniversary or holiday, etc.
- ❑ Dusk is the new “outside play time”
- ❑ Smoothies or ice cream for dinner.
- ❑ Watch a lightening storm as a family while in the garage. Make popcorn and rate the thunder.

# Tips from other moms with MS

- “ I try my best to put unnecessary pressure on myself for the holidays. I used to go "all out", but MS has made me put things in perspective, prioritize and simplify. If the thought of the holiday is overwhelming to me, we may just plan to eat out or order sides/desserts. That way I know we will still eat a good meal, but I do not have to spend hours doing things that can be simplified. Planning ahead is a huge part of the holidays as well. The days leading up to a holiday, I do as much as I can while I am feeling energetic. I do this knowing when the day comes, I may feel like doing next to nothing, so I try to be prepared for that. Also, it makes the actual holiday less stressful for me.”
- “PLAN AHEAD!!!!!! I have found that when I plan ahead and do a little bit of stuff at a time I don't get stressed out.”
- “Do not over commit to helping with the holiday events. Divide up the meal planning and make only what you really need. Vacations are the only time I feel like I escape the day in and day out reality of my disease. I plan ahead and research where I am going make sure events are kids friendly. I do most of my traveling during the morning when I feel better. I am willing to rent a scooter if it allows me to spend the day at the zoo with my kids. Summers are a challenge with the kids home and in camps. I stay organized and plan and have people I can call as back up if I can not get them from camp on time. Learning to build a network of people who can help.”

# Fun, Easy, and CHEAP Indoor Activities for Kids

- 1. Have an indoor picnic.
  2. Build a fort out of blankets (use chairs, couches, yarn- anything to hold up the blankets!).
  3. Make sock puppets.
  4. Finger paint with pudding.
  5. Playdough- use rolling pins and cookie cutters.
  6. Dance PARTY—dance to your favorite songs.
  7. Have a tea party.
  8. Read nursery rhymes.
  9. Make your own indoor hopscotch with masking tape on carpet/wood.
  10. Pedicures.
  11. Play school—have the child be the teacher.
  12. Make a letter book. Let the kids take a picture of something that starts with each letter of the alphabet.
  13. Look at photo albums.
  14. Make a movie of yourselves, then watch it.
  15. Paint with water colors.
  16. Play Barbies.
  17. Play with matchbox cars.
  18. Play board games.
  19. Color with crayons. Take off the wrapper and see the different ways you can color with them.
  20. Make paper bag puppets.

# Some Fun, Easy, and CHEAP Indoor Activities for Kids

- 21. Watch a movie and eat popcorn.
- 22. Go on a treasure hunt.
- 23. Bake cookies.
- 24. Play dress-up.
- 25. Make paper hats.
- 26. Make a healthy snack.
- 27. Make a relay race or obstacle course in your house—be creative!
- 28. Play hide and seek.
- 29. Indoor snowball fight with socks.
- 30. Build a fort out of cardboard boxes and duct tape.
- 31. Make plans and invitations for a party.
- 32. Play tic-tac-toe.
- 33. Make your own puzzle out of poster board or cardstock, color and cut it out.
- 34. Make your own matching game.
- 35. Swim in the kitchen—put down a tarp, fill up a little kiddie pool with warm water and let them play!
- 36. Make Valentine's décor.
- 37. Make a car track all around your house with masking tape.
- 38. Play "Monster in the Middle."
- 39. Apple stamps. Cut an apple in half horizontal and use it as a stamp using washable paint.
- 40. Make lacing cards with their favorite cereal boxes.

# Resources

- National MS Society (programs, kids camps, support groups, etc.)
- *Keep S'myelin* is a colorful, engaging, informative, and reassuring newsletter to help children and their parents talk and learn about MS together.
- Pinterest- fun website for activities with children.
- “Mommy Isn’t Feeling Well Today”, *Parent’s Magazine*, September 2010, page 96.
- Homework: find other parents living with MS! Contact your local MS chapter, attend a program or support group, etc.

# Questions, etc.

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Thank you so much for listening! If you have any parenting with MS questions, or would like to share ideas or resources, please feel free to e-mail me at: [jsthomas@treatmentnetwork.org](mailto:jsthomas@treatmentnetwork.org)