National
Multiple Sclerosis
Society

MS JOURNEY CLUB

A program for children
who have a parent
with multiple sclerosis

PARENT'S HANDBOOK

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National Multiple Sclerosis Society

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ACKNOWLEDGEMENTS

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We offer special thanks to Melissa Roby and the staff of the Ohio Valley Chapter for bringing the *MS Journey Club* program to our attention. Ms. Roby, in collaboration with Cancer Family Care, developed the original program and curriculum. We also thank Cancer Family Care for working with the Ohio Valley Chapter in developing the model on which the *MS Journey Club* program is based.

We also thank Janet O'Brien and the Allegheny District Chapter for conceiving of and developing the *Timmy's Journey to Understanding MS* cartoon project. *Timmy's Journey* is an animated cartoon sharing a little boy's adventure learning about MS.

The *MS Journey Club* program has been funded through these Program Honor Roll chapters: Central New England, Central Pennsylvania, Dakota, Eastern North Carolina, Gateway Area, Great Basin Sierra, Greater Connecticut, Greater Delaware Valley, Greater North Jersey, Greater Washington, Indiana State, Mid Atlantic, Mid South, National Capital, Nebraska, Northwestern Ohio, Oklahoma, Rhode Island, South Florida, Southern California, and Upstate New York.

Some materials in this manual were adapted from *Implementing the Nurturing Program—Program Implementation and Resource Guide*, Fran Kaplan, MSW, Stephen J. Bavolek, PhD, Family Development Resources, Inc.

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MS JOURNEY CLUB
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MS JOURNEY CLUB

CHILDREN'S COMPONENT

Session 1—Telling Your Family's Story

- Orientation
- All about me
- What is MS?
- This is what MS looks like to me
- Activity—Vision
- Wrap-up and family time

Session 2—Land of Feelings

- Let's talk about feelings
- Activities
  - Fatigue
  - Feelings Mask
  - Balloon Expression
- Wrap-up and family time

Session 3—Land of Change

- Let's talk about change (I)
- Let's talk about family roles
- Activities
  - Numbness
  - Feelings Puppet
- Wrap-up and family time

PARENTS' COMPONENT

Session 1—Telling Your Family's Story

- Orientation
- Telling your family's story
- How to talk with your children about MS
- Wrap-up and family time

Session 2—Land of Feelings

- Identifying and handling your feelings
- Your child's feelings
- Activity—Body Scan Drawing
- Wrap-up and family time

Session 3—Land of Change

- Effective communication
- Communicating using "I" statements
- What changes has my family experienced because of MS?
- How can my family handle change?
- Wrap-up and family time

CHILDREN'S COMPONENT

Session 4—Land of Families

- Q&A time
- Let's talk about change (II)
- Activities
  - Coordination
  - Spider Web
  - Pass It On game
- How we communicate
- Wrap-up and family time

Session 5—Land of Support

- Let's talk about your support network
- Activities
  - Balance
  - Communications exercise
- Wrap-up and family time

Session 6—Land of Fun & Relaxation

- Let's talk about stress
- Let's talk about fun
- Activities
  - Speech
  - My Special Place
- Wrap-up
- Graduation ceremony

PARENTS' COMPONENT

Session 4—Land of Families

- Q&A time
- Establishing family rules
- Changing family roles
- Wrap-up and family time

Session 5—Land of Support

- My support network
- Family activity—communications exercise
- Wrap-up and family time

Session 6—Land of Fun & Relaxation

- Managing stress
- What you do for fun and relaxation
- Wrap-up
- Graduation ceremony

MS JOURNEY CLUB

As a parent you may struggle with how to talk to your children about MS and the ways it may affect their lives. You may also be seeking information on parenting and MS. Improving or maintaining family functioning is key to helping you and your children adapt to life with MS.

MS Journey Club is a six-week, group-based program that meets for a two-hour session each week. *MS Journey Club* provides a supportive educational environment and curriculum designed so all family members attend together and learn complementary skills. During each session, you and your children meet in separate, professionally facilitated groups. Each week you cover one to two topics or areas of concern (i.e. the symptoms of MS, feelings, changes in family life, and support systems), while the children engage in activities and discussions that parallel what you are discussing. To enhance the learning process, the children take part in games, activities, and art projects that introduce and reinforce the topics discussed.

MS Journey Club allows you and your children many opportunities to voice concerns, dispel misunderstandings and myths about MS, and learn about MS together. It also helps you develop strategies for meeting the challenges of parenting with MS.

PROGRAM OVERVIEW

- The program consists of six weekly sessions, each session lasting two hours.
- You and your children are asked to attend each session.
- Each session will follow the same format.
- At the end of each session, everyone joins for Family Time.
- Everything discussed in the group is confidential.
- You should bring your handbook to every session. Children should bring their passport to every session.

Over the next six sessions, the group will be discussing a wide range of topics—feelings, communication, stress management, and how to have fun. The children's program corresponds with the parents' program. Children will learn many of the same ideas and techniques through play, role-play, games, and art, as well as through group discussions. Each child is provided a passport at the beginning of the program. Upon completion of each session's activities, each child's passport will be stamped.

The children have three major rules for their group:

1. Stay in the room.
2. Be kind to things and to others.
3. Speak softly and use a respectful voice.

The rules for the parents' group are:

1. All ideas are welcome.
2. No judgments are made about anyone's ideas.
3. It's okay to repeat or build on others' ideas.
4. Anything goes—wild and "far-out" ideas are good, too.
5. Everything discussed in the group is confidential. You are not to disclose any identifiable information about other group members without the person's expressed authorization.

Additional rules:

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This handbook corresponds to the topics and activities that will occur in each session.

TELLING YOUR FAMILY'S STORY

Talking with Your Children about MS

Even in the face of a serious illness, your children can be helped to handle the trauma and go on with their lives. They can be taught what they need to know, and be given the kind of support and understanding they need. Even if the parent with MS returns to full health, a child can be greatly affected by Mom or Dad's serious illness.

Children sense something is different at home and they try to figure out what the problem may be. There are three main reasons why it is important to be honest with your children about what is going on:

1. Your children are affected by everything that happens in the family.
2. The more serious the situation, the more they will be affected.
3. Withholding information and keeping secrets from your children, in any way, will inevitably make things worse.

Openness and honesty are sound, guiding principles for dealing with your children. Because they can imagine things that are much worse than the truth, it is important to include your children as soon as possible.

From the beginning it is recommended that you tell your children:

- That Mom or Dad has a disease
- The name of the disease
- Your best understanding of what may happen

Children can understand and absorb different kinds of information at different ages. In addition, children vary in their learning styles.

You are the expert on your children and can be the best judge of what they can understand. You know each child's level of maturity and how they have handled tough situations in the past. If you feel that your child is upset or confused about something, follow your "gut feeling."

If you and your spouse/partner have differing opinions about your children's needs or levels of understanding, it is best to work this out between you so that you can approach your discussions with each child as a "team." A family counselor can be a helpful resource for these kinds of discussions.

How can you explain your illness to your children?

There are six main worries or questions most children have:

- Your children may worry that they caused your MS by something they did or did not do. "Magical thinking" can be a way that children cope with situations over which they have no control. (Suggested answer: "Nothing you did made me get MS.")
- Your children may worry that something you did caused your MS. One child said that his mom got MS because she worked too hard. (Suggested answer: "Nothing I did made me get MS.")
- Your children may worry that something they did made your MS worse. (Suggested answer: "No one knows what makes MS worse, so nothing you said or did or could say or do will make my MS worse.")
- Your children might be afraid that the illness is contagious. (Suggested answer: "You can't get this from Mom/Dad. You don't catch MS like you catch a cold.")
- Your children will want to know who will take care of them. Who will do the "Daddy" things while Daddy is sick. (Suggested answer: Go into detail about who will be taking care of these things—for example, who will babysit for the children when Mom is at the hospital with Dad).

- Faced with the news of a parent's serious illness or disease, all but the youngest children will wonder, "Will my parent die?" They may or may not ask the question out loud, but it is important to know that the concern is there and needs to be addressed. Your children may need to understand your beliefs about what death is and what may or may not come after. As you listen to your child, let his/her concerns guide your answers. (Suggested answer: "Most people with MS live as long as everyone else—MS is not a fatal disease most of the time. You will always be loved and taken care of.")

TELLING YOUR FAMILY'S STORY

Ages and Stages

It is important to tailor your responses to the ages of your children. What makes sense to a 12-year-old won't make sense to a pre-schooler. One can identify roughly three different age groups—toddler through pre-school (2–5), school-age (6–12), and teens (13–18).

PRE-SCHOOL AGE (2–5): Explain the disease on your child's level. Use dolls, drawings, or puppets to help. Don't go past your child's attention span. Don't go beyond your child's ability to understand.

Example: Daddy has an illness called multiple sclerosis. It . . . makes him very tired . . . changes the way he (walks, sees). The doctors are taking care of Daddy now, and we hope he'll start to feel better soon.

SCHOOL AGE (6–12): Children at this age may have a lot of questions about the physical aspects of the illness. They may want more detail. Also children in this age range may want to go to doctor's office or the hospital to see how the doctors are trying to help Mom or Dad.

TEENS (13–18): A teen may react in many different ways. As teens, they are struggling to move away from the family and yet may feel anxious about doing so, particularly in light of the parent's illness. Most teens need a lot of information; it is important to answer their questions honestly and openly. Since many teens are concerned about privacy, make sure there is someone outside the immediate family with whom they can talk on a regular basis. The teen years are also a time of intense self-involvement. Though they may sometimes seem oblivious to what is going on in the household or with their parent's MS, they are not.

One conversation isn't enough. There is no need to try and cover everything at one time. The information will need to be repeated and expanded as your child gets older.

Child's Name	Age	What have I told him/her?	What more do I want to tell him/her?

LAND OF FEELINGS

All of our lives we are told that certain feelings are acceptable and that other feelings are unacceptable. It is normal and healthy for any one person to experience a wide range of feelings. Feelings occur and need to be expressed. Write down those feelings you show and those that you try and hide.

Feelings I Show	Feelings I Try to Hide from Others
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

HOW MY FEELINGS MAKE ME FEEL . . .

How I feel emotionally

How I feel physically

How I feel after sharing

Three Rules for Expressing Emotions:

1. Respect yourself; don't hurt yourself.
2. Respect others; don't hurt others.
3. Respect the environment; don't hurt the environment.

Some things to think about . . .

What are your own vulnerabilities and what are your children's? How do you express sadness, anger, worry, and happiness? What are the emotional and physical signs that you notice in your children? How do they express anger, sadness, worry, happiness? Do your children mask their emotions?

Write Down a Few of these Emotions and How You Express Them . . .

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Write Down a Few Emotions and How Your Children Express Them. . .

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Ways to Help Your Child Express His/Her Feelings ...

Emotional and physical feelings are okay and should always be accepted; however, the behavior associated with the feeling may not always be acceptable. Behavior must have limits.

How can you help your children with their feelings?

- Identify and name the feeling you see or think you see. "You look sad . . . happy . . . confused." Let your child agree or disagree with your perception—this shows your child that you are listening to and accepting his/her feelings.
- Let your child lead the conversation—don't do all the talking.
- When your child makes a request, it is important to respect it even if you can't fulfill it. For example, if your child asks you to go outside and play, don't just say "no," but say you wish you could but you can't because you are tired, have to start dinner, etc. Children, just like adults, like to know their feelings are honored.

Other Ideas . . .

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BODY SCAN DRAWING

Emotions are something we can feel in our body… Where do you feel your emotions? Show this with these colors...

SAD

SCARED

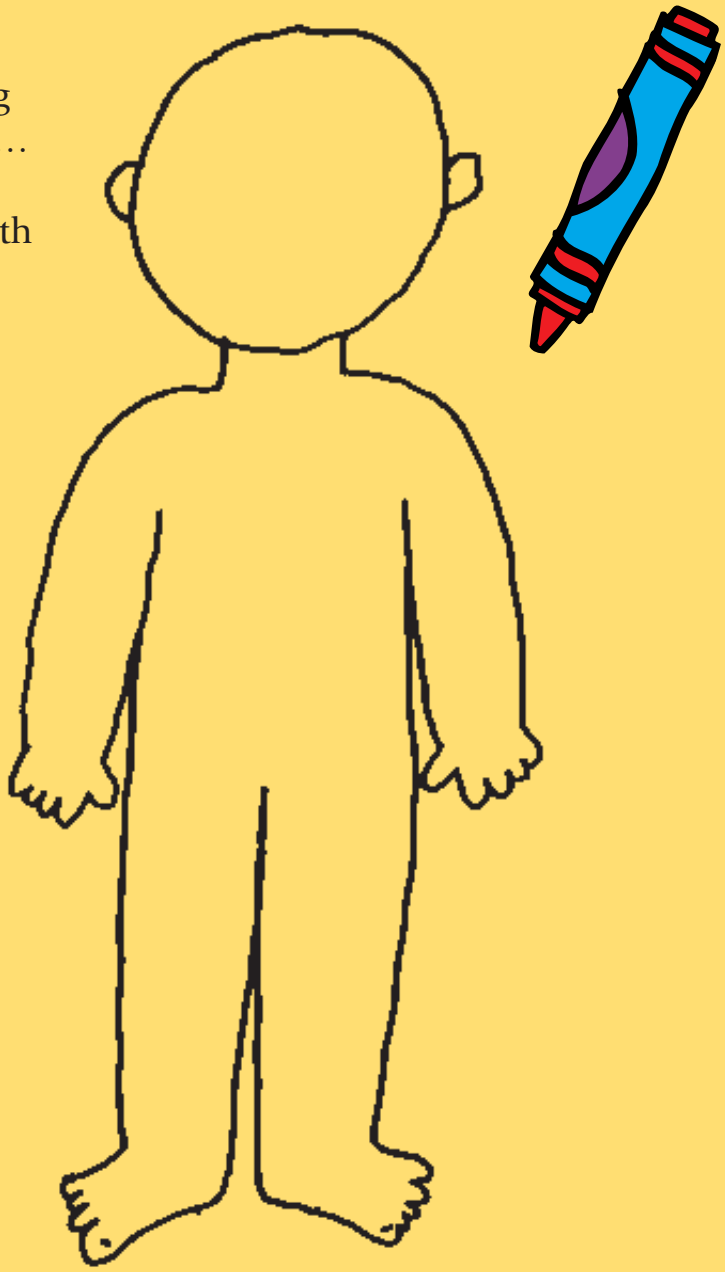
HAPPY

GUILTY

MAD

JEALOUS

WORRIED



MANAGING ANGER

Anger is not a bad feeling. What can make it bad is the way it is expressed.

It is important to address the feeling of anger right away. If not, the tension within you may build to the point where you explode. At this point logic takes a back seat and you may find yourself "out of control." Remember—you can ask forgiveness, but you can never take back words spoken harshly.

What are some ways to express your anger?

- Take a "time-out" and leave the room.
- Exercise.
- Hit a pillow (not a person!).
- Scream and yell in private.
- Talk about why you are angry (but remember that you may need some time to calm down first).
- Keep a journal of when/why you get angry.
- Have an imaginary conversation with the person you are angry with.

Other ideas . . .

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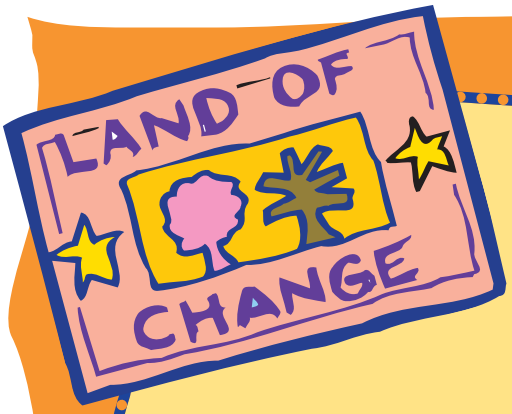
It is important that you teach your children how to express their angry feelings. Even more important—they take their cues from you, so make sure you model appropriate behavior.

These are some ways people communicate feelings. Which feelings do you think the pictures represent?



COMMUNICATING

Why Use "I" Statements . . .

- To avoid using blaming statements
- To take responsibility for your own feelings
- To confront someone about a problem or concern in a non-blaming way

How to Communicate Using "I" Statements:

I feel _____ (state a feeling)

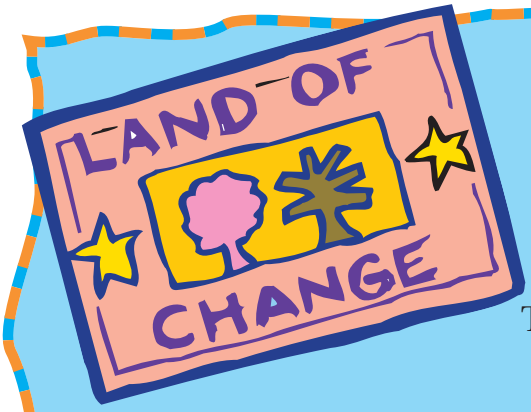
When _____ (describe the exact behavior)

Because _____ (state the need that relates to that feeling and any thought or belief related to it)

What I want is _____ (describe the exact behavior that would meet your need)

There are good uses of "You" messages:

- To give choices—You have a choice to take the trash out now or at 6, but it needs to be done.
- To give praise—You did an excellent job taking out the trash.
- To get clarification—Are you tired or hungry?
- To ask questions—Do you want toast or a bagel?
- To reflect feelings—You seem angry right now.



The big and little changes in my family have been:

Changes	Surprised me because . . .

What have been the hardest changes in your family?

Changes	Hard because . . .

FAMILY RULES

Whether large or small, changes can have an impact on each person in the family. Changes can disrupt a family's sense of structure and routine. One way to get this back is to establish family rules. Rules let all members of the family know what types of behavior are expected. Family rules help to instill a sense of fairness and the spirit of cooperation. They also lay the groundwork for effective discipline in the home.

Family rules:

- Involve everyone in the family in the rule-making process.
- Include dos and don'ts.
- Design rules to promote and reinforce cooperative behavior.
- Help your children learn appropriate behavior through parental modeling (parents are expected to practice what they preach).

Guidelines for creating family rules:

- Identify specific behaviors you want your children to have.
- For every "Don't" rule, there needs to be a "Do" rule, i.e., don't throw shoes in the living room; do put shoes in the bedroom closet. Without a "Do" rule, children may not know what to do instead.
- If you get rid of a behavior, it must be replaced with another behavior.
- It is easier to change behavior from one to another, rather than just dropping a behavior.

Rules must be age-appropriate. You wouldn't have an 11 p.m. curfew for an eight-year old, but that may be appropriate for a teen. The issue of fairness comes in here.

Family rules must be:

- Fair
- Clear
- Reasonable
- Do-able

It may also be necessary to add or replace rules periodically. A change in your family's situation may warrant revised rules. Remember to be flexible.

How does my family make a list of family rules?

- Set a time for the entire family to meet. Try to make sure you won't be interrupted.
- Have a large piece of paper and something to write with.
- On the piece of paper create three columns, Dos, Don'ts and Consequences.
- Invite family members to come up with a list of rules. Remember—you also need to come up with punishments if the rules aren't followed and rewards if the rules are followed. A reward could be a half-hour on the curfew, for example.
- Involve everyone in the process. Children are more likely to "buy into" the rules if they have a voice in creating them. You, as the parent, will need to keep the discussion on track. Lead off the discussion with what guidelines you'd like, and have your children come up with the dos and don'ts. Ask leading questions—"Ellen, what rule should we have about homework?," "What rule should we have about using the telephone?," and so on.

CONSEQUENCES (Rewards and Punishments)

The purpose of a consequence is to help children learn right from wrong.

- Reward—consequence for a desirable behavior
- Punishment—consequence for an undesirable behavior

Benefits of rewards and punishments:

- Help children learn right from wrong.
- Help children develop a strong moral code.
- Help children learn to make good choices.
- Help children feel a sense of success when they follow the rules.
- Help children identify and value positive behaviors.

Types of rewards:

- Praise
- Touch
- Privileges (for example, an extra 1/2 hour of playtime)
- Objects (toys, stickers, etc.)
- Allowance

Rewards we have in my family are:

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-

Types of punishments:

- Loss of privilege
- Being grounded
- Restitution (for example, pay back for item broken)
- Verbal expressions of your disappointment
- Time-out

Punishments we have in my family are:

-
-
-
-
-

THE _____ FAMILY'S RULES

Dos	Consequences (Rewards)
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

Dont's	Consequences (Punishments)
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

CHANGING FAMILY ROLES

- Have the roles changed in your family? If yes, how?

- How do your children feel about these changes?

- Do you feel that your children have more chores or responsibilities than other children?

- How do your children feel about any extra chores or responsibilities they may have?

- Can you think of any additional responsibilities that may be inappropriate for a child or teen?

- A natural reaction to additional chores is for a child to be angry. How can you help your child deal with this feeling?

Recommendations for Success

- Make sure that whatever you ask of your children is age-appropriate. A five-year-old shouldn't be asked to cook dinner, but may be able to help put dishes in the sink.
- A rotating schedule of chores provides variety. No child likes to do the same chores all the time, particularly if they are chores they hate.
- Thanking people in your family is very important. Although people tend to expect their family members to be helpful, showing recognition and appreciation makes people feel valued. Parents *and* children need to remember to say thank you.

WAYS TO PRAISE YOUR CHILD

What is praise?

- ***Praise for being*** is noticing and appreciating a person, e.g., "Thank you for just being you."
- ***Praise for doing*** is noticing and appreciating what a person has done, e.g., "Thank you Bob for clearing off the table."
- It is important to separate the two—you don't want to combine a person's goodness with his or her actions. Otherwise children—and adults—may begin to think you only like them when they do something for you.
- Praise those behaviors that you want to have happen.

Be able to accept praise yourself—remember your children learn from you!

THIS IS MY SUPPORT NETWORK . . .

- ***Center:*** Write in the names of people who are very close to you and without whom life would be very different or difficult.
- ***Middle circle:*** Write the names of people who are close, but not in the "inner circle," who can be relied upon for help.
- ***Outer circle:*** Write the names of people whom you see less often but are a part of your social support network.

LET'S TALK ABOUT STRESS . . .

My definition of stress is:

When I am stressed I feel:

The things that stress me out the most are:

The ways I relieve stress are:

12 TIPS TO RELIEVE STRESS FOR CHILDREN AND ADULTS

When you get that "stressed out" feeling, why not try:

- Deep breathing/muscle relaxation
- Meditating/praying
- Listening to relaxing music
- Exercising (stretch, walk, run, swim, bike)
- Playing with your pet
- Closing your eyes and recalling a fond memory
- Finding humor in things
- Expressing your feelings
- Eating healthy foods
- Making a list to help yourself get organized
- Making time to have fun
- Taking a time out

Other ideas:

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I will to try the following new ways to help me relieve stress . . .

NOTES

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