

This myelin activity book was inspired by numerous workshops and meetings with families living with MS. The purpose of this booklet is to help children explore their feelings about MS as well as help them better cope with having MS in their family. We also hope that parents will find this booklet a helpful tool in discussing MS with their children.

Note to parents

Myelin's activity book has been designed for children who have a parent with multiple sclerosis (MS) and want to understand and share what they are experiencing. This booklet can be read in sections and serve as a starting point to discuss issues most relevant to your child's situation.

We recommend that you be on hand to answer your child's questions when reading this booklet and doing the suggested activities. This will give them a chance to gain a better understanding of MS and the effect that it is having on the family. Honest and open communication may enhance your children's adjustment to MS and bring family members closer together.

Thank you

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Now that you know more about MS, it will be easier for you to understand your father or mother and to really enjoy all the special moments you spend with your family.



A little reminder

- 1- **Get information and ask questions to learn more about MS.**
- 2- **When you feel sad or alone, find activities you enjoy and do them.**
- 3- **Keep smiling and enjoy all the good times.**
- 4- **A good sense of humour always helps!**
- 5- **The MS Society of Ireland has many activities for young people with a parent with MS. You can help us find a cure for MS by volunteering or raising funds. Call 1850-233-233 to find out how you can help.**



Don't lose hope, as researchers are working hard to find the cause and cure of MS.

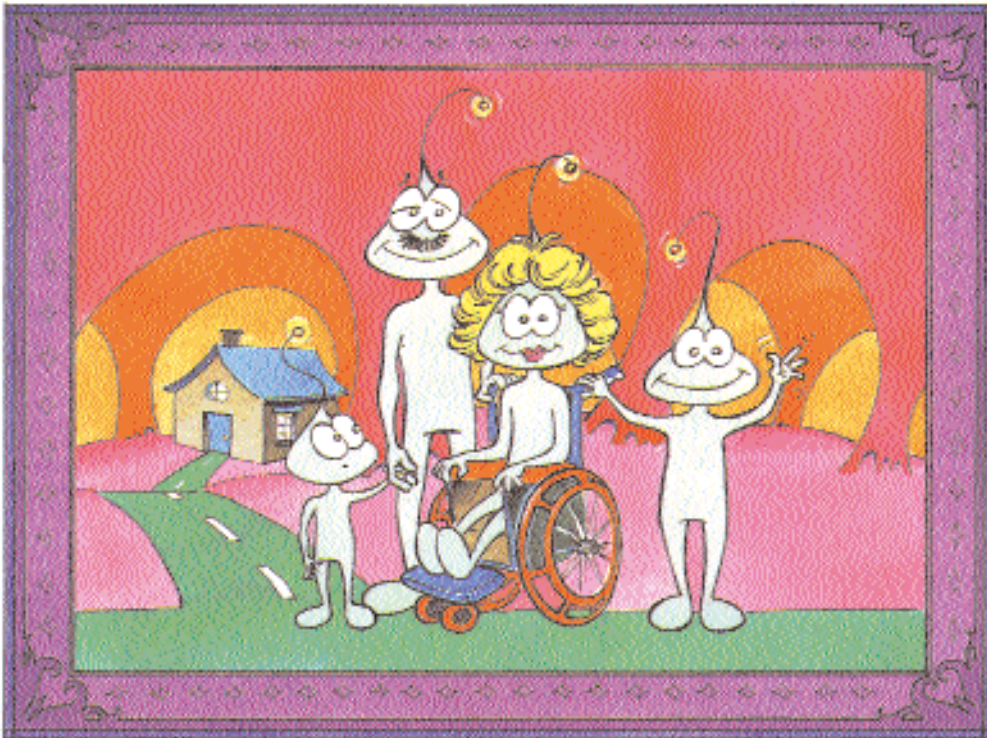


The fight against MS continues...

TIME TO SAY GOODBYE


I hope this booklet gave you a chance to:

- ✓ answer your questions about MS;
- ✓ help you understand your feelings;
- ✓ discover practical ways to help you cope with MS.



Myelin's family wishes you all the best...



-  • Before I go, I would like to meet your family. Would you like to draw them for me?

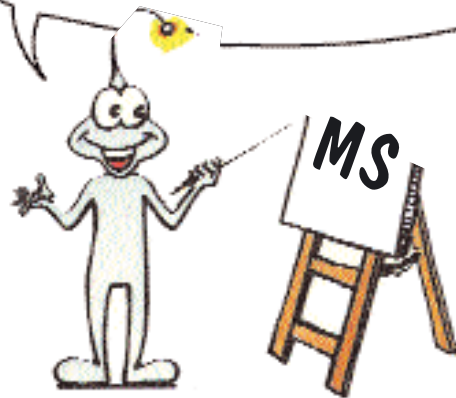
Hi there!

My name is Myelin and I'm looking forward to showing you what I know about MULTIPLE SCLEROSIS.



You will be able to show me what you know about multiple sclerosis, too!

Did you know there is a simple way to say multiple sclerosis? It's M for MULTIPLE and S for SCLEROSIS.



To have fun with this booklet, you'll need a pencil, an eraser and your crayons, If you like, ask your father, your mother or someone else to read this booklet with YOU.



Let me be your guide...

IN THIS BOOKLET...



You will find information on MS.

First, you will discover what MS is, what its symptoms are and its characteristics.


Then, with my help, you will be able to see what changes MS has brought to your life.

Of course, you and I are going to talk about certain things that can happen when your Dad or Mum has MS.



You know, I also need
to TALK about things I find sad
and scary. After you have talked to someone,
you'll see, you will feel a lot better!

Through games and activities, I am going to help you understand your feelings and help you find practical ways to cope with MS in your family.

Watch for this little sign () it will let you know when you have something to do.

To start,

I have prepared a few questions on MS for you.

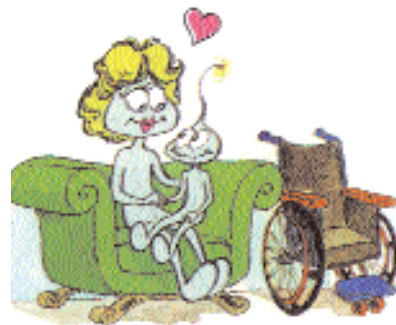
Your answers will help you understand what you already know about MS and what you have yet to learn.

 • To answer these questions, place a check mark (✓) in the right box.

Don't worry if you don't know all the answers, you will find them out by continuing to read this booklet.

Special moments!

When someone in the family becomes ill, it can bring family members closer together. Sticking together, helping and sharing with one another through the rough times and good times can make your family feel very close.



Besides, if your father or mother is at home, you may have a chance to spend more time together



• Draw me some of the special moments you have with your parent with MS.

1.	3.
2.	4.



• Tell me what is happening in your drawings.

Drawing 1. _____


Drawing 2. _____

Drawing 3. _____

Drawing 4. _____



With MS, there are several things you can do to cope with what happens to you

-  • In the following activity, circle the letter(s) of your choice.

How do you cope?

1. **You would like to take part in an activity with Mum, but she says she's too tired:**
 - a) You continue to ask her until she gives in.
 - b) You find an activity that you can do by yourself or with your friends.
 - c) You sulk.
2. **Your friends notice that your mother has trouble walking and they ask you what is wrong:**
 - a) You get angry and tell them to mind their own business.
 - b) You tell them that your mother has MS.
 - c) You would rather not say anything and find an excuse to leave.
3. **With your new responsibilities, you find that you no longer have enough free time with your friends:**
 - a) You do your duties in any case, but angrily.
 - b) You go and see your friends, leaving some of your chores undone.
 - c) You talk about it to your parents, and together, you try to find a better solution so that you have time to see your friends.
4. **Your mother has not been feeling well lately, your marks at school have gone down a lot and you're having trouble concentrating:**
 - a) You explain to your teacher what is happening at home.
 - b) In addition to worrying about your mother, you're afraid to fail your school year, but you decide not to talk about it.
 - c) In any case, you think that you aren't good at school and that it has nothing to do with your mother's MS.
5. **Your father has been getting angry more often lately:**
 - a) You think it is your fault.
 - b) You get angry as well.
 - c) You try to be patient, it is probably the ups and downs of MS that are making him impatient.

Answers to the test on coping

All answers are possible, but you should feel better if you choose the following ones:

1. b 2. b 3. c 4. a 5. c



Myelin's Questionnaire

	YES	NO	I DON'T KNOW
1 MS is a disease that affects nerves in the central nervous system.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2 Mostly children have MS.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3 Symptoms are abnormal things that happen in the body.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4 MS is a fatal disease (you can die from MS)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5 You can catch MS like you catch a cold.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6 An attack is when a lot of symptoms appear or the symptoms that were there before are worsening.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7 A remission is when symptoms disappear or are not as bad.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8 Symptoms of MS may differ from one person to another.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9 All people who have MS will need a wheelchair sooner or later.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10 MS should be kept a secret.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Answers to the questionnaire

YES = 1 point for #1-3-6-7-8
NO = 1 point for #2-4-5-9-10
DON'T KNOW = 0 points
 If you have 9 points or more: Congratulations! You know a lot about MS.
 If you have 6 to 8 points: You know MS quite well.
 If you have 5 points or less: This booklet will surely help answer a number of your questions.

MYELIN EXPLAINS WHAT MS IS

MS is a disease that affects nerves in the central nervous system.




The **brain** is like a computer that sends electrical messages (called **nerve impulses**) to the various parts of the body.

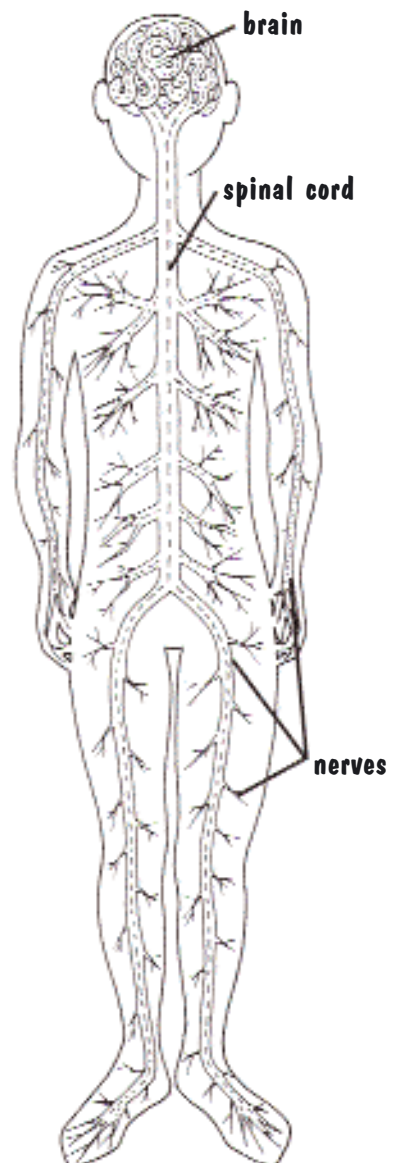
The **spinal cord** is like a big highway connected to the brain. It is filled with nerves where the messages go back and forth. The spinal cord and brain together are called the **central nervous system**.

There are **nerves** all over the human body. They are like little roads that help carry messages to tell your muscles: **MOVE!**

For example, if mum wants to take a pencil, what happens?

Her brain sends a message to her hand to go and get a pencil and bring it near the sheet of paper.

-  • On the drawing of the human body, can you draw me a line that shows where that message starts and where it has to get to?



Everyone feels angry at one time or another. It's what you do with your anger that can be good or bad for you.

You can express your disagreement as long as you don't break anything or hurt anyone. It is preferable to do these types of things when you're feeling angry:

- talk to a friend or family member about what's bothering you.
- run or play ball with your friends.
- give your pillow a few punches to get rid of your anger. You'll see, it will make you feel better.
- think about what happened, write it down in a diary or make a drawing, read a book or listen to music...



- Under each drawing below, write down how Myelin feels. What could Myelin do to feel better? Draw your answer or write it in the box on the right-hand side.

Solution to the Maze Game (p.18)

There are nine (9) obstacles to avoid:

the gravel, the unpaved trail, the phone booth, the steep slope, the staircase, the swinging doors, the suspension bridge, the people to go around, the narrow (inaccessible) washroom door.

Congratulations on all the obstacles you avoided! If you managed to avoid them all, that's great!

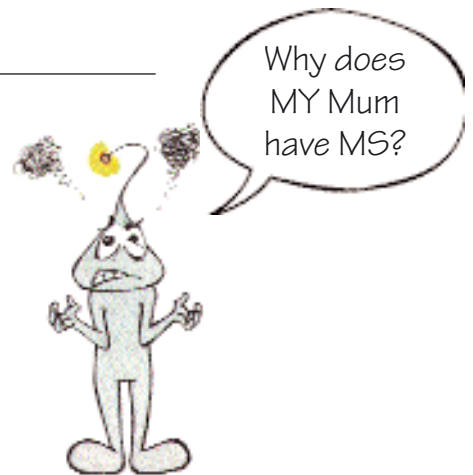
Solution to the Mystery Word (p.11)

Feeling

It's not fair!

Are you mad sometimes because your Mum or Dad has MS? _____

It's okay to hate MS at times, because there are so many things that can change.



- Using the following questionnaire, try to identify the things that make you angry. This will help you better understand anger. Place a check mark (✓) in the box of your choice.

Questionnaire on anger

1. Do you get angry if...

	Not angry at all	A bit angry	Very angry
a) You are given more responsibilities at home.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) A family activity is cancelled.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Your parent with MS has to use a wheelchair.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) You have less free time with your friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) People stare at your parent in a wheelchair.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Your friends ask you what your parent has.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Your parent with MS can no longer play sports with you.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Your parent with MS often says that he or she is too tired to play with you.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Are there other things that sometimes make you angry?			
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. What do you do if you're asked to do something that makes you angry?

(circle the letter(s) of your choice)

- a) I talk back or I yell.
- b) I hit or throw things.
- c) I run away to my room.
- d) I feel sad.
- e) I don't show my feelings.
- f) Other things: _____

3. What do you do to feel better after getting angry?

(circle the letter(s) of your choice)

- a) I talk about it to better understand what happened.
- b) I do a physical activity (playing, running outside) that makes me feel good.
- c) I write or I draw.
- d) I try to forget about it.
- e) I don't do anything.
- f) I go and see my friends
- g) Other things I can do: _____

We don't yet know why, but when a person has MS, the myelin covering the nerves in the brain or spinal cord (sometimes both) is damaged and that causes problems.

It's a bit like when you hurt yourself. Sometimes, you heal well and, with time, nothing shows.

Other times, your injuries leave scars. Scars on the myelin are called **scleroses** - or hardened tissue. The sclerosis can block or slow down the electrical messages that are travelling through the nerves.

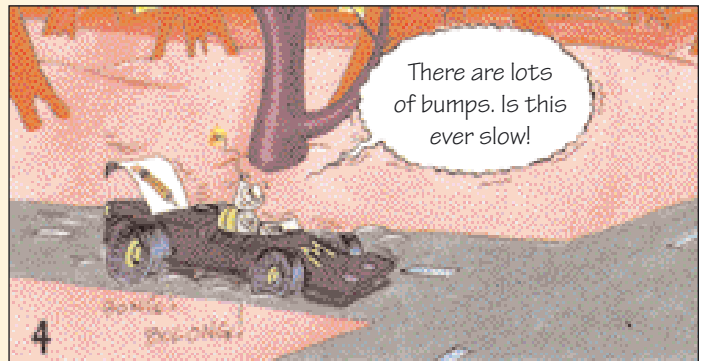
Just imagine that the message travelling in a nerve is like a racing car zooming along at top speed on a beautiful highway. Everything goes well until the car encounters an obstacle on the road and can't go any further.



Messages travel 50 metres per second.



If the myelin is repaired...



The message may get to the hand, but more slowly.

When the road is well repaired, then Mum has no trouble picking up her pencil. Otherwise, OOPS!, the pencil falls on the floor or her hand trembles. Have you ever seen that happen?



Did you know that...



MS is not a fatal disease. You cannot die from MS.

You can't catch MS by touching a person who has it, or by holding an object that this person has touched.

It is mainly adults between the ages of 20 and 40 who get MS – twice as many women as men.

Despite what we already know about MS, no one can tell in advance who will get this disease.

Children of persons with MS do not have a significantly higher chance of developing MS as adults.

MS may be different for each person.

The symptoms of MS may not be too serious and may change over time.

MS may cause sudden problems, as it is unpredictable.

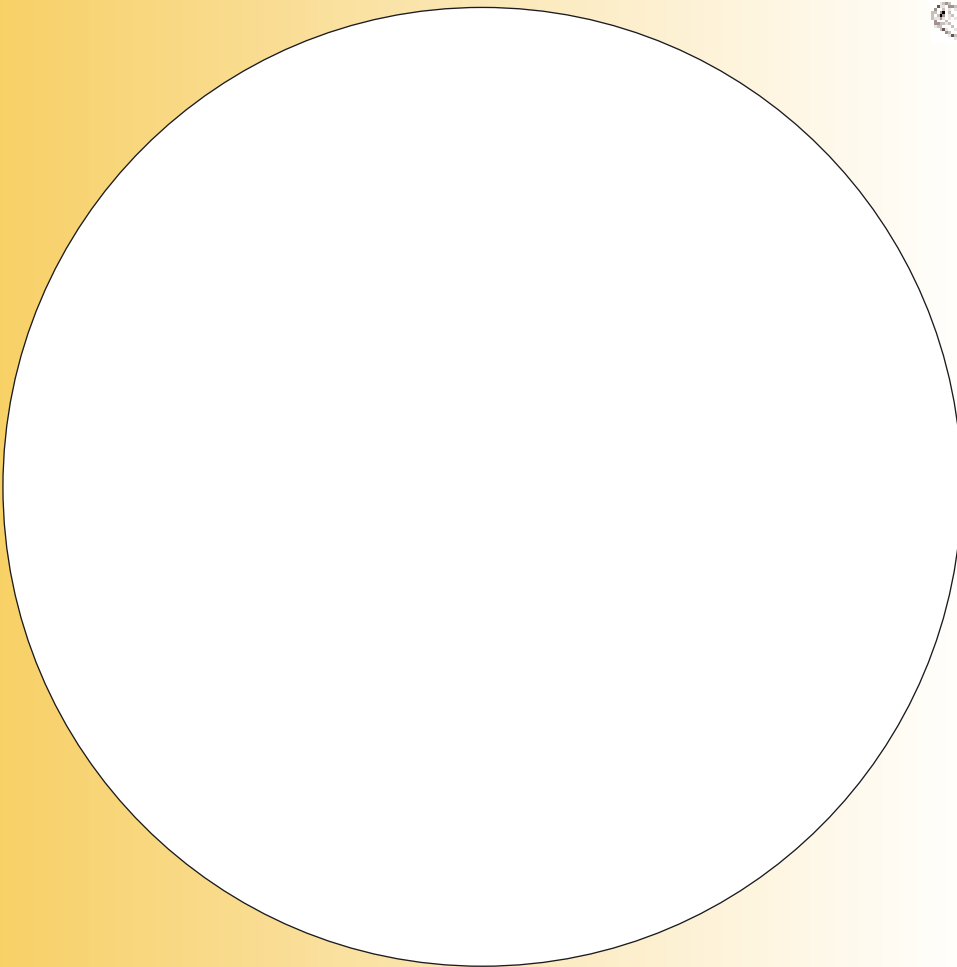
Researchers are still looking for the cause and cure of this disease.

It's not anyone's fault – neither Mum's, Dad's nor your own – if one of your parents has MS. There is nothing that you could have done to prevent it from happening.



Your circle of feelings

- Using the list of feelings, write the 4 feelings you experience most often on the lines beside. Then colour the box on the right of each feeling, choosing a different colour for each.



1- _____

2- _____

3- _____

4- _____

- With these 4 colours, fill your circle by showing how often you have those feelings.

The feeling you have the most frequently will take up the largest part of the circle, while the one you have the least often will take up the least space.

- For each of these 4 feelings, give me an example of a situation where you have felt that way.


1- I feel _____ when _____

2- I feel _____ when _____

3- I feel _____ when _____

4- I feel _____ when _____

It's important to talk about your feelings!

-  To help you better recognize your feelings, look at the list below and circle how you sometimes feel. Put a question mark (?) beside the words you don't know yet. You can look them up in the dictionary or ask someone to explain them to you.

List of feelings							
							
Happiness	Sadness	Anger	Fear	Helplessness	Confusion	Confidence	Love
I feel...	I feel...	I feel...	I feel...	I feel...	I feel...	I feel...	I feel...
calm	alone	aggravated	fearful	dependent	anxious	at ease	affectionate
content	depressed	aggressive	frightened	discouraged	confused	capable	close
cheerful	disappointed	angry	nervous	guilty	disorganized	confident	devoted
delighted	discouraged	annoyed	panicky	helpless	distressed	courageous	generous
enthusiastic	hurt	frustrated	scared	incompetent	lost	determined	kind
fulfilled	miserable	furious	stressed	paralyzed	mixed up	important	likeable
glad	rejected	grouchy	terrified	powerless	surprised	proud	loving
happy	sad	mad	threatened	ridiculed	shocked	responsible	patient
satisfied	unhappy	impatient	timid	useless	undecided	sure of myself	understanding
thrilled	upset	irritable	worried	vulnerable	uneasy	strong	warm

Oh no, not another symptom!

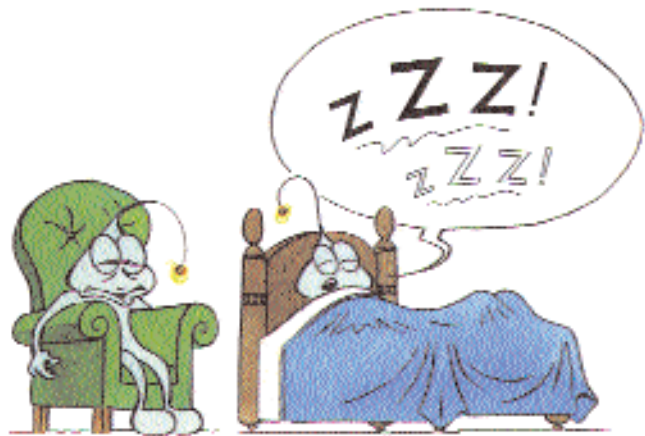
The abnormal things or changes that happen in the body are called symptoms. Your parent who has MS may have one or more symptoms at a time. Symptoms of MS may be different from one person to another. Also did you know that the symptoms of MS can appear or disappear as if by magic?

- Place a check mark (✓) beside the symptoms your Mum or Dad has. Don't worry, your parent certainly doesn't have all these symptoms!

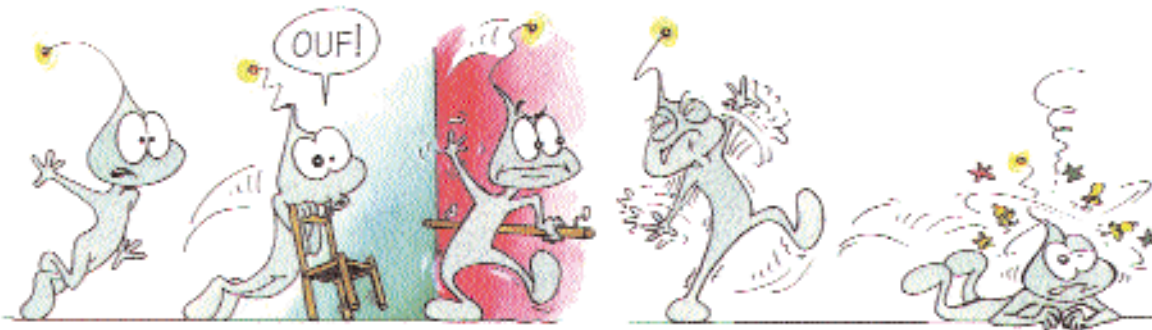
Possible symptoms of MS



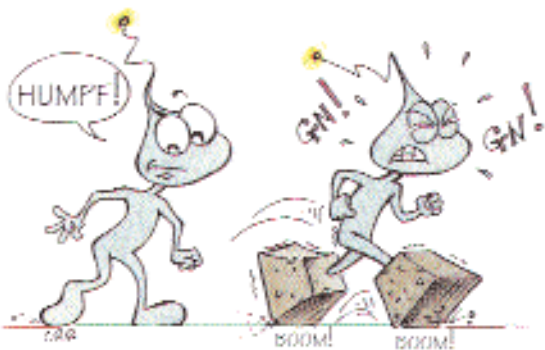
No apparent problem



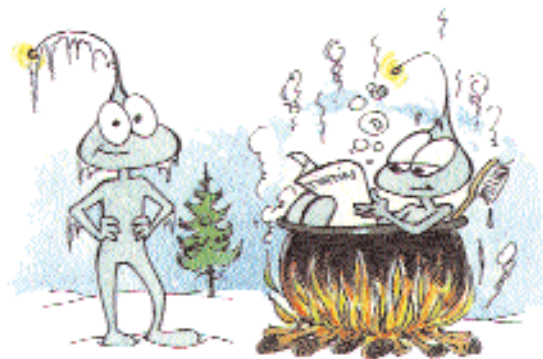
Fatigue



Loss of balance



A feeling of heaviness or dragging feet



Loss of sensitivity

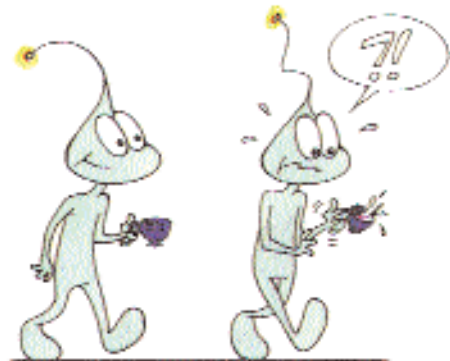
Possible symptoms of MS (cont'd)



Speech problems



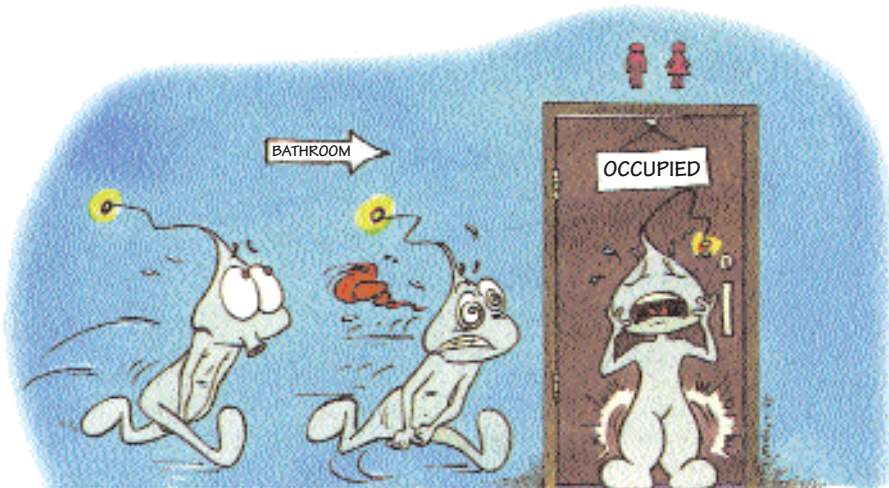
Memory problems



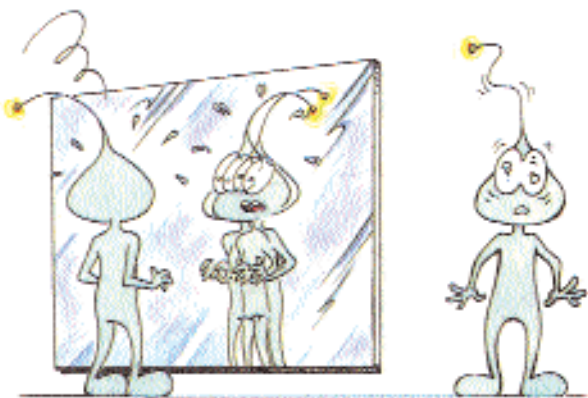
Tingling or shaking



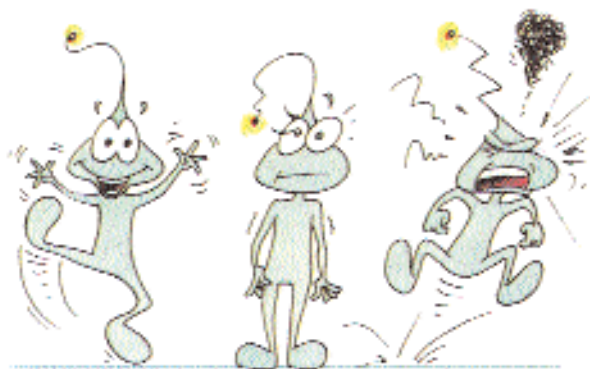
Constipation



Incontinence (always having to go to the bathroom)



Vision problems



Sudden changes in emotions

HOW DO YOU FEEL ABOUT MS?

It's possible that MS may:



make you sad



make you angry

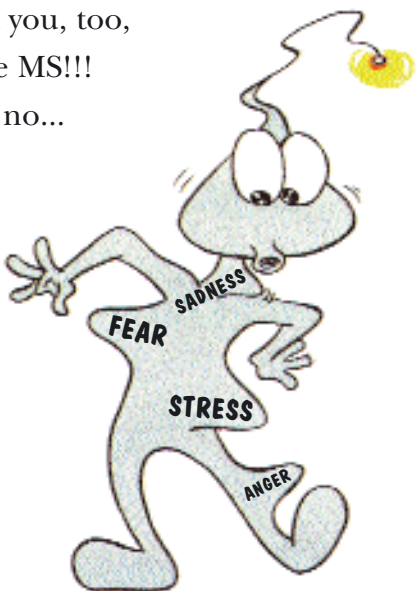


make you scared

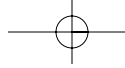
It's normal when lots of things change!

Everyone has feelings. There are no good or bad feelings and each person reacts to MS in a unique way. Some youngsters keep everything inside while others let their feelings out by getting angry or crying...

It's not good to keep all your feelings inside. It's important to let them out. If you don't let your feelings out, you may end up not feeling well, like getting a stomach ache, or pains in your legs. You might even think that you, too, have MS!!!
But no...



It's so much better when you express your feelings, it's such a relief.



 • Do you like having responsibilities? Explain why or why not.



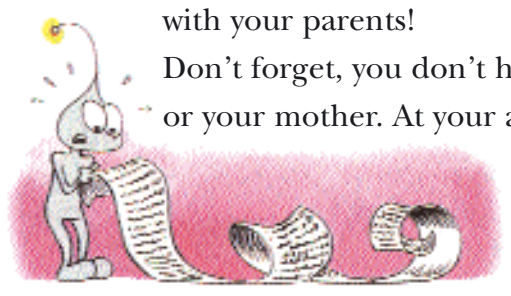
MS may force you to GROW UP quickly!

Take note!


If you think you have too much to do, it's important that you talk about it with your parents!

Don't forget, you don't have to take on all the responsibilities of your father or your mother. At your age, it's important to play and see your friends.

Besides, you already have a full-time job: school.

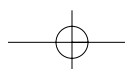


To help you in case of emergency

 • Fill out the following list with a parent; copy it and keep it near the phone.

Emergency phone list	
Mum at work:	_____
Dad at work:	_____
No. 1 person to call:	_____
No. 2 person to call:	_____
Police:	_____
Fire department:	_____
Ambulance:	_____
Family doctor:	_____
Other phone numbers:	_____

Remember, if you don't know who to call, you can dial "0" for the operator. Write down your full address and telephone number below.	



The ups and downs of MS

Having MS is like travelling through mountains and valleys. There are ups and downs.

The downs are called **attacks**. That's when new symptoms appear, or when the MS symptoms get worse.

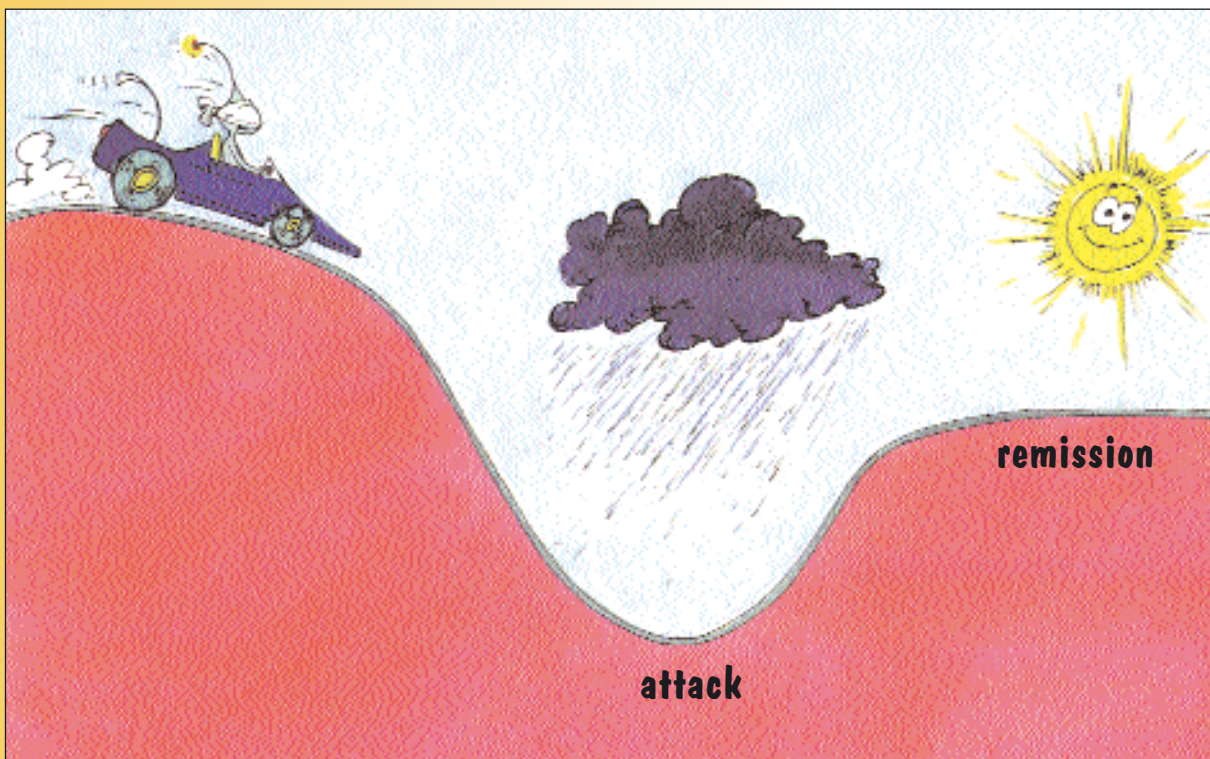
The ups are called **remissions**. That's when the person with MS feels better and the symptoms disappear, or are not as bad. With MS, some remissions last for weeks, months or even years. Some people don't have remissions or big attacks – symptoms increase little by little, through the years.

Handy hints to help you remember these words:

When things we don't like attack us, it's called an **ATTACK**.

When good feelings have returned...
mission accomplished!
It's a **REMISSION**.

How MS can develop...



MS is unpredictable. It's like having a blindfold over your eyes. There is no way of knowing ahead of time if there will be an attack or a remission. So it's very important to live day by day and really try to appreciate the good times.

And above all, it's important not to give up hope! Because now there are medications that help reduce the frequency and severity of attacks.



Can you find the right definition?

You are going to learn a lot of new words to better understand MS.

 •By drawing lines, can you find the right definition for each word below? (See example)

- | | |
|---------------------------|---|
| a) Myelin | Series of nerves located in the brain and spinal cord |
| b) Multiple | Main passageway for nerves (long highway in the middle of the body) |
| c) Sclerosis | Electrical messages that travel through the nerves |
| d) Attack | When the disease gets worse |
| e) Remission | Means “hardening” in Greek |
| f) Nerve | A word meaning “many”, since many areas of the brain and spinal cord are affected |
| g) Spinal cord | Covering surrounding the nerve that helps send electrical messages |
| h) Nerve impulses | Pathways that electrical messages travel through |
| i) Brain | When the disease is stable |
| j) Central nervous system | A place where nerve impulses can start |

Scoring Chart for Right Definitions


a) Myelin	Covering surrounding the nerve that helps send electrical messages
b) Multiple	A word meaning “many”, since many areas of the brain and spinal cord are affected
c) Sclerosis	Means “hardening” in Greek
d) Attack	When the disease gets worse
e) Remission	When the disease is stable
f) Nerve	Pathways that electrical messages travel through
g) Spinal cord	Main passageway for nerves (long highway in the middle of the body)
h) Nerve impulses	Electrical messages that travel through the nerves
i) Brain	A place where nerve impulses can start
j) Central nervous system	Series of nerves located in the brain and spinal cord

 • Tell me about two things you do well by yourself.

1. _____


2. _____

So that I don't forget any of the things I have to do, I make myself a list.

 • Now it's your turn to tell me, by writing down in the notebook below, what things you have to do at home.

Notebook of things to do



 • Place a star ☆ next to the new things that you have learned to do. Congratulations!



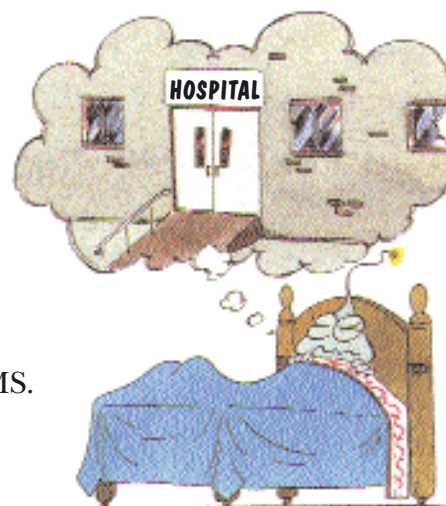
When your parent goes to the hospital

When your parent goes to the hospital, you may feel sad or worried, or just curious to know what is happening there.

At the hospital, Mum or Dad may have medical tests done in order to see whether everything is all right.

At times, your parent will be given medication to help control or fight MS.

Going to the hospital can help relieve the symptoms of MS.



- How do you feel when your parent goes to the hospital?

- What helps you?

Do you have a lot of things to do?

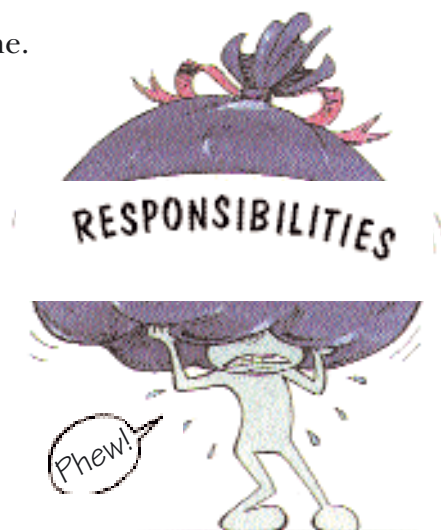
With MS, sometimes you are expected to do more things to help at home.

You may be frustrated at not having enough time to do the things you enjoy.

You may feel that you have more responsibilities than other youngsters your age...

But, did you know that many children in families where no one has MS have responsibilities at home?

They may help set the table and make their bed. By having responsibilities, you learn to do things by yourself.





Mystery Word

The Mystery Word Puzzle will give you a chance to have fun with some new words that you have learned

- | | | | |
|--------------|-----------------|--------------------|---------------|
| aid | game | multiple sclerosis | shyness |
| alone | happiness | myelin | six |
| attack | hospital | nerve | spinal cord |
| brain | impatient | nerve impulse | sun |
| cane | kin | nervous | symptom |
| confused | loss of balance | numbness | tired |
| dad | love | remedy | trembling |
| disappointed | medication | remission | unfair |
| eye trouble | memory loss | run | unpredictable |
| fatigue | mind | sad | walker |
| fear | mum | seen | wheelchair |
| frustrated | most | she | |

- Find the hidden words and try to discover the mystery word:

(mystery word, 7 letters)

Hint: the letters left over form the mystery word

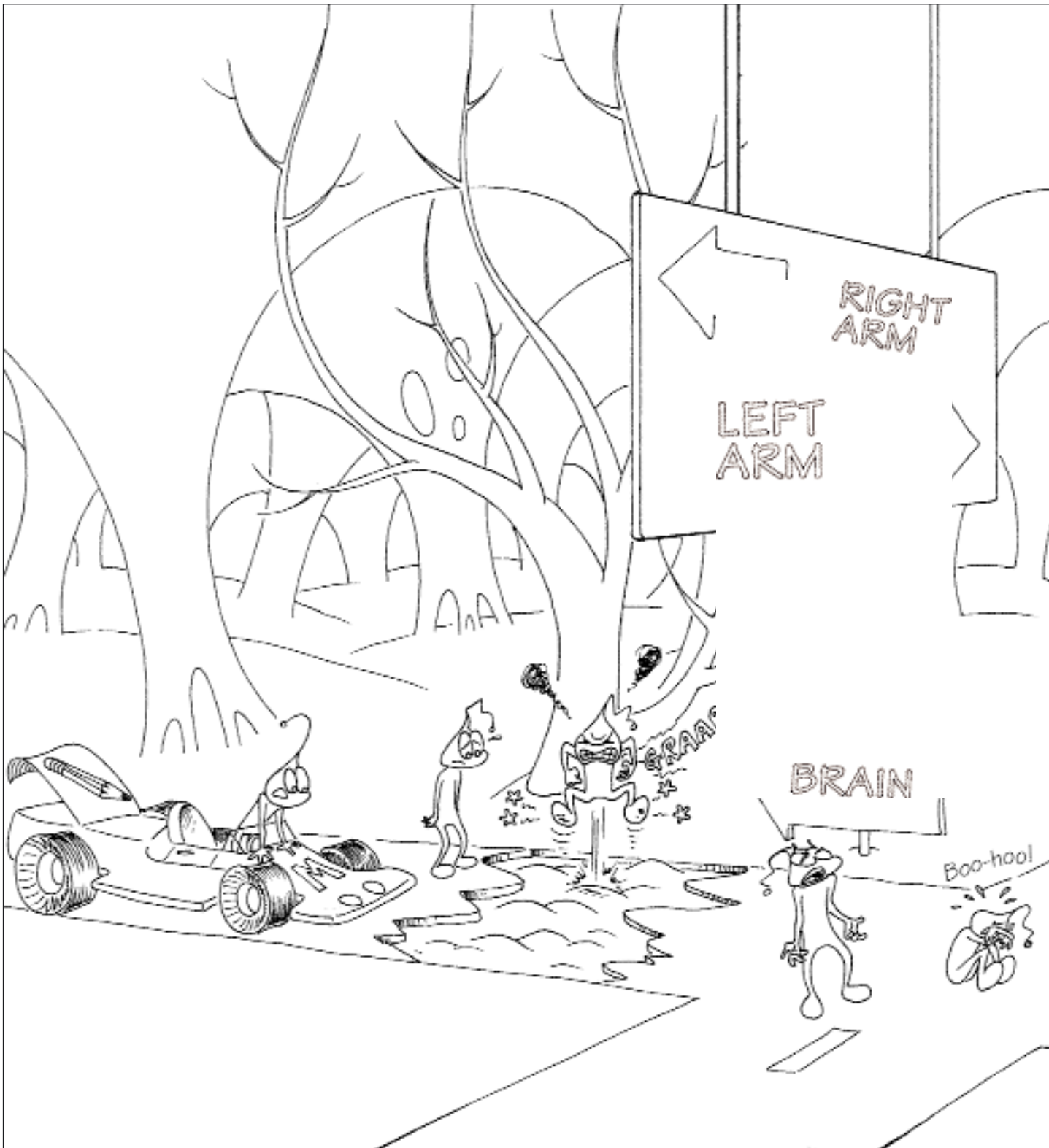
D	E	S	U	F	N	O	C	X	N	U	M	B	N	E	S	S
I	G	S	E	R	T	N	E	I	T	A	P	M	I	T	I	S
S	N	E	Y	U	U	E	F	S	H	Y	N	E	S	S	U	O
A	I	N	E	S	R	R	E	M	E	D	Y	O	O	F	N	L
P	L	I	T	T	E	V	A	G	A	A	M	R	N	L	P	Y
P	B	P	R	R	K	E	R	S	H	D	E	I	E	O	R	R
O	M	P	O	A	L	I	D	O	K	L	D	A	R	S	E	O
I	E	A	U	T	A	M	S	I	C	N	I	H	V	S	D	M
N	R	H	B	E	W	P	N	S	A	M	C	C	E	O	I	E
T	T	E	L	D	I	U	E	N	T	O	A	L	D	F	C	M
E	B	O	E	T	N	L	N	I	T	T	T	E	E	B	T	F
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N	E	I	T	I	M	L	A	Y	U	Y	N	W	T	A	L	I
A	R	L	N	A	N	R	E	M	I	S	S	I	O	N	E	G
C	U	D	G	D	R	O	C	L	A	N	I	P	S	C	H	U
M	E	T	S	Y	S	S	U	O	V	R	E	N	E	E	S	E

You will find the solution to the Mystery Word on Page 29.

When the message can't get through... It's so frustrating!



•Have fun colouring this drawing





• Under each of the names, tell me whether that sunshine is a friend, a sister, a brother, a grandparent...



• If you have more than 4 sunshines in your life, add as many more as you have, with the names of each person.



• Near the big rays of each sunshine, write down why you like that person.

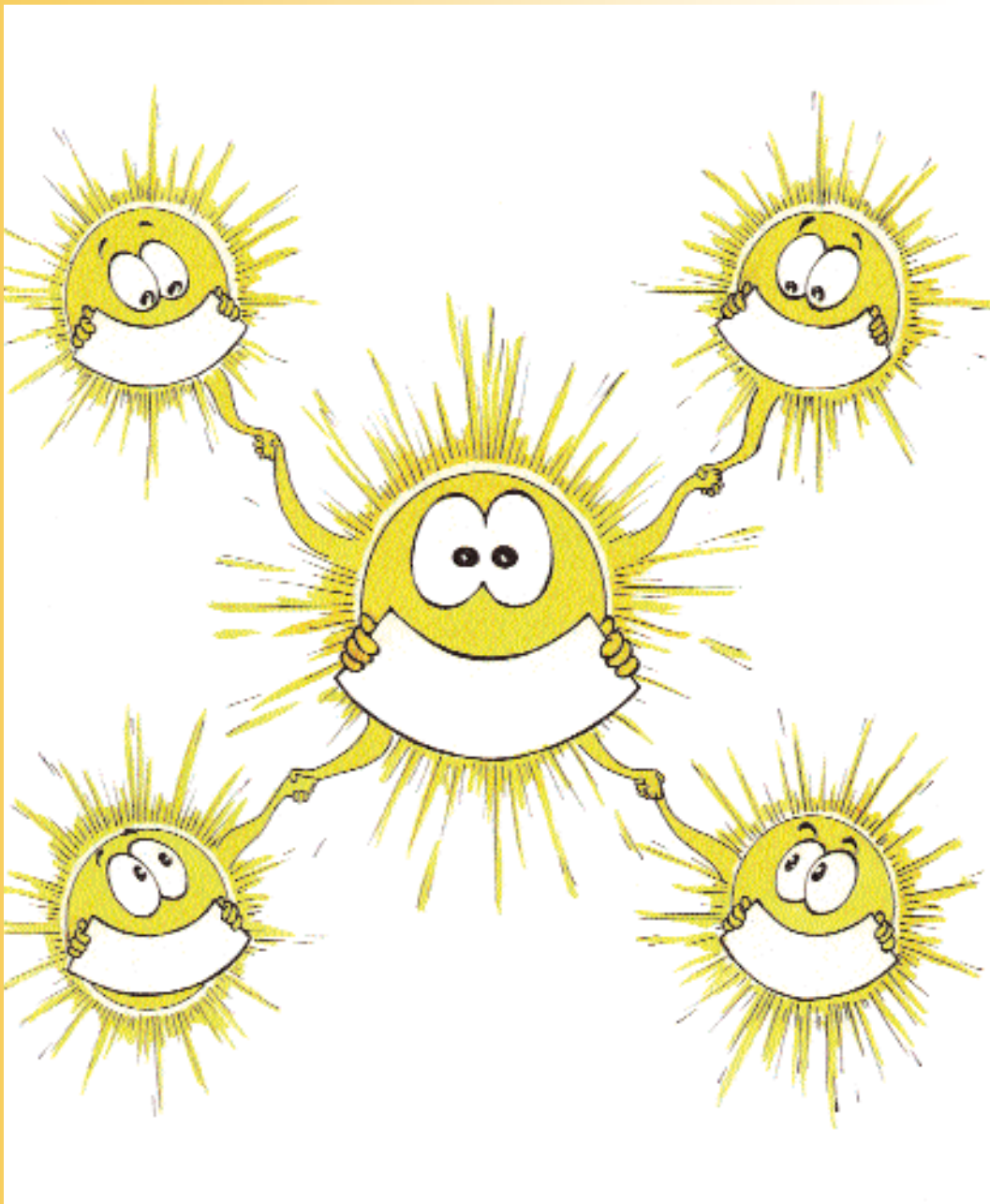
It's good to have someone you can talk to and confide in.



• Tell me, who is your best friend?

My best friend is Fido.

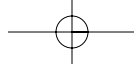
When you look at the sunshines in your life...



You can also get together with other youngsters who have a parent with MS, like you. You'll see that it feels good to share your feelings and experiences with other youngsters who are in the same situation as you.



You don't feel alone anymore.



-  • Tell me what your favourite activities are and draw three.

*Activities I can do
with my friends*


*Activities I can do
by myself*

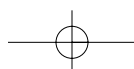


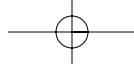
The sunny faces around you

Other people around you can cheer you up when you are feeling sad or alone or when you want to take part in an activity that Mum or Dad can't do.

They are the ones who can make your life sunny at times when you need it the most. They are the "sunshines" in your life.

-  • The big sunshine is you, so write your name on your smile. Use the smiles on the other smaller sunshines to write in the names of the people who are important to you and who you like to be with.





The Changes in Your life...

MS may cause changes in your life.

Your family activities may change, as well as your relationships with your parents, friends or relatives. How you feel about yourself may change too.



• What things have changed in your life?

In your family	With your friends and relatives
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

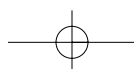
Personal feelings

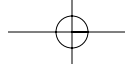
• Tell me, by writing in this triangle, how MS has changed your life.

• Next to each change, indicate a plus (+) if you liked that change and indicate a minus (-) if you didn't like it.

• What change did you like the best?

• What change did you like the least?






When you learned that your Mum or Dad had MS

When you found out your Mum or Dad had MS you may have been surprised. You may have felt scared, upset, or angry. Maybe you didn't feel anything at all because you didn't really understand what it meant to have MS.




 • How did you react when you found out that Mum or Dad had MS?

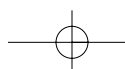
• How old were you? _____

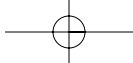
• Who told you? _____

There are questions that many youngsters ask themselves when they find out that their parent has MS:

- Will Mum or Dad die?
Rest assured, MS is not fatal
- Will I get it?
MS isn't contagious and children of persons with MS do not have a significantly higher chance of developing MS as adults.
- Will my parent end up in a wheelchair?
Not all parents who have MS will eventually need a wheelchair.
- What will happen?
There is no way of knowing in advance what will happen! MS is different for each person and can change at any time.

 • What questions do you ask yourself?





When family activities are cancelled

With MS, some family activities may change.

Sometimes, family activities are cancelled because your parent with MS:

- feels too tired.
- can no longer take part in some activities.
- uses a wheelchair and outings are more complicated because places



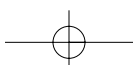
• What family activities are more difficult to do now?

• Are there any activities that you like to do and can still do with your family?

• Did you know that the MS Society has fun special events like the Super Cities Walk, Swimathon, Mini Marathon, Walks and MS Read-a-thon? Have you and your family ever volunteered or participated in these activities?




• Draw an activity that you enjoy doing with your family?



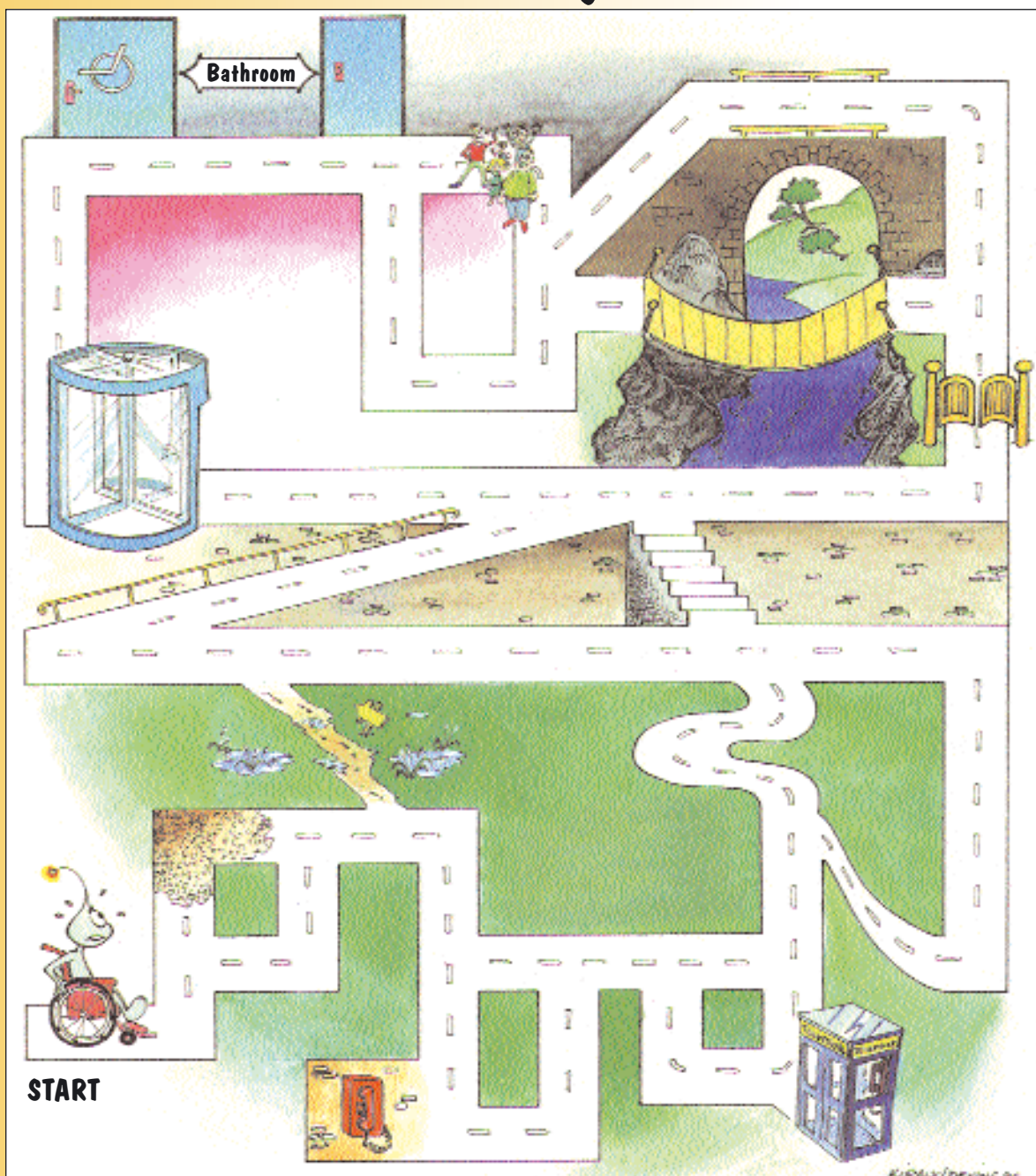
Would you like to play the maze game?



This is a story about what happened to me one day.

- 
 • Once, I really had to go to the washroom badly. But I had to find a way to get there. It wasn't easy because I was in a wheelchair and there were a number of obstacles along the way. I had to call Dad to tell him that I was going to be late getting home. Luckily, I succeeded in getting to the washroom in time... Phew!
- What path would you have taken if you had to go to the washroom as badly as I did?

Yikes! I need to go... Quick!



It's important to communicate!

Maybe you feel that grown ups are not telling you what they know about MS and you would prefer to know what is happening.

Perhaps you're afraid to upset Mum or Dad if you talk about MS. You must tell them how you feel because they may not know how worried you are.

It's true that the effects of MS sometimes make us sad. Mum and Dad also have emotions, like you do! Talking about these feelings may bring you closer together and help you find ways of better coping with MS.

Don't be afraid to ask questions, since your fears are often worse than the answers you'll be given.

Obtaining information can reassure you and may help you become better prepared for changes that may occur.



When parents get upset...

With MS, your parent is sometimes more easily upset than usual because they are not feeling well or things aren't going the way they would like.

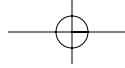
For example, it may bother Mum when you run all over the place or leave your school bag lying around.

At times, your parent with MS may be too tired to answer all your questions.

Maybe you think it's your fault if your father or mother gets angry or becomes more strict with you.

However, it may not be because of what you say or do that your parent is becoming upset, but rather because of the ups and downs of MS.





• Tell me about a time when your parent with MS was impatient.

• How did you react? _____

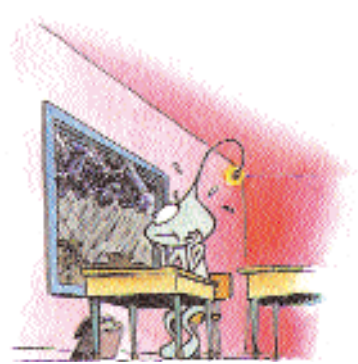


Oh no! Things aren't going well... Is this an attack?

It's not easy when Mum or Dad has an attack.

You may be very worried. You may be frightened or become upset because your parent isn't feeling well.

You may have to cancel a family activity that you like or spend less time doing it because Mum or Dad is too tired.



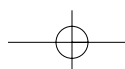
• Can you tell me about a time when your parent with MS had a harder time than usual doing something? _____

• How did you feel? _____



Walking on our own two feet is hard to beat!

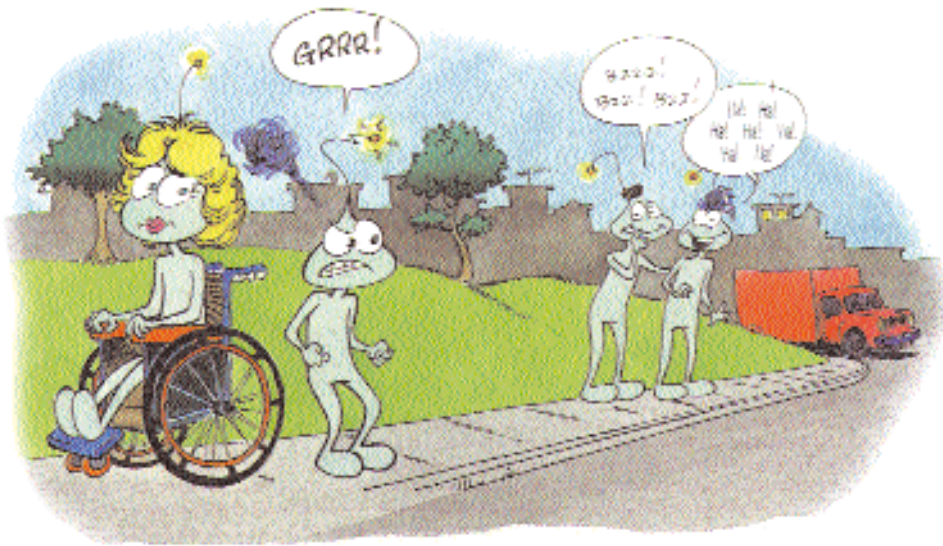
During an attack, Mum or Dad may need a cane, a walker or a wheelchair, because they find it harder to walk. At those times, if your parent doesn't have anything or anyone around to help, your parent may lose his/her balance and fall.



Can you remember whether that has ever happened?

If your parent needed some support (a cane, a walker or a wheelchair), you may have been upset or even angry because you didn't like that.

Sometimes, you may feel embarrassed or uneasy because of your friends' reactions.



We may feel frustrated over not being able to go everywhere

• Have you ever been in a similar situation? Can you tell me about it?

• What did you do? _____

Please note!

Not all people who have MS will need a wheelchair. It may only be necessary at times when Mum or Dad don't feel as good as usual.

In fact, it's really a good idea to have a mobility aid to help the person who has MS get around, because it lets them maintain their energy **to be able to do more things.**