



Positive Parents

Family Matters



Special thanks to:

Respondents of the Positive Parents Survey
La Trobe University Masters of OT Students

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Disclaimer: Information contained in this booklet should not be used for individual medical advice. Readers must seek their own medical advice as required

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Positive Parents, Family Matters

This booklet has been designed for parents living with multiple sclerosis, and their partners, in relation to a parent survey responses and relevant literature. MS staff and La Trobe University Masters Students have collaborated to develop this booklet, with the aim of promoting healthy and positive family functioning.

Within this booklet you will find information on managing your thoughts and feelings, as well as tips on talking with your children. This booklet contains suggestions of interactive and child-friendly activities that you might like to try at home with your family. We have also included financial resources and information on additional services that you might find helpful in the future.

You are welcome to utilise this booklet at your own pace, or work through it sequentially. We encourage you to record your experiences, thoughts, and reflections in the spaces provided.

We hope this booklet will help you and your family to strengthen your communication, relationships and assist you in effectively navigating any challenges that may arise.

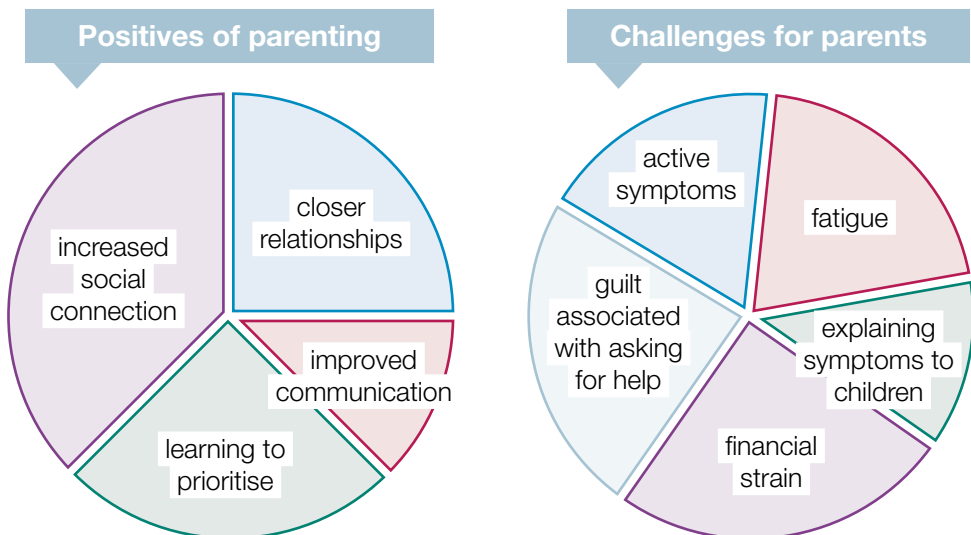
A Note for Parents

Being a parent can sometimes feel like you are on a rollercoaster, where you encounter both rewarding and challenging experiences. Adding multiple sclerosis into the mix may create additional challenges.

Common experiences among parents include:

- Struggling with time and energy management
- Experiencing financial strain
- Being able to provide caring and nurturing environment
- Raising loving and happy children
- Realising inner strength
- Developing a close-knit family unit

Results of the Positive Parent Survey:



Thoughts & Emotions

It is completely normal to feel sad, angry or disappointed when faced with life's challenges. However sometimes it may be difficult to overcome these emotions, and we become stuck in negative thought patterns.

If we can identify these patterns, we may be able to learn to challenge them and begin to see the world as more than just good or bad - with every negative event having some underlying positivity.

By learning to reflect on events with perspective we can change our outlook

before we commit to negative actions.

The goal of this exercise is to help you consider different outlooks to cope with minor setbacks. Recall a setback that you experienced, the thoughts surrounding it, and the consequences of these actions in the table below:

Event	Reaction	Thoughts/Feelings	Consequences
Burning dinner	Negative	"I've ruined everything" Disappointed Annoyed	<ul style="list-style-type: none">• Getting angry• Throwing out dinner
Burning dinner	Positive	"I can fix it" "It's not the end of the world"	<ul style="list-style-type: none">• 'Saving' dinner• Being creative
	Negative		
	Positive		
	Negative		
	Positive		

Coping with Stress

Sometimes life's stresses can begin to add up, leaving you feeling overwhelmed. When you're beginning to feel stressed, positive and healthy coping strategies and personal skills may help to manage these emotions.

You might find it helpful to imagine stress as rain that fills up a container; with coping strategies turning a tap to let out some water (stress). Come up with some of your own skills and strategies that you use or would like to use when you begin feeling overwhelmed by stress in the space provided.

Stress:

- Work
- Relationships
- Fatigue
- Symptoms
- Maintaining household

Maximum Stress Capacity:

- Low mood
- Anger
- Frustration

Coping Strategies:

- Talking with family
- Relaxation techniques
- Accessing MS support
- Talking to a health professional

Add your own coping strategies below:

“We are survivors of experiences,
not victims to circumstances”

- Anonymous

Talking with your Kids

Deciding when and how to speak with your children about multiple sclerosis can be a complex and daunting task. It is natural to want to protect your children by keeping information about multiple sclerosis from them. However, children can be very sensitive to what is happening in the family, so being honest with them can help to facilitate open lines of communication.

Keep it simple & age appropriate

- Stick to using simple language
- Use simple examples that your children can understand
- Encourage them to ask questions, if and when they are ready
- Remember, don't feel like you have to tell them everything at once!

Helpful Tip:

Comparing the damaged myelin sheath surrounding nerves to a worn-out electricity cable may help children to better understand multiple sclerosis.

Reassure your children

Without accurate information, children may develop unrealistic worries about multiple sclerosis. Make sure you reassure them that they are not responsible for the onset or progression of your symptoms and that you are likely to live a long life. It is important for your children to know that it is okay to express any feelings and questions they may have. Involving another trusted adult in the conversation (such as a grandparent) that your children can turn to helps them know that they are not alone.

Keep the conversation going

Due to the changing nature of multiple sclerosis, it's important to create regular opportunities for your children to express their thoughts and feelings. As children develop and changes occur, you may find that you need to adapt your conversations to reflect their understanding.



Multiple sclerosis can be unpredictable - it's okay to not know the answer to everything!

How will my child react?

Generally, children are able to cope well in response to learning about multiple sclerosis when adults are open and honest.

However, it is normal for children to sometimes express their distress in different ways, depending on their age and temperament. Some may throw tantrums and “act out”, while others may withdraw.

These difficulties may come and go - however, if you are concerned about your child's wellbeing, it's important to speak with MS Connect or your GP.

Videos, books, and props may be helpful to explain multiple sclerosis to your children. Other resources:

- MS for Kids (MS) msforkids.org.au
- Has your Mum or Dad got MS? (MS)
- Changes and Feelings (MS)
- Creating Resilient Families DVD (MS)
- Talking with your kids about MS (MS) ms.org.au
- Keep S'Myelin (MS USA) nationalmssociety.org
- Annie and Dan (MS UK) mssociety.org.uk



“Living with MS is about taking each day as it comes and enjoying each moment as they happen”

- Anonymous

Staying Positive

Each family and person living with multiple sclerosis will have their own unique journey. Sometimes it becomes easy to get stuck on the challenges that you are experiencing, and lose sight of all you have achieved so far. Try not to forget to set aside time to reflect on the positive things that have happened in your life!

Staying positive is not about ignoring the negatives. It's about recognising the things you can't change, and discovering how you can make the most of things you can control.

Sometimes you may experience 'bad' days where you feel overwhelmed, frustrated or low. This is a completely

normal experience, however if you find yourself unable to shake these feelings, don't be afraid to ask for a helping hand!

Accepting and identifying that you might need help may be a difficult task for some people. However it is important to try and remember that your family, friends and MS Connect are only a phone call away.



Family Activities

Establishing a routine may be helpful for you and your family in making sure your family activities are enjoyable and successful. You may like to try and organise a set time for a family activities once a week where everyone can decide on a fun activity to do together.

Below are some suggestions that you and your family might like to try:

You may like to try some of these activities as a family when you are feeling tired or fatigued:

- A movie night complete with popcorn and snacks
- Reading a book as a family
- Construct your very own creations from Lego or other building blocks
- Bubble making
- Photography
- Board games or card games
- Put on a puppet show with sock, finger or shadow puppets
- Arts and Crafts: practice your origami skills, or create your own book, card or stress ball together

You might like to try some of these low cost and easy activities together

- Create your own board games and puzzles
- Build your own blanket fort
- Try creating your own paper aeroplanes
- Playing 'dress ups' together
- Create a mini scavenger hunt around the house
- Try playing a family game of Charades or Pictionary
- Make a quick batch of playdough
- Blow up a balloon and start a game of balloon-volleyball

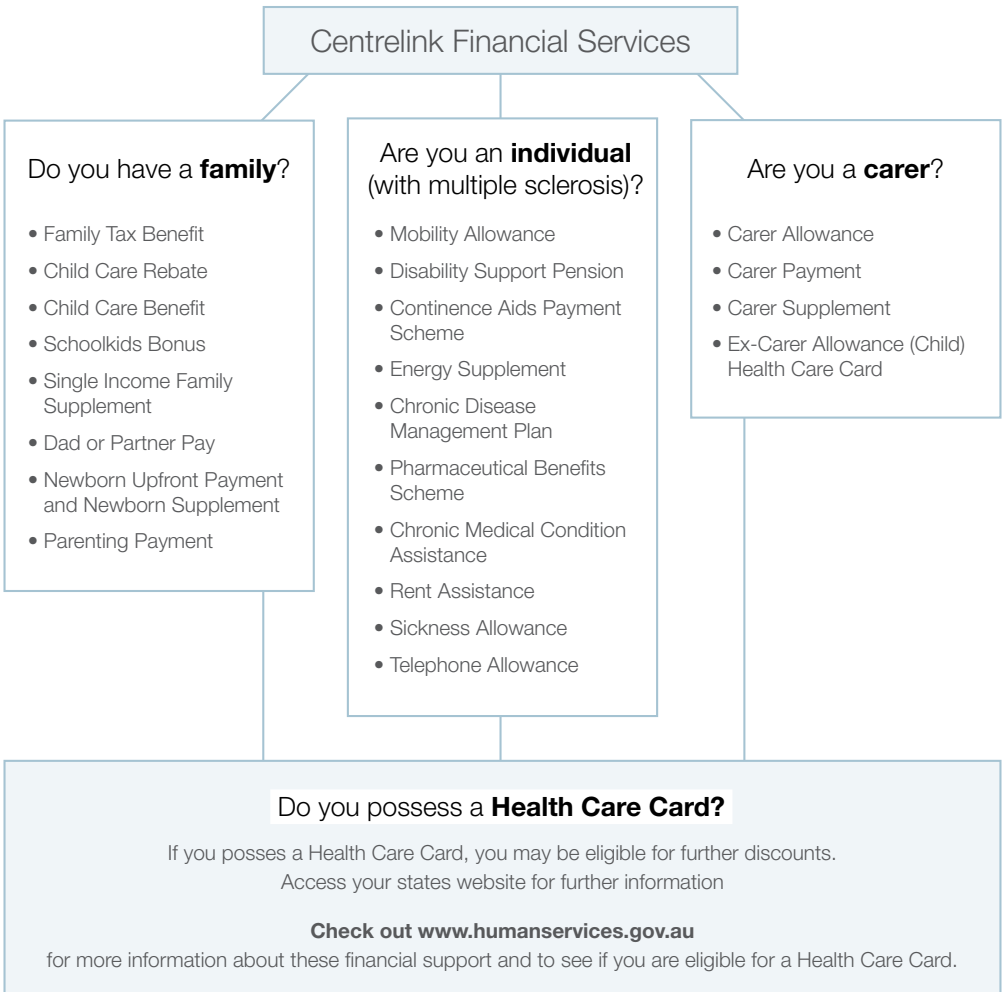
Your family may enjoy these outdoor activities

- Having a picnic in the back yard
- Starting a veggie patch or herb garden
- Cloud watching
- Chalk drawings
- Set up an obstacle course in backyard
- Designing, creating and flying a kite
- Going for a drive or short walk to look at Christmas lights
- Create a mini golf course in the back yard using jam jars or empty tin cans for holes



Centrelink Financial Services

There is no doubt that raising and maintaining a family can be a difficult task. However there are a number of services available to assist you in supporting your family. Centrelink offers a number of financial supplements and direct payments to assist families with covering medical costs and additional expenses, assisting carers financially in order to maintain family function, and other payments related to raising children.



Support Services Across MS (ACT, NSW, TAS and VIC)

MS: www.ms.org.au

- Go for Gold
- Peer Support (Online, Face to Face, Telephone)
- Social Work
- Information and Education
- Family Matters Online Series
- MS Australia Facebook Page

Australian Capital Territory Support Services

Scholarships and Funding:

- Companion Card - www.communityservices.act.gov.au
- Care Financial Counselling Service - www.carefcs.org
- Young Carer Bursary Programme - www.carersact.org.au

Emotional Support and Services for Carers

- Counselling - www.each.com.au
- Information and advice for carers - www.carersact.org.au
- Respite and other support - www.anglicare.org.au or www.anglicare.asn.au

Home Life and Transport

- Meals on Wheels - www.mealsonwheels.org.au
- Home Help, Personal Assistance, Home Maintenance - www.duo.org.au
- Other Services - www.communityservices.act.gov.au
- Taxi Subsidy Scheme - www.assistance.act.gov.au

New South Wales Support Services

Scholarships and Funding:

- Companion Card - www.nswcompanioncard.org.au
- Commonwealth Financial Counselling - www.dss.gov.au
- Financial Support and Concessions - www.adhc.nsw.gov.au
- The Young Carer Bursary Programme - www.youngcarersnsw.org.au

Emotional Support and Services for Carers

- Counselling - www.youngcarersnsw.org.au
- Respite and other support - www.anglicare.org.au or www.anglicare.asn.au
- Advice for carers - www.carersnsw.org.au

Home Life and Transport

- Meals on Wheels - www.nswmealsonwheels.org.au
- Home Help, Personal Assistance, Home Maintenance - www.adhc.nsw.gov.au
- Taxi Transport Subsidy Scheme - www.transport.nsw.gov.au

Tasmania Support Services

Scholarships and Funding:

- Find Help Tas - www.findhelptas.com.au
- TasCarepoint (DHHS) – 1300 769 699
- Concessions Tas - www.concessions.tas.gov.au
- Financial counselling - www.financialcounsellingtasmania.org.au

Emotional Support and Services for Carers

- Carers Australia Tasmania – www.carerstas.org

Home Life and Transport

- Taxi subsidy and Parking Permits - www.transport.tas.gov.au/passenger/concessions
- Companion Card – www.companioncard.dpac.tas.gov.au

Victorian Support Services

Scholarships and Funding:

- Financial Counselling Community (Anglicare) - www.anglicarevic.org.au
- MoneyHelp - www.moneyhelp.org.au
- Carer and Companion Cards - www.carercard.vic.gov.au
- Young Carer Scholarships
- www.carersvictoria.org.au or www.bursaries.youngcarers.net.au

Emotional Support and Services for Carers

- Counselling - www.carersvictoria.org.au
- Carer Advisory Line - www.carersvictoria.org.au
- Respite - www.respitevictoria.org.au

Home Life and Transport

- Meals on Wheels - www.mealsvictoria.org.au
- Home Help, Personal Assistance, Home Maintenance - www.accesshomes.com.au
- Multipurpose Taxi Program - www.taxi.vic.gov.au
- Other Services - www.dhs.vic.gov.au

Notes:

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Contact Details:

MS - www.ms.org.au

MS Connect, Information and support line

8.30am–5pm, Monday to Friday

Free call: 1800 042 138

Email: msconnect@ms.org.au

Translating Interpreting Service (TIS):

131 450 and ask for an interpreter who speaks your language, then ask to be put through to 1800 042 138

Teletypewriter users (TTY):

133 677 and ask for 1800 042 138

Speak and Listen Users:

1300 555 727 and ask for 1800 042 138



Multiple Sclerosis Limited, commonly known as MS, is the preeminent source of information, advice and services for people living with multiple sclerosis.

We're a combined entity of ACT, NSW, Victoria and Tasmania with more than 60 years' insight into how to live well with the disease.

We're here to help people live their lives with multiple sclerosis and provide them with the best long term options and life outcomes.



MS Connect, freecall 1800 042 138



www.ms.org.au



msconnect@ms.org.au

