MULTIPLE SCLEROSIS
SOCIETY OF INDIA

Guide for MS Caregivers

MSSI®
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SOCIETY OF INDIA**

Guide for MS Caregivers

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Foreword

The care of persons with long-term disease conditions requires inputs in various dimensions. In addition to the medical treatment and care, there are far too many other aspects in daily life as well as in long-term perspective, which need to be attended to, for enhancing and maintaining the quality of life afflicted with such diseases. These are usually taken care of by family members, especially in traditional and transitional societies like ours. The experience of the caregivers, the impact on the affected persons, and the dynamic interaction between them, can be mixed with more difficult and negative parts than positive. The recognition of the role of caregivers in the overall medical management of the concerned disease, has been relatively recent. It is also now well-recognised that sharing of experiences as well as their modulation can improve the subjective well-being of the persons, thus facilitating the overall process for everyone including the medical teams.

As such, in addition to the advocacy, the benefits of formal or semi-formal groups of caregivers are numerous and wide-ranging. This has led to a wide range of caregiver movements for medical, neurological and psychiatric disorders, besides disability conditions.

The value of the caregiver movement in the context of severe disabling conditions like MS can hardly be overemphasized. As part of my clinical work and managerial responsibilities, I have seen the need for all possible support for conditions like MS. The MSSI deserves compliments for their work and dedication.

The caregiver movements have fascinated me since the early years, as being complementary to the medical services provided, and in over the 40 years of my career as a psychiatrist, I have become increasingly convinced about the indispensable value of this movement across health problems and disabilities.

In recent decades, I have had the good fortune of being involved with and learning from many caregiver movements, especially for mental health problems and psychosocial disability. I consider myself fortunate to now be associated with MSSI and learn more.

Prof. (Dr.) Nimesh G Desai

MD(Psych), MPH (USA), MRCPsych (UK)

Director

Institute of Human Behaviour &
Allied Sciences New Delhi

Acknowledgment

I would like to acknowledge the help of all the people involved in this project, more specifically, the authors and reviewers that took part in the review process. Without their support, this book would not have become a reality.

First, we would like to thank MSIF for awarding us the small grants without which this guide would not have been possible. Our sincere gratitude goes to Tanya Raj for compiling the contents of the guide despite her busy schedule.

Second, I would like to acknowledge the valuable contributions of the reviewers, Renuka Malaker and Mamta Gupta, for their inputs on quality, coherence , and content presentation of the chapters. I would like to thank Dr. Nimesh Desai for helping us strategise our caregiver support initiatives. I would also like to express my gratitude to all the caregivers who participated in the survey.

Last but not the least, I would like to thank Honeycomb Creative Support, who gave us a quick turnaround despite the pandemic situation and we are ever grateful to them for accommodating our request and prioritizing it at short notice.

Shankar Subramanian

WMSD Representative - India

Preface

For the last 23 years, as a caregiver to a person with Primary Progressive MS living in India, I have seen the changing landscape of caregiving at both the country and personal level. In India, we now have certain rights and schemes for caregivers like Income Tax exemption and allowances under the Rights of Persons with Disabilities Act, of 2016 (RPWD Act, 2016) in which the list of disabilities was expanded from 7 to 21 conditions and now also includes MS. At the personal level, I have been through anxiety, depression, exhaustion, guilt, feeling uncared for, while searching for information on how to manage my home and work and how to cope with physical and mental exhaustion.

This led me to believe that there is a huge unmet need in the area of caring for caregivers. Moreover, it also pushed me to think of all the other caregivers who need a resource that would help them manage their lives better. We have approximately 2500 registered PwMS. If we apply a simple formula, it means that each PwMS has at least one Primary caregiver. So we are looking at no less than 2500 caregivers who might benefit from this guide!

As India is in the grip of the second deadly wave of COVID-19, it has become imperative to mention that the caregiver's challenges have increased manifold cutting across the mental and physical boundaries.

> Caregiving has a completely different meaning in India mainly because a) family members are the primary caregivers b) there is limited, expensive institutional and almost non-existent trained staff support or facilities for chronic illnesses like MS.

We understand and are cognizant that caregiving is individual centric and complex because of multiple factors.

This year, under the World MS Day global theme - Connections, we decided to turn the spotlight on MS family caregivers and provide a relevant resource in the form of a guide that will help them to prepare, manage and cope with caregiving duties.

To make this guide informative and easy to navigate, we gathered information from different sources, spoke to a diverse group of caregivers for PwMS and medical experts. With the help of the information provided in this guide, it is our endeavour to help caregivers maintain a healthy balance between physical and mental well-being.

We at MSSI salute all the caregivers for their tireless service and send wishes for your well-being and resilience. We hope you enjoy reading this guide and it will make a difference to you and improve the quality of your life.

Renuka Malaker

Honorary National Secretary

Introduction

About MSSI

Multiple Sclerosis Society of India (MSSI) is a registered voluntary, non-profit organization established in 1985. We work for the welfare of people affected by and living with Multiple Sclerosis in India. Over the last 34 years we have been working to help improve the qulity of life of Persons with MS (PwMS).

We conduct our activities at two levels. At the head office level, we work to create awareness, amplify the work, need and challenges faced at the chapters' levels, advocate for the rights of the person with MS, influence policy and policy change, work with the policy implementer to improve quality of life and universal coverage. At the chapter level, through our chapters in Bengaluru, Chennai, Delhi, Hyderabad, Indore, Kolkata, Mumbai, and Pune, we provide services like physiotherapy, nurse care, scholarships, monthly day care programs, medical camps, and seminars to lend support to many of our registered members. Barring a few paid office staff, all our offices are managed by either Persons with MS (PwMS) themselves or by caregivers or family or friends in an honorary capacity.

We provide services like physiotherapy, nurse care, scholarships, monthly day care programs, medical camps, and seminars to lend support to many of our registered members

About Multiple Sclerosis International Federation (MSIF)

The MS International Federation is a unique global network of MS organisations, people affected by MS, volunteers and staff from around the world. The movement is made up of 47 MS organisations with links to many others. MSIF's vision is a world without MS and their mission is to inspire, mobilise and bring the world together to improve the quality of life of everybody affected by MS and to end MS forever.

About Multiple Sclerosis

Multiple Sclerosis (MS) is a disease of the central nervous system, affecting its functioning unexpectedly and repeatedly, resulting in devastating disabilities in young people in the prime of their lives. MS has various symptoms ranging from extreme fatigue, visual disturbance to total paralysis, making simple everyday tasks impossible to perform.

MS is one of the most common neurological disorders and causes of disability in young adults. There are 2.8 million Multiple Sclerosis Persons (MSPs) worldwide. Most people with MS are diagnosed between the ages of 25 and 31, with around twice as many women diagnosed than men. The cause of MS is not yet known and neither has a cure been found, although there are treatments available that can help some forms of MS and stop its progression.

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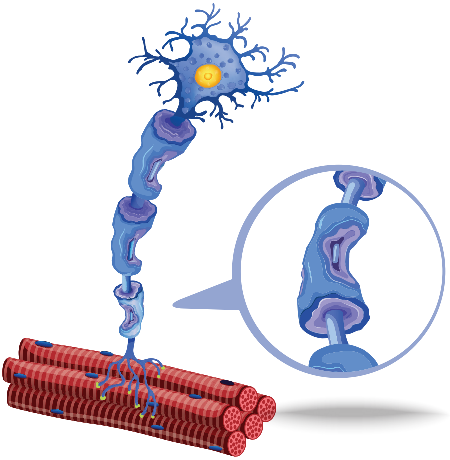
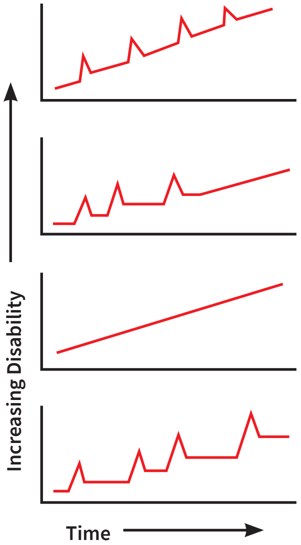


MS makes life unpredictable for everyone. MS, a progressive autoimmune disease, is characterized by episodes of inflammation and degradation of the fatty myelin sheath surrounding the axons of the brain and spinal cord. Attacks of MS may lead to inflammation and injury to the myelin sheath resulting in blocked or slowed nerve signals, that may lead to difficulty in controlling vision, muscle coordination, strength, sensation and other bodily functions.

Types of MS

The International Advisory Committee on Clinical Trials of MS defines four basic MS stages.

A lesser known Radiologically Isolated Syndrome (RIS) is not considered a form of MS, but has MRI abnormalities which are consistent with lesions of MS. In a 2020 study, it was found that little over half of people with RIS go on to develop MS within ten years.



Progressive-relapsing Multiple Sclerosis

Steady decline since onset with super-imposed attacks.

Secondary Progressive Multiple Sclerosis

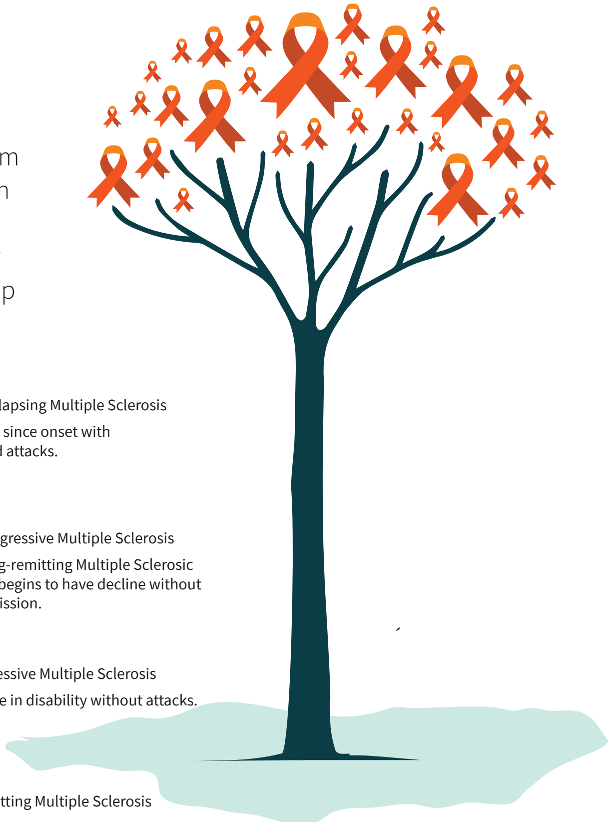
Initial relapsing-remitting Multiple Sclerosic that suddenly begins to have decline without periods of remission.

Primary Progressive Multiple Sclerosis

Steady increase in disability without attacks.

Relapsing-remitting Multiple Sclerosis

Unpredictable attacks which may or may not leave permanant deficits followed by periods of remission.



Treatments for MS: There are numerous ongoing studies worldwide on the therapies for MS and scientists around the world are actively working to find more effective treatments for progressive forms of MS. Currently, there are more than a dozen disease-modifying therapies approved by the U.S. Food and Drug Administration (FDA) to treat all types of MS. Each drug has an indication from the FDA for the type of MS it can be used to treat. There are currently more treatments available for relapsing forms of MS than progressive forms.

About Caregiving/ Caregivers

The Merriam-Webster dictionary defines caregiver as a person who provides direct care for children, elderly people, and/or the chronically ill.

When it comes to MS, caregiving is much more than just direct care; it sometimes also involves acting on behalf of the PwMS. Along with primary caregivers who are the immediate family of PwMS, there are professional caregiving services also available.

> The Merriam-Webster dictionary defines caregiver as a person who provides direct care for children, elderly people, and/or the chronically ill.

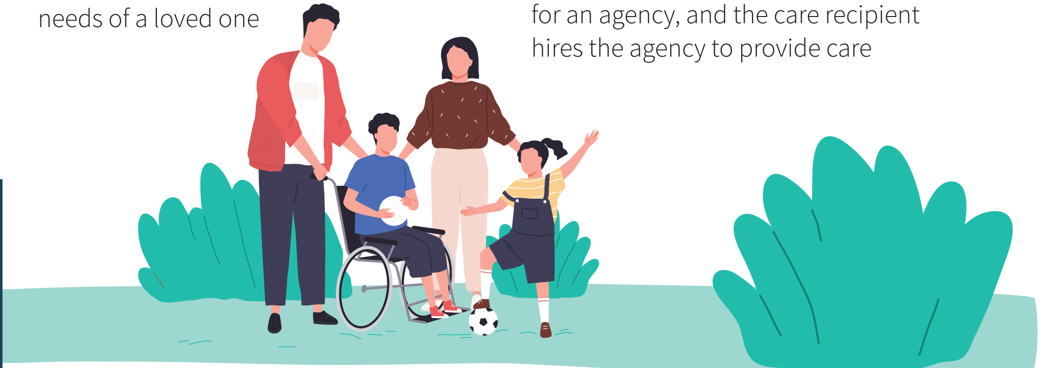
Though all caregivers have the desire to help others in common, sometimes the similarities start and stop there. There are a wide variety of caregiver roles covering a wide range of industries. In the non-medical care industry alone, there are several types of caregivers.

Types of Caregivers

Below we have brief descriptions of each to give you an idea of what these jobs are like and what their daily responsibilities entail.

- **Family Caregiver:**
  A family caregiver is a relative who provides emotional, financial, nursing, social, homemaking, and other services on a daily or intermittent basis for an ill or disabled loved one at home. Most family caregivers volunteer their time, without pay, to help with the care needs of a loved one

- **Professional Caregiver:**
  A professional caregiver is hired to provide care for a care recipient. These caregivers can provide medical or non-medical care in the home or a facility. Their career is to assist another person in a way that enables them to live as independently as possible. Professional caregivers work for an agency, and the care recipient hires the agency to provide care



- **Independent Caregiver:**
  An independent caregiver is a term commonly used to describe a home care professional who does not work for an agency. An independent caregiver is employed directly by the family. There is no intermediary agency between the care recipient and the caregiver.

- **Private Duty Caregiver:**
  A private duty caregiver can provide a broad range of services, from medical and nursing care to bill paying and transportation services. Their goal is to provide whatever the care recipient and their family needs for them to remain independent in their own homes. These caregivers can work independently or for third party agencies.

- **Informal Caregiver:**
  An informal caregiver, typically a family friend or neighbour, provides care, typically unpaid, to someone with whom they have a personal relationship. This differs slightly from a family caregiver in that an informal caregiver is typically not directly related to the care recipient.

- **Volunteer Caregiver:**
  A volunteer caregiver usually works in either respite or hospice care. A volunteer provides breaks for someone who is caring for an adult with a disability, chronic illness, or frailty. They provide non-medical companionship, supervision, and a friendly new face for a person with special needs so that the caregiver has some time away.

New vs Long-term Caregivers

Be it a new caregiver or a long-term carer, the initial days can feel overwhelming. However, with proper planning, caregiving for a PwMS can be eased out and made manageable.

Given the long-term care required in case of MS, it is of critical importance that caregivers not only understand the government policies available to them for assistance, but also gain a good understanding of the financial management of care. However, the most important aspect of this all is self-care, which becomes easy to overlook, but plays a critical role in sustaining the lifestyle in the long run.

100% of respondents feel that a good mental and physical health is important for a caregiver

Contingencies and Financial Planning

Anticipating what the future may hold and planning finances around it is an extremely important element of financial planning. Unforeseen expenses such as scans and tests such as CD19, CD20, immunoglobulin tests, etc., could be expensive.

Living with MS and caring for a PwMS can change the dynamics significantly, including loss of physical abilities, independence, financial earning power, emotional ties, and options for the future. The changes that come about over time can be overwhelming and hence it is important to anticipate and be prepared for contingencies.

Some changes that can be anticipated are loss of income that can come about due to the breadwinner being a PwMS or because of caregiving duties and changes in family roles, loss of time to care for one's own needs along with caring for your loved one, reduction in social life, friends and family, and physical mobility and dependence where assistance is needed.

Have a robust financial plan and funds saved for a rainy day

Take time for self-care and rejuvenation

Focus on the people most important to you, they are likely to stay around and be supportive

Find joy in the small things of life and spend time nourishing things that both you and your loved one care about

Don't hesitate to ask for help

Ways to Plan your Finances

Check the income tax deductions – there are provisions in the Income Tax Act that provide deductions for persons with disabilities, along with reimbursements of medical expenses.

Pick up health insurance benefits – understand the policy on what is covered as cost of care and what is excluded. Compare plans and pick up the one that most suits your needs.

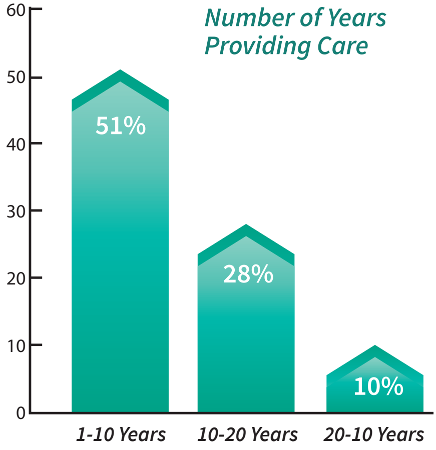
Explore all resources regarding disability income – there are numerous ways the government supports people with disabilities, so ensure to look at all angles.

Look into your state benefits – even as the government has policies that are directed centrally, each state government also offers myriad options which differ with regions; ensure to check these and apply for the benefits.

Consult a certified financial planner – who understands your income, your background and can provide unadulterated advice.

Care Management

A caregiver needs to don multiple hats when it comes to caring for a loved one. Apart from looking into the regular medications, etc., there are several day-to-day elements that also come into play. There are regular household chores such as cleaning, shopping, cooking, laundry, childcare and transportation; care-related tasks such as dressing, bathing, feeding, toileting, exercising, transportation, doctor visits, and medication schedules; daily activities such as work, recreation, entertainment, exercise, hobbies, private time, and religious activities.

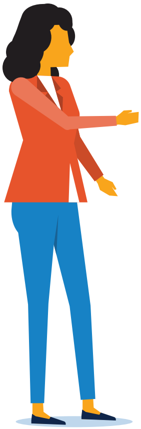


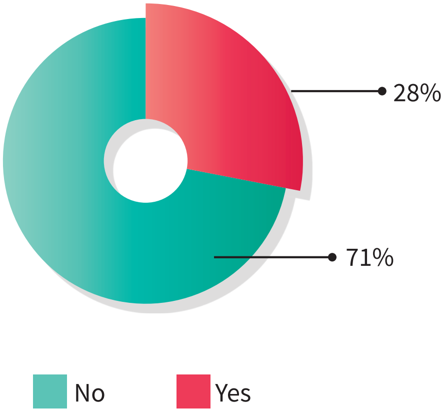
In order to lessen any burnout, try to:

1. Re-evaluate regular schedules and plan tasks with ample breaks
2. Seek out advice from professionals such as doctors and nurses on tips and techniques for bathing, dressing, toileting, and safe transfers
3. Depending on the severity of symptoms, assess if adaptations in the home are required, any use of mobility aids, and the amount of assistance needed
4. If needed, hire professional help
5. Seek assistance from family and friends and don't try to do everything on your own
6. Ask questions about the MS symptoms and their management from your doctor
7. Keep track of medications, administering injectable drugs, or performing intermittent urinary catheterization
8. Have key information and contacts handy (see the Appendix)

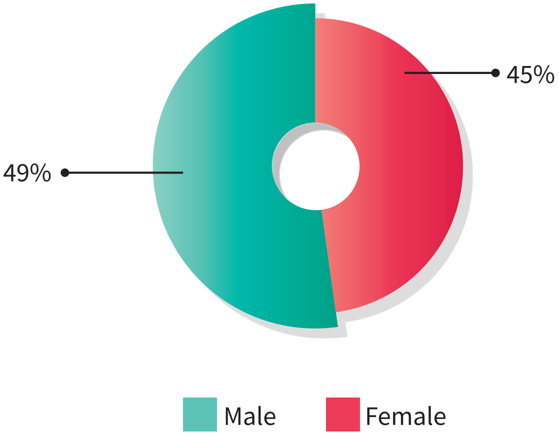
Insights from some Family Caregivers of PwMS

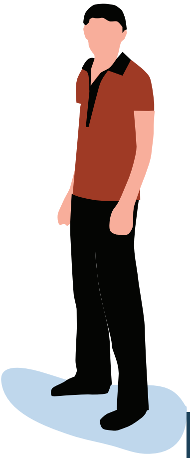
Are you aware of the types of caregivers?





Primary Caregiver





Mental Well-Being

Researchers report that the emotional stress of caring has little to dowith the physical condition of the person with MS or the length of time the person has been ill. Emotional stress seems more related to how ‘trapped’ caregivers feel in their situation. This, in turn, seems to be closely related to the satisfaction they have in their personal and social relationships, and the amount of time they have available to pursue their own interests and activities.

In the middle of everyday caretaking, it is common for caregivers to experience feelings of grief, depression, feelings of hopelessness and despair, fear, sadness, anger, guilt, and frustration.

Stress is the feeling of being overwhelmed or unable to cope with mental or emotional pressure, whereas depression is a term commonly applied to a wide variety of emotional states. It may range from feeling down for a few hours on a given day to severe clinical depression that may last for several months. Mild, everyday ‘blues’ are not much of a concern, but persistent depressive bouts must be diagnosed by a mental health professional.

If you notice sadness, irritability, loss of interest or pleasure in everyday activities, loss or increase in appetite, sleep disturbances like insomnia or excessive sleeping, agitation, fatigue, feelings of worthlessness or guilt, problems with thinking or concentration, and persistent thoughts of death or suicide, you should immediately consult with a mental health professional.

Signs of stress and depression

- Chronic irritability/resentment
- Continual boredom
- Excessive nervousness or anxiety
- Feeling overwhelmed
- Nightmares
- Worrying
- Distractibility
- Difficulty in making everyday decisions
- Clammy hands or sweating
- Constipation/diarrhea
- Dry mouth
- Headache
- Heart palpitations
- Stomach aches
- Muscle spasms or tightness
- Fatigue/weariness
- Sleeping disorder
- Short and shallow breathing

Things to do to Alleviate Stress and Depression

Communicate your needs and feelings with your loved ones

Realize that you can't fix everything

Make time for outings, but refrain from making overcomplicated plans and activities if it involves PwMS

Have a list of backup people who can be contacted for help at short notice

Set aside 45 minutes to 1 hour each day for a relaxing activity like listening to music, reading, etc.

Make exercise or yoga part of your daily routine

Try alternative therapies like aromatherapy, massage, guided imagery, meditation, etc.

Get a good night's sleep

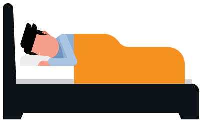
Keep a tab on types of food consumed

Seek professional help at the right time

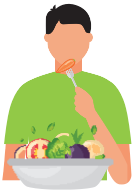
Prioritise your life along with caretaking

Physical Well-Being

Along with the mental well-being, it is also important for caregivers to take care of their physical health - not only does it sustain a long healthy life, but also gives ample energy to act in the capacity of a caregiver.



- **Ensure to get a good night's sleep and stick to regular bedtimes –** ask your doctor for help if you are caring for someone with MS. Chronic illness can be exhausting; PwMS and their caregivers both need as much quality sleep as they can get

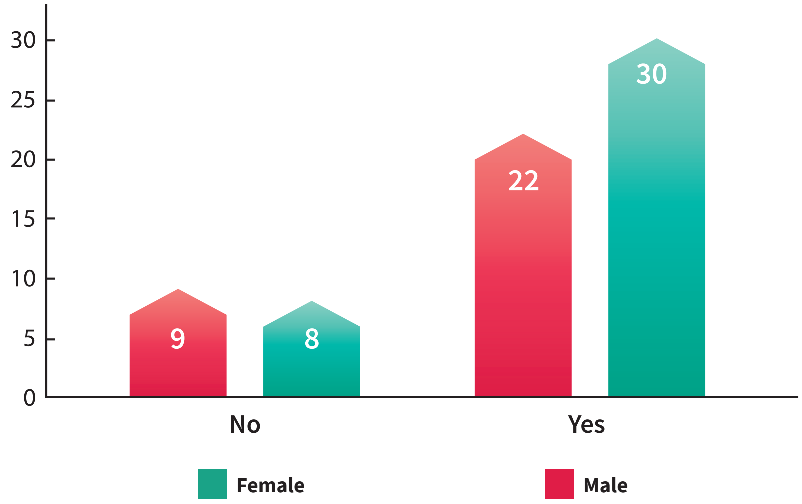


- **Eat nutritious food –** having a diet low in fat and high in vitamins and fibre can help you feel better, while maximizing your energy

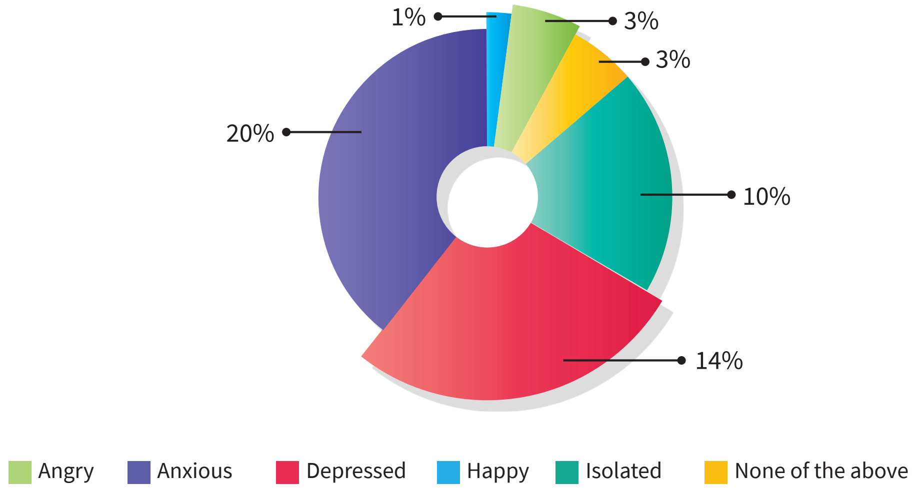
- **Exercise regularly –** go for walks, yoga, or whatever helps you feel fit. Any form of cardiovascular exercise, increases strength and adds to a more upbeat attitude. Yoga and aerobics are also excellent workouts for busy caregivers who can benefit from stress management
- **Reach out –** having a support group, such as MSSI, can help you connect with other patients and caregivers and establish a valuable network for exchanging ideas, new research news and encouragement

Insights from some Family Caregivers of PwMS

Do you get personal time?



Emotions



Quality of Life

The quality of life can be adversely affected for caregivers and even though PwMS may live healthy, active lives, 30% require a level of informal, unpaid caregiving at some point in their lives. In up to 78% of cases, this care is provided by a spouse or partner. The daily requirements of caregiving can result in physical, psychological, emotional, social, and financial stressors. Those providing care may need to confront having to make significant changes to their working lives, may experience an impact on their personal and social lives, and may have to adjust their living arrangements and other practical aspects of life.

Existing research on PwMS has largely focussed on negative impacts of MS for carers and has painted a rather bleak view of the future. There is, however, an emerging body of literature regarding positive impacts of MS on partners, such as gaining insight into illness and hardship, personal growth, a re-evaluation of life’s priorities and goals, and a greater appreciation of life and of one’s own health. MS caregiver experience is highly variable and depends on contextual factors.

To maintain a positive outlook:

Have your own support structure, especially a handful of trustworthy people, who you can count on during contingencies

Ensure to make time for social events, like meeting family and friends, going on outings, etc.

Talk to trusted friends and be open and vulnerable in sharing your burdens

Put equal emphasis on your well-being and happiness as that of the PwMS

Know when to take a step back and seek help if needed

Appendix – Key Information

Emergency Room Checklist

When faced with an emergency, it is easy to lose sight of the important things you need. Below is a quick list of things to keep handy when rushing to the emergency room:

1. *Name and number of the primary consulting doctor for the MSP, along with any specialists, such as neurologists, physiotherapists, etc.*
2. *List of prescriptions and medications being administered*
3. *Medicines and shots*
4. *Brief medical history*
5. *Insurance card and policy details*
6. *Disability certificate issued by Government of India*
7. *Photo ID*
8. *Cell phone (and charger)*
9. *Small amount of cash for incidentals*
10. *Blankets and sheets*
11. *Change of clothes*
12. *Rain gear, like umbrellas, etc.*
13. *A bottle of water*
14. *Easy to carry food*

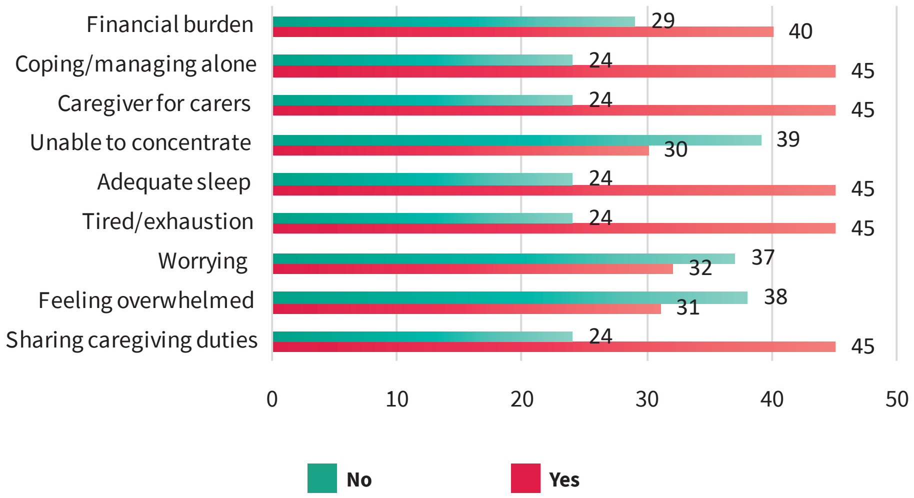
Home Emergency Information

Whether at home or travelling, apart from the above list, it is important to have most things in order. Some things to keep handy (use the DIY lists in Section 3 to record them):

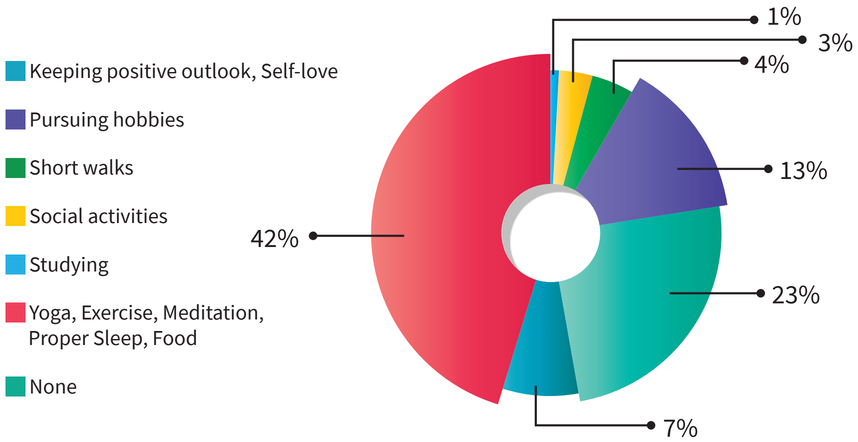
1. *The list of names and phone numbers of your healthcare providers*
2. *Contact details of family members and support network members*
3. *Names and model numbers of any medical devices*
4. *Copies of health insurance membership cards*
5. *Phone numbers of key services, including the local emergency management agency, ambulance service, building manager or landlord, and MSSI details*

Insights from some Family Caregivers of PwMS

Common Caregiving Challenges

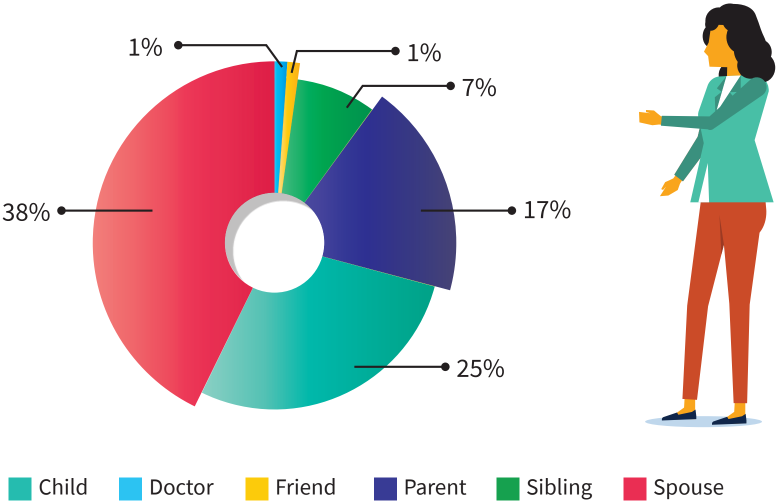


Selfcare Routine

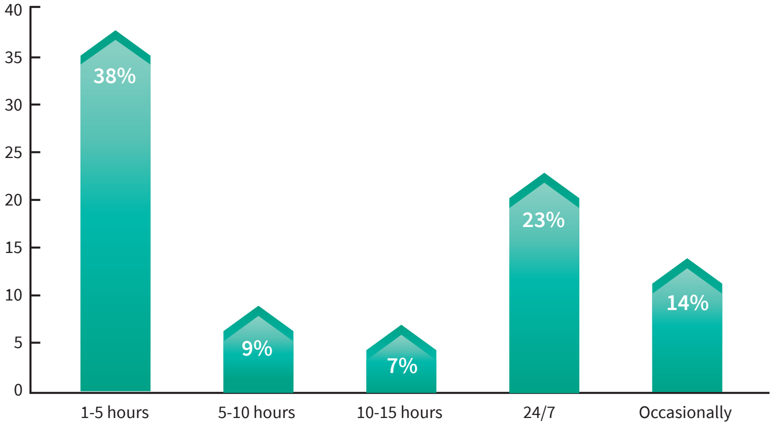


Insights from some Family Caregivers of PwMS

Relationship to PwMS



Time spent on care



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www.caregiversaathi.co.in

DIY: Important Contacts – Doctors

Specialist	Contact Number	E-mail Address	Address
Neurologist			
Physiotherapist			

DIY: Important Contacts – Hospitals

Name	Address	Contact Number	E-mail Address

DIY: Important Personal Contacts

Name	Relationship	Address	Number

DIY: Medical Information of MSP

Symptoms	1st Detected	Recurrence Rate	Doctor's Advice

DIY: Medication and Pharmacy Information

Medicine	Last Dosage Date	Next Dosage Date	Numbers Left

DIY: Important Tests Calendar

Test Name	Last Test Date	Report	Next Test Date

DIY: Upcoming Doctor Visit

Doctor's Name	Visit Date	Prescription	Next Visit Date

DIY: Location of Key Documents

Document Name	Date	Stored In	Remarks

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