

# LIVING LONG-TERM WITH MS: CAREGIVERS, RELATIONSHIPS, AND THE FUTURE

Training for families and loved ones supporting a person with MS for several years

Sustaining support without losing yourself: tools for long-term caregivers

<b>Duration</b> : 2 hours	<b>Modules</b> : 4 modules
<b>Lessons</b> : 16 lessons	<b>Audience</b> : Long-term caregivers and families of people with MS
<b>Format</b> : 100% online, asynchronous	<b>Provider</b> : N° 11757351875
<b>Certification</b> : Qualiopi	<b>Price</b> : On request

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## Course description

MS is a long-term illness, and long-term support raises unique challenges that initial diagnosis training does not address. This 2-hour training is specifically designed for families and loved ones who have been supporting a person with MS for several years. You will learn how to endure without exhausting yourself, how to maintain a couple's relationship when roles have changed, how to envision the future as the illness progresses, and how to continue living your own life while remaining present. This training provides long-term caregivers with concrete tools to cope without sacrificing themselves or losing their identity.

## Module summary

<b>MODULE 1</b>	The long-term caregiver — portrait of an unknown reality	4 lessons
<b>MODULE 2</b>	The long-term couple relationship	4 lessons
<b>MODULE 3</b>	Envisioning the future with clarity	4 lessons
<b>MODULE 4</b>	Resources and support for long-term sustainability	4 lessons

## Learning objectives

### Learning objectives

- Recognize the specific challenges of long-term caregiving and identify burnout risks
- Understand and process the difficult emotions of prolonged support without judgment
- Navigate the transformation of couple dynamics and intimacy after years of MS
- Anticipate disease progression and organize legal and financial decisions
- Access specialized resources and support systems for sustainable long-term caregiving
- Build a future for yourself while remaining present for your loved one

## General information

<b>Duration</b>	2 hours
<b>Target audience</b>	Long-term caregivers, spouses, and family members of people with MS
<b>Prerequisites</b>	None, training accessible to all adults
<b>Price</b>	Sur devis - TVA non applicable (article 261-4-4° du CGI)
<b>Certification</b>	Qualiopi - Attestation de fin de formation
<b>Organization</b>	DYNSEO - N° de déclaration d'activité : 11757351875

**Lesson 1 - What changes when you have been providing support for years**

- The gradual increase in responsibility becoming full-time caregiver without deciding to
- The caregiver identity that gradually absorbs your personal identity
- Fatigue of duration: more insidious and dangerous than acute exhaustion
- What long-term caregivers do not say: weariness, resentment, desire to escape

**Lesson 2 - The difficult emotions of the long haul**

- Chronic guilt: never doing enough, feeling anger, wanting time for yourself
- Repeated white mourning: each new loss is a mini-mourning
- Ambivalence: loving deeply while simultaneously being unable to bear it
- Naming these emotions without judgment as the first step to processing them

**Lesson 3 - The risks of long-term caregiver burnout**

- Caregiver burnout: definition, frequency, and health consequences
- Late warning signs: feeling nothing anymore, being on autopilot
- Why long-term caregivers are particularly at risk
- How to recover from established exhaustion: first concrete steps

**Lesson 4 - Finding meaning in support**

- What experienced caregivers have learned about themselves and the relationship
- Moments of grace in caregiving: recognizing and nurturing them
- Finding meaning without romanticizing suffering
- Building a caregiver identity that does not engulf you

**Lesson 1 - What Duration Does to a Couple's Relationship**

- The progressive disappearance of reciprocity: when one gives more than the other can return
- The partner turned caregiver: how this shift transforms the relationship
- Relational fatigue: no longer knowing what to say beyond the illness
- What keeps couples together despite everything according to research

**Lesson 2 - Intimacy and sexuality after years of MS**

- How MS impacts sexuality long-term: fatigue, pain, sensory disturbances
- The evolution of your own desire in response to changes in your partner
- Redefining intimacy beyond sexuality: other forms of closeness and tenderness
- Consulting a sexologist or couple's psychologist: when and why

**Lesson 3 - Reinventing the relationship on new foundations**

- Accept the previous relationship no longer exists without giving up the present one
- Find new ways of sharing adapted to current abilities
- Maintain common projects and pleasures, even modest ones
- Talk about the relationship itself: how to open these difficult conversations

**Lesson 4 - When the relationship is in danger**

- The signals that the relationship is seriously in trouble
- Couples therapy in chronic illness: why it is special
- Separation when support becomes impossible: without taboo and without judgment
- Rights and protections of a spouse separating from a person with disability

**Lesson 1 - Anticipating the progression of the disease**

- Talking about possible evolution with your loved one and neurologist
- Scenarios to anticipate: increased help needs, wheelchair, adapted accommodation
- Preparing important decisions now while your loved one can still participate

- Advance directives in MS: a gift for the future

## Lesson 2 - The legal and financial organization

- Future protection mandate: mutually designating each other for future decisions
- Guardianship and curatorship: what they mean, how to avoid or prepare
- Financial organization: joint accounts, powers of attorney, insurance, inheritances
- The notary specialized in vulnerable persons law: when to consult

## Lesson 3 - Consider appropriate accommodation without guilt

- When home care is no longer possible: criteria for honest assessment
- Facilities adapted to severe MS: MAS, FAM, ESAT — knowing them
- How to approach this topic without it feeling like abandonment
- Visiting and choosing a facility together: giving them as much control as possible

## Lesson 4 - Your own future

- Your life after years of support: preparing for this chapter
- Your own professional, personal, relational projects not to be sacrificed
- Thinking about your retirement, health, social network: the caregiver also has a future
- Envisioning without betraying: building your future while remaining present today

## MODULE 4

## Resources and support for long-term sustainability

4 lessons

### Lesson 1 - Specialized SEP resources for long-term caregivers

- SEP France: specific program for caregivers, helpline, local groups
- ARSEP: funding for research, updated information resources
- SEP care networks: coordination, support, assistance for families
- Specialized SEP social workers: an unknown and valuable resource

### Lesson 2 - Psychological support for long-term caregivers

- Why long-term caregivers particularly need psychological support
- Finding the right professional: psychologist, psychotherapist, psychiatrist according to needs
- Group therapy for caregivers: proven effectiveness, specific benefits
- Practice analysis for professional caregivers: a valuable support tool

### Lesson 3 - Financial assistance and rights for long-term sustainability

- The PCH (disability compensation benefit): regular review according to changes
- The renewable caregiver leave: your rights updated
- Assistance from mutual insurance companies and pension funds for caregivers
- Local associations that can help you with procedures and daily life

### Lesson 4 - Testimonials and Perspectives

- What long-term caregivers for MS have found to cope: concrete strategies
- The resources that really make a difference according to experienced caregivers
- What the MS community can offer you: solidarity, expertise, humanity
- You are not alone — and your commitment is extraordinary, even when you doubt

## Teaching methods

- Online self-paced training accessible 24/7 from any device
- Interactive video lessons with real-life testimonials from long-term caregivers
- Downloadable practical worksheets and decision-making tools
- Access to a resource library of specialized MS support organizations
- Certificate of completion delivered at the end of training
- Optional follow-up support and community forum access