BACK ON TRACK

LIVING WELL WITH MS

BACK ON TRACK

MS AUSTRALIA

MS Nurses Australasia Inc

Contents

Introduction

A practical, easy-to-read companion guide to the video series

How to use this guide: This handout is organised into four segments that match the four video episodes. You can read it before watching, follow along during the video, or revisit it afterwards to help you remember key points and plan your next steps.

Important note: This resource is for general information and support only. It does not replace advice from your neurologist, MS nurse, GP, or other healthcare professionals. If you have new, worsening, or worrying symptoms, seek medical advice promptly.

Language: People experience MS in different ways. When this guide says “may” or “can”, it reflects that variability—your experience may be different.

Episode 1: Navigating The Early Days

What this episode covers: The lead-up to an MS diagnosis can be incredibly fast for some people and slow for others. This episode focuses on the diagnostic process (why there are so many tests),how MS is diagnosed and common feelings at this time, managing when and how to disclose your diagnosis, how to manage work and study needs, how to organise and manage ongoing support and practical ways to communicate with your healthcare team and your family and friends.

Key takeaways:

- There is no single test that diagnoses MS—clinicians use your story, examination findings, and test results together.
- Many tests are done to rule out other conditions and to plan safe treatment.
- MRI is a key tool for diagnosis and ongoing monitoring; it does not use radiation.
- If you feel overwhelmed, it is normal—ask for information in small chunks and repeat questions as often as you need.
- Building your “A-Team” (your trusted supports and healthcare team) early can make a big difference.

Practical tips you can use now

- **Prepare for appointments:** write down symptoms (what, when, how long, what makes them better/worse) and bring a short question list.
- **Take a support person:** an extra set of ears can help you remember what was discussed.
- **For MRIs:** tell the radiology team if you’re anxious or claustrophobic; ask about supports such as music, scheduling at a calmer time of day, or (if appropriate) sedation.
- **If a lumbar puncture is suggested:** ask what the test is looking for, what to expect on the day, and what after-care is recommended. Consider taking someone with you.
- **Ask for clarity:** “Can you say that in a different way?” or “Can you summarise the next steps?” are good questions.
- **Seek emotional support early:** psychological support can help if the process has been distressing or if you feel dismissed or not believed.

Questions to ask your healthcare team

- What information do we have so far, and what are we still trying to confirm?
- What tests are being ordered, and what is each test looking for?
- What should I do if I develop new or worsening symptoms while waiting?
- Who is my point of contact between appointments (MS nurse, clinic line, GP)?
- What are the next steps and likely timeframes?

Quick glossary

- **MRI:** A scan that uses magnetic fields and radio waves to create detailed images of the brain and spinal cord.
- **Contrast:** A dye injected into a vein during some MRIs to help identify areas of active inflammation.
- **Lumbar puncture (LP):** A procedure to collect a small sample of cerebrospinal fluid, sometimes used to support diagnosis.
- **MS nurse:** A nurse with specialist knowledge in MS who can provide education, support, symptom advice, and care coordination.
- **McDonald criteria:** International diagnostic criteria used by neurologists to diagnose MS.

If there are any other technical words used in the episode that you didn't understand you can look them up in the **MS Glossary** here

Resources

Below are links to some useful resources that you may want to explore after watching this episode:

- Learn more about the **McDonald Diagnostic Criteria** here
- Find resources for **carers, family and friends,** including a guide on supporting someone with a new MS diagnosis here
- MS Australia's '**What is MS?'** video is useful educational resource for helping others to better understand MS
- Learn more about navigating **disclosing MS to your employer** here
- Find guides for **employers and employees** here
- Watch a webinar with psychologist **Dr Sally Shaw** here

Episode 2: Sorting It Out

What this episode covers: This episode focuses on day-to-day decisions and finding balance after diagnosis—independence, navigating work or study, planning for pregnancy and parenting, managing difficult emotions such as fear and loneliness, managing mental health challenges such as anxiety and depression and managing the vast amount of information and decisions in MS.

Key takeaways

- Independence and accepting help can coexist—setting "ground rules" early helps everyone.
- Uncertainty is part of MS; some people find it helpful to reframe uncertainty as "we don't know—so it might go well."
- Disclosure is personal: some people tell no one, some tell everyone, most are in between.
- Invisible symptoms (like fatigue, pain, bladder/bowel changes, mood changes) are real—even when others can't see them.
- Work and study supports (adjustments, flexible hours, exam accommodations) can be put in place early, even "just in case."
- Family planning conversations matter early because some treatments and timing decisions may affect pregnancy plans.

Practical tips you can use now

- **Independence:** practise simple phrases such as "Yes, I'd like help with X" or "Not today—thanks for offering."
- **Disclosure planning:** decide (1) who you're telling, (2) why you're telling them, and (3) what you need from them (practical help, emotional support, flexibility, or just awareness).
- **Key message practise:** prepare 2–3 sentences you can repeat (for example: "I have MS. It's different for everyone. I'm working with my healthcare team and I'll update you when I know more.").
- **Work/study:** consider early conversations about reasonable adjustments; for study, register with disability/learning support services early so help is ready if you need it.
- **Emotional health:** if fear, low mood, or worry is "stealing your joy," talk to your GP, MS nurse, or a psychologist—support can be helpful at any stage.
- **Family planning:** if pregnancy may be part of your future, raise it early with your MS team so treatment choices and timing can be planned around your goals.
- **Parenting with MS:** build your "village" and plan rest as intentionally as tasks; fatigue planning is a key parenting strategy.

Questions to ask your healthcare team

- What symptoms should I report urgently, and what can wait until my next visit?
- What supports exist for work/study (letters, assessments, allied health referrals)?
- How can I explain invisible symptoms to my family or workplace in a clear way?
- If I'm thinking about pregnancy (now or later), how does that affect treatment planning?
- What mental health supports do you recommend (and how do I access them)?

Resources

Below are links to some useful resources that you may want to explore after watching the episodes:

- In this **webinar** Associate Professor Vilija Jokubaitis discusses **family planning, pregnancy and fertility** in women with MS
- Find more resources on **fertility, pregnancy and intimacy** **here**
- The **MS Australia website** provides reliable evidence-based information on MS including MS research
- The **MS Member Organisations** provide reliable information on the supports and services (including peer support groups) available in your state or territory and other evidence-based MS resources:
    - » **MS Plus** for people living in ACT, NSW, Victoria and Tasmania
    - » **MS Queensland** for people living in Queensland
    - » **MS WA** for people living in WA, SA and NT
- The **MS International Federation website** provides reliable evidence-based information on MS including international research and initiatives

Episode 3: The Action Plan

What this episode covers: This episode focuses on building an action plan with your MS team, including logistics and decisions about disease-modifying therapies (DMTs) and medication adherance, complementary medicines. This episode also explores MS Brain Health and lifestyle modications to protect brain health over time, such as attention to diet and exercise, not smoking, managing mental health, cognition, sleep hygiene and stress. Tricky topics such as managing bladder and bowel issues are also discussed.

While you watch: Use the spaces below to capture what your team recommends for you. Treatment decisions are individual—your MS type, past relapses, MRI activity, lifestyle goals (including pregnancy plans), and your preferences all matter.

Action Plan

My current treatment / proposed DMT:

Why this option was recommended:

How it’s taken (tablet/injection/infusion) and how often:

Monitoring plan (blood tests, MRI timing, other checks):

Possible side effects to watch for and who to contact:

Brain health goals (sleep, movement, mood, smoking/alcohol, other):

My top 3 questions to follow up at my next appointment:

1)

2)

3)

Resources

Below are links to some useful resources that you may want to explore after watching the episodes:

- Learn more about **MS Treatments** including disease modifying therapies here.
- You can find the *Brain health – time matters* report on the **MS Brain Health website**.
- You can read the MS Australia **Living Well with MS guide** and listen to an accompanying podcast here.
- You can find **quit smoking resources** at the **Quit website**.
- You can read a guide to **Bladder and Bowel Wellness with MS** here.
- You can read a guide to **Building Confidence and Connection: MS & Intimacy** here.
- Find out more about **MS Fundraising** opportunities you can get involved in at these links:
    - The May 50k
    - MS Readathon
    - Brissie to the Bay
    - MS Moonlight Walk
    - MS Super Splash
    - MS Gong Ride
    - MS Mega Challenge
    - MS Walk, Run & Roll
    - MSWA Step Up
- The **MS Australia Clinical Trials Network** is a central point of information for people interested in participating in or conducting a MS clinical trial and for news about MS clinical research and trial activity. You can visit the network here.
- The **Trial.Smart program** is a series of nine modules for people living with MS and their communities to raise awareness of and provide education about clinical trials in Australia. The modules are between 20 and 30 minutes long each, involve a story book and interviews with experts, and are designed to be engaging and conversational. You can access the program here.
- Find out more about the work of the MS Australia Lived Experience Expert Panel (LEEP) here.
- You can find out about **Peer support groups** at the MS Members list under the episode 2 resources.

Episode 4: Living To The Full

What this episode covers: This episode focuses on living life to the full with MS by answering common lingering questions about travel and MS, managing hiccups and challenges, and ensuring ongoing support. This episode also explores symptoms in MS, working out what is new, how symptoms behave, and managing fatigue. Groups that can sometimes feel like they have been left out, such as children and adolescents, older people, males and menopause are also addressed. Genetics and family are also discussed with a focus on MS Brain Health.

Key takeaways

- It's common to carry "background questions" about MS for months or years—writing them down and bringing them to appointments can reduce mental load.
- Not everything you hear about MS is accurate; older information can be especially frightening and may not reflect today's treatments and outcomes.
- Quality-of-life issues matter (for example: bladder/bowel changes, sexual function, fatigue, mood, cognition). If your team doesn't know about them, they can't help you manage them.
- Living well with MS often means building routines and supports that protect your brain and body and your relationships, identity, and enjoyment of life.
- Small, steady steps are usually more sustainable than trying to change everything at once.

Practical tools from this segment

- **Keep a running questions list:** When a worry pops up (at night, on social media, after a symptom), write it down. Take the list to your next appointment so your brain doesn't have to "hold" it.
- **Reality-check scary information:** If you read/hear something frightening, ask: "How old is this information?" and "Does this apply to my MS, my treatment, and my situation?" Bring it to your MS team rather than trying to solve it alone.
- **Talk about the "awkward" symptoms:** Bladder, bowel, sexual function, and intimacy concerns are common in MS. You deserve support with these—raise them early so they can be assessed and treated.
- **Plan for fatigue like it's a real workload:** schedule rest the way you schedule tasks (especially if parenting, working, or studying). Ask about pacing/energy strategies from an OT or physiotherapist.
- **Protect your mental health:** Fear, low mood, and anxiety can be part of living with MS (and sometimes part of MS itself). If these are reducing your quality of life, psychological support can help at any stage.
- **Stay connected (your way):** Connection can be MS-specific peer groups, sport, the gym, creative communities, faith groups, or friends. You can opt in and out as your needs change.
- **Be appointment-ready:** bring your top priorities, paperwork/letters, and any forms early. After the visit, review what was decided and contact the clinic/MS nurse if anything is unclear.

Questions to ask your healthcare team

- What are the most important things for me to focus on over the next 3–6 months?
- What symptoms should I report urgently, and what can wait for my next review?

- Who can help me with fatigue/energy planning (OT, physiotherapy, exercise physiology), and how do I access them?

- How can I get support for bladder/bowel changes or sexual function concerns?
- If I'm feeling low, anxious, or isolated, what mental health supports do you recommend?
- What should my monitoring plan look like (MRI, blood tests), and what changes would prompt a treatment review?

- Are there reputable resources you recommend so I can avoid misinformation?

Resources

Below are links to some useful resources that you may want to explore after watching the episodes:

- You can listen to psychologist Dr Sally Shaw's podcast **But You Look So Good** **here**
- Find resources on **MS and Mental Health** **here**
- You can find **tips for travelling with MS** **here**
- You can find the **National Public Toilet** map **here**

Further Resources (ask your MS team for local options)

- **Your GP and neurologist/MS clinic** can help with referrals, mental health supports &, symptom management
- You can find a list of **MS Clinics** across Australia **here**
- **Emergency support:** If you feel unsafe or at immediate risk, call emergency services. If you need urgent emotional support, contact a crisis support line in your area (in Australia: Lifeline 13 11 14).