



MNDALS
Association of South Africa

TAKING CONTROL FROM DAY ONE

A Quick Start Guide for MND Patients and Families





YOU HAVE MORE POWER THAN YOU THINK

Receiving an MND diagnosis can feel overwhelming, but you're not powerless. This guide will help you take charge from the very beginning.

WHAT YOU CAN CONTROL

01

Your Response to Information

- How much you research and learn
 - Which questions you ask your medical team
 - How you communicate with healthcare providers
 - When and how you seek support
-

02

Your Care Journey

- Which specialists you see
 - How you prepare for appointments
 - What treatments you pursue
 - How you build your support network
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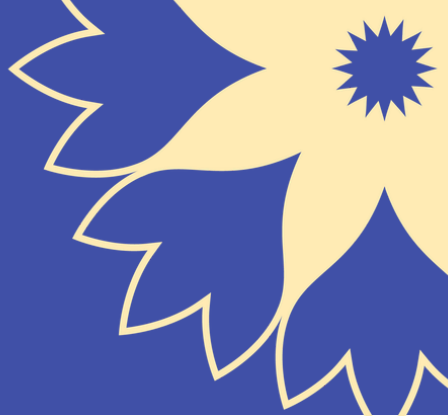
03

Your Daily Decisions

- How you adapt your environment
 - What equipment you research and choose
 - How you maintain your independence
 - When you ask for help
-



BUILDING CONFIDENCE STEP BY STEP



1 GET ORGANIZED

- Create a medical file for all your documents
- Start a symptom diary to track changes
- Research your specific type of MND
- Write down all your questions

2 PREPARE FOR HEALTHCARE

- Schedule follow-up appointments
- Research your medical team
- Learn basic MND terminology
- Prepare your first question list

3 UNDERSTAND YOUR OPTIONS

- Research local specialists and clinics
- Understand your medical aid benefits
- Learn about SASSA disability grants
- Connect with MNDA SA resources

4 START BUILDING YOUR TEAM

- Identify who can help with different needs
- Have honest conversations with family
- Set up systems for communication
- Begin planning for the future



YOUR EMPOWERMENT TOOLKIT



Essential Skills to Develop

- **Research Skills** - Using reliable medical websites and databases
- **Communication Skills** - Speaking confidently with medical professionals
- **Organization Skills** - Keeping track of appointments, medications, and documents
- **Advocacy Skills** - Standing up for your needs and preferences
- **Planning Skills** - Thinking ahead and preparing for changes



Key Resources to Bookmark

- **Medical Information:** PubMed, MND Association websites
- **Healthcare Access:** Provincial hospital contact numbers
- **Financial Support:** SASSA website and local offices
- **Equipment:** Approved medical aid suppliers
- **Emotional Support:** MNDA SA support groups

You are capable of learning these systems. Thousands of families navigate MND successfully every year. You don't need to become an expert overnight, but each small step builds your confidence and control.

Start where you are. Use what you have. Do what you can. You've got this.

**FOR MORE SUPPORT AND RESOURCES
REACH OUT TO US**



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