



**MNDALS**  
Association of South Africa

# Building Your Support Network

Creating and Managing Your Personal Care Team



# YOU ARE THE CEO OF YOUR CARE TEAM

Building a strong support network isn't about giving up control - it's about **strategically getting the help you need** while **staying in charge of your decisions**.

## Identifying Your Support Needs

### Medical Support Team

- Neurologist (MND specialist)
- General Practitioner (primary care coordination)
- Physiotherapist (mobility and strength)
- Occupational Therapist (daily living adaptations)
- Speech-Language Therapist (communication and swallowing)
- Dietitian (nutritional support)

### Personal Support Team

- Family members and close friends
- Home care assistance (as needed)
- Transport assistance
- Household help
- Emotional support companions

### Professional Services

- Legal advisor (for planning documents)
- Financial planner or accountant
- Insurance representatives
- Equipment suppliers and technicians



# FINDING QUALITY HEALTHCARE PROVIDERS

## Research Before You Choose



### Questions to Ask Potential Providers

- What experience do you have with MND patients?
- How many MND patients do you currently treat?
- What is your approach to MND care?
- How do you coordinate with other healthcare providers?
- What are your availability and communication preferences?
- What are your fees and medical aid arrangements?



### Where to Find Qualified Providers

- HPCSA (Health Professions Council) website for registered professionals
- Medical aid provider networks
- Hospital-based specialist clinics
- Referrals from other MND patients
- MNDA SA recommendations

# FINDING QUALITY HEALTHCARE PROVIDERS

## Building Professional Relationships



### Communication Strategies

- Be clear about your expectations
- Share relevant information between providers
- Schedule regular check-ins and reviews
- Provide feedback on treatments and services
- Maintain professional boundaries





# TEACHING FAMILY AND FRIENDS HOW TO HELP

## ■ HAVING "THE CONVERSATION"

### Start with Honesty

- Share what MND means for you and your family
- Explain how the disease might progress
- Be clear about your values and preferences
- Discuss fears and concerns openly
- Ask about their questions and worries

## ■ SETTING HELPFUL BOUNDARIES

### Be Specific About Support

**Instead of:** "Let me know if you need anything"

**Say:** "I can help with grocery shopping on Saturdays. Here's my preferred list and stores."

**Instead of:** "I want to help but don't know how"

**Say:** "I need help with meal preparation twice a week. Are you available Tuesdays and Fridays?"

## ■ SAMPLE SCRIPTS FOR COMMON SITUATIONS

**For Meal Preparation:** "I'm having difficulty with meal prep. Could you help by bringing dinner on Tuesdays? Here are foods I enjoy and can manage easily..."

**For Transportation:** "I need rides to medical appointments. Can we set up a schedule? I usually have appointments on Wednesday mornings..."

**For Emotional Support:** "When I'm having a difficult day, the most helpful thing is just sitting with me and listening, not trying to fix everything."





# MANAGING OFFERS OF HELP



## Creating a Help Coordination System

### The Helper List

- Keep a list of people who've offered help
- Note their strengths and availability
- Match requests to the right people
- Rotate requests to avoid overwhelming anyone



### Communication Tools

- WhatsApp groups for family updates
- Shared online calendars for appointments
- Meal train organizations for food coordination
- Simple task management apps





# MANAGING OFFERS OF HELP



## When to Accept Help vs. Maintaining Independence

### **Accept Help When:**

- Tasks are physically challenging or exhausting
- You need emotional support during difficult times
- Someone offers expertise you don't have
- Accepting help allows you to save energy for priorities



### **Maintain Independence When:**

- You can complete tasks safely
- Doing things yourself gives you satisfaction
- You want to practice skills while you still can
- You need to maintain your sense of control



# BUILDING PROFESSIONAL CARE RELATIONSHIPS

## Home Care Services

### 01 When You Might Need Professional Care

- Personal hygiene assistance
- Meal preparation and feeding support
- Mobility assistance and transfers
- Medication management
- Companionship and monitoring

### 02 Finding Quality Carers

- Research registered care agencies
- Check references and qualifications
- Interview potential carers
- Start with part-time arrangements
- Evaluate compatibility and skills

# BUILDING PROFESSIONAL CARE RELATIONSHIPS

## Coordinating Your Team

### 01

#### Regular Team Meetings

- Schedule monthly or quarterly reviews
- Share updates on your condition and needs
- Coordinate care plans and schedules
- Address any concerns or conflicts
- Plan ahead for anticipated changes

### 02

#### Information Sharing

- Create a central medical summary
- Share relevant updates between providers
- Maintain privacy while enabling coordination
- Use technology for efficient communication

# DEALING WITH DIFFICULT SUPPORT SITUATIONS

## When Family Struggles to Help

### Common Challenges

- Family members who are overwhelmed by the diagnosis
- People who want to help but don't follow guidance
- Conflicting opinions about your care decisions
- Family members who avoid discussing MND

### Strategies

- Be patient with others' adjustment process
- Provide written instructions for tasks
- Include family in medical appointments when appropriate
- Consider professional family counselling if needed



# DEALING WITH DIFFICULT SUPPORT SITUATIONS

## When Professional Providers Disappoint

### Red Flags to Watch For

- Poor communication or unavailability
- Lack of MND knowledge or experience
- Not coordinating with your other providers
- Dismissive attitude toward your concerns
- Inadequate service delivery

### How to Address Problems

- Communicate concerns directly first
- Document problems and attempted solutions
- Seek mediation through professional bodies if necessary
- Don't hesitate to change providers when needed

# QUICK SUPPORT NETWORK ASSESSMENT

## 01 Monthly Review Questions

- Who are my most reliable support people?
- What types of help do I need most right now?
- Are there gaps in my support team?
- How well are my providers communicating?
- What support arrangements need adjustment?

## 02 Planning Ahead

- Anticipate changing needs as MND progresses
- Build relationships before you desperately need help
- Cross-train multiple people for essential tasks
- Develop backup plans for key support roles

**Remember:**  
Asking for help is a sign of wisdom, not weakness. You're building a team that allows you to live your life on your terms.

**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**



083 467 8018



[mndasouthafrica.org](http://mndasouthafrica.org)

**NPO 155-413 | PBO 930013853**



**MNDALS**

Association of South Africa