



**MNDALS**  
Association of South Africa

# Building Your Support Network

Creating Your Personal Support System





# YOU DON'T HAVE TO DO THIS ALONE

Building a strong support network isn't about admitting weakness - it's about being smart. The most successful caregivers are those who strategically build and manage their support systems.

## Communication During Intimate Care

### 01 Practical Support:

- Help with caregiving tasks and personal care
- Household management (cleaning, shopping, cooking)
- Transportation to appointments and activities
- Respite care so you can take breaks
- Emergency backup when you're unavailable

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### 02 Emotional Support:

- People who understand your caregiving journey
- Friends and family for non-MND conversation
- Professional counselling when needed
- Spiritual or religious community support
- Online communities and support groups

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### 03 Expert Guidance:

- Healthcare providers and therapists
- Equipment suppliers and technicians
- Legal and financial advisors
- Other experienced MND caregivers
- MNDA SA resources and staff



# BUILDING YOUR SUPPORT TEAM

## Family and Friends Support



### Identifying Potential Helpers:

- List family members and friends who've offered help
- Consider their strengths, availability, and reliability
- Think about people who enjoy different types of activities
- Include both nearby and distant supporters
- Consider people at different life stages and circumstances



### Recruiting Effectively:

- Be specific about what help you need
- Offer flexible timing when possible
- Match tasks to people's strengths and interests
- Start with small commitments and build up
- Express genuine appreciation for their willingness to help

## Teaching Others How to Help

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

**Ask for Specific Help:** "Could you help with grocery shopping on Saturdays? Here's our usual list and preferred stores."

### Sample Support Requests:

**For Meal Support:** "We need help with dinner on Tuesdays and Fridays. I can provide recipes and shopping lists, or you could bring something you enjoy making."

**For Transportation:** "Could you drive us to medical appointments? They're usually Wednesday mornings and take about 2 hours total."

**For Household Help:** "We need help with laundry and light housekeeping every other week. Would Saturday mornings work for you?"

**For Respite Care:** "I need 3-4 hours every other weekend to run errands and have some time to myself. Are you comfortable staying with [name] and helping with basic needs?"



# BUILDING YOUR SUPPORT TEAM

## Managing Your Support Network



### Organization Systems:

- Keep a list of helpers with their contact information and preferred tasks
- Create a shared calendar for appointments and help schedules
- Use group messaging for updates and coordination
- Develop simple instruction sheets for common tasks
- Maintain backup contacts for essential help



### Communication Strategies:

- Provide clear, written instructions for care tasks
- Give regular updates about changing needs
- Set expectations about reliability and commitment
- Express appreciation regularly and specifically
- Address problems directly and kindly



# PROFESSIONAL SUPPORT SERVICES



## When to Consider Professional Help

### Signs You Need Additional Support:

- You're feeling physically or emotionally exhausted
- Care needs exceed what family and friends can provide
- You need specialized skills or equipment operation
- Safety concerns require professional expertise
- You need regular, reliable respite time



## Types of Professional Support

### Home Care Services:

- Personal care assistance (bathing, dressing, grooming)
- Companionship and monitoring
- Light housekeeping and meal preparation
- Medication management and reminders
- Specialized MND care experience





# PROFESSIONAL SUPPORT SERVICES



## Types of Professional Support

### **Healthcare Professionals:**

- Private nurses for complex medical needs
- Physiotherapists for home-based therapy
- Occupational therapists for equipment and adaptations
- Speech therapists for communication and swallowing
- Respite care providers for planned breaks



## Types of Professional Support

### **Household Services:**

- Cleaning services for deep cleaning and maintenance
- Meal delivery services for nutritious, appropriate meals
- Grocery delivery and shopping services
- Laundry and domestic assistance
- Garden and maintenance services





# PROFESSIONAL SUPPORT SERVICES



## Finding Quality Professional Support

### Research Process:

1. Ask for recommendations from healthcare providers and other MND families
2. Check credentials and insurance coverage
3. Interview potential providers about their MND experience
4. Start with trial periods to assess compatibility
5. Have clear written agreements about services and expectations



### Questions for Professional Caregivers:

- What experience do you have with MND patients?
- What training have you received in disability care?
- How do you handle emergency situations?
- What are your availability and scheduling preferences?
- Can you provide references from other families?



# EMOTIONAL AND PEER SUPPORT

## Connecting with Other Caregivers

### Benefits of Peer Support:

- Understanding from people who share your experience
- Practical tips and solutions from those who've been there
- Emotional validation and encouragement
- Information about resources and services
- Perspective on challenges and successes

### Finding Your MND

#### Community:

- MNDA SA support groups and events
- Online forums and social media groups
- Local hospital or clinic support groups
- Community organization caregiver programs
- Faith-based caregiving support groups

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## Professional Emotional Support

### When to Seek Counselling:

- Feeling overwhelmed, depressed, or anxious regularly
- Relationship problems with your loved one or family
- Difficulty adjusting to changing roles and responsibilities
- Grief about losses and changes in your life
- Need for professional guidance on difficult decisions

### Types of Professional Support:

- Individual counselling for caregiver-specific issues
- Couples counselling for relationship challenges
- Family therapy for broader family adjustment
- Support groups led by mental health professionals
- Grief counselling for anticipatory and actual losses

# MANAGING SUPPORT RELATIONSHIPS

## Setting Healthy Boundaries

### With Family and Friends:

- Be clear about what help you need and when
- Don't accept help that comes with criticism or judgment
- Set limits on advice and unwanted suggestions
- Maintain your right to make decisions about care
- Balance accepting help with maintaining independence

### With Professional Providers:

- Establish clear expectations and agreements
- Maintain professional boundaries while building rapport
- Communicate changes in needs or dissatisfaction promptly
- Remember that you're the employer/coordinator
- Don't hesitate to change providers if necessary

## Dealing with Difficult Support Situations

### When Helpers Don't Follow Instructions:

1. Provide clearer, written instructions
2. Demonstrate proper techniques personally
3. Explain the importance of consistency
4. Set consequences for not following guidance
5. Find new helpers if problems persist

### When Family Members Are Critical:

1. Set clear boundaries about acceptable behaviour
2. Focus conversations on your loved one's needs
3. Limit time with consistently negative people
4. Seek mediation through counselling if needed
5. Choose your battles wisely

### When Professional Help Disappoints:

1. Communicate problems directly and specifically
2. Document issues and attempted solutions
3. Give providers reasonable opportunity to improve
4. Don't hesitate to change providers when necessary
5. Learn from each experience to choose better next time



# MAINTAINING YOUR SUPPORT NETWORK

## ■ REGULAR NETWORK MAINTENANCE

### Monthly Review:

- Are your current supporters meeting your needs?
- What gaps exist in your support system?
- Who needs appreciation or recognition?
- What changes in support will you need soon?
- How can you better support your supporters?

### Quarterly Assessment:

- How has your support network evolved?
- What support arrangements are working best?
- What new types of support do you need?
- How can you expand or strengthen your network?
- What support can you offer to others?

## ■ SUPPORTING YOUR SUPPORTERS

### Show Appreciation:

- Thank people specifically for what they do
- Acknowledge the difference their help makes
- Remember their birthdays and important events
- Include them in celebrations when appropriate
- Write notes or give small gifts occasionally

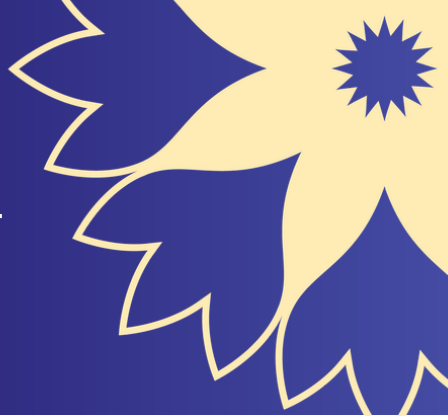
### Prevent Helper Burnout:

- Rotate responsibilities among multiple people
- Be flexible with scheduling when possible
- Don't overuse your most reliable helpers
- Check in on their wellbeing and availability
- Help them feel valued and important



# GROWING INTO SUPPORT LEADERSHIP

As You Gain Experience



## Share Your Knowledge:

- Mentor newly diagnosed families
- Provide recommendations to other caregivers
- Share resources and strategies that work
- Connect people with helpful providers
- Support improvements in MND care services

## Build Community:

- Help organize caregiver support activities
- Contribute to online forums and discussions
- Participate in MNDA SA programs and events
- Advocate for better caregiver resources
- Build bridges between different support communities

**Remember:** Building a support network takes time and effort, but it's one of the most important investments you can make. A strong support system doesn't just help with caregiving - it helps you maintain your own health, relationships, and sense of self.

**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 CAREGIVER SUPPORT GROUPS AND  
ADDITIONAL RESOURCES, CONTACT US**



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