VIGYAN 2047 Volume 2 No. 11 November 2025 Pages 26–29

MIND and MND

Kaartik Gupta

Motor Neuron Disease (MND) is often described as a disorder of movement, but the lived experience is equally psychological. Muscles weaken, yes—but so do routines, roles, and certainties. Under that pressure, families renegotiate identity, meaning, intimacy, and hope. Expanding on the earlier overview, this article takes a deeper look at how mind and MND intersect, what to expect across the course of illness, and how practical, evidence-informed psychological care can sustain dignity for patients and caregivers alike.

A new diagnosis tends to upend time. People oscillate between frantic googling and numbness; sleep becomes erratic; meals are skipped; small tasks feel pointless. This stage is not pathology—it is adjustment. Three anchors help:

- **Orientation without overwhelm:** A clear summary of "what we know, what we don't, and what we'll monitor" reduces the sense of free fall. Clinicians should translate medical terms into everyday language and state the next two or three actions only (e.g., physiotherapy assessment, swallowing screen, introduction to a support group).
- **Rituals that keep the day stitched together:** Fixed wake/sleep times, brief morning light exposure, regular meals, and a short daily walk or stretch maintain circadian rhythm and mood.
- **A coping map:** Patients note three helpful habits (e.g., prayer, journaling, calling a friend) and three unhelpful spirals (doom-scrolling, skipping meals, arguing late at night). The aim is not perfection; it is noticing and nudging.

Depression and anxiety are frequent, understandable responses. Grief recurs with each loss of function—"living loss"—and does not obey tidy stages. Most people improve when sleep, pain, and practical supports are addressed. Seek professional help if any of the following persist beyond a few weeks: pervasive sadness, loss of interest, hopelessness, significant weight change, severe guilt, panic attacks, or thoughts of self-harm. Treatment options include:

- **Cognitive-Behavioural Therapy (CBT):** Challenges catastrophic thinking ("I'm a burden," "Nothing will help") and pairs it with behavior change: energy-matched activity planning, pleasant-event scheduling, graded exposure to avoided tasks (e.g., short public outings with mobility aids).
- **Acceptance & Commitment Therapy (ACT):** Builds skills to carry difficult emotions while continuing to act on values—connection, creativity, faith, service. Helpful when symptoms cannot be "fixed" but life can still be chosen.
- **Medication:** When indicated, antidepressants and anti-anxiety medicines can be effective. Start low, go slow, and review for interaction with respiratory status and daytime alertness.

A subset of people with MND develop cognitive or behavioral change—slower thinking, trouble planning, impulsivity, apathy, emotional blunting, or loss of empathy. Families may misread these as "stubbornness" or "not trying." Early screening prevents conflict and guides safety decisions (e.g., driving, finances). Practical responses:

- Use **simple, concrete steps** instead of multi-stage instructions.

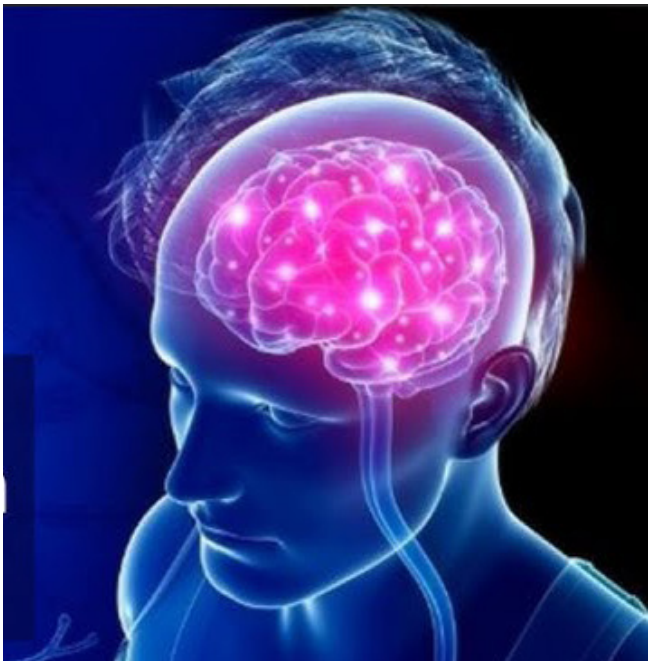
- Prefer **external scaffolds:** calendars, alarms, checklists, labeled drawers.
- Keep **choices limited** ("this or that?" rather than open-ended).
- Involve a psychologist or neuropsychologist for targeted strategies and capacity assessments when major decisions arise.

Sleep disruption—due to anxiety, cramps, position changes, or early respiratory compromise—drives daytime fatigue and low mood. Basics first: regular sleep window, minimal noise/light, no phones in bed, caffeine cut-off 7–8 hours before bedtime, a warm rinse and 10 minutes of breathwork or progressive relaxation. If morning headaches, non-restorative sleep, or witnessed pauses in breathing occur, ask about **nocturnal hypoventilation;** non-invasive ventilation can dramatically improve energy and cognition. Pacing matters: alternate activity and rest, cluster errands geographically, and pre-book "recovery slots" after clinic days.

Communication is more than speech—it is identity and control. Even before speech weakens, introduce tools:

- **Low-tech:** yes/no cards, alphabet boards, topic cue cards.
- **Voice banking:** record phrases while speech is strong; later, synthesized speech can sound like "you."
- **AAC devices:** from smartphone apps to eye-gaze systems. Start training early so tools feel familiar before they are essential.
- **Conversation hygiene:** one person speaking at a time, facing the listener, short phrases, confirm key points, avoid background noise.

MND reorganizes the household. Partners juggle employment, caregiving, and finances; children observe distress they cannot decode; elders worry about costs and honor. Noticing caregiver strain is itself a clinical task. Red flags include sleep debt, irritability, somatic complaints, isolation, and a sense that "nothing I do is enough." Support includes skills training (safe transfers, energy conservation), scheduled respite (even two hours weekly helps), peer groups, and transparent discussions about intimacy, privacy, and roles. Reassure caregivers: **resentment is a signal of overload, not a moral failure.**



Physiotherapy and occupational therapy become more effective when paired with psychological goals. Instead of generic exercise, anchor movement to **personally meaningful outcomes:** "walk to the garden with my daughter," "sit on the balcony for tea," "attend temple once a month." Motivational interviewing techniques help set realistic, values-based targets. Track progress with micro-metrics—metres walked, stairs climbed, minutes on the balcony, number of weekly outings—so improvements remain visible even when disease fluctuates.

Pain and cramps discourage activity and worsen mood. Treat both the symptom and the meaning assigned to it ("pain means I'm declining rapidly" → "pain means I must review stretching, hydration, and meds today"). Pseudobulbar affect—sudden, disproportional laughing or crying—can be socially disabling yet responds to medication and psychoeducation. Explaining to family and friends that these episodes are brain-signal mismatches, not insincerity, reduces embarrassment and isolation.

In India, distance, language, and stigma can block access. Many families first seek help from informal healers or avoid mobility aids due to perceived "defeat." Practical adaptations help:

- **Regional-language education** materials and videos for patients and carers.

- **Tele-psychology** check-ins for those far from tertiary centers.
- **Community physiotherapy camps** and partnerships with local colleges for caregiver training.
- **Low-cost home changes:** rails, non-slip mats, decluttering, raised toilet seats, bed-side commodes, portable ramps.
- **Financial planning early,** including disability certificates, government schemes, and crowdsourcing guidance where appropriate.

Desire and intimacy do not end with diagnosis. Fatigue, body-image shifts, and practical barriers can. Normalize conversation. Adjust timing (earlier in the day), positions (to reduce breath strain), and expectations (focus on closeness and touch, not only intercourse). Acknowledge grief when roles change from partner to caregiver; both can coexist. When needed, a counselor can mediate difficult conversations gently.

Advance care planning prevents crisis-driven decisions. Discuss preferences for feeding, respiratory support, admission thresholds, and the place of care. Clarify who speaks for the patient if decision-making capacity is lost. Document choices in language the family understands; revisit periodically. This is not "giving up"—it is **protecting the person's voice** for the future.

A stepped psychological care pathway

Step 1: Baseline (first month).

- Screens: PHQ-9 (depression), GAD-7 (anxiety), brief cognitive screen; sleep and fatigue checklist; caregiver strain index.
- Foundations: orientation, day-structure, sleep hygiene, safety review, first physiotherapy plan.
- Connections: support group link, tele-follow-up schedule, WhatsApp helpline hours.

Step 2: Consolidation (months 2–6).

- Weekly CBT/ACT-informed sessions or structured check-ins.
- Communication plan (voice banking/AAC), home modifications, mobility aid acceptance.
- Track four micro-metrics (e.g., metres walked, outings/week, hours of restful sleep, enjoyable activities/week).
- Caregiver respite plan and skills training.

Step 3: Maintenance and adaptation (beyond 6 months).

- Monthly reviews; crisis plans for infections or falls.
- Re-assess mood, anxiety, cognition each quarter; adjust meds/therapy.
- Revisit goals of care; prepare paperwork; update contacts.
- Celebrate continuity: birthdays, family rituals, small trips, projects (photo albums, oral histories).

Aarav, 42, engineer. Terrified of "becoming a burden," he stops meeting friends. CBT reframes the burden belief; activity pacing plus a portable stool lets him attend his child's cricket match for 30 minutes. He records his voice for future AAC, which paradoxically reduces anxiety now. PHQ-9 drops from 15 to 6 over eight weeks.

Meera, 58, teacher with mild frontal changes. Family fights over finances and driving. A capacity assessment shows poor risk judgment; keys are removed, and online banking is switched to joint control. A whiteboard task list and pillbox reduce daily friction. The family interprets apathy as disease-related, not laziness; conflict eases.

Standard scales (ALSFRS-R, 6-Minute Walk Test, Timed Up-and-Go) are useful, but **patient-defined indicators** keep motivation alive: "number of evenings on the terrace," "calls with my sister," "pages of my memoir," "times I prayed in congregation," "home-cooked meals enjoyed." Plotting these on a simple chart transforms invisible effort into visible achievement.

A compact toolkit

- **Daily:** fixed wake time; sunlight (10–15 min); one valued activity; 10 minutes of breathing/mindfulness; fluids and protein with each meal; tech-free wind-down.
- **Weekly:** one social contact, one enjoyable outing, caregiver respite slot, check home safety.
- **Quarterly:** mood/anxiety/cognition screen; review goals of care; audit equipment and home modifications.

OVIHAMS (Om-Vidya Institute of Homeopathy & Allied Medical Sciences) runs an **integrated pathway** for people living with MND

that pairs individualized homeopathic prescribing with physiotherapy, occupational and speech therapy, nutrition counseling, sleep hygiene, and structured psychological support. The emphasis is pragmatic and measurable:

- **Person-centred metrics** at every visit (walking distance, stairs climbed, sleep quality, fasciculation intensity, daytime energy, mood/screen scores).
- **Home-safety audits** and caregiver coaching to reduce falls and friction.
- **Medication stewardship** alongside homeopathic care (e.g., timely referral for NIV, cramps/pain management, pseudobulbar affect).
- **Documentation discipline** that turns lived changes into trackable graphs so families can *see* progress.

Clinically, many patients report improvements in sleep continuity, anxiety management, cramps, nausea, urinary discomfort, and activity pacing; several regain meaningful mobility with concurrent physiotherapy and nutritional repletion. These outcomes are **case-based and observational**—they do not prove disease modification—but they do show how homeopathy can be combined responsibly with standard rehabilitation to support comfort, adherence, and day-to-day functioning. OVIHAMS advocates **evidence-seeking practice:** wherever feasible, the team proposes **N-of-1 designs** (alternating treatment/washout blocks with standard measures like ALSFRS-R, 6-Minute Walk, Timed Up-and-Go, hand-grip strength, sleep/fatigue scales, and surface-EMG counts) to turn single-patient journeys into analyzable learning without sacrificing individualization.

Shanti Foundation partners with OVIHAMS to make MND care **visible, understandable, and reachable.** The foundation:

- Produces **multilingual educational content** (print, video, community talks) to reduce stigma and promote **early symptom recognition.**
- Runs **caregiver training modules**—safe transfers, pacing, basic physio, communication supports, sleep hygiene—through colleges/NGOs in Hindi, Bengali, Tamil, Kannada, and English.

- Pilots **low-cost rehab kits** (rails, non-slip mats, resistance bands, spirometry education leaflets) and connects families to financial assistance where possible.
- Encourages **measurement culture** (simple logbooks/phone forms) so small wins are recorded and shared with the clinical team.
- Supports **practice-based research** with OVIHAMS by helping design N-of-1 protocols, consent processes, and outcome dashboards—so community care adds to the knowledge base.

MND may be a disease of motor neurons, but it is lived in stories: tea on a balcony, the sound of a familiar voice, a grandchild's laughter, evening prayers, a page of memories. Psychology's task is not to deny decline, but to protect meaning—by reducing fear, organizing days, strengthening relationships, and keeping choices visible. When multidisciplinary medicine meets compassionate, measurement-minded psychological care, people do more than endure. They adapt, connect, and continue to author a life—one measured, mindful step at a time. ◆

Dr Kaartik Gupta *is clinical psychologist at AKG's OVIHAMS in New Delhi. He is reachable through kaartikgupta@gmail.com*