My Care Needs

I have motor neurone disease (MND)

Name:	Date:
Who to speak to about my care needs	☐ Me
	☐ My family member/carer. Name: Phone:
	☐ My treating healthcare specialist: Contact person: Phone:
	☐ Please refer to my GOC (goals of care) / ACP (advanced care plan)
Communication	☐ My speech is affected – please be patient!
	☐ I communicate via: ☐ voice ☐ writing ☐ phone/tablet ☐ eye-gaze
Calling for assistance	☐ I need the buzzer placed where I can access it
	☐ I am UNABLE to use the buzzer, check on me regularly
Breathing	☐ **DO NOT LIE ME FLAT** - it causes breathlessness or choking!
	☐ I get short of breath: ☐ talking ☐ walking ☐ showering ☐ at rest
	☐ I use NIV / BiPAP: ☐ as requested ☐ at night ☐ day and night
	☐ I need help to put my NIV / BiPAP mask on and off
	☐ Please talk with my treating respiratory team, before adjusting the settings on my NIV / BiPAP Respiratory contact:
Physical function	☐ I have weakness in my lower limb/s: ☐ left ☐ right
	Mobility: ☐ independent ☐ assistance ☐ walker / cane ☐ wheelchair
	Transfers: ☐ independent ☐ with assistance ☐ standing lifter ☐ hoist
	Moving in bed: ☐ independent ☐ need some help ☐ completely dependent
	☐ I need help to regularly re-position my body and limbs
	☐ Do not lift or pull me by my limbs
	☐ I need regular pressure care for: ☐ elbows ☐ buttocks ☐ heels ☐ other
	☐ I require an alternating air mattress for pressure care
	☐ I use a neck collar to support my head
Personal care	I need assistance with: ☐ showering ☐ toileting ☐ shaving ☐ hair ☐ dressing ☐ skincare ☐ brushing teeth
	Equipment for personal care: ☐ shower chair ☐ mobile commode ☐ tilt-in-space commode
	☐ I need my NIV / BiPAP for toileting

Bowel / bladder	☐ I experience bladder incontinence
	☐ I experience bowel incontinence
	☐ I use continence aids: ☐ pads ☐ pull-up pants ☐ uridome/sheath ☐ catheter
	To manage constipation I need: ☐ adequate fluids ☐ medications ☐ enemas
Eating & drinking	☐ **NIL BY MOUTH (NBM)**
	Current diet: ☐ full ☐ cut up ☐ soft ☐ minced ☐ pureed ☐ full fluids
	Current fluids: ☐ thin ☐ thickened. Level:
	☐ I have a feeding tube (PEG or RIG). Frequency of feeds:
	☐ I use oral nutrition supplements Brand: Frequency:
	☐ I need help with feeding
	☐ I use adaptive aids or cutlery due to upper limb weakness
	I need: ☐ extra time ☐ minimal distractions ☐ to sit upright
Saliva	☐ I have thick/ropey saliva I use: ☐ saline nebuliser ☐ medications ☐ oral suction ☐ cough assist
	☐ I have thin/runny saliva, with drooling. I use: ☐ absorbent wipes ☐ medications ☐ oral suction
	☐ I need regular mouth care. Frequency:
Medications	Medication route: ☐ whole ☐ crushed ☐ liquid ☐ PEG ☐ sub-cut injections
	Name of medications:
Other comments	

Acknowledgment: This resource was developed in collaboration between the National MND Lived Experience Network and the State MND Associations.

Developed: November 2024