

Supplementary Materials

DEPENDENT CHILDREN		AUTONOMOUS CHILDREN	
MORNING	ALL DAY/NIGHT	ALL DAY/NIGHT	
<p>Discontinuation of nutrition/tubing cleaning for children fed by tube/gastrostomy</p> <p>Management of vomiting in the morning for some, drainage</p> <p>Preparing equipment and clothing for the child to use when getting up</p> <p>Morning wash, hair brushing, getting dressed</p> <p>Placing into the wheelchair</p> <p>Preparing breakfast for children who eat solid food (blending food)</p> <p>Eating a meal (between 20 and 45 minutes)</p> <p>Reception of home care workers (physiotherapy, etc.)/Accompaniment to the medical educative center morning and evening/Accompaniment to the physiotherapist, transfers between the wheelchair or stroller and the vehicle</p> <p>Play time, cuddles, stimulation, educational and sensory games, story reading</p> <p>Exercises related to speaking and chewing learned by speech therapists (internal mouth, tongue and face massages)</p>	<p>Medication preparation and administration (at least twice, morning and evening, up to four times per day)</p> <p>Diaper changes several times a day (urinary and fecal incontinence); changing the urine bag, if necessary</p> <p>Parenteral feeding connection (several times a day: morning, noon, 4 pm, evening) for children who feed during the day (1 hour 1 h 30 min)</p> <p>Mobilization, massages: several times a day to avoid bedsores and work on sensory stimulation, at least when getting up and going to bed (can last 1 hour for children in pain)</p> <p>Verticalization for children lying down or seated who can no longer walk</p>	<p>Monitoring of medication intake</p> <p>Ensuring that the child remains well seated</p> <p>Monitoring that the child eats correctly and that food is swallowed correctly</p> <p>Cutting of food including meat</p> <p>Preparation of toiletries, clothes, etc.</p> <p>Assistance for getting dressed/Ensuring that the child is well dressed</p> <p>Placement of splints</p> <p>Preparing the toothbrush</p> <p>Checking that the tap is not running</p> <p>Checking the school bag, help with homework</p> <p>Continuous monitoring and reminders of what to do because of very frequent forgetfulness</p>	
NOON			<p>Meal preparation (blending food)</p> <p>Eating a meal for children who eat solid food (up to 1 hour)</p>
AFTERNOON			<p>Nap time</p> <p>Playtime, cuddles, stimulation, educational and sensory games, story reading, physiotherapy floor exercises for muscle flexibility, wheelchair rides</p> <p>Possible reception of home care providers for activities, such as music therapists</p> <p>Snack (compote, yogurt) for children who can still eat solid food</p> <p>Taking medication to relax and sleep</p> <p>Transfers to the bed/sofa/lift/kitchen seat/transfer table/shower trolley with numerous mobilizations and lifting</p>
EVENING			<p>Washing in the shower trolley (can last 1 hour for spastic children in pain)</p> <p>Evening meal preparation (blending food)</p> <p>Evening meal for children who still eat solid food (up to 1 hour)</p> <p>Putting on pajamas</p> <p>Connecting nutrition for the night</p> <p>Mobilizing and positioning the child for the night</p> <p>Help with falling asleep (30 min - 1 h)</p>
NIGHT	<p>Night sleeping next to the child or camera surveillance</p> <p>Nocturnal awakenings for some several times a night (pain, change of position, chest draining, suffocation by saliva, crying, tears, reception of the general care nurse, if necessary, etc.)</p>	<p>ONE-OFF TASKS</p> <p>Administrative procedures related to the disease</p> <p>Hospitalization</p> <p>One-off consultations</p> <p>Purchase of medication</p> <p>OTHER TASKS NOT RELATED TO cALD</p> <p>Coordination of other family members (trips to school, extra-curricular activities for other children, etc.)</p> <p>Professional activities</p> <p>Household chores (preparing meals, shopping, cleaning, laundry, etc.)</p>	

Supplementary Figure 1. A set of tasks cited by caregivers of children with cALD as part of their daily routine. Transplanted children were not included as their mothers did not devote more time to them than to non-sick children (except for medical appointments).

Supplementary Table 1. Description of the symptoms observed by parents during the development of their children's disease ($n = 12$, transplanted children were not affected by any of the symptoms)

Symptoms observed	<i>n</i>	% (<i>n</i> = 12)
Decline in school performance	12	100
Dysgraphia	12	100
Speech disorders*	12	100
Problems with vision*	12	100
Difficulty running*	12	100
Spatial orientation problems	11	92
Difficulty swallowing*	11	92
Incontinence episodes*	11	92
Stiffness when walking, need for assistance *	10	83

Wheelchair dependency*	10	83
Complete loss of voluntary movements*	10	83
Total incontinence*	10	83
Cortical blindness*	8	67
Hyperactivity	7	58
Tube or gastrostomy feeding*	7	58
Aggressiveness	6	50
Memory lapses	4	33
Disinhibition	4	33
Hearing disorders*	4	33
Loss of communication*	4	33
Seizures*	4	33
Personality disorders	3	25

*Clinical symptoms used in the calculation of the NFS score.

MFD: Major functional disability.

MFDs are indicated in bold.

Supplementary Table 2. Healthcare professionals included in regular follow-up and current frequency of consultations

	At diagnosis	Currently*	Frequency of consultations (no. per year)			
			Median	Average	Min.	Max.
Pediatrician/neurologist	14/14	13/14	2	4.8	1	14**
Endocrinologist	7/12	8/12	1	1.4	0.5	3
Physiotherapist/psychomotor therapist	8/12	12/12	142	164	52	364
Speech therapist	7/12	6/12	52	61	4	104
Occupational therapist	6/12	8/12	52	47	2	112
Home care nurse	0/12	4/12	235	313	52	730
Psychologist	4/12	3/12		Occasionally		

*For the two deceased children, end-of-life follow-up was taken into account.

**A child was followed up in a clinical trial requiring monthly visits.