

EXTRAORDINARY CARE EXAMPLES

Compiled by North Dakota Family Caregivers who provide extraordinary care

Extraordinary care is defined as “exceeding the range of activities a legally responsible individual would ordinarily perform in the household on behalf of a same aged individual without extraordinary medical or behavioral needs.” An assessment method that accurately captures extraordinary care, particularly for children, is needed to insure the correct individuals are participating in the program. Capturing the extraordinary needs of children is difficult because extraordinary care for a 1 year old vs for a 10 year old is very different based on the developmental levels across the age span. Therefore an assessment that is developmentally accurate and assesses activities of daily living, medical needs, and social-emotional needs is needed.

As family caregivers, we have all been trained to meet our child’s extraordinary needs by physical therapists, occupational therapists, speech therapists, respiratory therapists, nurses, different medical specialists, pharmacists, and dieticians. If someone is hired to provide Medicaid covered services to our children, this is what we train them to do. However, some of these extraordinary cares cannot be delivered by anyone except the primary caregiver who has been trained by medical personnel.

We have in-home support service hours authorized under the ND waivers that are not being utilized both because of the quality of staff available and because of the workforce shortage. The work is exactly the same, the only difference is that a non-legally responsible individual is paid to complete these tasks and we are not. The American Academy of Pediatrics recommends that family caregivers should be paid to reflect the skilled care being provided as stated in the **American Academy of Pediatrics Advocacy Action Guide on Paid Family Caregiving** released in late 2024. (Document has been uploaded in 2305 testimony for January 27, 2025 hearing with Senate Human Services Committee).

This list is not an all-inclusive list as every individual has different diagnoses and needs. However, we wanted to provide you with examples in order to provide a clearer picture of what extraordinary care is being provided by family caregivers.

Thank you for your time and dedication to our state.

COMMUNICATION

- Interpret body language and vocal cues to determine how individual is feeling (feeling good, pain, illness, emotional upset, etc)
- Encourage use of assistive communication device activated with eyes
- Encourage use of assistive communication device activated with finger

MEDICATION PREPARATION & ADMINISTRATION

- **Oral medications:** accurate measurement of meds, mixing meds with food due to taste or flavor aversions, prompts and encouragement to prevent individual from spitting meds out
- **Meds given through feeding tube:** accurate measurement of liquid medications in syringes, crushing and dissolving medications in syringes, administration of medications via feeding tube
- **Med passes per day:** 2 - 7 or more depending on diagnosis
- Constant monitoring for side effects from medications

NEUROLOGICAL DAILY CARE OR EMERGENCY (Epilepsy, hemiplegic migraines)

- Insure seizure medications are given as prescribed at the same times daily
- Administer emergency medications, monitor vital signs, and give oxygen during a neurological emergency
- Prevention/reduced exposure to neurological event triggers such as illness, lack of sleep, stress, pain, sensory overstimulation
- Monitor 24 hours a day, 7 days a week because a neurological emergency can occur at any time, without warning
- 1:1 care so we can assess and intervene at a moment's notice

RESPIRATORY DAILY CARE OR EMERGENCY

- Use emergency inhaler or nebulizer along with monitoring vital signs
- Use of a tracheal tube and cares required
- In need of a ventilator for part or all of the day
- 1:1 care so we can assess and intervene at a moment's notice

METABOLIC DAILY CARE OR EMERGENCY

- Multiple blood sugar and ketone checks throughout the day and night
- Management of nutrition and hydration orally and via feeding tube throughout the day and night to maintain metabolic stability
- Increase of above cares if metabolic stability decreases in an effort to prevent a prolonged hospital stay
- 1:1 care and constant monitoring so we can assess and intervene at a moment's notice

OVERNIGHT MONITORING AND CARE

- Monitor and provide care overnight if alarms sound indicating the need for assistance with feeding tube, trach, or a neurological, metabolic, or respiratory emergency.
- Reposition for safety and skin integrity
- Monitor individual for safety and flight risk concerns

EMOTIONAL AND SAFETY DAILY CARE OR EMERGENCY

- Constant monitoring due to flight risk
- Interpret body language and cues to determine emotional triggers, prevent emotional emergencies and maintain safety
- Provide support during an emotional emergency to maintain safety of child and others Prepare and insure access to many positive activities throughout the day as attention span is short and when left to guide their own activities the individual's safety is at risk

BATHING

- Transfer into and out of bath/shower and complete all washing, drying, and skin care tasks
- Provide emotional support and encouragement to allow bathing to occur due to sensory issues and/or fear

TOILETING

- Manage bowel and bladder incontinence
- Transfer onto and off of toilet
- Supervise for safety and assist with hygiene and clothing management
- Provide emotional support and encouragement to allow toileting and hygiene to occur due to sensory issues and/or fear

DRESSING

- Obtain clothing, complete all dressing tasks
- Provide emotional support and encouragement if clothing color or feel is not something that feels safe for the sensory system that day

GROOMING & HYGIENE

- Hair brushing, teeth brushing etc all completed for her
- Wound care

MOVING FROM PLACE TO PLACE (WHEELCHAIR OR WALKING)

- Ceiling lift or physical transfer
- Complete position changes throughout the day and night for skin integrity and comfort
- 1:1 assist with gait belt for balance, safety, fall and injury prevention
- Properly apply orthosis devices and set up adaptive equipment such as stander or gait trainer

PULMONARY CARE/TRACH CARE

- Needing to suction as needed 24/7
- Change trach for cleaning as prescribed
- Keeping the area clean

FEEDING TUBE CARE

- Wound care of feeding tube site
- Change feeding tube every 3 months

EATING

- Physically feed due to being unable
- Prepare, weigh, and calculate food to be eating orally and food to be given via feeding tube
- Prepare and measure out food to be given strictly via feeding tube, refill as needed throughout the day, constantly monitor for appropriate temperature of food/formula
- Meals often have goals to increase oral motor skills, decrease food aversions, and meet calorie needs
- Provide encouragement and prompts throughout meal to insure meal is eaten

DRINKING

- Physically hold water bottle if unable
- Calculate fluids to meet hydration goals
- Provide encouragement, prompts, and assistance throughout day to insure individual stays hydrated

PORT CARE

- Properly caring for port and surrounding area
- Adding heparin in the correct dosage for port care
- Accurate measurement and preparation of medications administered through the port
- Monitor for side effects and infection

HOME PROGRAMMING

- Home exercise programs as prescribed by physical therapy and occupational therapy
- Home sensory programs as prescribed by occupational therapy
- Home feeding and speech programs as prescribed by speech therapy
- Home programming as prescribed by ABA specialists
- Adaptation of leisure and play activities