

Comprehensive Care Near the End of Life for Persons with Intellectual Disabilities Palliative Care: The Gold Standard for Advanced Disease

Patients with advanced, progressive, life-threatening illness need an interdisciplinary approach that attends to psychosocial issues, advance care planning, and symptom management—the essence of palliative care—for all suitable patients. Chronic disease management includes planning for the later stages of the disease, and providing anticipatory education for possible complications and end of life planning.

Patients are often choosing between several forms of potentially life-prolonging therapies, each with its own side-effect profile. What distinguishes the various treatment options for progressive, chronic diseases is the way in which they balance the patient's (and family's) goals of care.

What changes over time as patients move through the trajectory of progressive, life-limiting disease is often the goals of care. They may start with life prolongation as the primary goal, with preservation of function as a second goal, and be willing to tolerate various uncomfortable treatment side-effects, hoping for comfort, but not seeing it as the most important goal. These goals often shift over time: for one individual, accepting loss of function, if it is the price for life-prolongation, may be a worthwhile goal, and at a later point in treatment, comfort and life closure may over-ride both life prolongation and maintenance of functional status. Hospitalization may be helpful for that individual, if the burdens of hospitalization, IV antibiotics, tests and procedures are not experienced as overly burdensome, or may not: these are fluid decisions.

As life draws to a close, for persons with or without an intellectual impairment, an understanding of what the goals of treatment are, what treatment benefits and burdens are: **for the individual in the context of their life, setting and family** is imperative. Discussion needs to address the individuals' best interests, along with what has been quality of life, and what will likely cause excessive suffering. One of the underpinnings of medical care is to “Do No Harm,” and the best interest of the patient should remain foremost in the healthcare team's treatment approach. The “terminal stage” of illness is connected to when the burdens become too great.

Persons with intellectual disabilities present unique challenges as they age, and near the end of their life span due to communication barriers, decreased use of utilization of health screening, poorly defined decision-makers, lack of clarity regarding goals, lack of comprehension, lack of death education and experience with death and dying.

End of life planning and advocacy for this population ideally would include:

1. Education for persons with Intellectual Disabilities, their families and their caregivers related to advance directives/advance care planning, death and dying, hospice and palliative care
2. Early and clear understanding of efficacy of CPR, appropriateness of either Comfort One or attempted resuscitation; its burdens and benefits.

3. Access to Hospice care, access to palliative care and advance care planning consultation to assist with completion of advance directives, and review of goals of care along the trajectory of the end stage illness.
4. Opportunity for provider/community forums to dialogue about unmet needs
5. Clear guidelines for decision making related to withdrawal of life prolonging interventions: **caring** should never be withdrawn.
6. Bereavement care for persons with intellectual disabilities, and their families and providers.
7. Maximization of time in most familiar setting
8. Early discussion of likely disease course and anticipatory guidance as the illness changes over time, frequent discussion of benefits and burdens of treatment possibilities with all relevant individuals.
9. Excellent symptom management throughout disease course, when hospitalized the care-providers thoroughly informed as to how to interpret cues, and non-verbal communication.
10. Clear understanding of local regulations and laws pertaining to end of life
11. Laws that reflect the ethical principles involved in care of the whole person throughout their lifespan, an understanding of death and dying, and the need for language that is understandable and usable.

Our situation:

No organized End of life education for group homes for persons with DD exists; policy pertaining to CPR/Comfort One is confusing, currently runs counter to intent of Comfort One to protect the dying from undo harm.

In Montana, Guardians cannot make decisions to withdraw and withhold care: Mt. must involve the courts. Historically (I have been told) old pattern was automatic DNR for DD individuals, now it is case by case, must meet “terminal stage” for MD comfort to order.

Not all states are like Montana. The experts encourage care providers to avoid the courts if at all possible.

Part of the problem comes from the way our law is written: related to terminal illness, and the community’s understanding of what constitutes a “terminal illness”:

Montana Advocacy lawyer appears to an interest in changing legislation, appears to be pushing decision in the opposite direction of what national standards indicate best practice.

Model state:

New York has done very comprehensive work on end of life education, and empowerment of the guardians and families that care for, and make decisions for, or participate in shared decision making for persons with Intellectual disabilities at end of life. Involved family members and guardians have clear guidelines, nicely spelled out, but may make decisions to withhold and withdraw care. Partnership between state agencies, Hospice and palliative care strong and visible.