

A Physician's Guide To Life Choices In The Adult Person With Mental Retardation And Developmental Disabilities (MR/DD)

The determination of appropriate life extending measures for persons with mental retardation poses a significant ethical, moral and legal responsibility on the family and clinicians. Many persons with intellectual disability are capable of self-determination; however, a significant number of individuals require surrogate decision makers to assist with important life decisions such as resuscitation, assisted feeding, and aggressive therapy for life-threatening or terminal illnesses. Patients with severe behavioral problems challenge the treatment team to make decisions based on patient outcome versus expected obstacles to medical compliance. A single, clinical feature such as age, etiology of retardation or functional status should not determine the advanced directive status. The appropriate advanced directive is dependent on a comprehensive assessment of the patient's medical condition, functional status, and quality of life.

There is no clinical evidence that patients with MR/DD have diminished outcomes from aggressive medical interventions, such as coronary artery by-pass surgery, cancer resections, chemotherapy or other invasive procedures. Such outcomes are not published for patients with medical problems requiring ICU care. Anecdotal experience indicates that persons with mild to moderate retardation will tolerate these interventions. Patients with severe retardation or multiple handicaps pose unique challenges to the hospitalist.

Decision-Making for Young or Healthy Persons

Young, healthy persons with mental retardation should receive full medical measures to extend life or correct reversible health problems. The patient with MR/DD is at higher risk for developing post-operative delirium or ICU behavioral problems (**See Delirium Handout**). These management challenges can be addressed through a combination of behavioral approaches and appropriate psychopharmacology. Deterioration of function

produced by delirium or medical complications may be corrected over weeks or months of consistent work.

Decision-Making for Frail Patients

Physically-frail patients with MR/DD require careful consideration of resuscitation or aggressive medical interventions based on expected outcome and quality of life. All patients with MR/DD should be carefully considered for each type of medical, surgical, or pharmacological interventions, e.g., chemotherapy, and each intervention must be weighed against potential complications such as diminished quality of life. For example, the patient with MR/DD with metastatic carcinoma may not be an optimal candidate for painful, prolonged cycles of chemotherapy, while a woman with MR/DD and breast cancer may be an excellent candidate for mastectomy despite the relative risk of post-operative delirium.

Assessing Complications Encountered During Treatment

The patient with MR/DD may show evidence of functional decline during episodes of severe medical illness. If the medical problem is reversible, then the functional decline may reverse as well. These individuals should not be placed on DNR status based on potential, temporary functional or cognitive decline that may improve with time and habilitative services.

Dying patients with all levels of disability should receive aggressive care through hospice to assure adequate pain management and to maximize quality of life.

Advanced directives and major health decisions should not be affected by the type or severity of behavioral problems. Severe, medical problems often worsen behavioral problems. The quantity and quality of behavioral symptoms are irrelevant to the decision about advanced directives and medical interventions. Medical and life support decisions are also unrelated to financial resources or a patient's ability to pay for healthcare.

Difficult or complicated decisions about patient treatment can be referred to the hospital's ethics committee or patient advocacy for full consideration. Patients may need the support of a patient advocate to assure decisions are made on medical probabilities rather than a predicted outcome or misperceptions about the quality of life experienced by retarded persons or the meaningfulness of their existence.

Conclusion

Patients with MR/DD and life-threatening health problems require evaluation on a case-by-case basis. Decisions should consider quality of life and patient rights. Dying patients should receive hospice care.