

Caring at the End of Life

When someone is very sick and not expected to recover, they are considered to be at the *end of life*. The AAIDD believes that people with intellectual and developmental disabilities (IDD) deserve the same care and respect as anyone else during this time.

Four important principles guide this care:

- 1. Dignity** Every person has value, no matter their disability. Having a disability doesn't make someone's life less important. Decisions about stopping or continuing treatment should always be made with respect — never just because someone has a disability.
- 2. Respect for Choices** Whenever possible, caregivers should find out what the person wants and honor those wishes. People can share their preferences through words, actions, or behavior. Those who know the person best can help figure out what they would want.
- 3. Protecting Life** In general, caregivers should work to protect and support the person's life. If someone hasn't clearly shared their wishes ahead of time, treatment should continue unless there is no doubt it is the right thing to stop. There are rare situations — like when treatment only causes more suffering with no chance of getting better — where ending treatment may be appropriate.
- 4. Fairness** Everyone deserves access to good end-of-life care, including hospice, pain relief, and spiritual support. Insurance should cover what's needed, and people shouldn't have to move somewhere more restrictive just to get proper care.

Planning ahead matters. Ideally, conversations about end-of-life wishes should happen before a person gets very sick, so that their voice is heard when it matters most.
