

CHOSeN Transition Program

Things to Consider During Transition

As your child approaches 18, we understand that navigating this process can feel overwhelming. We're here to support you every step of the way. Transitioning a pediatric patient with a complex medical condition requires careful consideration and planning.

Insurance and Medical

There are a number of questions to consider with regard to insurance, SSI, and other medical concerns.

- How long will the individual be eligible for this coverage?
- What does their plan cover (medical, dental, prescriptions, etc.)?
- What insurance coverage will the individual have in the future?
- Will the individual be eligible for SSI?
- Is the individual on any medical waiver programs?
If so, which ones?
- What services is the individual currently receiving?
- Do they know and understand their medical diagnosis and prognosis?
- Do they have a current medications list with dosages?
- Do they have a portable medical passport?
- Have you as the parent/caregiver completed paperwork for continued access to your child's medical records?
- Do they need referrals to adult care specialists?
- Does the adult child need medical supplies at home, nursing care, etc.?
- Do they know their wellness baseline information (diagnosis medications, etc.)?
- Can they obtain a written summary (medical records) from their current primary care physician/medical HOMW and subspecialist?
- Have they chosen an adult medical home?

Guardianship

What is it?

Guardianship is a legal relationship between a competent adult and a person over the age of 18 whose disability causes incompetency (a ward). The disability may be caused by mental illness, developmental disability, age, accident, or other causes.

A developmental disability or mental illness is not, by itself, sufficient reason to declare someone incompetent. Competency has to do with a person's ability to make an "informed decision," or with the risk of harm they may experience due to their inability to provide for themselves or manage their affairs.

The guardian can't interfere with marriage decisions, can't vote for the ward, and can't consent to sterilization of the ward.

How to request it?

Parents are not automatically guardians of their adult children. The law presumes that all persons 18 years of age or older are competent to make their own decisions unless proven otherwise. Parental legal rights end when the child reaches the age of maturity. In order to continue their parental authority after their child turns 18, the parents must file for guardianship of their adult child. One or both parents may be the guardian(s).

A petition for guardianship is submitted to Probate Court in the county in which the proposed ward lives. The family must provide the court a physician's or psychologist's report providing the diagnosis and the actual mental and functional limitations and prognosis that demonstrates the need for guardianship. The proposed guardian also must submit a plan detailing how the ward's financial, medical, and other needs will be met.

Assistance and Process

Many registrars and clerks of the Probate Court can be helpful in explaining necessary forms and how to fill them out. Attorneys familiar with guardianship laws and procedures could also provide assistance.

The legal requirements for beginning a guardianship and the necessary paperwork are complex, but the law allows you to represent your own interests in a guardianship matter. You might be able to answer some of the simpler questions, but more complicated issues probably will require an attorney.

Most guardianship proceedings take a minimum of two weeks to as long as two months. Talk to your social worker for additional options, if needed.

Consult your physician for additional information and instructions on DNR/AND.

Fees

The cost to obtain a private guardianship varies county-to-county, attorney-to-attorney, and guardianship-to-guardianship. Discuss fees and services with an attorney and get an estimate of their range, if the attorney is charging an hourly rate. Look for another attorney if they aren't willing to discuss this.

The ward's assets, including most governmental benefits, can be used to pay all or part of the guardianship. Some attorneys require that all – or a portion – of the fee be paid in advance. This is common, so don't be offended by this request. Yet, there is nothing wrong with shopping around for a lawyer.

Education

Individuals can attend high school until age 22. After that, there are a variety of options including independent living or an adult day program. If your child is in public school, ask for guidance through their counselor or assigned special education facilitator.

Emergency Procedures

Advanced directives

Advanced directives inform whether doctors should continue to keep the person alive using extraordinary life-sustaining procedures, such as cardiopulmonary resuscitation (CPR), artificial respirators, and artificial feeding. The dying person may still be able to give doctors instructions about treatment. But often, the patient is not able to communicate with the doctor because they are unconscious, heavily medicated, or otherwise unable to provide informed consent. When this happens, the patient's parent/guardian may be consulted about what treatment should be given to the patient.

“Do Not Resuscitate” Order (DNR) and “Allow Natural Death” (AND)

A “Do Not Resuscitate” order or “Allow Natural Death” order informs the treating medical staff not to revive a patient (e.g., CPR, respirator, or other means of artificial life support) if their breathing or heartbeat stops. The order can specify which methods would be withheld. Medical facilities will probably ask a guardian to sign a statement indicating their wishes regarding resuscitation and artificial life support for their ward. There are many factors that go into this decision – including the wishes of the ward – but the guardian has the ultimate authority to decide what measures will be carried out.