

Considerations for Guardianship & Medical Decision-Making



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INTRODUCTION

Parenting is a lifelong process, and it is particularly so for parents of children with serious illness, where the child’s chronological age may not correspond with their developmental baseline. While your child is a minor, you can make all medical decisions for them just by virtue of being their parent. But when your child reaches adulthood (age 18 in most states), their legal status changes, and they are now presumed to be capable of making all major decisions on their own, regardless of their disability. This can create many problems for parents and others who are caring for them. However, many of these problems can be avoided if you go to court to become your child’s legal guardian. Having guardianship lets you make medical decisions for your child and provide uninterrupted access to medical care and supports.

Without guardianship, it may be difficult to get medical care for your adult child when they need it. The reason has to do with liability. Doctors and other healthcare providers must make sure that their patients understand the care they are receiving. If a treatment or procedure is deemed to be risky or complex, your child must be able to understand the risks of the procedure, and show that they do. It makes no difference if you, the parent, understand the risks and accept them. If something goes wrong and your child hasn’t given their informed consent, the healthcare provider could be held liable. Sometimes medical procedures must be postponed while parents go to court to get guardianship.

Even getting your child’s medical information can be problematic when they are adults. Under the medical privacy (HIPAA) laws, healthcare providers are not supposed to disclose a patient’s medical information without consent. If your child doesn’t have the ability to give consent, their medical information isn’t supposed to be shared. Some medical insurance companies refuse to provide information to parents of young adults — even though the parents are the ones providing the insurance. All of this can make it difficult, if not impossible, to manage your child’s medical care.

To avoid these problems, it is critical that you take steps to become your child’s legal guardian before they reach adulthood.

Courageous Parents Network encourages you to consult experts on any questions you have about the process, the laws of your state, and your guardianship and surrogacy options.



What is legal guardianship?

Guardianship is a court process. Each state has its own guardianship laws, forms, and procedures. Every state will require you to show that your child is “incapacitated” and unable to make important decisions independently. Before placing your child under guardianship, the judge will consider your child’s medical condition, cognitive abilities, functional abilities, and the harm that could result if a guardian is not appointed. The end result of the guardianship is that you or another person the judge appoints will be able to make decisions for your child and speak on their behalf in all important matters.

Parents sometimes feel confused or even defensive about the concept of guardianship. You have dedicated your life to caring for your child. The process can feel invasive, inconsiderate and unjust. You may feel that your parenting choices or intentions for your child are being judged or questioned. It is helpful to keep in mind, however, that this process is in place for a very good reason — to protect adults with significant needs who can’t advocate or speak for themselves, especially in a clinical setting. These laws exist to protect all individuals, regardless of whether or not they have the benefit of loving families with a demonstrated record of good care and decision making.

Besides allowing you to direct your child’s medical care, having guardianship has other benefits. You will be able to decide your child’s education placement, obtain public benefits on their behalf, and advocate for them. When an important decision needs to be made, no one can talk to your child and get their consent for something they may not fully understand. Everyone must come to you for permission.

Advocating for your child



THOUGH YOUR CHILD may have never developed an ability to express specific preferences, whether verbally or with use of an assisted communication device, all children have some ability to communicate their wants and needs. Children who are medically complex are often dependent on others to understand non-verbal cues or expressions that display their preferences. Family members are likely in the best position to interpret and respond to these subtle, yet meaningful, interactions. So, you have likely demonstrated to others, including your child’s care team, the ability to make appropriate decisions on behalf of and in the best interest of your child.

Being granted guardianship is a continuation of what has already been established: that you are in the best position to understand, interpret and clearly state your adult child’s needs. You can advocate accordingly.

Legal guardianship requires a court-ordered process to determine who the decision-maker should be. This can feel like a sudden and swift change for parents, to be abruptly removed as the go-to “middleman and manager” of your child’s care. It impacts even the simple things, such as making appointments, access to records and speaking to your child’s care team. It is critical that you anticipate this change and take steps towards guardianship before your child reaches adulthood so that you can ensure continuity of care and uninterrupted access to their medical supports. ●

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Who should be the guardian?

One of the most important tasks is to determine who will be the most appropriate legal guardians. Should the guardian be one or both parents, a sibling, family member or another adult, or some combination? Guardianship can also be provided by professionals as a service for those with limited options. This decision will look different based on the family dynamic and circumstances, and there is no right or wrong decision.

Consider the advantages and disadvantages of all scenarios, and seek advice from trusted sources. Keep in mind that guardianship decisions can affect benefits and programs that will help support (and fund) the care of the adult child for example, in most states, a legal guardian cannot also be a paid caregiver. Make sure to understand those limitations before making a decision about guardianship.



Some questions to consider

- Consider family dynamics: Are the parents divorced? How does this help or hinder the caregiving? Is there a sibling who seems particularly interested in this guardianship role?
- What are the short and long term plans for housing and caregiving for the individual? Will care be provided by the family or others? How might guardianship impact those arrangements?
- Who is most capable of taking on the responsibility of guardianship? Do they understand and can they carry out the long term vision and goals of care?

How palliative care can help

As the transition to adulthood occurs, you may be thinking more about your child's future and adulthood in new ways. Certain milestones of independence may have felt out of reach for much of your child's life. You may already have spent years living with anticipatory grief and mentally preparing for your child's end of life — but now you need to make a mental shift to address the needs of your child as an adult.

It may begin to feel different to care for an **adult child**, logistically, physically and emotionally. It can be daunting and overwhelming, to navigate all the changes that occur as your child moves from the pediatric to adult world, requiring you to learn new systems and find

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new supports. In essence, this is a transition for all family members. Access to services, questions about who will care for your adult child as you (and they) age, considering supportive residential options, and creating a safe and purposeful adulthood may all be explored in this process.

You deserve and will benefit from guidance and support as you work through guardianship. A social worker with a palliative care or sub-specialist's team can help you navigate the details, and identify and explore any emotions you may experience. Seeking advice from other parents and being part of a shared experience may also be valuable.

Additional resources

More on this topic can be found:

- Watch the videos, ***When it's a Long, Indefinite Timeline***
<https://courageousparentsnetwork.org/video-library/when-its-a-long-indefinite-timeline>
- Check out the blog post, ***A Blessing and a Burden***
<https://courageousparentsnetwork.org/blog/a-blessing-and-a-burden>
- Read the Courageous Parents Network Guide, ***Planning the Transition From Pediatric to Adult Providers for the Fully Dependent Child***
<https://courageousparentsnetwork.org/guides/planning-transition-from-pediatric-to-adult-providers-for-the-fully-dependent-child>

Becoming your child's legal guardian

The process of planning for guardianship may be initiated by your child's school, medical providers, or by you, the parent. It should begin in your child's mid-teens, and preparation to file for guardianship should ideally take place in the year before they reach adulthood (18 in most states). In general, parents (petitioners) will be at the mercy of the timeline of the courts, and sometimes the process can be exceedingly slow. The earlier you begin, the less rushed and vulnerable you will feel about the critical end dates.

- **Getting information and support**

Social workers can help you determine requirements for guardianship and provide support. Some states may offer a transition team through a public health program, or your pediatric hospital may have a transition program. Information about transition

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timelines and guardianship guidelines is also widely available on the internet, but be sure to check requirements for your state of residence, because each state has its own laws and procedures. Check your local area for guardianship and legal planning seminars, which are frequently offered free of charge by attorneys and special education advocacy organizations.

- **Getting legal help**

It is generally recommended that you hire an attorney to assist you, if you can afford to do so. Ask other parents for their recommendations about who to hire. Experience is important too. Make sure the person has had several years' experience representing parents in guardianship matters. If you can't afford to hire an attorney, you may be able to manage the process yourself, taking advantage of online resources and the experience of parents who have done so before you. Some parents get assistance from public agencies, although this depends on your child being deemed eligible for agency supports. Most states have volunteer organizations that provide free legal help to those who are income eligible.

- **Getting documentation**

Before you start the court process, you will need documentation of your child's incapacity in a form that the court will accept. Again, you must check the requirements for your state. For example, some states require a psychologist, a social worker, and a physician to all sign off. Your child's medical team may be able to provide the documentation you will need, or if they cannot, you can seek an evaluation from one or more independent professionals.

End of life care

In some states, you won't be able to sign end-of-life orders for your child, even if you are their legal guardian. This means you must get special authority from the court to place a Do Not Resuscitate (DNR) order or Medical Order for Life-Sustaining Treatment (MOLST) order. It is upsetting to have to return to court at such a difficult time. Although there is nothing you can do about it, it helps to prepare emotionally.

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CONCLUSION

A process that requires planning and patience

As your child transitions from childhood to adulthood they, and you, will experience a vast array of changes — physical, emotional and practical. Nobody can predict what someone else is likely to feel, but many of the more day-to-day aspects of the transition can be predicted and addressed. The more you know and plan for, the easier the transition is likely to be.

Glossary

TERM	DEFINITION
Incapacitated person	An individual who has a clinically diagnosed medical condition that results in an inability to receive and evaluate information or make or communicate decisions.
Guardianship	Guardianship means obtaining the legal authority to make decisions for another person. A “guardian” is the person appointed by the court to make decisions on behalf of someone else. The person over whom the guardianship is granted (the child or the adult) is referred to as the “protected person.”
Guardianship appointment standard	The person has a clinically diagnosed condition that results in an inability to receive and evaluate information or make or communicate decisions to such an extent that the individual lacks the ability to meet essential requirements for physical health, safety, or self-care, even with appropriate technological assistance. Less restrictive alternatives, such as supported decision-making, are not enough.
Guardian	An individual or organization appointed by a court to make some or all personal and medical decisions for an incapacitated person, only as ordered by the court.

For more information

Here are a few websites with articles that may be helpful.

- <https://gottransition.org/six-core-elements/implementation.cfm>
- <https://futureplanning.thearc.org>
- <https://www.sciencedirect.com/science/article/pii/S1525505020302754?fbclid=IwAR1oje8x7EdmB10YyEjR6evxNI57dNH4ODGazLqGrrBuJV1Dkpckd0DUTc>