

Making Decisions



Guardianship and Other Options for Supporting Young Adults



Children's National®

Introduction

Turning 18 is a life transition with important social and legal effects. Eighteen-year-olds are no longer considered “minors”, but young adults¹. Everyone becomes a legal adult at this age, without any judge or court being involved. Automatically, “by operation of the law,” young adults gain some rights that used to belong to parents/guardians.

At 18, every person gains all the legal rights and responsibilities of adulthood. This includes making decisions about education, work, finances, and health. Young people choose how involved their parents/guardians should be in their healthcare decisions, including surgery and admission to the hospital.

Some young adults have intellectual disabilities or other disabilities and cannot make these healthcare decisions by themselves. Legally, their parents or guardians can no longer approve medical treatment without their permission. This is true even if the parent has always made all of the child’s medical decisions.

If the young adult is cognitively unable to give this permission, then the parent may need to go to court and request legal papers from a judge. Only a judge can remove the rights from someone over 18.

At Children’s National, we treat many young adults who still need medical care after they turn 18. This includes young adults with chronic health conditions, special healthcare needs, or intellectual

disabilities. It is important to plan ahead to avoid being caught by surprise. In the child’s early teenage years, it is important for families to:

- **Understand** what their child’s **long-term healthcare needs** will be;
- **Know what support** the child will need to manage his² future healthcare;
- **Decide who will provide that support;**
- **Create a lifetime plan of care** for some, which might include trusts, Medicaid, disability benefits, or continuing special education services until age 22.

Children’s National is committed to a shared decision making process, keeping parents/guardians involved whenever possible. Our role is to ensure that our patients, or another appointed adult, can make medical decisions in accordance with Washington, DC, law. We also want to help our young adults get the right medical care and support, and protect their legal rights.

This handbook provides important information that will help young adults and their parents or guardians make informed decisions about future healthcare. It was created by the Children’s National Older Patient Committee, with a grant from the Children’s National Board of Visitors. It provides a general discussion of choices available for families who want – or need – to remain involved in their child’s medical treatment. ■

¹ The medical term “young adults” includes any patient aged 18 and older who is seen at Children’s National Health System.

² The term *his* is used to refer both to female and male young adults.

SECTION 1:

Guardianship Basics

WHAT HAPPENS WHEN MY YOUNG ADULT TURNS 18?

Once a young adult turns 18, parents are no longer considered to be their child's legal guardian – regardless of health status or need for medical care. In the District of Columbia, Maryland, and Virginia, all 18-year-olds are presumed fit and legally able to understand the benefits and risks of healthcare, and to provide consent for their own treatment.

When a young adult turns 18, he is the only one who decides how much, or how little, his parents can be involved. If the young adult wants parents to continue to receive information about his healthcare, he will need to sign a release to allow Children's National to provide information to the parents. Without the signed release, Children's National cannot legally discuss anything about the patient's care with anyone but the patient. In some cases a parent can go to a judge when the now-adult child lacks "capacity" – meaning his ability to process information is impaired.

WHAT IS ADULT GUARDIANSHIP?

Guardianship is a legal way to protect someone who has an intellectual disability which prevents him from making safe, informed life decisions. A proposed guardian (parent, relative,

or adult friend) can ask a judge to grant that person the power to make decisions, including medical decisions, and act on the young adult's behalf.

The judge may appoint a guardian when the new adult lacks intellectual "capacity" to make informed decisions about his day-to-day care. For example, an adult who cannot physically speak or write, but who can communicate by blinking, still has capacity. A 19-year-old with severe dyslexia and other sensory input issues might still have capacity. But a cognitively impaired young person, who cannot reasonably understand the need for medical treatment, may not have capacity. In those cases, a judge might appoint a guardian.

Guardianship is a court-ordered relationship that cannot be reversed easily, except through revocation, which involves another court proceeding. Some parents say they have been advised to obtain "guardianship" of their child. This is not always the best or most accurate advice. It is best to consult an attorney, or another organization knowledgeable about guardianship issues, to understand all possibilities. Please see the resources Section 7 at the end for contact information for associations that can help you find an attorney.

Guardianship involves three questions in the following order:

1. Does the young adult need a guardian due to **"incapacity?"**
2. **Who** should be appointed?
3. **What powers** should the guardian have, and with what oversight (if any)?

So, if a child merely needed help with paperwork to get disability benefits or receive special education past age 18, a very limited guardianship might be imposed. If the child needs complex medical treatment or cannot handle any finances or household tasks, the powers of the guardian might be expanded.

OPTIONS FOR SUPPORTING YOUNG ADULTS

Children's National aims to ensure that all patients receive the care they need in a timely fashion. Most of our patients will be able to make their own healthcare decisions when they turn 18, but there are various ways that young adults who need help can be supported in their decision-making. These supports are usually based on the young adult's ability to understand his condition and communicate how they want to be treated. The general guideline is to provide the least restrictive support possible. A partial list of options includes:

- Make independent decisions
- Make decisions with support
- Have an advance directive

- Have a durable power of attorney
- Seek a court appointed developmental disability lay advocate with medical decision-making authority
- Obtain permanent guardianship

An advance directive is a written document in which a patient says what type of medical care he would want in the future, if he were to become unable to make his own medical decisions. It can be used by adults with no cognitive impairment, who are currently able to make all of their own medical decisions. There are two kinds of advance directives:

- A living will states what type of medical care you do or do not want if you ever cannot make your own medical decisions. Usually a living will applies when you are in a final stage of illness.
- In a durable power of attorney for health care you appoint a person to make decisions for you, if you become unable to make them for yourself.

The Admissions Office at Children's National has copies of the advance directives forms, along with an information booklet which explains how to complete the forms. For many of our young adults, these forms can be completed before medical treatment, and no other documents are needed. Our hospital social workers can help answer questions about these forms. They can be reached through our Family Services office, 202-476-3070.

Advance directive forms only apply to adult patients who are fully able to make all of their own medical decisions. Some young adult patients can talk with their doctors and make some simple medical decisions by themselves, but they may not fully understand complex decisions. For example, they might not understand the risks and benefits of consenting to surgery or other medical treatment, taking a drug, or completing medical treatment at home.

Legal guardianship may still be required for these patients. However, if the young adult understands the idea of appointing a trusted adult to make his medical decisions for him, it may instead be possible to use a durable power of attorney form. Our hospital has a special power of attorney form in Section 7 at the end of this booklet which may apply in these cases. This is a voluntary durable power of attorney form which is approved by our hospital's Legal Department. Our social workers may be able to help decide if this form applies. ■

SECTION 2:

Determining how much support an individual will need: Competency and Capacity

.....

Some young adults with mental illness, developmental delay, or other cognitive impairment have difficulty communicating with their providers about their medical options when faced with critical healthcare decisions.

.....

They might be unable to understand the risks and benefits of treatment or unable to follow through on recommended treatment by themselves. Most patients over age 18 have the right to make informed decisions about how they live their lives, including their medical treatment. However, they must be deemed "competent" (able) or have the "capacity" (power) to understand the risks and benefits of their decisions.

It is important to note that the laws of the District of Columbia and the counties in Maryland and Virginia define the words "competent" and "capacity" differently. Therefore, it is critical that you review the legal definitions in your own state. Children's National is required to follow District of Columbia law for patients receiving medical treatment at our hospital, regardless of the law where the patient lives.



HOW DO DOCTORS EVALUATE COMPETENCY?

Doctors have many ways to evaluate competency, including tests for mental and physical functioning. Different tests assess mental and/or physical capacity, depending on the source of the disability.

MY CHILD IS NOT FULLY INCOMPETENT. CAN HE/SHE STILL MAKE DECISIONS?

Possibly. A person who is in the early stages of a progressive disease, or has an intellectual disability, mental illness, or head injury, may be competent enough to express their opinions about certain matters. In deciding whether a person is competent to make a particular decision, one should evaluate:

- **how complex** the decision is;
- whether the course of action the person wants to take is **consistent**

with the way the person has lived his earlier life; and

- **how dangerous** the concerns of a specific course of action are.

WHAT IF MY YOUNG ADULT HAS NEVER BEEN ABLE TO MAKE INFORMED DECISIONS?

If your young adult has never been capable of making informed decisions, filing a guardianship petition may be the best option to ensure proper future adult care. In circumstances where the parent does not wish to seek guardianship, we may be able to provide care with the parent's consent based on D.C. law if the patient is certified to be incompetent to make medical decisions in accordance with D.C. law. The social work department can help you explore this option if it applies to your child. This would apply only for care given at our main location in Washington, D.C.

MY CHILD IS NOT COMPETENT. WHAT PROOF OF INCOMPETENCY DOES THE LAW REQUIRE?

Proof of incompetency differs in each state and sometimes in each county. Again, it is crucial that you review the legal definitions in your own county or state. A good question to ask that is common to DC, Maryland, and Virginia is: can the child receive and evaluate information, and make a reasonable decision on that information, so he can have daily necessities of life? ■



SECTION 3:

The Permanent Guardianship Process

This section will provide a brief overview of how to file for guardianship if needed. It is based on the formal-sounding constitutional right that “no person shall be deprived of life, liberty or property without due process of law” and we are exploring that right in this discussion.

HOW IS A FILLING GUARDIAN APPOINTED?

A guardian is appointed by a judge in a court hearing, once a court receives a petition from an interested person (parent/guardian).

WHAT IS IN THE PETITION?

A petition is a document that contains the necessary details of the guardianship case and states what the court is being asked to do. The petition has all of the basic facts about the situation of the young adult, and the reason for seeking guardianship. What is needed in a petition varies from state to state and within individual counties. A lawyer usually writes and files the

petition in court. For children living in DC, this can be done at no cost to the parents. The petition must be filed at the courthouse in the county or district where the patient lives. This starts the legal process.

WHAT ADDITIONAL DOCUMENTATION IS FILED WITH THE PETITION?

In DC:

The court will appoint and pay for a neutral expert who reports directly to the court as the judge’s eyes and ears. The job of the expert is to represent and help the patient (not the parent) in court. The expert’s report will be included with the petition.

In Maryland:

Maryland has an extra step, requiring that two recent doctor certificates be included with the petition. The doctors' forms can be filled out by a primary care physician, a psychiatrist or social worker, or a specialist who knows the patient well (including doctors at Children's National). One of the health care providers must have examined the patient within 21 days of filing the petition. The petitioner (parent/guardian) must obtain and present these certificates to the court.

In Virginia:

A report must be filed before the hearing, prepared by one or more licensed physicians, psychologists, or other licensed professional(s)/social worker(s). The petitioner (parent/guardian) must obtain and present these certificates to the court.

WILL THERE BE A HEARING?

Yes. In all guardianship cases, there will be a court hearing on the facts presented in the petition. The petitioner (the person who wants to be the guardian) must present "clear and convincing evidence" of the need for guardianship. However, it is very rare that there have to be witnesses and formal testimony. Most of these hearings take only about ten minutes for the judge to read the paperwork and make a decision.

In addition, the petitioner must present evidence that he is fit and the right person to be appointed; is capable of carrying out the responsibilities of a guardian, and that no one of higher

priority is available. However, in DC, Maryland, and Virginia, there is a presumption that the parent is preferred over a stranger, and this presumption can be overruled only for "good cause", such as a bad criminal record or substantial medical problems of their own.

WHO MAY BE APPOINTED GUARDIAN OF MY YOUNG ADULT?

Based on the guardianship law, the court will appoint the best-qualified individual available. This is usually a parent; but it may be a grandparent, adult sibling, or another person whom the court deems better able to act on the young adult's behalf. The person appointed guardian must also occasionally report the status of the young adult's health, finances, etc. to the court.

ARE THERE REASONS NOT TO SEEK FULL GUARDIANSHIP FOR MY YOUNG ADULT?

With guardianship, a young adult may no longer have any authority to make decisions about his personal life. This loss of personal freedom may be upsetting to the young adult, particularly when the person has some decision-making ability. Generally, a guardian should be appointed only if there is no better alternative. In many cases, guardianship is necessary to protect the person from harm or to provide needed services. However, guardianship should be obtained only after other alternatives have been fully considered.

COSTS

The costs of seeking guardianship for an adult are not nearly as high as one might think. In DC, it is usually free. The DC Court prefers to see guardianships in place for at-risk adults, so there is a special fund within the court to pay these costs. The resources section gives several options.

In Maryland and Virginia, some attorneys charge a flat fee, others charge by the hour. The costs for

your attorney should average around \$1,000-\$1,500 for a typical case. Please note that, in both Maryland and Virginia, an independent attorney is also appointed to protect the young adult or child's rights, and the parent might be asked to pay those fees as well. Both states have legal aid societies that can do this for free for those who qualify. ■

SECTION 4:

Emergency Guardianship

WHAT IF THERE ISN'T TIME TO FOLLOW NORMAL GUARDIANSHIP PROCEDURES?

"The Emergency Doctrine"

This doctrine allows doctors to provide treatment in medical emergencies. If a child or adult of any age needs emergency or life-saving medical treatment, Children's National will provide care without waiting for a court order or guardianship hearing. For example, if a patient arrives here and is bleeding profusely, we will provide treatment to stop the bleeding. If he arrives and needs emergency surgery, it will be performed.

However, if the need is less urgent, we cannot use this doctrine. So, for example, if your child needs dialysis "in a few days", we may have to get a court order.

When the situation is urgent, and decisions must be made quickly, the law supports appointing an emergency guardian. For example, a person may require medical treatment that should not be delayed for the time that it usually takes to appoint a guardian. In this situation, an emergency guardianship may be the best solution.

WHAT IF THE PATIENT IS ADMITTED IN OUR HOSPITAL AND NEEDS URGENT – BUT NOT EMERGENCY – CARE?

D.C. Code 21-2204. Certification of Incapacity

This law allows for two professionals, who are licensed to practice in the District of Columbia to say that a patient is unable to make informed medical decisions. The two

professionals must complete a form stating that the patient is incapacitated. The form must be completed by one medical doctor who is treating the patient in the hospital, and one psychiatrist or psychologist. In some cases, our hospital's psychiatrist or psychologist can fill out part of the form. The form is normally used for temporary guardianship, to allow urgent treatment for hospitalized patients. After the form is completed, it is placed in the patient's chart. It is usually only valid for the patient's stay in the hospital, or about 30 days. In cases where the patient's condition is permanent and total, we may continue to use this certification on a permanent basis. Our social workers can help you understand if this may apply to your child's condition.

WHAT IS THE PROCEDURE FOR EMERGENCY GUARDIANSHIP?

The procedure is similar to that of a regular guardianship case, except that the court process moves much faster. To begin an emergency guardianship case, an interested person files a petition with the court to request emergency protective services. As with other guardianship petitions, one might want to consult an attorney before filing a petition. If the young adult is in the hospital, the hospital's social work or legal department may be able to assist you. The courts always have a judge who can be reached 24 hours a day.

Usually you and your lawyers will need at least one business day, and sometimes more. A judge reads the emergency petition as soon as it arrives and



decides if there must be a court hearing immediately or within a few days or a week.

WHAT DOES THE COURT DECIDE IN AN EMERGENCY GUARDIANSHIP HEARING?

The court must decide whether the young adult lacks the ability to make or communicate responsible decisions due to mental disability, disease, or severe alcohol/drug use or other "incapacity." This includes choices for healthcare, food, clothing, or shelter. The court must decide if there is a less restrictive option to support the person's welfare or safety. The court's decision includes whether there is anyone else available who is authorized by law or court order to give consent to the emergency protective services requested by the petitioner. All courts will appoint an attorney for your child to be sure his rights are upheld.

In DC and Maryland, these emergency hearings are often on the same day the petition is filed. In Virginia, it varies by county. In all three, the speed varies with the type of emergency. ■

SECTION 5:

Additional Information

WHEN SHOULD I START THE GUARDIANSHIP PROCESS?

The process should start before the person turns age 18. A legal guardian may be required if your young adult has a condition that does not allow him to make a decision on his own. If you are the birth parent or you have already been named your young adult's legal guardian by a court, it is important that you apply for guardianship right away. This process can be long, so it is best to start learning about the guardianship process when your child is age 17. You cannot actually start the process until your child turns 18, but you can learn about your options in advance.

THIS PROCESS SEEMS COMPLICATED. SHOULD I GET AN ATTORNEY?

We strongly recommend that you consult with an attorney when planning for your young adult's future. The resource section gives the names of several organizations that may guide you to low-cost or free legal resources. Attorneys who work with young adults with disabilities understand their needs and have experience preparing the necessary legal documents. An attorney will also be helpful in managing court processes, and can help the process go faster. You can complete many of the forms and actions discussed in this brochure on your own – in fact, some forms are available on state agency websites. ■

SECTION 6:

Summing Up

Making decisions about one's own health and managing complex healthcare is a learned skill. It is crucial for families of children with complex or chronic health conditions, or intellectual differences, to think about the future. Begin discussions with your child during his teenage years. Include your child's healthcare providers in the conversation. The goal is to educate

patients about their health condition and to slowly transfer responsibility before reaching age 18. Starting early will help prepare patients, families, and providers for this transition. Everyone involved will have a better understanding of how best to continue to provide support and assistance to young adult patients. ■



SECTION 7:

Where Can I Get Legal Help?

Hiring a lawyer can be both time-consuming and expensive. The following guidelines may help you choose a qualified and affordable attorney in your area.

ASK AT YOUR LOCAL COURTHOUSE

Call, visit, or look on the internet for the courthouse in the county or district where your child lives. Most courthouses have a Family Court Division, with an office that provides free support services for persons seeking guardianship. They can help you get the required paperwork. They may also be able to link you with an attorney who can provide legal services with low or sliding scale fees, or pro bono (free) services.

CONTACT THE BAR ASSOCIATION IN YOUR STATE

This organization may be able to refer you to lawyers who specialize in guardianship issues. Ask them if they can refer you to someone in your area.

CONTACT YOUR LOCAL LEGAL AID BUREAU

If your household income is low, you might qualify for free legal advice. Legal Aid can tell you if you qualify and refer you to a lawyer in your area.

DISTRICT OF COLUMBIA RESIDENTS ONLY

The process for filing and obtaining guardianship is done through the DC Probate Court. In DC, adult guardianship cases can be referred to an attorney who can represent the patient in court at no cost to the patient or family member, because the DC Court pays for the court costs under DC Code 21-2060. The family may choose an attorney they prefer.

To begin the process, contact the DC Superior Court Probate Division.

**DC Superior Court Probate Division
Probate Court Building Court A**

515 5th ST NW, 3rd Floor
Washington, DC
202-879-9460

Children's Law Center

www.childrenslawcenter.org
501 3rd St NW, 8th Floor
Washington, DC 20001
(202) 467-4900

**Quality Trust for Individuals
with Disabilities**

www.dcqualitytrust.org/advocates/attorneys/
4301 Connecticut Ave NW, Suite 310
Washington, DC 20015
(202) 448-1450

MARYLAND RESIDENTS

The process for filing and obtaining guardianship is done by petitioning the Circuit Court in the county in which the patient resides. The paperwork for filing may be obtained at the courthouse or online. Two locations are:

Family Support Services

Montgomery County Circuit Court

50 Maryland Ave, Room 1500
Rockville, MD
240-777-9400 (general)
240-777-9426 (guardianship)

**Family Support Services of PG County
Prince George's County Circuit Court**

14735 Main ST
Upper Marlboro, MD
301-952-3322 (general)
301-952-5001 (guardianship)

VIRGINIA RESIDENTS

The process for filing and obtaining guardianship is done by petitioning the Circuit Court in your county. The state of Virginia does not have specific forms for guardianship. The first step is to contact an attorney and he will help with gathering the necessary documents. Some possible resources include:

Fairfax County Bar Association

4110 Chain Bridge Rd, Fairfax, VA 22030
703-246-3780

Arlington County Bar Association

1425 N. Courthouse Rd.,
Suite 1800, 1st Floor
Arlington, VA. 22201
703-228-3390

Alexandria Bar Association

520 King Street, Suite 202
Alexandria, VA 22314
703-548-1105

Loudoun County Bar Association

P.O. Box 201
Leesburg, VA 20178
703-777-0523

**Prince William County
Bar Association**

9311 Lee Avenue Third Floor
Manassas, Virginia
703-393-8865

Virginia Guardianship Association

P.O. Box 9204, Richmond, VA
804-261-4046
www.vgavirginia.org

SPECIAL POWER OF ATTORNEY

Name: _____

I _____
(Patient)

residing at _____

hereby appoint _____
(Agent's name)

residing at: _____

as my attorney-in-fact ("Agent").

My Agent shall have full power and authority to act on my behalf. This power and authority shall authorize my Agent to exercise the following legal rights and powers:

Make decisions regarding my health and well-being, to include the provision of medical care, or long term care should the need arise, at appropriate institutions; and, the termination of life support and/or medical treatment, should either be or become necessary.

No person who relies in good faith on the authority of my Agent under this instrument shall incur any liability to me, my estate, or my personal representative. I authorize my Agent to indemnify and hold harmless any third party who accepts and acts under this document.

If any part of any provision of this instrument is found to be invalid or unenforceable under applicable law, the rest of the provisions will still be valid.

This Power of Attorney shall become effective immediately, and shall not be affected by my disability or lack of mental competence, except as may be provided otherwise by an applicable statute.

This is a Durable Power of Attorney. This Power of Attorney shall continue to be effective until my death. This Power of Attorney may be revoked by me at any time by providing written notice to my Agent.

Dated: _____

By: _____

Witness Signature: _____

Name: _____

City: _____

State: _____

Witness Signature: _____

Name: _____

City: _____

State: _____

Witness Signature: _____

Name: _____

City: _____

State: _____

This instrument was acknowledged before me on this _____ day of _____ by _____.

(Notary Public Signature)

My commission expires _____

ACKNOWLEDGMENT OF AGENT

BY ACCEPTING OR ACTING UNDER THE APPOINTMENT, THE AGENT ASSUMES THE FIDUCIARY AND OTHER LEGAL RESPONSIBILITIES OF AN AGENT.

Dated: _____

9/2018



Children's National®

111 Michigan Ave NW | Washington, DC 20010 | 888-884-BEAR (2327)

ChildrensNational.org

DC | HEALTH

WE ARE
DISTRICT **DC** **GOVERNMENT OF THE
DISTRICT OF COLUMBIA
MURIEL BOWSER, MAYOR**