

Health Care and Developmental Disabilities

A Message to Patients

Here are ideas that can help you make medical decisions for yourself or help you choose someone to decide if you can't. Details on the rights of patients with developmental disabilities are found in a [booklet](#) called *References for Patients, Families, and Providers*. Click on the blue link to find the booklet on the Internet: <https://alternativestoguardianship.com/how-to-references.pdf>

1. You Have the Right to Make Your Own Health Care Decisions



You become an adult when you turn 18. As an adult, you have the right to make your own health care decisions. You do not lose this right just because you have a disability. Your right to make medical decisions can be taken away by a court if you are not able to understand or to communicate and you did not name someone else to make medical decisions for you.

2. You Have the Right to a Support Person



You have the right to ask for help in making health care decisions. You can name a trusted family member or friend to be your support person. The support person can go with you to medical appointments or be with you for emergency medical services. With your consent, a support person can have access to your private medical records and information. You can name more than one individual to act as a support person. You can tell the doctor, nurse, dentist, or other health care professional that you want a support person. Your request must be accepted. Your right to a support person is protected by a law known as the Americans with Disabilities Act.

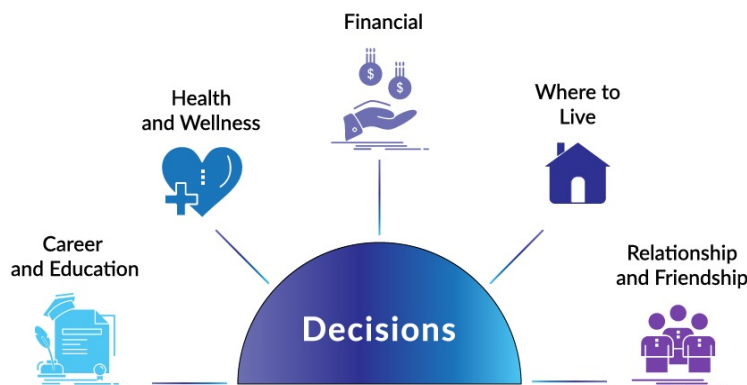
3. You Have the Right to Extra Help



If you have a disability that makes it hard to make medical decisions or explain your decisions, you have the right to have extra help from doctors, nurses, dentists, and hospitals. If you are deaf or hard of hearing, you may need a sign language interpreter. If you can't read, you may need someone to verbally read to you what the documents say. If you have a learning or intellectual disability, you may need someone to

help explain medical issues to you. You may need to see images instead of words. You may need extra time to make a decision or you may have to come back to the medical appointment on another day, after you have had time to think more about the problem. You may need to use a communication device. Getting extra help is your right under the Americans with Disabilities Act.

4. You Can Sign a Supported Decision-Making Agreement



You can name one or more individuals to help you make decisions in your life. Health care is one of the areas that can be included in a document that is called a *supported decision-making agreement*. With a supported decision-making agreement, **you make**

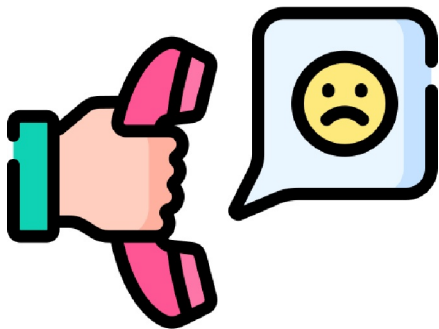
the decisions for health care services. The support person merely **helps you** understand the risks and benefits and possible choices. The support person helps you communicate the decision to the doctor or nurse or dentist. State and federal laws protect your right to have a supported decision-making agreement.

5. You Can Choose Someone to Make Medical Decisions for You



There may be times when you are unable to make your own medical decisions. This may be caused by medication, an accident, or an illness that makes you not able to understand or communicate. You can make a plan in case this ever happens to you in the future. You can sign a document called a power of attorney. It allows you to name one or more trusted individuals to make medical decisions for you if doctors believe you are unable to understand or communicate. Doctors, nurses, dentists, and hospitals must respect the decisions of the person chosen by you to make decisions when you are unable to understand or communicate.

6. You Can Complain if Your Rights Are Violated



You have the right to file a complaint if your rights are violated by a doctor, nurse, dentist, or hospital. If you are told that you can't make your own medical decisions, or if your right to support is denied, or if your power of attorney is rejected, you can ask for a supervisor. If the supervisor does not respect your rights, you can file what is called a grievance with the manager of the medical office or hospital. You can have help from a family member, friend, or other trusted person to make the complaint. If you do not agree with the final decision of the medical provider, you can file a formal complaint with one or more government agencies. These agencies are listed in the reference booklet mentioned on page one of this document. You can have someone help you file a complaint. You can also ask for help from an organization known as Missouri Protection and Advocacy Services. They have lawyers who are trained about the rights of patients with all types of disabilities. Their contact information is found on the next page.

7. If You Are in a Guardianship, You Can Ask the Judge to End It



Thousands of adults with mental or developmental disabilities are living under an order of guardianship. Many of them have had the right to make their own medical decisions taken away by a judge. For those adults, medical decisions are made by their guardian.

If you are in a guardianship, you can ask the court to end the guardianship totally if you believe it is no longer needed. Or you can ask that it be changed to give you back the right to make your own medical decisions.

If you and your guardian both agree to change the guardianship to restore your right to make medical decisions or to end the guardianship entirely, a judge can make that happen without the need for a court hearing.

If the guardian does not agree to end or change the guardianship, you can ask the court to do so by sending a letter to the court. The court would appoint an attorney to represent you. If you are unable to send the letter, another person can send the letter to the court for you. A judge may require medical proof that you have the mental ability to make medical decisions or other major life decisions. If the guardian refuses to have you evaluated by a doctor or psychologist, a court-appointed attorney can ask the judge for an order appointing a professional to conduct such an evaluation.

An organization known as Missouri Protection and Advocacy Services (Mo P&A) can help you try to end or change a guardianship. They have lawyers who can advise you or represent you. You can contact the Application Unit of Mo P&A or fill out an [Online Request for Help](#) form. Contact the Application Unit using one of the following methods: call 1-800-392-8667, or for TDD Users at 1-800-735-2966; send an email to app.unit@mo-pa.org; send a letter to Application Unit, Missouri Protection and Advocacy Services, 925 South Country Club Drive, Suite B, Jefferson City, MO 65109.

8. You Can Report Abuse or Medical Neglect



If you believe that you are not receiving necessary health care services, you can report the problem to Adult Protective Services. You may be living on your own, with a family member, or you might be under the care of a public guardian. It is neglect when a guardian or caregiver fails

to provide you with needed medical or dental care.

If you believe you are being physically, emotionally, or sexually abused, that your needs are being neglected, or that you are being bullied by someone, you can call the hotline at 800-392-0210. The hotline operates 365 days per year from 7 a.m. to 8 p.m. People who are deaf or hard of hearing may utilize Relay Missouri by calling 1-800-735-2466. A report of abuse, neglect, or bullying also can be made online: <https://health.mo.gov/safety/abuse/>

If you need emergency medical services, you should press 911 on the phone.

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