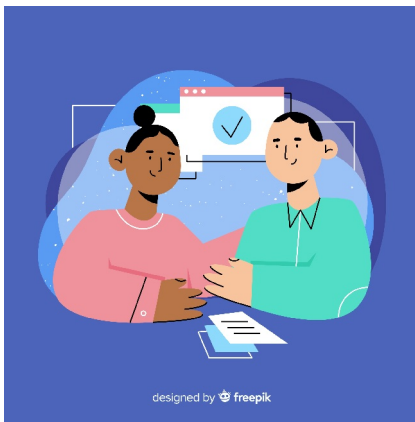


Health Care and Developmental Disabilities

A Message to Families

The following suggestions can assist parents and other family members of adults with developmental disabilities to help them make medical decisions and, if necessary, to advocate for them in a health care setting. More details on the rights of such patients and families can be found in a [memo](https://alternativestoguardianship.com/how-to-references.pdf) titled *References for Patients, Families, and Providers*. <https://alternativestoguardianship.com/how-to-references.pdf>

1. A Family Member Can Be a Health Care Supporter



Although an adult has the right to make medical decisions without assistance, they also have the right to someone help them decide. The support person can attend medical appointments or emergency services, discuss medical options with the patient and provider, help the patient understand risks and benefits, and help the patient communicate decisions to the provider. A patient can designate a family member as a support person orally, with a written request for an accommodation under the Americans with Disabilities Act, or with a written supported decision-making agreement.

2. A Family Member Can Have Permission to Access to Medical Information



With the consent of an adult patient, a family member can be given information about the patient's diagnosis, condition, prognosis, and options. This includes access to medical records. Regardless of their disability, a patient can designate a family member as a personal representative and can sign a HIPAA waiver to overcome any confidentiality issues.

3. Sometimes a Family Member Can Be Designated as a Health Care Agent



General Rule: An adult patient can sign a durable power of attorney for health care in which a family member is designated as their agent in the event a doctor finds the patient to lack the capacity to make their own medical decisions. Even if a patient lacks capacity to make medical decisions, they may have capacity to select a health care agent. To have capacity to sign a medical power of attorney, a

patient merely needs to understand that there may be times when they cannot make their own decisions and that they want to name the family member as the person who can make decisions for them under such circumstances. This delegation of authority must be given voluntarily by the patient and without undue influence or pressure.

Exceptions: *When the document is executed* – a medical power of attorney is not valid if, at the time it was executed, the adult did not understand that they were delegating authority to another person to make medical decisions for them in the event they were found to be incapacitated by a doctor. They must understand what they are signing and communicate a desire to delegate such authority to the person they name in the document. *When consent is given for a medical procedure* – an agent cannot give or refuse consent for a medical procedure under a medical power of attorney if, at the time consent is requested by a medical provider, the patient has capacity to give or refuse consent themselves. The agent can only give or refuse consent at a time that the patient is incapacitated (when they can't understand the risks and benefits or cannot communicate their decision).

4. A Family Member Can Help a Patient Fill Out Documents



A family member can help a patient fill out forms protecting medical rights. Counseling may be available through organizations such as Hulme Resources Inc. Sample forms are available for: (1) designation of ADA support person; (2) HIPAA release of information; (3) designation of a patient representative; (4) designation of a health care agent; (4) power of attorney and advance directive; (5) complaint to DHSS for hospital violations; (6) supported decision-making agreement; and (7) health care passport listing relevant medical information and needs of the patient.

5. A Family Member Can Help a Patient Challenge the Denial of Rights



A family member can assist a patient to object to the denial of the patient's right to: (1) a support person or support services; (2) designate a personal representative to have access to medical information and records; (3) designate a health care agent to make decisions for them in the event they are found incapacitated by a doctor; and (4) any other rights of a patient.

When a patient's disability prevents them from challenging the denial of their rights, someone can advocate for them. Unless they are in court, an advocate does not need to be a lawyer. A family member can be the patient's advocate in administrative settings.

As an advocate for a patient whose rights have been allegedly violated, a family member can: (1) ask to speak with a supervisor; (2) file a formal grievance with the health care provider; (3) file a complaint against a hospital with the Department of Health and Senior Services; (4) file a complaint against any public or private health care provider with the Office of Civil Rights of the United States Department of Health and Human Services; or (5) file a complaint with a professional licensing agency that provides oversight to medical doctors, nurses, or dentists. More information on how to file a complaint with a state or federal agency is found in the Reference booklet mentioned on page one of this brochure.

A family can seek legal assistance for the patient from Missouri Protection and Advocacy Services. If it intervenes, Mo P&A would represent the patient, not the family.

6. A Family Member Can Help a Patient End or Change a Guardianship



If someone is in a guardianship and that person or their family member believes it is no longer needed, a petition can be filed with the court to end the guardianship entirely or to modify it to restore medical rights. A family member can ask the court to terminate or modify the guardianship. A lawyer is not needed. The family member would send a letter to the court. The letter would explain factual reasons why the guardianship should be ended altogether or why the court should at least restore to the adult the right to make their own medical decisions.

If the family member is the guardian, the letter should inform the court of this fact. It should explain if the adult agrees with termination or modification of the guardianship. A written statement from the adult can be attached to the letter of the family member. It would be helpful to attach a statement from the adult's physician, psychologist, or social worker that the professional believes the adult can make their own medical decisions, with the assistance of a support person if that is the case. If a joint petition is filed by the guardian and protected person, the court may terminate the guardianship without the necessity of a hearing.

A family member may also help the adult contact Missouri Protection and Advocacy Services to ask for legal assistance to end or change the guardianship so their medical rights are restored. 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.

7. Families Can Petition for a Guardianship



If an adult lacks the ability to understand risks and benefits of a medical procedure or cannot communicate a decision, even with assistance, a guardianship may be needed. In such a case, if a valid medical power of attorney does not already exist, and if the patient presently lacks capacity to sign one, a guardianship can be used to empower someone to give informed consent to a medical provider on behalf of the patient. Under such circumstances, a family member can ask

the court to appoint a guardian to make medical decisions for the patient. A guardianship could be limited to medical decisions. It could also be temporary. A family member can hire an attorney to file a guardianship petition. If they do not have funds to retain an attorney, they can file a petition on their own.

8. Families Can Report Medical Neglect



If a family member believes their loved one is not receiving necessary health care services, they can report the problem to Adult Protective Services. The loved one may be living on their own, with another family member, a licensed facility, or under the care of a public guardian. It is neglect when a guardian or caregiver fails to provide an adult who is dependent on them with needed medical or dental care.

If a family member believes their loved one is being abused or neglected medically, financially, or otherwise, they 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 or neglect can be made online: https://apps4.mo.gov/APS_Portal/ If it is a medical emergency, call 911.

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