



# Making Medical Decisions for Someone Else

**A Vermont Handbook** 



A publication by the Vermont Ethics Network



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There may be times when you are called upon to

make medical decisions for someone else. This resource is available to answer questions that may arise and to help guide you in this process.



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### Introduction to Medical Decision-Making

Imes have changed. Just a few decades ago, when a person sought a doctor's care there was little for anyone to "decide." Medically, not much could be done if you suffered a stroke or contracted tetanus from stepping on a rusty nail. Today it is a different story. Advances in medical science and technology now make it possible to extend life beyond natural limits, sometimes far beyond. Indeed, it is increasingly possible to extend life past the point that some people say they would want to live. Survival is no longer the primary question, quality of life is.

This is a huge change, and one that has greatly complicated medical decision-making. For all its wonderous advances, medical science tells us only what **can** be done. What **should** be done depends on the individual and their priorities, goals and values. Adults have a right to refuse any treatment they do not want, even if they lack decision-making capabilities.

Often a person can weigh risks and benefits of proposed treatment options and make a decision for themself after talking their choices through with their doctor and family members or friends. That is the ideal way to do it.

Some people, however, are unable to make decisions for themselves. They may be unconscious or confused or too sick to grasp the condition they are in. Perhaps they suffer from Alzheimer's Disease or severe developmental disabilities. Maybe they are only temporarily incapacitated because they had a stroke or were in an accident. But decisions still have to be made. A doctor can't make these decisions for the person; someone else must decide on the individual's behalf. Except in an emergency, no medical treatment may be given without the informed consent of the individual or their designated decision-maker.

You may be that designated decision-maker. Perhaps you are the **health care agent** named in the person's advance directive. Or maybe a judge appointed you to be the **medical guardian**. Or maybe you are a family member or close friend of the patient, and the doctor has turned to you and asked, "What would this person say if they were able?"

You will need to be prepared to answer this question.



### Who is This Handbook For?

If you make health care decisions for someone else — or might at some future point — this handbook is for you. When you make medical decisions for someone else, you are acting as a surrogate decision-maker — which is the general term used in this handbook for a person who makes decisions for someone else.

### There are three kinds of surrogate decision-makers:

There are three general kinds of decision-makers: Health Care Agent, Guardian, and Surrogate. In all cases, this is the person who is making decisions for someone who is not able to do so for themself.

- **1. Health care agent.** A special kind of surrogate decision-maker, where an individual has signed a legal document called an advance directive authorizing you to make health care decisions for them in case something happens. In Vermont, this used to be called a durable power of attorney for health care. If you are named in an advance directive to make medical decisions for someone else, you are a **health care agent**.
- **2. Guardian.** Another special kind of surrogate decision-maker where a court has appointed you to serve as medical guardian and specifically authorizes you to make health care decisions for someone else. A guardian is directly answerable to the appointing court. (See <u>Appendix B</u> for more information.)
- **3. Surrogate.** Even if nobody has formally named you as their health care agent, you may still be asked to make medical decisions for someone else. Family members, close friends or people with a known close relationship to the person are sometimes called upon to make decisions when the person cannot speak for themself. In this case you are a surrogate decision-maker.

The scope of authority of each kind of decision-maker is a little different, but all share the responsibilities and challenges of health care decision-making for someone else. This handbook describes what it is like to make decisions for someone else, what to do while there's still time to think about it, and what to do in a crisis. It also talks about situations that you may face and tells where to get more help. (See <u>Appendix E</u>: Table of Decision-Maker Authority for a comparison of the different types of surrogate decision-makers.)



## What is it Like to Make Medical Decisions for Someone Else?

A long-time friend of the family, who is like an uncle to me, asked me if I would be his health care agent under an advance directive he was planning to sign. I didn't know what to say or think, so I said, "Sure. I would be happy to." But I don't really know what I'm getting myself into. What am I getting myself into?

If you are designated to make medical decisions for someone else, your job is to make decisions consistent with what the person would decide if they were able.

#### This includes:

- ◆ Getting the same medical information the patient would get. You should have access to the person's medical records and any information you need about their health or health care. If you are having trouble getting their medical information, contact the medical facility's privacy officer and ask for help.
- ◆ Talking with the medical team about treatment choices. You will need to ask questions and get explanations, so that you can understand the person's medical condition and treatment options as much as possible.
- Asking for consultations and second opinions from other doctors.
- ◆ Consenting to or refusing medical tests or treatments including life sustaining treatment in many, but not all, cases.
- ◆ **Deciding whether to transfer care of the person** to another doctor or health care facility (such as a hospital or skilled nursing home).
- ♦ Getting the doctor and other medical professionals to communicate with the **person** if they are still able to understand information.

Being someone else's health care decision-maker can be difficult. But there are several key things to remember:

- You can say yes or no. If asked to make medical decisions for someone else, you can say no. It may be hard enough coping, even without the added responsibilities of making health care decisions. But it can be an important way to help someone you care about.
- ◆ Anxiety is normal. It is not unusual to feel lots of emotion, stress, and doubt. You may not be comfortable around doctors, the medical words they use, or busy hospitals. It is a big responsibility and can be a tough job. But there are many places to go for help. You are not alone. See Section VI.



Making medical decisions for someone else — you have the special responsibility and priviledge of doing something important for another person.



- ♦ **Keep the person involved.** Even though they are not able to make health care decisions, they might still have something important to say. If you can communicate with them, try to involve them in the decisions as much as possible. If they are able to express meaningful choices, these should always be sought out and honored.
- ♦ It's not about your money. There could be questions about money and insurance, but your own money is not at risk. Being someone else's medical decision-maker does not make you owe or pay anything with your money or risk being sued. It is only the individual's money and insurance that is involved.
- ♦ **Inaction has consequences, too.** You will be expected to make decisions. The doctor is relying on you for guidance, so consult with the medical professionals involved and try to sort out the best options for the person.
- Respect culture. The person's cultural background might be one of many factors affecting how health care decisions are made. In some cultural groups, for example, the whole family is involved. Be aware of cultural beliefs and do your best to understand how, or if, the individual's culture might impact the decisions they would make.





### What Should You Do While There is Still Time?

### Understanding the Person's Values and Wishes

Now that I have become my dear friend's health care agent, is there anything I should be doing before I'm called on to make decisions?

Your first task is to learn as much as possible about *what matters most to the person* if they were seriously ill. What choices would be in line with their values, religious beliefs, personal priorities, and past decisions? What fits with the person's "life story"? How would they want to live the final chapter of their life? This is important to learn ahead of time because you must try to make decisions as the person would, even if that means going against the way you would decide for yourself.

Try to prepare in advance with the person for whom you will be making decisions. This means having conversations about their values and priorities *before* a crisis arises. Not everyone can do this, but if there is still time, you will be glad that you did. Learn what is important to them in making decisions about their health. What are their hopes and fears for the future? What are they willing to sacrifice for a chance at getting better? What are they not willing to sacrifice? Don't be afraid to use the "D" word: *Dying*. It's hard to talk about illness and dying, but it's a lot harder to make decisions without having a sense of what matters most to them.

### Tips:

- ◆ One way to begin the discussion is to share stories. Ask about their past experience, what was meaningful, what happened when others in the family were ill

   anything to help draw out values and beliefs.
- ◆ Another way you can get the conversation going is by using **The Medical Decision-Maker Quiz** in <u>Appendix A</u> of this guide. The quiz will help you find out how well you know the health care wishes and values of the person for whom you will be making decisions. It will help start a conversation and might result in better mutual understanding.

Telling stories
can be a way to find
out about the person's
wishes and values.



### Steps to Follow in Making Medical Decisions



Find out the facts.
Find out the options.
Decide based on what the patient would want. If there is no way to know what the patient would want, do what is best for the patient.

Carla stood in the hospital hallway with the doctor who was explaining the seriousness of her mother's condition. Some time ago, her mother had named Carla as her health care agent in her advance directive. But Carla is still in shock over what is happening. And she is now being asked to make some very big decisions about her mother's care. How does she begin?

Use these basic steps to help you make decisions on the person's behalf.

1. Learn as much as you can about what the person would want given their current medical situation. As stated above, your main job is to make medical decisions as the person would, based on their beliefs, values, previously expressed wishes and decision-making history. If the two of you talk about care preferences while they are still able to make decisions, you will have a much better idea of the choices they would make. However, it is your job to make decisions based on what you think they would say, if known, or what is in their best interest.

It is important to try and communicate directly with the person. They should be consulted to the greatest extent possible about all treatment decisions. Don't assume communication is impossible. Sometimes a person who cannot speak or who has Alzheimer's Disease or severe developmental disabilities may be able to make their preferences known. A person with a speech or movement impairment may be able to communicate by the squeeze of a hand or the blink of an eye. Work closely with the doctor, nurses and other staff as you attempt to communicate. Even when communication and response does not seem possible, it is important to tell the person what is happening and why. Sometimes they can hear you but cannot let you know it.

You may be tempted to do only what *you* think is best for them. Try to resist this temptation and instead think of what they would want done.

**2. Find out the medical facts.** This requires talking to the doctors and getting a complete picture of the situation. A health care agent or guardian is entitled to see the medical records just as the patient would. They are entitled to all the same information the patient would get, and to have access to doctors as the patient would. Full cooperation from the medical team is expected.



#### Questions you can use:

- What is the person's condition?
- If you don't know exactly what's wrong, what are the possibilities?
- ◆ Are tests needed to know more? Will the results of more testing make any difference in the treatment plan, or in the outcome? (If not, why do the test?)
- What is the purpose of each test? What are the risks of the test? Is the test necessary?
- Is the information you will learn worth the risk?
- How severe or advanced is the disease or problem?
- ★ Is the disease or problem treatable or fixable?
- ♦ What do you think will be the likely course of this disease or condition?
- ♦ What will recovery look like: going home or going to a rehab facility or nursing home, etc.?
- **3. Find out the options.** Make sure the doctor describes the risks and benefits of each option, including the option of declining treatment or changing the treatment goal from cure to comfort. In comparing options, ask:
- How or will each option improve the patient's condition or help them to feel better?
- ◆ Can this procedure be done on a trial basis first? What is a reasonable amount of time for a trial? Is the doctor willing to stop after an agreed-upon trial if the treatment is not meeting the desired goal?
- ♦ What defines "success" for this option? (It may not be what the patient would consider a success.) What is the success rate for people in similar situations?
- ♦ What will it mean about the person's ability to do things and to communicate meaningfully with family and friends?
- ♦ What are the possible side effects?
- ♦ What option does the doctor recommend, and why?



#### 4. Figure out what the person would decide if they were able.

- ♦ If you know what the person would choose, you should act on it. If they left written instructions, do your best to honor them.
- ◆ If you do not know the person's wishes for the decision at hand, you still might have solid information to figure out how they would decide. The goal is to make decisions based on what they would want, not what you would want for them. Consider their values, religious beliefs, past decisions, and past statements.
- **5.** If you just don't know what they would do, choose the option that is in their best interest. If you have little or no information on what they would want, then your job under the law is to do what you believe to be best for the person. In weighing the options, you should consider what a reasonable person in the same situation would decide, and the benefits and burdens of each reasonable option. Don't be influenced by whether the person is poor or has a long-term disability. You must not base decisions on your own wishes or what you would like best.



What would they want? The aim is to choose as they would probably choose, even if it is not what you would choose for yourself.





### Working Within the Health Care System



Ellen's mother was undergoing treatment in a hospital. Ellen had never spent time in a hospital before and it seemed confusing. While the medical staff was working hard as a team, the same staff was not there all the time. Their schedules shifted depending on the time of day, the day of the week, and the week of the month. Her mother had several doctors, including a hospitalist who changed each week and other specialists overseeing her care. It was stressful not knowing who to talk with and being in a place with so many sick people.

Being thrust into the hospital or other medical setting can seem like visiting a foreign country. Even for people familiar with the routines of the healthcare system, it can be challenging. Here are some tips that may help.

#### What Can You Do?

◆ If your authority to make medical decisions comes from a document (advance directive or guardianship order), be sure you know exactly what the document says. The document should give you guidance on how to exercise your authority.

Often the instructions in an advance directive are vague. (This is actually quite common, given how hard it is to predict what may happen.) Because of this, you may have to make the best decision you can with the information you have. Consider past discussions the person had with you or others that may shed light on their wishes and values.

If your authority comes from a guardianship order and there is something in the court papers that you do not understand, ask the court to explain it.

- ♦ Make yourself and your role known to the medical staff. Make sure any advance directive or court document appointing you as medical guardian is in the medical chart and staff know what the document says. Have a copy ready to show to people involved in the person's care. Keep in touch with these people.
- ♦ Understand the Individual's Goals of Care. You play a vital role in deciding the goals of the person's care. One goal may be to cure disease and prolong life. Another is to relieve suffering and provide comfort. Yet another may be to achieve a good death. When a person has a serious or life-threatening illness, these goals sometimes come into conflict with each other. The person's values and priorities should determine the balance between goals. For some people, one goal takes priority over another during the course of an illness. For others,



goals may change as an illness progresses. If the person's values and priorities are unknown, the decision-maker should set goals they believe will serve the person's best interests (goals that a reasonable person in the same situation would set).

Talk with the medical team about the individual's goals and values. As shifts change and different doctors and nurses become involved in the person's care, you will often be the one to give them information about the priorities. You may have to repeat the same information many times. Try not to get frustrated. This is an important role of a medical advocate.

• Monitor the Overall Care Plan. Every hospitalized patient and nursing home resident should have an individualized care plan. The care plan covers key things about the person's care, such as treatment goals and how those goals will be achieved. Often the care plan is written down in a special form kept in the person's chart.

### Care Plan Key Components

- 1. The main goals of care;
- 2. Whether the person has an advance directive and contact information for health care agent;

- 3. How the health care professionals should respond if the person's heart or breathing stops (e.g. Do Not Resuscitate [DNR]);
- 4. Whether a breathing machine should be used if the person has difficulty breathing, or whether it should be used for a limited time;
- 5. Whether there are other life-sustaining treatment issues that might be particularly important for the patient that should be documented in the chart or on a DNR/COLST form;
- 6. Whether medically administered fluids and nutrition should be used if the person cannot take in enough orally, or whether these should be used for a limited time;
- 7. Whether antibiotics should be used in case of infection.
- 8. Whether the person should be transferred to another health care setting if their condition worsens; and
- If the person develops significant symptoms, whether tests should be done to diagnose the problem, given that many tests cause discomfort or burdens and may not change the outcome.

Monitor the care plan. Be sure it reflects the patient's goals. Suggest changes as the patient's condition changes and make sure the plan is being carried out.

If you have questions about the care plan or if you do not agree with parts of the plan — or the way it is carried out — you should discuss your concerns with a health care professional or ask for a formal care planning meeting. A care planning meeting includes all of the health care team and provides the medical decision-maker with an effective way to ask questions, resolve problems and ensure that the care plan best meets the person's needs.

♦ Stay informed about the person's condition. Medical conditions can change quickly. Find the person who can best keep you informed how the patient is doing. Stay involved and be flexible.



Be Visible
Be Informed
Be Involved
Be Heard



- ◆ Be ready for transfers to another medical setting. If the person is moved from one section of the hospital to another or to a different facility, make sure that everyone knows the goals of care and the treatments to be continued, begun or stopped after the transfer. Meet with the new medical team or head nurse to be sure that they are aware of the care plan and any ordered treatments.
- ◆ Advocate on the person's behalf and assert yourself with the medical team, if necessary. If you think that the person would not want a treatment that is being offered or provided, it is your job to speak up. It is also your job to speak up if you think they would want a treatment that is not being offered or provided. If you are confused by the doctor's recommendations,

don't stay quiet. Be respectful, but insist that medical issues be explained to you in words you can understand.

Sometimes a doctor might recommend a treatment that you believe the person would not want or you might request a treatment that the doctor believes is inappropriate. Most differences of opinion about the course of treatment can be resolved through discussion about the treatment options, the effectiveness of possible treatments, and how that aligns with the values of the person.

Ask the doctor to explain the risks and benefits of the treatment and to review any reasonable alternatives. Find out what will happen if you do not consent to the treatment. Tell the doctor why you think the person would not want the treatment. If the doctor is refusing to provide a treatment, ask the doctor why the treatment is not appropriate. Find out under what circumstances the treatment might be appropriate. Explain why you think the patient would want the treatment.

♦ Ask for a second opinion or transfer, if necessary. If you and the doctor still cannot agree, or if you are just not sure what to do, there are additional steps you can take. You can ask for a second opinion. If you do this, be sure that the second doctor has all the information needed to make a recommendation about treatment options, including information about the person's goals and values. Or you can ask the doctor to help you find another doctor who will provide the treatment you believe the patient would want. Be a squeaky wheel if need be!



- ♦ Consider a time-limited trial of treatment. Sometimes it is difficult to weigh the benefits and harms of a treatment. Trying a treatment for a period of time may show if it improves the person's situation. Be sure everyone is clear at the beginning of a trial course of treatment that the treatment will be stopped if it is not achieving the intended goal.
- ◆ Make use of all available resources. The world of modern medicine can be complex and confusing, and hospitals have people who can help. Social workers can provide emotional support and practical assistance, patient advocates can make sure your concerns are heard, palliative care specialists can assist with symptom management and clarifying goals for care, and ethics consultants can help you and the medical staff work through complex situations.
- ♦ Consider hiring a private care manager if you are unable to work with the medical team on your own. A care manager, who usually has an advanced nursing or social work degree, can help you understand the medical situation and advise on care options.

### **Talking with Doctors**

Prepare well for the time you have with the doctor.

You may have limited time with the person's doctors, so prepare in advance to get the most out of the each visit.

- ◆ Make a list of questions to ask the doctor, such as concerns about symptoms, changes that have occurred, or medication reactions. If you have concerns about whether the person is receiving the care and treatment they would want, say so.
- ◆ Present your points or key questions right away. Find out how much time the doctor has to talk with you and begin with the most important problem first. If you know what you would like done, say so at the beginning. If you have questions, ask the most important ones first.
- ♦ **Don't hesitate to ask questions.** For example, ask: What will this treatment do? What would happen without the treatment? What are the side effects? How long will it take? What if the person has a reaction to the treatment later? Make sure you understand. It may help to repeat what the doctor told you in your own words, to be sure there are no misunderstandings.
- **◆ Take notes** to help you remember what the doctor says.
- ◆ **Consider bringing a friend or relative** of the person with you to help you remember what to ask, what the doctor says and for moral support!



### Helpful Documents to Be Aware of and to Use if Appropriate: DNR Orders and COLST Forms

Ordinarily, medical personnel — including emergency medical technicians

An advance directive alone may not be enough to insure that a person's wishes to limit treatment will be honored.

("EMT's") and other first responders — do everything they can to keep people alive. They are trained to do everything unless a doctor authorizes some limitation of treatment. Some seriously ill or dying people are sure they do not want certain medical procedures or treatments at the end of life. Others do not want to be taken to a hospital if a medical issue arises, or be given aggressive treatment. An advance directive alone may not be enough to insure that a person's wishes to limit treatment will be honored because advance directives are not recognized by emergency medical personnel and first responders. A DNR/COLST order is necessary to ensure that a preference to limit treatment will be honored across all care settings — particularly in an emergency.

### DNR Orders and COLST Forms Do Not Mean No Treatment

Most people want comfort care even when they don't want any other medical interventions. Some people want treatment for other conditions. Make sure the medical staff understands what the DNR or COLST says and that they know what is desired as well as what not to do.

As a medical decision-maker, you may need to decide whether the person should have a Do Not Resuscitate ("DNR") order or Clinician Order for Life-Sustaining Treatment ("COLST"). These are medical orders signed by a doctor, nurse practitioner, or physicians assistant that tell everyone — including first responders — not to do certain things that would normally be provided. They are powerful tools for ensuring that a person's wishes to limit treatment are respected, because they are recognized by all medical personnel in all health care settings. They can be used for a person who is at home, in a nursing home, or in a hospital. If there are specific procedures or treatments that the person would not want, talk with the doctor about whether a DNR/COLST order is needed.

**DNR Order.** A DNR is a medical order telling medical personnel not to perform CPR. If you are the medical decision-maker for a person who would not want CPR under any circumstances, or if the person's wishes are unknown but you believe that using CPR would not be in the person's best interest, it is appropriate to discuss a DNR order with the doctor. Ask about the likely outcome of CPR for the patient, and about pain, discomfort or side effects the procedure might have. This may help you decide.



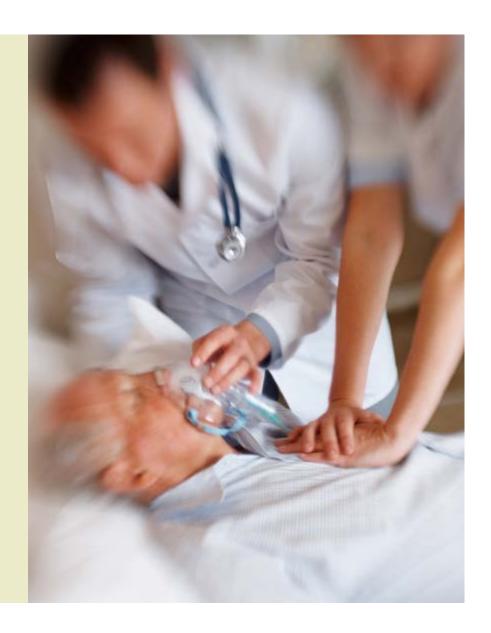
**COLST Order** — **Clinician Order for Life Sustaining Treatment** addresses more than CPR. It covers orders for treatment such as intubation, mechanical ventilation, transfer to hospital, antibiotics, artificially administered nutrition, or other medical interventions. It can be used in outpatient settings and health care facilities and may include a DNR order. If a person would not want to have some or any of these treatments, or if the person would not want to be taken to a hospital if 911 was called, talk with the doctor about completing a COLST form.

#### **About CPR**

CPR is used when a person's heart or breathing stops. People trained in CPR use this procedure to try and start breathing and circulation again by pressing down on the person's chest and forcing air into the patient's lungs. The person is usually then put on a breathing machine (also called a respirator or ventilator) and given strong medication.

Unlike most medical treatments, CPR will be provided if indicated unless there is a signed DNR order stating that CPR should be withheld.

Only one out of every six hospitalized patients who undergo CPR survive to discharge, and the odds are worse for out-of-hospital CPR. Patients with advanced or terminal disease, who are seriously ill or who want to avoid aggressive interventions at the end of life, should discuss a DNR order with their physician.





### Resolving Disputes and Getting Help



Trish visited her father every day in the nursing home. She knew he was having a harder and harder time eating, even though the nursing home staff spent considerable time assisting in feeding him everyday. His doctor said that he could be fed by a tube into his stomach, but she thought her father would not want that. Her brother and sister both wanted to start the tube feeding, and Trish felt pressured.

You may be part of a family or network of friends who are grieving about the medical condition of a loved one or under stress because of a medical crisis. You may have to make decisions that others, including the person's doctor, care team, or family members may or may not agree with. This can be challenging.

### What to Do if There is a Disagreement

Going to court to resolve disagreements is rarely necessary and it should always be the option of last resort. Try to resolve disagreements informally as often as possible.

**A. Understand your legal authority.** Sometimes it is perfectly clear who should be making decisions for another person. Sometimes it is not so clear. Sometimes family members and friends of the person disagree about what should be done, and conflicts arise.

If you are the person's medical guardian or the health care agent named in a valid advance directive, you are the person with legal authority to make decisions. Make sure that a copy of the document that gives you legal authority is placed in the patient's chart. You may consider the opinions of others, but you have the final say and your ultimate duty is to the patient.

The patient's "next-of-kin" is not automatically the medical decision-maker, according to Vermont law. However, in practice, family members are consulted and frequently act as surrogate decision-makers.

If there is no medical guardian or health care agent, ideally the decision-maker will be the person who knows the individual best and who is most familiar with their goals and values. Except for decisions surrounding DNR/COLST orders, Vermont has no legal framework to specify who will make decisions when there is no agent or guardian. Generally for these decisions, health professionals look to the individual's next of kin or those with a known close relationship to the person for guidance. That said, it is not automatically the next of kin who will make decisions for a person if they are unable. (See <u>Appendix E</u> for Table of Decision-Maker's Authority.)



If it is unclear who should make decisions or there are differences of opinion about what to do that cannot be worked out, it may be necessary for someone to file a petition for guardianship with the Probate Court. (More information about guardianships can be found in Appendix B.)

Regardless of who the decision-maker is, they have the responsibility to make decisions in accordance with the advance directive or as outlined in a court order, if there is one. If someone disagrees with the appointed decision-maker's decisions or believes they are not following the instructions of an advance directive or court order, they can ask the probate court for a hearing. Ordinarily, however, the court will intervene only if an advance directive's instructions or the terms of a court order are clearly being violated, or if the advance directive is invalid.

- **B. Keep the family informed, if appropriate.** You may have the legal authority to make medical decisions even if other family members disagree. Most people find it much easier to make difficult decisions when there is agreement among family members. Good communication in advance of a health crisis can make all the difference.
- **C.** Use key communication tools. If disagreements arise, make sure you are not talking past each other and that everyone has the same understanding of the medical facts.
- ♦ Listen carefully to what others have to say.
- ◆ Respect their points of view.
- ◆ Try to understand why they are taking positions different than yours. Repeat back their position to make sure you understand it.
- ◆ Think about what past events or attitudes might be causing them to take such a position.
- ♦ Remember that you are seeking to stand in the shoes of the patient and to advocate the patient's preferences and values, if you know them, rather than your own.
- **D.** Ask for a care-planning meeting if that might be helpful. If there is a dispute about the type or quality of care the patient is receiving in a hospital or nursing home, you can request a care planning meeting to discuss what the plan is, whether it is being carried out, and how well it is meeting the person's needs. (See page 10 for more information about care planning meetings.)



**E. Ask for an ethics consult if necessary.** Ethics committees and individual ethics consultants deal with ethical issues such as end-of-life decision-making and goals of care. They help to educate the staff and to sort out difficult problems. They usually don't make decisions, but serve in an advisory role. When there is conflict between the decision-maker and the family or the doctor, an ethics committee or an ethics consultant can help those involved to better understand each others' views, explore choices, and come to a common understanding.

**F.** Ask for a palliative care consult if appropriate. Many hospitals now have special palliative care teams that focus on a person's comfort, symptom management needs, quality of life and support for their family. These teams can often help patients, families and decision-makers through the process of clarifying goals and treatment options in complex situations.

**G. Consult the hospital chaplain.** A hospital chaplain is a professional spiritual care advisor employed by the hospital who provides spiritual care and guidance as part of the healthcare team. A hospital chaplain does not represent a particular faith, but rather is there to support the spiritual needs of patients, families and hospital staff in a time of crisis.

#### H. Other resources to help you.

- Patient Advocate. Some hospitals have Patient Advocacy Offices to help patients exercise their rights and to advocate for them within the hospital.
- ♦ Office of the Health Care Advocate. This is a special project of Vermont Legal Aid, Inc. that assists Vermonters with health care and health insurance problems for free, regardless of their income, resources, or health insurance status.
- ◆ Long-term care social worker. Nursing homes and assisted living facilities may have an in-house social worker to help residents and families meet their needs.
- → Long-term care resident and family councils. Residents and family members have the right to organize advisory councils in nursing homes, and sometimes these councils exist in assisted living, as well. If your problem is one shared by other residents such as not enough attention from nursing assistants, frequent pressure sores, unhealthy conditions, or poor food joining with others on such councils can be very helpful.



- ◆ State Long-term Care Ombudsman. Vermont has a long-term care ombudsman program. Ombudsmen are independent staff or volunteers serving nursing homes, residential care, or assisted living facilities. They are advocates for residents in long-term care. They can be very helpful in resolving complaints, mediating problems, or helping the resident and/or the decision-maker talk with the medical team or institution.
- ◆ Clergy or spiritual advisor. If you are part of a faith community, you can call on your clergy for confidential advice, reassurance, help with the grieving process, help in sorting out differences with others, and help in understanding your own reactions in light of your spiritual beliefs and the patient's beliefs. Remember, when making decisions for another person it is their religious or spiritual beliefs that matter, not your own.
- ◆ The National Hospice and Palliative Care Organization (NHPCO) provides numerous informational resources online at <a href="www.caringinfo.org">www.caringinfo.org</a>. You may also be able to find good information on the internet or in printed material in a hospital or clinic's resource library. One particularly helpful booklet, <a href="Hard Choices for Loving People">Hark Dunn</a>, a hospice and nursing home chaplain, looks at both the physical and emotional issues of decision-making, especially as they may relate to life support systems and technologies. Other helpful resources include <a href="Hardbook for Mortals: Guidance for People Facing Serious Illness">Hardbook for Mortals: Guidance for People Facing Serious Illness</a> by Joanne Lynn, MD and Joan Harrold, MD; and <a href="Being Mortal">Being Mortal</a> by Atul Gawande, MD.
- ◆ **See** <u>Appendix C</u> for other helpful resources in Vermont.

### **Getting More Information on the Law**

As someone who is making decisions for another person, you may have more questions. For law-related information about health care advance directives, guardianship, deciding for others, and related issues, go to the following websites:

ABA Commission on Law and Aging: <a href="www.abanet.org/aging">www.abanet.org/aging</a> or <a href="www.ABALawInfo.org">www.ABALawInfo.org</a>

Vermont Judiciary: www.vermontjudiciary.org

Vermont Guide to Health Care Law:

www.vtmd.org/sites/default/files/VermontGuidetoHealthCareLaw2.28.17.pdf



# Situations Often Faced by Health Care Decision-Makers

The following tips are about some special challenges you may have in making medical decisions for someone else.

### **Experiencing Grief**

When a loved one is dying, it is normal to have thoughts about how you will react and cope after that person's death. You may experience painful visions of life without them and anticipate feelings of terrible grief and mourning, while at the same time being expected to act as their decision-maker.



You are not alone. These reactions are normal. Sometimes they include feelings of depression, fear, or focusing excessively on particular concerns about the dying person or particular tasks. This process of anticipatory grief is a natural part of adjusting to the reality of the loss. It is also a time, if possible, to complete unfinished business with the dying person — for example, saying "good-bye," "I love you," or "I forgive you." Not everyone experiences anticipatory grief. Even if you do, the feelings of grief and bereavement following the death may be much different from what you felt beforehand.

You may also feel guilty after the person dies, asking yourself "Did I make the right decisions?" For help in coping with grief or guilt, look for hospice and social work resources or specialized grief and bereavement support groups or counseling services in your area.

### **Making Sure Pain and Symptoms are Well Managed**

You may need to help the person get pain relief. Most pain can be managed. It does not have to be a part of being seriously ill.

**Talk to the person to find out as much as you can** about the pain. If the person cannot talk, try to observe their reactions. Try to determine:

- ♦ Where is the pain? When did it start?
- ♦ Does it come and go? When?
- ✦ How intense is the pain?
- ◆ Is it getting better or worse?
- ♦ How does it affect sleep or daily activities?



**Talk to the doctor about the pain.** Be sure to know what medications the person is taking. If the doctor can't help, you can ask for a referral to a pain specialist or a pain clinic. Here are 10 questions to ask the doctor:

- 1. What is causing the pain?
- 2. What is the plan for treating the pain?
- 3. What are the benefits of the treatment?
- 4. What might be the side effects? How long will they last? How will they be treated?
- 5. What should I watch for and call you about?
- 6. What should I do if the pain gets worse?
- 7. When will you check again and see how the person is responding to the treatment?
- 8. What is the cost of the pain medication and is it covered by insurance?
- 9. Is there a lower-cost medication?
- 10. Are there other ways the pain could be treated?

### **Should Hospice be Considered?**

For any person who may be dying, consider hospice care. Hospice is a program that uses a team for medical care, pain management, personal care, and emotional and spiritual support to meet the individual's needs and wishes. Hospice also helps and supports the family caregivers.

Hospice staff is on-call 24 hours a day, seven days a week. They focus on supportive care, comfort, and pain relief; they may provide needed drugs, medical supplies, and equipment. Additional services are available when needed — such as respite care, support from trained volunteers, or in-patient care. In most cases, hospice is provided in the person's home, but hospice care can also be given in freestanding centers, hospitals, nursing homes, and other long-term care facilities.

Hospice care is paid for under Medicare, by Medicaid, and most private insurance plans and managed care plans. Families and doctors often wait too long before they consider using hospice. If someone has a serious advanced or terminal condition, find out when and how hospice could help. For more information, call the tollfree help line of the National Hospice and Palliative Care Organization at 800-658-8898 or visit their Web site at <a href="https://www.nhpco.org">www.nhpco.org</a>.



### What to Do in an Emergency

If the person is in a hospice program, you probably will get special instructions to call hospice staff rather than 911. Hospice staff will address the individual's and your concerns and will contact the doctor if needed. If you call 911, the person will be taken to the hospital and will be given appropriate emergency medical treatment. This could include CPR and other aggressive life-prolonging treatments unless there is a DNR order or COLST order in place. (See page 13 for more information.)

If there is a DNR or COLST order, have copies on hand and be sure to give one to the first responders so they know whether to treat aggressively or to focus on comfort care. If there is an advance directive, give a copy of that to the ambulance crew as well. But be aware that an advance directive is not binding on first responders and will not prevent the patient from receiving life-saving treatment if it is indicated.

### What About Surgery?

Sometimes decision-makers are asked to consent to surgery that a doctor recommends. Here are a few tips:

- ◆ Ask why the surgery is necessary, the likely outcome, what will likely happen without it and what the risks are, especially given the person's age and current health condition.
- ◆ Find out how long recuperation will take and what the person will have to do to recover.
- ♦ Think about whether the person would want the surgery given the balance of risks and benefits. Is the surgery likely to restore them to a quality of life that they would consider acceptable? Would they want the surgery no matter what?
- ◆ Ask the surgeon how many times they have performed the operation and the outcomes.
- ✦ Consider getting a second opinion.
- ◆ If you decide to consent to the surgery, get all the forms you will be asked to sign at least a day or two before the operation, if possible. Read them carefully and ask about anything that's not clear.



### Withholding and Withdrawing Life-Sustaining Treatment

In making decisions for someone else, it's important to understand that there is no ethical or legal difference between withholding a treatment, and withdrawing it after it has been started. In the past people have worried that if someone was put on a ventilator, then they would have to stay on it forever. This is not the case. Any treatment that is not benefitting a person, or is no longer achieving a desired goal can be stopped.

### **Artificial Nutrition and Hydration**

Artificially administered nutrition and hydration is a medical treatment which can be limited like any other. Health care professionals must always make reasonable efforts to help a person eat and drink normally. Those who want to and can eat should be supported in doing so. But when someone can no longer take fluid or food by mouth, a feeding tube can be used. There are two types of tubes. A nasogastric tube is put through the nose, down the throat, and into the stomach. This is usually used on a short-term basis. For a longer term, a gastrostomy tube is put by surgery through the skin into the stomach or intestines. Intravenous (IV) lines may be placed into the veins of the arm or hand to give artificial nutrition and hydration (TPN).

Feeding tubes help many patients to get the fluids and nutrition they need. Yet there are some cases where the benefits of feeding tubes may be unclear for a seriously ill or dying person. Sometimes artificial feeding and fluids for a seriously ill person can increase suffering and be more harmful than helpful.

As someone's decision-maker, you may have to make a decision about artificial nutrition and hydration.

- ♦ Check the person's advance directive if there is one, or try to figure out what they would say, if they were able.
- → Talk with the doctor about the likely outcome. Will it extend life significantly or will it merely prolong the dying process? Will it lead to improvement or restoration in the patient's functioning, or will it increase suffering?





- ◆ Ask about side effects, pain, or discomfort in providing or not providing food and fluids. For example, in some cases artificial nutrition and hydration can build up fluid in the lungs and other areas. Dehydration does not necessarily cause pain or a feeling of thirst in a dying patient. Its most frequent symptom, dry mouth, can be managed with ice chips or moistened swabs to the mouth.
- ♦ Discuss the possibility of a time-limited trial for various treatment options, to see if the treatment will help.
- ♦ Whether or not artificial nutrition and hydration is used, make sure the medical staff continues to ensure that the person is comfortable and any symptoms they are experiencing are well managed.

#### **What About Medical Research?**

People who cannot make their own decisions sometimes are eligible to become subjects in a research study. As a medical decision-maker, you might be asked to give your permission for the person to participate in research.

Before deciding, make sure you understand:

- ♦ If the law allows for you to consent for research on behalf of the person.
- ♦ What the research is trying to find out.
- ♦ What the person will have to do as part of the research.
- ♦ How being in the research differs from ordinary medical care.
- ♦ What the risks are.
- ♦ What the possible benefits to the patient are, if any.

Think about whether the person would want to be part of the study. Remember, nobody is ever required to participate in research. You might want to give permission if being in the research stands a good chance of benefiting the person — or even if there is no likely personal benefit, but very little risk. But if being in this research means that the person might be worse off, without any real chance of direct benefit, just say no.

<sup>\*</sup> The questions on pain were taken from "Pain: Questions to Ask Your Doctor," by the Midwest Bioethics Center, Community-State Partnerships, adapted from the "Rhode Island Consumer Guide to Pain," Joan M. Teno, M.D., Associate Professor of Community Health and Medicine, Brown University Center for Gerontology and Health Care Research, and the "Pain Action Guide," American Pain Foundation, Baltimore, MD.



### Appendix A

# The Medical Decision-Maker Quiz: A Tool for Better Understanding

**Instructions:** As health care decision-maker, answer these questions in the way you think the person would answer them. Then ask the person to answer them and compare your answers. Where the answers differ, discuss why that is.

**Important:** This is not an advance directive. The questions are for discussion only.

1.	Circle ho	ow much	you fear	the 1	following	near the en	nd of life:
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- (1) Very Little (2) Some (3) Very Much
- a. Being in pain 1 2 3
- b. Losing the ability to think 1 2 3
- c. Being a financial burden on loved ones 1 2 3
- d. Losing control over my medical care 1 2 3
- e. Losing ability to practice my faith 1 2 3

### 2. Is it more important for you to:

- a. Have your wishes followed at the end of life, even if family members or friends disagree, or
- b. Have family and friends all agree on decisions, even if different from how you would decide, or
- c. I am uncertain.

### 3. Here are things about end-of-life care that some people believe. Do you agree?

- 1. If a dying person can't get enough nutrition by mouth, a feeding tube should always be used if it will keep the person alive.
  - a. Yes, I agree
- b. No, I don't agree
- c. I don't know
- 2. Once a treatment is started to keep someone alive, it's sometimes okay to decide to stop and withdraw it when the person's quality of life is very low.
  - a. Yes, I agree
- b. No, I don't agree
- c. I don't know
- 3. You are very sick, and the doctors cannot stop the disease. With all possible treatments, you might live for another few weeks. During that time, you would be on a breathing machine. You would drift in and out of consciousness. Without these treatments, you would die in a few days. Would you want the breathing machine and other treatments?
  - a. Yes, I think so
- b. No, probably not
- c. I don't know



4.	I. You have severe Alzheimer's disease. You can't get out of bed, and you can't recognize or talk with your loved ones, but you are not in pain. You could live like this for many months. However, you get recurring infections which are treated with antibiotics. You get another infection, this time pneumonia. If the doctors give you an antibiotic, you will almost certainly recover from the infection. Without the antibiotic, you will die ir a few days. Do you want the antibiotic if you can otherwise be kept comfortable?							
	a. Yes, I think so b. No, probably not c. I don't know							
5.	5. You have poor circulation, which resulted in one leg being amputated. Now, your other leg develops gangrene and doctors recommend amputation because it could be fatal. You also have moderate dementia causing mental confusion. Would you want the operation?							
	a. Yes b. No c. I am uncertain							
6.	You are in a permanent coma and have a tube inserted in your stomach for food and fluids. Would it be important to you that decisions about your treatment are guided by particular religious beliefs or spiritual values that you hold?							
	a. Yes b. No c. I am uncertain							
	If so, what are they							
7.	You were terminally ill, but a course of treatment might extend your life by six additional months. Would you want the treatment even though it has severe side effects — pain, nausea, vomiting, and weakness?							

a. Yes

b. No

c. I am uncertain



### Appendix B

### More About Guardianship

### When is a guardian needed?

There may be times when a person who lacks capacity and has no designated health care agent may need a legal guardian for health care decision-making.

Circumstances that may require applying for a court appointed guardian include:

- The person needs active advocacy where the clout of a guardianship order may be helpful;
- Friends and family are divided about the best decision, or cannot agree on who should be making decisions and someone has to have authority to make the final decision;
- The person has lifelong disabilities that interfere with decision-making, such as developmental disabilities; or
- The person has no actively involved family or next of kin that could serve as a decision-maker.

Treatment over refusal. Sometimes a person who has a legal guardian refuses a treatment that the guardian thinks they should have. It is important for the guardian to understand that when this happens, the guardian can't override the person's refusal of treatment. Instead, they have to go back to the Court for the judge to decide whether to authorize the treatment.

### Who can be a Guardian?

**Private Guardian.** Usually a private guardian is an adult family member or friend of the person who has lost decision-making capacity. The guardian does not necessarily live in the same household as the person. A private guardian is appointed by a Probate Court.

Public Guardian. A public guardian is a state employee who works for the Department of Disabilities, Aging and Independent Living. They will only be appointed if the person is in need of a guardian and has no friends or family to serve in this role. Public guardians specialize in supporting people with developmental disabilities and people with age-related disabilities. Some public guardians are appointed by the Probate Court and others are appointed by the Family Court.

NOTE: Public guardianship in Vermont is available to people who have been determined to have a developmental disability prior to age 18 or those who are age 60 or over.

### Who can apply for guardianship?

Any interested person (a friend, a family member, other person with a close relationship to the person) can apply for guardianship. It's okay for the person who is volunteering to be the guardian to start the petition, but it doesn't have to be that person.

#### How do I find the right court?

Every county in Vermont has at least one Probate Court and Family Court. A guardianship petition must be filed *in the county where the person who needs a guardian is living*. Sometimes the petition is filed by mistake in the county where the guardian is living. This can cause delays while the case is being sent to the right court.



### Do I need a lawyer to file a petition?

No. You can pick up a blank petition at any Probate Court in the state. Forms are available online at the Judiciary website (www.vermontjudiciary.org) by clicking on "Court Forms Library." You do not need any special training to answer the questions. When you have filled out the petition, give it or mail it to the clerk of the Probate Court.

If you are seeking appointment of a Public Guardian for a person with developmental disabilities, you can get a copy of the petition from the Family Court clerk, or from the website of the Department of Disabilities, Aging and Independent Living (ddsd.vermont.gov/programs/public-guardian). The completed petition should be delivered or mailed to the State's Attorney for the county where the person who needs a guardian is living. It is the responsibility of the State's Attorney to file this kind of petition with the court.

### How do I become a guardian?

After the petition for guardianship is filed, the court requests an evaluation of the person's need for a guardian and appoints a lawyer to represent the person. Issues of safety and a person's ability to understand choices and make decisions will be central to the court's deliberation. Usually, the court makes a decision 45 to 60 days after the petition is filed. In emergencies, it can be done faster.

### As a guardian, how do I get authority to see medical records?

Your order of guardianship is your authorization to see medical records. As medical guardian, you are entitled to see any medical records about the person, past and present, after signing appropriate releases. You stand in the shoes of the person for whom you act as guardian, and so are also entitled to discuss the person's condition and treatment with any health care professional who is providing treatment, and to get the same information as the person would get.

### As a guardian what authority do I have and what role does the court play?

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In general, a medical guardian may make decisions about medical care without getting specific approval from the court. Certain decisions (such as do not resuscitate orders and decisions to withhold or withdraw life-sustaining treatment) must be approved in advance by the Probate Court that issued the guardianship order. A decision to change residential placement (such as movement to a nursing home) must also be approved by the Probate Court except in emergencies. You can find out what your Probate Court expects by a call to the Probate Court Register. (See Appendix D for a complete listing of Vermont Probate and Family Courts.)

You are also responsible for making an annual report in writing to the Probate Court about the person's situation. In addition, the guardian should also inform the Court and family members of important medical decisions as they are made, regardless of whether these are brought to the Court. Good and timely communication can avoid problems later on.



### What if the person doesn't want a guardian?

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The Court should always appoint a lawyer to represent the person for whom a guardianship is being sought. If a person does not want to have a guardian appointed, the lawyer will let the Court know this. The final decision on whether or not to appoint a guardian is up to the Court.

# What if it's an emergency and the person doesn't have a guardian or the guardian cannot be reached?

A doctor can go ahead and give urgently needed treatment necessary to preserve the life or health of the person. The law assumes that the person would want this to be done under the concept of *implied consent*. The doctor can also request consent from the patient's next of kin if there has been no appointment of a guardian.

If there is an emergency need for a guardian, someone should contact the Court directly to explain the situation. If the person's health or well-being is in jeopardy, the Probate Court can grant a temporary emergency order of guardianship to prevent serious or irreparable harm to the person.

### How do advance directives work for people with guardians?

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If the person prepared an advance directive before becoming incapacitated, the guardian is required to follow the person's directions unless otherwise instructed by the Court. If the advance directive appoints an agent, the guardian is required to defer to the agent for medical decisions unless the Probate Court orders otherwise.

A person who already has a medical guardian may *not* appoint a health care agent or complete an advance directive. The guardian also cannot complete these documents or update old documents once the guardianship is in place. It is good practice, however, to support a person under guardianship in thinking and talking about future medical care and treatment wishes and to document those wishes in writing, if possible.



### Appendix C

### Other Helpful Resources in Vermont

#### Alzheimer's Association, VT Chapter

The Alzheimer's Association of Vermont provides regional and statewide education programs to family members, health care professionals and other concerned community members. The Association also offers regional Caregiver Support Groups for families and caregivers of persons with Alzheimer's Disease and related dementia illnesses. For information, call their office at 802-316-3839 or toll-free helpline 1-800-272-3900 or visit <a href="https://www.alz.org/vermont">www.alz.org/vermont</a>.

#### **American Cancer Society**

1-800-227-2345

### Vermont Association of Area Agencies on Aging

Vermont has five regional Area Agencies on Aging that serve clients who are 60 or older. Case managers provide assistance and support helping seniors access a variety of health and social service needs, and can assist them with advance care planning and the preparation of advance directives. For information and access to your nearest Area Agency on Aging, contact Vermont's toll-free senior helpline at 1-800-642-5119 or visit www.vermont4a.org.

#### Office of Public Guardian

The Office of Public Guardian (OPG) provides information about the guardianship process in Vermont and has twenty-four guardianship staff statewide to provide services to individuals in need of public guardianship. OPG is available to advise and support private guardians and can assist in providing information and technical assistance to assist in finding alternatives to guardianship. For assistance, call OPG at 802-828-2143 or for emergencies 1-800-642-3100.

### Vermont Office of Health Care Advocate (Vermont Legal Aid)

The Office of Health Care Advocate is a special project within Vermont Legal Aid which helps Vermonters with health care and health insurance questions and problems. It is a free service with no income or resource limits. For information, call their toll-free hotline 1-800-917-7787 or visit www.vtlegalaid.org.

### Vermont Long Term Care Ombudsman Project

The Vermont Long Term Care Ombudsman Project is a special project within Vermont Legal Aid, Inc. Project staff and volunteers advocate for individuals in nursing homes, residential care homes and assisted living residences. They also advocate for people who receive long term care services in the community through Choices for Care. Ombudsmen can help individuals resolve problems concerning their care and their quality of life and they can answer questions about advance directives and guardianship. They can also help residents and long term care consumers talk with their medical providers. For information, call 1-800-889-2407 or visit www.vtlegalaid.org.

#### Vermont Ethics Network



#### **Disability Rights Vermont**

This office provides legal representation and other services to Vermonters with mental health and psychiatric disabilities. For information, call 1-800-834-7890 or visit www.disabilityrightsvt.org.

#### **VNAs of Vermont**

The VNAs of Vermont is the professional association of not-for-profit home health and hospice agencies and Visiting Nurse Associations in Vermont. For information about home health services in your area contact 802-229-0579 or visit vnavt.org.

#### **Vermont Medical Society**

The Vermont Medical Society serves the public by facilitating and enhancing physicians' individual and collective commitments, capabilities, and efforts to improve the quality of life for the people of Vermont through the provision of accessible and appropriate health care services. For information, call 802-223-7898 or visit <a href="https://www.vtmd.org">www.vtmd.org</a>.

#### Vermont Advance Directive Registry

For information about advance directives and the Vermont Advance Directive Registry call 1-888-548-9455 or visit <a href="https://healthvermont.gov/vadr">healthvermont.gov/vadr</a> or contact Vermont Ethics Network at 802-828-2909.





### Appendix D

### Vermont Probate and Family Courts

#### **Vermont Probate Courts**

Addison Probate Court 7 Mahady Court Middlebury, VT 05753 802-388-7741

Bennington Probate Court 207 South Street Bennington, VT 05201 802-447-2700

Caledonia Probate Court 1126 Main Street, Suite 1 St. Johnsbury, VT 05819 802-748-6600

Chittenden Probate Court 175 Main Street Burlington, VT 05402 802-651-1518

Essex Probate Court 75 Courthouse Drive Guildhall, VT 05905 802-676-3910 Franklin Probate Court Franklin County Courthouse 17 Church Street St. Albans, VT 05478 802-524-4112

Grand Isle Probate Court P.O. Box 7 North Hero, VT 05474 802-372-8350

Lamoille Probate Court 154 Main Street Hyde Park, VT 05655 802-888-3887

Orange Probate Court 5 Court Street Chelsea, VT 05038 802-685-4610 Orleans Probate Court 247 Main Street Newport, VT 05855 802-334-3305

Rutland Probate Court 83 Center Street Rutland, VT 05701 802-775-0114

Washington Probate Court 65 State Street Montpelier, VT 05602 802-828-2091

Windham Probate Court 30 Putney Road, 2nd Floor Brattleboro, VT 05301 802-257-2800

Windsor Probate Court 12 The Green Woodstock, VT 05091 802-457-2121

#### **Vermont Family Courts**

Addison Family Court 7 Mahady Court Middlebury, VT 05753 802-388-7741

Bennington Family Court 200 Veterans Memorial Drive Bennington, VT 05201 802-447-2727

Caledonia Family Court 1126 Main Street, Suite 1 St. Johnsbury, VT 05819 802-748-6600

Chittenden Family Court 32 Cherry Street, Suite 300 Burlington, VT 05401 802-651-1709

Essex Family Court 75 Courthouse Drive Guildhall, VT 05905 802-676-3910 Franklin Family Court 36 Lake Street St. Albans, VT 05478 802-524-7997

Grand Isle Family Court P.O. Box 7 North Hero, VT 05474 802-372-8350

Lamoille Family Court 154 Main Street Hyde Park, VT 05655 802-888-3887

Orange Family Court 5 Court Street Chelsea, VT 05038 802-685-4610

Orleans Family Court 247 Main Street, Suite 1 Newport, VT 05855 802-334-3305 Rutland Family Court 9 Merchants Row Rutland, VT 05701 802-786-5856

Washington Family Court 255 North Main Street Suite 1 Barre, VT 05641 802-479-4205

Windham Family Court 30Putney Road, 2nd Floor West Brattleboro, VT 05301 802-257-2800

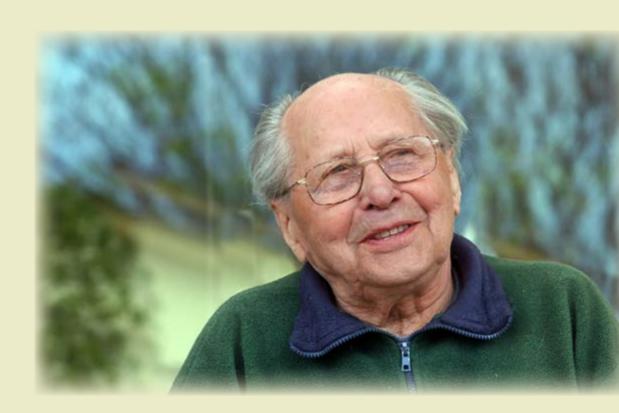
Windsor Family Court 82 Railroad Row White River Jct., VT 05001 802-295-8865



### Appendix E

### Table of Decision-Maker Authority

Type of Decision-maker	Who appoints	Restrictions	Scope of Authority
Agent under an advance directive	Person who signs the advance directive (no court involvement)	The maker of the advance directive can always revoke	Can be as broad or as narrow as maker of agency wishes
Private Guardian	Probate Court	Must return to court for certain medical decisions	As broad as conferred by the Court
Public Guardian	Probate Court	For certain elders who need a public guardian	As broad as conferred by the Court; may consult with Ethics Committee as needed
Public Guardian	Family Court	For adults with devel- opmental disabilities	<ul> <li>As broad or narrow as determined by the Court.</li> <li>DAIL Ethics Committee review for end of life decisions.</li> </ul>
Surrogate	For DNR/COLST decisions:  • Surrogate can designate orally at time of capacity.  • Consensus-based model when patient lacks capacity.  For all other medical decisions:  • No formal process for appointing a surrogate.	Must follow the legal process for consenting or withholding consent for DNR/COLST orders     No restrictions for all other medical decisions.	Broad; with statutory guidance only provided for DNR/COLST decisions





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