

Talking to Your Doctor About Act 39, Patient Choice and Control at the End of Life

Don't wait until it's too late to have this important conversation with your physician.

Many patients want the comfort of knowing that Vermont's Act 39 will be available to them. An important lesson learned since the enactment of this law in May of 2013 is that if you want the option to use the law, it's important to discover whether or not your physician would support your choice to use it. Additionally, seeking treatment from a physician who shares your values and is capable of telling you the bad news, as well as the good news, is important to ensure that you make informed healthcare decisions.

Optimal times for having this conversation occur when you provide your physician(s) with a copy of your advance directives or discuss the use of the Clinicians Orders for Life-Sustaining Treatment (COLST) form, a nonhospital medical order for people with serious illnesses. If you raise the issue immediately after receiving a terminal diagnosis, your physician may be less receptive.

After explaining that you believe in being prepared, that you wish to avoid unnecessary suffering at the end of life, and that you would like to make sure that you would be on the same page in an end-of-life situation, ask your physician with specific language: **"If I were terminally ill and wanted to use Act 39, would you be willing to write a prescription for life-ending medication?"** You need a "yes" or "no" answer. If your physician seems reluctant to prescribe but seems unopposed to aid in dying, ask her if she would be willing to participate as the Consulting Physician, who would confirm your diagnosis, prognosis and mental capacity.

It is important to ask only your doctor; do not ask your physician's office staff, nurse, or physician's assistant or leave a request on voice mail.

Above all, you should not enter into a conversation with your physician about the option of using Act 39 by demanding assistance or approaching him with a sense of entitlement. Although we have the legal right to aid in dying in Vermont, your physician is not required to participate and may have valid reasons for declining.

Common responses from physicians include:

- "I will help you," or "I will be there for you when the time comes." This may mean "I will refer you to hospice and palliative care," or "I will be sure you are kept comfortable, but I may not write a prescription for life-ending medication."
- "Let's talk about that when the time comes," "We can talk later," or "For now, let's focus on treatment." Physicians who make these kinds of statements are stalling or trying to change the subject. More often than not, these physicians will elect not to participate when the time comes.

- "I don't know anything about Act 39." A medical director can talk to your doctor physician-to-physician, provide her with a packet that includes all the necessary information, and answer questions. Give your physician our toll-free number, (800) 247-7421, and assure her that Compassion & Choices strictly protects confidentiality.
- "My employer will not allow me to participate." The law permits providers to prohibit physicians from participating only if all three of these conditions are present:
 - The patient is a resident in a facility owned by the organization
 - The patient intends to ingest the medication on the organization's premises
 - The physician has been notified in advance and in writing of the organization's policy

Nothing prevents a physician from participating when the patient is off the premises. The law also prevents a provider from punishing a physician who participates in this way. Many physicians are unaware of these provisions of the law, and even those who are aware may not be comfortable participating under these circumstances.

- "I don't believe in that," "I would never do that," or "I'm against that." Consider these kinds of statements to be a possible red flag. Your physician may not practice patient-centered care or be less willing to provide you with adequate pain medication or provide an early referral for hospice or palliative (comfort) care.

If your physician declines to participate, you should evaluate your relationship with that doctor. **Will she make an effort to refer you to another physician who will?** Has she provided you with excellent care? Do you have a long relationship with this physician?

For patients at a critical treatment juncture, changing physicians may not be the best option. It may be better to continue treatment and look for another physician who will support your choice to use Act 39. A physician's willingness to participate in aid in dying is just one of several factors to consider when making such an important decision.

If you elect not to change physicians or cannot find a physician willing to commit to participating in Act 39, it doesn't mean you won't be able to use the law. One of the services provided by Compassion & Choices' client support program includes helping to locate participating physicians for qualified patients. Although we cannot promise to find the two participating physicians required, we can usually find participating physicians – if we are given enough time. This is one of the reasons why people who want the option of using Act 39 should contact us early, as soon as they know they are terminally ill. **Due to confidentiality issues, we cannot provide the names of participating physicians to people who are not receiving our free client support services.**

If you have any questions about talking to your physician about Act 39, please contact Vermont State Director Linda Waite-Simpson at (802) 881-3189 or call our End-of-Life Consultation Program at (800) 247-7421.