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Help for the helper

New surrogate consultant adds clout to FEN members' Advance Directives

By Janis Landis, FEN Board Member

In our last FEN magazine, we invited readers to share any bad experiences loved ones faced at life's end when their wishes were not followed – even with a clear Advance Directive (AD) in hand.

Readers responded (page 2), and it was never more clear that surrogates – those family or friends charged with safeguarding patients' desired care and treatment – need determined, expert support.

FEN is committed to providing that assistance to help ensure ADs are enforced.

We have implemented the first step in this initiative by hiring Surrogate Consultant Althea Halchuck. She brings exceptional skills and experience to this vital position.

Here is how Althea can help you and how you can reach her.

If you are having trouble getting an Advance Directive honored, for yourself or as a surrogate for another individual, help is just a phone call away. Althea will review the issue thoroughly with you and go over the directive.



'Providers should never second guess or bully a surrogate trying to honor an advance directive.'

– Althea Halchuck

She will lay out your options, such as speaking to the physician in charge, armed with specific information on the patient's legal rights. Or, she may help you assert your legal authority as surrogate when other family members disagree. She also can ensure that adequate pain relief is being provided, if that is what's needed.

Finally, if all these efforts do not resolve

SURROGATE *continued on page 2*

What you told us re: EOL care

Following are excerpts from some readers' comments about the end-of-life treatment their loved ones received.

Constant pain; inadequate relief

A for-profit hospice became involved when my mother was resident in an assisted-care facility. She was in constant pain, wheelchair bound, losing vision, and wanted to end her life. Hospice did not provide adequate pain relief, and she lingered for many months.

Marilyn R.

An angelic nurse

I was a surrogate, after years of being a personal rep and other titles. At the end, it was very difficult. Thank goodness for an R.N. who saved my mother more pain, and kept me from "giving in" to the doctors. She whispered, "Don't do it."

SURROGATE *continued from page 1*

the issue, Althea will contact our FEN attorney to determine what legal avenues are available.

Two things are especially important to remember:

1) Our consultant will not suggest what medical treatment should or should not be given. The Advance Directive is the determinant. If the patient or the surrogate wants all possible medical interventions, that is what we will work toward. If, on the other hand, the AD calls for only palliative care, we will pursue that.

2) Be assured that all these consultations, including any legal action taken by our attorney, will be done at no cost to you. We will not bill you, the patient, or the health insurance company.

You can reach Althea in two ways:

Email fensurrogate@gmail.com

Phone 800-491-6713

If you don't have this info handy, you'll find it on the finalexitnetwork.org website under "Services."

Althea will respond to you as quickly as possible, generally within 24 hours. If you have an acute problem, please indicate that you need an immediate reply and we will try to ensure that happens.

We welcome feedback if you use this service or have suggestions on other ways we can help.



My mother was dying and the doctor wanted to do a transfusion. The R.N. told me it would only increase her agitation. I called it off and mother died peacefully 30 minutes later. We were both fortunate.

Anonymous

Guilted into agreeing

Doctors wouldn't listen to me about what I knew my mom would want. They seemed as though they knew best and pushed needless surgery on her, which only made her lose quality of life. I reluctantly agreed to the surgery because they guilted me into it and were dismissive of what I felt she would want. They placed incredible pressure on me and pushed until I gave in ...

Anonymous

'Experts' overwhelm surrogates

The patient wanted only the minimum done, only that with a high likelihood of improving their life. Instead, seriously invasive, weakening, and expensive procedures were repeatedly inflicted. The surrogates were overwhelmed with the pressure of the experts and assembly-line situation.

Anonymous

Bullying tactics

... On the advice of my mother's doctor, we wanted to deny a treatment the hospital staff wanted to give her and they engaged in very bullying behavior. I had to get our doctor on the phone so I could withstand their bullying ...

Lyn M.

Pain drugs not available

My sister and I had met our mother on day one at a senior home. My sister had done all the communication with this place. That evening, the hospice lady showed up. Not until then was I aware that this place didn't allow all pain drugs to be used.

I was shocked and upset. Yes, I felt my mother, 94, was ready to die and sure she didn't want to suffer unnecessarily. She was suffering from Alzheimer's, and all of a sudden could no longer walk with a walker. I wanted her to be able to access all drugs that would help her with this goal.

Peg

Let's hear from you!

FEN is gathering stories and testimonials to display on its website and share on social media, to spread awareness about Final Exit Network and the unique, vital services we provide to qualifying persons at the end of life.

If you have an experience or story you would like to contribute, please email it to finalexitnetworkcontact@gmail.com with "Member Story" in the subject line. We will be featuring a new story each month.

To read the current story, go to our website home page finalexitnetwork.org and scroll down.

Another painful story of surrogate necessity

My mother's death was tragic and painful. Her husband (my father) was named her surrogate, yet he was 88 years old and not available. (I was the one who stayed two nights with her in hospice; everyone else went home.)

Basically, I had no idea if I had any power to change things. My mother ... was in severe pain to the point of moaning for one (full) day and one night. She was in a large, inner-city hospital, but the hospice unit was full, so she went to a different unit. Those nurses didn't seem as skilled as a hospice nurse should be ...

This "extra unit in the hospital" was useless. I kept asking the nurses to give Mom more pain meds, and they would look at her chart and say, "It's not time yet." I'm a pharmacist, and I told them that, and I knew she could get more! So, they finally called the doctor, and he added other pain and anxiety meds ...

So, this was hard to see, and I complained to the hospice manager after her death the next day, but not sure how much that helped. I had no idea I could have said I was next in line as a surrogate. Could that have been possible?

The (fall FEN magazine) article about Esta and her husband made me realize that my husband and I should go over things with surrogates. I sure don't want to die in pain!

Christine F.

Halchuck brings vast experience as advocate

Althea Halchuck, FEN's new surrogate consultant, is the founder of *Ending Well! Patient Advocacy, LLC*, and in early 2020, she became a Board Certified Patient Advocate practicing in Arizona.

Her advocacy focuses on end-of-life care and planning, aiming to help people have "a good death."

In 2012, she earned an Executive Juris Doctorate in health law from Concord Law School, a division of Purdue Global.

Halchuck's end-of-life experience is varied and extensive. For seven years, she was a long-term care ombudsman in California, has been a certified thanatologist since 2016, and was a practicing end-of-life doula and death educator before joining Final Exit Network.

For 15 years, she has been involved in hospice, first in California where she was a law school intern in a pediatric hospice, Providence TrinityKids Care. There she helped develop and launch an art therapy program to promote health and healing for children after the loss of a sibling.



Althea Halchuck

Since 2012, she has been a hospice volunteer at the bedside of dying patients.

Halchuck has training in clinical ethics and served on two bioethics committees. The majority of bioethics cases involved making healthcare recommendations for "unbefriended" people lacking capacity and a surrogate at their end of life.

From 2014-2018, she served on a Compassion and Choices steering committee trying to bring Medical Aid in Dying to Arizona.

Kalchuck has also practiced as a mediator who negotiated end-of-life disputes as a patient advocate. She has training and experience in all facets of conflict resolution and facilitation, including mediating civil cases in Los Angeles County, and consumer and family/elder cases in L.A. County and the city attorney's office.

Since 2015, she has also served on a federal mediation panel with the Department of Homeland Security.