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THERE ARE ANSWERS

Any idiot can face a crisis; it's this day to day living that wears you out.

ANTON CHEKHOV

Chekhov's words were no doubt intended to be a backhanded encouragement. They elicit a knowing smile from those of us facing the day-to-day struggles of modern life—mortgages, diapers, cranky bosses, sibling fights, aches, and pains. Such mundane troubles wear us out, and a crisis now and then can seem a welcome diversion.

But what would Chekhov say to people facing a crisis that had become day to day?

What would Chekhov say to people like Sharon:

My father had Parkinson's disease for many years. He became dangerous to himself and to my mother to the point that the doctor put him into the hospital for surgery for prostate problems and then into a nursing home. At that time we were told he also had Alzheimer's disease.

After four years of being in a coma (brought on by undetected diabetes), amputation of first a toe, then

a leg, there would come the amputation of the other leg and both hands. He had been in a coma for months but showed extreme pain in his facial gestures. He had not recognized me for about four to five years. My father was a wonderful man, husband, poppa, and grandpa who was loved by all.

He was also a proud man and very self-sufficient. It was so sad to see his weakness take away every part of him except breath—due to feeding tubes and life support.

Sharon and her mom faced life-and-death questions on a daily basis for four years. “Do we continue treatments?” “Do we ‘pull the plug’?” “Do we remove the feeding tube?” I wonder if Chekhov pictured such questions being answered by “any idiot.”

And what would Chekhov say to people like Jim and Julie?

Julie endured eight surgeries and biopsies and four regimens of chemotherapy. We experienced the dread and terror of two years of watching Julie receive, and then react to, those powerful drugs ...

She lost her hair three different times. She would get deathly sick. Her face would turn white, her eyes dark. Her fingernails became knurled and black. Her mouth and entire GI track would break out in open, bleeding ulcers. Her white blood-cell count was often below 1000. A common cold could have killed her. She underwent a full course of radiation and a six-week, risky bone-marrow transplant. At one point, she had hanging over her, thirteen IV bottles filled with powerful drugs and antibiotics. We also experi-

enced five unsuccessful trips out to the National Cancer Institute. Their state-of-the-art experiment failed.

Jim and Julie lived in a health care crisis for seven years before Julie went home to heaven. For them there was always the wondering: "Will this drug work?" "Is the cancer really gone?" "Do we try this risky experiment?" They faced these questions, all while raising four kids and serving in full-time ministry.

And what would Chekhov say to Debbie:

I am a mother of three beautiful triplet girls. They were born three months early, despite fourteen weeks of bed rest and medication to try to prevent premature delivery. As a result of their extreme prematurity, two of the girls are handicapped.

The girls are two years old now and I am having a hard time trying to make sure everyone gets what she needs. Amanda is a normal two-year-old; Jennifer cannot crawl, sit up, or walk but mentally seems to be about fifteen months; and Rachel can sit up and crawl but mentally seems to be ten–twelve months. Both Jennifer and Rachel do not eat and need g-tube feedings (feeding through a tube into the stomach) and medications around the clock besides physical therapy, occupational therapy, speech therapy, and feeding therapy. Everything I do is devoted to and revolves around them and their needs, but I still go to bed at night knowing how much better they could be if I could do more ...

Our church was great in the beginning, and people were always helping me, but as the girls

showed evidence of lasting problems, the help stopped. The problem is that I need help now more than ever. I have had a nurse in the home twenty-four hours a day for two years, but they are cutting that down to nothing by Christmas because the girls are off oxygen and their ventilators ...

To top everything off, right now the girls are in a rehabilitation facility for three months for intense feeding therapy. They are miserable there, and I have had to put Amanda in day care so I can be there for Jen and Rachel. We have no family nearby to help with all this ...

Debbie is looking ahead to years of daily crises of disability with her kids. She and her husband will ask: "How will the kids get an education?" "Where will the money come from to pay for therapy?" "Are we ever going to get a break just for us?"

We Are in a Dilemma

Crises like the ones just described are being rehearsed everywhere. Twenty-eight years in a wheelchair has introduced me to the world of advocacy, and with it, thousands of people who were either sinking into or surfacing out of suicidal despair. Decades of visiting hospitals and rehab centers has introduced me to the business executive with Lou Gehrig's disease whose body was shrinking and shriveling; to the young athlete paralyzed from a spinal cord injury and living in a nursing home; to the Vietnam veteran coping with a strange new mental illness; and to the teenager with cerebral palsy sitting on the sidelines, watching her classmates date, and drive cars.