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More than Same-Sex Marriage: Law, Health, and Defining Family

*Karen D. Thompson**

“Love is a Dangerous Promise”

You and I have spent many hours
With never a thought of time
We were working and laughing and watching the world
Nothing much else on our minds
But every so often we’d stop and look in each other’s eyes
And out of the silence would come the questions,
The secret fears in our lives:

Will you be there for me when I really need someone to hold me
And will you care for me?
These are the words you told me:
I’ll be there, I’ll be there for you
When you really need someone to hold you, I’ll be there.
Yes, love is a dangerous promise, but I’ll be there.
–Judy Fjell

Little did I know just how dangerous a promise love would be. Walk with me for a moment in time.

In 1979, Sharon Kowalski and I fell in love. We made a commitment to be there for each other for the rest of our lives. We exchanged rings. We bought a house together. We shared hopes and dreams similar to any other couple. We lived in a committed relationship for four years and considered ourselves married. We were extremely closeted. We believed that as long as we kept our personal lives separate from our professional ones, we would be safe.

On Sunday, November 13th, 1983, Sharon looked at me and said, “Save Monday night for me.” For us Monday night never came as Sharon

*Hastings Consortium Keynote Address, © Karen D. Thompson, March 6, 2013. Karen Thompson is Professor, Human Relations Department, St. Cloud State University, St. Cloud, MN. In this speech, the author discusses the legacy of her landmark case in the gay rights movement, *In re Guardianship of Kowalski*, 478 N.W.2d 790 (Minn. Ct. App. 1991).

was hit by a drunk driver later that afternoon and sustained a traumatic brain injury. She would be considered in a coma for the next few months. As she came out of the coma, she did not speak, had severe short term memory deficit (her long term memory was mostly intact), had quadraparesis, and used a wheelchair. She was very different than she was before. But different does not mean less than. You cannot compare this Sharon with the old Sharon.

Our lives as we knew them were shattered. Due to the inability to legally sanction our relationships, no legal recognition of our families, no partnership benefits, and little or no protection of our basic human rights, nightmares like Sharon's and mine can occur. I arrived at the hospital and spent over two hours trying to find out if Sharon was dead or alive. No one would talk with me because I wasn't "family." If we had been married, I would have had immediate access and immediate input into Sharon's care.

Since Sharon was "single," Sharon's parents were given the authority to act as Sharon's guardians. They didn't think friends should visit as often as I was visiting. I was taken out of Sharon's room one evening and informed that no one could love Sharon like family loved Sharon. Family could meet all of her needs. If I didn't stop visiting so often, they would see to it that I couldn't visit her at all. They made plans to move her out of the St. Cloud area, where Sharon had lived the last six years of her adult life, to a nursing home in Hibbing, Minnesota, closer to their home but three hours from our home, for their convenience in visiting.

Could they move her from a hospital with a rehabilitation facility to a place with none? Could they separate us? I was spending hours a day talking with Sharon, playing her favorite music, stretching out her hands, fingers, legs, feet, and toes in hope that she would regain use of some parts of her body. We were making progress.

I made a video tape of Sharon demonstrating many of the things she was relearning. I asked her which ball she wanted. She reached up and took the ping pong ball. I asked her to touch her chin with it, take it to her hip, drop it into my hand. She did word association. I'd show her a picture and she would point to the appropriate word. She practiced washing her face. She was learning to brush her teeth. She picked up a glass and took a drink of water. You could see her swallow. I did this so she could see her progress and also as proof that she was understanding and responding, when many of the medical personnel thought I was imagining movement and responses.

In order to protect Sharon's and my rights as a couple (what a joke—we had none) and Sharon's right to the best possible medical care, to live where she wanted to live, and to see the people she wished, I entered into a guardianship struggle with Sharon's parents. I never wanted to enter into this struggle. I've never been a threat to Sharon's parents. We shouldn't have to choose between biological family and chosen family.

I really believed that the guardianship statute would protect us. It asked who was best qualified to be Sharon's guardian. I knew that I could prove I was best qualified. What would Sharon want and what would keep her in the most normal situation as possible? Of course she would want to live where she lived before the accident and with the same person rather than in a nursing home.

I was stunned by the July 1985 court decision. It ruled that the ongoing struggle between Sharon's parents and me was detrimental to Sharon and gave full guardianship to Sharon's father to remove the conflict. The irony was that I had asked for counseling and the judge said, "You can lead a horse to water but you can't make it drink it." I had requested mediation, my minister with their priest, and they had refused. PFLAG had written Sharon's parents the neatest letter saying, "We understand your pain and your anger. Could we please sit down with you and talk with you?" Her parents gave the letter to their attorney who responded, "I merely ask you to mind your own business. Quit harassing my clients or we will take legal action."

The judge ruled that "this poor disabled girl needs the unconditional love of her father." The court gave full power to the father who had said he would never believe I was a loved one of Sharon's and he would do everything he could to separate us. Within twenty-four hours of the court order, he ordered that I could never see Sharon again. All of her friends and support group from the six years of her life prior to the accident went down with me, guilty by association. The Minnesota Civil Liberties Union (MCLU) and disability rights groups were denied access to Sharon as well. Only people on a visitation list approved by her father were now allowed in to see Sharon. Within forty eight hours of the court order he moved her to the nursing home in Hibbing that, over a year before, the court had ruled did not have the appropriate facilities for Sharon.

And the question I was to ask for the next nine-and-a-half years was "Why Can't Sharon Kowalski Come Home?" My whole perception of reality has been shattered. The world as I believed it to be simply did not exist. As the journey began, I believed all the ideals I had been taught this country stood for. I believed in truth and justice, that the law would protect us.

I should have been able to visit Sharon while the guardianship order was under appeal. But two of the three judges on the appellate court voted to remove the statute for us. The third judge dissented stating that it was a blatant violation of the Minnesota statute staying orders until the appeal is heard. By luck of the draw, out of the ten appellate court judges we were to get those same two judges who ruled against us in appeal after appeal.

It took us five years to get Sharon tested for competency which, by law, is required every six months to a year. When Sharon went into that coma, she lost all of her basic human rights. But she came out of the coma

after a few months and we couldn't get her tested. Why? If she was proven to be competent shouldn't people be glad? If not, what harm would the testing do? I'll never forget the picture of the parents' attorney standing in the court room with a Bible in his raised hand saying that to test Sharon for competency would cost her hundreds of thousands dollars in the personal injury case settlement. She would be worth more money if they could argue that she would have married and had children. Sharon would not be tested until that case was settled.

A disability rights group testified in court that they had a typed conversation with Sharon in which she answered numerous questions such as, "What did you do prior to the accident?" She typed out "teach." "What did you teach?" Her response was "P.E. and Health." "What is your favorite flower?" She typed "columbine." The judge ruled she couldn't understand nor could she communicate in any way. He even denied her the right to be in the court room because of her "medical condition." Sharon could be anywhere you could push a wheelchair.

The MCLU had several conversations with Sharon before they were denied visitation. On one occasion their attorney had asked me how Sharon was feeling. I asked the attorney to ask Sharon. She typed "shitty." Sharon was asked, "What are you and Karen?" She typed "gay." Her father said on the stand in court that Sharon couldn't understand what it meant to be gay. She was like a child now. It probably meant she was having a gay time. When asked by the MCLU attorney what gay means, she typed "to love someone of the same sex."

The MCLU believed that she could clearly express her wishes, that she felt her rights were not being protected, and that she wanted them to represent her. The court ruled that Sharon was incompetent and therefore could not hire them. They continued to rule her incompetent without a competency hearing. The MCLU appealed all the way to the United States Supreme Court asking the question "shouldn't the rights of a person with a disability be at least as vigorously protected as those of a convicted criminal?" They never did get standing in the case.

We lost our first amendment rights, freedom of association, as we were separated for over three and a half years. For those three and a half years I lived with the memory of that July day before we were separated, the desperation in Sharon's words as she typed out, "Help me. Get me out of here." I tried to reassure Sharon that I would do everything possible to get her out of there but that my visitation time was up and I had to leave. Sharon then typed, "Take me home with you." I was haunted daily by the look on her face and the trust in her eyes that said, if you love me, you'd get me out of here, and Sharon's belief that I would. And I couldn't make it happen.

Over the course of our long separation I continued to battle in the courts to get Sharon proper rehabilitation and proper care. I knew that with

every defeat, with every appeal that was denied, that every time a state statute was removed for this case, it cost Sharon quality of life for a lifetime. I lived from one court hearing to the next always believing that next time things would be different. They never were. I cried myself to sleep night after night only to be awakened by nightmares about what was happening to Sharon. Many times I just wished that I wouldn't wake up the next morning. But I was Sharon's only hope and somehow I had to survive.

I was devastated by Sharon's responses to a friend we snuck in to see her. When she was asked if Sharon knew why I wasn't there, she responded "no." When it was explained to her, she typed out "I thought she left me." Had we not been excluded from marriage, I could have been there for her. I was doing everything humanly possible to break our case open and I still felt as though I had failed her.

The Office of Health Facility Complaints investigated a violation of Sharon's Patient Bill of Rights. Sharon indicated to them the visitors she would like to see. They found the nursing home to be in violation of the Patient Bill of Rights and gave them five days to become in compliance. The courts found that the Patient Bill of Rights only imposed duties on the nursing home, not the guardian. Therefore since the nursing home must go by the wishes of the guardian, the guardian could remove the Patient Bill of Rights. How frightening!

We filed through the Vulnerable Adult Protection Act that Sharon was not receiving proper care. It was found that she was receiving the level of care ordered by her doctor. Therefore, the nursing home couldn't be found in violation. Dr. William Wilson stated under oath that to give Sharon occupational therapy was a complete waste of time since Sharon would never be able to hold down an occupation. That's not the purpose of occupational therapy. He was also the doctor who wrote the medical order stating I should never be allowed to see Sharon again since we might have had a prior sexual relationship and he feared sexual abuse.

We filed a conflict of interest with the Professional Ethics Responsibility Board for Attorneys. Jack Fena represented both the parents in the guardianship case and Sharon in the cases against the drunk driver and, through the Dram Shop law, the establishment that served him to the point of inebriation. The parents and Sharon were clearly in conflict. The ethics board responded that there may or may not be a conflict. They were "sick and tired of these wacko relationships between people like Karen Thompson and this poor disabled girl" and deferred to the courts to decide. The courts ruled that since the ethics board had not found any conflict there must not be any. No one investigated. They just passed the buck back and forth.

These and many other Minnesota statutes were ignored or changed as the state of Minnesota upheld the guardian's right to violate Sharon's rights

in over twenty appeals through the probate, appellate, and state supreme courts. But most importantly of all, Sharon lost the right to recovery.

Sharon was finally tested for competency in September 1988, five years after the accident. The testing proved Sharon could understand, could communicate and make many of her basic life choices, and was not getting appropriate care. As a result, she was moved to a different institution in January 1989 to receive rehabilitation. Once there, the medical team requested that Sharon be allowed to see visitors she wished to see. My visitation rights were reestablished in February 1989.

I cannot begin to express how devastating it was to see how much ground Sharon had lost. My nightmares became reality. Sharon could stand with support and do standing pivot transfers before we had been separated. I had believed she might be able to walk with a walker someday. Now she was curled up in a fetal position. You couldn't stretch her legs out past a 90-degree angle. Her feet were arched backward. Her toes were curled up under her feet. Her left arm had become like part of her body. It took major surgeries to cut the muscles and tendons in her legs, feet, and arm so Sharon could be washed and dressed more easily, so she could sit in a wheelchair in a better position. She still can't do standing pivot transfers today. What a horrible loss unnecessarily. Now we need a hoist lift or must do a two-person carry transfer.

Sharon was learning to eat before we were separated. Now she was fed through a feeding tube only. She had loose teeth from gum disease and a fungus growing on her tongue that was so thick we had to scrape it off daily. When asked how that could happen, a speech therapist responded, "lack of proper oral care."

Sharon was moved closer to our home in June 1989 and I was finally allowed to take Sharon to events outside the nursing home as long as we had a staff escort since the court feared sexual abuse. I refiled a petition for guardianship and couldn't win even after her father withdrew. I fought the system for two more years even though there was no other party of record. The medical team finally documented everything we ever could have wanted. I can't tell you how difficult it was to sit in the courtroom through numerous hearings and listen to all the medical testimony describing Sharon's condition, discussing her regression, using words like neglect, negligence, and inappropriate medical care. I heard them say over and over that too much time had passed and that Sharon had lost some opportunities for a lifetime.

In April of 1991 we received the judge's decision once again denying me guardianship. It found that I had "outed" Sharon even though nursing home staff gave examples of Sharon saying she was gay. As Sharon came out of her coma, I talked with her about the need to come out to protect our rights. I told her that if I came out I'd probably be bringing her out with me and she laughed and spelled out, "ok." Then I asked her, "Aren't I the

most likely person you know to stand up and support gay rights?” She typed, “least likely.” She knew me pretty well. I feared I’d lose my job, my family support, my friends. What I’ve learned is that our fear of coming out is far worse than anything that could happen to us out. In the closet I lost everything that was of value to me.

It found that taking Sharon out in public was putting her on display, using her for a cause and was detrimental to her physically, psychologically, and socially in spite of all the medical evidence to the contrary. It found that Sharon couldn’t understand or communicate which was in total contradiction to all medical testimony. It found Sharon needed to be institutionalized despite unanimous professional testimony finding no need for her to be institutionalized. It found I didn’t understand the Iron Range mentality—the Iron Range is the part of northern Minnesota where Sharon was born and raised. I don’t understand racism, sexism, ableism, homophobia, heterosexism, etc., wherever I see them and they are not just on the Iron Range in Minnesota. The court went from fearing sexual abuse if she came home to saying it would be infidelity or adultery should I ever be in a relationship with someone else.

Obviously we appealed. We received the appellate court decision on December 17, 1991, exactly 12 years from the date Sharon and I had exchanged rings. It overturned the lower court ruling and ordered that I be appointed guardian with full powers. It found that the district court judge is not allowed to make findings of fact unsubstantiated and in total contradiction to the court record. He had abused his discretion.

It’s difficult to believe that we spent over eight years of our lives and over \$300,000 to arrive at the 1991 decision. The decision was a just and right decision. The court finally found that Sharon, a woman, a lesbian, a person with a disability should:

- have the right to be heard;
- be allowed to see whoever she wanted to see;
- be allowed to go out in public wherever and whenever she chooses; and,
- be allowed to live in the least restrictive environment.

Those are basic human rights I thought we already had. The court did go a step further and found Sharon and me to be a “family of affinity which ought to be accorded respect.” Many thought the legal fight ended then, but it took until May 1992 for me to be awarded guardianship by the probate court which was ordered to do so. The court dragged it out until August 1992 to issue letters of guardianship so I could act as guardian.

Needless to say, the years before that ruling had been very difficult. It had been years since I had seen Sharon and I wasn’t sure, no matter how hard I tried, that I would really ever see her again. I was traveling around the country speaking to break the case open and to fundraise to pay my legal fees. I was wishing my life away from one court hearing to the next.

My future with Sharon seemed bleak. I would never stop loving her or fighting for her. As painful and overwhelming as this ordeal was, I came to the realization that I also needed to move on with my life. I had to start living again.

I made the decision to be open to other relationships. Sharon had taught me how to feel, to love, and to live each day fully. Now, I was losing everything she had taught me and I was wishing my life away months at a time awaiting court decisions. The decision to move on with my life was a decision to somehow survive. I didn't want to go back to the person I was before I met Sharon. I needed to start the healing process for myself and I did. But anyone who became involved with me would know that Sharon and I were a package deal, that I would never leave Sharon or stop trying to bring her home.

One of the people I reconnected with during this time was Patty Bresser. Patty was a teacher and a coach at St. Cloud State University from 1979 to 1981 and knew both Sharon and me from that time. Although Patty returned to her home state of Connecticut in 1981, she still kept in touch. As our case garnered national attention, Patty followed it in the gay press. She sent cards during the holidays and offered support. While I was fighting the legal system, Patty became a registered nurse and did graduate work at Yale University. In the spring of 1990, Patty and I finally acknowledged that we felt something for one another. But Sharon was still in an institution and I needed to get her out. I still loved Sharon with all the depth of my being but I loved Patty too. This was unfamiliar territory for me. There were no role models for this that I knew of and yet, I saw possibilities.

The accident itself had changed Sharon's and my relationship, but it never changed the love we felt. That was a given. Because of the court's interference, first by separating us and then by dragging on the legal case, we didn't know the impact Sharon's brain injury would have on redefining our relationship. We hadn't been allowed to work through it. I didn't know what Sharon wanted or needed from me. Only time would tell. Finally, I reached a major conclusion. I needed Patty in my life full time. Regardless of how long it would take to wrap up the legal case, I needed to stabilize things at home. The only way all of our questions would be answered was to give it a try. I invited Patty to live with me and eventually, I hoped, Sharon.

While Patty and I were establishing routines and getting used to life under the same roof, we continued to look for ways to enable Sharon to come home. Patty knew I was doing everything I could to make it possible for Sharon to live at home. She was extremely supportive and didn't want Sharon in a nursing home any more than I did.

We turned our attention from the legal system to the health care system, a system that's willing to spend a lot more money to keep people

institutionalized than to enable them to live in independent living environments. We have a throw away mentality. We throw away things perceived to be used, old, or not as good as before. And we do it with people as well as things. In order for people with disabilities to live outside of institutions they need access to programs that are available. Many times people don't even know these programs exist. When I was searching for ways for Sharon to come home to live, it seemed almost impossible to find information on available programs.

During the course of my research, I found the CADI waiver program. CADI stands for Community Alternatives for Disabled Individuals. It seemed this might be the program through which Sharon could move home and have all of her needs met. The CADI waiver allowed for the conversion of money being paid to the nursing home. If Sharon were deemed an appropriate candidate and enough support services could be provided at no more than what it was costing to keep her at Trevilla (the nursing home where she was living), she could move home. The CADI waiver covers adult day services, respite care services, case management services, personal care services, etc.—all the things that Sharon needs. Sharon met the eligibility criteria and, at long last, it all seemed possible.

Nine and a half years following Sharon's accident, after hundreds of thousands of dollars in legal fees and too many sleepless nights, what Sharon and I had wanted and asked for in 1984, the chance to get on with our lives, actually happened. Sharon was allowed to come home on April 29, 1993. Throughout the court proceedings I heard people say, "Sharon is better off dead than living like that . . . so severely physically disabled." I also heard, "She's better off a vegetable than a lesbian." A judge told me that Sharon couldn't be cared for outside of a nursing home but on April 29th of this year Sharon will have been home for twenty years.

I couldn't quite believe that after all the years of heartache my chosen family was actually home together. A life I had only dreamed about, a life of hope, of possibilities, of happiness was finally beginning. Sharon's move home marked a new beginning for us. Our lives are not the same as they were before. We live one day at a time, each day to the fullest. We live in the moment. This is the greatest gift Sharon has given us. She doesn't remember yesterday and has no real concept of tomorrow. All we have is right now and we've learned to live it to the fullest.

Over the years Sharon was described in the press as a "quadriplegic," "a poor disabled girl," "the eerily silent daughter trapped in her twisted body," and "a poor kid laying there in diapers needing to be turned every two hours." I want the world to know that none of these descriptions is in any way accurate. Sharon Kowalski is a sensitive, funny, loving, intelligent and thoughtful woman. Too many people couldn't get past the reality of her disability. Instead of seeing Sharon and getting to

know her, they saw a person in a wheelchair, with short term memory deficit, and felt sorry for her. Where there were possibilities, they saw only limitations. She was patronized, humiliated, and treated as if she were totally invisible or incapable.

It is long past time that people get to know Sharon Kowalski. The pictures of her which I'll show you in a few minutes give you some idea of who she is and what she's like. The simple fact of her survival during the years of legal struggle is a testament to her strength of character. That she survived with her personality and sense of humor still amazes me.

When I look at Sharon now, I can't help but notice what our separation cost her in terms of physical potential. There are times I can hardly keep from crying. But I refuse to concentrate on that. There are many things that Sharon can do and so much improvement that she has made since moving home. I concentrate on our life together now, on how much we still love each other. She is an incredible human being and I can't imagine my life without her in it.

Sharon has adjusted to her new surroundings. Even though the move home was positive for Sharon, any change is difficult for someone with a brain injury. It's wonderful to watch Sharon living again, interacting and laughing with others. We attend potlucks, concerts, have friends over for dinner, play games, fish, and travel. Fifteen years after the accident, Sharon began standing in a standing frame and twenty-three years after the accident, Sharon started to talk.

And here are pictures of our family today. For us, we still use this definition of family:

Two or more persons who share resources, share responsibility for decisions, share values and goals, and have commitments to one another over a period of time. The family is that climate that one comes home to, and it is that network of sharing and commitments that most accurately describes the family unit, regardless of blood or adoption or marriage.¹

Sharon, Patty, and I continue to learn as we go along. There is no magic formula for living with a person with a disability, no how-to manuals on creating a family like ours and keeping it together.

Let me share an example of one of our experiences when Sharon needed to go to the emergency room following a recommended health procedure. There was a complication during the intubation after which she wound up with aspiration pneumonia. We were asked our relationship to Sharon repeatedly, in the emergency room, in the x-ray department, by the admission's nurse, and by the physician. We always respond that we are a

1. AMERICAN HOME ECONOMICS ASSOCIATION, HOME ECONOMICS, NEW DIRECTION II (1975).

family, which never seems to be an acceptable answer. I was asked if I was her mother or her sister or her friend. Finally, I responded that I am her guardian. Then, they start asking about Patty's relationship. We told them that she has my power of attorney to act as Sharon's guardian if I'm not available. Then they asked to see our guardianship and power of attorney papers. They scanned them into the record in the ER but we were still asked about our relationship to Sharon by many other staff. The issue is that not everyone is asked for proof of relationship (a spouse for a marriage certificate, a parent for custody papers or birth certificates). The irony is that they never asked for identification when we produced our papers.

Weeks later, when our experience was brought to the attention of the nurse manager, we were asked if we wanted to file a complaint. We said no. We just wanted people to learn from our experience so we made a video about family for the hospital, which is now shown in various department trainings.

So much of what we have learned has come through trial and error. Laughter and love have brought us through the rough spots and helped us appreciate how fortunate we really are. We have a wonderful life together. Sharon is happier and healthier than she's ever been since the accident.

Why do I share Sharon's and my story? I share it not to depress people but to empower. It is the teachable moment. As much as I'd like to believe our story is ancient history, it's not. These stories are still happening today.

Our story crosses so many boundaries between women and men, people with disabilities and people who are non-disabled, people who are gay and those who are non-gay. It helps people to not only understand the issues cognitively, in their heads, but also emotionally, in their hearts. Our case shows how powerful building coalitions among different groups can be. Women's groups, LGBT groups, and disability rights groups worked together with us. We must advocate and demand legislation which ensures equal rights for all people, people of color, people with disabilities, women, LGBT, people of all ages, sizes, religions, classes.

I share our story because what happened to Sharon and me, the hell we have lived through, did not need to have happened. We should have had the right to marry. We should have had the rights, privileges, and protections that marriage usually provides. I would have been able to see Sharon immediately. I would have had immediate input into Sharon's medical care. Sharon would have been allowed to come home.

But even when we do gain the right to marriage, there are things we still must do as demonstrated by the Teri Schiavo and other cases. The press contacted me during the Schiavo debate in the courts and asked for my response to the similarities in our cases. They believed that even if Sharon and I had been married, there still could have been a fight. I responded that they had missed the point. The similarity was that neither

Teri Schiavo nor Sharon Kowalski had an advance directive. If they had had advance directives, we most likely never would have heard of either case.

We need to build a record of what we would want if we were to experience an illness or accident where our competency was in question. The first line of protection is to come out!! Gay or non-gay, come out for your protection and the protection of those you love. Gay or non-gay, everyone must have these conversations with their loved ones. National Healthcare Decisions Day is April 16, 2013.²

Advance care planning is an organized process of communication to help individuals understand, reflect upon, and discuss goals for future healthcare decisions in the context of their values and beliefs. When the process is done well, it has the power to produce a written plan (a healthcare directive or an advance directive, or a designation of a durable power of attorney, or a living will) that accurately represents an individual's preferences and thoroughly prepares others to make healthcare decisions consistent with those preferences.

Advance care planning is about:

- Having conversations with loved ones;
- Choosing someone to make medical decisions for you if you were unable to make them yourself. This should be someone you trust, can talk with, and discuss your values and goals; someone willing to accept this responsibility, able to follow your wishes, and able to make decisions in stressful situations;
- The kind of medical care you would want if you had a severe brain injury and were unlikely to recover; and,
- Reflecting on religious, cultural, and personal values that may influence your decisions about treatment.

It's about:

- Having multiple conversations over periods of time;
- Taking your time and not rushing through things;
- Asking questions and being informed;
- Living and quality of life; and,
- Can include directions about death.

When your written plan is completed, make copies for the person you have chosen to be your healthcare decision maker, other family members, your physician, and your medical record.

I can't stress enough how important advance care planning is. It is very frustrating to me when we don't take advantage of every opportunity to educate our community on the need for advance care planning. Last November, in Minnesota, there was a ballot measure seeking to make marriage between one man and one woman part of our state constitution.

2. www.nhdd.org; <http://vimeo.com/36052824>.

We spent countless hours and dollars to become the first state in the country to defeat such a measure. One of the issues I had with Minnesotans United for All Families—the group spearheading the Vote NO effort—was that they didn't want me to discuss advance care planning, even a little. They wanted the message consistent each and every time. While I understood the need for that, I repeatedly told them that we were missing many opportunities to educate people in our own community, and our straight allies, on what they needed to do to protect themselves and their families. Marriage is good but the Teri Schiavo situation should have made it clear that marriage is not enough for anyone, especially not for the LGBT community. We defeated the measure, which was a tremendous victory. However, we still cannot legally marry in Minnesota and there continues to be a need for the goal to be “more than same sex marriage.”³ It is also necessary to be able to validate families however they are constructed. Families change and adapt with aging, long-term illnesses, and disability. Advance care planning is a necessity.

Please don't leave yourselves vulnerable as Sharon and I left ourselves. A drunk driver saw to it that our lives would never be easy. The courts made our lives impossible for years.

A Thirty Year Celebration program was held for Sharon and me at St. Cloud State University. A CD was designed for us that is available at <http://www.youtube.com/watch?v=oHlNcb6SIIM>.

We must answer questions like, “Why couldn't Sharon Kowalski come home?” It was past time to free Sharon Kowalski and it's time to free all the Sharon Kowalskis who are imprisoned one way or another by society's attitudinal and physical barriers.

How much needless pain and agony must there be? How many broken and shattered lives are enough? It's time to free all of us to define our own identities, to define our own families, and to live free of fear.

3. Same-sex marriage did become legal in Minnesota as of August 1, 2013.
