## Jewish Voice

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## Living Judaism

## **Hope from Trauma**

Listening and Learning about Loss, Love and the Gift-<u>Rabbi Goldie Milgram</u> with Amy Kaufman

Shauna Rose Kaufman had many hopes and dreams for her future. But there would be no future. On her way to work on June 18th, 2009, Shauna lost control of her car on a wet road around a dangerous curve. Sliding into a telephone pole, she died instantly. It is every parent's worst nightmare. Shauna was 17.

Shauna Rose Kaufman died tragically in a car accident when she was 17 years old.



Shauna was an artist and an actor. She was passionate about people and about justice. She thought about things deeply and wanted to help others. She decided to be an organ and tissue donor because she thought it was the right thing to do.

Shauna's wish to donate her organs was not honored, however, because of an error and a lapse in the system. The state of Delaware has now implemented a new policy mandating that the Delaware Office of the Chief Medical Examiner (OCME) refer all organ and tissue donations to the Gift of Life (GOL) agency housed in Philadelphia. This policy is referred to as "Shauna's Hope."

Shauna's mother, Amy Kaufman, agreed to talk with me about her continuing journey through loss and grief and how she was able to do something to honor her child who shone so brightly but for far too short a time.

"We just wake up every day and think "this can't be right". Each day startles us as we must realize that she is gone." The words of Shauna's mom echo the pain of every parent whose child died suddenly, without warning. Our discussion considers questions such as:

What can those confronted by the intense trauma of unexpected death do to have the nightmare days ahead unfold with some sanity? How can you and I help them? What if organ or tissue donation is involved? What do we assume is helpful that might be really hurtful?

**Rabbi Milgram**: As a rabbi with a background in social work, I know that a family that experiences sudden loss is in agony and shock. There are major decisions to be made, and the family is almost surely in no condition to make them. For Jewish families it is often Jewish professionals or community volunteers who step in to help provide psychological and spiritual supports, to explain the traditional burial and mourning practices of our people.

Your situation was quite different since you are a Jewish family living in a rural area, participating in a synagogue without a rabbi, without a Jewish cemetery. You were without someone to physically be there with you and for you, to help guide you on the impossible journey through the immediate shock of your daughter's death, all the necessary decision making about her body, her burial and her legacy.

Amy: Yes. You have to think quickly when there's an unexpected death, make rapid choices, choices you have to live with forever. One moment you are being told your child is dead and the next you are being asked to make tough decisions such as how to deal with the medical examiner's office, the funeral home, and cemetery arrangements. I was also immediately concerned with rescuing Shauna's artwork from her car before it rained again and beginning the process of bringing her sister, Holly, home from China where she had gone just five days earlier on a long anticipated trip. And, then, if there's no local Jewish cemetery, will her body dwell far from our ability to visit? Or do we approach the Catholic cemetery across the street from our home; is that really an option? You have no idea of how to get through the nightmare your life has become with one knock on the door about your beautiful, amazing, teenage daughter.

**Rabbi Milgram**: First, let's talk about what kind of support those experiencing such a trauma need, then how you resolved the Jewish ritual and ethical issues.

**Amy**: The hardest thing for me was, and is, people giving advice, often unwanted, about how and how long we should grieve and what is considered normal. The victim's unit of the state police was ineffective; the only resource they left us with was information about a self help group that meets once a month. Friends and family were very helpful in driving us where we needed to go and easing our burdens, but we also needed someone who could understand what we were going through. The woman assigned to us from the victim's unit was young and didn't have children. How could she possibly even begin to understand how parents feel when they learn they must outlive their child? This isn't something we can get over or recover from; our anguish is a reflection of our love.

Jewish tradition provides an important framework for grief: seven days, then thirty, then a year. It at least allows us a way to see our way from one day to another. If you are suffering in pain, you want to know when it will end. The pain of the loss of a child doesn't ever end, but the spaces between periods of wrenching agony do become longer. The indescribable pain of losing a child is equal in intensity to our love for her or him.

Professionals and non-professionals said such thoughtless things to us, so hurtful and insensitive. Shauna had an accident; there was no alcohol, no distractions. She made a bad turn on a wet road and died in a car crash that no one witnessed. It was just a horrible mistake.

**Rabbi Milgram**: You needed immediate support, compassionate listening, someone's full attention, not advice. You were in no position to help family, friends or neighbors to integrate their own difficult reactions either. Do I have that right?

**Amy**: Exactly. My family now lives daily with death; it has become a part of who we are. We have seen both the good and bad in people. Many want to distance themselves, telling themselves that this couldn't happen to them. It is understandable, but we do live in a world where terrible things happen, often in just an instant. On the other hand, there are many who have embraced our family and our pain, and it means so much. How we treat mourners is a reflection of what kind of society we live in. Unfortunately, on this aspect, Americans do not score well.

**Rabbi Milgram**: Without a congregational rabbi, were there Jewish supports for you in the part of Delaware where you live? How did you figure out the burial? Under the circumstances, was it possible for *taharah* to be done, the traditional washing of the body before burial?

**Amy**: Our Jewish community may be like many in rural areas. It does not employ a rabbi, but there is a lay leader who helps families. No one can plan for tragedy. There are ways I wish things could have occurred differently. I've always been a fairly strong person, but I really needed someone to hold my hand and guide me in religious matters. For example, we were told that Shauna had to have an autopsy and we didn't know they could do the washing first. My husband's mother was raised Orthodox but our families were shut down in shock. At the medical examiner's office, after having a chance to sit with Shauna, I just said, "We're Jewish and we don't want embalming." Even that was a lot to get out during those first hours.

**Rabbi Milgram**: Indeed, embalming is not a Jewish practice; we allow the body to be returned to nourish the earth. In fact, while some Jews began to stipulate cremation as their preferred burial during the early days of the environmental movement, we now know the crematoria both destroy residual nutrients the land could absorb and their extreme temperatures contribute to global warming. The best recycling proves to be organ and tissue donation. But first, tell us about the funeral.

Amy: The funeral was well attended and the phone rang constantly. Two friends in particular answered the phone for us. Shauna left an impact on those who knew her and even on those who didn't. From Amherst, Massachusetts where she attended summer camp, to the D.C. area where my husband and I grew up and where Shauna attended leadership training through The Interfaith Alliance, to Turkey where just seven months before her death she and I were able to participate in a dialogue trip to foster understanding -- Shauna made an impression. She had a very diverse group of friends. Three young men stayed up late at night scanning childhood photos into the computer to create a memorial video for the servAmy: The funeral was well attended and the phone rang constantly. Two friends in particular answered the phone for us. Shauna left an impact on those who knew her and even on those who didn't. From Amherst, Massachusetts where she attended summer camp, to the D.C. area where my husband and I grew up and where Shauna attended leadership training through The Interfaith Alliance, to Turkey where just seven months before her death she and I were able to participate in a dialogue trip to foster understanding -- Shauna made an impression. She had a very diverse group of friends. Three

young men stayed up late at night scanning childhood photos into the computer to create a memorial video for the service. They also conducted interviews. Their kindness meant so much. Shauna had done a lot in her short life, and I am thankful she was able to achieve all she had. She was a wonderful artist and writer, was involved in theatre, performed comedy improv, and had a passion for equal rights. Her funeral reflected her spirit of compassion and love.

After the burial we came back to our house and yard where we had the traditional hand washing station. The hand washing felt very holy and it was meaningful to share it with our friends. Shauna's burial was a full Jewish burial. A Catholic friend, Sue, made sure the grave diggers knew to leave all of the dirt. With instructions by telephone from a rabbi, Sue actually went to the site and made sure they did it right. We had been to the funerals of Sue's sister and mother in the previous six months, just feet from where Shauna would be buried. Our lay leader helped us to consecrate the ground with old, no longer useable prayer books. We placed them in the ground before they lowered the coffin. This was very powerful. I can still feel the way the books felt in my hands and hear the sound they made as they fell to the ground. We chose the Catholic cemetery to have her nearby, right across the street; Shauna would have appreciated being right in the middle of things. Shauna was upset when Sue's sister, Joy, died. Somehow it felt manageable that we would stand in the same place that we had stood to share our friend's tragedy. The cemetery did not have a Jewish section; they simply said, "We are all one in God." I liked that. I knew Shauna would like that.

Three musician friends led us in singing "By the Rivers of Babylon" as we buried her. As is the Jewish way, her friends finished filling the grave, which I understand is nothing that cemetery had ever done. It was almost the ultimate interfaith dialogue; that is what we wanted and they allowed it. Our traditions were honored and treated with great respect. A family friend, a rabbi, Haim, was wonderful. He flew in from California to conduct the service, which was beautiful, and when the funeral home filled, he encouraged people to sit on the floor and he welcomed the cries from Shauna's one-year-old cousin. We were very fortunate to have Haim to bring us into the first night of *shiva* (week of mourning after burial).

Rabbi Milgram: How was the shiva experience for you?

**Amy**: Members of the congregation and the lay leader led the other nights of *shiva*. By the third or fourth night, I was joining in and saying 'You know, when Shauna did this' and "remember when Shauna did that" and so on. It was so very helpful to me; I really didn't want it to end. At the end of shiva we walked up the street with the community lay leader who helps with life cycle events in our congregation. This ritual is supposed to mark our transition back into the world and that is when my anger came out. Shiva is a buffer, a really important buffer, that eases our confrontation with reality. Many of our Christian friends told us that when they next face a death, they want to have shiva; that it is really incredible.

**Rabbi Milgram**: What about her headstone?

**Amy**: It's been nine months now and we need to make a decision. We were hoping to be helping Shauna choose a college right now. Having that replaced with choosing a headstone is part of what makes our lives so difficult to move through. It is just all out of order. When we were in a

Jewish graveyard in Suriname, we saw they used the symbol of the tree being cut down for a young life cut short, the Tree of Life. It is symbolic in so many ways. We saw Shauna like a tree growing before our eyes and cut down far too young...her life far too short.

**Rabbi Milgram**: So meaningful on many levels. It is a Jewish tradition to plant a tree when a child is born and when two marry, a branch from each individual's tree is used to help hold up the huppah (marriage canopy). Jewish scripture, Torah, is called an *Eitz Chayyim*, a Tree of Life. And the headstone itself is symbolic. One of the 105 names for God in Judaism is *tzur*, Rock, and in the Zohar we read that each soul is cleaved from that Rock and that our yearning for connectedness and unity in life is our souls seeking for the One. When we visit a grave and leave a stone, it symbolizes our soul, cleaved from the One, clinging to the memory of the soul that has ascended.

A grieving parent once told me something that I used to open my recent book on the meaning and deep psychospiritual value of Jewish rites of passage, <u>Living Jewish Life Cycle: How to Create Meaningful Rites of Passage at Every Stage of Life</u>. She said the time after her child's death was like a dark tunnel lined with velvet hands. She felt those hands helping the family through. By the end of shiva she was able to come somewhat out into the light of day to realize and appreciate that those hands were connected to familiar faces of friends and community who really cared.

Amy: Yes, that's it. What a beautiful way of putting it.

**Rabbi Milgram**: It is beautiful how creatively and Jewishly you shaped the mitzvah a soul cannot do for itself on its travels into Mystery; how you returned your daughter's body to the earth with dignity and love. I am aware there was an additional level of trauma to all this. Tell us please what happened in regard to the matter of organ and tissue donation.

Amy: I almost intuitively knew something had gone wrong with the organ donation plan. Immediately after seeing her I pointed out to the medical investigator and three state policemen that she was a donor. But then, I never heard anything, and I thought that just could not be right. I made many phone calls on my daughter's behalf to find out what had happened. I was not going to give up on Shauna's last wish. It turned out that the systems were not in place or legal authorities coordinated in the ways necessary for the donation to go through. The State Police and the Medical Examiner's office are completely separate. The police only sometimes took note of the driver's license request for organ donation and made it known during transition of the body. But in non-hospital deaths, the referrals to Gift of Life are left up to the medical examiner's office. In Shauna's case the referral was called in too late and not until the following day.

**Rabbi Milgram**: Shauna's hope to have others live through the donation of her organs and tissues fell through the bureaucratic cracks.

**Amy**: Yes. My personal awareness was raised in trying to find out what happened to her donation. The awareness is both about the mitzvah and about the practicality.

**Rabbi Milgram**: I trust you mean the mitzvah of *pikuakh nefesh*, of saving a life. Perhaps only two decades ago, Jewish law opposed organ donation because with the transplant methods used at the time the chances of successfully saving a life were not high. With the rapid pace of research and technology, the scales shift radically in its favor. Across the spectrum of Judaism it is now considered a major mitzvah to leave your organs and tissues. Orthodox Jews have a specific organ donation card available at the <u>Halachic Organ Donors Society</u> and must consult their rabbis first for living organ donations on a situation by situation and organ by organ basis.

**Amy**: Shauna's driver's license indicated she wanted to be an organ donor. I knew that, but I also knew that my husband still held onto old superstitions that organ donation was not necessarily a Jewish practice. It is true for most people that it is often harder to unlearn something that it is to learn it. So for many of us, we still hear the old words in our head that our rabbi or priest may have uttered about desecration of the body. But in the hours following Shauna's death, I remembered our conversation about her signing up to be a donor.

Through the process of pursuing Shauna's wishes to be a donor I learned that the organ donation group Gift of Life (GOL) offers bereavement counseling (three to five sessions for free), which is really critical, and they have good people. The nuts and bolts of organizing the donation requires a lot of paperwork, and GOL has people specially trained to assist the newly bereaved. You will receive a phone call and be guided through the process by this nonprofit organization. You know, our grieving is as unique as each of us is. People may be in denial or hysterical; there are no wrong reactions when you receive what may be the most devastating news of your life. Those involved in assisting the bereaved have to be professionally trained in all aspects of grief as well as in the donation process.

**Rabbi Milgram**: How did the policy materialize and how was it implemented?

**Amy**: Part of what was so amazing was that this was a collaborative effort and the idea to name it "Shauna's Hope" did not come from us. The important thing is that we got "Shauna's Hope implemented quickly, within three months of Shauna's death, making every sudden death in the state of Delaware a mandatory referral as a possibility for organ and tissue donation. Families still have to agree even when there is a pre-existing organ donor document, and next of kin must be notified, but they would be contacted by remarkable, kind, well-trained professionals who also know how to counsel and support them in a time of horror.

Emotionally, it is not easy. You experience a very tragic death with no notice, like we did, and you will have to make this decision, if it hasn't already been made, to donate your loved one's organs and tissues. Some from Shauna's generation just do it automatically when they get their driver's license, but they have not talked to their parents about it. Shauna and I did talk about it, so I knew and wanted to honor her intent. There are so many issues around donations, such as the criteria to ensure the donation will be safe for someone to receive. These include asking grieving parents difficult questions such as: "Is your son a homosexual?" or "Did your daughter do drugs?" Authorities are sometimes reluctant to pursue permission for organ donation because of the need to make these inquiries as well as to screen for AIDS. A person who has lived in Northern Europe for a certain number of years can be screened out of eligibility to be a donor because of mad cow disease. Together with Chris Graham from Gift of Life, we worked to move

these questions to the organ donation agencies and out of the hands of the medical investigators who are often already overburdened. In addition, the questioning has been transferred to professionals trained to work compassionately with families in trauma. There are many screening mechanisms to ensure the safety of organs received, and while it's frustrating that a lot are screened out, it emphasizes the need for a larger pool of donors.

Rabbi Milgram: And are there other issues?

**Amy**: Well, there are many social issues that have arisen as I contemplate my immersion into the world of organ and tissue donation. How do we define family and next of kin? How should we treat mourners? Many things. For me, there are also deeply spiritual questions about how we live our lives and how we think about our physical bodies and the existence of the soul. Shauna's hope was all about intention, intention is something that really matters in life and death.

**Rabbi Milgram**: Intention, we term it *kavannah* in Judaism, the intention to do a mitzvah even after her last breath would be gone. A very holy intention that has resulted, through your efforts, in changes in the policy of your state regarding organ and tissue donation. An intention that will save many lives. You explained that "Shauna's Hope," as the new policy is called, was a team effort between Gift of Life, The Delaware Office of the Chief Medical Examiner, and your family. Now that "Shauna's Hope" is in effect, are you continuing your activism on other fronts and what do you recommend regarding other states' policies?

Amy: One thing that was very powerful or transformative to me about the implementation of "Shauna's Hope" was that in our situation there was a mistake made and the right person identified it as a mistake and righted the wrong. A government official or officials in general took the initiative to try to make things right; that doesn't often happen. In this case, it was fairly miraculous that those involved decided to embrace their mistake and really create something positive. It was Hal Brown who did that, the Deputy Director of the OCME. Hal, and everyone at OCME, have been extremely compassionate and kind. They face trauma intimately, see death on an almost daily basis, and have a real interest in seeing something positive come from this. I remember a conversation with Hal in which he told me that the matter of the mistake would be handled internally, but he knew "I didn't care about that." I did not know how he knew that, but he was right. Fixing the mistake and going above and beyond to create something with positive results is far better than punishment. And it was Hal who said he wanted to call the policy "Shauna's Hope" unless I could think of something better. I couldn't.

Today I find myself working on ways to raise awareness of organ and tissue donation. I hope our story can serve as an example of how important this simple tie to our life cycles can be. It was devastating to us that our daughter's wishes were not carried out because of the mistake made, but through this mistake, we have come to learn just how important organ and tissue donation can be and how it can help tie families to the world at the same moment that the world is collapsing all around them. No matter what we believe, we can generally agree that our bodies will not serve us after we leave them, but they can help others. We can truly help to repair the world.

There has already been an increase in donations in Delaware, and the policy was just established

in September 2009. It is shocking the small number of organ and tissue donations that had occurred in non-hospital deaths prior to "Shauna's Hope"; since then the numbers have doubled and, by this point, possibly tripled in our area. Because of the new policy and the training on it, OCME investigators in both hospital and non-hospital deaths are aware of checks and balances that were not previously imposed.

Continuing to work collaboratively, we hope to reach out to other regions and states. The Gift of Life region is the largest in the country, covering all of Delaware, the eastern half of Pennsylvania, and the southern half of New Jersey. "Shauna's Hope" is an unprecedented policy. We would like to see it adopted throughout the Gift of Life region and to have it serve as a model for other regions throughout the country. Shauna was the kind of person whom most of us thought could change the world. It does give us hope that this is part of her legacy.

Amy and Ian Kaufman live in southern Delaware with their daughter, Holly, who is 14, They have an environmental consulting business. Amy has studied agriculture, botany and animal science; she is also a weaver. She has begun the next chapter in her life by going back to school for liberal arts studies and is currently preparing to write her thesis. The Kaufmans are learning how to run their new foundation, the Shauna Rose Kaufman Foundation.

To learn more about Judaism and organ donation visit these links: <a href="http://www.pjvoice.com/v8/8701donation.html">http://www.pjvoice.com/v8/8701donation.html</a> and <a href="http://www.pjvoice.com/v14/14701organs.html">http://www.pjvoice.com/v8/8701donation.html</a> and <a href="http://www.pjvoice.com/v14/14701organs.html">http://www.pjvoice.com/v14/14701organs.html</a>