

A Brave New Challenge and

A Big Question in Shobi's Heart

Several months ago, Shobi was clowning at a fair and ran into Zachery's parents. My heart leaped with recognition. It was like meeting family. I had been so close to them for 18 months while their infant son was in the hospital. Then one day Zachery died and I never saw them again. That was three years ago. I expressed my concern to them on how I had missed seeing them. They commented "Yes, we not only lost Zachery, we lost all of you too!" Wow, it brought tears to my eyes. Imagine losing all that support. All those people you have come to love as caregivers and then with the loss of your son, you also lose the support too. They saw the tears in my eyes and as we had done on so many occasions, we hugged. They were well on their recovery with new twins babies, but Shobi was left with a big question in her heart. What can we clowns do?

It is something to ponder for the hospital and the hospital clowns. Can we provide a service where we go meet the families later to just visit and to ease the separation. I'm sure the hospital social workers have people who deal with this, but imagine what a clown could do here. Maybe it could be a sibling's birthday party or just a party with the clown, or just a visit on the way to the hospital. It would do more than all the psychology in the world.

I asked a few other clowns their ideas on the subject.

Sharing Our Inner Sparkle

-- Anita "Toot" Thies of State College, Pennsylvania

Thanks for raising the issue with the example of Zachery's parents of the role of the hospital clown in following up with families who lose a child. I think it would be wonderful for hospital clown programs to get something set up that is more formalized. Here are some of the benefits I can see from some families I've known:

- ♥ Helping siblings (and the family) to connect with joy after the death. I was a hospice clown to the family of a toddler named Stephen, (with many hospital and home visitations) and after his death his older sister, Amy asked me to teach her clowning and we went together to clown at nursing homes and in churches. It was one way for Amy to express her creativity and find some joy and fun after her brother's death. Also, I became her special clown friend.
- ♥ Helping parents by sharing in and keeping alive the memory of their loved one. In another hospice clown situation, I worked with and clowned with Jessica, during the last six years of her struggle with leukemia. (during her two times of remission we did clown programs at her school etc.) After Jessica's death, I kept in touch with her mom mostly by written cards and occasionally by telephone and to this day her mom still sends me cards at holiday times (9 years after Jessica's death).
- ♥ Often in a clown's presence, the child will connect with that playful, laughing essence that illness threatens to eclipse.
- ♥ One of the gifts I believe a clown can offer to the family after the death is the sharing of the inner sparkle that the clown saw in the family's loved one. For the parents to be able to recall that after the death can be a comfort. Also, when we clown with the same children over a long period we grow to love them and we grieve deeply too.

The Gap in Our Health Care System from Patty Wooten

I think this "inner sparkle" is an incredible way to help a family through the grieving process. By the clowns sharing with the family what they saw and experienced, it will help to ease the guilt of "not enough" messages that could linger in their minds. As a nurse, and former hospice nurse, I want to validate how important this follow-up sharing is to facilitate the healing process of grief and loss.

I think a post separation clown visit would be a wonderful thing to offer the family via phone and schedule for the appropriate time. Perhaps if it was a death, this contact could be made 3-4 weeks afterward. With managed care there are less and less staff with less time to do these "non revenue generating" activities that mean so much to a family and increase the "humaness" of the institution. Even the fact that the clown offered would mean so much to the family.

The Lingering Questions -- Shobi

We can understand the need of the family and the patient. It is a wonderful thing to bring our "humaness" into the health care system – to bring our "non-revenue generating activities" to those in need of our special gifts. We can offer this, but to what expense? Do we have the time? Do we have the emotional stamina? Do we have the spiritual support needed to carry out this kind of program in a consistent manner? How do we process all the emotions connected with these visits and with whom?

On the following pages is the story of a group that is trying it out.

Jeannie Lindheim's Hospital Clown Troupe

Jeannie Lindheim decided to start her Clown Troupe while on a trip to Russia with Patch Adams. She has been teaching acting since 1970 and in 1996 clowning was a new avenue to explore. After the trip she decided to offer a day-long workshop called *The Art & Joy of Hospital Clowning*. She thought about 6 people might sign up - twenty-five people registered and there were 25 on the wait list. They did their first hospital visits in May of 1997. The HCN reported on this amazing troupe in Vol. 4 No. 2

Their hospital visits are as a troupe of 2 to 10 clowns. Jeannie says "We do improvisational theater clowning. The key to this type of clowning in a Troupe is to be totally in the moment, with yourself and with each other." Every clown has gone through extensive training experiencing spontaneous clowning. This makes the troupe different from most Alleys that I have learned about in the USA.

Beth Regan (article on next page) lives in Norwood, MA and has been clowning for 4 years, She has been with Jeannie Lindheim's Clown Troupe since the beginning of the troupe in May, 1997. Beth was inspired to clown after hearing about Jeannie's trip to Russia with Patch Adams and wanted to be able to bring that joy to children in Boston area hospitals.

A Brave New Journey -- Clown Home Visits



Front Row Left to right: Eliza Klureza, Jeannie Lindheim; Kate Schalk, Marlyn Strong, Joyce Friedman. Top Row: Mark Gorman, Diann Siegel, Anne Jackson, Beth Regan, Cheryle Lekousi, Ginny King, Linda Simon, Valerie Overton, Treather Grossman, Nancy Pease.

By Beth Regan aka "Beth-a-Belle"

Home visits are a way for us to extend our clowning throughout the continuum of care from the hospital environment to the home. Some children may be returning home to continue their recovery while others are returning home to face the end of their disease in a comfortable, familiar environment. Bringing a child home brings on different fears and stresses for the caregivers. In the hospital, the family may be fearful of the disease, but the caring for the child is in the hands of the nurses and doctors. At home, they may be the ones responsible for administering medication and monitoring the child along with the heightened stress and the emotions. Having a clown enter a home with love and peace can alter the feeling in the home, not just for the time we are there, but long afterwards. Many families will even videotape the visit to have a reminder of a joyful time and to play again for the child.

Home visits are incredibly rewarding for the clown, but they also carry many responsibilities both administratively and emotionally. As our clowning with children is coordinated with the Child Life Department, we start with our Child Life Specialist. The Child Life Specialist can inform the parents as their child is being discharged from the hospital that a Clown Home Visit is an available service. Once the word is out, friends will begin to call and ask if you can see their child or a friend's child.

Scheduling

Scheduling can be time consuming. We have found that it is efficient to have one person responsible for organizing and gathering all the pertinent information and communicating it to the troupe to limit the number of phone calls to the family. The family would contact the coordinator and request a visit. The coordinator would find out the age and sex of the child, the best times to see the child, what types of activities do they enjoy, who might be present, any special circumstances along with the address and directions. The coordinator would let the parents know what to expect from a clown visit: how long the visit may last; that the clowns will be in character the entire time; and, things the clown might do. We reassure them that our goal is to be present in the most loving and joyful way possible, and that we will be sensitive to their needs and the child's needs.

The coordinator then e-mails all the clowns with the specifics and requests that the clowns respond with their availability. It may be that one clown goes alone or that 2 clowns go together. The coordinator calls the family and arranges the date and lets them know who will be coming. It is then confirmed with the clowns.

Home visits can last anywhere from 30 minutes to 90 minutes. Clowns must be prepared with many activities. Each visit is very different. There may be many extended family members there or it may be very intimate with the child and the parent.

Cheryl Lekousi aka *TicToc* wrote this about a home visit in her journal.

“I found that I needed to be flexible. I arrived on time, but the family was not quite ready for me, so I stayed out of sight of the child until they were ready. I was asked to sing to him while holding him on my lap for pictures I ended up being very close to the child, much closer than in the hospital. I went with my instincts, tried to be in my clown all the time, but found it difficult when the parents asked me questions I couldn’t really answer “in clown.” The parents talked about what he would say before his illness. My visit ended up being much longer than planned, but seemed to work for everyone.”

When arriving at a home visit, it is very important to be in character the moment you leave your car or approach the home. The child or other family members may be watching from the windows. It is their home and one must be respectful of their space and enter carefully, slowly and quietly. That may mean taking your shoes off, so be sure you have clean socks on! Bubbles are a great icebreaker. If the child is apprehensive, the clowns can blow bubbles to amuse themselves and engage in parallel play without directly involving the child. Once the child appears interested, the clown can look over at the child and begin to slowly approach the child and begin to interact with the child directly.

Siblings and parents need to be brought into activities, but always remember to check in with the child who is sick to see how they are responding. Engaging everyone in a song is a great way to build unity and have everyone involved. On one visit Kate Schalk aka Kow Girl Koo had a slide whistle conversation with the mother, the grandparents put on silly glasses and everyone was laughing. The clown was later told that this was the first time in weeks that they had laughed and it was very appreciated. By helping the parents lift their spirits, we are creating an energy that can be felt by the child. The heaviness of caring for a child who is ill must seep out, no matter how hard they try to keep those sad feelings tucked away.

Laughter is contagious

During one home visit, Tic Toc, who is also a day-care provider so well versed in children’s songs, was singing a favorite song with the child and mother. Tic Toc forgot all the words, so the mother carried the clown through. At the end of the song they all laughed. It was their laughter that made the young boy laugh. It was at that point that the clown realized what the parent’s laughter did for the little boy. It reminds us how important it is to focus on the parents as well as the child. The parent’s state of mind is transferred to the child and plays a role in the healing process.

Many of the children we have visited are in wheel chairs or have limited mobility so often we are on the floor making sure that we are staying in their line of vision. One child was placed on the grandfather’s lap while sitting on the couch, with the mother and father on each side. The clowns settled on the floor directly in front of the child so that he could see the clowns and the toys.

As in the hospital, take your cue from the child. One visit was with an 11-year-old girl who was given *A Clown Manicure* -- this is when we put stickers on each fingernail of the child. Kids love this, especially the teenagers. The Clown Manicure turns into a skit that exaggerated the set-up of putting the sticker on each nail and then marveling at each finished nail



Beth-a-Belle commandeers the outing bus.

One can have all the props that they have ever used at any gig and it still may not work with that particular child, so be prepared to improv. While at one home, the mail came through the mail slot and it kept coming in, it was a month’s supply of mail. The clown made up a whole skit just from the mail. It made it personal and “at home.”

When leaving the home, we stay in character and will leave a clown bookmark, a clown doll and/or a clown pencil for the child. Determining when to leave a hospital room or a home is always difficult. Be aware of signals the child and/or the parents are giving you that it is time to leave. Always leave on a high note.

Another home visit is offered when we leave. Some families immediately say yes, but others may not want another visit. It is important not to take this personally. There are many reasons that families may not want future visits or people coming into their homes. It is important for them to know that if they change their mind they are welcome to call.

Processing the Visit

After leaving each home, we process the visit. If a clown does a visit alone, we suggest that the clown express their feelings by calling another clown who has done a visit with that family if possible or another clown that has done home visits. If there are two clowns, they discuss how they felt, what worked and what didn’t work as well. The clowns will e-mail the troupe about the visit, so that other clowns know what worked and didn’t and get an update on the child so they are prepared for their visit. It is important to keep in mind that the child will change day to day either due to the progression of the disease or medication or time of the day so even though you may have heard how some things worked, they may not work the time you visit. Be flexible and in the moment.

The very first home visit that we did was performed by 2 clowns. A mutual friend referred the family to us. Jeannie called the family on a Wednesday and asked when they would like us to come, Thursday or Friday. The father responded, “You better come tomorrow, I don’t know if she’ll be with us on Friday.” We entered their home and there were about 12 people there – the parents, grandparents, sister, cousins, aunts, uncles and a caregiver. The child was very ill and we were not sure how much the child took in, but it was very clear at different moments that the child experienced us.

We did a variety of skits ranging from juggling, magic tricks, one clown getting their head caught in the other clown's prop bag, and music. As we were leaving, the father approached us and thanked us for helping to lift their spirits and said, "She'll have this to take with her." The girl passed away the next day. It was very difficult for the clowns who had done the visit. We know that there are children who we clown for that will not beat the diseases they are fighting, but it was the first time we knew a child had died. I felt a great honor in having been able to give that gift of joy and love, but it was a very emotional time. Our troupe is having a hospice worker and a pediatric intensive care doctor speak with us about the special circumstances involved with seriously ill children and how to prepare and process our visits.

A Special Little Boy

There is a family that our troupe has been visiting three times a month for the past six-months. The child has a terminal illness and



may only have a few months to live. This little boy loves music and loves to see his father wearing funny glasses. He loves props he can wear and see in a mirror, or a prop that his parents wear. Just recently, the child celebrated his 3rd birthday and the clowns were

invited to the party. The clowns were there not just for the child and his family, but their extended family and friends. As the clowns were leaving, the father said, "I have been looking forward to this day so much and it was better than I ever imagined."

The clowns that have clowned for this little boy and his family are not sure how they will deal with his death. How will the clowns comfort one another? Will this "burn them out"? Will they maintain a relationship with the family? If they don't what would that mean to the family, would that add to their loss? The clowns have become friendly with the parents, but the clowns are still careful to respect our clown rules, no questions about the illness or personal questions. How does this appear to the family? Do they think we're not interested or concerned?

As we do more home visits and encounter different situations we are faced with more questions. Do we provide home visits for a child who is recovering from a broken arm or since we have limited resources, do we visit only children who are facing serious illness? The relationship you build with a family that you visit once versus the relationship you build when visiting a family for over 6 months, on what personal level do you allow yourself to become involved with the family? Do you want to be informed when the child passes away?

Our troupe has been performing home visits for 9 months, so we all are fairly new at this type of clowning. In our clown meetings and via e-mail, we continue to communicate to each other about our experiences, make suggestions on how we can improve and support one another on becoming individually and collectively the best possible clowns we can be.

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