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WHAT IS LOST IS FOUND

Deborah Gough

I have been teaching at a rehabilitation counseling training program for almost 20 years at Northern Illinois University. I train students who will become Rehabilitation Counselors for the deaf. Most of them will work in voc rehab, although a lot of our students work in other settings as well.

One of the things that I notice in training these people, is how important it is that we understand what happens to people on an emotional and spiritual level when they deal with loss due to a disability or any life long change. That is, how we all deal with grief.

One name that comes up often when we talk about the process of grieving is Elizabeth Kubler Ross. Dr. Ross developed wonderful information on this subject back in the '60s. Unfortunately, a lot of her work was misunderstood, as our thinking about loss tends to be very linear. The thinking was that there are stages, and that you complete one before you move on to the next. And then at some point an individual comes to a complete state of acceptance.

What I learned in terms of training students is that there are a couple of problems with that theory. Most people I know who have experienced loss of one kind or another, didn't quite identify with those stages. The other thing I noticed is that we need to find parameters to help people who were going through a grieving process—rather than simply seeking to define it.

I also noticed how hard it was for students, when working with people, to keep their own emotions from intruding on the therapeutic process. They had difficulty being around people who were struggling with loss and grief. They didn't know how to be there for people dealing with grief without getting upset or afraid or worried about that person. This means that there are usually more than one person struggling when loss strikes—neither with a good grasp of what to do.

Several years ago I met a clinical psychologist from Evanston, Illinois, Dr. Ken Moses. He had developed a very different perspective and understanding about how loss and

grieving works—a very positive, growth enhancing and optimistic, and most importantly, a non-pathological view of the process of grieving.

Dr Moses has a son who was born blind and mentally retarded, or so they thought at the time. That was the diagnosis at birth. His son, now in his early 20s, actually has a visual impairment, and has mild CP. This experience allowed Ken to take his model of understanding of loss and grieving and apply it to disability issues. His ideas seemed to answer a lot of the questions I had. And this is what I want to share with you today.

Audience Member: When I drove home from getting my hearing aids five years ago, I cried all the way from Baltimore to Washington, DC. My family can't understand that. How can I explain this type of loss to other people?

Deborah Gough: Other people may not see these things as being as serious an issue as it feels to you. People don't understand why you may be grieving so much.

Audience Member: You talk of the grieving stages—does a person go through each stage and not return to a stage? Or do they sometimes go back and forth?

Deborah Gough: People go back and forth, and in and out, as they need to in that time. We will talk about that more today. A lot of people have been told that there is a linear progression, and that once you go through a “stage,” you don't go back. Let me just tell you, in my experience that is not true. The problem with having been told that that is true is that when it happens to you, you think that you are all done with the grieving process, and then one day you may slide back into it again. And you may feel that there is something wrong with you—that you are doing something wrong. That's another part of the difficulty of this process, and it's another part of why it's so hard to explain to people how you really feel.

Audience Member: I am an outreach contractor and I work with deaf and hard-of-hearing people everyday. I am amazed at the number of people that I see that who have quit their jobs. They stop driving their car. They become isolated. And they can't see that they don't stop living because they are deaf. They seem to be in some kind of denial stage. I need a way to break past that.

Deborah Gough: I think that you've probably raised what a lot of service providers name as the number one problem in dealing with clients—denial. It causes a lot of confusion and frustration with them as to why clients may not be able to cope as they themselves may be doing. So there is a lot of frustration with the fact that people have denial and how long they hold on to it.

Audience Member: I became profoundly deaf 15 years ago. I feel as though I have been in and out of the various stages of trying to accept this. And I would like to know a little bit more about how I can tell if I have reached acceptance or am still in denial.

Deborah Gough: Very good question. And I will pose another question that I think some people might think about. Do you think that acceptance really exists?

Audience Member: I find that I may go through a process and get to where I think I am dealing fine, and feel that now I am OK. And then a situation will come up, and it just sends me back into a tailspin. Sometimes that lasts for six months. I want to add that it has been eight years, and I really wonder how long this will continue. I would just like to know how to minimize the tailspin so I don't allow this to upset me for so long.

Deborah Gough: I do some individual counseling, as well as a lot of group work. The people who concern me most are the people who don't experience the negative, who don't experience the painful stuff, who stay positive and hopeful, telling themselves that they are becoming a better person. Now some of that is probably true. But there are other things to consider. If we don't look at the other parts and deal with them, it's very, very difficult to work through grief and achieve change. A lot of people try to work out all of the painful stuff alone. And then when they're with other people, they try to be brave and strong. So I have a different definition of what "strength" means.

I work with people who struggle with big challenges in their lives. For some people, it takes a lot more courage and strength to let others know how they really feel. That's what's really courageous.

Audience Member: Can you say a few words about stress and how it effects us?

Deborah Gough: First of all, everybody has stress. Secondly, when you can't hear in a hearing world, that increases the stress phenomenally. Working through loss and its very painful feelings is physically, emotionally and psychologically depleting. So stress can go up and up and up.

One of the things that I learned very quickly about working with people who have experienced significant loss is that we are all socially trained to respond to people in need in a certain way. What we've learned to do, even as little children, is to confront people who are in denial. We think that if we just explain it correctly to these people, they wouldn't be in denial. And that is a mistaken belief. Denial is there for a purpose, and we need to realize this.

Secondly, when we see someone who is highly anxious, nervous, or upset, we feel the need to calm them down. In this culture, we don't tolerate pain very well. We don't tolerate anything that is uncomfortable. If you have pain or stress or whatever, we look for relief—perhaps in a pill.

Anxiety is there to serve a purpose. When people are truly afraid, and you are with them, it is very natural to want to comfort them, and assure that that everything will be OK. That is the first thing that we learn to do.

I was asked to do a workshop with the parents of children with disabilities—very young children—infants and toddlers who had recently been diagnosed with a variety of different disabilities. When I asked the coordinator for this program what they hoped I would do for these parents, she told me that they wanted me to assure them that everything would be OK. I told her I could not do that. I don't know it is going to be OK. None of us do. It would be a lie and these parents would know it.

When people feel guilty, we want them to not feel guilty. I talked to a woman who was a speech therapist, and she was upset because her sister has a 6 year old son with Down's Syndrome. At every family get-together, her sister would come up to her and tell her of her guilt because she felt that her son's condition was her fault, because she had had romantic feelings about another man a couple of years before becoming pregnant. She truly believed this. Her sister tried and tried to talk her out of this belief—as most people would. But her sister could not take it in and continued to harbor her guilt.

When people are depressed, we feel like we must cheer them up, and so attempt to think of all kinds of diversions. But how well does this actually work? It doesn't. Sometimes, if we're talking clinical depression, medication may help, but more often we're too quick with that solution also.

Finally we have angry people. We all get angry at things. We get angry at our hearing loss, as well as other losses. Anger is a very normal, necessary, helpful feeling. I worked with a group of parents of children who had been recently diagnosed as being deaf or hard of hearing. One mom was angry. She got angry with doctors. She got angry with audiologists, and she got angry with early intervention personnel. And she felt guilty about being angry. She told me she thought she had to stop the anger she was feeling. I told her that she might not want to do that, because that anger was serving a purpose for her. It was getting her child a lot of what he needed at that time, because it was providing energy for her.

So we're going to talk about the fact that these feelings are not the problem. A lot of people think the problem is due to feelings, and they are not. Feelings are really opportunities to learn things and to figure things out. They help us figure out who we are; you cannot live the rest of your life being who you were. Of course you can try, but it is very expensive emotionally. It can cost you relationships. It can cost you hope and vitality, and being genuine for both yourself and for other people. If you try to maintain being someone who you are not, it's very exhausting, and your life becomes very superficial.

One of the things Mike Harvey said this morning in his speech was about letting go. He talked about letting go of who you were, and how painful and frightening that can be to find new identities. I am myself the mom of a boy who has autism. My boy, Kip, is 10 now. I want to share with you something about letting go of whom Kip was when he was born. He is the youngest of five. As good a mother as I am, and as experienced as I am, I had to deal with all of these same issues that we have talked about. Denial. I was right there in denial for a long time. I had a little boy who was 18 months old and still could not talk at all. He never asked for a bottle. He was about six when he started to be able to say Mama. Denial was pervasive for me. It was very hard to let go of the belief that Kip was just a regular kid who played differently. That's what I used to say. "Kip is okay. He just plays differently." Looking back on it now, the letting go was very painful and difficult for me. And it happened in an instant. For some people it happens when you get a diagnosis. That's when you really know. For some people, it happens before the actual diagnosis, when you simply know. And sometimes it is long after the diagnosis before you really get it.

When Kip was more than 18 months old. I put him to bed, and he was facing the side towards the wall. And when I laid him down he just lay there contentedly staring at the pattern on the wallpaper. I had put him to bed for 18 months, and this was the first time it hit me he would rather stare at the wallpaper than look back at me and want one more kiss, or one more song, or one more book, or a drink of water. He never did those things. He simply lay where I put him. At that moment the whole world just changed forever.

So, it didn't happen when my husband tried to tell me that he thought he was autistic—which he had said months before. It didn't happen when he was three when we had him technically diagnosed. For me it was a relatively painless thing to get his diagnosis—though that certainly is not true for everyone.

Letting go sounds so simple. But it is not, because it involves changing our life forever. Working through loss and grief does not have a recipe. With a recipe, we go through a process and theoretically we should all come out the same, with the identical finished product. It does not work that way. So one of the things that I have learned about loss and grieving is that this process needs to be looked at as being more of a map. If five people from Florida tell us how to get from here to St Augustine, we would probably get five different suggestions. But it doesn't matter. We would all still get there eventually in our own way, in our own time frame.

That is a little bit how grieving really works. There are a few things we need to know about this process. The first thing about loss and grieving is that it is an unlearned process. We don't have to read textbooks about grieving in order to know how to do it. It's automatic. That's a good news/bad news kind of thing. Once you get it—once you really understand what's been lost, grieving can begin. You cannot time it so that it occurs at a convenient time. It doesn't work that way. You don't have to worry about starting it up. It starts by itself.

The third thing is that all of this is a feelings process. This is not a process that you can necessarily think your way through. I know a lot of people are very cerebral types. My husband is one of them, so I am very familiar with that type. This type feels that they should try and think their way through a difficult situation, analyze it, and figure it all out. Then they should be fine, and just bypass all the feeling part. If only.

The only way to work through these painful feelings of grief is to share these feelings with significant others. Not alone in your room. The question is, who would be a significant other? Right away most people think spouses or parents. Sometimes these are not the people who will be significant in this process—for a lot of reasons. Not that your significant other, as you normally think of that person, wouldn't want to help, but sometimes it just doesn't work that well. It's sort of paradox that the people who are most important to you, the people you love the most, sometimes aren't the best people to help you with this. Why do you think it is? Why do you think they're just not the best person to help you out here?

Audience Member: Sometimes they're grieving, too.

Deborah Gough: Exactly. They're grieving, too. Also, they don't want to see you suffer, so they may look for band-aid solutions to help you. It hurts them to see you in pain. They're grieving the loss, though it is a different loss from their point of view.

Let's talk about where all of this begins. We all have dreams. We dream about what we want to be and how our life is supposed to be. We dream about what we're going to do in our lives, and what our children will be like. We also have profound, deep attachment dreams to spouses and marriage and how we think things should be. We project into the future. You do and your spouse or partner does, too.

One of the dreams that spouses or partners have is that they will protect and take care of you. I think very typically in different ways, it goes both ways, but men especially feel compelled to take care of those they love. But things happen which we can't protect each other from. You can't make it go away, and the dream may be shattered.

I had a dream—a belief that I still hold onto, that I would always protect my children—that I would never allow anything or anyone to harm them. If they got hurt, I would be able kiss them and make it better. That was my dream. When you have a child with a disability, that dream is shattered. Not only the dream you had about who that child was going to be, for them as well as for you, but now you've lost a second dream about your ability to protect your child. In an instant it's shattered.

Some people try and hold onto those dreams even though they are shattered. They try to hold it together with super glue and duct tape. It doesn't work. So to whom do you talk? Who will be that significant person that you can really talk to? Sometimes it's a peer counselor. Sometimes it's your next door neighbor. Sometimes it's somebody you happen to meet at church. Or it may just be a friend who you just happen to really connect with.

Don't be surprised if it's not your mother, or your wife, or your brother or sister or significant other. When people are struggling with issues of loss, it is very important to remember that people are fighting to hold on. They're fighting for their lives. To attempt to get them to let go of what they had hoped and dreamed of is very, very difficult.

How can you help them? You can't pry their fingers off of it, although you might like to. It's more important for them to hold on than it could ever be to allow you to help them let go. Letting go has to come at their time, on their terms.

But we do have to let go. We have to find something new—a new way of being in the world. Following loss and change we are not the same person we were before. It doesn't mean you are not as good or as strong, or as important, or worthwhile. I have no doubt that you are. I have no doubt that you are stronger, smarter, and have more depth to you as a person. But we only get to this point by fighting to get it. No one can hand it to us.

The flying Walendas were a circus family from Eastern Europe. They were very famous in this country for a couple of things. One was the particular act that they did. They were a high-wire act. And they were all family. The patriarch of the family, Carl, was the head of this whole team. He was in charge. They had an act where they would ride on a bicycle across a high wire, one person on the bike, and then one person on each shoulder,

and one on each of those shoulders, like a pyramid. The second thing they were famous for was that they always worked without a net. No net. Never! They had brought another family member over to join the act. They trained him, and they thought that he was ready. He was part of this bicycle act, and apparently he was not ready. There was a horrible accident. He lost his balance, and that caused everyone to fall. It was a horrific accident. They all fell, a couple died, a number were very seriously injured. Carl Walenda was seriously injured, but did survive. The family never performed again. Carl did. He started working alone doing high-wire acts, just walking across the high wire. But to make it interesting, he started doing so outdoors from one building to another building—a skyscraper to another skyscraper. And of course, no net. You can't put a net on the street, it wouldn't help him anyway, he was so high up. The other important thing to think about is that he couldn't practice. You know, you can't stop all of the traffic in a city so he could do that. So every time was a first time. And he was very successful. People came from everywhere to do see him do this.

One time he was doing an act in Puerto Rico, and when Carl did his act, he used two things to help him. One was the long balance pole. The other thing that he had was a guy wire that is strung along parallel with the rope, so that if you fall you can at least grab that, and you could hold on long enough to get rescued.

In Puerto Rico there are a lot of winds off the ocean and he started from one building and got about halfway out on the wire. And then the winds came. This is on film and you may have seen it. He got about halfway out on the wire, and you can see him get blown off balance. The struggle is unbelievable. It goes on forever. You think it will never end. He struggles and struggles to regain his balance until finally he falls—and he falls, and he falls. And he falls holding onto the balance pole all the way down. He died with his balance pole in his hands. It's a horrific thing. He couldn't let go. This balance pole was all he knew. He knew that guy wire was there. He knew he could let go of his balance pole and grab it. He was holding on to what he knew—even though it meant his death.

This is such a parallel to loss and grieving. We hold on so firmly to the old ways of thinking, the old beliefs, the old ways of coping that have always worked for us before—even if they are not working now. We do this—and we need to learn to let go. The problem is when we do let go, what can we grab hold of? If I am not who I was before, who am I now?

That is a question that is sometimes too frightening for people—too difficult for people to contemplate. It can take time to ready ourselves for it.

I will touch on a few things based on some of these things that you mentioned earlier. First: Denial. It's extremely important as part of this whole process. Denial is a very sophisticated mechanism that we all have. It is not a conscious decision to utilize denial. People talk about someone choosing to be, or deciding to be, in denial. That's an oxymoron. You can't choose to be in denial. If you are choosing it, then you are aware of it. It doesn't work that way.

Denial serves a purpose. No one ever is prepared to deal with all of the implications of significant life changes. What do we call people who walk around expecting every

horrible and horrific thing to happen to them, and watching for it and trying to plan for it? There is a clinical name for it: Paranoid. If you weren't in denial, you would be paranoid. So it is kind of a no-win situation in this regard.

Denial serves the purpose of buying us some time to prepare. When you are going to face the truthful impacts of a life change, as you do with hearing loss, it is often too difficult to take it in all at once. There is just too much. That's what we call post-traumatic stress syndrome—when people are taking in too much without preparation.

Denial buys you time to do two things. The first one is to find external supports. Who will be your significant other in facing this change? Who knows how to help me handle this? Who knows me best and will support me? We need this when we face change and we search for it. At the same time we are also looking for internal strength, asking ourselves if we have what it takes to do this. Sometimes we don't think that we do. Sometimes it takes us a while to remember that we have come through other things and survived.

Denial has a very important function. You can't talk people out of it, because it's more important to them to hold on to it than it is for you to talk them out of it. If you know someone in denial or you love someone in denial, how can you help? By talking about it. I don't mean confronting them. The only time denial is going to yield is when two things happen: First, when the function's been served and the person has had the time to find their resources, as well as internal strength. Second, when they feel safe. They have to feel safe.

If someone's in denial, as I was about my son's autism, they feel very vulnerable. I was terrified. And whoever confronted me I felt was not safe to be around, and I avoided them. So sometimes it's a matter of waiting it out—but staying there, not abandoning them, but abiding with them.

Why is this so hard to explain to other people? There are a few reasons. People have their own issues of grieving for your loss. They love you and it is painful for them too. They don't avoid the subject because they don't love you. It's because they don't know how to help you. They don't know what to say to make this better. They too feel lost and frightened. When people are frightened, they do things, and they say things that you may find upsetting, or at least, not supportive.

In the process of grieving there are certain components that weave in and out. Certainly there is denial. There is also a lot of anxiety involved in grieving. That anxiety also has a positive purpose. That purpose is to work as an energy source for you. That anxiety tells you, be ready, be awake, because something important is about to happen here. You are about to make a discovery that is painful and important. So if we try and take away that anxiety, we also may be taking away the opportunity to find out what that something important is. Anxiety is not necessarily a problem, it's an indicator that something important is going to happen.

There are lots of other words we could use but thus far we have depression, anger, guilt, and fear. Each one of these has a very positive and useful function. When we experience

these painful feelings, we need to examine them as we work through them—this is a major part of the work of the grieving process.

These feelings don't come one at a time. It's chaotic. It's a very messy process as I am sure you know. How do you explain to someone, that you are angry and guilty and depressed, all at the same time? They ebb and flow, as you need them to figure things out about whom you are now.

Depression helps you assess competence. People who don't feel competent or worthwhile feel depressed. We need to question—now, given what has happened, who we are and are we still competent—worthwhile as a human being? You never have to think about that until something happens to make you question your competence.

When something like this happens—a significant loss, what might be the first angry thought be that goes through your mind? “Why me?” That's the question. And then: “That's not fair!” Now, this is not a rational adult talking, but that's part of what we hold on to, that good things happen to good people. Bad things happen to that jerk down the street. So we have to work through what it all means. Are there rules in life? Is there fairness in the universe? Big questions.

We also have guilt to deal with. The woman felt guilty that her little boy had Down's Syndrome. What the heck is that about? It's about a couple of things. It's about that woman learning the limits of her power. If you are going to believe that you control the universe about your kid, then, by God you have to accept the consequences. If you make everything happen for that kid, then everything that happens circles back to you. This kind of thinking was less painful for her than admitting the fact that she could not control that universe. That is a scary way to live.

The last one is fear. Fear is a big one because we're afraid of all of the other feelings, too. Fear has a lot to do with the attachments that you have. You are very vulnerable to dreams being lost. Is it worth the risk? That is the question. You have the option to not attach and to live an isolated, meaningless life. That's an option. Some people go that way.

How can we best help people who are experiencing these feelings? How can we best help ourselves? The first thing is to try and understand what's happening. To understand what is going on and to be aware of the fact that this is not only a normal process, but it is a necessary and healthy process to become more aware of who you really are, and who you are becoming. When you are challenged, you find out about yourself. When life is too easy, we don't learn a whole lot.

The second way to be helpful is to stick with the person who is experiencing these issues—to not be scared and try to divert them from grieving, but to talk about those real feelings. If they can't talk about their real feelings, you can talk about your real feelings about their loss and how it affects you, and how much you care, and how much this hurts.

Finally, acceptance. I don't talk a whole lot about acceptance as in “everything is okay now.” I don't know that that really is ever an option. But what I do know is that people

can come to a point of “acknowledgment.” That's how I tend to think about it. I think that's what Dr. Ross meant when she talked about acceptance.

There is a really important difference. Acknowledgment means I understand fully the impacts on my life as a result of this event. I am clear that this is a lifelong challenge. I know it is painful but I am changing and am figuring out a lot of things that are hard to figure out. That's acknowledgment. It means, “yeah, I get it. I get what's happening. I am fully aware, and I am working on it. And I'm sharing all of my feelings with people who really matter to me.” That is about as good as it can get.

At times, talking about acceptance can be demeaning to people who are grieving. That's the bar that has been put up there and they are expected to jump that high and to achieve this level. No one chooses these losses. This is tough stuff. But it's how well you deal with what comes your way that allows you to grow and change and become, as Dr. Harvey said, more of who you are in a different way.

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