

Episode 123 - Christine Scott: Shadow Grief: Perinatal Loss and Bereavement

[00:00:08] Welcome to in social work. The podcast series of the University of Buffalo School of Social Work at www.socialwork.buffalo.edu. We're glad you could join us today. The purpose of in social work is to engage practitioners and researchers and lifelong learning and to promote research to practice and practice to research. We're in social work. Hello I'm Charles Sims and this is in social work. Pregnancy is most often a time of happiness and anticipation. The expectant parents and family look forward to a future filled with the joys and fears of what raising that child may bring. Unfortunately there are times where prenatal loss or early infant death brings a tragic and seemingly incomprehensible end to that future. Christine Scott is the executive director of the Western New York perinatal bereavement network and bereaved mother of Jacob Wesley Scott who passed away, May 27 2000. In 2007 Ms. Scott created the Wings of Love. Memorial fund in memory of her son. This fund offers to bereaved parents in western New York. Financial assistance for unexpected burial expenses when they tragically lose their baby. Ms Scott's involvement with the network began as a volunteer and in 2011 she was appointed the network's executive director. Ms Scott has a bachelor's degree in Health Services Management from Indiana University where she graduated with high distinction. She was previously the March of Dimes director of program services for 31 counties in upstate New York.

[00:02:02] She was previously the March of Dimes director of program services for 31 counties in upstate New York and has been a member of the Western New York Genesee Valley Finger Lake and central New York Regional perinatal forums. In a discussion with Rebecca Rouland Polmanteer a Ph.D. candidate at the University at Buffalo School of Social Work. Ms Scott discusses what is meant by perinatal loss as well as the bereavement process of the parents and family. She also offers strategies for addressing this uniquely painful experience. Finally Ms Scott talks about the work of the perinatal network as an example of how other communities can meet the needs of people facing perinatal death. The Western New York perinatal bereavement network provides outreach within the eight county region of western New York. Its mission is to assist the community in meeting the needs of people facing perinatal death finally this podcast was recorded in May 2013. So you may hear references to events or programs that have occurred in that time's recent past or may occur in its near future. This is Rebecca Rouland Polmanteer and I am a doctoral student at the University at Buffalo School of Social Work. Today I am joined by Christine Scott executive director of the Western New York perinatal bereavement network. Hello Christine. Hi Rebecca. So to get started talking about this topic can you explain to me and the listeners what prenatal bereavement means and other words what kinds of deaths really qualify as a perinatal loss perinatal bereavement is a loss of a baby death of a baby due to miscarriage atopic pregnancy stillbirth or early infant death.

[00:03:59] And if you want to break down the loss further when we talk about early loss we talk about a loss occurring before 20 weeks gestation which is a miscarriage a fetal death is any loss occurring after 20 weeks gestation as in a stillbirth a neonatal death is a death of a newborn from 0 to 27 days and post-natal death refers to the death of a newborn from 20 days of life to the first year. So when we talk about perinatal bereavement and the work we do those are the types of losses. Thank you for sharing. Can you speak a little bit about your personal experience with perinatal loss and bereavement. My personal experience goes back to when I found out I was pregnant with our second child. I had a 4 year old son at home. My first pregnancy was basically textbook and it was perfect. I should say he was born right on his due date and very healthy baby boy. The second pregnancy wasn't as perfect as the first and you're really never prepared to handle what news the doctors will share with you. But in January of 2000 I found out that I was pregnant with our second son and about four months into the pregnancy I started getting very ill and a lot of things were

happening so I went for extra blood work. And they found out that couple of things are happening with my own health. I was starting to go into kidney failure my liver wasn't working so great and I didn't have a very good blood clotting mechanism. I was diagnosed with help syndrome after the fact but they were really concerned about my kidneys. So five months into the pregnancy me and my unborn son Jacob we were on dialysis together to keep us both alive. That lasted for about four weeks.

[00:06:12] We were on hemodialysis three times a week for four hours a day. Basically the dialysis machine did the function of what your natural kidneys would do. My kidneys were not functioning at all. So that's why I needed the hemodialysis machine. The last time I was on them with Jacob I felt great when I got off. Usually hemodialysis a really really tough situation since they cleanse your blood of all toxins for four hours a day three times a week. But I got off the machine and I went for a sonogram right after at that appointment they were measuring every week the growth of Jacob and when I went to the sonogram appointment that was the appointment that I found out that there was no heartbeat and I had to go deliver him that same day at the hospital and he was stillborn. Oh I am so incredibly sorry for your loss. Thank you. Thank you very much. I mean it's just something that when you talk about it it will be 13 years. This may 27 when he was 26 weeks he was 13 and a half ounces. He was 10 inches long and he was the perfect little baby boy. He was just born sleeping. Wow what an incredible story. Now at the time were you working with the Western New York period Natal bereavement network or did your experience fuel your practice.

[00:07:49] My experience definitely fuelled what I am doing just to finish my story when I deliver Jacob stillborn back in the 13 years ago there wasn't a lot of support like there is today and then there was different reasons perinatal loss is a silent grief and we're trying to change that that's what the network does. We're trying to change that. But after I delivered Jacob my liver got better and so did my blood clotting mechanism because that's what happens with help syndrome helps syndrome very rare. Toxaemia that you can only get when you're pregnant. It is very rare but my kidneys being scared they did not reverse and actually the rest of the story is that Jacob's original due date in September. My mom gave me a life saving organ to live. She donated one of her kidneys because after I delivered Jacob I needed a kidney transplant or a lifetime of dialysis to survive. So I also did receive the gift of life. In September of 2000. So it's just to be faced with all that loss and there wasn't a lot of support back then. So after I got a handle on my kidney transplant and my health got improved and got better I really wanted to help others and they really got involved with the network and the network was a very tiny little program under hospice at that time it was a group of professionals that got together to try to help the community and help the hospitals in perinatal loss. And so that's why I started volunteering with the network in 2004. Wonderful. Now since 2004 What has your experience been because you started as a volunteer and now you're the executive director. I am so I feel very blessed because in 2004 when I was a volunteer there was a lot of changes and then I felt a lot of great passion.

[00:10:03] And there's a lot of bereaved moms and a lot of professionals that were a part of our network that are just as passionate as I am. So to take it to the next level. Hospice was changing. Their programs around and we were really growing the need in our community to support parents who suffer a perinatal loss is just really incredible huge need. So when hospice was changing their programs around we knew we could handle it and try to become our own not for profit public charity. So I was hired part time to take the little program that was under hospice and make it our own 501 c3 non for profit public charity and that happened in September of 2011. So since then I was then promoted to executive director. When we have a staff of one that's myself. We are a volunteer lead. We cover the counties in western New York. And the need is incredible. We support 13 labor and delivery hospitals in our area and all of them have in-house bereavement programs and some are led by the nurse managers some are led by a special bereavement coordinator but we collaborate with those hospitals for standardized care across the board. We want to make sure

parents that are suffering perinatal loss in their families get quality care and we can get into the different things that we provide the hospitals with and educate them on. Wow it sounds like you're doing fantastic work and western New York. Thank you it's much needed work and I always say it's teamwork. I couldn't do it by myself. It really really takes a dedicated team and we do we have a very dedicated board of directors.

[00:12:01] We have dedicated bereaved parents that are volunteers and we all work together as a team. Wonderful. Now so far in your conversation you've talked quite a bit about the loss of a child. Can you share what shadow grief is and how losing a child is different from any other type of loss. Yes perinatal loss is like I said before. It really is a silent loss and we say it's a silent and loss because others in our society may not feel comfortable about talking about the loss with the family. And then this kind of creates where the parents are feeling more guilty they feel alone and very lonely because it's very hard to talk about the death of a baby when an adult dies. You have a piece of the past that is lost. But when a baby dies a piece of the future is lost and you are significantly changed forever. And the parents. Their loss is their hopes dreams future Joy parenthood. Sometimes it's standing in the culture. Different cultures believe different things. So when we look at perinatal loss in the grief that bereaved parents go through we call that shadow grief because when a parent loses a child they're going to carry their grief with them for the rest of their lives. Wow that is a great explanation an overview. Now when a parent or parents experiences a loss what are some things that as providers we should share or things that are helpful for parents to hear. Well when a parent loses a child it's really a lifelong grieving and healing journey in the process is really individualized an ongoing experience of grief.

[00:14:02] We always say there's no right or wrong way to grieve. Grief is intense sorrow great sadness experienced as a result of death but it is also a normal reaction and a natural reaction for the death of a loved one. When a parent loses a child they're helpful in that so helpful responses. And a lot of people will say not so helpful responses that then just create more sadness for the parents. But when I go out and I educate the community in the hospitals because we all have to work as a team. When a family loses a child you know some of the things to say are. I am so sorry for your loss. I always say I'm so sorry with you for your loss because I also am a bereaved mom. Sometimes there are just no words to say. So you can say I'm at a loss to know what to say but I sense how difficult this must be for you. Sometimes you just might want to ask them if they want others near always answer questions honestly and know that some questions just don't have an answer. The biggest question is why did my baby die. Well sometimes there are no answers. In New York State about approximately 1700 babies are born stillborn every year across the nation 30000 babies are born stillborn every year. 60 percent of these babies do not have have. There is no reason why they were born stillborn. So sometimes there just aren't any answers. Parents who want to feel validated that indeed they are parents even though their babies are not here with them on Earth.

[00:15:58] Some of the things that are not so helpful that parents hear very often we have to be very aware of what we're saying to bereaved parents. I understand how you feel when I educate. I always say nobody understands how anyone feels even though you might have experienced a similar situation. Everybody grieves in this so everything is so individualized. Death was a blessing. That's another one of the not helpful responses. It was God's will. Something good will come of this. You're young you can have more children. That's very hurtful for parents. In my case I always use the example that I was young I was only 29 when I lost Jacob but I had to have a kidney transplant which brings the whole nother medical issues to the forefront. I could not have any more biological children. I did go on to adopt a child but that's a thing and can be very hurtful for so many. So many people in the last one is be strong don't cry. It's okay to cry. Crying is good. It's part of the grieving process. It's a natural form of our body releases these toxins. And crying is okay. Thank you for sharing that information. Now when families and parents lose an infant or lose a child what are some of the needs they experience as they're coping with perinatal loss well some of their needs.

And I know say we have to meet parents where they're at. There are a lot of different resources out there but parents want to feel validated. They want people to listen to their story.

[00:17:54] Sometimes a parent sharing their story over and over again that is very very healing for them. When a parent loses a child there is a lot of characteristics of grieving and the grief that they go through there is a lot of self blame anger isolation emptiness parents feel like a failure because the betrayal of one's own body letting them down. I felt like a huge failure when I lost Jacob. You know you also feel responsible you just don't understand why your baby died and what could you have done to prevent this. Well most the time there is nothing you can do to prevent it. It just something that happened. And parents also feel devalued you know their grief is minimized as I as I talked about before that society really doesn't know how to handle the death of a baby because it's a death of the future when an adult dies. You have those memories to look back upon. You don't have that when a baby dies. So those are some of the things parents feel when they lose their baby. And so validating and listening to their story and providing them different resources and help like what we provide at the network is very helpful to families. Thank you. Now speaking of the resources and services you provide at the network. Can you talk a little bit about what kinds of support you do offer to bereaved families. Sure. Well the mission of our network. And that's the western New York perinatal bereavement network is to assist the community in meeting the needs of people facing perinatal death.

[00:19:42] So the death of a baby due to a miscarriage atopic pregnancies stillbirth and early infant death we are a group of professionals and bereaved parents. We have been in existence for over 25 years as a program but now we became like I said earlier a non for profit 501 c3 in September of 2011 and we are supported we have different groups of volunteers and a board of directors and what we do is we provide support programs and linkage in resources to families. So what we do is we collaborate with our 13 labor and delivery hospitals. When a parent loses a child we have a parent authorization release form. And so the hospital presents them with their information in this authorization form and then the form is then given to me. I then follow up with a sympathy packet to the family in the sympathy packet. It is information about our network. There is a variety of different things that the parent can get they can get a newsletter which is free for a year. That comes out quarterly and it's the Forget-Me-Not newsletter that is created the editor is one of our board of directors and bereaved moms. She does a really good job of putting this together. We also offer support for burial or cremation. When you lose a child you're such in shock and disbelief. Now you have a very limited time not only to create a lifetime of memories and a very small window of 12 to 24 hours but now you have to think about the goodbye how you want to say goodbye to your child. So we will support them with funeral arrangements burial and cremation options and financial grievance. Sometimes families do not have the financial means and are going through a rough time.

[00:22:03] And that's where wings of love Memorial Fund comes into play. The Wings Of Love Memorial Fund. I started that I founded that program and my husband in 2007 September of 2007 and the mission of that memorial fund is to ease some of the unexpected financial burden placed on grieving families during the tragic loss of their infant so that we can financially grant up to three hundred fifty dollars. We work with many different cemeteries and funeral homes. We have the West Seneca seniors that make our butterfly urns for us and they make them with just so much love and so we offer butterfly urns to our families. So there's different things we offer to our families through the wings of love Memorial Fund which is now program of the network. Since September of 2007 we have granted over 30000 dollars to families to bury their baby. Such a great need. Wow that is fantastic. It is in so many people. Donations they donate to the wings of love. A portion of our fundraisers go to Wings of Love because there is such a great need in our community. Sometimes I won't get a call for weeks. Two weeks ago I had the eight wings of love cases within a seven day period. So it varies. And so we work with the families we work with the cemeteries we work with the funeral directors and we want all babies buried with dignity.

[00:23:51] We want to help the families because we know that they're in a state of shock and they have to make decisions and so we can help them with planning memorial services and things that they might not think we can help them along the way. So that's the memorial fund. Fantastic. So you are doing such fantastic work in our community to really to your organization. Yes well the Wings of Love is a program of the network. But yes it's two. I'd like to say they're together but it's a little supper because you have so many parents were there. So if I'm going to continue on what the network does so we have the Wings of Love Memorial Fund and then we also have our hospital support. Like I said we have 13 labor and delivery hospitals that we support. We have volunteers that make handmade burial gowns. They make Angel pocket they crochet baby blankets. We have volunteers over western New York who just donating these to our programs. What we do in turn is we then distribute them to all of our 13 labor and delivery hospitals. We have bereaved parents organizations that make memory boxes. We supply our hospitals with 3D foot print supplies. We have disposable cameras leave mom created a moment in her arms forever in our hearts in memory of her son. So if there is not a camera available or mom and dad go into the hospital and their anticipating the joy and the birth of a healthy baby and then tragedy happens and the baby's born stillborn or dies shortly after birth. Sometimes people are prepared with these things. So we make sure our hospitals have all these supplies. We promote education in our hospitals like I had said it earlier. Healing from the start.

[00:25:56] It's really takes a team effort in the hospital to make a lifetime of memories in that very short window of time footprints 3D 3D footprints pictures. We work with now I lay me down to sleep and they can come into the hospital to take pictures of the families. They're also a non for profit organization. We collaborate with. So there's a lot of things that go on collaboration between all community agencies and our hospitals to help parents who have to suffer this tragedy. And I think the word collaboration is really the point that stands out there that this really is something that spans communities and really works to help families in need. So that's fantastic really collaboration and teamwork is so important. Some of the other programs we offer is the sibling bereavement program. When parents lose a child. A lot of the focus is on mom. We want to focus on the family as a unit. We want to focus on mom, dad, the children at home the grandparents. When we look at grandparents we look at grandparents grieving double grief they're grieving for their grandchild but they're also grieving for them because they can't take the pain away for their child that's losing their child. So it's a double grief for grandparents and we offer them support programs. Also the sibling bereavement programs we offer to the children at home because we know that they express grief according to their developmental stage and personality. So what we offer families is we give them a in their sympathy packet. We send them an age makes a difference sheet and it breaks down the ages ages 2 to 6 6 to 9 10 to 12 and teenagers.

[00:28:11] And suggestions on how parents can support them at where they're at and their developmental process. So how are they understand death at age 2 versus what the need to know and how they're going to understand death at age 10. And it always gets tricky because as adults it's hard for us to make sense of why a baby died. Now we have to try to explain to the children. So we want to offer that resource to parents so we send them a letter we send them out informational sheet age makes a difference. And we send them a child a happy pill we just teamed up with a wonderful company that was set up by another bereaved mom everything happy. And their mission is one to love one to give. So we have several donations of these little stuffed animal happy pals and we send them the family. And I see them at work. It really provides hope and comfort that this child can hold onto when this is a very sad and tragic time for the whole family. So that's our sibling bereavement program. Then I also explained our Forget-Me-Not newsletter that's quarterly. We have poems stories events we share all of our resources in their support group information and we have a wonderful printing company that donates our printing for this and our editor is also a bereaved mom. So we have that program. We offer another program to our parents. It's called our

parent telephone support team where we train parents who had a healthy place in their hearing journey to support parents who have suffered the tragic loss of losing their baby so we will pair parents up.

[00:30:08] If I wanted a phone call or if someone had a stillbirth. Twenty five weeks I would be paired up with this mom. Not that I know how she feels because you don't know how anyone else feels but she can relate to the experience mom who have miscarriages. We will pair them with another mom who has suffered a miscarriage so that our parent telephone support team and a lot of friendships are made through that group. So it's really wonderful. It sounds absolutely wonderful. And again what a wonderful program to have in the community. We do. We also offer a parent parent support group. So it's a professional facilitator. Parents to support each other. And we have our network based support group was called the tiniest angels. There's also hospital based support groups footprints on the heart hopeful heart to heart and these are all different support groups that parents can go through throughout the month for support as a community and as collaboration. We have to meet parents where they're at. So maybe the third Wednesday doesn't work for a parent who really needs support for the tiniest angels but footprints on the heart through sisters hospital maybe a Tuesday will work for them or carrying arms through Millard Fillmore Suburban Hospital. So we all collaborate we all hold support groups in order to support our parents. We have different events we hold throughout the year in all these events are some of them are fund raising some of them are to support events. But it's a chance to get together to just show that unity and create a lot of community awareness and remember and honor our children.

[00:32:11] An annual event that we hold each year is an evening to remember basket raffle and an adult evening out and we hold it in church hall. And every year approximately 200 baskets are made in memory of babies and we raffle them off. We have a deejay and it's a really great night for parents to get out. Every year we have a Parents Day breakfast. It's our wings of love parents day breakfast. This is going to be our fourth year. It's really to celebrate invalidate that we are parents. Mother's Day is one of the hardest holidays for a brief mom but also for a bereaved dad because he has to watch his wife suffer and a lot of times parents that don't have children on Earth they don't feel validated as a parent. And we host this breakfast to make sure that all of our parents know that indeed because their children on this earth they still are their mother they will always be their mother and they all always will be their father. And it's a beautiful family breakfast. We have a candle memorial service in years past with a balloon release. Last year we had a beautiful flower release into the Niagara River. We have a new event which is our elegant evening to remember and this is a big gala we have and it's an award ceremony. What we want to do is we want to recognize everyone in our community organizations physicians nurses volunteers that make a difference in the life of another experiencing this tragedy. And we just had our event last week. We awarded 11 individuals with awards.

[00:34:16] Our theme this year was the gift of time. And we really just want to honor these folks for their gift of time and making a difference in the life of another and by helping them through perinatal loss. So that's our elegant evening. Remember every October its pregnancy loss and Awareness Month and we host our walk to remember which last year was our 20th annual over 900 people attend this event. It really started off 20 years ago is very very small as 25 50 people gathered to pay tribute to their child to their baby. But it has grown so big in Erie County it's held at Cheektowaga Town Park every Columbus Day weekend. It held on a Sunday and parents walked to create awareness and to memorialize and honor the baby that's gone too soon. We have a memorial service. We have music a balloon release. We plant a Bradford Pear trees. We have a one mile Memorial Walk and a family picnic afterwards. We want to break the silence and we have joined forces with those around our nation and started a October 15th candle vigil. We have two sites last year that we held. One was at Acacia Park the other was in Olean it's called Gavins light and around the world at 7 o'clock. There's a wave of light to memorialize and honor our children that have

passed. So there's a lot of things we're doing to create community awareness during the month of October. That's fantastic. Now so far we've talked quite a bit about the western New York perinatal bereavement network that you are such an integral part of. Can you provide your Web site.

[00:36:24] And if you have maybe other relevant resources as well in case listeners would like to obtain more information about perinatal loss and bereavement sure they can check our Web site out. www.wnybn.org. So it's our initials in this website. We have so many wonderful resources. We have things that can be downloaded and printed a whole bunch of support. I talked about how children grieve and to support children and grandparents and we didn't even touch base with how men and women grieve differently. All of these resources are on an informational helpful brochures and sheets can be downloaded and printed. We have all of our support groups our community support groups that we collaborate with. We have Oliver vents the Wings of Love application. If you know somebody that needs services and want to fill out an application to qualify for wings of love we have a resource page. There's a lot of online help nowadays with Facebook and national organizations. You have them Miss Foundation and the national share office. Compassionate Friends. All of these Web sites and national organizations are here to help you. So we definitely can't do it alone. It's all collaboration. Sometimes parents don't feel comfortable coming to a support group but they feel comfortable on a blog for just googling information. So all these resources are on our Web site great. Thank you for sharing. Now so far in our conversation we've covered quite a bit of information related to peering into lawsuits and perinatal bereavement. Is there any additional information that you would like to share or something that you feel listeners would benefit from.

[00:38:35] Well one of the things the last thing I want to share is basically the words we didn't touch base on was the certificate of stillbirth in New York state law from the certificate of stillbirth went into effect on March 21st 2012. And I want everybody to know that if they know somebody or if they personally have experience or stillbirth is they are eligible to get the certificate of stillbirth for their baby. And we have the forms on our Web site you can just go ahead and click that link and you fill out a very small application that's sent to the Department of Health in New York State. So it's sent to Albany and if you need any assistance with that. All of our contact information is on our website what you can reach me personally at the 7 1 6 6 2 6 6 3 6 3 or email me directly at [christine@WNYPDN dot org](mailto:christine@WNYPDN.org). We just want everyone to know that there is so many resources and support that you don't have to suffer in silence. And we really want to provider family's hope that in time that your heartache will be less painful and that you'll be able to incorporate the death of their baby into their life. What a powerful message it is it's really powerful and that's why we're here. We're here to meet families where they're at to provide hope and to help them through this life long healing journey. Well thank you Christine for participating in today's podcast. We greatly appreciate you taking the time to share your knowledge and expertise with not only me but of course all of the podcast listeners.

[00:40:32] Thank you so much for having me. We really appreciate it. You have been listening to Christine Scott's discussion on perinatal loss and bereavement. This is Charles Sims your host inviting you to please join us again for in social work Hi I'm Nancy Smyth professor and dean of the University at Buffalo School of Social Work. Thanks for listening to our podcast. We look forward to your continued support of the series. For more information about who we are as a school our history our programs and what we do we invite you to visit our Web site at www.socialwork.buffalo.edu.