
Sharing Information on Death and Loss: Learnings from a Personal Experience

Merry Barua*

When my son Neeraj turned nine, Mother passed away suddenly. We had just moved to another city I was devastated. Her loss hit me the way the loss of a mother hits anyone. But perhaps more. In the entire firmament she was the only person who really seemed to 'get' Neeraj. Other than me, she was the only one who had the stamina to be around the charged particle that Neeraj was at that time, without a break. She was the only one who could get me the respite I so desperately needed. The only person who seemed to fathom what I was experiencing.

This was 1989. Autism was still an enigma. There was little literature to help me understand my son with his smattering of words but little meaningful communication, and eye gaze as easy to capture as mercury. I barely understood how he was experiencing life; neither, it seemed did the experts. And there was no Google God Of All Answers to turn to.

Immersed in my grief I made arrangements to travel to Kolkata from Delhi where we were living, with Neeraj of course. So immersed was I in my own loss that it never occurred to me to speak to Neeraj, then nine, about his 'Didun'. He was simply the extension that went where I did. I had been given to understand that he understood very little, and I did not have the words to share what had occurred.

At my parents' home Neeraj stumped and raced and charged around as usual. There was also some exhibition of what can be described by the blanket term as 'challenging behaviours', which I put down to his autism. He threw himself around, cried, broke a few things. I reacted by feeling stressed to my soles. And we came back home.

Three years later and as suddenly, my brother, younger to me by a little over three years, passed away. Neeraj was at this time going through a deeply challenging phase. There were intense behaviours that included

hitting and breaking, and also some very gross ones. This was also the time when I had finally and successfully got myself some training, and was considering running a home-based program with him, and halting for a while the special needs school he attended. When news of my brother hit, thanks to the training, I was a little bit wiser, a little more informed about autism, and with greater respect for my son. I knew I had to share information of the loss with him. Not sure how I would do that and needing the time to deal with it myself, I decided to take my time with it. That my brother had passed away in another country, and he would be brought to Kolkata while we lived in Delhi made that a possibility that I was very grateful for. I went to Kolkata but left Neeraj behind in Delhi and none the wiser that his much loved Mamu was no more.

As parents we often practice what I think of as 'selfish love'. Of course we love our children. But its more about 'my' life, 'my' experiences, 'my' loss, what 'I' can or cannot do, and what 'I' want for my son; its very little about what my son can or cannot do, or wants or does not want, or the heroic effort he has to put in to make sense of our world. Back from Kolkata as I set about implementing our home program, I started to see Neeraj differently. A person in his own right. Our engagements changed. Our interactions changed. The reason for his behaviours when my mother passed away finally began dawning on me. I realized the utter confusion of the little fellow at seeing his beloved Didun lying inert, sensing the roil of emotions in his mother, the house teeming with tearful people, seeing her carried away, wondering what was happening and not having the language to ask questions to quell the turmoil and unsettlement that he was experiencing. For the first time I was trying to see the world through Neeraj's eyes.

It's not that there had been no reference to death earlier. Of course there had been, but more in passing:

something in the news, a reference someone made to the passing of an acquaintance; but no effort to help Neeraj understand this complex concept. And in passing I had also unthinkingly linked death to old age.

So after my brother passed away in his thirties I went to Kolkata, came back, and consciously got down to familiarize Neeraj with people going away and going away for good, with death and loss, and to prepare him for the news of his Mama passing away.

Neeraj and I had that time on a few occasions taken the Rajdhani train to Kolkata. So Neeraj was familiar with the business of our teeming railway platforms, of people spewing out of compartments as others got on. I talked about how there were always people on the platforms. When a train arrived while some people got off the trains, it was important that others who were on the platforms get on and leave, otherwise there will be no place left on the platform for all the people arriving on different trains. So while there were people coming on every train, there were others leaving on other trains. That made sure that people did not fall off the platforms and there was place for all the new people who were arriving. Using this analogy I moved to how earth and our world was like a railway platform. Every day there were thousands of people being born in different parts of the world. If no one left the world, soon there would be no place for more babies to be born. That is why while there were people being born there were others who were dying. This way there was place in our world for all the new babies.

We then talked about the babies who had been born in our family and amongst our friends. We talked about Neeraj being born too! Once we had done the sharing and laughing about all the births and the little people we could now talk about how some people had to leave the world so there would be place for the new babies.

Neeraj was at this point a child who was constantly on the move and appeared largely disconnected from people around. But as we know, that does not matter. He walked around while I talked. And I knew he was listening. To keep him connected I kept our conversations dramatic and interesting, but not tragic. But here was the important thing: I was also able to tie up our conversations with the outlook that Neeraj and I tried to practice; the belief system that saw our responses to life experiences as a choice. Of knowing that many things happen in life that are not to our liking, and that we can choose how to respond to those events.

That when such things happen we can choose to feel angry, upset, irritated, sad etc, or we can choose to feel okay, comfortable, happy.

Neeraj was learning by and large to choose the latter. My effort to help him reach this stage has been sorely tested. Over and over. A few years after his Mama passing away another dear young uncle Opu Mama suddenly passed away. Shaken myself, I sat Neeraj down and shared the information with him. We talked about how Opu Mama was gone and we will never see him again. Of course we will miss him. We could always think and talk about all the lovely times together, all the fun things Opu Mama would say and do. And how Opu Mama would love it if we thought of these things and laughed and were happy whenever we thought of him.

A couple of years after that P, a vivacious young friend Neeraj had known since he was seven lost her life at age nineteen. Age clearly had nothing to do with death. We talked about how sometimes people leave when young, and it was time for P to leave so more people could come into our world. We would of course miss her a lot and it was okay to miss people who go away. We talked about all the fun memories. Of all the joy that P had given everyone who knew her. That P's parents after their initial shock and devastation chose to celebrate their beautiful vibrant daughter's life rather than continuing to mourn it helped reinforce Neeraj's positive outlook to death and loss.

A few years later there was another sudden loss when Neeraj experienced the passing of his much loved Aunt Sita. And I could only marvel at how well Neeraj had learnt to deal with loss and change as a part of life.

Neeraj is petrified of my dying; or rather my going away and never coming back. But over all he is able to handle death with great dignity and acceptance. The analogy of the train station, along with the life beliefs that we follow and that I have tried to help Neeraj to imbibe continues to help Neeraj in facing death and loss with equanimity. Our life-belief of acceptance. Of the power of choices. Of knowing that there are good times and bad, hard times and easy, times of aching loss and exulting gains, but that through it all after the initial pain or joy, whether I choose to stay content or angry/sad/disappointed is my choice. Neeraj has learnt to choose joy and contentment for most parts. And that made things easier.

I no longer have to refer to our train station analogy. Neeraj has gone beyond that.

This of course has been my personal experience. Not everyone will want to subscribe to the life beliefs that Neeraj and I try to practice and that is okay too. But with or without that, the analogy of the train station has been helpful for many.

The following are some of the things I have learnt from my mistakes and my experiences.

- Speak to the child about the loss. Do not assume he/ she will not understand or won't care. It is scary to hear something being discussed, but not having the full information, not understanding the import of what has occurred and not having the words to ask for that information.
- Use a matter of fact tone, a pleasant demeanor when conveying information of the loss. Avoid a tragic tone and facial expression. Keeping it light will your child in processing the information better as well as help to keep death and dying from turning into an obsessive interest. Of course this depends largely on how the adult helping the child cope is herself/himself dealing with the loss.
- Be clear, concise, concrete. Avoid terms like "His soul is here with us." It will set your child off wondering where the soul was. Or "We have lost him." You don't want your child going out searching for the 'lost' person. Or "He has gone to sleep". Your child might end up being petrified of going to sleep. Say "He died," and use concrete visuals to help them understand
- Acknowledge your child's feelings. "You are missing Aunt Sita; it is okay to miss her." Acknowledging your child's feelings is a truism not just for feelings over death, but also for everything. Acknowledging our child's feelings – of loss, anger, irritation, fear, anxiety, also joy and happiness – is critical to his/her mental wellbeing.
- Include your child in the process of saying goodbye to the person. Include in the rituals. When a young friend lost her husband, she took her little boys, one of who was on the spectrum, to the cremation. One can include the child in the cremation / burial, in any religious rituals, prayer meetings etc. Of course, and this goes without saying, prepare the child for the behaviors that would be expected of the child at the rituals.
- Do not link death with age. Young people die too.

- If someone is sick and dying, then there is time for preparation. One could talk of the body as a machine that sometimes gets worn out and then stops working.
- Use concrete examples to explain death. The train station is an example of an analogy that is helpful because it is concrete. So is the analogy of the machine.
- There will be anxiety as your child tries to deal with the loss. This is the time to ensure that routines are followed. Use visuals to introduce any changes in routine
- Use a social story to talk about the illness or death. Write a story about the funeral, or for after, to prepare the child for the changes.
- Take time to look at pictures of the deceased in family albums. See those times as a celebration of memories, fun memories, warm memories, rather than a weeping over what is gone.
- Conversations around the departed can carry on for days, months, or years. Whenever there is a reference to the person is a good time. Conversations are not about the death; but rather about the memories.

My experience of helping Neeraj understand and cope with death was triggered by an actual experience of losing a loved one. But with the wisdom of hindsight, I know now that this is something one would want to introduce the child to anyways. I really don't think there is any age for that. Death is so much a part of the cycle of life; yet we treat it with such fear. Of course circumstances often create the fear. I am afraid of my own death because I do not know what will happen to Neeraj when I am gone. But even without such circumstances, death is feared. Yet there are communities that celebrate the passing of their loved ones. These are belief systems that mainstream communities look down on and denigrate. And yet they are a beautiful way to look at life and death.

So with our children with or without autism it makes sense to introduce death organically. Death is all around us and I do not mean that in a morbid way. Without death there cannot be life! We have many opportunities to introduce death. The younger the child, the more light and easy do we want to keep it. Our language too has to keep in touch with the developmental level. But largely the comfort level of the adult who initiates the discussion determines the age at which we start.

The tricky one is preparing my child for my own passing. How do I prepare him for the inevitable? And then when

I do pass away, who shares the information with him and how?

This has been a huge concern with me. So Neeraj and I have already embarked on this journey. When there is reference to any person who we know has passed away, including ones from the past, or when there is any report of a death in the news I sometimes link it to my death. If there is news of an accident I may talk about how this can happen to anyone. One day Mama too will die. I also talk about getting old. The engine of my body is wearing out. I see the anxiety in his face when we talk about my going away. But that anxiety has lessened over the years and if we keep talking about it I feel that Neeraj will be better able to face it when that happens.

However, if my death happens without his knowing, I don't know who will inform him about it or how. Writing this piece makes me think that perhaps I could write a letter that could be read out to him when I pass away? Or have written instructions on how the information is imparted to him? I don't know. Yet. But hopefully we will get there.

When Neeraj and I talk about any of the many loved ones who are gone, Neeraj sometimes looks keenly at my face - he has terrific eye contact now - as if trying to gauge my feelings about the event. Our children take their cue from us. When he sees my face all warm with good thoughts of the loved one, he too relaxes. That's the way I like it.

I am sure there are many other ways of preparing our children to deal with death and loss, that caregivers have devised to suit their situations. But the core of this is firstly to know that individuals with autism are not blocks of wood sans emotions. Nothing can be further from the truth. The death of a loved one affects them the same way as it affects others. Some individuals may laugh when a loved one passes away. That is because it is hard for them to express their feelings in expected ways, not because they are happy about the death.

Secondly, our kids not just take their cue from us they are also deeply affected by our behaviours. While I grieve the passing of a loved one, the manner in which I do so, may well be the template for my child.

Finally, hiding information of the death of loved ones is never a good idea. There is always the possibility of them hearing about it in passing and getting confused

and distressed. But more importantly, it is not respectful of their abilities and personhood to believe that they do not deserve or are not capable of handling this information.

* *Merry Barua, Director, Action For Autism (www.autism-india.org), is an activist and a specific needs educator who pioneered the autism movement in India.*

Merry has over two decades experience in working with individuals on the autism spectrum, from the functionally significantly affected to the very able, and in a range of settings. She is also parent to a son, Neeraj, who has autism.

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