

Chapter 6

The well trodden path to death's door - a light for the way

Pam Jackson

In this chapter we read the stories of four girls going through the stages along this well trodden road – Monica, Charlene, Anna and Agatha.

Death and loss come to each one of us. It's a well trodden path that can be walked in hope and can end in acceptance and peace. It is the most important and the hardest thing we ever do. Yet we are so often afraid and do not know what to say when we meet it. How do we comfort those who have lost loved ones? And even harder, how do we talk to those who are dying, especially when they are children? Death is something that many of the girls have encountered, with devastating effects on their lives, before coming to Ons Plek.

For those who want to read further on counselling related to death and loss, some relevant publications are listed at the end of Chapter 11 under the heading 'Suggested further reading'.

Monica's baby: Coming through the emotional reaction of denial

A familiar sound woke me. The phone again! Childcare worker Joyce Mateta was phoning my home early in the morning to tell me to come quickly. A new girl, admitted only three days before, had awoken to find her baby dead beside her.

My stomach full of butterflies, I went in. All the girls were still in pyjamas. The mother was in shock; she had tried several times to wake her baby, unable to believe what her senses were telling her. Joyce couldn't believe her either, when she was first called to help. She too tried to wake the baby, and when I arrived thirty minutes later, knowing logically that the baby was dead, the part of me that still did not want to believe it made me go straight to the little body on the bed to make sure.

It's called denial, this reaction. When something happens that is too much for us, something we really don't want to happen, our minds just don't quite grasp it. We feel numb, part of us knows the news is bad while the other part tells us it is not true. Denial can be a good thing because it gives us time to adapt to the bad news and get our strength together to face it.

So when I found Monica, the young mother, insisting on staying next to her baby "in case she needs me, I just want to stay", I was not worried. I knew from experience that it can take two or more weeks to fully believe a death has really happened. Denial is only bad if the bereaved cling in the long term to the illusion that the death has not happened. Monica was alternating between disbelief and belief.

So a few of us sat quietly with her and the baby while she processed some of the shock, allowing her to talk and responding just enough to show that we understood. It's hard, we were tempted to break the mood by changing the subject, or chatting quietly among ourselves.

I always have to remind myself at these times that this is part of my denial, part of my pain at this loss and a wish to carry on as if nothing had happened. If I, who am not the mother, cannot take the pain, I am reinforcing the mother's denial. I am saying, through my actions, that this is too tough for anyone to take - and yet the mother will have to take it. She will have to take it in isolation, surrounded by people but carrying her pain on her own, if we also cannot endure the pain.

In time, Monica would go through all the stages of loss that Elisabeth Kübler-Ross¹ and others have identified and documented as stages that all of us go through when dying. These stages are applicable when we face any loss, not only our own death. They apply when we lose a loved one, and to a lesser extent even when we lose a favourite item, or lose a skill, a job, anything.

The stages are denial (and isolation), anger, bargaining, depression and acceptance. Guilt is also present in these stages. The stages do not always arise in the same order, and we move back and forth between them as we adapt to a death or other loss.

As Monica allowed more "awareness [of the death] to penetrate"², the stage of denial would gradually pass, but the stage of isolation would deepen. Monica's pain was something no one could take away from her. In the end only she could pass through all the stages of loss. However, we could increase her sense of loneliness by avoiding all



¹ Kübler-Ross, E. 1970. *On Death and Dying*. London: Tavistock.

² Poss, Sylvia. 1981. *Towards Death with Dignity: Caring For Dying People*. London: George Allan & Unwin. Page 14

discussion of the pain she was feeling. For weeks she was quiet. Then one day she asked the questions which had been eating her up inside. "Did the baby die because I climbed a tree once when pregnant? Was this a punishment from God? Did I kill the baby because I didn't change the nappy often enough, or clean the bottles properly?"

We explained about cot death. We reassured her about her standard of baby care, which had been good. We knew that guilt is a feeling all humans have when someone dies. Could we have been nicer to them? Did we do everything to save them? It's not a logical feeling, and just reassuring her that she had done nothing wrong did not help. Monica needed time to express and explore her guilt, to enable her to move on to the next stages of anger, depression and acceptance. Today, Monica is married and has three children. Like all bereaved parents she has never forgotten the pain she experienced, but she has learnt to live with it.

Charlene and her mother: Through anger to acceptance

Anger is a hard stage to deal with, when coming to terms with loss. It shows that the person is out of denial, but still fighting the situation. It is difficult to live with an angry person, particularly as the anger expressed is not usually about the illness or death of the loved one but about other mundane matters. When a dying child is going through this stage, no one can do anything right. No one can move anything, touch or talk to the person without eliciting an angry response. Counselling is very difficult, because the person is looking for a fight. The bereaved person or the dying person is asking, "Why am I sick?" or "Why did my mother have to die?" The dominant feeling is "It's unfair". And yet this stage is absolutely necessary; without it, the person cannot move on.

At Ons Plek the phone rang again. A social worker from another agency was requesting an admission. This time it was for a girl aged 14, whose mother had recently died from injuries sustained when she wandered in front of a truck while drunk. She knew of only one relative, who had agreed to take on a younger brother. For a long time before the mother died she had not slept at home; she had moved between friends' houses. She was known to have been involved with a bad crowd.

I agreed to the girl's admission, knowing that she could be very difficult and disruptive to the project. Firstly, she would have strong feelings of shock, anger and depression, all of which would require therapeutic counselling and all of which might be expressed in very disturbed behaviour, which in turn might disrupt the other girls. The fact that she was already living an unsettled life, not sleeping at home, mingling with drinking friends and not attending school, also meant that she would really struggle to settle down and might well run away. This was the sort of child that Ons Plek was started to help. This is why our work is often not seen as 'successful'. Children, already seriously traumatised, are not admitted to Ons Plek on the basis of the likelihood that they (and we) will be successful in changing their lives.

The girl, Charlene, settled down well at Ons Plek and attended Learn-to-Live bridging school for street children. In counselling sessions, discussions were initiated with her around the death of her mother. She was not expressing her grief at this point and her feelings could not be insensitively forced into the open. However, if everyone, including Charlene, acted as if nothing had happened, her feelings would surface years later or lurk beneath the surface, undealt with and unconscious and yet intruding on her future life. The focus in counselling began with discussion of more concrete activities like funerals which provided opportunities for expression, but did not demand intense discussion of feelings until she was ready to do so.

When social worker Carmen de Vos interviewed her, Charlene said that she didn't feel much, and in any case she hadn't stayed with their mother, but she was worried about her younger brother; but this did not mean that she experienced no feelings, only that she did not express them. Childcare worker Nomfundo Pilisani took her to the mortuary, meeting her brother and a relative there, partly to identify the body, but mainly to say her goodbye to her mother. Volunteer Lucia Oosthuysen, a trained Lifeline counsellor who was also doing her life story with her, took her to a church where she would be able to place the ashes, and helped her to plan the service she wanted with the minister. Later, she prepared Charlene for the service by getting her to write a letter to her mother which expressed what she would have wanted to say if she had had a chance to say goodbye, and how she was feeling now. Arrangements were made for the brother and relative to attend the service and for contact between the children to be maintained.

Charlene kept asking to visit her old neighbourhood, which we could not allow because her hosts were drinking families. Yet we knew that her visits would aid the mourning process. When Lucia Oosthuysen took her 'home' to see her old shack, she ran around excitedly visiting old friends.

The visit risked evoking some feelings that would result in destructive behaviour or depression. It was a risk we had to take, because failure to mourn can result in mental disorders. Many people believe they are protecting people from further pain by avoiding any reminders of a painful event. But emotional pain is there, and if suppressed it will fester. It needs to be felt and expressed in a supportive atmosphere, but at the grieving person's own pace.

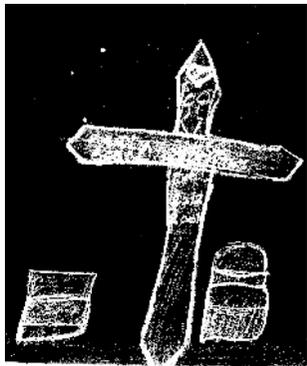
Often sulky, Charlene was worse after the visit. Four days later she ran away. She was found two days later and brought back by childcare worker Lulekwa Matho. She remained really unhappy and alternately angry and withdrawn, repeatedly saying that she did not want to be at Ons Plek.

The possibility that a staff member would react to Charlene's angry, cheeky attitude with anger, and spiral her anger to the point where she ran away again, was high. I asked her to sit down with childcare workers Joyce Sethole and Nomfundo Pilisani and myself for an interview that we conducted in English, Afrikaans and Xhosa. My plan was to discuss her unhappiness at Ons Plek and what could be done about it.

I also wanted her to think through what she wanted for her life, how she planned to achieve it and where she needed to be to achieve it. I was hoping that, having been in her community for a few days, she would be more realistic about her options.

Charlene sat on the very end of the bed, shoulders hunched and eyes looking slightly away. I told her we knew she was very unhappy, that she did not want to come back to Ons Plek. When there was no response Joyce asked Charlene what she wanted to do. She explained that we did not want her to be unhappy and if there was a way she could go back to the community we would consider it. Having already explored this option, we were sure in our own minds that none of her contacts would be suitable to care for her. We were not holding out false hope either, by offering this option. Charlene was being very rebellious and appeared to be harbouring fantasies about her ability to live with friends forever. Given the chance to think through the alternatives, without negative pressure from us, I believed there was a good chance that she herself would decide to stay at Ons Plek.

Her unhappiness, which she said stemmed from the other girls' behaviour, would not



diminish in the community because these kinds of behaviour were common. I waited for opportunities to gradually link her unhappiness to the death of her mother, if it became evident that there was a link. In the meantime, each time she offered a solution, we asked her to consider certain questions to help her evaluate it. We did not discount the suggestions ourselves. We asked: Where would she live? Would the families she said would care for her, pay for her to go to school? How long could she stay at someone's house? If she 'strolled' in the area with other homeless children, how would she prepare for adulthood?

When she had explored possibilities of going 'home' and was looking miserable, I said that it could be difficult to live with other girls, especially when you hadn't chosen to come here and when you dreamed of going back to your home and your mother and your own life.

She remained silent, but tears slowly rolled out of her eyes. Through all of the long silences we tried to guess her feelings from the non-verbal clues she was giving, but she was difficult to read. We suggested these feelings tentatively in a questioning way, steering away from telling her how she felt.

Joyce said, "You look angry, Charlene" and she nodded. I sensed that this was more of a breakthrough than the tears had been. We sat in silence; she could not say what was making her angry. Still linking the running away and the death, hoping to strike a chord in her with at least some of my words, I said, "You have got a lot to be angry about and sad. You first lost your dad ..." She nodded and said, "of TB." I continued, "... then your mom and the house, your brother and all your friends. And then you were brought here and you have to live here because there is nowhere else. Perhaps you will be unhappy anywhere, not only at Ons Plek, because there is only one place you want to be. All you want is to go back home, but when you go there is no home" (said very gently, but I thought this was the crux of her misery and anger). Throughout this she was nodding and wiping away her eyes.

Wondering if she had had any chance to say goodbye to her mother, I asked if she had spoken to her in the hospital before she died.

She mentioned that her mother couldn't get out of the way of the truck because she was drunk. I wondered to myself if this was part of her anger. Anger against the loved one is part of the aftermath of many deaths, but it may not be acknowledged.

This child might have been angry with her mother for drinking even before her drinking led to her death. Now that Charlene was talking, we could listen and reflect back to her the feelings and thoughts she was having. Feeling understood and accepted, she would be encouraged to explore her feelings further as she sought to explain them to us. If she had angry feelings towards her mother she would raise them. It was important for us to go with what concerned her most, and not presume to know exactly how she was feeling.

With prompting, she then described the accident, how it had started with her mother's boyfriend chasing and hitting the mother, how he had run away, leaving her mother in the road, how he had later returned to fetch his hat which was lying at the side of the road once the neighbours had called the ambulance for the mother, and how he had never been seen again. Quite how accurate her description was, was not questioned at this stage – there would be opportunities to do this in later sessions.

She did know where he worked. She was very angry with him. I asked her what she would like to do or say to him if she saw him in the road.

"Nothing," she said, she would walk away. It is often helpful to imagine what one would say if one got a chance to do so without there being any consequences, but Charlene could not imagine any different response.

She also described her fear of the man, who beat everyone when he drank, which was why she had not slept at home prior to her mother's death. Further probing led to her expressing feelings of powerlessness with regard to the man.

Given that Charlene was a confident girl, I was surprised by her inability to give voice to a message she would have liked this man to hear, even in his absence. This led me to ask if she usually talked easily about any sad or angry feelings, and if she was similar in this to her mother. She responded that she had never been able to share her feelings and her mother was the same.

"You must often feel lonely?" I asked. She nodded hard. "What did your mother do when she was sad or angry?" "She drank," was the ominous reply. At this point I did not warn her directly of a possible similar pattern developing for her. I just linked her mother's drinking and apparent lack of emotion so that it would become a conscious thought in her mind.

The reasons for her withdrawal from us on some days and her refusal to talk were now much clearer. She had always handled emotions like this. Her unhappiness was not so much with anything at Ons Plek as with her own life.

The interview had started with the presenting problem of her not liking the Ons Plek girls. When nothing substantial came up in relation to this we still stuck to fairly factual discussions of her future possibilities, knowing that a lot of more difficult feelings must exist about the death. The aim in a counselling session is always to move at the client's pace and gain their trust by focusing even on apparently mundane things which concern them. Having found us trustworthy on these matters, perhaps the client can trust us on a more serious matter, particularly someone like Charlene who does not talk easily.

Several serious emotions had been raised in this session, particularly anger - anger about her mother's death and anger at her mother's boyfriend - which were linked to her current dissatisfaction at Ons Plek.

None of these emotions could be resolved in one session. Charlene left the interview still with strong feelings of anger and loss, but with a quieter spirit and feeling more connected to us. The reduction in her feeling of isolation would help her to stay at Ons Plek. Providing an understanding environment in which she could express her anger in an acceptable way would help her adapt to her loss.

Monica and Charlene mourned the loss of their loved ones. They all went through the stages of denial, anger, guilt, depression and, to different degrees, acceptance. After the angry stage Monica was depressed that she would never see her baby take his first step and grow up. Charlene was depressed at the reality that she would never spend time with her mother again, that she would not be at her wedding. In the depressive stage they accepted the realities of their situations, but without hope. In the acceptance stage they saw possibilities for happiness despite their loss. As with anger, they needed to talk in the depressive and acceptance stages.

Anna, a 15-year-old girl with AIDS that she had contracted during a gang rape, vowed to infect as many men as she could while she was experiencing the stage of anger. When she had exhausted her anger, she entered the stage of depression. This stage is about loss. Anna, who was now nearing death, mourned the loss of her health, her schooling, her ability to dance, activities which had made up her life; and she mourned the loss of her father. She achieved some sense of acceptance, and called us all to her deathbed in hospital a few days before she died, to say goodbye. The stages of the process are the same for those who are bereaved as for those who learn that they have a fatal disease.

Finally, if all the necessary work has been done in the previous stages, the bereaved person or the person who is dying can move towards acceptance. Writing about acceptance in those with a terminal illness, Sylvia Poss says, "The reality of the terminal situation has been faced, raged over, bargained with, mourned and finally accepted. It is an experience of completion, achievement or preparedness for what lies beyond... Acceptance is not happiness but a preparedness to die."³ The journey towards accepting that one is going to die is so personal that often the person knows before the doctors do that this is going to happen.

'The Murderer' - guilt and the importance of saying goodbye

Death visited Ons Plek again one day, in the form of an innocent murderer. Bang, bang, bang, on the front gate. Three policemen and a frightened 13-year-old girl, Agatha, stood on our doorstep. The girl's community had stoned her because they believed she had murdered her child. The police thought so too, but they were gentle with this poor, confused and very obviously naïve country girl. The police asked us to please take care of the girl while they traced her father.

Hearing this from the police I got butterflies in my stomach. The butterflies, as always, centred around my own feelings of helplessness in the situation. I get them every time I sit with anyone who is suffering from strong feelings of sadness and devastation related to death. How would we get the girl to talk? How would we help her, especially with her feelings about the enormity of her action? The road map I turn to is always the same: use therapeutic skills learnt in psychology and social work. The skills of the counsellor help the client to explore their problem themselves. Get the client talking. Listen, paraphrase or reflect the feelings experienced. Put what the client has said together, explain it back to the client and see where they move from there. And then follow 'nose to the ground', and repeat the process. Sit through some painful silences and wait and pray. Afterwards, one can cry and work through one's own feelings. The client will always arrive somewhere. Their feelings will be clarified. Even if no solution is found, they will feel supported and gain strength for their struggle. And so I have been through many interviews, sometimes holding onto my chair to keep myself from running away.

Agatha told us that she lived in rural Transkei and her father was in Cape Town. When her mother had realised that she was pregnant she had sent her to Cape Town to tell her father. Every day she had woken up planning to tell her father, and every day she was not brave enough to open her mouth. One evening her stomach was sore, so she asked a neighbour for some medicine because her father wasn't home yet. The neighbour shouted at her. When she was alone back in the tiny, dark shack the stomach pains grew stronger. After a long time of terrible pains a funny-looking thing came out of her. She didn't know what was happening to her. It made no noise and it didn't move. She wondered if it had been planted inside her by a devil and she wanted to end the



³ Sylvia Poss. *Towards Death with Dignity: Caring For Dying People*. National Institute Social Services Library No. 41. George Allan & Unwin. page 14

frightening experience and to go back to normal (to deny what had happened). She was afraid, and wrapped it up in some rags, scooped a hole outside the shack with her hands and buried it. The next morning one of the neighbours had noticed a dog sniffing around the hole and found the dead baby wrapped up in rags. And then they had stoned her. The police had arrived and rescued her.

Agatha told us the story openly, simply and with the naïvety and innocence of a much younger child. I wondered whether she had any idea of the enormity of her actions. I thought she must be in partial denial after all her frightening experiences. She knew what had happened, but she did not seem to realise that she might have killed a baby. I feared for her mental state when she realised this, and felt the guilt that must surely follow.

A few days later, after we had met the very confused father who wanted to send Agatha back to her mother as soon as possible since the police were not pressing charges, we sat with her again. I knew it was very important for her to process some more feelings about what had happened, but I was not sure if she was ready to do so. I also wanted to offer her some ritual, some way to mourn the baby. We talked in more detail about what had happened, and how she was feeling now. When she described the excruciating pain and then this little thing that came out of her, her confusion at the time and her terror of "this thing" were quite evident. Her emotions at the time of the birth had been so intense that she could not tell us if the baby had been alive or dead or even if it had been a baby. She said she thought it was dead. I commented that it was normal to be so confused, on her own like that and never having given birth before.

When someone is dying it helps to have a chance to say goodbye and to say everything you want to say to them. I asked Agatha if there was anything she would like to say to the baby if it could hear her. "I want to say I'm sorry for killing it," she whispered straight away. I asked her what her beliefs were about life after death. She said she believed the baby would live with God. Did she think she could ask God to pass on the message to the baby that she is sorry, I asked. She thought a priest could ask God to do that for her. She thought it would carry more weight if he asked.

We organised a memorial service for her, and asked the priest to convey a farewell message to her baby via God and to assure her of God's understanding, which he did. She appeared greatly relieved after this.

We sat with her father and helped Agatha explain to him everything that had happened. He wept, and made arrangements to travel back to her mother with her so that she too could understand everything. Agatha would have to stay at Ons Plek while he worked to earn the fares home, because the community were still angry with her. When he fetched her, he said he had never known there were such places as Ons Plek to help people when they really needed it.

How to break the news

It's that phone ringing again. Time and again the ringing phone heralds death. We have had to break the news to several girls that someone in the family has died - often after a phone call. The child comes in from school cheerfully, and one or other of us is there, wondering how to break the news. "What words should I use?" the new social worker asks supervisor Renée. "Wait until I get there, we'll do it together," is her response.

The truth is that there is no way to soften the blow. Careful introductory words, preparing

the person for what has happened, are interrupted. From our faces and our attitudes the person already knows that the news is bad and demands to know what has happened. The news hits like a sledgehammer once the words sink in, no matter how it has been phrased. All one can do is break the news with as gentle an attitude as possible, and then stay with the person. Use all the tools that counselling offers. The news breakers that the bereaved are angry with are those who break the bad news and then run away, leaving the person on their own to process what has been said.

If you have to break the news to a child or an adult that they have cancer or HIV, do it in the same way, make time to answer their questions, and do not be surprised if they ask you the same questions again tomorrow.

Many people believe that children know nothing about death, and that they should be protected from this knowledge which is too difficult for them to cope with, especially when it is the child himself or herself who is dying. Studies that have been carried out show that children have their own definite ideas about death, depending on their ages, their experiences, their rate of maturation and their cultural background. I have worked with many other younger children who spoke peacefully of angels fetching them. These children had gone through all the stages of grief that adults go through. They had been able to discuss all their feelings in their own way and at their own level.

You do not have to say, "You have cancer and you can die from it, you know." Nor do you have to give a full analysis of how the disease will progress. Wait for the questions to come, and make sure that you are receptive to them. Usually the child (or adult) will be in some denial, not ready to face death, and will be focused on what the treatment is. Only as they themselves see that the treatment is not working will they start moving towards the stages that prepare them for death.

Be sensitive to the needs of the child (or adult). Listen, and show by your responses that you understand their feelings. Or sit silently but supportively. Accept their feelings, do not judge and tell them they should not feel angry, or should not feel that they are to blame. Do not tell them to have faith, to trust in God. You may feel better, but the bereaved person will not. Feelings are real, and they change over time. The road to acceptance of a death is made easier if one is allowed to feel what one feels, share it for a period of time and then move on to the next stage.

Jackie Draai⁴

Dear Ma
 Ek is baie lief vir mamma ek miss vir ma
 Ek sal nie vir ma virgeet nie ek sal altyd daar wees vir ma
 En ek het altyd saam met ma 'n lekker tyd gehad en my suster
 ma se baba
 En ek dink baie na haar van sy weg is
 Ek doen alles nie reg nie van sy weg is
 Ek verlang haar en mamma
 Ek is lief vir julle twee.

Another letter to her mother:

Mamma, ons weet Mamma was baie bekommerd oor ons. Ons ding aan us as ons op die regte paadjie loop. Ons leer om eendag iets in die wêreld te word. Ek het gedink ek sal eendag vir ma werk, maar nou is Ma nie meer daar nie. Ma, rus nou van die hout kap!

⁴ Jackie Draai is the writer's real name, used at her request. She wrote this letter to put on her mother's grave.

The poem reads:

Dear Mom
 I love mommy very much and miss mom; I will never forget mom and i will always be there for mom; And I always had a good time with mom and my sister baby; And I think about her alot since she has gone; And i do all the wrong things since she has gone; I miss her and mommy; I love you two.

Another letter to her mother:

Mommy, we know that mommy was very worried about us. We feel good when we are on the right path. We are learning to become something in the world oneday. I thought that someday i would work for mom, but now mom is no longer here. Mom, rest now from chopping wood!