

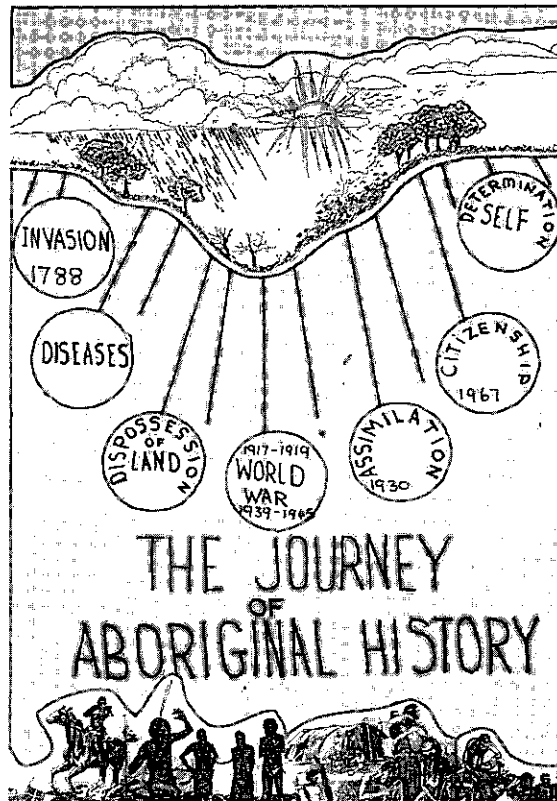
part two

Bringing The Work Home

by

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Aboriginal history (see page 32)

'Let me take you on a journey
of Aboriginal history'



introducing 'sugar'

i'd like to tell the story of 'Sugar' because to me it is a story of trying to find new ways of working, of trying different things, taking new steps. In early 1996, as a member of the Aboriginal Women's Health and Healing Project,¹ I had the opportunity to watch a video of the work of the CARE counsellors of Malawi.

The ten of us involved in the Aboriginal Women's Health and Healing Project really enjoyed watching this video. It really touched me very strongly and I couldn't wait to come home and work with the ideas. I specifically thought about how this sort of work could be used with diabetes as it is an illness that is causing a lot of harm within Aboriginal communities. Not long before watching the video, a doctor had asked us here at Murray Mallee Community Health Centre to organise something for three people who were very sick with diabetes and constantly coming into hospital.

I said to Jenny Baker, who was one of the other members of the Aboriginal Women's Health and Healing Project, 'Jenny, wouldn't this be fantastic to use with diabetes?' And she said, 'Yeah Barb, we should do it together'. We went away from that day with a sense of excitement, with a

feeling of, 'Wow, we've got to use this'. I couldn't wait to get to Murray Bridge, where I work, to try it.

I developed an exercise which I first of all showed to the other members of the Aboriginal Women's Health and Healing Project. It worked very well and I couldn't wait to give it to the people. That was going to be the big test.

setting the scene

In the exercise I played the role of diabetes or 'Sugar'. I carefully set the scene in ways that I felt were culturally appropriate. As an Aboriginal person I knew that it would be wrong to put other Aboriginal people on the spot, or single people out. To avoid this I came up with a number of questions that I gave to the participants which they could ask me and I would respond. The participants were very happy to start by asking these simple little questions I had already come up with. If I had expected them to come up with their own questions straight away it might have been difficult to get people to participate. Giving them questions took away the uncomfortableness. I had hoped that after they had asked me these set questions that a general

conversation would begin, and this is what happened. At the end people came up with their own questions that they would have been afraid to ask at the beginning.

I had been impressed at the way the CARE counsellors of Malawi had invited communities into conversations with one character representing AIDS: Mr/Mrs AIDS, and one character representing community care: Mr/Mrs CARE. As I was doing this work on my own I only developed the one character: 'Sugar'. I thought it would be too complicated for me to play two characters, although I had seen how well this had worked in the video from Malawi. Just having the one character, 'Sugar', meant that she had to be very versatile. She spoke of the ways she was affecting people, but also at times played the role of an educator.

Perhaps we will explore using two characters later on - who knows what future directions will hold. This is just a starting point. It's not perfect. I wouldn't want to put it across as perfect. It is just to give people ideas. I want people to go off and develop their own ways of working. If it came across as perfect it could scare people - expectations might get too high. Every situation is different and every community is different. I'd like

everyone to have the freedom to develop things in their own way.

talking to sugar

The group: *Who are you?*

Sugar: *My name is diabetes but a lot of people call me Sugar. You can call me Sugar. I can be anybody's disease but I do my best work with Nungas² because they can't quite control me yet.*

There was a man in the group and when I said they could all call me Sugar it created a lot of laughter!

The group: *How do you work?*

Sugar: *It's my job to make sure you don't get enough insulin or none at all. Most people know about my condition. I'm very popular and I'm all over the world - I'm pretty sure of having a job until I retire. Years ago it was hard for me to get a job with you people because there were great hunters who lived off the land, good tucka [food] and plenty of exercise. You people were healthy.*

At this stage I referred to a poster about 'healthy bodies' that I made for the program.

Now though, thanks to this thing called urban living, you have heaps of shops to go to and are tempted by the smell of food, by television, books that always show cakes, chocolates and fatty foods. You have very little exercise. All

this just makes me so happy.

The group: *How different are you from a healthy body?*

Sugar: *To explain that I need to introduce you to my family. I come from very strong kin relationships as I know you do. Aboriginal people have strong family relationships and I totally rely on my blood relatives.*

There's my Mother Heart - without her I'm a goner, and three sets of twins - Cousin Kidneys, Cousin Pili's [eyes] and Cousin Feet except they're not here today - gone walkabout. My main man is a gland called Pancreas. This is where I do my best work. I affect all these parts of the body - all my relatives. This is what makes me different from a healthy body.

At this point I refer to a poster about 'unhealthy bodies'.

The group: *What don't you like about your job?*

Sugar: *Well I come in two types of diabetes and I don't like this part of my job. I have to remember the families that have my history.*

First of all there is Type 1, or Juvenile Onset Diabetes. My work here is usually with young people below the age of thirty, but it can happen at any age. With Type 1, the pancreas produces no insulin because the cells that make it have been destroyed by the white cells of the body. People therefore require insulin injections to control their blood glucose levels.

Then there is Type 2, or

Mature Onset Diabetes. This usually happens in people who are over 40 years old and especially if they are overweight. Type 2 often responds to diet, appropriate exercise and weight reduction, but sometimes tablets and then later, insulin, may be required.

I would give out a handout at this point.

The group: *What makes you powerful?*

Sugar: *I become powerful when people are shamed, divided, and isolated. I become powerful when people are overweight, including pregnant women with big babies; when Nungas over 40 never get their eyes tested, neglect sores, don't eat properly, don't use medication and injections, don't visit diabetic clinics or programs, don't have blood pressures taken, never have urine tests; when they do no exercise; and when they stay home and away from people who know about me.*

The group: *What weakens you?*

Sugar: *It weakens me when Aboriginal people have a chance to ask questions, to talk together in their own ways. It weakens me when people are no longer alone, when they stand together. Other things also weaken me - people taking responsibility for their own health, weight loss, diets, blood pressure checks, foot care, trachoma clinics, people controlling their blood sugar glucose levels. All these things weaken me.*

As Sugar answers what weakens her she becomes weaker and weaker until she is almost under the table!

different conversations

What we got out of it was quite magical. The most important thing was that, after we had been through these questions and answers, the participants started asking their own questions of Sugar. The conversations afterwards went on for an hour and a half, just discussing the issues that came up. The exercise seemed to lead to the possibility of people asking their own questions, questions that they had never felt free to ask before, and this led to new sorts of conversations.

It was obvious by the end that some people had never understood diabetes before. Maybe professional people had tried to explain and they'd been too ashamed to say 'I don't know' or, 'I don't understand'. I think we learned that we need to break diabetes down so that the people can understand.

When I asked one woman who is normally very quiet what she thought of the poster she said, 'I'd never understood what Sugar was about. That's given me a real vision.' She wasn't responding to me, she wasn't responding to the diabetic sister or the dietitian, she was responding to Sugar. It was just so different. It wasn't about me, Barb, it was because she could have a direct conversation with Sugar. Another woman was

giving herself injections and she was wondering why it was so difficult. She wasn't moving the needles from place to place. We talked and talked. At the end of it I just went 'like wow!' (thumbs up)

humour

It was really good to play Sugar. I am naturally a bit of a clown, and for a lot of Aboriginal people that is our survival tool - our humour, our joking. To create that sort of environment with Sugar was really good. They really loved it. It was because of the humour that they were able to pick it up better. The male who was there, when he sees me walking down the street, he still says, 'Here comes Sugar!' It's really rippled.

curiosity

The relationship of the participants to Sugar was one of curiosity. Anger didn't creep in at all even when Sugar was extremely boastful. At times Sugar said really, really awful things like: 'If you don't look after your feet you'll get sores and your limbs can drop off'. After I said it I felt quite awful for saying it, but it wasn't me, it was Sugar speaking.

I think using imagery of weakening or strengthening Sugar was better than showing aggression. The idea of asking 'what makes you strong?' 'what weakens you?' was an excellent idea from the Malawi video.

When Sugar was answering the question 'what weakens you?' she actually started to go down, to wilt. It was making her weak. When I ran the program here I actually got under the table - it weakened Sugar so much.

professional relations with sugar

It was wonderful to see how the other health professionals entered into a relationship with Sugar. They started to call me Sugar, and to ask questions of Sugar. To see professional people come into it and accept this whole new process, I think that warmed me the most. The diabetic sister now uses 'Sugar' in some form with mainstream clients. They have also been using the video that we made with other health professionals. The podiatrists send me very positive feedback on coloured pieces of paper in the shape of little feet! I send my notes back in black, yellow and red - Nunga coloured feet!

culture

I wanted to bring in some cultural aspects so that they could really relate to Sugar, so they felt they belonged to Sugar. Otherwise it would have been far too mainstream and that's often the problem with other programs. That's why our people are getting lost because often there are no attempts to talk about these things in culturally appropriate ways. By talking about our people's history, we made

the link between them and Sugar.

I tried to make the exercise culturally appropriate. By giving them the questions first meant that everyone was a part of the process in a non-threatening way. By not using jargon, people felt that we were all speaking the same language.

I think that often Aboriginal people have felt shamed at asking questions, or that Sugar is just too complicated to understand. The way the questions were given reduced

shame - they became a part of talking with Sugar. The fact that we were talking about Nungas and our history and our culture also reduced shame.

togetherness

Perhaps the biggest thing that reduces shame is doing something all together - breaking down the isolation. Sugar is just one of many issues facing Aboriginal people's lives. This offered

a different way of seeing Sugar. They looked at Sugar that day as something that should be taken notice of, something that is affecting the Aboriginal community. It's a community problem. If it's not affecting you it's affecting your grandmother, uncle or aunty. Every family is effected by diabetes, one way or another. By all talking with Sugar it gave the feeling that together we need to take notice, and that together we can take action.



Grief: remember, reflect, reveal

Grief is an area that we have so much work to do on in the Aboriginal communities. It's hard for us to develop programs in a lot of areas, including talking about diabetes or heart disease, if there is so much grief in our communities. So many of our losses have been unjust and unacknowledged, and because of this they can be difficult to deal with, difficult to grieve. For a long time I have been interested in trying to find ways of talking with Aboriginal people about these issues.

At Camp Coorong (*Dulwich Centre Newsletter*, 1995, No.1) we talked a great deal about deaths in custody, the links between grief, loss and injustice and trying to find culturally appropriate ways forward. This year, issues of grief once again touched my own life when I heard about the West Terrace Project.

west terrace project

In our day if you had a stillborn baby, or a baby that died soon after birth, the health professionals would remove the baby and take care of all the arrangements. The mother often wouldn't even see the baby's body and they wouldn't know where the body was taken. The West Terrace

Project has involved trying to find the location of the graves of these children. There had been many, many enquiries over the years about where the babies had been buried.

Apparently there were so many enquiries that they found there were 30,000 babies supposed to be buried at West Terrace Cemetery. People wanted to know where. I was one of these mothers. I lost my son Michael shortly after his birth. I didn't know where he was buried and so I got involved in the West Terrace Project. I attended the ceremony of the unveiling of the Baby Memorial that is dedicated to all the lost children.

West Terrace Cemetery, Adelaide Baby Memorial

Under a Bay tree, a small sitting space formed by a curved wall of quarried stone which directs attention to a symbolic bowl of water made of granite on which floats a broken chain of white daisies in bronze.

The water symbolises calm, the white daisies innocence and the broken chain - a life cut off. The plaques are in the shape of leaves set in ceramic tiles and the whole memorial is in the form of a carpet of bay leaves - bay leaves do not change when they fall.

(Extract from Dedication and Unveiling of the Baby Memorial. West Terrace Cemetery, Adelaide, South Australia. Sunday, March 10th, 1996)

When I went to the ceremony at the West Terrace Cemetery I didn't see any Aboriginal women at the unveiling, and it bothered me. I thought that out of 30,000 babies there must be Aboriginal babies out there. Where were the people? That made me think that we need to get out there and talk, spread the word, share with them about the West Terrace Project. So I began to tell my story and send information out to other Aboriginal women.

speaking out

As I was doing this I was asked to present at the Stillbirth and Neo Natal Deaths (SANDS) Conference. I agreed. I thought it would be an opportunity for me to share my story which would be healing for me, and I also wanted to tell the stories of Aboriginal people. I knew that I'd be the only Aboriginal person at the conference. I wished that there would be more of us but I also knew how daunting these conferences can be for me.

I decided to try to use my own grief as a way of joining. We all had that in common. I thought I could tell my own story of grief and then make the links to the broader stories of grief that we as Aboriginal people have experienced. I thought it might be healing for all of us. I began by telling my own story.

my story as an aboriginal woman – the loss of a twin in the 1960s

Today I am going to share a part of my life with you and reflect on what it was like for me as a sixteen year old in the 1960s.

In those days we had an Aborigines Act where some Aboriginal people were given an Exemption which allowed us to mix with the wider community, but it also indicated that we ceased to be Aboriginal.

This act prevented many of my people from returning to their birth places on the missions. Also there was a loitering act which prevented people of many different races congregating together. This included mixing with our own people as well as our white friends.

In those days, we were not even citizens of this country. This didn't happen until 1967 when we could vote.

As a young girl growing up in these times I had a sense of not belonging and trying to hang on to my identity. During my school days I failed to fit in to the school system and spent my time in a special class till I

was thirteen, and was able to get myself a job in a factory. It was good to get away from being called 'blacky' and 'dummy'. By this time I figured out that I didn't have anything in that head of mine but there wasn't anything wrong with my hands. By the time I was sixteen I felt like an old woman and fell in love and became pregnant ... even got married. But, like many Aboriginal women, I didn't like Doctors and Hospitals. After all, I wasn't sick. Pregnancy to me wasn't a sickness, it was a natural condition.

After getting a bit of pressure from my mother to book into the hospital, I decided to go there seven months into my pregnancy. During the birth it was noticed that I was delivering twins, both boys. The first twin was 7lbs, the second was only 3lbs 14oz and he was breech, plus he had chest complications. I remember the joy of having two sons.

Two days later my son, Michael, passed away. I was young and death scared me and I wasn't encouraged to talk about it. The hospital took care of the burial which was to be at West Terrace Cemetery. There were no funeral services in those days. I had a baby to take home. My other son, Shawn, has been a constant reminder all these years and always will be, but that was the practice then - how times have changed!

Then early this year, I found out through the media about the project known as the Baby Memorial at West Terrace Cemetery which had been prompted by the requests of grieving mothers.

It was then that I was able to cry again. I couldn't believe that after all this time that I had unresolved grief. I felt disbelief - I am a Health Worker and know all about grief and the process... I couldn't help thinking about the mass graves. Going to the Baby Memorial Service was a great relief to me and my children.

After the service I needed to know where Michael's resting place was, but, following many enquiries, I found that he wasn't even at the West Terrace Cemetery!!!! At this stage I decided to write my story for other Aboriginal women and give them information and details of the West Terrace project.

A very special thankyou to the researchers at the West Terrace Cemetery, for their dedication and compassion for this project.

A happy ending for my story is that I have found out, finally, almost 32 years to the day, where my son is buried: the Cheltenham Cemetery was my son's last journey, his resting place.

telling my story

Talking about my own story first was a bit emotional for me. I'd only just found out where Michael was buried. It was a bit emotional and that was clear in my voice. The Stillbirth and Neo Natal Death Support conference was a very moving time for a lot of women who had lost their babies. Women were finally talking. So many of us had been told not to, that it might upset us. A lot of the

mothers who had lost their babies had been told: 'You've got to let go and move on now'. And that's the worst thing you can say. There is a lot of pressure to grieve in particular ways. We are trying to challenge this. We are trying to allow people to grieve in their own ways. Now we are talking, following it through.

My story was an old story, my loss. I used it as an indicator of how long grief can be with us. I also used that story to show that it wasn't just about my grief, that it's also about Aboriginal people and our 'griefs', all the different sorts of losses and injustices that we are trying to find our ways through.

At the SANDS conference there were no Aboriginal people except myself. I told my story in a way to let them know what it was like in the days when we weren't citizens of this country, when we couldn't vote. I told my story in these ways because we're always trying, us guys, always trying to get them to understand!

Telling my own story of grief was a way of joining with the non-Aboriginal people there. In some way I saw that grief could help us join - to create the context for us to talk through the broader losses. I wanted to talk about injustice in a healing way because, for us as Aboriginal people, telling the stories of injustice is a part of our grieving, a part of honouring our histories. Once I had told my story I thought, 'Okay that's my story. I've made the connection with the audience, now to move on, to let people know what it's like for us as Aboriginal people.'

externalizing 'grief'

I had decided that I would try to play the character of 'Grief' and to invite the audience to ask me particular questions. I knew this would be very different to externalizing AIDS or Sugar, but I thought that it might help us to find common ground from where I could share the experiences of Aboriginal people. I wanted to make sure we could talk about our losses and injustices as Aboriginal people in a healing way. Playing the character of Grief and giving the participants questions to ask me was just a starting point. I'm telling this story in the hope that it will give people ideas that they could work on, so that they can come up with their own ways of working.

talking with grief

The group: *Have we met you before?*

What is your name?

Grief: *Yes, you could have come across me sometime in your lives, in one way or another. My name is Grief and I'm the response to loss. I'm a process or a way of doing things.*

The group: *Has your presence been with Aboriginal People?*

Grief: *Yes and for a long time. To give you a good picture, allow me to take you on a Journey of Aboriginal History through some of the events in this country's past (loss of land, sickness, deaths, health, loss of language). You need to read in-between the lines for*

many happenings: removal of children, deaths in custody, rights and culture.

At this point I put up a poster of the 'Journey of Aboriginal History' (see page 25) and encouraged people to fill in the gaps on the poster which I had left blank.

The group: *What's your way of doing things?*

Grief: *Let me talk about the different ways that people relate to me. I'm like stepping stones, and people step differently.*

When I spoke about stepping stones I talked in my own language and had a dialogue with the audience. I tried to talk about stepping stones from an Aboriginal perspective. One of the ways I did this was to focus on little griefs as with death all around us sometimes it is too overwhelming to talk about at first.

aboriginal ways of grieving

Aboriginal people have their own ways of grieving. A part of Aboriginal people's story telling is that we hold onto our loved ones that aren't here any longer. It is a part of our history, who we belong to, who we are related to - our ancestors.

When an Aboriginal person meets another Aboriginal person we work out how we know each other through our relatives. We often refer to people who are no longer alive. Our old people are still very much with us.

Through them we identify each other. I might not know your parents, but who were their parents? We constantly reflect and remember these people.

All my histories are through my grandmother. Everybody knows of her and her children. Hanging on to those old people is very much part of our strength. It is a part of our story-telling. They are talked about and so they are still with us.

When I talked about stepping stones it was with the hope that this metaphor would give a sense of movement, a sense of where people have been at and where they might move. We discussed the many different reactions people can have to loss. We talked about finding our own ways, our own individual ways, and our own cultural ways of grieving.

The group: *How close is loss to you?*

Grief: *Very close - we are partners. As I said before, Grief is the response to loss. Let me give you a definition of loss: 'It's something or someone you had or loved that has gone out of your lives'.*

People don't fully understand how broad loss is. Let me share with you the many different losses and you may be able to reflect on the Journey of Aboriginal History and the Journey of Grief.

At this point I tried to invite people to consider the losses and injustices that we as Aboriginal people have experienced and how we are trying to come to terms with these.

The group: *How can we deal with*

you?

Grief: *There are many ways, people do it differently. Some people do it through having support available, talking about their grief, through maintaining spiritual and religious beliefs, through expressing feelings and stories - Men it's okay to cry. Some people help by gently encouraging the person to tell his/her own story, through listening far more than they talk. Never try to measure another person's grief. Their grief is what they say it is. Treat with love and respect any person who is grieving. Remember that every individual will grieve their own way.*

the beginnings of a conversation

It was a very moving experience. By starting on what we had in common it allowed me to share broader stories in a powerful way, a joined way. People were very open. It was wonderful to talk with the non-Aboriginal people afterwards. They were coming up to talk and hear more. I think it is good for non-Aboriginal people to hear these stories from Aboriginal people in the ways that we choose to tell them. It invites them to understand what has happened to Aboriginal people. It seemed as if a conversation had begun, a conversation that could be healing for all of us.

a different feeling

The session had a whole different feeling to Sugar (see 'Introducing Sugar' this newsletter). Grief is such a sensitive issue so I did it in very different ways. I couldn't use humour. I couldn't be boastful. It was difficult as I had to shift from being silly and yet still get the message across. I love being boastful and silly and making people laugh. The humour was the one thing I did miss. Grief isn't a funny thing. It is a sad and delicate thing. We can't be laughing about it.

honouring grief, talking together

I feel very close to Grief for lots and lots of reasons. I think the young children that we have now, the youth, really need to be in touch with our histories, including our histories of loss and how we have dealt with them. In some ways it is honouring of our grief. I wanted to get over to the people that grief is natural, normal, a thing that we have to go through. A lot of our people don't want to talk about Grief as we've had a lot of losses. Often it seems as if we are just moving from one death to another. Sometimes our people just get so weary. Sometimes it's just too much to go to one more funeral. We have to find ways of grieving together. It's far too hard to do on our own. I wanted us to look at Grief together, in a positive way, not a negative way but in a way that names the injustices,