

## The forgotten art of dying

By Ruth Ostrow

THE issue of losing children has been on my mind the past few weeks since running a story on friends who lost their daughter, particularly as I've been besieged by letters.

Though I gave coverage to many of them in last week's column, one letter has arrived which I feel I really want to run in full because of the points it raises about palliative care for terminally ill children in Australia.

With this year's Palliative Care Week -- which has just passed -- focusing on home-care for children, and a recent decision by the Victorian Government to fund a paediatric home-care service, I feel the letter has topicality as well as profound poignancy.

It is very raw and harrowing to read, and I hesitated before publishing it. But it opens a window on a world I believe we should all be made aware of.

Says Dr Helen-Anne Manion, highly awarded palliative carer -- who runs the voluntary organisation Home Hospice in Sydney -- in response to the letter: "Home is a most vital part of the process of dying. Home is where we belong, where we can 'live' until we die. This is particularly important for children. Dying has been over medicalised. We have forgotten how to die naturally, and how to care for the dying. When we bring people home it transforms death from a medical event to a natural, communal event."

Here is the uncut letter from Sarah Morrison from Canberra: "Dear Ruth, "Your column on Vanessa and Michael and the death of their little girl Layla brought me back to our own circumstance. We lost our 15-month-old daughter this year and in Australia's Palliative Care Week, I thought I'd write to you.

"My husband and I know first-hand the importance of palliative care and the significance of dying in the home. Our daughter was born with a congenital heart disease, quite a common disease which all babies have a one-in-100 chance of having. Our daughter had a particular CHD in which she had a one-in-10,000 chance of having.

"She had open-heart surgery at nine weeks old, again at nine months old and countless viral infections, blood tests, chest X-rays, ultrasounds of her heart, and ECGs. She was on medication all her life.

"This year, a final medical option was put forward; however, as her parents we chose not to accept this offer. The medical profession respected our wishes and made every effort to give us all the necessary information to ensure our daughter would be comfortable at home.

"It is often harder for parents to bring children home to die, but for Georgia home was the end of intervention. The medical staff were marvellous but she was quite terrified of hospital. If a doctor even put a stethoscope on her back she'd scream.

"We wanted to keep her safe, but she hadn't felt safe, having had over 100 blood tests. There was nothing else that could be done for her other than to love her and keep her comfortable. This could only happen at home.

"Though it was our choice to have her at home, it was her choice as well. Many people would say, how would she know, she was 15 months old? She may not have understood the concept of dying (we certainly didn't) but she knew when she was safe in her own environment with her family.

"Before we took her home the pain management specialist from the hospital came to see us. He had to be blunt. 'This is what to do if she's in pain, this is how to use the oxygen. This is what her breathing will do when she starts dying, this is what you need to look for.' It was tragic to listen to, holding my little girl in my arms, and very frightening. But we had made our choice.

"It was suggested she may live for up to two months; however, we were quite sure our little Georgia would not be with us for that long. We were right. She chose to die six days after returning from hospital.

"At 1pm we knew the time had come to draw on our courage. Her eyes were shut, she was still alive but her breathing had changed. My husband and I lay her on a sheepskin on the lounge floor and began to make the plans. If it wasn't me, her father or her grandmother, one of us never left her side.

"A palliative nurse dropped by, a phone call was made to her paediatrician and the priest, followed by a visit from our GP who confirmed our greatest fear, it would only be a matter of time now. She was in no apparent pain, she was surrounded by those who loved her stroking her hair and lying beside her. Our little girl was going. She died at 5.15pm, her heart simply stopped.

"While what followed will always be a cloud, I remember the house being full of immediate family, full of tears, of love, of support. Each person said their goodbyes in their own way. It is a testimony to what a special, brave little girl she was that 500 people came to her funeral.

"My memory will be of her lying on our bed, dressed in her pyjamas with her favourite teddies by her side, with her baptismal candle faintly glowing by her side.

"It fills me with pain that I could not save 'my girl'. The hardest thing as a mother is living with the knowledge that you're going to have to let her go. Nothing can prepare you for the death of a child. But my husband and I are so grateful for our time with her, particularly at the end."

Fiona McAlinden, manager of family support for Very Special Kids in Victoria, which provides palliative care for children in their homes or in a VSK hospice, says it is very important that the family get to choose and feel empowered when their child has a life-threatening illness.

"Not everyone can handle home-care. Some parents are just too frightened of pain management. But we want to support parents in whatever choice they make. It's a terrible thing they are going through and we don't want them to feel regret that they didn't do enough for their child," she said.

At the end of her letter, Sarah Morrison says her greatest wish is that other parents are offered the choice of palliative home-care. On this issue, she and her husband have no regrets.

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First published in The Weekend Australian SAT 05 AUG 2000