



My dear husband Rudi and I were married for 35 years. We met at Church and he became the step-father to my children. He was loving and devoted. He cared for his step children like they were his own. He felt things deeply and passionately. He loved traditional Hungarian cooking, bee keeping and photography.

He was a professional metal spinner. He started his metal spinning business, Alpha David Art Metal, late in life and I left my job as a radiographer to work with him. We worked together there until he retired.

I was 62 and Rudi was 79 when he fell ill with heart disease. When Rudi was discharged from hospital in 2015 neither the doctors nor his family expected that he would live as long as he did. We lived in Central Victoria, 20 kilometres from the closest town, and were on our own at home. Our two children were grown up and living in Melbourne so I became Rudi's full-time carer. My daughter and son were very supportive emotionally, and tried to help as much as they could. However, Melbourne was over two hours away, and both of them worked full time so there was only so much they could do to help physically. We received cards and phone calls and the occasional visit from friends and family, but that was about all.

My life was consumed with supporting him for over 2 and a half years. We were too far out of town to be eligible for services. The council offered someone that could sit with Rudi for 2 hours a fortnight so I could go shopping. However, since it would take forty minutes to get to town and forty minutes to return I felt it was hardly worth the hassle, so I refused their help. I would have liked someone to help with showering once a week and an occasional nursing visit. The greatest challenge during this time was isolation and exhaustion. Caring for a loved one is constant, physically demanding work. I was always worried whether the decisions I was making in caring for Rudi were good ones.

There were no agencies that supported me as a carer. I didn't receive any help at home or from services in town. Rudi was permitted 12 free consultations a year and we divided it between the physiotherapist, podiatrist and dietician. I had to transport him to all his appointments, there were no home visits.



Rudi had two hospital stays during that time. One was for a gall bladder operation and the other was for a kidney infection. Each stay was about 2 weeks. Apart from that he was at home the entire time until his final stay in hospital. It was our preference that I cared for him at home. Over this time, the house needed a ramp put in to accommodate a wheelchair, and the bathroom needed alterations to allow me to shower Rudi. Fortunately, the house was open plan and fairly lowset so nothing too major needed to be done. In addition, for the first four months after he came home from hospital in 2015 we needed to hire an electric hospital bed.

Rudi was approved for a Kylie mattress and chair protection products for incontinence which took so long to arrive (18 months) that I ended up buying my own. We did not have an end of life plan, except to keep Rudi at home for as long as possible.

I would have liked to have had him at home for longer but once Rudi lost his core strength, it was impossible for me to care for him at home on my own. He was admitted to Yea Hospital for several weeks before he died and I visited him every day. He was well cared for there and his pain was controlled well with oral medication right up until the last few days. He died in October 2017.

My advice for anyone that is caring for someone at home with a terminal illness is to plan well. Hope is not a strategy. I wish we had planned better before the crisis was upon us. We had no real plan and just rolled from crisis to crisis in a reactionary fashion. Having a plan will not bring on a crisis, but it will give you peace of mind. You don't have to use it. I also suggest you accept help with anything that is offered, no matter how little, from family, friends and the government. And DON'T run out of medication, because it will happen in the middle of the night, when no pharmacies are open.

Despite the difficulties we went through, caring for Rudi was a happy time together. I am very grateful for that.

**We thank Karen for sharing her story of caring for Rudi.**





Our beautiful Ethan was born with a very shortened life expectancy of only six months - one year. He came to live with us at ten months via foster care, and he remained in our permanent care until his passing at 14 years and four months old. We have a very close relationship with Ethan's birth parents, and they are considered a very valuable part of our family.

I was 43 years old when Ethan came to live with our family, and I was his primary carer throughout his life. Loving, looking after and caring for Ethan were some of the most beautiful and painful experiences of my life. Losing him was like I had lost a limb and my heart was so very broken. But I cherish every moment I had with him, and I would give everything I have to have him back with me. I miss giving him kisses and hugs. I miss his laugh and his funny noises, and even his poopy nappies!

Ethan was born with Hydranencephaly and therefore he had fluid in place of parts of his brain. Although he was profoundly disabled, he was a very happy little man, and such a huge part of our family. I had always made the decision very early on, that I would never keep Ethan here for me, even though I miss him each and

every day, I know that I made the right decision to let him go, as his little body was tired and his seizures were getting so much harder to manage. It was both the easiest and hardest decision of my life. I also made the decision that I did not want him to pass in hospital if I could manage this.... And as a result, Ethan had the most beautiful passing that I could ever have imagined.... So comfortable, so peaceful and with us all around him...The only thing that was wrong was that he left, and we will never see or touch him again.

We are situated in the leafy Eastern Suburbs in an old 1927 Californian Bungalow house, that we have had renovated a couple of times, always with Ethan in mind. We have lived in the same house for nearly 30 years.

As Ethan's primary carer and Mum, I obviously did the most for Ethan, as I was not working and my husband Derek was the main breadwinner of the family. But Derek was and always will be a great support for me, and he has been my strength to get through this time, obviously along with my family (my other 4 children and their partners), and of course Ethan's birth family. We always talk of him every day. I would also say that Ethan's care team were obviously a great support to me always, and I miss seeing them and dazzling them with all the things that Ethan had overcome. I will never forget the Royal Children's Hospital (RCH) Palliative care team, who felt like family from the first time we met. They were there to listen to my raw emotions, and to support me and the family and to guide us through this last part of Ethan's beautiful but too short life. They will always mean the world to me.



It was the Palliative Care team at RCH that reached out to EPC as the outreach program to work together with them so that Ethan could pass at home. I can honestly say that the support and compassion we received from everyone at EPC was amazing. We had music therapy, and we sang to Ethan. He had massage therapy, and nurses who were here everyday near the end. They were so beautiful with Ethan, especially Amber who I will never forget. She bought a beautiful and fragile orchid to give to me when Ethan passed. She was the one who I called when he died, and who had been here through the day. I will never forget her kindness and how gentle she was with us that night.

During Ethan's last months we were a part of the EPC Biography program. This was a lovely way to talk through Ethan's life and relive some of the beautiful memories we had with our Ethan. It is such a lovely journey to take and I treasure the books that we have given to our children, that they now read to their children to keep Ethan's memory alive.

As I managed all of Ethan's care myself, I really didn't want or need anyone to help me with his day-to-day care, as he was full 24hr care for his whole life. But if I ever needed any help, I knew that help was available.

The only extra costs would be the medicines for Ethan near the end, but it was a small price to pay to keep him comfortable.

The greatest challenges I had and we had as a family was the waiting and the wondering when we would lose Ethan. One day he would have a good day, and the next a bad day... but I was most grateful again, that Ethan could sleep the last few weeks of his life between my husband and I and I could cuddle him all night and be there when he needed me. We could tell him over and over again how much we all loved him, and everyone could have their own private time with him.

Ethan took his final breath in his own bed and he just quietly went off to sleep, so peacefully...

I consider it an absolute privilege to be there holding his hand when he left, and to quietly and privately give him his final ever bed bath before he left our house in the care of the loveliest ladies who loudly played Ethan's favourite Michael Bubl  song with the windows down all the way up the street in the early hours of the morning. They also took a flower from our garden that went along with Ethan. Such a beautiful touch.

The advice I would give to people is to make the choice that suits you and your loved one, you can't change your mind after they've gone. I would also say that take every thing that is offered to you, even if you don't think you need it. The bereavement counselling that I had from Lisa at EPC was invaluable, and it was so good to just have someone to talk to and to vent to!

Our family cannot thank EPC enough for everything they did for our beautiful Ethan and our family. We are forever grateful for all of the care and attention you gave us at all hours of the night and day. There was always someone on the other end of the phone who could help you.

I know we made the right choice to have Ethan pass quietly and comfortably in his bed at home, but there is no way that we could have managed everything without the wonderful nurses, therapists and staff at EPC and of course RCH. Even after Ethan had passed away things ran smoothly. I had already spoken with a funeral home a few weeks earlier, which I know may be hard for people, but I wanted to make my choice with a relatively clear head. I know that without EPC working in collaboration with RCH Palliative Care that things would have been so very different.

Thankyou EPC for giving our Ethan the very best passing that was possible. We are forever grateful.

**We thank Robyn for sharing her story of caring for Ethan.**