Palliative Care Stories 2018

Palliative Care Victoria
Living, dying & grieving well
Marco is 13 years-old and lives with a very rare, life-threatening condition that has resulted in severe epilepsy and an intellectual disability.

“Marco was not developing as he should when he was younger and he was either screaming or sleeping,” said Caterina, his mother. “It took years for medical professionals to identify what was wrong. We were getting almost no support, so we did the best we could.”

Very Special Kids, Victoria’s only children’s hospice and family support, has supported Marco’s family since 2009 and linked the family with trained family service volunteer Maddie, in 2016. Maddie visits regularly and spends quality time with Marco and his younger brother, Lucas.

“It was hard recognising that we needed help but it has changed our lives for the better,” said Caterina.

Maddie visits regularly and spends quality time with Marco and his younger brother, Lucas.

“Maddie has been part of our family now for two wonderful years. She has given a commitment to us and the boys and we can rely on her. Otherwise it would be a parade of people coming to the house, which is very unsettling,” said Caterina.
“Seeing Marco’s face when he’s out is wonderful,” said Maddie. “Recently we went to see the inflatable Peppa Pig World. We walked in and his face just shone with the expression ‘What is this Peppa Pig World, and why haven’t you brought me here before?’ He was so excited!

“He also loved visiting the Children’s Farm in Collingwood. He was so engaged and talking about the animals.”

Marco’s 11-year old brother, Lucas, has always looked out for his older brother. “We play around a lot and I’m pretty good at making him laugh,” said Lucas.

Very Special Kids also runs special events just for the siblings of children with a life-threatening illness, as so much of their lives can be focused on their brother or sister who is ill.

Lucas and Maddie formed a connection fairly quickly.

“It’s been good having Maddie here. I can be myself more without Marco. We usually do things we might not be able to do if Maddie wasn’t here. We have a lot of fun,” said Lucas.

“Lucas is very tolerant of my lack of skills in computer games but he’ll throw a Frisbee with me even though I’m not very good. The siblings I’ve met are a remarkable group of young people. They are very considerate and helpful,” Maddie observed.

Maddie doesn’t think of her work as volunteering any more: “It’s something I do and we just hang out. Although I spend most time with the boys, Caterina and I sometimes have a cup of tea in the kitchen and debrief about what is going on.”

When Maddie takes the kids out, Caterina and her husband, Matthew, can have a conversation or coffee together. “We are very grateful. Trust is a big thing,” said Caterina.

Marco’s future is a concern for Caterina and Matthew but they don’t let it get in the way of day-to-day life.

“We try to surround him with people who are supportive and loving, so Marco reaches his full potential, and to make sure Lucas doesn’t miss out.”
Rachelle gave up work to care for her husband, Simon Smith, who has a life threatening heart condition. Support from Anam Cara Geelong makes a huge difference.

“The stress for me started after Simon’s first heart operation. He was only forty three. My best mate had gone down and I had a household to run. I couldn’t leave the house without fear that something would happen to Simon,’ said Rachelle.

“Our son, Elijah, was just three at the time. Thankfully there’s a cartoon with Florence the Ambulance as a hero and I could explain to him why ambulance officers were often here to take Daddy to hospital.”

Simon has a defibrillator and pacemaker in his chest. “If that goes off I can’t be touched, as there could be residual shocks. I can’t have a transplant, as this disease would affect it.

“I went from being an active husband to doing nothing. You can imagine the extra activity and responsibility that Rachelle had to take on,” Simon said.

“We’ve been to hell and back,” said Rachelle.
“The grief and loss kicked in for me. I missed the old Simon, the active man in the house. I missed the happy, uplifting communication because our discussions became focused on his heart.

“After a while it started to bring me down, and I started to get sick. I’m his wife, but also his carer, and I couldn’t do this alone. So our household needed help,” she said.

Welcome respite

“Anam Cara Geelong - ‘Daddy’s day care’, as Elijah calls it - has made all the difference to us,” said Rachelle.

Erika Pickering, Diane Wright and others started Anam Cara Geelong in 2007. Along with a small staff, they provide day and overnight respite, and end of life care for their guests who have a life limiting illness. The presence of a registered nurse means Simon is in good hands.

“Once Simon started coming here a couple of days a week, things settled down. I had a day that I could get my hair done, see girlfriends, or even catch up on a bit of sleep,” said Rachelle.

Late last year Simon stayed at Anam Cara for 10 days while Rachelle and Elijah went home to Perth.

Focus on enjoying today

“The focus here is not on what’s wrong with you, but on how to enjoy today,” said Simon. “It has brought the cheekiness back for me. There’s a lot of banter and fun.

“I enjoy gardening and craft activities with Erika and other volunteers. I make things here for Elijah and he does the same for me at kindy. We get more of that quality father-son time, which is hard to get normally. I also help out with new activities using modern technologies, and that gives me a sense of purpose.

“I felt honoured when they asked if I would like them to make a print of my hand. This is something all guests can do, and the handprints are displayed in our activities room. Each handprint honours the diverse lives we’ve lived and I enjoyed recalling my many interests while creating my handprint with Erika.”

“It’s the little things here. They give us so much love. Anam Cara means ‘soul friends’, and you couldn’t get a more appropriate name for what happens here,” Simon said.

“I don’t feel like I’m in palliative care. I used to think it was just for the end of life but now I know it is helpful much earlier in a terminal illness. I don’t intend to go to heaven any time soon. But I know that as long as I’m still breathing, there are opportunities to be doing things and enjoying the life that I’ve got,” said Simon.

“The focus here is not on what’s wrong with you, but on how to enjoy today,”

It is all about making the most of life. Erika was 72 when she retired. “I thought I’d give up the nursing but keep volunteering at Anam Cara. Life’s too short to stay in our own little holes! Anam Cara is in my heart. It’s a big, big part of my life. Its about friendship, joy and life,” said Erika.
Last year Sasja found that his lung cancer had returned. Tony, a local Morwell palliative care volunteer, visits him every Tuesday.

Daily life was getting harder for Sasja, a Latrobe Valley caravan builder in his forties. Cancer and chemo had weakened him so much that he would run out of energy trying to heat up canned food in the microwave.

“I couldn’t cook, clean or do my laundry. The palliative care people in Morwell suggested I consider moving to an aged care facility and I decided to do that.”

“That’s when I met Tony. He helped shift my belongings. As I don’t have enough room for my collection of war models and star trek spaceships here, Tony is looking after them for me.”

“Having Tony come around and talk to me is a big thing.”
Friendship makes a difference
It isn’t easy being a relatively young man with many interests but very little energy due to a serious illness. Boredom is always a risk. Sasja looks forward to Tony's visits every Tuesday.

“Having Tony come around and talk to me is a big thing. We talk about news, sport, my health and all kinds of things.

“If I need something done, Tony often drives me to the shops at Moe. I don’t have the energy to catch the three buses there and back,” says Sasja.

A better life
“Some days are better than others, but my health has improved since being here. I’ve put on weight. They can keep a close eye on me and manage my pain,” says Sasja.

Tony agrees: “I could see a physical difference in Sasja within two weeks of his move to aged care. It has helped him tremendously. He is sleeping and eating better. The staff here can do things he was struggling to do on his own. Sasja has really picked up.”

Giving and receiving
“Giving back is what inspires me to volunteer. I would say my role is to be a friend,” says Tony, who has been a palliative care volunteer for many years, having retired early.

“It helps me to be a good friend to him and our friendship enriches my life.”

“It also broadens my perspective. Sasja has invited me into his life. I’ve been able to talk to him about things he’s done in his life that I haven’t done in mine. I can get into Sasja’s shoes to some degree, to understand more about how he feels. It helps me to be a good friend to him and our friendship enriches my life,” says Tony.

Very sadly, Sasja died a few weeks after this interview. Vale Sasja.

Sasja & Tony
In their retirement Jimmy and Maureen had a ball driving through Victoria and New South Wales, playing bingo at almost every stop. “I retired quite young so we travelled around doing what we wanted to do... One year we won $50,000 playing bingo! I just loved it.”

Later on, at home in Glenormiston, Maureen became ill and bed-ridden with lung cancer. “Palliative care people came to see how they could help. They did everything they could for her. A palliative care doctor even came during his weekend off and sat with her. I was there holding her hand at the end. It’s been a pretty hard run since then.

“I don’t think you ever get over it, but I have all these good people looking after me. I still talk to Maureen and have meals with her...it’s one of the ways I’ve coped so far.

“The volunteers from South West Healthcare’s Palliative Care Team have made a big difference for me. I was on the verge of going nowhere before Margo and Christine came. They’re both locals, and talking with them has been great. I don’t think I would have got through it without them.

“Margo takes me for drives, and Christine works in the garden with me. She also takes me to bingo sometimes.” Though they’ve never won much at bingo, Jimmy loves having the two to talk to - “otherwise it’s just the cat or the galah out the back.”

Friendship helps with grief

Jimmy’s wife Maureen of 48 years died 8 months ago. Palliative care volunteers Christine and Margo still visit him every week.
Being together, gardening

“Providing company and connection is a core part of palliative care,” Christine says.

“Jimmy’s garden grew while our friendship grew.”

“When I started to help Jimmy, it was beautiful weather and perfect gardening time. It was great for both of us. I learnt a lot about gardening from Jimmy, and he had a hand to get his vegies growing again... Jimmy’s garden grew while our friendship grew. It’s been a good journey in a very difficult situation.”

Margo often drives Jimmy to the cemetery with flowers fresh from the garden. “I’d been caring for my husband, Alan, who had pulmonary fibrosis. Many times I could have done with an extra hand or someone to talk to. So I thought I’d help someone else who might need a hand... It’s very rewarding to be involved as a volunteer.”

Christine signed up to become a palliative care volunteer one day after work. “I wondered if I could ever do this, but the training was thorough... For me it is about connecting people within the community. I enjoy seeing Jimmy every week. I know there are some days when he’s not really on top of things, and other days when he laughs a lot! It’s good to be with Jimmy on any of those days.”