



GOULBURN VALLEY
HOSPICE CARE SERVICE INC.

Precious time



Eleven people in the
Goulburn Valley reveal
what it is like to look
after a family member
in palliative care



Pippa Wischer

Pippa Wischer is a digital storyteller who works with photography, text, video and sound. She has a Master of Fine Art (Research) from Monash University and has lectured at Swinburne University in digital media. She has had numerous solo and group exhibitions, including exhibitions in Parliament House, Victoria, at the National Gallery of Victoria, the State Library of New South Wales, the Australian Centre for Photography and the Ballarat International Foto Biennale. She is the author of *The Dreamers; Life, Death & Dreams*.

Website: www.constructionofus.com.au



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Project management by Carmel Smith

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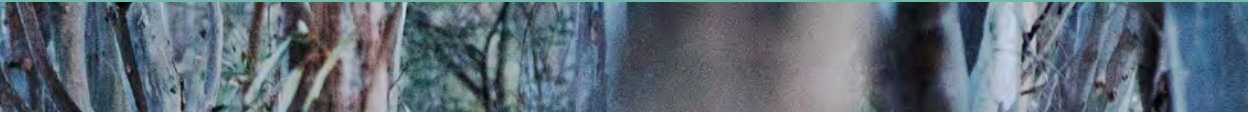
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Precious Time:

Carers in the Goulburn Valley



The Carers in the Goulburn Valley project reveals the experiences of eleven people caring for someone they love who has received, or is receiving, palliative care. The carers talk openly and frankly about what it is like to hear that there is nothing more the medical community can do. They reveal the impact it had on the one they are caring for, family and friends, and on themselves. They share some of the joys as well as some of the challenges of their role as a carer, and what it was like for them dealing with grief. The carers also share the benefits and difficulties of looking after a loved one at home, and acknowledge how the experience has changed them.



Jen is caring for her partner Rohan, who was diagnosed with cancer not long ago. They are giving each other strength to face their latest challenge head on.



I knew something was wrong. We'd been together for three years when Rohan became sick. He'd never had a sick day before, but he was going yellow, and getting weaker and weaker. He'd started to avoid showering and was staying in bed.

We went to the GP and then to the specialist, who didn't mince words. She basically said that the carcinoma is inoperable. It's terminal, but it is controllable. I was in tears. I had known in my gut that it was going to be bad news. It's still very hard to hear that your partner has a terminal condition and you don't know how long he's got.

I went into shock. I went through a multitude of emotions. I went through hurt, and anger, but I stepped up and I knew how to deal with it. Rohan has no close family in Shepparton, as his sons are over two hours away. I love him so much and I wouldn't want to be anywhere else but here.

The oncology specialist introduced us to Hospice. They are very helpful in managing the illness, and offer support for carers. They ring us regularly to see how we're going and we can ring them 24 hours a day. We had physical support such as putting a rail in the bathroom, and they ask about Rohan's pain levels and help us to manage that. They're amazing. They're all specialised palliative care nurses, and they can talk us through medical situations. I know that I have peace of mind with them on speed dial.

They held their first ever carers support group and I was invited. There were ten carers caring for 'carees' as we call them. It was a very broad spectrum of carers and it was exceptionally eye opening. I realized that I wasn't alone; there are a lot of people out there caring for people they love. We're meeting now once a month and it's been great for me.

Paula is the counselor for the carers, and they provide an ongoing service for carers after the dearly departed have gone, so I'll have access to their support network for as long as I need. I know they'll be there for me. You do become a family. They're wonderful, and I can't speak highly enough of them.

“ I realised that I wasn't alone; there are a lot of people out there caring for people they love.



There is a twenty-year age gap between us and I knew going into this relationship that Rohan was likely to go before me. That never deterred me. I just hoped that we would have a lot longer than we've got. It has changed our relationship and it's brought us so much closer. We now communicate about everything. We've talked about the funeral, the will, the 'party, not a wake', we've organised the finances and the powers of attorney.

I don't go a single day without waking up and thinking about Rohan not being there any more. Sometimes I go to bed and I'll watch to see if his chest is moving, and when it is, there is huge relief. I wake up every day hoping that he's still breathing next to me.

Rohan has never been scared of death. His positivity in life has always inspired me, and in a way, that has rubbed off on me. I'm very emotional, and I will have peaks and troughs, but when Rohan came along, those peaks became waves. We're chalk and cheese in that respect, and he calms me. He keeps me steady in some ways.

Rohan getting sick encouraged me to go out and get a job I enjoyed. It's my dream job. It's a casual job but it's enough for the moment, as I go with Rohan to his appointments and care for him.

He's my soul mate. We've had partners in the past, and marriages in the past, but we came into each other's lives for a reason. He saved me from a bout of serious depression and if it weren't for him, I wouldn't be here today. His bravery made me stronger, and because of that, I am now able to be strong for him.





Kylie cared for her partner Aaron who was diagnosed with neuroendocrine cancer. Surrounded by his large family and his soul mate next to him, Aaron died five months later.

Aaron's the sort of person who didn't complain about pain, so when he was up during the middle of the night screaming, I knew that something was wrong. He had pain in his belly and despite numerous hospital visits, he wasn't getting any better. His local doctor sent him to get a CT scan the next day. He told me he had cancer in his pancreas. That was in May. Six weeks later he was in a lot of pain and they did more tests and found that he had neuroendocrine cancer. It was in his pancreas, the lining of his stomach, and his liver.

When someone's sick, all you want to do is care for them; think of them. It was a bit of a shock at first, because I didn't really know what the palliative care team was doing here when they came out with their folders. However, they were fantastic. They were in constant contact with the hospital and the palliative care unit to work out the best way to help Aaron, but unfortunately nothing helped with the pain.

Hospice taught me how to give him his injections, his pain relief. I don't think I would have come through it without Hospice. They were honest, but caring at the same time. Aaron always wanted it straight; he just wanted to know what was going on. It was great that I could ring anytime and talk to them about medication or anything. They'd pop in when he was having chemo. They were always there for us. Always. Hospice gave us so much of their time. They're just beautiful.

My family was great, and his family was fabulous while he was sick. His mum would come in and sit with him for hours on end. She was fantastic. They were long days for me because I still had to feed the animals and I needed daylight for that. One day I surprised Aaron when he was sitting outside in a wheelchair. I'd brought our big dog Hudson, who just ran straight to Aaron. It was so beautiful. Aaron had tears in his eyes.

Half way through his chemo, Aaron's tumours had shrunk by 50% so we were high-fiving. They did say there would be no cure for him, but we were hoping that we might have a few years.



“ I got the pastoral carer to do a little wedding ceremony for Aaron and I. We gathered some flowers out of the garden.

We planned a holiday to Port Douglas but Aaron was getting worse. He couldn't eat. He was just shrinking. He was very sick. When we got home, I took him straight into Shepparton Hospital. He'd lost far too much weight and couldn't do the chemo. They sent him to Melbourne, to a palliative care unit in Kew.

At 5 o'clock on the day he died, I got the pastoral carer to do a little wedding ceremony for Aaron and I. We gathered some flowers out of the garden. In my mind we got married even though it's not legal. Later that night, most of his family was in the room with us. We were sitting around talking. We thought he was going to die that night. About 9 o'clock we saw him take his last breath and then his chest didn't go back up again.

I buried him with a wedding ring on. We'd had a beautiful engagement party the previous year. It was the best day of our lives; we just loved it. We were going to get married in Murchison, along the river, but it didn't happen. He just got too sick too quickly.

From the day we met we just knew. We just knew straight away that we were soul mates. I can't believe we didn't have more time; just under four years together. He was only 43. I've gone through the first of everything; his first birthday without him, the first Christmas, my birthday... and I've just passed the first anniversary. It's really hard for me to come to terms with it. I feel him here. That's why I don't want to move from here.

I don't know what the future is for me now. I know I've got to keep moving forward, and I know I've got to get work. I was thinking of nursing and I have thought about volunteering too.

I can't believe that my soul mate's gone. We were perfect for each other. I like talking about him. I don't want him just to be a memory in my past.





John was with his partner Tom for 32 years. Tom survived a number of illnesses before he was diagnosed with Meningioma. John looked after Tom during his last year and is thankful they had that time together.

There was a history of cancer in Tom's family. He had very bad skin cancers on his head, so we were referred to the neurosurgeon in Melbourne who diagnosed it as Meningioma. At that stage it was on the brain, not in the brain, so it wasn't affecting Tom's brain function greatly. Tom didn't have the attitude of an 83 year old, so the specialists went ahead with surgery, which took eleven-hours to remove the cancer.

Tom did a course of radiation therapy at Peter Mac in Melbourne. He was able to come home at weekends, so he'd do that or I'd go down to him. At the end of that, they did an MRI and couldn't find any cancer, which was fantastic news.

The last thing Tom wanted was to be in a nursing home. So I was bathing him and giving him medications at home, and I was fine with all of that. When I went to work, I'd always make sure he had the hands-free phone beside him. I was at work one day and he called me because he'd fallen a few hours before. He hadn't wanted to trouble me. He'd grazed his face and arm but we got him cleaned up. My work knew the situation and they were great. They let me bring Tom into work and he'd sit out the back and my colleagues would come and sit with him. They were fantastic. I can't thank my boss enough.

But then Tom started getting some weakness in the left hand side of his body, and everyone thought it was a stroke. They did another scan, and his Meningioma was back. They gave him 4 to 6 months. It was only then that I realised that this was the end. I was looking after Tom the best that I could. It all happened very quickly. He was in hospital for two weeks, and then he came home. He died two weeks after that. In hindsight, it seemed like a flash.

I was able to talk to the people at Hospice and ask them anything. The good thing about them was the moral support. They kept bringing me equipment in case I needed it. I can't speak highly enough of them. Even now they meet me with a hug and a laugh and I can always have a bit of a joke with them.

The last two weeks were probably the most valuable in my life. It gave us the opportunity to talk, all hours of the day and night. Tom and I would just sit and talk.

“That last fortnight was the most valuable fortnight I’ve ever lived.



In hindsight, that was the best two weeks, because we were able to discuss anything and everything. It left me with a clear vision of what he expected from me. People talk about the grieving process and I really think those two weeks were my grieving process, because the things we talked about were terminal things. ‘When I’m gone... After I go’..., these were the terms he used to start the conversation, so I knew he was thinking about dying. I really feel that was my grieving process.

When Tom died I rang the undertakers and it ran through my mind...what do I say? Nothing sounded right. Hospice had given me the little booklet about what to expect and things I should do if I could; domestic things, like putting in his false teeth. I knew it had to be done, and it didn’t hold any fear for me, so why shouldn’t it be me? I could do that.

I don’t see what I did as being wonderful. It was an extension of love for Tom. For better or worse, in sickness and health... Even though we didn’t have that, we still lived it anyway, because that’s what a partnership is about. You just do it. You want to do it for their benefit. I still love him, and I miss him, but I wouldn’t want him back, not in the condition he was in.

I look back now and that last fortnight was the most valuable fortnight I’ve ever lived. I guess knowing how much he depended on me, and how much I tried to live up to that, I appreciate that fortnight deeply. It means a lot to me to have been able to do that.

Since Tom died I’ve become more extroverted because he was quite a private person. When I moved in with Tom I adopted the life that he was living. I enjoyed the 32 years we were together immensely. Now I’m looking at a new circle of friends and life has changed for me. Tom was very private, but now I don’t care. I am who I am. It’s me.





Frances and her two sisters helped their father, Frank, after he was diagnosed with cancer. He continued to look after his wife, Maria, who has dementia, until his last hospital admission, and his death a month later.

Twenty-five years ago Dad was having trouble with his water works so we went to a specialist and they said he had polyps on his bladder. At that stage the polyps weren't cancerous but we knew they would become so eventually. Early this year, dad started to have more bladder blockages, and the doctor said it wasn't looking good. We knew that he would have to have surgery, and there would be more infections and that one of these would take him in the end.

Mum has old age dementia, so she is stuck in a time when she was in Italy living with her parents. Dad looked after Mum and managed his infections. When he was really sick, we thought we'd put mum into respite just to give dad a bit of space, but when he came home from hospital, he wouldn't allow it. He wanted her with him, even though it was difficult. He was with her until the end. He was amazing.

My eldest sister was looking after mum and dad five days a week, and my other sister and I were working full time so we did the mornings, evenings and weekends. Dad's infections were getting worse, so the doctor suggested we get Hospice involved. They were fantastic. They spoke to dad and asked him what he wanted, and where he wanted to die when the time came. He was so easy going that he didn't care.

Hospice organised the medicine dad needed to manage his infection and pain at home, and the nurses explained everything. I can't speak highly enough of them. We could ring any time we wanted, and they were so good. Knowing that Hospice was there made a big difference, and they'd regularly come around and check on dad.

We promised dad that we'd look after mum, and we do the best we can. It's really hard to see how mum is. You can't have a real conversation with her, but sometimes she makes us laugh.

Initially it was hard to get a diagnosis for her because of the language barrier, but dementia is in the family so we suspected it. My eldest brother used to keep an eye on Mum and Dad when he was alive, as he lived next door on the farm. When he died ten years ago, mum's paranoia crept in. We didn't realise that was the start of

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the dementia. Dad wanted to be closer to us so we could help look after Mum, so they moved to town four years ago.

In June this year dad couldn't get out of bed. I rang the Hospice nurse and she was fantastic. Dad had an infection so we took him to the hospital, but he never came home. The morning Dad passed away I was with Mum. Even though we knew the end was close, it was still a shock and I didn't want him to be alone at the end. I think dad would have preferred us to be with mum though, because dad said he had all these people looking after him. He wanted us to look after mum instead.

We tried to tell mum that dad passed away, but she didn't get it and sometimes she asks for him. We decided not to take mum to dad's funeral; we didn't know if she would comprehend what was going on. I know it seems weird, but I wasn't upset that she didn't go. It was my time to be with dad and his memory and to give him a nice send off. He looked good and at peace at the viewing. I placed his TV remote and his hat in his coffin, his favourite things. He always had his hat with him.

Even now I don't think he's gone. In the back of my mind I kept thinking that he'll get through this, but in a way, I'm glad for him to have a bit of peace. He was in good spirits about it all. As he said, 'I've had a good life. There are people worse off than me.' He made peace with it. That was his attitude.

Mum and dad sacrificed everything for us, taking the risk to come from Italy to Australia after the war. Compared to them, we have it easy. Like dad used to say, 'That's life.'





Kathy cared for Louis at home after he was diagnosed with stomach cancer. Choosing alternative treatments, his strength and positivity helped his family and friends deal with his illness.

Louis had reflux and he had been to the doctors a number of times. Eventually he had a gastroscopy, and they said he had an ulcer. We didn't realize until later that it was stomach cancer, and that it had metastasized. The medical team told us there was nothing they could do. Chemotherapy would extend Louis' life if he could handle it, but he decided not to do that.

I had breast cancer a few years ago and had surgery and chemotherapy. The chemotherapy made me feel awful but the statistics were good, and even now I don't think that I'd do it differently. But for Louis, we made the decision to focus on his quality of life.

We started a juicing regime that was pretty intense. He wasn't eating food, but having supplements, and green juices every four hours. It was quite demanding. We started filtering the water and everything was organic, and he had some good results. It made us a lot more positive. I couldn't have stood it if he had come home, put himself to bed and said, 'I'm going to die.'

I heard about Hospice, and they said they'd do whatever worked for us. We had medication here just in case, but we didn't need it until the last week or so. Hospice were very good. They brought out all the things we needed, like the bed. I didn't realize that there was such a range of things that could assist us. You don't want to rely on family and friends all the time, and they're not always equipped to help you.

My children were great. The two near here took time off work and the two in Melbourne would come up during the weekends. They took it in shifts to help out. They were consistently around for the last month.

We don't have any regrets about looking after Louis that way, and nor did Louis. I think it kept him healthy for a while; no sick days and he wasn't really in pain. Eventually he became weak and lethargic, and his body started to shut down. He still had the green juices until the last couple of weeks when he started to vomit, and after that all he had was water. It was all quite quick, although it didn't seem like that at the time.



“ For Louis, we made the decision to focus on his quality of life.

Louis didn't want to go to hospital, and we could manage with a little help. We're glad we chose to stay here. It is hard though, because you see everything and not everyone can manage that. He was quite lucid until the last little bit, but it is hard to see how far down someone goes before they pass away.

Louis never really talked about dying. He really thought he'd kick it, right until the end. We talked about having a Macedonian funeral, but he never brought it up again. I didn't ask those questions because I didn't want to be too blunt.

Louis' parents don't speak a lot of English. I asked them if they wanted to have a viewing, and to have a few of the traditions at the cemetery, but we also do things like the memorial horse ride, which Louis would have loved. We always respected his parents and their traditions. I'm quite happy about the way we did it.

After the funeral, it was probably a bit of a relief. The sale of the orchard hadn't gone through and there was a lot to do. I was so busy getting things done. A friend advised me to be careful of the slump a few months afterwards, and she was right. You get over the first few months of busy, when people are still hovering, and then it drops off. I was so busy caring, and then there was a big hole, but I have learned to ask for help, and to accept it.

I try to get involved in something that takes my mind off it. Getting up in the morning is quite hard, because there is a sense of physical loneliness, and emptiness. I think that this is when we should have been enjoying our life and doing things together. I try not to reflect on the bad bit, but think of the good things.

Louis was a bit of a rebel. He was very honest and loyal and we always had a really close relationship. Anything he wanted to do we had done, so I don't think he had any regrets.





Chrissie is caring for her husband John, who was diagnosed with Arnold-Chiari malformation eleven years ago. Their family feels they are now closer as they talk openly with one another about everything.

People were treating John like he was drunk, because he'd be falling out of the car at nine o'clock in the morning. He had had headaches for a couple of years. They were getting more and more regular so we went to the doctor. The CT scans didn't show anything so the doctor just kept prescribing painkillers. This went on for years. John was getting worse on his feet, so we went to see an ear, nose and throat specialist. John was then diagnosed with Arnold-Chiari malformation.

It was scary when we were first told. We made the mistake of coming home and googling. Some of the things were horrible, but everyone's different. They think he was born with it, but it could have been caused by a head cold, or a fall.

It helped a lot when John went into rehab after the first operation, because we could see the situations of others. I was just glad John was coming home, so we were better off emotionally. John may not be able to kick the footy, but he can still talk to his son, still interact with him and give him cuddles. There might be a few things we can't do, but there are still a lot of things we can. I think you just learn to do other things.

Six months after John's first operation he was meant to go back to work, but he never recovered enough and they pensioned him off. Two years later they operated again. It got to the point where he was coughing and blacking out. There were a couple of scary moments there. He's had about sixteen operations since then.

Our doctor recommended we get help from Hospice. He said it's not just for people in palliative care and they got involved. Now, Hospice come around, and they call every few weeks to see how I'm doing, and how John's doing. They ask if we need anything, including liaising with the doctors or getting scripts, and they're really good. It's a relief just knowing they're there. If anything happened they'd be here in a flash. I know I don't need them a lot at the moment, but I can see us counting on them more often in the future.

People think it only affects John, but it affects the whole family. You learn to handle what you can. The kids seem to be all right. Chloe's 19 and she's studying nursing. Keith is 15 and at school. John was first diagnosed 11 years ago, so I think the kids are

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okay because they grew up with it. Keith struggles a bit more sometimes, but he reckons that dad isn’t sick; it’s just dad.

I can usually tell if John’s having a bad day. The kids help out too though. If I’m not around and they know he’s having a bad day, they’ll jump in and help out a bit more.

I wondered if John and I being together all the time was going to make us or break us. It was a big adjustment, but we’ve dealt with it together. We had a few years together before his pain started and that helped. We still have our moments, but it’s normal stuff. I think we handle it.

I like that we get to be a family, and that John’s getting to see the kids grow up. I think the fact that we’re open and honest with each other keeps us together. It’s brought us a bit closer too. We don’t get petty about things. There are bigger things in life to worry about. Talking helps us a lot I think.

I don’t know what it would be like in John’s shoes. He’s put up with so much pain for so long now, that it’s normal to him. That’s the hardest thing. Making sure he’s comfortable is the most considerate thing I can do for him.

It’s been a journey. I just take each day as it comes. It sucks sometimes. I chose to grow old with John and I feel a bit ripped off that it’s being taken away from us. It isn’t how we chose our life to be, but I wouldn’t be anywhere else.





Heather cared for John after his diagnosis of Motor Neurone Disease three years ago. He died peacefully at home, surrounded by his family. He was so well loved that nearly 1,500 people attended his funeral.

It started with John's big toe, which wasn't working properly. When we went to the second neurologist we were told he had Motor Neurone Disease and to get our affairs in order. It was gut wrenching. There's no treatment so you've got nothing to fight.

John and I grew a lot closer, and we shared more. We had always been busy with work and life, but then it was just us. During the night when neither of us were sleeping, we would talk for hours about nothing and everything. I came to know him again as the person I had fallen in love with 35 years ago.

I think that the kids have always been close to John, but this gave them the opportunity to say everything they wanted to say to him, and to do everything they wanted to do with him. It also gave John the time to enjoy his genuine interest in other people.

We had help from the district nurses and Hospice, and John was happy with that. While I was nursing I looked after palliative patients in hospital, and I had looked after my parents. It is extremely important for me to look after someone I love, and I wanted to do that for John.

We were never rude or disrespectful, but it was a bit of a party here leading up to John dying. Fortunately he was quite lucid the whole time. All the family arrived and his best friend stayed the night. We cracked a couple of bottles of champagne and we celebrated John's life with good stories while he was still here. John was much more comfortable surrounded by the people he knew, and it was really important for me, and for the kids. We had a lot of people here and no one wanted to go home. I had to kick them out at 1am.

The next day we knew it was close. John waited for everyone to be here; his mum, our kids, his family and best friends. That was good. It was really beautiful because John had no breathing issues and no distress. He just closed his eyes, took one breath, and that was it. It was so peaceful. It just seemed a bit surreal. I was more concerned about my three children, that they were okay.

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John had told us everything that he wanted to happen at the funeral. I had written everything down, so when he died I just opened the book and there was the answer. That took the pressure of us as a family, which was fantastic because it stopped all the arguments and made things much easier.

Of course I miss him, but I guess I didn't realise how much I used to do for him either, because I put a lot of things on hold. He was the most important thing in my life. Doing all those things that I'd let go is keeping me busy, and helping me not to think about how heartbroken I am.

I always think about John. The thought that he's not here is in my head every second. The days are okay because I go flat out, and the nights are okay because I play Candy Crush, and then I go to bed. Friends include me in things and I'm fortunate that I have family around. My daughter comes around every other day and she's so wonderful and very supportive. People ask, so you do have to accept their help. There is a lot of help out there, for everyone, but you do have to look for it. I know I can call Hospice and they'll be here, even at 2am.

I will start doing something, but I don't know what that will be. I've thought about helping with palliative care, perhaps staying at someone's house and helping with the cooking or whatever, but I'm not too worried about that yet.

It's made me realise how precious life is, and how you can come unstuck with one sentence from your doctor. It's made me appreciate life. John taught me to say the important things you need to say to people. You need to tell them that you care for them. What he did was amazing, and he certainly left a legacy for so many people. I miss him dearly.





Arja and Teagan cared for their dad John. John's primary care fell to his daughters, who helped him to live independently while his cancer progressed.

Teagan: I had a phone call saying my dad was in hospital. He'd had a fall, so they had scanned his brain and found a large cancerous tumour. He was rushed to Melbourne. He really needed surgery and I had to give them permission, despite the high chance that dad wouldn't come out of it, or may have no memory of us afterwards. We later found out that the primary cancer in his lungs was already at stage 4. We knew then that dad would be in palliative care and the treatment would be about giving him quality of life.

I think the doctors thought Arja and I were just kids at the start, but our roles were reversed. We were caring for our dad. It was really tough for us to see our dad like that, but it gave us the opportunity to spend more time with him. We were able to make lasting memories with him in the last 14 months of his life.

Hospice used to come to see us once a week and they would always be on call if we were having a terrible day. They were always here for dad to talk to and to make him feel better. Arja and I will be forever grateful for their support.

Dad went into hospital for the last few days, and was surrounded by family. He had a sip of beer, we played the Essendon theme song, and he passed away. I felt he was in a good space, but for a month or so afterwards, when I closed my eyes, all I would see was my dad taking his last breath.

Arja and I have always been really close, and we've both been married since dad passed away. We are lucky to have such supportive partners and family, so we never felt alone. To have had that time with dad was really good, and I don't regret any of it.

“ It was really tough for us to see our dad like that, but it gave us the opportunity to spend more time with him.

Teagan & Arja



Arja: I was overseas when I heard dad was sick and it wasn't until I got home that I learnt he had stage 4 lung cancer. With the extent of his injuries from the brain tumour, the only way dad could leave hospital was in our care. After a month, we realized that it was in dad's best interest if Teagan was home during the day to look after him.

We'd look after him in shifts. Teagan would give him his medication in the morning and I'd do it at night because dad would often forget. Dad insisted on living in his own flat, and one day I found him totally collapsed. In the back of my mind, I was always wondering if this was going to be the day that I found him passed away.

Hospice are on call 24 hours a day, so we could ring them and they'd tell us if we needed to go to hospital or if they could help us. They really helped with prescriptions and medications, and they gave us a wheelchair and whatever else we needed.

During his last days, Hospice organised for dad to go into their special palliative care suite and they made him very comfortable. He had a private room, and there was a couch and a pull-out bed that we could stay on. There was a private courtyard and a little kitchen. They were really good.

We were lucky because dad could tell us what he wanted for his funeral and remains. He was a die-hard Essendon supporter so he really wanted to have some of his ashes spread at the MCG or at Windy Hill. Windy Hill said it was actually really common and we scattered some of his ashes there and let some balloons go. It was a beautiful day and it was great to be able to honour what dad wanted.

I cried most days for six months after dad's passing. By the third month I wasn't really sleeping so I went to my doctor for advice. He told me that I was going through the normal grieving process. You don't know when grief is going to hit you and you never expect it. After the birth of my son it just hit me; dad was never going to meet my son.





Stan was diagnosed with liver and bowel cancer a year ago. Their bike riding days behind them, Carol is looking after Stan at home.

Stan was told that he had cancer on the liver and cancer on the bowel. They booked him in the next day for chemo. It was very overwhelming. Nothing was discussed, but the next day we came in and had a nurse talking about the side effects for half an hour, and that was even more overwhelming.

After the second treatment, which was stronger, Stan was very sick. He wasn't eating any more. He lost 10 kilos in a fortnight and he hasn't put it on. At that point they changed the treatment. He's getting used to the chemo. He's been doing it for months. Now it's only every fortnight and he's been improving a bit ever since. He gets high sometimes and he can't sleep. All of a sudden your whole life changes.

The doctors are all friendly, and I feel very lucky to have all these fantastic people around me. I know from these people, that everyone loses a partner at some point; it's just life. Life still goes on afterwards, so that strengthens me.



The oncologist organised Hospice to come, and they're great. They look after Stan's needs first and foremost, and they're great company. They're all so fantastic. We know them all by name and they're like a big family. They come for me as well as Stan, and I feel that is very important. It is not always easy.

Stan wants to die at home. He doesn't want to die in hospital when it comes to that point. So the council comes around and they've cleaned the spouting, changed the smoke alarm and the toilet seat. We feel secure here. We've got our privacy here. I think that's really important in your old age.

We are very independent and a bit tougher. I think the fact that we were bike riders has made us what we are now. I loved Stan as a bike rider. He was very strict on

“ We are very independent and a bit tougher. I think the fact that we were bike riders made us what we are now.



himself when he was the ride leader in the Ulysses Club. He knew all the roads, and he would have up to forty people following him. We rode all over Victoria together until only last year.

Attitude is the most important thing because the doors are closing. You don't think you're getting old, so you just get on with life. I try so hard to keep busy and walk every day. I need life and I need people around me.

I adore Stan. We've been married for 20 years, and together for 25 years. I just love every bit of him. I've never loved a person like him. He is extremely determined. He never gives up on anything. I can't really explain it.

My family supports me but they're not here. They have their own lives. They don't live in Shepparton and they all work, but they ring me up regularly and see how things are going. However, I get so much support from people around me. It flabbergasts me that people from work ring up and ask if there is anything they can do.

I take time out to look after myself. I listen to the birds, I read books, and I read at least two books a week. I write about how I feel and what we've done every day. I think that's my outlet at the moment, away from what normally goes on. I love my garden. There's always a fair bit of work to be done, but I look forward to doing it. We have a good life. That's enough for me.

My first thought is always Stan. What can I do for him? Is he comfortable? As a carer, I carry all his burdens. I don't want him to die because I love being with him. We're very special to one another. We always have been.





Glenda cared for her husband Norm after he suddenly collapsed at home. He was diagnosed with lung and brain cancer, and died seven months later.

Norm was diagnosed just over 12 months ago with terminal lung cancer and a secondary brain tumour. Nobody knew about it. He was a fit man. One night he went strange all of a sudden. Initially I thought he was having a heart attack but his eyes went right back into his head and he started screaming. He started to fall but he was tall and there was no way I could hold him. I called Triple Zero and the ambulance came. They revived him and they took him to the local hospital. They then airlifted him down to Monash at 3am.

He was in intensive care for ten days. The hospital provided a flat for people like me and I had to share it with another woman. I'd never done anything like that in my life. All of a sudden, my husband has a seizure, he's got terminal cancer, and I'm living in a flat with a perfect stranger. It was such a strange thing but I was able to spend my days in intensive care with him.

Hospice was there when Norm came home. They'd come out and see Norm and make sure he had everything. They brought a walker, and a seat for the toilet. They were looking after me too, but I wasn't really aware of it because I was so focused on looking after Norm. I don't know what I would have done without them. I could call them up any time of the day or night. They were angels.

I didn't have time to think about myself. I was really thinking about Norm all the time. When does he need his medication? What will he want for dinner? I was trying to keep him comfortable, and make sure everything was right for him. I didn't think about the bigger picture. If I'd sat and thought about it, I don't know whether I'd have coped. Being on autopilot was my coping mechanism.

After the seizures started again, he went to the beautiful little hospital in Tatura that caters for people in Norm's situation. They sorted out his seizure medication and he came home. His tumour started taking over again, and this is the really hard part, because it started changing his personality. He started getting angry and nasty with me, and that was pretty hard. In the end, I had to say that I couldn't cope any more.

“Hospice came and they put things back together again. They were so calm when we needed them to be.”



I knew it wasn't him; it was the tumour. Hospice came and they put things back together again. They were so calm when we needed them to be.

Norm was back in Tatura, and I called in to see him one morning and he was sleeping. I thought I'd duck up to Shepparton to do my shopping and come back. But on my way back I was T-boned by a hit and run driver and the next day I was in Melbourne at the Alfred Hospital. I was in a very bad way; I don't remember anything because they put me in an induced coma. They waited five days to operate, and two days after that, Norm passed away. I didn't get to say goodbye, so when I was in rehab I wrote a letter to Norm and they read it out at Norm's funeral.

I was in rehab for over 2 months. I kept bursting into tears, but I had a job to do. I had to get well. I had missed saying goodbye to Norm, so I had to get well enough to say goodbye properly.

We had the memorial for Norm last week, which was absolutely beautiful. We couldn't have asked for a better day. We were in this old cemetery under the shade of this ancient tree. Quite a few people came forward to talk about Norm. It was a really good day. I grieved. I grieved for what I'd lost, and I grieved for what I lost in the accident too. It was one of the first positive experiences that I've had in a very long time.



We didn't have any children, so we had a pretty intense relationship for 43 years. I cry. I get very emotional. It wouldn't be right if I didn't, but I've found an inner calmness and I don't let things get on top of me any more. There is always a silver lining. You just have to go out and look at the moon every now and then.



Goulburn Valley Hospice Care Service Inc.



Goulburn Valley Hospice Care Service provides a range of services to care for people in palliative care, and to the people caring for them.

Hospice is a Not for Profit Organisation with deep roots in the community, and is run by a voluntary Committee of Management. The organisation promotes and develops excellence in palliative care, and is a strong member of the Goulburn Valley Community. Hospice's model of care with twenty-four hour specialist palliative care nursing support was developed in response to the specific needs of the community.

As well as specialists' nurses, our team includes allied health, and a team of dedicated, specially trained volunteers. Our aim is to help make the lives of our patients and their carers a little easier, helping them to live their lives as fully as possible.

The service has fundraising groups who work tirelessly to ensure our 24/7 model continues into the future. The jewel in our crown is the Hospice Opportunity Shop, which as well as raising money, is a place of healing for many of our carers. They volunteer to work there, and it is a way for them to help Hospice, which supported them when they were caring for someone who has died.

Our fundraising groups include, Friends of Hospice, The Hospice Car Rallye, Our Country and Western Team, The Fruit Loop Bike Ride, and Baking from the Heart. There are also many individuals who come up with innovative ways to raise money for us, and we at Hospice are grateful to them all.

If you are interested in supporting the service in any way, or would like to make a referral to the service, please contact us at:

Goulburn Valley Hospice Care Service Inc.
102 Balaclava Rd, Shepparton. Vic. 3630
Ph: 03 5822 0068
admin@hospice.shepparton.net.au
<http://hospice.shepparton.net.au>

Our Vision

A world where life limiting illness, death and grief are managed with respect and compassion.

Our Mission

Our mission is to lead, promote and develop excellence in Palliative Care.

Our Values are:

Respect

We respect each other, our patients and their carers, and respect their right to have a choice

Trust

We trust in each other and will show trust in those we serve at all times

Teamwork

We value each other as team members, providing support to one another, working cooperatively and respecting each other's views. We value working with other providers. In particular we see ourselves as part of a team with our patients and their carers

Dignity

We treat everyone as someone worthy of respect and maintain their dignity at all times

Belief

We believe in each other and the value of what we do and we believe in the capacity of our patients and their carers

Our Objectives are:

- To provide access to community based palliative care 24 hours a day, 7 days a week
- To provide Palliative Care at point of service free of charge
- To support the needs of our patients, to limit pain and distress
- To assist terminally ill persons to die in their place of choice
- To support and assist family and friends throughout the illness, death and bereavement
- To provide a comprehensive service, that is integrated with all appropriate community services. In particular specialist medical, nursing and pastoral care, bereavement counselling and volunteer support
- To provide care in accordance with individual needs and wishes
- To recognise and respect cultural and religious beliefs in relation to death, dying and bereavement.
- To demonstrate a strong commitment to education, both at a service and community level





What we provide

Community based twenty-four hour, seven day a week support from a Specialist Palliative Care Team for residents of the City of Greater Shepparton, free of charge. This includes:

- Nursing Care including pain and symptom management
- Bereavement Support Program
- Family/Carer Support Program
- Volunteer Support Program
- Equipment loan free of charge.

What can a patient expect?

- Safe and high quality care that is provided by skilled and competent staff
- Care that respects culture, beliefs, values and personal characteristics
- Open, timely and appropriate communication in a manner that can be understood
- The opportunity to participate in all decisions and choices about care
- Maintenance of privacy and confidentiality of personal and healthcare information

Who can be referred for care?

- Any person, of any age, who has a life-limiting illness, for example:
- Cancer
- Neurodegenerative disorders e.g. Motor Neurone Disease, Dementia, Parkinson's Disease
- End Stage Organ Disease e.g. Renal and Cardiac failure

Who makes the referral?

- Health Care Providers, e.g. GPs
- Family/Friends
- Patients - self referral



Thank you

We would like to thank the carers and patients who volunteered to participate in this project. The passion and love of the carers for their patients, whether they were family, friends or neighbours is demonstrated in their storytelling. Thank you for sharing the highs and lows of caring for someone who is dying. Also thanks to the specialist nurses who work with our service, our allied health team, and all the General Practitioners and other community services who we work with in the Goulburn Valley for their commitment and dedication to the person dying, and to their family. This project demonstrates that it does take a community to care for our dying.

Warm regards,
Carmel Smith

Executive Manager
Goulburn Valley Hospice Care Service Inc.



Precious
time

