

The Two of Us

Stories of people with a life limiting illness and palliative care volunteers



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Palliative Care Victoria Inc.
2/182 Victoria Parade
East Melbourne VIC 3002
T +613 9962 9644
E info@pallcarevic.asn.au
W www.pallcarevic.asn.au

Reg. Inc. No A0022429M
ABN 88 819 011 622

Foreword

Victoria is fortunate to have around 2,000 trained palliative care volunteers who support people with a life limiting illness and their families on a regular basis.

As valued members of palliative care teams they contribute in various ways to improve the quality of life of the person who is ill and to support their carers.

Companionship and respite, recording life stories, assisting with transport to appointments, art and craft activities, and support during bereavement are among the diverse activities of trained palliative care volunteers.

To celebrate National Volunteer Week and National Palliative Care Week in May 2015, we decided to 'go behind the scenes' and invite pairs of palliative care volunteers and the people they support to tell us about their relationships.

These eight inspiring stories illustrate how these are mutually valued and enriching relationships.

Former strangers become good friends, they share talents and interests, they learn from one another and they enjoy each other's company.

There is warmth, compassion, love and humour. There is respect, dignity and honesty.

They celebrate life with a heightened sense of the value of the moment, of the day to day things we often take for granted.

There is clarity about what matters most in the face of our mortality – our relationships with loved ones, what gives meaning to our lives, cherished memories and life stories.

They demonstrate how a strong community spirit and the gifts of caring for one another contribute so much to living, dying and grieving well.

Appreciation

Our warmest thanks to, John and Mark; Josh and Yasmine; Maureen and Jasmine; Patricia and Claudia; Peter and Ros; Ray, Joan and Jenny; Sigrid and Tonya, and Tamara and Carol. We greatly appreciate your generosity in sharing your stories with us.

We would also like to thank the following palliative care services for their support in bringing this project to life: Ballarat Hospice Care, Barwon Health Palliative Care Program, Goulburn Valley Home Hospice Care Service, Melbourne City Mission Palliative Care, Peninsula Home Hospice and Very Special Kids.

Thank you, Pippa Wischer, for the way you take us with you into these encounters, so we can listen as you did, with our hearts as well as ears, and see, as you did, beyond the lens to grasp the spirit that enlivens these relationships.

Pippa Wischer is an award winning visual artist who specialises in capturing authentic experiences that reflect and examine the multi-layered and interconnected aspects of our lives. She produced *The Dreamers* – a book, exhibition and videos - for Palliative Care Victoria in 2014. Further information about this book is available at: <http://bit.ly/Preview-The-Dreamers>

Odette Waanders

CEO, Palliative Care Victoria
National Palliative Care Week, May 2015

We've become friends

John Hunt, who has been deaf since birth, was diagnosed with cancer in 2013. Nine months ago, Mark Killen, a volunteer with the palliative care service Peninsula Home Hospice, offered to act as safety spotter when John worked in his workshop. They've been meeting each week since then.

John's story

When I first met Mark I was a bit unsure about how we would communicate. I gave Mark a book to learn basic signs, but we realised that maybe signing was not the best way for us to communicate and we'd use the iPad and that was a better way for us.



I think it all started because someone told me I would need a volunteer to help me with my needs. I really do rely on him, you know. I go to the workshop to make frames for the jigsaw puzzles I've done. Mark came for the first time and it was good for Mark to watch me to make sure I was doing it all okay. I think he learned a lot from me. There's one more project to go. It makes me feel good when Mark's with me in the garage and we make frames together. Sometimes I have problems with my computer and I really rely on Mark to come and help, because he's really good and fixes up the issues for me. It's great.

I'm in palliative care, and it's keeping me alive. I have cancer, so I have many appointments, almost every day really, from Monday to Friday. My daughter Faye, she knows most of my medical history; she's got such a good memory. Faye lives in the deaf world, so it's easy for us to communicate and understand one another. Sometimes if I have a problem, she'll do all the groundwork for me arranging GP and hospital appointments. She comes with me to all my appointments and visits me in hospital when I stay. She's the biggest joy in my life. It's good that Mark has got to know Faye and my family. His wife Joanne is wonderful. She has such a lovely personality.

If it wasn't for Mark I think I'd feel the lack of somebody to talk to. I talk about my family, he talks about his family; it's a discussion. It's really enjoyable to have a chat with Mark. I don't have any brothers or anyone like that; I need other men to talk to, to have a man to man chat, so it's good to have Mark to have a bit of male company and men's discussions. We talk about health sometimes. We'll talk about everything really. If I had a brother it might be a little bit different. I don't have any other male friends. I feel like Mark has stepped in as a brother.

I couldn't do without Mark. I look forward to his visits. I want him to keep coming. I definitely will need a volunteer to help for as long as I'm alive.

Mark's story

I was feeling very nervous at first, and spent most of the night before practicing all of these signs to use with John. The first day I turned up I found John to be an open, friendly and communicative guy. But it was a little bit tricky, because I didn't feel the signing was working, and I could feel that John was a little bit frustrated which I could understand, but we just persevered. Using the iPad one day, I knew I could type far more quickly than I could sign, and I just found it such an effective way to communicate. Once we got over that hurdle, we haven't looked back.

We've been meeting since July last year, and the original intent was the woodworking out in the garage. I know nothing about woodwork, so I did learn a few things, but my main purpose was to make sure everything was safe really; that was it. John knew exactly what he was doing. We went to Bunnings one time to get the timber and I wasn't sure what my role was going to be, but John managed it without any trouble at all.

I look forward to catching up with John, and I always feel at the end of it that we've both got something out of it. Sometimes we watch question time in parliament on telly and that always gives us a chuckle. At the start, John introduced me to his family through some family

videos that he had, and I had photos on my phone of my family, and that was really important for both of us. It helped to build the relationship as we were both brave enough to share that personal information.

In February, my wife Joanne and I were honoured to be invited to the 100th birthday celebration for John's wife Laura, which was fantastic. It was great to meet many of the people I'd seen on video. We were made to feel so very welcome, and it was a combination of the deaf community as well as the speaking community. It was just a great occasion.

So now when I come here, I'm not anxious about what the conversation's going to be about; I just know there is going to be a conversation. I don't think of John as being sick. I think of John as being someone who needs my help from time to time. I still try to keep it at a professional level, but we've become friends. There's no doubt about that.

I believe this relationship, this role that I've had, has definitely grown me as a person. I feel more confident in new situations, and I put it down to the volunteer training and the work that I've done with John. I feel happy that I can say that I'm helping John, but I'm getting something out of it, and that's OK. It's an important part of my life as well.



"If it wasn't for Mark I think I'd feel the lack of somebody to talk to."

Superheroes

Twelve-year-old Josh Concilia has Kabuki Syndrome and was diagnosed with Leukaemia several years ago. Five months ago, Josh's parents, Jenni and Frank, were introduced to Yasmine Luu, a volunteer with Very Special Kids. Yasmine also likes comics and superheroes and visits Josh on Sundays to dress up and play.

Josh's story

When I didn't have cancer there was always a big smile on my face. I never worried about anything. When I was in treatment I was worrying and every single day I'd wake up being scared or something. Now I feel that I've just overcome this big, big obstacle in my life and I jumped over it and I think we're going to get through it.

Sometimes before I met Yasmine, I was so sad at school that I didn't want to talk to anyone, but now people wouldn't know that I'm sad. I just talk to everyone and I'm very, very happy and want to be a great friend to them, like Yasmine is to me. I started high school this year and have new friends, sort of like Yasmine.

I love meeting new people and when Yasmine came in and we started talking to each other, I knew she would be my second best friend. Okay, first best friend! It makes me feel very special when Yasmine comes here. I even forget what I have to do that day.

My favourite play is when we have to stop these people and go back in time, even before superheroes were imagined and no one knew who they were. It's pretty weird because the time machine is kind of in Dad's man cave; don't tell him! Mainly we play with my figurines and make them go on adventures. One time we had to save Bruce Wayne from something and we ended up saving Bruce Wayne, but the sad thing still happened.



L-R Yasmine, Josh

I have this Joker costume. I love it. It reminds me of the Dark Knight when the Joker was doing some mean stuff. I like it when he does the mean stuff and is planning traps. He's very smart. Sometimes I'm evil; sometimes I'm put under a spell for a thousand years; and sometimes I pretend to be a vampire.

We're all going to Comic-Con. I have my outfit all set up. There are one or two characters that I might go as, and I'm still debating about Hell Boy, but that is difficult because my face has to be red. I like Agent 47 from Hitman, so I might go as him and wear a suit. Maybe I might go as the Joker...

My little sister Mia had this friend called Emily and I used to play with them, but every single time, I felt that I'd like a friend like that. And then when Yasmine came I knew I'd found a friend like that. Thank you, Yasmine, for being my best, best friend. You are the coolest girl I've ever met.

Yasmine's story

It was so good meeting Josh. We were talking about comic books and I asked Josh what his favourite comic book character was and he said "Deadpool", and from that moment it was "Yep. This is perfect."

I look forward to seeing Josh every second Sunday. It's super great. I like playing around and I get to share all these things that I've collected over the years. Last week I brought a collection of Harry Potter wands and we were playing around with them. Batman is the main superhero I bring over because we can battle each other which is fun. I just look forward to it all the time because Josh is my best friend too.

I volunteered overseas building houses for a while. The last house I built was with a family of 13, so I knew I loved kids. When I came back to Australia, I did a subject called Genetics, Health and Society and the Lecturer told me about Very Special Kids. I went to an info session and did the training and was given Josh as a client. It's been about five months since then. Volunteering adds to my life. I get to talk about Josh all the time when I'm out with my friends. I love it.

Josh is leaving soon for Disneyland. I'm going to miss the times we have and I don't know anyone else I'd have imaginary playtime with. I can't dress up in costume without him. If I had to dress up in costumes alone, people would think I'm weird. Josh and I saw a mask on the Internet so I bought it to wear at Comic-Con. It's a really cool rorschach mask from Watchmen. It's thermo, so if you breathe, it changes. It's very cool.

I haven't grown up I think. I like using my imagination. I've learnt never to take anything so seriously, because everything can change. Nothing is set in stone; you can always hop in the 'time machine'. It's a good analogy for life, I think.

Jenni and Frank's story

Josh missed school all of 2012 and most of 2013. He only went back part time last year and now he gets to go every day apart from treatment days. I think it was hard having missed so much school. Since Yasmine's been coming over, Josh doesn't get so stressed about going back to school and he's starting to make some new friends at school, which has just been beautiful.

The two of them have a ball together, running around the house with costumes on, with weapons in their hands, chasing each other. No time for worrying about anything while they're doing that.

Cognitively it's been really good for Josh to focus for that length of time. It's quite an intricate role-play that he and Yasmine do and that's been really good for him. If we asked Josh to go for a run, he wouldn't be able to do it, but he and Yasmine can run up and down those stairs ten times. There are just so many added bonuses and benefits that we could never have anticipated. The rewards are just overwhelming.

Yasmine's friendship with Josh is unconditional. She does everything, and is confident to do it, and not too worried about what we think. She'll just play with Josh and have a great time, running through the house, and I think that's just absolutely beautiful.



"Thank you, Yasmine, for being my best, best friend."

We solved the world's problems!

Len Boorman received palliative care from Melbourne City Mission. Jasmine Humphreys volunteered to act as companion to Len, and to give respite to Maureen, his wife and carer. Len died six months ago.

Maureen's story

Len and I met on a blind date; I was 17 and we got married when I was 19. We would have been married 58 years in February. I feel very privileged to have had such a lovely husband as I did and very grateful that we had all those years together. We've had a wonderful life. He was a very positive man and didn't let things beat him. He had the triple whammy; losing his sight, all the operations he had on his bowel, and then the cancer. So he did have a lot to contend with, but he never lost his sense of humour except when he was very sick. He was always making us laugh.

When someone you love is hurting, you try and help. You just do it.

Len died six months ago now. We were fortunate that we knew the journey that we were on, and we knew that Len wouldn't recover from this cancer. He wasn't frightened of dying. We had time to talk things out, to find out what each of us wanted. I held him as he passed away. I went to pieces afterwards and I don't think I could have done it without the help of all these lovely people at the hospice.

We first met Jasmine a year ago. It wasn't like meeting a stranger and the three of us hit it off. It was special; really special. Jasmine was so important to Len, because it meant he had something to look forward to, someone he could talk to about whatever he wanted, including his first love, the sea, and he'd tell her all sorts of things. Having Jasmine here, I was able to leave the house knowing Len was perfectly all right, and Jasmine knew what she had to do. We were very lucky.



L-R, Jasmine Humphreys, Maureen Boorman

There's only certain things you can say to your own family, but if you've got someone like Jasmine, if you want to open up and cry you can do it, whereas you really don't want to let the family know how it is affecting you because it makes it worse for them because they're suffering as well. The feeling that Len had was that Jasmine wasn't just a volunteer coming in, but he felt that she was an extended part of the family.



I think Jasmine is such a good listener. She is such a calm person. She's very special. When she came in through that door, so peaceful, I noticed Len always had a smile on his face when he saw Jasmine. He was a different person when she was here. I felt good just having her here. It's her vocation.

I'm not frightened of dying; I've had a life. I've had a good life with Len. I miss him so much. When my time comes, I just hope I don't suffer.

Jasmine's story

It was a perfect match, because not only was Len an Englishman like my father, but they were both in the Merchant Navy and when I heard this, I had a goose bump moment.

I wish I'd spent more time with my father and listened to all his seafaring stories. Every week I looked forward to having Len tell me more about his stories. I guess this is why I was able to really engage in the conversation because I was genuinely interested. But not only that, we did solve the world's problems, you know.

I went away for three weeks as my aunt was dying in Japan. I wasn't the primary carer but my mother was, so I went to support her. After I came back, Len had really deteriorated. It was very sad, and although we expect it, we know we are in this role because we want to look after people, but it still is sad in this situation. So over time the role changed. At first it was companionship but then he was not fit enough to be engaging in those conversations anymore, so it became more about companionship with Maureen I think. The role slowly changed in that way.

It's a very rewarding role. I started the training about two years ago now, so compared to some of the others in the field I'm still a baby, but it enhances my life. Every connection is different, but I learn so much about life, about what is really important in life. Not many things out there are, but I think we lose sight of that and being able to engage with clients in this special way, I think I'm the winner rather than the other way around.

I was also the recipient of palliative care back in England and I watched how it was done, and I was totally impressed. That's how I came into the program in the first place so I knew if I was nervous, an emotional wreck, it just wouldn't work, because you are in that role to support the family, not to join in, in their emotional ups and downs.

We tackle this question of death very differently; each one of us has a different path to dying, and different ways of dealing with it, or not dealing with it. Len was very grateful, and when you have that sense that someone is grateful, it makes it so much easier for the carer.

When I heard Len had died, he was in my thoughts for the whole week. It's not easy for us either. You still feel sad, but my connection with Len was so strong, that I felt more privileged that I had had the opportunity to meet Len and Maureen. Every volunteer would tell you that there are always one or two special relationships that you have, and I have no doubt in my mind that Len was definitely one of them. I learned so much from Len. The way he lived his life was very inspiring.



"...you are in that role to support the family..."

We clicked straight away

Pat and Claudia were district nurses in Victoria, and both love playing golf. They met a few months ago when Claudia, a volunteer with Peninsula Home Hospice, offered to visit Pat once a week to give Pat's husband Kevin some respite. Pat was diagnosed with Motor Neurone Disease four years ago.

Pat's story

Kevin and I were living in Tura Beach near Merimbula. We lived on the golf course and I drove a golf cart. It was a good life. When I was diagnosed with Motor Neurone Disease, we decided to come back to Melbourne.

Our two sons live near here and our daughter Sandy who lives in Canada has just visited for a couple of weeks with her two little boys. It was wonderful, we really enjoyed it. By the time she can get out here again, if I'm still here, I might not even be able to communicate with them, so it was good having that time. I've just got to look at all the good things that have happened in my life and just go with that; not worry about what's down the track. That's the way I'm looking at it.

We only met a couple of months ago, but Claudia and I clicked straight away. Claudia plays golf now and has been a district nurse, so it's great to be able to talk to somebody who's got similar interests to me. We talk football and sport and families. I don't see the point in talking about death and dying. We just talk about the happy things.

"I can't get down because it will drag the whole family down."

I think my father was like that too. He got prostate cancer and he got it in his spine and he ended up almost a paraplegic and he just accepted it. I think I've got a lot of my father in me now. When I was diagnosed I thought, "Crap happens." I can't get down because it will drag the whole family down. Nursing has probably helped because I had more of an understanding but I don't think it's had a big impact on how I've dealt with it. I think it's just me. But I do hate being cared for; I love being the carer, but you can't do much about that. We've all got to go somehow, but I've drawn the short straw unfortunately. I'm lucky I was as old as I was before I got it. I could have had it while I was young and missed seeing the kids grow.

A good friend of mine knew someone who went to Switzerland to be euthanized only a month after she was diagnosed. I think that would be really tough on the family; a tough decision to make. It's not something I'll even consider.

Kevin had a knee replaced three times and his other knee's now packing up. I was running around after him for years, so now the role's reversed. But he's very determined and he'll keep doing it as long as he can, but it worries me. When Claudia comes over, he quite often does the weekly shopping, takes himself out and has a coffee and catches up with our little granddaughter. It's good because it gives him time off not to worry for a while.

I really appreciate all the time Claudia's gives me. It's great; she's become a friend. We have good laughs and good talks...and wait until Richmond plays Geelong!



Claudia's story

I've only been coming a couple of months... it goes quickly when you're having fun. Pat's a cricket wiz as well, which is fantastic. Not long after we first met we were watching the cricket and Pat was telling me all the stats. But she'd still rather be on the golf course.

It's been very rewarding for me and Pat's husband Kevin knows Pat and I share the same interests and so he can go off and have a coffee or go to the physio. He's injured at the moment, but he's an old farmer and very stoic.

I'm staggered at Pat's acceptance of her diagnosis and her situation. She's just amazing. She probably does feel angry at times, but she's philosophical about it. She's grateful for the life she's had rather than ungrateful for what's happened to her now, which is pretty stunning to me. We really hit it off like two old pals. It was almost like it was predestined that we meet each other somehow.

We don't talk about death and dying very much. Pat's not really interested in that. I reckon Pat's got this innate ability to deal with it, and I'm pretty inspired by her really. There is very little we can do together, but we never run out of things to talk about. I think Pat enjoys me coming as much as I enjoy coming here.

When I was district nursing, I met these wonderful volunteers who'd come and sit with people. I put that on my list to do one day and a few years after I finished nursing I did my volunteering course. I've been doing it since 2003. You have to forget you were a nurse; that's fairly important. When you're a nurse, you're doing tasks, whereas when you're a volunteer, you don't have any particular tasks you have to perform, so you learn to just be with a person and to let them decide what they'd like to do with you, and I just fit in. I've done lots of different things with people and it's all been good. Being with Pat is lovely. I'm in clover.

I was getting to the point where I thought that there are other things I could do instead of volunteering. When I started seeing Pat, it renewed my enthusiasm for volunteering and giving back something. Being with Pat has changed me in subtle ways. The way she behaves, is a good lesson for me. So I try to be a bit more patient. I've been fortunate that I've got to this stage of my life, so it makes me feel very privileged really.

Connecting through art

Peter Hinchliffe was admitted to palliative care over six months ago. He met Ros Pollard, an artist and a volunteer with Barwon Health, when she stopped by for a chat. Peter has been inspired to paint and draw since then.

Peter's story

I was admitted here for palliative care over six months ago, and Ros came in for a social chat and to help. At the time I thought "Everyone, please leave me alone." Nine times out of ten you haven't processed it yourself and that's all part of this journey, I guess, but Ros offered the art side of things, which has been good.

I've got some brain tumours and it was good to push through that and make shapes and things. Initially that was difficult, but it is a helpful exercise and good therapy. Ros would bring out a new box of pastels and I quite enjoyed it. It's a good barometer of how I'm feeling, and the meditation and breathing exercises Ros does helps with the pain too.

We got everyone drawing, which was fun. I used to love it when I was seven or eight, and my mother used to have art books. In the hospital, everyone, including my family, started having a go. Everyone's first thoughts were, "I can't draw" or "I'm embarrassed to do it." But once they got started, as my niece said, "This is so absorbing." My family and many of the nurses contributed to it too. Ros has got the knack of getting people into it.

Some weekends I've been dead tired but I just keep pushing on a little bit and keep on enjoying it. Otherwise it would be a sit on my bum kind of weekend. With the brain tumours, it's hard to see sometimes, and it's good that I can concentrate and know that I am making things work again.

It was funny how the drawings brought out childhood memories for my family. One sister commissioned me to do our horses and dogs, so they brought the memories back. And my family seem to appreciate them too. It is good for a lot of reasons.

With the physio and therapy I'm stronger and more independent than I was when I first arrived. Hopefully, I can build my strength up more, become independent and walk out the front door. I normally live on a farm where I'm in amongst the seasons.



Ros's story

I've been coming to see Peter for at least six months and I've followed him around as he's been moved from palliative care to various other facilities before he was moved here to rehab. I'm a volunteer, so I enjoy meeting people like Pete and spending time with them, so I don't mind if they don't do the art activity. It's more about just offering it, because you can spend a lot of time in a hospital room and you haven't got much else to do except think about your situation.

In 2009, I spent 5 months as a long-term patient in hospital with a life-threatening condition. I did have a lot of time in the hospital room for reflection. When I left hospital, I decided to go and study this art therapy I'd come across.

My biggest aim is to spark that bit of joy in people, no matter their circumstance. So I thought if there's a more enjoyable way of getting people doing something, I think that could be healing in itself. The art therapy is also good for my own health, and it's a little more flexible than childhood teaching, which was my previous career. Art therapy with a holistic focus is something that I'm really passionate about, and I'm now studying Fine Art.

Initially Pete had some finer pencils and then we brought in some pastels. They help his hand-eye coordination and it's a good activity for the brain, as well as enjoyment. It's about having a go and not expecting too much but just enjoying the process of getting something on paper.

Every drawing has a story behind it as well. One of the nurses drew her home town from the Philippines and as she's a long way from home, it was expressing what was important to her. I've found that especially if you've got a few worries, if you start doing a piece, your body can just relax and it's like a bit of a meditative state I guess. Often we judge ourselves so harshly. A lot of unconscious thoughts can come up once you've got something on paper too, reminding you about other times, or family, or whatever. Even trying something different is good. And if someone's a bit unwell, sometimes people don't know what to say, and this gets them opening up and chatting.

Peter and I have sometimes done a bit of relaxation and meditation. I'm quite humbled to sit with people who are going through a hard period in their life. It's nice to help them through difficult times; it's really rewarding being really present and offering kindness to someone else. I guess when you have a little understanding, even though every person is different, you can relate to each other.

L-R Peter Hinchcliffe, Ros Pollard



The positives in our lives

Ray and Joan Senior met Jenny Sim a year ago when she started visiting them as a volunteer from Goulburn Valley Hospice Care Service, to keep Ray company and give Joan some respite.



Joan's story

The hospice wondered if we'd like a volunteer to come and see us and it was the best thing that ever happened to us. It's been marvellous. Jenny's been like a daughter to us. She's done so much for us, and has a heart of gold. She's easy to talk to and she's taken me to appointments and shopping. It's been really amazing.

A year ago we'd been told that Ray was dying, so here we are. It's affected all his muscles, so it has been terrible for him. We've been married 32 years and I love the man so it hasn't made me feel happy to see him deteriorate like this, but we do the best we can. He's still got his brain working all right and he knows his family and gets enjoyment out of seeing them, so that's been good.

Ray was the fifth in a family of seven and we get together once a month and we have a lovely time talking. We used to go out to lunch but that's beyond us now, so they come here and bring plates of cake and have a good time. So we've got a lot of positive things in our lives. It's not all gloom and doom.

Having Jenny here is a great joy. I can't begin to tell you how much I love her. She means more to me than a friend. I asked Jenny one day, "If Ray goes before me, will you still come and see me?" She said, "Of course I will." I thought that was pretty special.

Ray's story

I've never been a great believer in religion, but I've always said, if God exists, he'd come down one Sunday and have a barbeque with us.

I've got mitochondrial myopathy, which is very rare. I played tennis until I couldn't run, and I played golf until I was having trouble walking. Then I played bowls for two years until I started falling over and people were picking me up off the ground and standing me up again, so that finished my sporting life. I got to 83 but don't think I'll make a hundred.

Jenny lived for a while out at Dookie, and I was born and bred on a farm five miles from Katandra West, so we knew a few people in common and that made it easier at the start. Jenny looks after Joan very well. We both have doctor's scripts to get and we need somebody like a taxi driver. If Joan wants to go anywhere, she's only got to ring Jenny and she'll be there.

On Thursday I get locked up again for a fortnight! I've been into the aged care home to give Joan a bit of a break, but I go into a hospice this time. I get a lot of rest there. The nurses are so kind. It's their job, but they do it well.

Jenny's story

I was nervous when we first met, as I was just starting out as a volunteer with the hospice. But it's been lovely. Ray knew my in-laws, and a lot of other people we know. I didn't actually know Ray, but I knew his brother Neville, who was a truckie.

I think we're all pretty lucky that this has worked as well as it has. It's been over twelve months. We didn't think Ray would still be around now, but he's a tough old thing; a bit of a miracle. It has been hard, but he still has his sense of humour. As an Essendon supporter, he has to have a sense of humour!

Occasionally I take them shopping or to appointments but usually we just sit here like three old things dissecting the world. When Ray goes into the hospice, Joan and I will go out for lunch one day, and I'll go and see Ray. It's good for Joan to have a rest. Last time Ray came home from hospice brighter, as if he'd had a holiday.



L-R Jenny Sim, Joan Senior

Ray and Joan are two beautiful people who have become my friends. So it's gone from being a support role to a friendship. It really is just like having mum and dad back. I just love these two. They're very much part of my life now, to the point where my kids ask after them. It's probably not the normal hospice volunteer relationship I think, but ask me about that in a few years' time.

It's given me a different focus, I guess. I was a nurse many years ago, and I've always enjoyed helping other people, doing lots of volunteer work. I wanted to do hospice support for a long, long time, but I never, ever thought I'd enjoy it as much as I do. It's a very special relationship, and it's a very special time for me. So when Ray does go, eventually, and it'll probably be another twelve months the way he's going, I'm going to be heartbroken. But I'll still be here for Joan. Always.

I had a girlfriend who died of cancer when she was in her thirties. Hospice sorted her out and her family were just brilliant. She told me she wasn't going to see me again and she told me what to wear to her funeral. On the day of her funeral, her 8, 12 and 14 year old children were outside playing, and it was just so much better than any death I'd ever had anything to do with before, and I instantly thought, "I want to get involved with that." So now I'm retired and I've got time, I can do it. And love it. It's like putting something back, I guess, feeling useful when I'm perhaps not as useful as I used to be. So it's because of Jo, and the bright red outfit I had to wear to her funeral.

"It's not all gloom and doom."

Life story

Sigrid has been sharing her life story with Tonya, a palliative care volunteer at Barwon Health over the past 5 months and creating a valued legacy for Sigrid to give her family.

Tonya's story



Sigrid's story is inspiring - she came out from Germany during the war and had all these amazing life experiences. It's a beautiful process hearing about the life she's had, hearing her words and feelings, and the way she is so selfless. She thinks about her daughter rather than herself, and wants to leave her this legacy of her life's story. When you think of palliative care, these aren't necessarily the things you conjure up at the end.

My first husband passed away five years ago from stomach cancer, and he was only thirty-five. After going through the process I went through with palliative care, with the help and support they offered me, I wanted to give something back. I'm in a place now where I feel comfortable helping people like Sigrid. I can identify, in part, with what they are going through, their families and loved ones, so it is really important for me. It's something that I love to do. I love poetry, I love writing, and thought this would be a really good fit.

I think it's giving me a purpose. I'm very passionate about this now, very passionate about helping children and families going through this. I'm setting up support groups for wives who've lost their husbands. It's been life changing for me, but in positive ways. It's great meeting beautiful people like Sigrid, because in palliative care and those end stages of life, there is amazing clarity that comes when you face your own mortality.

Sigrid's resilience, her strength her dedication to her family and her humility are very inspiring. It's an absolute privilege to hear her story.

One of the things that struck me about this is that when I first met Sigrid, she was a total stranger, and then all of a sudden, this total stranger is telling me the most intimate details of her life. You can't help but sometimes strike up a relationship with them, and Sigrid and I are now friends and continue to catch up.

Sigrid's story

I was introduced to palliative care through my doctor. One of the nurses explained to me my options, and asked how I wanted to be looked after. I said that when it gets that bad, I don't want to be at home any more. So I've been in the hospice for six months, I have made friends and I feed the birds. It only took a day to settle in.

I don't mind at all talking about death or anything. When the time comes, it comes. Look, what I've done wrong, I've done wrong - I can't turn the

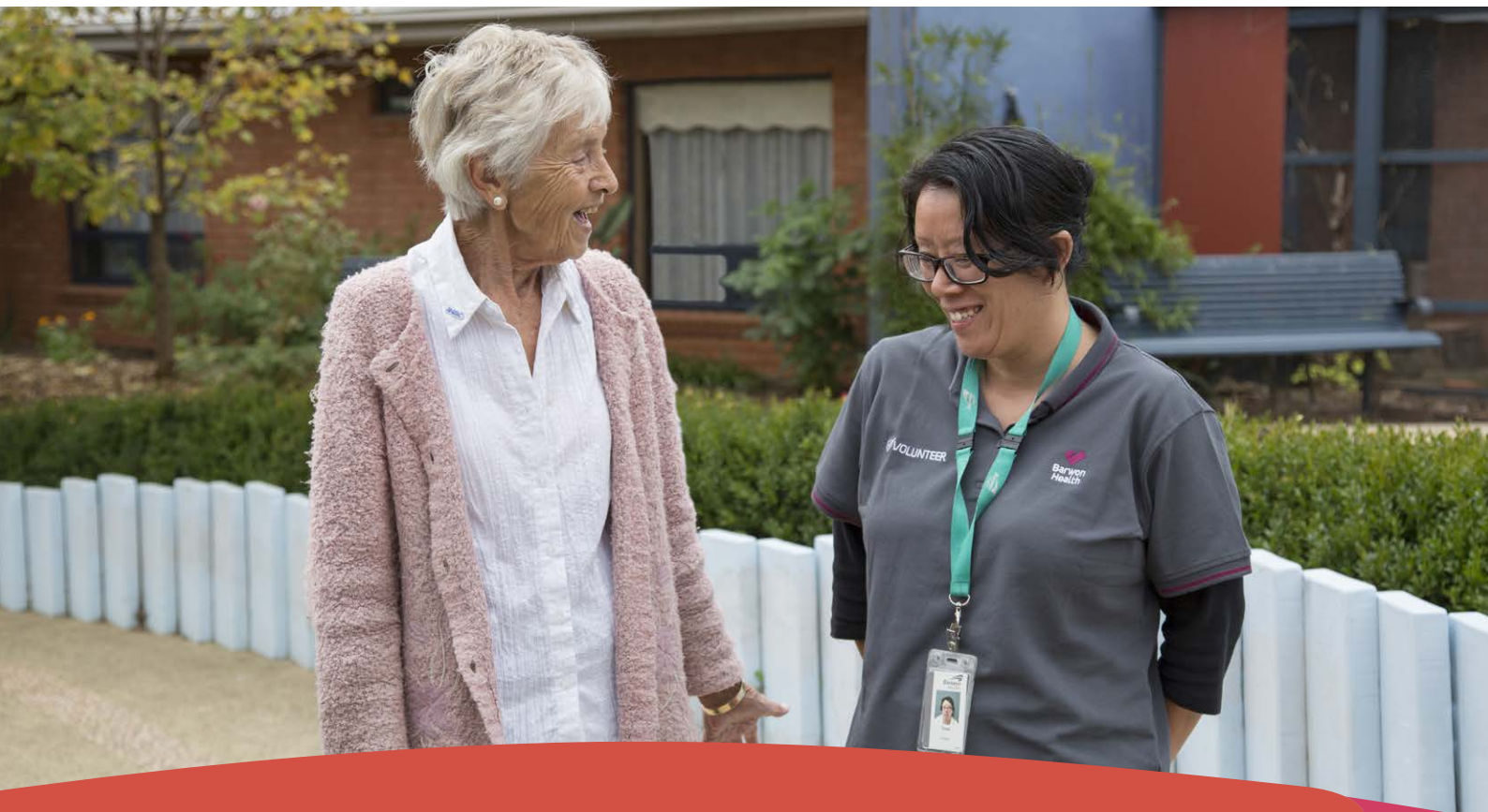
clock back so I hope God will forgive me. I have a strong faith and it's very comforting. I want to be cremated. I said, "For heaven's sake, don't have a celebrant who doesn't know me from a bar of soap standing up there and saying how wonderful I was." I don't want that. I want something very low key, and they know that, so as far as those things are, they're sorted.

I seem to have known Tonya forever. We got on very well, right from the beginning. We talked and covered, oh gosh, virtually my whole life history that I can remember. It was a good thing too because there are probably things that my daughter doesn't know, and she's the only one left. She's been wonderful to me. I lost my oldest daughter with ovarian cancer; they were both absolutely amazing girls. My marriage was good. I had a very good husband and they used to call us "the honeymooners" even when we had been married over twenty years, but it wasn't enough time. When I look back, I find it strange that all down my line, from my grandmother onwards, we all lost our husbands.

There were downs, of course, but there were also a lot of good things. I think the story of my journey more or less shows my family what I believe, that I'm not scared, that I do the best I can. The hard times, the disappointing times become rather unimportant as you go along. I want it to be uplifting and I'm very excited about recording my life story now.

I wish to thank Tonya so very, very much and I'd like her to know how very much it has helped me, and how much it will help my family when I'm not here. Somehow she dug it out of me; I don't know how, but being able to talk to her has been a tremendous help. Just meeting Tonya was a comfort in a way because I made a friend.

Sometimes I feel quite guilty. I'm sitting here and I'm so content. I have my music and I'm doing a bit of crochet. Everybody that I've come across, they've all be absolutely amazing, but Tonya sticks out; of course she does. She has done a lot for my children, and my grandchildren. They can say "That's Granny's life", so it's all good.



"I think it's giving me a purpose.
I'm very passionate about this now..."

We look forward to Tuesdays

When Tamara Elisha was no longer able to drive due to treatment for cancer, Ballarat Hospice Care sent volunteer Carol Scott to help Tamara get around. It's been a year and even though Tamara is driving again, they still see each other every week.

Tamara's story

Carol was assigned to me as a volunteer by Ballarat Hospice Care because I couldn't drive for a while. I remember we met at the Wellness Centre and I was with my mum and I felt that we got on straight away. Carol's volunteer role was to drive me around and run errands, so each Tuesday if I had to go anywhere, Carol would drive. It's been great. I've really enjoyed it. I'm driving now and the Tuesdays have become less busy but I'd really miss Carol if we didn't meet. It doesn't feel like a year.

Bunnings is a regular spot for us. At the moment I want to do something with the laundry floor, but I can't quite figure out what I'm going to do, whether to paint the floor or put tiles or lino down, so we gather samples and I have a think about it. It will have to be something really easy because I'm not a tradesperson. I reckon anyone can paint the floor, and you can get these tiles that you stick down and that's pretty easy.


I was diagnosed with cancer in October 2013. It's been pretty amazing finding out what's available. You just have to hook into the system and there are so many services out there to help people. It's pretty great. With Carol, when I wasn't driving, it was really helpful. I really like Carol and I look forward to her visits. I haven't needed volunteers in my life before my diagnosis, so it's a bit different for me.

I've had my dog Lammy since he was 2 months old; he's 12 now. He's my family. He keeps me company. A little while ago I had to board him in a dog kennel, and the one I chose is right on the highway. I had huge anxiety about getting onto the highway, so Carol showed me how. We must have taken the same route about thirty times until I got comfortable!

A couple of times I wasn't doing too well and Carol stepped right in and took me to the doctor. I've got another scan result on Thursday, but I'm trying not to pre-empt it this time; it doesn't help. This time it shouldn't be too bad.

Recently I've gone back to tap dancing and I'm really enjoying the classes. They're not hard steps; they're pretty easy exercises and they do a lot of repetition. I haven't actually got tap shoes yet but I'll be doing it as long as my body holds up.

I've always been the kind of person who joins groups, and since my diagnosis I've had to slow down. There are a few groups I go to; the dancing and the cooking. There's a meditation group that also sounds like a healing and support group that I want to go to, so I'm just starting to find my way out again. People are very caring and it's nice to have that in your life. We do need that type of energy when you're going through something like this.



"Recently I've gone back to tap dancing.."

L-R, Tamara Elisha, Carol Scott

Carol's story

I've met some beautiful people, Tamara included, and I still remain friends with families even after their loved one has passed on; you just build a rapport with people. There's a lot of trust when you walk into their house. It's just fantastic and you can give of yourself. I enjoy it. You've got to place yourself with each person, because you're dealing with different scenarios. At first, you're always apprehensive because you don't know the people and you don't know personalities, so you always walk in on eggshells. But you soon get to know the person. I do enjoy being with Tamara.

Tamara and I have had lots of fun; we've had lots of laughs and she's taught me a lot. She's shared her faith with me, when I was going through that rough time with my old dog Wally. It was lovely for Tamara to say that she'd pray for Wally and me. She didn't have to do that, so in a little way she'd teach me to share more. She's taught me all about op-shops; we love our op-shops. And I remember when we bought the fluffy polar fleece sheets. Tamara was a bit unsure about it, and then she blamed me because she didn't want to get out of bed!

I was really excited when Tamara got permission to drive again as having the car makes a difference. She's brighter, not as down. It's a good thing. I think she's got better control of her pain too, and that makes a really big difference.

I was a Div. 2 nurse and a really good friend of mine had a major stroke and he ended up in a nursing home. He knew what was going on but he couldn't communicate. I decided to quit and put a room on and brought him home. He was such a good friend when I first moved here, and I thought I've got to repay this man, so I did. Hospice was great and they would come out and check on how we were going. They were just brilliant and nothing was too much bother. I had a volunteer come out once a fortnight so I could go and do all my chores, and when Fred passed on, I knew how grateful I was for the support, so I thought 'What am I going to do with my life now?' and that's how it all started.

I've got a crook back, and when I was working, the only thing that kept me going was massage. When you're on a pension, you can't afford all those luxuries so you just plod along. I know it sounds stupid, but volunteering puts you on a plane where you get away from feeling, 'Woe is me' because you're doing something, and particularly when you've got a good rapport, it's special. I think, 'I've got nothing to worry about. I'm having a good day today.' I enjoy Tuesdays. I look forward to it.

About Palliative Care Victoria

Palliative care helps people with a life-limiting illness and their families to live, die, and grieve well.

The aims of palliative care are to improve the person's quality of life, to promote dignity and comfort, and to support family and friends involved in their care.

It can help people of all ages and with a wide range of conditions, such as cancers, chronic diseases, dementia, and degenerative conditions.

Trained palliative care professionals include doctors, nurses, physiotherapists, occupational and speech therapists, counsellors, social workers, other staff and trained volunteers.

Whole person care

Palliative care looks after the whole person including their physical, social, spiritual, emotional and cultural needs.

Help is available to discuss and share goals and choices about future care and other arrangements, as well as getting legal advice, financial assistance and other information.

Palliative care assists you to be at peace with yourself and those you love. It can be very helpful to talk about fears, feelings and any regrets, especially with those close to you.

Many people find this is a time when they think about the meaning of their life. Palliative care has counsellors and spiritual care workers who can assist.

Support for family

Palliative care also gives practical and emotional support to family and friends. This can include care advice, equipment, a break from providing care, carer support groups, and counselling.

Where can I get palliative care?

Most palliative care is provided at home by a community palliative care service. It is also provided in a hospital, a hospice (a special unit that provides palliative care), or other health or care facility.

Ask your GP or contact your local community palliative care service or Palliative Care Victoria.

Do I need to pay?

Most palliative care services are free, although private therapists, some hospitals and hospices may charge fees. If you are unsure, ask the palliative care team.

How do I get palliative care?

You or your GP or a family member or friend can contact a community palliative care service directly.

A referral from a doctor is needed for admission to a specialist palliative care facility (sometimes called a hospice) or hospital.

“It can help people of all ages and with a wide range of conditions...”

Palliative Care Victoria

Palliative Care Victoria can help you find a palliative care service and provide information about palliative care. We can also link you to other helpful information, organisations and services.

If you wish to speak in another language, let us know and we will arrange for a telephone interpreter.

Free call: 1800 660 055

Phone: (03) 9662 9644

E-mail: info@pallcarevic.asn.au

Websites: www.pallcarevic.asn.au
www.pcvlibrary.asn.au

Palliative Care Victoria was established as a charity in 1981. We work with government, palliative care services and other groups to enable people to receive high quality palliative care when and where they need it.

We want more people to know about palliative care, and to help the community deal with life-limiting illness, death, grief, and loss so they can live, die and grieve well.

You can download a useful free booklet about palliative care from:
<http://bit.ly/Living-dying-grieving-well-booklet>

Call us for a free printed copy.

We also welcome inquiries from people who are interested in becoming palliative care volunteers and will link them to relevant palliative care services.



