

# The Two of Us

Stories of people with life limiting illness and palliative care volunteers



**PalliativeCare**  
VICTORIA  
Living, dying & grieving well

# Serenading the fish, enjoying life!

Nino brings music, laughter and life with him when he spends time with his new friends at Anam Cara twice a week. His best mate is Mandy who says volunteering at the hospice has transformed her life after the death of her mother.

## Nino's story

*I do better when I come here to day hospice.* I can bring a guitar and play music and sing. Sometimes I tell jokes, and I serenade the fish! In springtime, the fish fall in love, so I sit near the fish in the tank and I serenade them. In Italy I sang in a choir in a church. I also used to serenade the girls. You never stop laughing.

Last year the manager Tessa came to my place and asked if I wanted to come here to stay for a couple of nights. It was fantastic. Mandy brought me coffee and tea and she would make sure I was okay. I have sore legs and they're weak because I have prostate cancer, so Mandy helped me to get into my pajamas, and to get into bed. Nice room. Warm. In the morning Mandy woke me up with a cup of coffee and she helped me to get dressed. They all treated me very well.



After that I started coming to day hospice once a week, but I enjoyed it so much I would come twice a week. Now the only time I miss it is when I have to see the specialist.

My wife Elena looks after me. Three times a week someone comes from the council to help me shower, which makes it a bit easier for us. My daughter Nadia is a nurse, so she does all the organisation and the paperwork. My wife understands English well enough to answer their questions over the phone, but it's too hard on paper; too many papers, and too complicated.

I love coming here. As soon as I arrive here, Mandy brings me orange juice. And after lunch she brings me a black coffee. She's very good to me. She's my best mate. And Tessa is good to me too. I can ask for anything and she'll get it for me.

We all get on well here. I was miserable at home and here I am happy because I've found all these new friends. I come here and I feel good. Someone said I bring life here, because I sing. That's who I am. We make things, and play games too. It's good to smile and be happy.

*I can't wait for Tuesdays and Thursdays. I don't have to think about it, but there is always something to do, and it's always something different. I don't think about my troubles or being sick. When I come here, it's like a new life for me. I wish it were three times a week. It's like paradise here.*





## Mandy's Story

I remember Nino's smile the first time I met him. He loves a chat. He's always ready with a smile, and is very friendly. He comes here twice a week when we have day hospice. Everyone loves him. He's very special.

*I love seeing how happy the guests are when they're here, and being able to help them. Sometimes it's just a matter of sitting with them. To me it's a privilege to be here and to help. I love it so much.*

The hospice has been a lifesaver for me. We live just down the road. One day my sister and I brought mum down to have a look, and she loved the place. We knew straight away that this place was special and mum said she would be willing to 'give it a go'.

The first time mum stayed for a few days was to give us a bit of a break. Then mum went to day hospice. She loved it. She said it was homely and friendly; she used to call it 'The Windsor on Yarra Street'. It's better than that, because it is full of love and care. It's a beautiful place.

While mum was coming to day hospice, the managers Sue and Tessa asked me to help out. I really enjoyed it and gradually learnt different things. When mum did die, I wasn't really quite sure what I wanted to do. Then Tessa talked me into coming here twice a week. It was the best thing I ever did. I just love it.

I didn't have any self-confidence before I started here. I found it hard to speak with other people and I couldn't look them in the eye. Tessa has taught me a lot over the last few years, I did some training and that's given me a lot of confidence away from here as well. I now walk with my head up when I'm walking down the street. I've learnt that it is okay to say what I think, and to talk to other people.

It's given me another purpose. I really look forward to the two days of day hospice, and doing a bit of respite with the beautiful Nino.

The guests can come and they can just be themselves, and the focus isn't on their illnesses. They can come here and have a bit of fun, or be a bit quiet, or even be a bit sad. It's not like being in a hospital; it's more like a home.

*It can be challenging for me when the health of a guest deteriorates. It can be heart wrenching at times, but it can be beautiful too. I don't believe you can care too much, as long as you keep it in perspective. There are people here I can talk to if I need to. It can be a real privilege to do this work. I get a lot out of it. It's been great.*

# Amber gives everything a go!

Amber is 6 years old and loves singing and dancing. She also has a rare form of Leukodystrophy. Yvette, a volunteer with Very Special Kids, comes to play with Amber, and offers invaluable support for Amber's mum Jenny.

## Jenny's Story

Six-year old Amber definitely gets her point across. She uses a special communication book and is at the 'why' stage, asking questions like why can't I walk, or why am I in pain? She's clever and understands everything that's going on around her; she just can't speak.

Amber has a rare form of Leukodystrophy. There are less than 100 cases in the world, and she's the only one in Australia. Thank heavens for social media as it allows me to keep in contact with the other families overseas.

I was invited to give a talk at Very Special Kids about what it is like to have a child with a life limiting condition. That's when I met Yvette, a trained volunteer with Very Special Kids.



L-R Amber, Jenny

It's nice for Amber to do things with Yvette. Yvette and Amber go for walks, read books and do crafty things. Yvette takes her to dance classes, which means that I can do something else, or I can be there like any other mummy and watch my kid dance. *It allows me to have a different experience, to be a mum, rather than a carer or a nurse. Sometimes I just want a break. Volunteers like Yvette make a big difference for us.*

Amber's vision is going, so I'm giving her as many experiences as possible. I go a bit crazy with things like birthdays. We have huge parties and invite all of Amber's class and most of them will turn up. As her vision gets worse, it will be something special that she can remember.

I've had a bit of a reality check in the last 12 months. Amber hasn't been super sick, but her pain is becoming an issue and her medications are not working as well. When two kids overseas with Amber's condition died recently, it made me realize there is no magic cure as yet.

People don't like it if I talk about death, but I need to accept that this is a potential future. But that doesn't mean we stop living.

*Amber loves doing things just like any other kid. She loves singing and dancing in her own way. I love how she will give anything a try so I've got no excuse.*



L-R Yvette, Amber

## Yvette's Story

The first day Jenny's mum had organised a princess theme for us as a way to get to know one another. We started off reading princess books but it quickly turned to farts! Amber loves anything to do with the body and body fluids, and she finds farts hilarious. So then we played 'Gas Off'. Jenny got the game to help Amber with counting, but you can't get Amber to stop laughing enough to count! So time blew by pretty quickly.

*Amber loves books. I'm always reading them to her. She doesn't like the really girly-girly ones, she likes the Princess Smartypants, dragons and pirates. There is a fun book with girl pirates we read often. One of the joys is seeing Amber's luminous smiles.*

I love dancing with Amber too. The dance class we go to is really good fun. Taylor Swift's Shake It Off is one of Amber's favourites. I used to be a dancer so I think it's great.

Very Special Kids thought Jenny and I would get along well. They were right - Jenny's a nurse and I'm training to be a nurse and we have a similar sense of humour.

It's hard hearing when Amber isn't well, but I'm also concerned about how Jenny is. Our open conversations, those great debriefs, help me to hold strong. It's a great way for both of us to work out how much support she needs. We're very lucky that we've got such a great relationship as it really helps to support Amber in the best way possible.

I've always wanted to volunteer. Very Special Kids had a nine-session training program that was very helpful. I've learnt a lot about myself. I'm definitely stronger than I thought I was. Now, facing the prospect of palliative care, in my nursing, or with Amber and Jenny, I have lot more strength, and a lot more knowledge.

*I never thought I'd get as much out of it as I do. I just love it. I recommend volunteering to everyone I can because I've found it to be very personal. The reward of building relationships with people like Jenny and Amber has been amazing.*



# Someone to yarn with

Ian's close friendship with Peter, a trained palliative care volunteer, developed after Peter started to visit once a week. Ian is a retired farmer/grazier who now lives with his daughter Bec, who cares for Ian while they manage his kidney, liver and heart diseases.

## Ian's Story

The ANZAC day parade last week was a great day out. We went in my 1944 Willy's Army Jeep. It's been in the family since my father bought it from the army. I wore my Uncle William's medals, I had one leg in the jeep and one leg out, and that's how we went in the parade! Karen, a hospice volunteer, came with us, and Bec's fiancé Fred drove.



L-R Ian, Peter

I was in respite and they sent me to palliative care. Last year they gave Bec a pamphlet about hospice, and said we'd need it. So Bec gave them a call.

*Bec reckons we were blessed when Hospice came on the scene.*

I just took it with a grain of salt when I first met the hospice volunteer Peter about a year ago, but we hit it off and it gradually built into a great mateship between us. He'd come over every week and help out, and sometimes more often than that.

Peter and I have similar interests. I had a cousin who would talk to me about things, but I only see him every blue moon now, and it's easier with someone who I see a bit more regularly. Peter and I talk about trucks, and farming, and how the world is running. It's quite interesting.

*It's made a big difference for me to have the volunteers coming. It also gives Bec the chance to get out and about. She works really hard and it allows her to do things while the volunteers are with me. It gives her a bit of a break too.*

They come and bath me, and dress me and feed me. It's a big help. And it's good to have someone to have a yarn with, to talk to about life, or go for a drive. Peter and I go out to lunch, and we go for coffee, just to get out. It's good.

I want to get out and go bush again. I'm a grazier; sheep and cattle. I had a place at Gurley near Moree. I loved it up there, and we had two properties at Weilmoringle, N.S.W. I'd go there but I can't travel now, so Bec runs the farm. She works so hard and does a wonderful job. She's good at what she does. When Bec goes away to manage the farm, the volunteers come over to look after me. And when I go into respite in Timboon, they come out to visit me too.

All I want to do is go back to living on the farm and work with the sheep and cattle. That's all I want to do. I was happy to be a farmer. I miss it terribly.

## Peter's Story

I wanted to give back to the community. I'm fit, and I've made some money so I do a lot of voluntary work, with Rotary and Hospice. I'm retired and I have the time,. That's how I met Ian.

A group of us did the nine-week course with Hospice, and a couple of weeks in I nearly threw it away. I wasn't sure it was for me but then once I got over that, things started to get really interesting. Hospice then put us with people they thought we'd get on with. Ian and I hit it off pretty well. He was fairly crook when I first saw him, and then he started to get better. One day I said "Let's go for a drive" and so we put him in the car and went for a drive. I really enjoyed that. I now bring him to Warrnambool for lunch or a coffee and he enjoys that too.

*Whatever Ian tells me is confidential, so we often talk about what's happening with his family and what's going on with him. It's his business, but it helps to share. I think that's why we are a bit closer than he is with some of the other volunteers.*

One day they were having a do at Ian's house, and I suggested he come home with me. So I brought him home, he met my wife, and we gave him a meal. To me, it's not just looking after the person physically, it is the person inside that matters. As volunteers we're there to help Ian, but to me it goes further than that, and sometimes I go out on my own just to visit him.

Now that people know that I'm in hospice, they ask me a lot of questions. It's amazing. I think people really want to know what the process is. *They think that once you go into palliative care, you're going to die straight away, and it isn't like that at all. Palliative Care staff are there to help Ian, and we're on the outside of that to help him to live his life better, by talking or just being a little bit of help.*

It isn't about just me and Ian either. Karen, another volunteer, does a lot with Ian too and we often work together. That's what gets me. We also work with the people from palliative care, who do the medical part of it. We're all on the same page. I believe hospice offers a great service, and we're here to help. It's been amazing to see hospice in the home. And it's good to give people the option to die at home.

A big part of the joy for me is being part of a team that works so well together. We help each other, and we know what the picture is, and we keep the co-ordinator informed, and it all works really well. I think more people should do it. We've had four intakes here, and there are now about 60 volunteers working in the home. It's a big community.



# Group support helpful with loss and grief

Maria met volunteer Glenda when she joined a group to help Maria and husband Phons deal with his life-limiting illness. After Phons had died, Glenda created a new group to support Maria and the other participants with their bereavement.

## Maria's story

I came to know the palliative care service when my husband Phons was in hospital. That's when they started with the life-limiting illness meetings where I met Glenda. Glenda was always ready with a cup of tea. Phons and I went to the meetings together. I always looked on the bright side, because at least Phons was there. I thought he'd always be there because he was going to go on forever.



L-R Glenda, Maria

*The group meetings helped me a lot. I thought I was the only one, but then I met other people and I saw that they were going through the same thing, or even worse.*

The group changed what we talked about at home, but death never came up. Dying never came up. It wasn't that we didn't want to know. I knew in the back of my mind that it was going to happen, but I didn't want to admit it.

In the end you wonder if it is ever going to stop, but once it stops, you feel guilty. When you have a husband or partner, you always have someone to fall back on, but when you're on your own, everything is left to you. But then he wasn't there any more. Phons died a year ago. You've got to take it in your stride.

The first time I realized that Phons was going to die was in the hospital. He took his rings off, and his watch, and he gave them to me and he said, 'Give those to somebody. I don't need them any more. I want to die.' That was the hardest thing for me. And he did die, but the palliative care staff were there to support me.

On the bad days I try to keep myself busy. I look at it this way; that's life and we're all going to die. The day you're born you make yourself ready to go out the other side. It doesn't matter who it is, and I've had a good life.

Recently I did a computer course that was fun, and I'm going to do a drawing class soon. I have a dog and I wouldn't know what to do without Jessie. I tell her everything.



## Glenda's story

I first met Maria when we started a group to support patients and carers dealing with life-limiting illness. I was the support person at the meetings for the six months that it ran.

*The first meeting was very difficult for everyone who was there. Phons and Maria were very much part of the group - they came every time and were great contributors and were able to lighten up the conversations when needed. The meetings were a really safe place where they could openly talk, and cry.*

Soon after this group finished, we organized a new support group on bereavement and we met every month for six months. This group was at a different point in their grief than the first group. There was always a trained facilitator, and I was there as a volunteer so there were always two of us to support the group. The group members decided when and where they wanted to meet, and each session they'd tell us what they wanted to talk about. We'd give them some of the resources and information, and they'd run with it.

We live in a small town and you run into people in the supermarket. I'd hear 'I don't feel like I need that group any more', and then I'd know we'd been a success.

I thought I might be bored when I thought my children grew up, and I really wanted to try volunteering. I'd worked as a nurse, but I found I enjoyed it more if I stayed back after work to be with the patients and their families. So I did the volunteer training here in Wangaratta. My first client was the most difficult client I've had in 15 years, but I was very well supported and it was great training. That set the precedent; if I can do that, I realised that I could do anything.

As a volunteer, I support various palliative care groups, and I also do respite with palliative care clients. I like helping even if it's only to give someone a bit of respite when it can be hard to get out of the house.

I have learnt a huge amount from the training. I feel like I'm a much better person. I look at all the mistakes I've made. I've learnt what to do in homes. I'm a much better mum than I was and I'm now a wonderful grandmother as a result. I'm much less judgmental. I'm far more relaxed about the little stuff; I just don't sweat it. I also have a much better appreciation of what I have.

*Most of the time volunteering is a very positive experience. I get more out of it than I put in. It's certainly made me appreciate life more, and I don't even care about getting old any more. I feel it has helped me enormously. Everybody wins.*



L-R Glenda, Maria

# Friendship and time out from caring

Shelley and Carole have become firm friends after Carole, a palliative care volunteer, offered to drive Shelley shopping every week. This gives Shelley a break from looking after her husband Mark, who has Motor Neurone Disease, and is something they both look forward to every Thursday.

## Shelley's story

I really look forward to Thursdays when I see Carole. It's nice to get out. For a few months there I didn't leave Port Fairy, and as lovely as Port Fairy is, I do need a break sometimes. Carole has made that so easy and she's been great. I can never thank her enough for it.

My husband Mark was diagnosed with Motor Neurone Disease three years ago. He has now lost control of his body below his neck. His speech is soft, but he can still swallow which means he can eat. His breathing has also been affected and he's now on a ventilator.

As I'm responsible for another person, especially the person I love most in the world, there are times when I wonder how I'd feel if I was in that position. There is no way that I could have dealt with it with as much grace as Mark. There's never ever been a time when he's said why me, or has been bitter. For him it is just what's happened, and we'll deal with it. I never thought I'd learn how to use hoists and PEG tubes, but you do.



L-R Shelley, Carole

It has been hard because you go from being normal to having a parade of medical and tradespeople coming in and out of your house. Mark was always the outgoing one but I'm a fairly private person. People do overwhelm me sometimes, so it helps that Carole is sensitive to that. You just click with some people.

*It has really made a difference to me since Carole and I have been going into Warrnambool in the last few months. I look forward to it every week. I'm not a big fan of shopping centres, but just to fluff around and switch off for a little while is a relief. It's like going in with a friend, and I get to feel like I'm part of the real world too.*

I feel comfortable talking about Mark's illness, but I am terrified about what's going to happen. There are very few people that I can talk to about those fears, but I can talk about it with Carole. Partly it is because we have that lovely rapport, but perhaps it is a different sort of friendship too. I know that further down the track, Carole and I will continue to be friends. It won't just end when I no longer need hospice.

I would have trouble putting Mark in respite. I want to have done everything I possibly could for him. I hate the feeling that I am going to lose my partner; I can't imagine my life without Mark. Even though he's not well, I still tell him everything. It is hard, but Mark and I have joy in our life. We have our own routine here and we're quite happy. He just loved his job, and if this hadn't happened he would still be working. In a way, we've had this really precious time together. We still have lots of lovely days and it's brought us even closer together.



L-R Shelley, Carole

## Carole's Story

We came to know each other while driving to Warrnambool to do the shopping every week. I would come and sit with her husband Mark while Shelley had a bit of a break, but then Shelley wanted to go into Warrnambool for shopping. The first time we drove, we felt comfortable to be really honest with each other, knowing there was no judgement. There was no need to hide things after that, and our relationship has been able to grow.

If we'd met at the garden group or somewhere like that, we would have become friends. We have similar interests and it has just been lovely to get to know each other.

I have gained an insight into the immense capacity that people have to take on a huge workload. Shelley is so organized and is so capable. I have great admiration for what she does, and for Mark too, because they work as a team on this. I'm really conscious that Shelley has so much on her plate and the house is so busy, that I don't want to overload her. If there's a message, I'll send it as a text; if I'm dropping off fruit, I'll leave it at the door. She's very gracious, and if there is something I can do to help take some of the pressure off, that's great.

I hadn't been in Port Fairy very long when I saw the advertisement in the paper. I thought that if people want to stay at home and their carer needed a hand, then that's really worth doing. I rang and the manager of Hospice was so welcoming. The people were lovely and the training was great. I'm not a medical person so to find something that was useful to other people was a really nice avenue for me.

*It's a privilege that people allow us to be there to help.*

As I've got older, I try to remember that I'm getting into the last part of my life, so I clean out those cupboards, and I try to be much more practical about my life. I try not to be frightened about getting old. I'm very, very fortunate.

*I now look forward to Thursdays. It has evolved into a lovely outing and Shelley is so easy going. I feel it is a treat to be out with her every Thursday.*



# We're like a second family

95 year-old Muriel is uplifted by her weekly visits to the local day hospice. Beryl, one of the volunteers, drives her there and she enjoys care, friendship and activities with other guests, provided by staff and volunteers, while her daughter Bev has a break.



L-R Beryl , Muriel

## Muriel's story

I'd just turned 95 when I first met Beryl eight months ago. She came to pick me up and take me to Anam Cara House here in Geelong, and we've been friends ever since.

I had an operation and I wasn't well afterwards. The palliative care team suggested that I might like it here, so they contacted the manager. Tessa came out to see me, and she talked me into coming. I didn't really want to come, but when I got here, I enjoyed it.

*At the start I didn't know anyone, or know what to do. I sat here and I thought, 'I'm not coming back'. I'm a homebody and I'm really shy, but they were all friendly and they all helped me. Nothing was a trouble to them. I found that I could talk to them. I've always been on my own, and I was never one to mix much, but I like the friends I've made here.*

Beryl now picks me up every Thursday, brings me here, and takes me home afterwards. I look forward to it and I keep Thursdays free so that I can come here. They'll do anything for me here. I was embarrassed at first, but now I just ask them and it's done.

I've been learning things that I didn't know before. We've coloured T-shirts with paint, potted plants and painted tiles, played different games and made music. I like all the games now, even though I can't see. I have a volunteer beside me to help me, so it's a joint effort! Of course, now I have all this stuff at home that I've made here.

I miss cooking and baking. I used to do things around the house but now I can't help at all. My daughter Bev looks after me. She does all the shopping and cooking, even though she's not well. When Beryl brings me here, Bev gets a bit of a break and can go out for an hour or two. I talk to Bev about what's going to happen when I go. We talk about her future when I'm gone.

*I've learnt to look on the bright side all the time from Beryl. It is good here. It took a while to get to know all the staff and volunteers but now I know them all. It's like a second home for me. They're all very special.*

## Beryl's story

I look forward to Thursdays when I take Muriel to Anam Cara House, Geelong. I always arrive a bit early so that I can have a bit of a chat with Muriel and her daughter Bev before we leave. We mostly talk about what has happened during the week. It's been very easy to walk into Muriel's house, sit down at the kitchen table and talk. We've got a very comfortable relationship.

Often when I get to her house, Muriel is not feeling well and she does not really feel like leaving the house. After we talk for a while she lightens up and decides to come with me. She is always in good spirits when we come home. But mostly she's pretty low. She puts up with a lot; she doesn't get much sleep and it's a big struggle. It's a struggle for her, and it's tough for her daughter.

When Muriel arrives here at Anam Cara House for day respite, she doesn't need me to be sitting with her all the time. She's beautifully independent. I just keep my eye on her from a distance. All the guests share all the volunteers and staff here, and the same volunteers come each week, which is easier for someone like Muriel who is visually impaired.

I've always been interested in people. I am a retired funeral director and grief counsellor. I liked the concept of this hospice, and I knew I wanted this to be part of my week when I retired four years ago. If I came here and it wasn't right with me, I would not have stayed. It's been good. This has become a family.



*I've always been a listener, but I also like a bit of fun and interaction with people, which is what happens here. I like the way that if we're sitting together Muriel will nudge me if something's funny, or not right. You wouldn't do that if you weren't comfortable with someone. I don't patronize Muriel. I treat her as an equal.*

From Muriel, I have learnt acceptance. Muriel accepts she is blind and the fact that she can't do anything about it so there is no point in grizzling. I've learnt not to take my eyesight for granted. There are lots of things I've learnt from this lady.

I keep coming to day hospice because we're all a family. When one of the family members is away we miss them. We all feel really valued. It's good for our wellbeing; good for our souls.

## Appreciation

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