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INTRODUCTION

Wominjeka to *Welcome to our Journey*. This book is a collection of real life stories from Victorian Aboriginal community members who are experiencing their own journey or have a family/ friend who are experiencing their journey at end of life. This book would not have been possible without the tireless work of Cherie Waight, Senior Project Officer Palliative Care at VACCHO.

On behalf of VACCHO and our Members I would like to acknowledge Cherie Waight's passion and commitment to Aboriginal health and palliative care which has ensured the successful implementation of this book and largely the Victorian Aboriginal Palliative Care Program.

Cherie has a strong connection to culture and spirituality and is a respected leader within the Victorian community.

The Victorian Aboriginal Palliative Care Program began in 2005 after the Department of Health funded the project as a pilot for six months. After the initial funding period, VACCHO was able to demonstrate the effectiveness of the Program and identify the need for continued recurrent funding.

With compassion and empathy, Cherie has guided our communities to create and enhance relationships with mainstream service providers and Aboriginal community health organisations to improve access to palliative care.

Cherie has been a strong advocate in raising awareness about the needs of Aboriginal people accessing culturally appropriate palliative care. All the while progressively achieving the Victorian Aboriginal Palliative Care Program Vision of:

• Creating a sustainable and culturally safe palliative care service system where Aboriginal people from Victoria can access palliative care services in the setting of their choice.

With many challenges to overcome during her own journey with palliative care, Cherie has done so with vigour and optimism, always looking forward to identifying "what's next?" but not forgetting to reflect. To reflect on the history of Aboriginal people in Victoria and the barriers that affect community accessing palliative care.

VACCHO acknowledges and appreciates the work Cherie has done with the Victorian Aboriginal Palliative Care Program to improve the health and wellbeing of Aboriginal people in Victoria.

Jill Gallagher AO

Chief Executive Officer - VACCHO Gunditjmara

ACKNOWLEDGEMENTS

Cherie Waight is a proud Yorta Yorta woman of great courage, wisdom and generosity.

As the Manager of the Victorian Aboriginal Palliative Care Program since 2007 she has provided visionary leadership in this pioneering role.

Cherie is also a passionate and eloquent advocate. Her powerful and moving presentations to Victorian and Federal politicians have highlighted the need to close the gap in palliative care - a mission that Cherie has pursued with the utmost dedication.

With patient and gentle guidance, Cherie has facilitated increased understanding and closer links between palliative care services and Aboriginal community health organisations across Victoria. She has facilitated the development of trust and understanding to walk the path together – so we can support people on their journey to the Dreaming.

Drawing on her rich cultural heritage and creativity, Cherie has used art and ceremony to bring us to a deeper level of cultural understanding and partnership. A highlight and historic milestone was the handing



over of message sticks by Aboriginal community controlled health organisations to the Palliative Care Consortia on the 25th July 2013.

Cherie has displayed remarkable altruism, resilience and determination in continuing to work for the benefit of others in the face of her own poor health and palliative care journey. Her lived experience, as well as that of many Aboriginal people, has informed her advocacy, practical recommendations and collaboration.

Palliative Care Victoria has great esteem, gratitude and respect for Cherie and her outstanding contributions and achievements. We are deeply touched by the wonderful dignity and respect Cherie affords to all people in her presence.

We will continue to do our utmost to ensure Aboriginal and Torres Strait Islander people receive the best possible care that respects their cultural heritage and wishes at every stage of their journey to the Dreaming.

Odette Waanders

Chief Executive Officer - Palliative Care Victoria

PERSONAL ACKNOWLEDGEMENTS

- Participants for their contribution, journeys and experience
- Jill Gallagher AO VACCHO Chief Executive Officer, for her continued support to the Victorian Aboriginal Palliative Care Program
- Cherie Waight for project management of the Victorian Palliative Care Program
- Margaret Clarke for editing the book
- Department of Health for funding the project, in particular the ongoing support from Ellen Sheridan
- Francisco Fisher for putting it all together

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VACCHO acknowledges the support of the Victorian Government.



Follow me

Follow me, take my hand, walk a little as I take each step slowly into my journey.

Sit a while with me as I watch our Murray River flow, feel my emotions, as I feel the land.

Comfort me as I stand strong in my mind, spirit and of my Country, and culture of where I belong

Yorta Yorta I hear you calling my spirits, family and ancestors as I enter into my Dreaming.

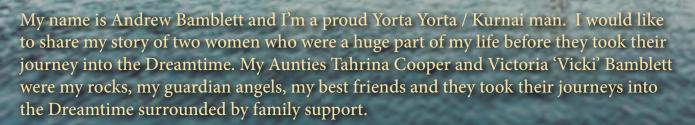
Cherie Waight Yorta Yorta

WALKING ALONE

Never be afraid to walk alone. Never be afraid to give yourself time to think and feel your emotions alone. A Journey of such is one's own Journey and a spiritual one to cleanse your body and soul, Take this time for you

Craig Holloway Yorta Yorta When we are ill with diseases such as cancer, we feel so alone and afraid But in reality we are never alone and there is always someone to talk to Someone who understands what we are going through. There are others who have faced illness, faced it and beaten it! Look around and I'm sure you'll find them. We began as the 'noisy three' and are now the 'noisy five' The young ones who support us and the oldies who survive. We have no secret handshake or password to begin And our doors are slightly open and we do let others in. What is said in the group stays in the group And comical or serious we are always in the loop. We talk in depth we laugh a lot, even read each other's thoughts There is no distinction who is boss, no rating ten to nought. We are daughters of our culture, tiddas one and all And we are there for each other especially if we fall. Our ideals, our group is universal and in fact it's not unique More than men we women are social and together secrets keep. So raise your cup up high your coffee, tea, whatever And know that as long as we have breath we will be noisy forever.

From The Noisy Ones



y Journey

As a Young

On the 9th July 2000 my beautiful Aunty Tahrina entered the Dreamtime. I was only a young boy when she took her journey and I sort of knew what was happening but didn't understand why? How? The thing I did understand was that my Aunty Tahrina wasn't going to be around much longer. This took a little time to sink in and by that time it was much later in her journey and I had an understanding that bowel cancer was the cause of her journey.

Aunty Tahrina was a bubbly, energetic and strong woman that loved and cared for everyone who was part of her life. "Love life and live it to the fullest", she never let anything or anyone bring her down. She was a woman who liked to play fun little games (pranks) on people just for laughs.

On the 29th July 2003 my equally beautiful Aunty Vicki entered the Dreamtime. I was a young teenager and found out from mum that Aunty Vicki was pretty crook, but I didn't know how crook and I didn't really understand why? How? As with Aunty Tahrina, I knew my Aunty Vicki wasn't going to be around much longer. Aunty Vicki was like my second mother and she was a very strong, independent woman who had a lot of values. She loved and adored her family from mum and dad, my nans and pops, Elders, Aunties and Uncles, cousins, nieces and nephews.

I was told that liver and bowel cancer was the cause of Aunty Vicki's journey. As a kid you don't understand these things and even explained to you it is a little hard to grasp. As a young Aboriginal man I now understand how and why these things happen but still don't understand why it happens to such beautiful people. These two women taught us that even in the darkest times you can have a positive outlook on life; that no matter what journey you take, it is up to the individual how they want to take that journey.

Family is everything in times like the above story I have just shared with you.

My hope is for other young Aboriginal people to understand why these things happen and that death is not the end of the road for someone; that they live on in our thoughts and our hearts.

Thanks for reading my story

Andrew Bamblett Yorta Yorta | Kurnai Dear Cancer Firstly I'd like to say I hate you so much. How dare you take so many precious people away from me!

What gives you the right to do that? You not only took my mother away from me and family and friends that love and cherished her so much; you then decided to attack her siblings, to send them through immense pain

and suffering. What gives you the right to pick and choose your target? You are so evil. You make me sick. But let me say I am waiting for you. I am prepared as much as I can be and I will take you on and more.

Regards

Anonymous

The Day I Was Touched By An Eagle

It was the year that death came knocking and I dare not reveal myself for I was not ready and he came close for he was my shadow. I needed to close the door, I needed to weep, I needed to soar like our totem of ancient times.

For he is Bunjil.

In modern times he is here and he is strong, wise and majestic. My spirits soared as Bunjil roared and in his presence I felt his strength I felt his wisdom and I felt his courage as he swooped and glided towards me with wings spread wide.

For he is Bunjil.

He came so close and I dare not move I was overwhelmed with emotion in awe of this magnificent creature and I felt the wind on his wings and as he whispered to me, I felt his wings touch my head as he caressed my soul.

For he is Bunjil.

Jill Gallagher Gunditjmara

LIFE IS A SPIRITUAL JOURNEY

For two years I was the primary carer for my mum when cancer attacked her spine and took away the use of her legs. It was a difficult time, and to watch her lose her dignity and independence knowing I could do nothing, broke my heart and spirit.

As a child I was adopted by a non-Aboriginal family and Peggy Waples loved and cared for me and she was my mother in every sense of the word. I always loved her but unfortunately I don't think I fully appreciated her or realised just how wonderful she was until I lost her. It was terrible and so sad to watch her go through her illness, she was a wonderful mother.

The day she died is deeply engraved within me. She kept looking into the

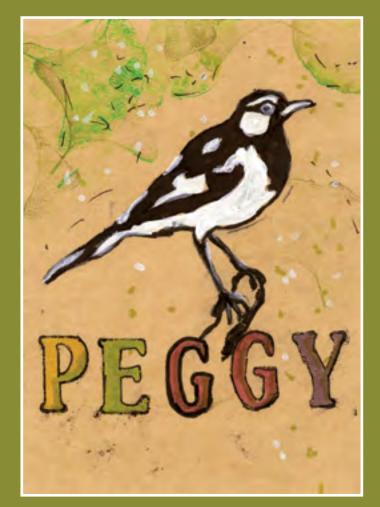
corner of the room and then said, "I'm going into that light." I knew what that meant and that I had to get the family there straight away. Mum always said that was my job and now I knew time was running out.

Later on I was sitting in front of the fire at home and it just went out and I knew that instant that mum was gone. After mum died I looked at her body and her eyes were glazed over; she was just a shell of a person and her soul had departed.

I had a spiritual connection with my mum and she came to visit me after she died. That week a cousin we had not seen for so long came to visit and mum's face appeared on his. It didn't freak me out, it told me she was ok

and that I would be ok. My brother validated her visits and said that he knew if she came back I'd be the one she'd come to. Then Mum came again to me on the way home from the funeral. She talked to me and although I couldn't see her I know she was there! She stayed with me for two weeks and then I instinctively knew she was gone. I believe she stayed to help me grieve, to help me cope with losing her and knowing she was there helped so much. I see people who pass on as birds and my mum – mum is a Magpie Lark and every time I see one I think of her.

Love you mum **Peter (Waples-Crowe)** Ngargo | Wiradjuri



VIA AIR MAIL You lay there so quite, barely moving and we're not sure you know we're here with you, My dad, my hero Them she holds your hand and so slightly your fugers move, a tear escapes, she smiles Not the happy smile you always knew, it's more relief in knowing you're still with us. You are the love of her life as she is yours, soul mates she tells me and I see that's true. You've been in hospital for weeks and now there's no illusion you're ever coming home But hope never leaves this room and we pray for a gentle passing free of pain. We take turns to read to you and wipe your brow to keep you as cool as we can. Medication is frequent but not enough to ease the pain; the nurses try but there's no comfort The doctor doesn't understand how you hold on to life when death is pending: But he doesn't know how stubborn and determined you can be. You're a man, a son, a soldier, a husband twice over, a father of five, a grandfather Today she smiles and reads the news you've been waiting for and after all those months of frustration A good provider and your duty is almost done. Veteran Affairs granted you a TPI, the gold card will come. Like young men of your time the war lured you to put up your age and put on a uniform In the jungles of New Guinea food was scarce, malaria frequent and an ulcer developed. The horror of war you saw stayed forever in your dreams, in your mind, And little did you know that four years of war would take you in the end. The battle is fought, your time is done and the angels have come to take you home, And we will see you in the kingdom of heaven where you wait for your soul mate Where you wait for your family and we know we are not alone. Your loving daughter

Margaret Clorke Mutti Mutti

Gone Far Away Into The Silent Land

You've gone far away into the silent land Where I can't hear your talk or laugh no more.

I remember you as you sat with your beloved cacti,

Gardening your one last passion. Now it's all browns and greys, No one to handle your beloved cacti. Leaves falling to the dirt dry ground, So sad to see your once loved garden coming apart. My heart knows the pain,

Feels the dryness and darkness.

From Your Loving daughter Cheryl Fitzclarence Kurnai|Gunai

The Peaceful Journey

My name is Joanne and my experience with Palliative Care was 21 years ago when I was quite young and I witnessed a family member go through his journey. His journey began with cancer of the lungs and it went on for three years. It started in the lungs but after two years of intensive treatment his condition deteriorated and it spread to other parts of the body. The hospital system wasn't what he wanted and our family was determined to take care of him, to do it our way and he wanted that too. As a family we gathered together and in the last months of his journey we took it in turns to care for him, to look after him in his own home. We are a large family and we all took shifts, to be there for him.

We did what he wanted it was all about him and his journey. Regardless of the time if he wanted to go out we were there. It could be two o'clock in the morning and he'd want to go to the beach or 'out bush' and see animals in the fields. Whatever he wanted we tried to do. It was about his end of life wishes, giving him what enjoyment we could so he was comfortable in his journey. Sadly it got to a point where he couldn't go out any more so we gave him little treats, like a gentle massage of his hands and feet; staying up late to watch movies with him and giving him different food treats. Sometimes it was just being there with him and having a good yarn; sharing our joy, sharing our stories.

He didn't want to go back to hospital and we tried to keep him home but unfortunately in the end he had a stroke and we had to call the ambulance and they took him to hospital. The whole time we never left his side, we promised him we wouldn't leave him alone and we didn't. His last days were spent in a coma and we were there with him. We constantly talked to him, said prayers and let him know we were there and that we would be there till the end and after. Day or night one of us was always with him. We'd like to think he found comfort in that and we sensed that he did have comfort at the end of his journey. We were there when he let go; when he passed over and we were sure he knew this and it was a comfort to him. I was with him at the end and I witnessed such a state of peaceful release on his face, as if his whole spirit, his whole energy was finally at peace and you could see his suffering was gone. We were so thankful that as a family we could be there for him. We are a big family and we all got together and did it. There was a real sense of family togetherness - we shared emotions, talking about how we all felt - we shared what we were going through - it was quite therapeutic in many ways - bonding, going through it together; it helped us cope with all of it. Of course there were stressful times but then there were many more rewards and that was greater than the stress.

I believe it was possible for us to always be there for him because we are a large family and we could take turns in making sure he was always comfortable and where we could we met his wishes. I believe we did well as a family in meeting his wishes and helping him in his end of life journey. The end I can best describe as a time of peace, for at that moment after all the suffering we watched him go through he finally seemed to be at ease, peace finally came. We supported him through his illness, through palliative care and now his spirit was free and we could see that; it was so beautiful to watch. We all know that one day we will all be together again.

Thank you for this opportunity to express how I felt. I feel ok and I believe it is because of his peaceful journey, it was lovely talking about it.

At the time of his passing I was only twenty years old and then it was quite scary. I was so young and in many ways still childlike. For me this was the first experience of this kind and I didn't know what to expect - but I know watching him in his journey I grew up a lot in that time. And I wanted his journey to be a lovely experience for him.

We all banded together and there was never a question of it being otherwise - the journey we shared with our family member changed my view on people passing on - people coming to the end of life journey. At the end it was a very peaceful experience and it brought comfort to the family - to us all to witness this, so much comfort. That's where the inspiration comes in to it - it wasn't just one person passing; he took us all on his journey and it was done so beautifully and this is such comfort to us, his family.

Till we meet again.

Love		_	_		
Joanne					
	And the second se	Sand Contraction	and the second s	and a sub-	 12.0

Thousands of candles can be lit from a single candle, and the life of the candle will not be shortened. Happiness never decreases by being shared.

Buddha



My little hands

Take my little hands and I will walk with you

I may not understand everything that goes on because I am small

I think the world is pretty wonderful and amazing

I may not understand when you sit and look sad and worried

I think laughter will bring back that smile

I may not understand when you're tired, and you need rest

I think that hugs will give you energy

I may not understand the journey you're on

I think that it's an adventure

Take my little hands, and swing me up. up. up

This is how I get to understand you and understand our journey together

By Jasmine and Sasha Hareko-Samios

Moonlight Warrior

James Victor John Wright entered the Dreamtime at Hamilton Base Hospital Palliative care unit on the 1/8/98. He was a father of four and married 36 years to his beloved wife, Eunice Wright . He was a beloved grandfather to many. To get you to dad's final days in palliative care I must first tell you of dad's journey upon diagnosis of terminal lung cancer. My father took his diagnosis head on. He had many things in which he wanted in order before he parted this world which was things such as the purchase of a plot at Hamilton lawn cemetery, writing his own eulogy, meeting with old mates to say goodbyes, and making sure all arrangements were done so his family did not have to worry. In the whole 8 weeks he had left on this earth, he spent most of his time with his wife, children and grandchildren. He prepared his grandchildren by telling them when he goes to heaven, lookup in the sky to the full moon and that's where I will be.

Admist all my grief and sorrow I purchased a book called *My cancer, my life*. In the book it had a whole chapter on terminal illnesses. Dad had refused any radiation or chemo at this time so I read the book in one night. It was quiet confronting but it had in it treatment available for terminal lung cancer, which would help dad with his pain and his coughing up of blood. I approached dad the next day, although I was very scared to do this. I gave him the book and I suggested he read about the radiation treatment used for palliative care for terminal lung cancer patients. God this was so hard to do! Here I am giving my father books to read to help him die better. Anyway, he ended up loving the book and made an appointment with his Dr who immediately referred him to Peter MacCallum in Melbourne. He only needed about 4 sessions of radiation. This treatment stopped him coughing up blood constantly and helped alleviate pain in his liver. It was such a good treatment.

So towards the end of dad's illness we needed to get a palliative care nurse on board at home to help dad with things such as medication, injections, daily observations etc. She was such a support to us as a family because at this point in dad's illness his whole family were terrified of anything and everything. The family thought that she was a very special, respectful and caring person and was greatly needed in such a hard time. Dad made the decision early on in his diagnosis that he would not wish to die at home and that he wanted us to take him to hospital for his last moments of life.

So that brings us back to Hamilton palliative care unit. This unit provided for us as a family, not only a place for dad to enter the dreamtime with dignity, respect and love, they also provided the family with a home. Although it was a palliative care unit they made it feel like we were still at home, providing us with food, tea, coffee, beds to sleep by dad's side. No requests were refused. When dad entered the Dreamtime he was very quiet and peaceful. The palliative care nurses dressed him in his pyjamas and we spent a couple of hours with him. There was no time limit for us to spend with him after he had passed.

That night we said goodbye to dad and we headed out to his farm in Branxholme. We could not believe it, the farm was lit up like daylight- It was a full moon! At that moment, the family new that dad was where he said he would be, in the Dreamtime.

On behalf of the family we would like to thank Hamilton Base Hospital and Peter MacCallum hospital for all their love and support throughout Jimmy's journey to the Dreamtime.

Tina Wright Gunditjmara



How The River Hows

It is my turn to tell the story of my journey through the river of cancer. I call it the river of cancer as I feel it keeps on flowing throughout my family and the people dearest to me.

In 1981, at a routine dentist appointment, the dentist encouraged my mum to have the lump he noticed in her neck checked out. She did so and it was bad news... my mother was only 34 and she had breast cancer - then I was only 17 years old. A couple of months later mum had her breast removed and she was devastated as she no longer felt like a complete woman. How she hated the fake prosthesis and my sister and I used to make a game of it and throw it around the room as if a 'hot potato'. Mum would say we were mad but our game kept her sense of humour.

They told mum she had to wait and be cancer free for five years before she could have reconstructive surgery. The time passed slowly but finally mum was five years in remission and she had the surgery done. It was incredible and again she felt like a complete woman.

The river of cancer stopped flowing.

In 1998 while at ten pin bowling mum attempted to bowl but the ball just slipped out of her hands. We thought she had a stroke but it was a secondary tumour that developed in the back of her head and was resting on the nerves and affecting her movements. However, not only was there this tumour, the primary cancer was in her lung:

The river of cancer was flowing again.

Over the next thirteen months mum endured multiple surgeries, endless medication, on-going seizures and the horrible side-effects of radiation. On March 1st 1999 mum entered her Dreamtime. She was at peace now - God Bless My Mum.

The river of cancer stopped flowing.

In 2005 my auntie came to see me to tell me she had lung cancer and she was terrified. But as afraid as she was, my aunty had hope, because she was going to participate in a new oncology drug trial.

The river of cancer was flowing again.

We anxiously waited for the results of the trial but during this time the cancer progressed and her pain grew stronger. Life was a struggle for her and her family and it was difficult to watch as her children were so young. It became harder and harder and many tears flowed into that river of cancer and at times it was bursting at the seams... it just wasn't fair! Aunty continued to fight her battle but after 2 years in palliative care, on March 15th 2007 the battle came to an end she entered her Dreaming. The river of cancer stopped flowing.

Good Friday 2008 a year after losing my aunty, my dad rang to say he had bad news... he was diagnosed with pancreatic cancer. I was gobbed smacked and so afraid I would lose him ... lose another parent; how is this fair I cried? I crumbled with a dead silence as my eyes welled with tears... I hated the world!

The river of cancer was flowing again.

The river of cancer was flowing again.

Easter Saturday came and I waited anxiously for my dad in the back garden. When he arrived I fell into his arms; my stomach churned, my heart felt heavy and my eyes welled with tears. Dad was as 'yellow as a canary' and I cried "why is this happening? I don't know what to say to you - how, when, why?" He told me it didn't look good and that he didn't have long and I was lost for words.

Dad's cancer was discovered late and time was of the essence, and two weeks after Easter dad had surgery but it was too late, the cancer had taken over. On May 10th dad's neighbour called to say she hadn't seen him for two days. My uncle went to check on him and found him unconscious and forty-eight hours later dad was placed in palliative care. To be near him, I stayed overnight at the facility and the next morning as I sat with a friend in the beautiful, peaceful garden they had, a crow flew down and my friend 'frightened' it away. It then flew to the guttering above the room where dad was and the bird's head was down as if looking into the room. I knew what it meant and I ran inside to dad. I sat next to him and let him know that I was going to be ok, that his grand- daughters were ok and that it was now ok for him to leave us. I told him "I love you dad". Just a day after arriving at the hospital dad took his last breath.

The river of cancer stopped flowing.

In 2009 through the family grapevine I was told another aunty had cancer of the liver that had been discovered by a routine blood test after feeling tired all the time. Given our family history we thought the worst.

The river of cancer was flowing again.

Over the coming months Aunty underwent surgery to remove the tumours as well as a portion of her liver. Aunty was young and this was really confronting for her. My Aunty is a high profile Aboriginal woman, a high achiever who works very hard and passionately. During her battle she juggled work, health and family. Aunty was determined never to give up on her health and wellbeing and is truly inspiring – she is so strong..... and I need to be strong!

And then there is my Tidda girl, my work colleague and close friend for whom the river of cancer has been flowing on and off in her life for twelve years. First it was breast cancer, then it got better, then it was dormant, but sadly, it raised its ugly head again and this is where we are now at. Tidda girl is a true fighter.

May the river of cancer stop flowing for my Nan, my Elder, my family and friends as we have suffered so much in a generation of time ... our grief is a never ending battle but we will continue to be strong, to help one another through the bad times and the good.

Karen Bryant | Gunditjmara

Jove Most gracious Gord, Your love extends beyond the circumference of the earth into the vast universe and beyond. There is not one single thing that you have created that cannot attest to Your love. Your love was shown on the cross. Your love was shown to me when you rescued me from the threshold of hell. You ransomed me from all of my iniquity and I am so thankful, Father. You love me in spite of all of my shortcomings. Father I pray that you find me faithful as I extend Your love onto those who hurt me also. May I always be ready to show love to anyone who does any injustice against me because You have shown your merciful love to me. Thank you for your love! Amen



Mum 1997

To Mum.....

It's been 15 years since you were taken away, But the memories are still strong, like yesterday. Your granddaughters are all grown up too, But each has a reflection of you, Which reminds me each day, The strength and love, you had in you!

Karen Bryant Gunditjmara

My name is Marlene and I was my husband Joseph's carer while he battled with stage 4 lung cancer. When we were told it was cancer they said he had 3 years but in fact it was just 12 months. Joseph was treated at Peter MacCallum Centre and chemo made him ill all the time. Those 12 months was such a stressful time waiting to see if the treatment worked and in that time we were so locked in and concentrating on nothing but his cancer and the treatment that we forgot to enjoy ourselves; we forgot to laugh; we forgot to live.

The doctors gave false hope with the chemo treatment and in the end we paid \$3000 for a 'miracle' pill that did nothing but give him a bad rash. We then questioned why it wasn't tried in the first place - still it didn't help. It wasn't the money it was the depth of disappointment when it didn't work.

- x what When told of Joseph's cancer I started crying and I couldn't stop. Joseph looked at me and said... "No, don't cry anymore". From that day forward I never cried in front of him again. When alone I cried my heart out but not in front of him.

> The day came when Joseph was combing his hair and when a large clump fell out he broke down and sobbed. He went bald early in his treatment and at first he always wore a hat. He was a very handsome man and when I told him how good he looked bald he never wore the hat again.

Tired of being ill all the time and disillusioned with the treatment, Joseph decided not to have any more and seemed resigned to dying. Chemo changed everything and in no time he became an old man, the way he looked, even the way he walked. A regret I have is that Joseph wanted to go to the cemetery and buy a plot for his grave. I couldn't do it; there was a fear if we did it then he would just give up and die. I said no! In hindsight I know it would have been good if we planned his funeral together.

Christmas Day we had our last meal together and he sat there and watched everyone, everything they did all they said. It was as if he had to take in everything around him. In bed at night if I got up he'd ask where I was going and to hurry back - it was as if he couldn't be apart from me. We

had been together for many years and very devoted to one another. Joseph hardly slept at night and by the time he did fall asleep I was wide awake. While he slept I would get up and potter around the house. It was strange because although I didn't get much sleep at all I had so much energy.

Joseph lost his mother when he was three years old and he was afraid of death. One day he asked me what I thought happened when we died, I said I believed his mother would be there to greet him. This put aside his fears and he liked the idea of his mother greeting him on the 'other side'. We talked about a friend that had lost her husband, how she was going to cope without him. Joseph said I wasn't to hide away when he was gone I was to laugh, enjoy life. He reminded me that in the last 12 months we had forgotten to do that.

A few days after Christmas Joseph had the hiccups and I gave him a drink and this made him want to go to the toilet. I called his son to help hold him up but we couldn't hold him and when we laid him down I knew he was gone. At first his son didn't realise but I knew straight away. I laid with him until the funeral people came to get him, I didn't want to let him go.

Joseph and I love karaoke and I recorded us singing together. Joseph sang *Crying In The Chapel* and I chose *Have I Told You Lately That I Love You* and another favourite of his was *My Way*. At his funeral I played the tape – Joseph sang at his funeral and they played *My Way* as he was taken from the church. It was as if Joseph did choose the songs he wanted.

I was all right at the funeral but once home when I rang my sister I couldn't speak as the emotions poured out and I couldn't stop crying. Joseph was gone and I had to live without him. Very quickly my sister was at my door – I cried for a week solid and couldn't stop. Joseph was a major part of my life and it has now been two years since he passed away. I live in the house we shared and I have lived, I have laughed but it is only now that I am able to go through his things and give his clothes away. I have a full life and I enjoy it but hopefully one day in the far future when I pass over, Joseph will be there for me.

Marlene Scerri

NERITA'S STORY

I was 15¹/₂ when mum first contracted breast cancer. I was in Year 11 at school and had started my VCE. First mum had an operation, started chemotherapy and then the radiation treatment. To begin, the first time they started triple strength treatments and I think they do the first time around to fight it hard. At the time the process didn't feel like palliative care as it all happened so fast.

Ironically, mum found out about her second bout of cancer in my last year at university. It was two weeks before my last exam and she never told me until I finished studies - she didn't want to risk four years of university when I had worked so hard.

This time mum's treatment, the process was more drawn out and it seemed at first that nothing happened and they just did tests and rather than do them all at once. They stretched them out one each week for a month. So much stress for mum, it was so unfair - the tests were done all over the place, from one side of town to the other. The first time it wasn't as bad but this time - this time it's in the bone and it's like they threw up their hands and said "we can't save this person so let's see what happens and maybe we can save the next person". Unfair or not, that's what it felt like.

I lost my father to a brain tumour when I was just a toddler. They first found out he was ill just after mum and dad were married and then after a while he seemed to get better and they had me. I was about a year old when the cancer returned everything seems to happen about the time of the big events in my life - it was only a year and a half later that he died. In 1989/1990 when my dad was ill, chemo was then experimental treatment and so archaic. He was told he was dying and they knew the treatment was just prolonging the inevitable, there was nothing they could do and he stopped the treatment and came home from hospital. I was just over two years old and being so young I can only remember snatches of that time. I believe then it all happened so fast and mum was only 24 when it started and 26 when he died. Then she was the age I am now.

When mum became ill I was too young to remember dad's illness so I didn't know what to expect. Except for dad our family didn't really have any experience with cancer as we have a history of heart problems so the family didn't really have the experience to handle it when mum got sick. This was a learning exercise for us all. I guess we handled some things right and some things wrong - then again there probably isn't just a right way to handle everything in life. What I mean is that sometimes people who are not in your position and see things from a different context may perceive what you think about a situation and the decisions you make as wrong.



The decisions I make now I might not have made three years ago as my perception on things has changed. It is certainly different from when my dad died for then I was far too young to appreciate how short life is, but now I do! Now I'm doing things a lot earlier than what I planned to. I'm going into the job I want now instead of five years down the track. I don't know what's going to happen five years from now and I don't want to miss out on something I could've done because it was seen as insensible when to me it's not. If you make life-decisions based on what is sensible then you're never going to be happy. Maybe my learning curve is to appreciate the time we have in life - you need to be courageous and make decisions based on what you want in life.

I think that I've learned more about mum as

a person more so than just as a mother; going through this process together I see a different side to her. In many ways we now take turn in 'being mum'. I do think it would've been harder in this situation if I had a two parent situation but because it's just been mum and me since I was $2^{1/2}$ we've had a codependent relationship.

Mum has enough to worry about and to ease her stress and anxiety I've taken over the management of her finances. When you decide to fully support someone you need to commit absolutely and I don't think that is hard to do! Taking control is nothing new for me, I do it at work; I've been trained to do it. What is sometimes hard to do is to make mum comfortable in her situation. Here you have someone who has been used to being on her own since she was 26, someone used to being independent and making her own decisions - she kept her own house and educated her child all by herself without help or interference. And now, now she has become dependent upon me and others and that's incredibly hard for her.

So many big changes in our lives has been hard for mum - of course there's been her big change and - her daughter has finished university and is now working - her daughter is getting married - her daughter is a completely different person who has her own life. Mum thinks she's holding me back and that's hard to deal with and you never make a resolution on that point, it's always there. There are times I feel - "ok mum, you're getting too dependent now, you need to settle down now" - this is where you do feel it, it's part of the process. I don't cope well knowing I can't do anything about mum's illness because I do have control issues. I can't control how mum feels from day to day and I can't control her treatment but I can control the environment she lives in. I can make sure she reduces stress and that she eats well - sometimes it's better to focus on the small things, that way you don't get bogged down and crazy and stressed and worried.

Just before Christmas mum almost lost her last fight in a period of a week and in that situation you don't know what to do. You try to do the right thing and take her to hospital and you think "this is it". That's not a healthy thing to live with each and every day but at some point you do learn to live with it. It doesn't become comfortable or easy but does become easier to live with.

All through this situation I still have to live my own life; I still have to be me because if I lose that then it's going to do mum more harm. I believe that mum doesn't only feel she's losing herself she feels she's done irreparable damage to me as a person and that's not fair on her.

You have to keep strong and accept support from family and friends, to be surrounded by positive reinforcement is important. But, you don't have to be strong all the time, if you do then eventually you'll break. We need to show our emotions, to cry, to laugh or sometimes just to get angry otherwise you do break or start to change how you feel about things. I was angry when mum was first diagnosed because she knew for some time and never told me. Of course you can't blame someone for having cancer and dying, it's not like they chose it that way - maybe if mum hadn't followed through with her initial treatment - would I blame her - maybe! But I was there and I know mum followed through with every direction, I knew this was something that just happened and there's no one to blame really. There was really nothing anybody could do in the situation - it was the 'Powers To Be' sort of thing and I get angry at them. I think sometimes you do need someone to blame - you need somewhere to channel it in a way.

I think sometimes you realise it's there and then you take a step back but for the most, life is so busy, there's work and life, your partner, friends, family. You grieve for a parent going through cancer, you grieve because treatment changes people, I've seen it and does it affect someone's personality in a major way? Maybe not, but there are the little things and when you know someone so well they do or say something and you think that's changed! Your temper changes, there may even be radical changes, responses change and you think back to how you used to think. It's like adapting to a whole new life, a new person and you have to accept you'll change as a result of it.

I think I've changed in many ways. I'm more measured in my responses to people; now I'm a lot more subtle and it's not outright 'in your face' like I was. Before it was just 'this is what I think'. Now I appreciate the little things in life rather than what I need to be. I used to take things for granted - an example is reading - I am a huge book fan and before it was getting out of hand. I love the quietness of reading and I like to be alone as I can't stand noise so I used to go to everything I just don't have time for that and recently I took a lunch break went to the park near work and read for a time - it was wonderful. One must have an escape otherwise in the end all end from coming too soon; too fast, and too fast might be months or even years. When living with cancer you must accept the outcome - but give up - no I'm certainly not there yet. I'll have my memories with mum - Paris, Dubai, Rome and my wedding coming up. These are my happy memories, especially being out of the country because it was as if we were away from it all. When we arranged our travels and the same with the wedding arrangements, for a while we didn't think anything else. If you aren't too blinded by the grief and anger you can find these wonderful moments and just carry on - they give you hope.

Together mum and I are making plans for her palliative care. In some ways it's good doing that preparation - you get more of an understanding of what's going to work rather than be totally in the dark which is worse. With our plans in place we know what we're doing and we feel comfortable and safe and that's so important. With planning we have some control over what happens, some say in what goes on. When mum is at a point where she can't make decisions for herself we've arranged what is to be done and it will be what she wants, so she will be part of the process. She won't be silent - we know what she wants. At least we talk about it and we're comfortable with it, as much as that is possible. Everyone has different experiences with palliative care in one shape or another. I'm still me, mum is mum and we're going through this differently. Some things we do well, some things we do wrong - as long as we're together, stick by each other and stay strong - as long as we hope!

Nerita Waight

Yorta Yorta

The Journeys

This is my story on our family's two palliative care journeys. My nana passed away from breast cancer and at the time I never knew she was that sick or having treatment. I was still at school and whenever she went away for treatment I was sent to stay with a family friend we called 'Aunty'. I was the baby of the family and in Year 11 at school and she would have been afraid if I knew, it would muck up my schooling. I didn't find out until the end of her palliative care journey when we all went in to say goodbye to her. I still had no idea she was passing from breast cancer, I thought she was old and it was her time to go. It was very upsetting when I found out the truth. She was trying to protect me; "we won't tell the baby" she would have said. I still think about it and wish she told me. I might have done things very differently and would have spent much more time with her and been much more considerate than I was.

We fell out and didn't really talk for 3 years and it was in the last stages of her journey that we made up. On reflection there was all that time wasted - time I could have spent with her. I feel so guilty, I should have let it go and connected with her more. I would have done things so differently if I'd known. It took me a very long time to handle the guilt, there were things I wanted to tell her and didn't and then she was gone and it was too late; if only I knew before her journey ended.



I remember once when nana and I were playing scrabble and I could see down her top - not that I looked at my nana's breasts but this instance I couldn't miss them. Her breasts were sagging and her bra was falling down and I didn't understand why and I was frightened. "Nana, are you all right?" I asked. "Your bra is falling down." She replied, "Oh, it happens when you get old" and I believed her.

I lived with my nana and even when she was having treatment, even when she had her breast removed she looked after me; cooked for me as she always had. I think back and I know she thought she was protecting me from being hurt but I wish I'd known something, I could have helped more - I was a brat then and maybe I would have been better to her. I know she protected me I just wish she'd told me.

That was my first experience with palliative care then last March my husband had a heart attack and we almost lost him; it was terrible. He works at Woolworths and he came home with what we thought was a cold. When he had chest pains we thought it was just to do with the cold. After three days he went back to work and seemed ok. He did say his left arm was sore and his chest was tightened but again we thought "the cold".

"Ok," I said. 'You go and lay down and rest."

That night I was going out with the girls and I didn't really think much about him being ill, it was just a cold. While I was out my husband

had a massive heart attack and my 11 year old daughter had to make the emergency call for an ambulance. On the way to the hospital he had arrested twice and this is something we are still dealing with; that night we nearly lost him. His heart attack didn't just happen he had been having it for 3 days... that cold we thought he had. Because of how it happened he damaged his left ventricle and they are important because the ventricles pump blood to the entire body. There was a lot of damage done. They put in a stent but he may need further surgery. Right now he has so much medication and he's on this international trial to test a new drug that is supposed to build up the muscles that have been damaged. The trial is for 5 years and the aim of it is to improve his heart and overall health, if it doesn't well that's another story we will face.

It is hard for my husband to be limited, it's hard for him to think that in 5 years the trial drug might not have worked and then what? One year has already passed and I told him he has another four years to tell that man inside him when he wants to do what he used to do to "bugger off". So that's where we are at the moment we are on our journey and it is just one day at a time.

Do you think that what you experienced as a child and not being told about your nana's illness, do you think it has had an effect on the way you react now? Absolutely - our children are told everything, they are never left out of the loop. I refuse to leave them out of it. When it comes to what happened to their daddy. I tell them we need to keep everything as normal as possible but be ready for change because things do always change - you have to keep faith, keep hope. They go about their daily routine, they play and they fight like normal children. They still stress out their dad by leaving things around and he still yells at them. It's that normal routine that makes a difference... yes he still yells at them but at night he says "come here and give me a kiss".

I am glad things are normal and the girls are on the journey with him - they are building their own story and their own relationship with him. It's good and better than me telling them how it is or hiding it from them because they build their own special memories. I tell them we haven't given up and we'll always keep fighting it. In our own way we are religious and my husband more so, far more than me. The children have also taken up religious values. We talk about what is important, especially family.

When I came home the other night there was a message right down the garage door. It said:

Mum, when you get home you have to be happy and have a smile on your face - leave your work behind and know that three people inside are looking forward to seeing you and they want to give you a hug and kiss you! It was beautiful and I took a photo of it. It's the little things they often do like leaving messages or having a bowl of fruit ready for me when I come home late. They are good girls.

This is the complete opposite to when I lived with my nana, when they kept everything from me. It took a long time to let go and get over the guilt I felt because I knew I treated my nana bad. I think about my husband's position and I could never keep my girls in the dark. The worst thing was that everyone knew about what was happening to my nana but me! You feel so much guilt, then comes the anger that no one in the family told me anything. It took a long time to get over it but now we are a close family and they know sometimes it still gets to me and they are careful about what they say in front of me. I tell my girls to make every minute count - make it all part of your journey.

My nana was a wonderful woman, mostly she was up-front, a strong, traditional woman who loved me and was only trying to protect me.

I want to thank Cherie for asking me to tell my story and also for telling me her story. She is such an inspiration.

Terori Hareko-Samios



As I lay here on my bed

I think about why I can't do anything,

Why I always have people come in and do everything for me.

My illness is too late to heal and recover my 'scared' heart,

I wonder if my family want me to live forever but I know my heart will stop one day.

Then I will be reunited with my family and follow them on a journey and I will always look down on my family, will always protect them.

No matter what I'll always be in your heart, always look down upon everyone.

And one day, one by one we will be reunited and then I'll take you on a journey and the spirits will always remain.

Kaitlyn Miller

My name is Roslyn Evans and I lost my brother, Lionel 'Grego' Cromelin to melanoma in September 2013. Grego got all the family together and told us about how ill he was and together we went through the process of sadness, anger and hurt and finally palliative care in his home. I truly believe that he prepared us all for that day.

I would like to share a poem written by my other brother Craig Cromelin.

Cancer you Mongrel

Cancer you freeloading mongrel,

I brought you into my world....as does everyone.

I harboured you in my body....for 48 years of my life I fed you and quenched your thirst

Now.... most things in life..... appreciate that sort of help

But.... NO....not you.... You mongrel

Cancer.... you waited....like a thief....like the prowling predator, that you are....you waited for a precise moment to strike.

Was I at my weakest moment when you struck???? I will never know.

But why....why me....what did I ever do to you?

And what gave you the right to take my life from me....from my family...from my friends....you mongrel? After all it was I who carried you into MY world.

When I first learnt of your initial strike against me...in the form of one of your many 'aliases'....in this instance..... Melanoma.

It made me instantly sick...and I felt my whole world stop, and start to crumble.

All of a sudden...you went from a silent free-loader to this angry, greedy...life sucking mongrel...that you are.

And not just content in causing harm to me...

You inadvertently....and deliberately affected my family and friends along the way...you mongrel.

Cancer....as your thirst to take my life.... got stronger and bigger...I tried my hardest to fight you off.

Cancer, you mongrel...I have never backed down from a challenge in my life.

This challenge was the hardest I had to face...in my life.

But with truck loads of support, love and encouragement from family and friends...I was adamant and determined...in my endeavours to beat you.

By staying in a positive frame of mind By agreeing to trial a new drug against Melanomas, by doing what was necessary.... I wasn't rolling over for you... no way...not that easy....you mongrel.

Cancer, you mongrel...all you ever do is Take, Take, Take...

You never give...and you are never satisfied until you take everything.

You tried to take everything that is mine...even my soul and spirit...didn't you...you mongrel.

Cancer...you mongrel

You took control over my body....you held it captive, like a prisoner.

You were mercilessly and strategically ruthless...as you started shutting down all the things I once took for granted.

Walking, standing, feeding myself, being outside, fishing, driving, having a few beers with family and friends, being able to go and do things when I wanted, going to the toilet on my own...and many more.

You were strangling the life from my body....you mongrel

You know what I hated the most...is you taking my dignity, my pride, my ability to do things for myself... I loved being my own man.

But you know what you didn't count on you mongrel

Whilst taking my pride and dignity...

I actually took back something from you... so yaaah

With love, strength and support from my family I won back time...time that was to me, my family and friends

Powerful...precious...memorable... purposeful...strengthening...valuable... irreplaceable...and it's all ours

Together, my family and friends have locked those moments away in their hearts so you can't have them.

I have moments and my memories locked in my heart...so I can take with me...on my journey so yaaah...you mongrel

Cancer...you mongrel

As hard as I fought, as much as my family gave me love and support, and encouragement

I couldn't defeat you

But victory isn't totally yours to gloat about you mongrel.

I have a victory too.....so yaaah

You want my body...then take it...but here is the irony and sweetest message of all from me to you...you mongrel You are going into the ground.....deep enough, so you will never see the light of day again....and stay there.

And my victory is this...

My family and friends....set my spirits free...my soul and memories I have given to my family and friends, for them to keep, for eternity.

I am now with my family and friends on the other side.

I am with my family here.

I am free of pain...

I am sad...but at the same time...happy... and I can visit my family and friends anytime....anywhere...I am no longer your prisoner....

I am my own man...or spirit again

I do though truly hope...that the day...will come when you...cancer, you mongrel... will never do what you did to me...to anyone again

So goodbye and good riddance you free loading mongrel.

Craig Cromelin

If you are doing anything, no matter what task, on life's journey and it is being done in a positive way - to the best of your ability
then there are no such things as mistakes.
Rather detours on the path to correctness.

Jason Kelly Mutthi Mutthi

Interview with Maleek Briggs 15 years (Yorta Yorta) and Peter Atkinson 18 years (Yorta Yorta) by Cherie Waight



Maleek Briggs and Peter Atkinson

Firstly, thank you for doing this interview with VACCHO.

What do you know about the meaning of Palliative Care?

It's people looking after people with an illness or disability - taking care of sick people.

As young Aboriginal boys, what do you understand about using the word 'journey' instead of saying 'palliative care'? Do you know what it means in our culture?

Not sure of that... its where you're going, life is a journey and you never know how it's going to go.

So if you heard someone was on a journey, what would you think?

If people are on a journey like that then you'd think something was wrong with them, you'd think they were sick or something.

Have you had experience of palliative care?

My uncle was in palliative care in the Shepparton aged care home. His room was painted like the bush so he felt at home cause he loved being in the bush. He felt happy and welcomed and so did family; better than those white walls all around you.

Were your family made to feel welcome there?

Yes, family could come and go. My nan came all the time when she wanted to and she could stay as long as she wanted. The nurses looked after him really well.

What does the Dreaming mean to you?

The Dreamtime, it's about family, connection, our way - our culture - our heritage; the way we are! It's family and family means stories - telling cultural stories. How we came to be here - our totem, it's Elders telling stories with family all around you.

What about cultural ceremonies, for example a smoking ceremony when an Elder doesn't want to use a bed another Elder may have used when sick? Elders should be asked to do ceremonies. There's differences in our journeys and people need to be treated good, all people should be treated the same. About Elders in hospitals, they need to get other people to go and see them, they should get out some times and asked to do ceremonies.

What kind of things would you like to see?

I'd like to go to other places and see other groups and what they do – how we are the same and how we are different. How they do their journey. I want to experience other areas and learn more.

Can you tell me what is of cultural importance to you?

Who we are; where we all come from. It's important that our people in hospital are treated good and not bad because of the colour of their skin. Make them feel at home.

What differences would you like to see happen?

We need to look out for each other more. Take care of people, make them feel safe

Would you like to help these people?

Yes, I would. It's important to look after Elders, to look after each other and to know what's out there. When other Elders in hospital get Elders to do things for them, ceremonial things they need.

How have you found the session today?

Today was good, I had fun and I learned about palliative care. My brother is autistic and it's good to know that someone one day will look after him. Yeah, today was good, I enjoyed it and I learned a lot – I learned we are all different. It's important to look after Elders - look after each other - to know what's out there.

Maleek, Peter, what would you like to see for young people in Shepparton?

More jobs - to look after our people. More chances and equality in the work place.

Maybe more young people need to work in palliative care because young people also go through journeys.

That would be good for Elders to get out just for a day because sometimes people are left in homes and hospitals and they need to get out for awhile. They need to go bush when they can.

Did you learn more about palliative care today?

Yes I did. I know we're all different and it's important to look after our Elders, we need to do it so they feel comfortable, more at ease because they can look at us and know us, we need to look after each other.

Thank you Maleek and Peter for sharing your stories and paintings with us.

Maleek Briggs and Peter Atkinson

Yorta Yorta

AN AUSTRALIAN BLESSING

May you always stand as tall as a gum tree As still as the morning mist Be as strong as the rock Uluru Hold the warmth of the camp fire in your heart May the creator Spirit always watch over you.

E. PIKE

NOONGAR ELDER FROM SOUTH WEST AUSTRALIA

PRAYER OF THE Aboriginal People

Father of all, You gave us the Dreaming, You have spoken to us through our beliefs. You then made your love clear to us in the person of Jesus. We thank you for your care, You own us, you are our hope. Make us strong as we face the problems of change. We ask you to help the people of Australia, to listen to us and respect our culture. Make the knowledge of you grow strong in all people, so that you can be at home in us, and we can make a home for everyone in our land. AMEN

YOUR JOURNEY



Kahli Luttrell

VACCHO

Welcome to my Journey Acrylic on paper

Artist's Statement

This artwork is about our journey in life. It's about the inner light inside of us that is always there. The light that guides us on our path through tough times leaving our mark - our imprint on our land and the people around us.

This artwork symbolises 'what lies behind us and what lies within us isn't as important as what lies inside us'.

The orange and red in the artwork is our path in life, the green is the land and our roots, and the branches are growing and guiding us to the light of our future.

WELCOME TO OUR JOURNEY