



# a journey lived

*a collection of  
personal stories  
from carers*

Palliative Care Australia

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Palliative Care Australia gratefully acknowledges the financial assistance of the Australian Government Department of Health & Ageing. However, the views expressed are those of the authors and not necessarily the Department of Health & Ageing or Palliative Care Australia.

Contributors: Private submissions have been supplied voluntarily.

Images: Sourced from individual private contributors

Design: Design Edge

ISBN: 0-9752295-1-6

Published: Palliative Care Australia  
January 2005.



*The dandelion symbol is the national symbol for Palliative Care. The dandelion is a gentle part of nature symbolising a wishing wand when lightly blown upon. The wind picks up the seeds and carries them to new destinations to create new life where they land*

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# Foreword

In my role as President of Palliative Care Australia I have met many wonderful people who have done a magnificent job in caring for terminally ill family or friends. All too often the contribution of this group goes unnoticed. This publication is a way of honouring those people and paying tribute to the wonderful work they have done.

Each year thousands of Australians provide high quality care to people dying from a terminal illness. However, we know many are unaware of the fantastic support services available to them during this very difficult time. We hope this publication will highlight those services and encourage Australian's to consider such care as an opportunity to be valued.

To those who have contributed to this publication, who have opened their hearts and for some, old wounds, I thank you. For many of you this is a way of remembering the person who has died. But this publication also honours you and your family, and the significant contribution you made to their end of life.

This publication also contains a story from Judy, a palliative care volunteer. Each week Judy and hundreds of volunteers all around Australia help care for people dying in their communities. They support not only the person at end of life but their family and friends. Without these volunteers, palliative care in Australia would be very different.

Finally, it would not have been possible to produce this publication without the support of the Australian Government Department of Health & Ageing. Palliative Care Australia is very grateful for their ongoing commitment to improving awareness and understanding of palliative care within the Australian community.

I hope you enjoy *a journey lived*.



Professor David Currow  
President  
Palliative Care Australia

# What is palliative care?

Palliative care is about caring for people with a terminal illness as well as their families and friends. Palliative care is care which 'palliates', or relieves pain and other symptoms. It is given when treatment to cure an illness won't work any longer. It aims to ease the pain, distress and many other physical, emotional and spiritual problems that are present with a terminal illness.

Using various techniques and knowledge, a team of many health care disciplines including doctors, nurses, allied health workers, chaplains and volunteers, provides coordinated physical, psychological, emotional and spiritual support.

Palliative care aims to make the person feel in control of their treatment and their quality of life. It involves family and friends, recognising that they, too, need to be prepared for the death of someone they love, as well as being there to offer help and support during the grieving process.

Palliative care adds to the range of medical treatments and services already being provided and works together with the specialists, general practitioners and nursing staff already involved. Sometimes palliative care helps in the decision making about when to stop some treatments.

Palliative care services provide a range of services to patients and their families. These may be nursing, medical care including consultancy to the person's GP, day care, counselling, diet advice, loan of equipment, physiotherapy, occupational therapy, social workers, bereavement support, pastoral care and a wide range of support from trained workers.

**Carers resources** If you are a carer, you're not on your own, there are a lot of resources available to help carers. Commonwealth Carer Resource Centres in each state and territory can refer you to services and give you practical information to help you, all for free.

Contact Commonwealth Carer Resource Centre on 1800 242 636 (free call except from mobiles) or visit the website [www.carersaustralia.com.au](http://www.carersaustralia.com.au)

**Need financial advice?** Centrelink has a Financial Information Service that can advise on wills, enduring power of attorney, funeral plans and bonds and how to administer a deceased estate. Contact Centrelink on 132 300.

**Financial help** Centrelink has payments available to assist when caring for someone who is terminally ill including Carer Payment, Carer Allowance and a bereavement payment. To find out more contact Centrelink on 132 717.

# Jacky's story

Written by her husband Alan Dillon

When you are 19 years old, gazing into the eyes of the love of your life, and saying “Til death do us part”, it is natural for us to believe that this death will only occur when life has been fully lived, when all dreams have been fully met, when all children and grandchildren have been hugged tightly... at least once. What you don't expect is that after years of working together towards a goal, of filling a family with love and a house with life that your beloved is taken before her 50th birthday, and only a few months before her first grandchild is born.

When my beautiful wife Jacky and I were told she had cancer we could not believe it – Jacky had always been fit and healthy, had regular check ups, and was only 48 years old. The news that Jacky had only six months (at the most) to live was shattering. I could only think of our 32 years of marriage together; 32 years now down to six months... in the blink of an eye.

It is human nature to get frustrated by those things that we cannot possibly make sense of nor control... and this frustration and anger set in. Why Jacky? Why her life? Why our life? Jacky had done everything right. A truly selfless person, she had always put her family and friends before herself – our two sons, Jason and Craig, were born before Jacky was 21. She never lamented loss of time or a limited youth, moreover only saw the richness that our sons brought to our life. Her family was everything – we were planning for early retirement, and extending our home and renovating in preparation for Jacky to look after our future grandchildren.

After the news, we decided to take a positive attitude and fight the cancer, one day at a time. I decided not to go back to work, so we could spend as much time together as possible. I wondered then just what would happen if I simply couldn't afford to take such an extended

period of time off work, and felt sympathy for those families who couldn't spend this last precious time with their loved ones.

One of the hardest moments for us was telling our sons, Jason and Craig. Jason was to marry Michelle in four days and as we never kept anything from them, we decided to tell them before the wedding. Of course they were devastated for their mother, but they wanted to remind us of the celebration of love that was marriage, and all that we had taught them. So we celebrated. It was a great wedding and took our minds off things for this short, joyous time. Everybody was asking Craig when he was finally going to marry his long-term partner Debbie and we had some great laughs. Two weeks later Jacky celebrated her 49th birthday. It was definitely a busy month, a happy month, but under toned with worry about what was to come.



The doctors said chemotherapy would buy Jacky some time, and as we had now realised just how precious every day was, Jacky started her treatment a week later. She had no trouble with the emotional elements of starting chemotherapy, such was her strength, even picking up the scissors and cutting her beautiful long hair. This was, I believe, her way of maintaining some sort of control, by telling the world "I know my hair is going to fall out, but I will decide when, and how this will happen."

The chemotherapy brought us into our first contact with Clare Holland House, which is set on the shores of Lake Burley Griffin in Canberra. We met the palliative care team there, who would accompany Jacky on her weekly visits to see the doctor for check ups and to monitor her medication. If Jacky was unwell and not up to visiting the doctor, they would come and visit us in our home. It was to become a lasting



friendship. We gained strength from their understanding and inspiration from their kindness. When faced with death, you can also be faced with the greatest of humanity.

Over the following weeks things were as good as could be expected. We were now getting daily visits from the palliative care team, the chemotherapy was doing its job, our hopes were

high and there were always family and friends dropping in to make sure we were ok. I had even learnt to cook! My friend Sid was a builder, and he was finishing the final touches on the house, so Jacky could see her dream home completed. We were surviving, but I soon realised that without all this help and support we would never have coped – I wondered how people could possibly cope without this support structure.

A visit to the specialist for Jacky's three monthly check up shattered our world again. The cancer had grown and the chemotherapy wasn't having an effect anymore. We were told they would stop the treatment. Jacky wanted to keep going but her body was getting weaker and they advised that she would not cope – it would simply make her too sick – but we were determined to fight on.

Life goes on in the midst of sadness – Jason and Michelle informed us that we were going to be grandparents for the first time. This news lifted Jacky's spirits and she was so excited, especially when we were invited to join them for their first ultrasound. It was a treasured moment. They shared with us the joy of knowing they were having a daughter and I also think they wanted 'their little girl' to know her Nan did get to see her.

Over the coming weeks Jacky's condition deteriorated. She was a fighter and never complained, and the nurses continually commented that this was one very special person they were treating. Jacky went to stay at Clare Holland House for a couple of days at a time for the next few weeks so they could monitor her medication. She felt secure there as she used to get frightened about being alone, especially at night. They understood this and had been

through it many times, thus providing an empathy that gave all of us strength and comfort. The prospect of death and dying was seen as a natural part of life at Clare Holland House, and they ensured that this final chapter was well spent, even realising the importance of ice-cream and jelly at 3am!

Jacky had decided she would like to spend her last days at Clare Holland House. Linda, a palliative care nurse, assisted with this difficult decision. Jacky moved into Clare Holland House but passed away three days later, surrounded by our family. I felt a deep sadness, not only for Jacky, our family and friends, but also for the palliative care nurses and doctors who had cared for Jacky in more ways than one. She had a way of touching the hearts of everybody who came into contact with her, but we all knew she was now free of pain and finally at peace.

Our family erected a playground at Clare Holland House in memory of Jacky, as she loved children and we wanted her spirit to sit quietly amidst the sounds of children playing. It was also our way of saying thank you to the whole palliative care team. My union, the CFMEU (Construction Forestry Mining and Energy Union), in partnership with Foxtel, organised to provide Foxtel TV to all rooms at Clare Holland House, including the staff rooms, which was another small token of our appreciation for the work Clare Holland House are doing.

I still drop into Clare Holland House regularly to say good day, and they take the time to make sure I'm doing okay. They have been a very special part of our family over the last six months, and will continue to be throughout our life. We will be forever grateful for the help and strength they gave Jacky, myself and our family, and the dignity and understanding they offered her as she closed her final chapter.

# Jack's story

As told by his wife Barbara Sawyer

How do you cope when somebody tells you the love of your life, the man who has been by your side for almost 50 years has an untreatable cancer, and only has a matter of “days, weeks, or if you’re lucky, months” to live? Lucky? I couldn’t believe what the specialist was saying was true – how could it be? Jack had always been a strong, healthy man – wasn’t there something they could do?

On our arrival home Jack, in a voice betraying little fear about what lay ahead, said to me, “sit down and I’ll tell you what my wishes are, and we’ll get on with it.” His wishes were simple enough – to visit his family in Victoria, his friends in Toowoomba, and to stay at home for the duration of his illness.

The first two posed no problems but once they were completed my dilemma began. Would I be able to cope with Jack’s illness at home, having had no nursing experience apart from sick



children? It seemed such a huge undertaking, but one I had to tackle for Jack's sake. A doctor friend then told me about a local palliative care unit, Cittamani Hospice Service at Palmwoods; a place I didn't even know existed. I contacted the service and a friendly voice told me someone would be down to have a chat with me shortly. That afternoon this calm, smiling person arrived and the case was assessed.

I soon realised I would come to rely on Jack's amazing courage and selflessness to sustain me through the journey that was only just beginning. The service organised a special mattress, aids for showering and toileting and information on medication. Working in tandem with our doctor, they gave me the confidence to see things through to their inevitable conclusion.



One of the nurses called regularly to make sure we were okay, and to talk over Jack's condition with me – nothing was too much trouble for them, and they gave me advice at any hour of the day or night.

As Jack's illness progressed I had to phone at 2am one night when Jack became very agitated. A calm voice at the other end of the line told me to increase the medication and she would be round in the morning. Unbeknownst to us all at the time, that was to be Jack's last day. The nurse arrived (in the circumstances that unfolded, it was unfortunate my daughter had briefly gone home to her house) and told me things were happening much faster than we'd thought; Jack was slipping away. As we sat on each side of the bed holding my dear husband's hands, nurse Jenny quietly said to him, "let go, Jack, let go" – he did. He quietly and peacefully left us.

*It was a relief to know everything was now quietly slipping*

One of the strangest coincidences was the timing of Jack's death. He left us at exactly the same time as our son's plane landed in Melbourne from the USA. It was almost as though he knew everything was now in place and he could quietly slip away.

I tell you these very personal details because my own experiences have taught me it is possible to cope with a terminal illness with the assistance of palliative care. When I was able to collect my thoughts later on, I had this tremendous feeling of satisfaction that I had been able to do this for the man I loved – due in large part to the confidence palliative care gave me. My association with them was only over a couple of weeks, but these were the most traumatic of my life.

However, things didn't end with Jack's passing. The counsellor from Cittamani maintained regular contact for the next 12 months to make sure I was coping with my grief. How's that for caring?

Many people in similar situations have contacted me since, wanting to know about my experience.

Each time I have assured them they can cope with terminal illness with the help of the palliative care service, and they will also feel the same satisfaction in fulfilling what most terminally ill patients want, and that is to stay at home with familiar things around them and the love and support of family and friends.



# Roy's story

As told by his wife Elinor Winter

Looking back, I instinctively knew from the expression on the doctor's face the news he was about to give us wasn't good. When he asked us to take a seat I prepared myself for the worst – little did I know how much our lives were about to change, or how important palliative care would be in helping me get through what lay ahead. So great was the impact of palliative care on me, I am now a volunteer carer myself.

Roy's first trip to the hospital was for prostate surgery in 1989. The procedure went well but we were given a scare after the surgery when a routine pathology report revealed moderately differentiated adenocarcinoma of the prostate. Fortunately our fears were allayed when a subsequent bone-scan showed no advancement of the cancer, allowing our lives to return to normal.

Roy and I had married late in life – we had three children, two girls and a boy – two of whom were still at school at the time of Roy's diagnosis. Roy was retired from his shift-working job as a process worker, and was enjoying having the freedom to do the things he loved most, like spending time with his children, gardening – mostly vegetables, walking the dog, reading and soaking up the sun.

However in 1992 Roy's health took a turn for the worse when he developed severe pains in his back. This time we were not so lucky. A bone-scan confirmed secondary growths in his spine and other parts of his body.

We had been planning an overseas trip for early the following year, which neither of us wanted to cancel, so after consultation with his specialist Roy underwent an orchidectomy. Roy recovered well and soon went into remission. At the end of March 1993 we left for England, the country of his birth.

*in the village where he was born, he spent much*

Having not been 'home' for over 30 years, this was to be Roy's 'holiday of a lifetime'. One of the main reasons for the trip was to visit relatives, some of whom Roy hadn't seen since WWII, and a whole new generation of nieces and nephews. Based in Somerset, at the home of Roy's sister and her husband in the village where he was born, he spent much of the time roaming the hills of his childhood. Together we enjoyed exploring other parts of England and Europe. We travelled down the Rhine, fell in love with Switzerland and attended the Edinburgh Tattoo. The happy memories of those six months will stay with me forever.

Back in England Roy began experiencing a lot of pain in his right hip. Whilst we were grateful all Roy's medical expenses were covered, since he was a British national, xrays confirmed Roy needed an urgent hip replacement operation. Five weeks later, after returning to Australia, this is what happened.



Roy's convalescence was good but slow. Since he had always been the one with the 'green thumbs' it fell to me to look after the garden. Although our son did the extensive mowing, we soon realised maintaining the garden and family home, as well as caring for Roy, was too much for me so the search began for a more suitable place to live.

After eight months of looking, we sold the house and moved up from Port Fairy to Warrnambool into a unit that better suited our needs. Despite operations for a prosthetic right hip and later, left knee, Roy became more mobile and his general health improved. However in 1997 he suffered severe spinal pain, this time in his lower back. Roy was referred to a pain specialist, who was also the palliative care doctor for the district. While he responded well to laser acupuncture, the pain returned even more severely when the treatment ended, so it was decided he should be admitted to the palliative care unit at Warrnambool Base Hospital (now South West Healthcare) for pain management.

It was here Roy was introduced to massage by a palliative care volunteer, whose visits became a regular and welcome part of his day. On home visits she regaled us with stories about her grandchildren. This was a welcome distraction for Roy, who was struggling with pain control despite the massages. It was during this period that I came to fully appreciate the support of the palliative care volunteers.

Early in January 1998, doctors suggested Roy undergo radiotherapy so we made the necessary arrangements to attend Geelong Hospital for daily treatments for two weeks. As difficult as it was to watch Roy undergo the radiology treatment, he took it remarkably well, and we were able to use the time to tour the area, shop, walk on the beach, relax and generally enjoy the break.

Back in Warrnambool, Roy and I joined a 'Living with Cancer' program run by the palliative care team. In such a friendly and relaxed environment we were comfortable discussing any issues we had. Without the support of the group, I'm sure it would have been a more lonely and frightening experience to go through. As the weeks passed, I noticed Roy seemed to be bending at the knees but because he was free of pain I didn't want to question him about it. Early in March he collapsed and had to be admitted to the palliative care unit. Doctors sprang into action trying to get him stabilised to enable him to go home. Roy was now paralysed from the waist down.

While Roy was in hospital an occupational therapist came to check our house, which we had rearranged and fitted with equipment, including a new bed, to allow Roy to return home in relative comfort once his health improved.



By now our children had left home, and with no other family nearby palliative support for me – as Roy's sole primary carer – was invaluable. Without it, I doubt I would've been able to cope. Another volunteer, Helen, was appointed, and later a council carer also came. This allowed me to have 'time out' for weekly card games, shopping, church activities or coffee with friends. District nurses came twice daily and also provided wonderful support.

Our eldest daughter came from Melbourne to visit as often as possible. Our son who lived locally saw Roy frequently, and I had a sister who travelled from Sydney twice to help out when things were getting tough. We also had regular visits or phone calls from loving friends – so I'd have to say we were blessed with a wonderful support network.

During that time Roy returned to the palliative care unit on two occasions for respite care. The first time I stayed nearby, however, the second time I arranged to visit our youngest daughter in Coffs Harbour. She had graduated from university the week after Roy's collapse and had since accepted a job offer. Having reluctantly moved away from her family and friends to take up the position, she missed her father and worried about his health, so I felt a visit to her would benefit us both.

From Warrnambool in Victoria my travel plans were disrupted, and I found myself stranded in Sydney overnight. At midnight the phone rang with news that Roy's condition had deteriorated and I should return home immediately. I changed my flights, returned to Melbourne, where I met my eldest daughter and we caught the earliest train to Warrnambool. Helen met us at the

station and we went straight to the hospital. Our son was already there and our daughter from Coffs Harbour arrived later that day.

The following week was the hardest in our lives as Roy struggled through each day. Someone from the family was with him 24 hours a day. Sometimes Helen took a turn at sitting with him until the final night when we were all there, including a beloved niece who had come from Sydney to offer her support. Roy died on 6 July 1998.

To have Helen and a niece to support us in our grief with their love and comfort was a truly precious gift. My own strong Christian beliefs gave me enormous strength but the love, consideration and support given to me during that difficult time by the whole palliative care team could never be overstated. I will be indebted to those wonderful souls forever.

Having been encouraged to join the Cancer Self Help Support Group, friends from there were of great comfort after Roy's death, and the loving friendships formed with my volunteers continue. If I am able to bring comfort and peace to any client my work for palliative care will have been worthwhile, and I will feel I have repaid some of the commitment shown to me. I find all I do very fulfilling and rewarding. I feel part of the team and enjoy interactions with other volunteers in courses, social events and meetings.

I hope my story will help in some way to promote the work of palliative care in Australia.

# Brian's story

As written by his wife Janine Sayers

It is always difficult to know where to begin with a story like this so perhaps I'll give you some background first.

My husband, Brian was diagnosed with a brain tumour on 18 February 1999. He was 41 years old and until then had been extremely fit and healthy. We had five beautiful children and ran our own business. We had no idea that our lives were about to be forever altered. A line in the sand had been irrevocably drawn for us on that day in February; the 'life before,' and the 'life after.'

Let me move on to tell you about the 'life after.'

Brian was operated on five days following diagnosis and some weeks later began a course of radiation and chemotherapy. During this time, we clung to the limited hope that was extended to us. However, by October, Brian required further surgery, allowing him some respite until just after Christmas. Around this time the pathology nurses suggested we call palliative care.

My first reaction was "But we don't need palliation." I feared what this meant. But the nurses took the time to explain what palliation could mean. I felt more comfortable when I realised that palliative care was much more than just nursing a dying person – it was about holistic support and understanding, ensuring that Brian could still 'live' as best he could in the time he had left. The services offered by palliative care other than nursing are also very valuable to the whole family, not just the patient.

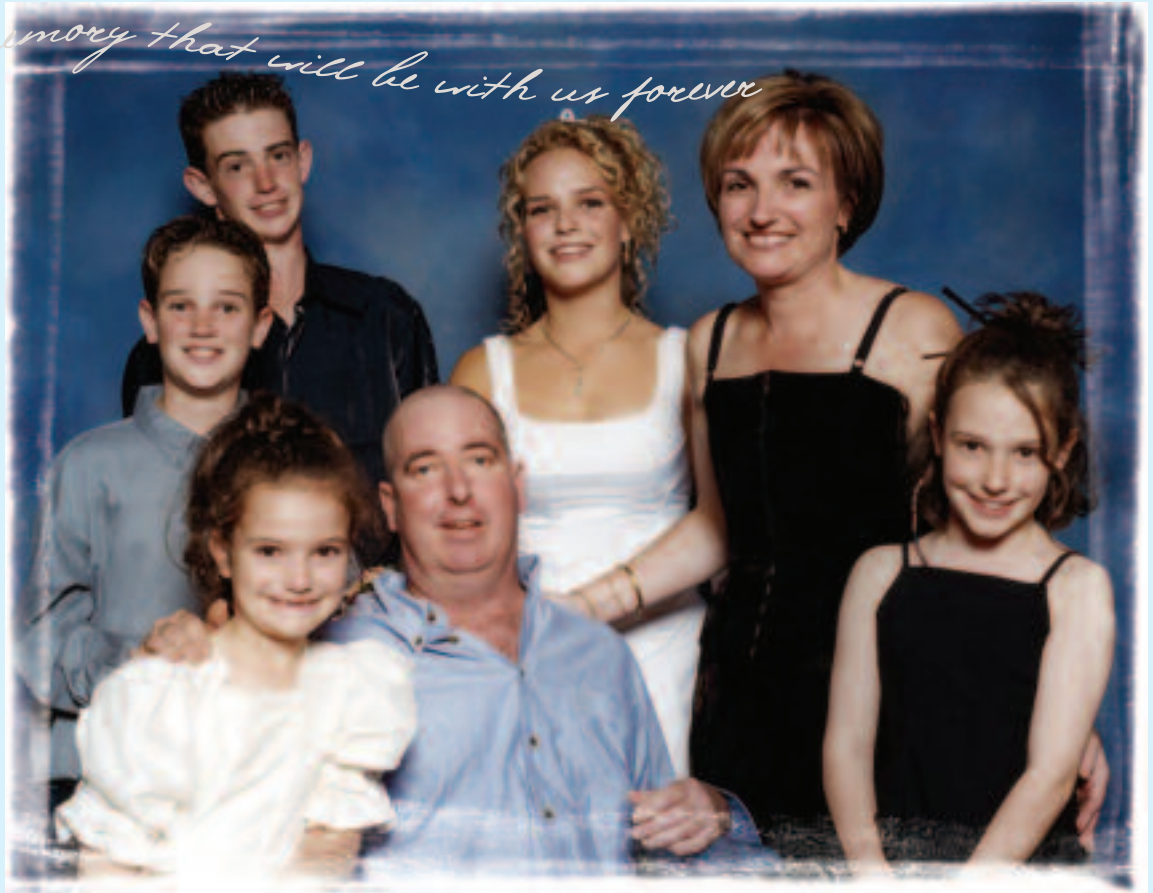
At about the same time I rang Brian's oncologist with concerns regarding his deterioration. He asked me if we had 'good support,' which I took to mean family and friends. He then said he would organise something for us. I had no idea 'good support' was a euphemism for palliative care.

When I asked my GP why doctors are so reluctant to suggest palliative care, he said some patients found it too difficult to deal with. My feeling (and Brian's too) was that as difficult as it may be, to know the truth about the diagnosis and what may lie ahead was essential. Without such knowledge decisions may not be made early enough so that as much as possible can be fitted into the well time left – a simple continuum of the best possible quality of life until the end.

We also found that Brian was able to enjoy the other services palliative care offered, whilst he was still well enough to appreciate it. In the middle of March, just eight weeks before he died, Brian was able to join us at our daughter's Debutante ball. One of the nurses helped bathe and dress him and escorted him to the reception centre. She then returned some time later to collect him and stayed with him until I returned home. It allowed me to help my daughter and

other children get ready and we were all able to enjoy the evening, despite our difficulties. It will be a memory that will be with us forever. Brian could not have shared in this precious family event without the invaluable assistance of palliative care. And the photos we have of that night, we treasure enormously.

Brian also very much enjoyed the massage therapy offered right up until his death. As a family, we really appreciated the work of the social worker involved with us. She helped Brian and I talk about the really difficult and confronting issues we had to deal with regarding his illness and impending death. We both knew we had things we wanted and needed to say but by ourselves we would just end up too upset. With a third party guiding us it was somewhat easier – we were then able to say things more easily and openly than when we were on our own.



The social worker also helped us make sure the children understood what was happening; that their father was very ill and not going to get better and would die. I found as an adult that we had to ensure we did not assume the children's understanding, and that we must let them express their version of what was happening. As a parent, I learnt not to assume my children's thoughts and perceptions. They can really surprise you with a depth of understanding that we don't often credit them with.

Although I mentioned earlier that palliative care is more than just nursing, I certainly cannot discount the wonderful support these nurses offered us. I looked upon these people as angels who would come and visit, medicate and reassure. They would laugh and cry with us. They gave me answers to questions I'd asked the doctors but the doctors found too confronting to answer directly. I had a need to know what would



happen and what to expect. The nurses answered me honestly and clearly, which allowed me to properly prepare for the difficult road ahead.

And Brian. I know he really appreciated the way they took such care of him. He was, prior to his illness a strong private person who kept his feelings and tactile nature confined to our immediate family. As he became ill he found that it was okay to be touched by others. It was wonderful to see this man reach out and talk to people and touch people in a way he couldn't before. He felt comfortable in a way I had never seen before – holding hands with men, and some of his friends would even kiss him. The nurses with their easy manner gave him love and dignity to the end and I know this helped him in his personal growth. He and I had every confidence in their treatment of him and I was constantly amazed how they were able to know what was wanted and needed and how they were able to

very carefully and gently get the doctors to see it their way – after all they deal with the dying constantly and very much acted in his best interests regarding his comfort and wellbeing.

Our whole family was included in Brian's care. I have young children and they were very much involved and encouraged to look after their father. They helped bathe him and would be encouraged to be part of the whole caring process. They were never frightened of their Dad or his illness because of their involvement, and no matter how busy the nurses must have been they always had time for us all.

Now to his death. I have to be honest – I was fearful. How would I know when the time came? How would we cope? I used to read death notices and marvel at families who had had someone 'die peacefully at home.' I would wonder at their strength. My parents, brother-in-law and GP were all fearful of him dying at home. How would

we cope? What scars would be left on the children? Would we ever be able to enter the room he died in again? And what if we had to sell the house in the future, how could we if Brian died there?

All of these questions and more conspired to convince us that Brian should die in hospital. So a fortnight before Brian died, palliative care organised a bed in a local private hospital as we felt his death was imminent. But after a little while in hospital, we worked out that home was indeed the best place for Brian. The nursing he got at home between the palliative care team and myself was far beyond what he received at the hospital. And Brian did really want to die at home. So we took him home, for the last time. We were frightened of death but as the social worker put it so succinctly "How could you be frightened? It was Brian after all."

The morning that Brian was dying – I knew. The nurses had told me there would be signs: his breathing would alter and his extremities would go a musky colour. So when I noticed this I called a nurse and she confirmed my observations. So I kept the younger children home from school and called the others back home. The younger children helped bathe him again – he even woke up. He couldn't talk although he tried. But he held our hands and he rubbed our faces. He knew right to the end where he was and who we were. I expect it was a great comfort to him. After he settled again I spoke to the children – one in particular had told me how frightened he was and he preferred his Dad die in a hospital. But we all agreed he looked so comfortable and at peace that we left him where he was.

And so Brian died peacefully in our lounge room. The children spent the morning and early

afternoon coming in and out of the house – they played outside and inside, until he died. One of them even worked on schoolwork at the foot of Brian’s bed. None of us were fearful. Brian taught us a lot that day. I am sure the dying have a lot to do with how and where they die. One of our sons had to be collected from Warragul that day and he was home only minutes before Brian died. I am convinced Brian waited, and then he peacefully slipped away.

We called a nurse and informed her that Brian had died. She came back and bathed him again – again with the children’s help. She then left us and told us not to send him away until we were ready. As we let people know, many of them came to the house. Many of them felt compelled to touch him and say their goodbyes. As a family we stayed with and touched and kissed him for hours. It was truly a beautiful healing experience.

We have no fears of that room at all, and when the time comes to move on, I know his spirit will come with us. The nurses always said we could do it, but I didn’t think we could manage such a monumental thing. However, with their help and Brian’s guidance we did indeed manage. The nurses were never judgemental – even though they knew home was the best place for Brian and all of us, they would have supported our decision to send him to hospital if we couldn’t cope. But I’m glad we didn’t.

Interestingly, when our GP arrived he was taken aback at what he saw. He admitted his lack of experience with death in the home and later told me he doesn’t like palliative medicine. When I asked him why, he answered, “Because they die.” I felt sad for him that he couldn’t take something positive from the experience of death. His input had been great and very caring and necessary.

The fact that Brian couldn’t be saved was indeed a huge shame, but what people gave to us was very special.

I remember saying to a nurse later that I felt we had done a “bloody good job.” The illness Brian suffered was a terrible one, so aggressive and debilitating. And we have all been robbed of a very special person, husband, father, son and friend. But we have also gained so much from Brian and those people who came with us on our journey. Palliative care gave us so much. The team gave Brian the nursing and the care he needed. They gave the rest of us the strength to see it through – palliative care became part of our family and a very necessary part. They saw us warts and all and were never judgemental or intrusive. As I said before, they were like angels who would appear, see things right and then leave us to be a family again.

The respite care offered was also a welcome relief throughout this time. Caring for a dying person is emotionally and physically exhausting, and I needed the respite to remain strong for Brian and our children.

I wanted to tell our story because I don't think enough is done to demystify illness and death in our society. The doctors don't always help with their approach – so many of them let their own fears influence them. One thing I learnt is that professionals are people too. They bring with them their own prejudices, cultural backgrounds, personalities and fears. We tend to think they know what's best for us because of their training and experience – but this is not always so. Especially when it comes to dying. What you feel, whether you are a professional or not, is valid. I found it important to say what I thought – to ask questions and even say “no” to some of the

doctors regarding Brian's treatment. In the end I was his advocate and had to act on his behalf, based on discussions we'd had earlier and my years of knowing him as no one else did.

I encourage people to speak up (even with their oncologists!) even though this is something I would never have done before. If you feel unsure about what you think, then ask someone before speaking out. Again, I found the palliative care team invaluable with their insights. I would say to them “This is what I think – does that sound reasonable to you?” Then I would find the courage to speak out to those who believed they knew best for Brian.

Palliative care is something not to be feared but embraced, if the need arises. I know my family would not have coped nearly as well physically and emotionally without the team. The palliative care team taught us not to be afraid and helped us find strengths we never knew existed.

One of the things I wanted to do was help others see this from a personal, 'normal' persons point of view. Not from a professional view. The nurses always said we could cope. I didn't think we could, so if I can help others see that it can be done and done well, then Brian's death can have some meaning. Our experience has been a tragic one – but it can't be for nothing. And one way to make sure it's not is to pass on what we have learnt to someone else. If I can help demystify death and dying in some small way then it won't be futile.

I hope the reader finds my story helpful. I have found writing this quite difficult at times and I'm sure it has taken me so long to do because of the enormity of the subject. There is so much to feel and think – writing it down has been somewhat confronting and draining, but maybe someday I'll find it healing too.

Thanks for the opportunity to pour my heart out.

# Alex's story

As written by his mother Jayne Turner

Seven years ago (on Daffodil Day!) my 25 year old son Alex was diagnosed with bowel cancer. He was engaged, and he and his fiancée were expecting a baby. Such a young man, full of hope and ambition, love and... life. You just never know what is around the corner.

What came next was a series of challenges and inspirations – borne out through his family and Alex himself, of course. Many of these challenges were made just that bit easier with the assistance of palliative care workers, who ultimately offered us the ability to grant our son his final wish – to die at home, surrounded by those he loved. A simple wish, yet so fundamental in this, his final journey.

Not long after his first diagnosis, Alex had a major operation to remove his large bowel and some of his small bowel. He was sent home with an ileostomy bag, and it was amazing for all of us to see how well he coped with this – it was a big ask for a young, strong man.

Unfortunately, five weeks after the operation, Alex had to go back into hospital as his small intestine had stopped working. The cancer had taken over.

Alex did not want to die in hospital and stated he would rather do so at home. Home meant at my (his mother's) and his stepfather's house, surrounded by all his family and friends. We were told at the hospital that we would not be able to cope – but they were proved wrong!

His sister, my daughter Sally, is a registered nurse and she took leave without pay from work. His brother, my son Paul, also took leave without pay so they could help care for Alex. The impact on their finances was great, but it was the most wonderful thing to witness as the bond between the three children became so strong. I shall be forever grateful to my children for putting love above all else.

As soon as Alex arrived home, Sally went to Daw House Hospice and they gave us enough medication to last until the palliative care team were able to visit to assess Alex's needs with regard to pain relief. They then liaised with our family doctor and also the Adelaide Hills Community Nursing Service. Each member of the household were given instructions on how to administer Alex's medication, and it didn't take us long to become quite good at this.

Alex and Jayne (his fiancée) decided to get married, so on the 13 October a sad but joyful service was held in our garden. Four days later, their beautiful daughter Bianca was born and Alex was able to be present at the birth. The Women's and Children's Hospital in Adelaide did everything they could to accommodate Alex and Jayne, including giving them a room with an extra bed in it so that Alex could lie down when he got tired.

*Their beautiful daughter Bianca was born and Alex was able to be present at the birth*

Alex decided he would like his funeral before he died, so on the 25 October 1998 everyone came to say goodbye – it was the most moving, emotional and happy day that you could ever experience.

On the 3 November 1998 Alex passed away at 4.45pm. We kept his body with us for about five hours, which was very important so we, the family, could say our special and private goodbyes to him.

None of this could have happened without the help of the family, palliative care team, family doctor and the Adelaide Hills Nursing Community, who were prepared to help Alex die in the manner and surroundings he wanted. Alex was able, in some ways, to take control over his death. He took control of the last few weeks of his life, and we certainly had some incredible and unforgettable times together during that period.



If he had been in hospital none of these special events would have been able to take place, and I do not believe that Alex's pain would have been managed so well. I feel so passionately about the need for people to be able to die at home, that I have joined the Palliative Care Volunteers Support Group. I hope, with all my heart, that I can pass on my experience to as many people as possible and help them die surrounded by the people and places they hold most dear.

The relatives/carers need as much support as they can get and the more information they receive the better it is for everyone. I am sure that more people would be able to die at home if more provisions were made for carers who usually work, but have to take leave without pay to care for their loved ones. I feel sure that if these provisions were made, more people would choose to die at home.

I have enclosed a piece of writing by Alex. Every morning he would get up, before the rest of the household was awake and add to the piece. He made his journey so wonderful and special for all of us, as he was never angry or afraid. He even told me that he was really looking forward to his next journey in life. He was such a special person and has left behind many memories, and of course his beautiful daughter, who looks, speaks and acts just like him.

I sincerely hope that more funds will be made available in the not so distant future, so that other families will be able to experience what we did – death as a gracious part of life.

## on the road to dying

*By Alex Collins*

The pros of knowing that you are going to die:

Getting to say goodbye to everyone.

Tell people how much you care about them.

How you get to build bridges.

Inspire people.

Encourage people to love one other.

To recognise deep long-standing friendships.

To feel good about the life you have lived.

It makes me feel special.

I believe that my soul and spirit will be released, but I will have no conscious thought, and therefore I won't be looking back wishing that I was doing things that others were doing, which allows me not to be sad now. Others are thinking about me as a parent and realising all of the moments I will miss out on, but I will not miss them because I will not be here.

However if my wife, family or friends want me to be with them, I still can and will be, on a spiritual level.

# Judy's story

## Being a palliative care volunteer

Could I really do justice in recounting someone's personal story, when all of my experiences were with people who often only had a short time to live? This was the question I kept coming back to when I was asked to write a story about one of my experiences as a Cittamani Home Hospice volunteer.

Despite having spent many hours, with countless people over the seven years I have been a volunteer, I realised that because I usually stayed overnight with patients (to give their carer or family some respite so they could get a good nights sleep) I had not really gotten to know people as intimately as other volunteers who help during the day, sometimes over a period of weeks or even months. But as I recalled the many faces, the humour and bravery of the wonderful souls that had come into my life, albeit fleetingly, I knew there were many stories worth telling.

Would I tell the story about Betty, who was being cared for by her two sons – both young men in their early twenties, who were lovingly caring for their bed-ridden mother in her last days? I remember when they told me, “she looked after us when we were babies and helpless, now it is our turn to look after her.”

Would I tell the story about Ted, dying of throat cancer and couldn't communicate who was being cared for by his wife June? When I arrived late one evening to stay overnight, I could tell June hadn't slept in ages. Despite her tiredness she still put Ted's wellbeing ahead of her own saying: “Ted has been through so much. I don't want him to go back into hospital. He wants to stay at home and die in familiar surroundings.”

And what about John, the devoted brother, caring for his sister Hazel who also wanted to die in the surroundings she loved?

Would I tell the story of the brave young man in his early twenties, who was being cared for by his devoted parents, or would I tell a funny story of my overnight closely watching a husband who was dying of a brain tumour and was determined to escape?

Suddenly all the people I had shared experiences with came flooding back. As you can see it would have been folly to try and write about any of them individually. Collectively though, I realised all of my untold stories had a familiar theme. A loved one was dying. They and their families wanted them to die at home surrounded by family and familiar things. For the person dying, it was important to have someone who loved them with them at all times – sounds so easy in theory but not always in practice. In most cases I was able to see the wonderful team of family, doctor, Cittamani nurses and volunteers all working together making sure the family and patient never felt alone.

*the special bonds that develop between the volunteers and families.*

It is quite awe-inspiring to have seen families plumb the depths of their energies and emotions and find resources they never knew they had. All of these families, after caring for their loved one at home, allowing them to die in familiar surroundings, said they would do it all again if they had their time over.

For myself, the thing I find so special is that I get to see people as they really are, and I can be who I really am. There is no veneer, just honesty and trust. There is no room for being false – there is just no time. The obvious pain of those I visit helps me to confront what is real and essential in life. Being able to support families who are often exhausted, stressed and having difficulty accepting what is happening with their loved ones is a very humbling experience.

So my story is not of one individual episode as a palliative care volunteer, but of all the families who have shown the common thread of courage, love, care, devotion and personal growth, the compassion and skill of the Cittamani nurses, who are on call twenty four hours a day, seven days a week, and the special bonds that develop between the volunteers and families.

It is truly a great privilege to be a palliative care volunteer.

*It is truly a great privilege to be a palliative care volunteer.*

# Jessica's story

As written by her mother Michelle Sutherland

When asked to pen this piece, I thought of all the other contributing writers and the sadness we must share. I am glad to offer my story because I know that when people think of death and dying, they often think of older people... but our daughter Jessica died when she was only three years old. This is her story...

Jessica Lorraine Sutherland, our beautiful daughter, was born a healthy, happy, and much wanted baby girl, on 24 July 1998. Jessie progressed through the normal stages in her first years, walking and talking like other children. She was a very happy girl with a kind heart, who loved us reading her stories at night, playing with her baby brother Jay, and watching her favourite videos, in particular 'Winnie the Pooh' and 'Bob the Builder.'

Jessie lived for Friday, which was her playgroup day. She had so many dear little friends, and those children's parents also became close friends to our family, as our bond developed through the shared joys and laughter of parenthood. Jessie's other favourite pastime was to go toy shopping and stopping for a baby cappuccino – we could see her in future years, sipping lattes with other 'trendy' young people. So many years away, and so much time we should have had with her before those days... but it wasn't meant to be.

We moved into a new house just after Jessie's 3rd birthday in July 2001. We were a happy family, oblivious to what was going to happen in the next few months of our lives. Jessie loved the new house and loved playing in the playroom, and she just adored her new 'Winnie the Pooh' bedroom.

Around the end of October, Jessie complained that she had a sore mouth and started saying that she felt 'wobbly.' It was then that I noticed she was walking somewhat like she was under the influence of alcohol. A couple of days later on my birthday, I decided to take my son Jay to my GP for his 18 month old vaccination. I also mentioned to my doctor that Jessie was walking strangely. My GP observed Jessie walking and told us we needed to see a neurologist urgently.

A couple of hours later on that birthday in October I was sitting talking to a paediatric neurologist at Monash Medical Centre. He mentioned that an MRI scan would need to be performed and he booked her in. He said. "You know what we are looking for don't you?" I said. "Yes, you are looking for a tumour." He just nodded.

It was then that our roller coaster started.

*She was a very happy girl with a kind heart,*



The very next morning, Jessica could not walk, her face had dropped to one side, and she was drooling and very hard to understand. We took her back to the hospital where she was admitted and we waited in anticipation of her MRI scan to find out what was happening. The night before the scan I was talking to Jessie in the hospital and I asked her if she hurt anywhere. She put her hand to the back of her head. I burst into tears and said to myself, "Oh no, she has a brain tumour."

On October 2001 Jessie had her MRI scan. The doctors called us into a room and in that room our lives changed forever. Jessica was diagnosed with a brainstem glioma (GBM 4) which was very, very aggressive. I asked if she was going to die and my heart almost gave up, on so many levels, when they responded that there was no hope for

a cure. For soon, my other heart, my Jessie's heart, would stop. I did appreciate the doctors not holding back on any information. I just wished that this was not happening.

Things moved so fast from there. We had a meeting with a surgeon who said he could operate to do a biopsy and try to remove tumour that spread. We agreed to this, as she was so agitated and frightened. The pressure in her head must have been unbearable. Jessica had a seven hour operation on 2 November 2001 and spent the next few days in intensive care. The doctor did remove quite a bit of tumour, but obviously he could not go into the brainstem.

When Jessica came home six days later, she barely talked and she could not walk. We received a phone call from Carol Quayle from the Paediatric Palliative Care Unit at the Royal Children's Hospital, to discuss palliative care.

*who loved us reading her stories at night, playing with her baby brother Jay*

My first reaction was one of complete denial – for to accept palliative care was to accept, with absolute certainty, that Jessica was going to die. I also had visions of them taking Jessie away to die. However, we decided to meet with Carol and she came over and discussed what palliative care services could assist us with. I had no idea that I could keep Jessica at home and that the palliative care team could help us in caring for Jessie. There were also other things offered that I had never even considered, such as musical therapy.

A nurse called Paula initially visited us once a week, increasing her visits over the next few months as required. We also started music therapy. Jessie seemed to like the music, particularly banging on the drums. The music therapist put a song together which I wrote and

sang at Jessica's funeral. It was the most beautiful thing I have ever heard. We were also given access to a counsellor who was lovely and made herself available for any concerns we had, from our feelings of grief and the unknown, to what we tell Jessie or her brother about what was happening.

Jessica had a couple of rounds of chemotherapy and after the second round, it became a struggle for the doctors to find a vein. I hated having to hold her down, and try to get the oral medicine down. Around the middle of January 2002 we finally decided to stop the chemotherapy. Jessica was having trouble sitting up so we knew that the tumour was on the move. The day we decided to stop the chemotherapy we told Jessica that there was going to be no more hospitals and no more needles and that she was going home forever. She gave us a smile. But without having the support of the palliative care team this would not have been possible at all.

Our palliative care nurse Paula arranged everything to do with the drugs to keep Jessica comfortable. The nurses were on call day or night and if I had any problems I could just ring and they would come out. Fortunately, Jessica slept with me at night and was very peaceful so there was no need for the nurses to come at night, but just knowing I could call was very reassuring.

I think the most important thing to us and to Jessica was that the nurses understood Jessica. They knew she didn't like being stared at and surrounded by people. Paula used to come in and say hello to Jessica and then sit to one side and just observe and answer any questions that we had. Sometimes she sat with her and talked and played little games with her.

The last few days before Jessie's death were something I would never forget. I was not scared of Jessie dying. I knew she would be at peace. I just wished she didn't have to die to beat this brain tumour. During this time Paula was visiting every day and advising me on the dosages of the medications such as morphine. She showed me what to do to make Jessie comfortable. It was important for me to care for my daughter. It was the last thing I could ever do for her, and the nurses were there to help guide me every step of the way. They were wonderfully supportive and reassuring.

The day Jessie died Paula was at our home. My son was asleep and most of our family had gone home. It was a great comfort to have Paula there for backup. I don't think I would have been as calm. Paula took our last remaining visitor into another room, and my husband and I were left with our beautiful girl as she commenced on

her new journey. Jessica died on 3 March 2002 at 1.10pm. It was a beautiful Sunday afternoon and she was on her couch watching television. She died in our arms so peacefully, held by her loving parents, the way she would have wanted it to be; in her new house which she loved so much.

It was nice to have Paula to remove Jessica's nasogastric tube and at my request she helped my husband and I wash and dress our beautiful girl.

I would like to thank Carol Quayle for meeting with us initially and explaining all about palliative care and what it involved. I would also like to thank our nurse Paula Vincent who is an amazing person, compassionate and understanding. Thank you also to all the team at Eastern Palliative Care. What was the most difficult time in our life was made just that tiny bit easier and I am forever grateful.

Peace, perfect peace Jessie.

# Greg's story

As told by his wife Gai Gibson

When my husband Greg was diagnosed with lung cancer in August 2002, he was only 54 years old. Although grappling with the emotional strain of what this diagnosis meant, I automatically presumed that because of my training as an occupational therapist, I would be able to provide the level of care Greg needed. However, I soon realised that this was not to be the case...

Living in rural NSW, on a farm 50 kilometres from the major centre of Orange, help seemed out of reach. It wasn't long though before I discovered the wonderful staff from the local palliative care team, and came to rely on them as a trusted source of advice and comfort through the last, painful months of my dear husband's life. The love and support of our two daughters throughout their father's illness was also a great inspiration to me as I came to terms with the inevitable loss of my best friend, and lifelong companion.

The doctors told us Greg's cancer was operable, so we took Greg to Sydney and he had his tumour removed at Royal Prince Alfred Hospital, where he was hospitalised for five weeks of radiotherapy. Greg returned home in time for Christmas with the family, but soon after developed complications, and was admitted to hospital in Sydney, this time in St Vincent's, for a further three months. I was fortunate enough to be able to stay with Greg the whole time and became his main carer within the hospital and the rehab centre. However, this time the news from the doctors was heartbreaking. They told us Greg had extensive lung damage – and had less than 12 months to live.

Greg was not able to return home until April 2003, but even when he did, his body, ravaged by the effects of radiation/radiotherapy, was so fragile he was on 24 hour oxygen, and was unable to walk more than 50 metres at a time.

From that point on Greg's health gradually worsened, and by June he was re-diagnosed with another tumour. Greg died at home in early October, just 3 days after his 55th birthday (this has significance explained later in this story.)

During his last months at home Greg required two oxygen concentrators to keep up the supply of oxygen to his weakened lungs. The need for oxygen was so great he was not able to manage for more than a few minutes at a time without this precious, life sustaining substance. And, since we lived in the country we seemed to be more prone to blackouts, so as a precaution we would always need quite a supply of cylinder oxygen in the house.

Aside from the oxygen cylinders, Greg needed other specialised equipment, which I was able to purchase before leaving Sydney using some funds from a small life insurance policy. These included a Roho mattress and wheelchair seat;



*Greg always wanted to be out and about*

an electric hi-lo bed; special padded commode/bathseat and manual and electric wheelchairs. I spent three weeks in Sydney running around purchasing these items from various suppliers because many were difficult, if not impossible, to come by in the country. This was an emotionally draining period but I knew Greg would need all these things on his return home. In hindsight, this was one of the best decisions I made, as it was so much easier to care for my husband with equipment that made him more comfortable and independent.

When Greg and I returned home in April 2003 I was able to go back to work on a part-time basis, even though I much preferred to be at home with my precious husband. Throughout his illness, Greg always encouraged me to maintain some interests away from home and the farm and our daughters were doing an amazing job

caring for their father. However, every time the mobile phone rang, my heart would sink – what had happened at home? Was everything OK?

Greg had developed severe nausea from time to time, which we think was caused by high calcium levels in his blood, and it had become a frightening experience to see him in such distress. He needed to have a drip every month to bring his level down. We tried going to ‘day procedures’ on the first occasion but they didn’t even have a bed to lie on, just a very hard recliner chair. Luckily for us the Palliative Care CNC offered the use of the Cancer cottage for the next two sessions – a real lifesaver.

Despite his illness, Greg always wanted to be out and about, and for close on five months this is exactly what he did. If it wasn’t around the farm, it would be trips to Orange to make small purchases for the garden, house or farm.

The effort of taking him out was enormous, but was emotionally rewarding for us all. For what was once a simple trip into town we now needed to take a seemingly endless list of supplies, including oxygen cylinders; an oxygen conserving device; wheelchair; Roho cushion; mask, as well as nasal prongs; morphine nasal spray; Ventolin; and mobile phone in case of breakdown. A doctor’s appointment at 11:00am required us to make a start at 7:30am – the care was constant.

Shortly after Greg’s return from hospital, we were visited by Helen, the palliative care nurse and Jenny, the community nurse. Greg immediately enjoyed this first visit and was able to say exactly what he would like to see happen with his care at home. He wanted to die at home but not until his birthday and was reassured by the fact that these two ladies would do everything in their power to assist him achieve these goals. From that day on, Greg looked forward to their visits.

Our daughters, Erin and Jess, and I also became very appreciative of their support for all kinds of things – medical, emotional and practical. I recall one occasion when Jenny arrived one weekend with her husband, who gave Erin a lesson on chainsawing in the paddock – to help with our wood supply over winter.

We were also very lucky to have another member of the team who provided the medical care Greg needed – a GP who did not insist on seeing Greg and took advice from the palliative care CNC or the community nurse. These three wonderful people became our lifeline in keeping Greg at home. Once Greg had decided he wanted to die at home, they made it very straightforward and easy to provide the care he needed. The support and advice they gave us regarding medication, diet, and pressure care was a great help to my daughters and I in providing the level of care Greg needed and deserved.

At the beginning we were able to leave Greg at home alone for about 30 minutes, as long as he had a back-up cylinder and a mobile phone at hand. However, we all felt increasing discomfort leaving him alone, and tended to ensure someone was always with him. At this time Greg really needed the three of us to be available to provide his care if we were all to remain sane.

One of the major issues causing stress for Greg throughout his illness became his superannuation. Soon after his diagnosis – about 12 months before his death – Greg realised there would be considerable benefit to me if he lived until he turned 55 years of age. This immediately became his goal and by the time he reached his birthday on 1st October, he looked at me and asked, “Would it be OK to die now?” As I mentioned earlier, he passed away three days later.

I tell this part of Greg’s story for a few reasons. Firstly, I believe it reinforces the significant role ‘the will to live’ can play in terminal illnesses. Secondly the medical team and palliative care staff were all aware and totally committed to trying to help Greg live until his 55th birthday. Finally, particularly for Greg, having a goal became a huge focus and reason for living.

Perhaps when people with terminal illnesses are receiving support, focussing on achieving goals is a great comfort to them as they leave the world. It shows that there is still a goal – that dreams should never cease and that every day serves a purpose – even for the dying. For Greg, however, it did come at a cost. The amount of anguish and stress we all experienced when things went a little awry and it looked as though Greg may not make his birthday was enormous. Keeping Greg in touch with his interests – his work, the farm, his family and friends – rather than always

focusing on medical appointments, medication and his illness became an important part in helping Greg survive as long as he did, and as long as he wanted to.

In hindsight I realise what a privilege it was to care for Greg and would like to encourage everyone who has someone terminally ill in their family not to be frightened by the inevitability of being with the person you love when they die – hopefully in their own home. Whilst it takes a lot of energy, there are many wonderful people only too eager to help and support you to care for your loved one at home. The amazing dedication and guidance from the palliative care staff meant the journey was far less daunting than it might otherwise have been.

For further information or assistance with palliative care please contact your local member association:

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**Palliative Care NT**

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**OTHER USEFUL CONTACTS:**

Commonwealth Carer Resource Centres:  
1800 242 636 (freecall\*)

Carer Respite Centres: 1800 059 059 (freecall\*)  
Lifeline: 131 114

\* Freecall from local phones. Mobile calls at mobile rates.

a journey lived

*a collection of  
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