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## Compare the pair - Two carer stories

Karen and Robyn are two Victorian women that provided palliative care for a beloved family member at home. Due to where they lived, Robyn was eligible for EPC's services and Karen was not. Being supported by EPC makes a significant difference to the carer's experience and often results in EPC clients being able to stay at home. They have kindly and courageously agreed to share their stories and we thank them.

### Karen's story (without the support of EPC)

My dear husband Rudi and I were married for 35 years. We met at Church and after working as a radiographer I left that to work with him at his Metal Spinning business until we retired. We lived in Central Victoria and when he fell ill we were on our own at home. Our two children were grown up and living in Melbourne so I became Rudi's full-time carer. We were 20 kilometres from the nearest town so my life was soon consumed with supporting him. He began suffering from heart disease in 2015 and had multiple hospitalisations. He died several weeks after being admitted the last time, in October 2017.

### Robyn's story (with EPC's support)

Our beautiful Ethan was born with a very shortened life expectancy of only six months - one year. He came to live with us, in the leafy Eastern suburbs of Melbourne, at ten months via foster care, and he remained in our permanent care until his passing at 14 years and four months old. Ethan was born with Hydranencephaly and therefore he had fluid in parts of his brain. Although he was profoundly disabled, he was a very happy little man, and such a huge part of our family. I was 43 years old when Ethan came to live with our family and I was his primary carer throughout his life. Loving, looking after and caring for Ethan were some of the most beautiful and painful experiences of my life.

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Robyn and Ethan

### Message from Gaylene

Welcome friends! I know the festive season would have been challenging for a lot of you in this time of celebration and grief combined. I hope you found some joy, however that looks for you.

We are excited about the opportunities ahead. We are embedding our new allied health and volunteer service models, as well as enhancing how we deliver care to our clients who reside in aged care facilities. Our goal is to prioritise those who need our services the most at any given time. Given that our state Government funding has not increased, we must continually review how to make our funding go further to meet the needs in the east.

Last year, we introduced video-telehealth as a regular service for clients who are stable. This initiative reduces the number of clinicians in clients' homes and saves on travel time, allowing us to care for more clients. Video-telehealth doesn't suit all stable clients and that's absolutely appropriate - we do face to face visits where required. We value feedback from clients or carers who have experienced our video-telehealth service.

Palliative Care Australia has commenced their federal government election campaign - Better access to palliative care - worth voting for! I would encourage you to explore and sign the online petition for improved funding for palliative care - [palliativecare.org.au/campaign/better-access-to-palliative-care-worth-voting-for](https://palliativecare.org.au/campaign/better-access-to-palliative-care-worth-voting-for).

Thank you for your ongoing support, and I hope you enjoy reading this newsletter.

Adjunct Assoc Professor Gaylene Coultou  
CEO, EPC

# Compare the pair – Two carer stories

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## Overnight Nursing care

**K:** If we ran out of medication or needed more or other help in the middle of the night Rudi just had to cope as we couldn't do anything. There were no pharmacies open and we couldn't get any nursing care or prescriptions overnight.

**R:** I knew that help was available if I ever needed any help during the night with nursing care or getting a prescription. We are forever grateful for all of the care and attention EPC gave us at all hours of the night and day. There was someone on the other end of the phone who could help us 24 hours a day.

## Nursing Care at home

**K:** I would have liked an occasional nursing visit at home. I was always worried whether the medical decisions I was making in caring for Rudi were good ones.

**R:** The nurses visited as often as we needed them and were here every day near the end. They were so beautiful with Ethan, especially Amber who I will never forget. She brought a beautiful and fragile orchid to give to me when Ethan passed, as she was the one I called when he died and who had been here throughout that day. I will never forget her kindness and how gentle she was with us that night.

## Available therapies and non-clinical support:

**K:** Rudi was permitted 12 free consultations a year and we divided it between the physiotherapist, the podiatrist and the dietitian. We had to travel to these appointments. No other free therapies were available to him.

**R:** All of EPC's services are free and they provided a lot of extra ones to Ethan and to us as a family. We enjoyed music therapy together where we all sang to Ethan and he also benefited from EPC's massage therapy. During Ethan's last months we were a part of the EPC Biography program which was a lovely way to talk through Ethan's life and relive some of the beautiful memories we had together. It is such a lovely journey to take and I treasure the books that we have given to our children, that they now read to their children to keep Ethan's memory alive.

## Carer Support:

**K:** As a carer there were no agencies that supported me personally, or assisted me at home. My daughter and my son were very supportive, however, they couldn't help physically. We were not eligible for council services aside from one that we rejected as it was not suitable.

**R:** As Ethan's primary carer and mum, I managed Ethan's 24 hour care. I was not working and my husband was the main breadwinner of the family. My husband Derek was and always will be a great support for me, and he has been my strength to get through this time, obviously along with my family (my other four children and their partners). We also have a very close relationship with Ethan's birth parents who were and are a very valuable part of our family. I was also well supported by EPC. I can also honestly say that the support and compassion we received from everyone at EPC was amazing.

## Greatest challenge you faced as a carer

**K:** The greatest challenge during this time was isolation and exhaustion. Caring for a loved one is constant, physically demanding work.

**R:** Before Ethan died, the greatest challenges I had and we had as a family was the waiting and the wondering when we would lose him. One day he would have a good day, and the next a bad day.

## What were you most grateful for?

**K:** When Rudi was discharged from hospital in 2015 no one expected that he would live as long as he did. His pain was able to be controlled with oral medication until the last few days when he was admitted. Despite the difficulties, we had a happy time just being together. I am very grateful for that.

**R:** I was most grateful that Ethan could sleep the last few weeks of his life between my husband and I and I could cuddle him all night and be there when he needed me. We could tell him over and over again how much we all loved him, and everyone could have their own private time with him right until the end.



Karen and Rudi

Donate to EPC's Care for the Carer Appeal and help EPC to support carers at [epcvic.org.au/donate](https://epcvic.org.au/donate) or scan the QR code. To read Robyn and Karen's full stories go to: [epcvic.org.au/news](https://epcvic.org.au/news).



# Volunteers Needed

We are recruiting members for our award winning Volunteer program. Becoming an EPC volunteer provides opportunities to enhance leadership skills, network with others, be active in your local community and make a difference to somebody living with a life-limiting or terminal illness. Come and join our team at EPC and see how your visit can change the day!

## Current opportunities include:

- **Biography** - join our award-winning team who have worked with over 1,700 clients to write their biographies.
- **Community Support** - provide companionship to clients, social outings and respite support for carers to give them a break.
- **Dog walkers and “furry” volunteers** - walk a client's dog, or bring your own dog to visit a client at home.
- **Hairdressing** - provide a hair-cut and blow dry to a client at their home.
- **Smile Makers** - photograph clients and their families to create lasting memories.
- **Those who identify as Male** - help other men in your community to feel understood and connected.
- **Chinese, Mandarin, Cantonese, Italian, Hindi and Greek Speaking** - help us with translation to communicate with our clients and also support our Biography program.

Volunteer training begins in August. For more information go to [epcvic.org.au/volunteers-services](http://epcvic.org.au/volunteers-services) or call our team for a chat on 1300 130 813.



# Giving Tuesday Appeal

We are thrilled to announce that we raised **\$5,616** for our Giving Tuesday appeal. This means we can purchase one new Syringe Driver and are close to getting another!

With a cost of \$3,000 each EPC needs your help to buy 10 more as they allow clients to stay at home and be as comfortable as possible. Our nurses thank you, our EPC community, for this essential piece of equipment.

Thank you to everyone who donated. If you would like to donate to EPC's Syringe Driver Appeal and help us buy 10 more, go to [epcvic.org.au/donate](http://epcvic.org.au/donate) or scan the QR Code.



# Safewill Free Wills Week

Save the date! This March we are partnering with Safewill to offer FREE Wills for an entire week.

 **Mark your calendar: 17 - 24 March** 

Did you know that only one in two Australians have a valid Will? Don't leave your future to chance. Write your Will for free with Safewill, and have a lasting impact on the future.

It takes as little as 20 minutes to complete, is reviewed by their affiliate law firm, Safewill Legal, to ensure it has been filled out correctly and comes with a year of free and unlimited updates.

Having a Will means knowing your wishes are respected and your loved ones will be taken care of when you're no longer around. It also provides an opportunity to leave a meaningful gift to EPC, supporting our mission and making a difference to the causes you care about.

For more information or to secure your free bespoke Will during Safewill Free Wills Week, go to [safewill.com/epc](http://safewill.com/epc).

## In Lieu of Flowers



Thank you to the families of the following people, who arranged for donations to EPC in lieu of flowers at their memorial service. We are so grateful that you thought of EPC during such a difficult time.

**George Dounis**

**Robert Beattie**

**Albert Wheeler**

**Keith Berryman**

When planning a memorial service, consider creating an EPC In memoriam page or requesting donations to EPC in honour of your loved one. This gives friends and family a way to express their condolences to you, or for you to thank EPC publicly. For more information go to [epcvic.org.au/donate](https://epcvic.org.au/donate).

## Gifts in Wills

Thank you to The Estate of Tina for their generous recent bequest.

## 2025 Key Dates

Jun 2	Registration Opens for POUND THE PAVEMENT 4 EPC
Aug - Sep	Volunteer Training Intake Sessions
Oct 12	POUND THE PAVEMENT 4 EPC
Oct 23	EPC Annual General Meeting
Dec 2	Giving Tuesday Appeal

If this newsletter has arrived at a difficult time, we sincerely apologise. If you would like bereavement support, please contact us on 1300 130 813. All donors are added to EPC's quarterly newsletter email list. To opt out, simply call us or email [fundraising@epcvic.org.au](mailto:fundraising@epcvic.org.au)

Eastern Palliative Care Ltd (EPC) is located in Melbourne on Wurundjeri Country. EPC wishes to acknowledge the traditional owners of this land, the Wurundjeri People and their Elders past and present.



## WE NEED YOUR HELP!



EPC is a not for profit organisation that relies on donations, bequests and fundraising to maintain service delivery. As our State Government Funding has not increased, we need your help more than ever!

Your donation will assist us to provide specialist palliative care for those that have a life-limiting or terminal illness, and their families, across Eastern Metropolitan Melbourne.

Please consider making a monthly gift to EPC to help maintain our vital services. To donate go to [epcvic.org.au](https://epcvic.org.au) or scan this QR code. Thank you for supporting us!



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