

# **A very special guardian**

**A guide for using your Will  
to help children and young  
people with life-limiting  
conditions and their families**





***“A gift in your Will is the most joyful thing. It gives those of us blessed with longer lives the chance to share our good fortune with children and families whose time together may be fleeting.”***

**Sister Margaret Noone AM,**  
Founder and Patron

# Laying the foundations



*I invite you to consider leaving a legacy that can continue to provide care and support for children and young people with a life-limiting condition and their families into the future.*

Within these pages you will have the chance to meet some truly wonderful people, including Jett, the little boy pictured on the front of this booklet in the arms of his adoring mum and dad. Jett's life has been beset with devastating challenges since birth. As you will read, the care and support made possible by Very Special Kids has helped him and his family create memories that they will cherish forever, no matter what the future may hold.

**It's not just children and their families who benefit from the support gifts in Wills can provide. For those who choose to leave a lasting legacy, they become a part of an important group of people, known as Very Special Guardians.**

Simply knowing that their kindness and generosity will continue changing children's lives after they've gone is a source of joy and fulfilment. This is something that volunteer Sue Hardiman, who you will read about later, expressed beautifully.

I hope you will be inspired by the story of Very Special Kids. I also hope you will join me in leaving your legacy to continue ensuring more children and young people can experience a better quality of life, and their families can cope with one of life's most difficult challenges, the death of a child.

**Thank you again for your time and your consideration today. I am truly grateful.**



**How the kindness and generosity of ordinary Victorians helped Very Special Kids transform the care of children and young people with life-limiting conditions and their families forever.**

I started Very Special Kids in 1985. It was born out of the grief of two remarkable Victorian families who sadly lost their young children to leukaemia. At the time, there was no appropriate care for families like theirs, and so the only support they had was from each other. The bereaved parents refused to

accept that any parent or sibling should have to face such distress on their own and when I learned of their struggles, I felt driven to help them. It's hard to imagine now how families coped alone with a seriously-ill child over 30 years ago. As a result of hard work and support from an amazing Very Special Kids community, it is a very different story today. Back then, families were expected to endure the pressures of caring for their dying children on their own, and counselling for bereaved parents and siblings was almost non-existent.

The death of a child is the hardest thing a person can face. With the help of dozens of like-minded experts and volunteers we were able to transform paediatric palliative care, by building Australia's first children's hospice and offering the emotional, clinical and practical support families needed to cope through their darkest days. Since then, Very Special Kids has helped thousands of families endure the death of a child.

Our original hospice provided thousands of seriously-ill children and their families with a home-away-from-home for over 25 years. Today, the clinical needs of children

are significantly more advanced, and children are living longer with these conditions into adolescence, thereby placing higher care needs on their families as full-time carers. The brand new world-class hospice will ensure internationally led best practice paediatric palliative care can continue to be delivered for children with life-limiting conditions and their families across Victoria for generations to come. It's an incredible achievement the entire Victorian community can be proud of – not least those extraordinary people whose gifts in Wills helped make so much of these great leaps forward in care possible.

***I invite you to become a Very Special Guardian, and with your kindness and generosity continue the journey I started for Victorian families.***





# Meet Jett's family

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**How our Very Special Guardians are helping little Jett and his family create happy memories and magic moments to cherish every day they have together.**

Jett was very ill before he was born. Diagnosed with a serious gene mutation known as KCNQ2, specialists didn't think he would make it. Although his parents Kristy and Damian were overjoyed he made it into our world alive, Kristy told me that the devastating reality of his condition left her close to despair.

Kristy shares: "As well as coping with debilitating issues with his bones, Jett suffers from severe and frequent seizures, sometimes as many as 20 times in a single day. And before we reached out to Very Special Kids, there were times when I didn't know how I would cope. Jett fell in love with the hospice so quickly, and so did we. Music therapy is his favourite. You should see his little face when he's banging out a tune on the tambourine or the maracas, or enjoying a good cuddle."

**Knowing that so much of this love and care is only possible because of the compassion of our Very Special Guardians – Kristy told me she finds that mind-blowing.**

*“To those who help make all this possible by choosing to leave a gift in their Will, I could never thank you enough. Only those like us who have experienced the care you supply can truly understand what it means.”*

“No-one can say for sure what the future holds for Jett. His condition constantly creates new challenges for him. But the fact that he is able to not only endure his life, but to enjoy it, that has so much to do with Very Special Kids.” By leaving a gift in your Will, you can provide future generations of seriously-ill Victorian children and their families with the tailored support they need at every stage of their journey.

**You will be improving their quality of life and creating more happy memories for their families to cherish after their final goodbyes.**

*“As soon as I walked through the door of the hospice, I felt the weight fall off my shoulders. I was deeply moved by the efforts of the specialists, nurses and volunteers to properly get to know Jett, the things he loves, the routines that bring him comfort and what makes him unique.”*



# Leaving your legacy

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**There are so many ways your legacy to the future will help the families who depend on us, but here are the three that I find most important:**

- You will help improve the quality of life for children with life-limiting conditions: your generosity will enable our paediatric care experts to offer every child tailored medical care ensuring they experience as much happiness and as little discomfort as possible during their shorter life.
- You will help ensure families don't have to cope alone: your support will help parents, carers and siblings navigate through their unimaginable situation, by providing counselling, respite, peer support and creating memories and moments of happiness to be cherished long after the child's death.
- You will help us continue to change lives for generations to come: Your kindness will live on and ensure that future generations of families throughout Victoria are supported through their child's illness and bereavement, by being provided with care for a wider range of complex medical conditions.

**Becoming a Very Special Guardian and leaving a gift in your Will for Very Special Kids is more than just another way to donate to a cause you care deeply about.**





**Wills are a wonderful opportunity to take comfort in knowing that the people that matter to you the most benefit from your life's work exactly as you would wish. When you add a charity you care for, like Very Special Kids, Wills are also an incredibly powerful tool for positive change.**



Here are three key considerations when remembering Very Special Kids in your Will:

- **Adding Very Special Kids to your Will is easy:**

Adding the causes that matter to you is an important decision that reflects your values and priorities. We suggest you talk to a competent solicitor who can help you draft your Will and make sure it reflects your wishes.

- **There's no need for your loved-ones to go without:**

Some people worry that their family might miss out. Adding Very Special Kids to your Will is all about putting family first — not just the families of children

we care for, but also your own. With your solicitor's help, you can ensure that both the causes you care about and the people you love benefit from your legacy exactly as you would wish.

- **You don't have to be wealthy to make a difference:**

All bequests, no matter what their size, can help make life better for very special children and their families. So please don't hesitate if you don't feel you have much to give. Every little bit helps, and it helps a lot.



**For legal advice in creating your Will consult your solicitor or contact [mail@vsk.org.au](mailto:mail@vsk.org.au) with any questions you may have.**

# Sue's lasting legacy

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**Remembering Sue Hardiman, super volunteer and beloved Very Special Guardian. For more than twenty years, Sue Hardiman devoted almost every spare minute of her time to volunteering with Very Special Kids.**

She did so because the plight of seriously ill children and their families touched her deeply, and if there was anything she could do to make their lives even a tiny bit better, she wanted to do it — whether that meant giving her time at events, organising community fundraisers or providing support and care for families.

For Sue, giving to those in need came easily, and it brought her great joy to see the comfort her efforts would bring.

She told us that this was why she made the life-changing decision to leave a gift in her Will and become a Very Special Guardian.

The future Sue imagined became a reality when sadly she died in 2021. She is greatly missed, but the comfort she took from becoming a Very Special Guardian is now felt by her loved ones — who know that her legacy lives on, helping to improve the lives of seriously-ill children and create positive memories for their families for generations to come.

**By becoming a Very Special Guardian today, your kindness and generosity will extend beyond your lifetime, just as Sue's has done.**

*"I am a great believer that people should give back and when you make a Will, you leave it to the people who can benefit. I know that my gift will support a family who needs respite, emotional support, counselling and care and that is satisfying to think I can help provide that."*

**Sue Hardiman**  
Volunteer and Very Special Guardian





*“I never want to stop changing children’s lives. And nor will you, if you become a Very Special Guardian today.”*

**Sister Margaret Noone AM,**  
Founder & Patron



## A final word

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**Thank you for taking the time to read this booklet, for learning more about Very Special Kids and Sister Margaret’s vision, and for considering a gift in your Will for Very Special Kids.**

We all want lasting good to come from our time on this earth. To leave something behind that brings care and support to families at the most difficult times is something to be proud of.

If you have made the decision to join us as a Very Special Guardian, I cannot thank you enough. You will

be joining a valued circle of people who will take the baton and ensure Sister Margaret’s hard work and commitment to children and young people with a life-limiting illness can continue.

I would be so grateful if you could also share your intentions with us, so we can have the opportunity to thank you for your gift during your lifetime and keep you informed of the value your legacy will have for years to come.

**Michael Wasley**  
Chief Executive Officer



For more information about  
leaving a gift in your Will,  
please call **1800 888 875**  
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