

NEWS

Edition 3 | 2020

*Lily's
legacy*

“
FROM THE
CEO

It is my hope, that one day we will live in a world where no child is born or diagnosed with a terminal condition.

Until then as CEO of Very Special Kids it's my mission to ensure that every child and their family receives the care and support they need.

Our families face life's most heartbreaking challenges with resilience, strength and an enduring compassion. Our team is humbled to be alongside them through these deeply personal and intimate moments of loss, love and grief.

Which is why we focus on continuous improvement across every aspect of our work.

Every step of our Hospice Rebuild Project will take a 360 degree consultative approach to ensure that it will be able to provide the best care now and into the future.

The new hospice will not only be world-class with state-of-the-art best practice clinical facilities to better support children of every age, size, nationality and functional capability; it will also reflect the community of supporters who will be at the core of making this project possible. Together we will need to raise \$22.5m to ensure no child or family endures this journey alone.

Led by our Capital Campaign Committee and Chairman Andy Penn (CEO of Telstra), consultative discussions and briefings have been held with staff, families, volunteers, local council and neighbours. Each stakeholder was given the opportunity to review plans, raise suggestions and gain further insights into how the new hospice will impact them. We are grateful for the overwhelming support from all those around us who are ensuring this project will come to fruition.

Current architect schematics are being reviewed by each nurse, doctor and carer to ensure that the final design meets not only the needs for each child but also for those who will deliver care. Architects schematics have been updated to consider all feedback put forward and will be submitted to town planning.

Whilst ensuring we focus on the future, we continue to provide 24 hour respite, family support and end of life care across Victoria. This is a very exciting next step; one that will benefit families and children for years to come. Thank you for your ongoing support in helping us reach this point.

Michael Wasley
CEO, Dad and Donor

Bringing help home

As we work towards the rebuild of our new hospice, Very Special Kids remains committed to continuing to provide the best care for families during the transition by assessing alternative channels for delivery of services.

With funding from DHHS we have trialled the delivery of in-home respite and end-of-life care to a selection of our children and families. This pilot objective is to determine whether respite and end of life care can be provided within the home, as one feasible alternative to the way in which we provide hospice care during the hospice rebuild period.

In-home respite and end-of-life care pilot

Summary of pilot to date:

- 15 Very Special Kids families have been selected to participate in the pilot
- Pre-care assessment of family homes for OH&S and operational considerations have been conducted
- Development of a risk assessment and mitigation plan has been created to ensure the utmost safety for all involved
- Staff who will participate in in-home care service (nurses and personal care workers), as well as allied health staff including physio and play therapist have been selected
- Development, review and update of policies and procedures for the delivery of in-home care
- Development of training resources for in-home care staff
- Training of in-home care staff
- Engagement of evaluation consultant to establish evaluation methodology, key metrics and data collection tools
- Discussions with key stakeholders including VPPCP and Complex Care at Royal Children's Hospital
- 7 in-home respite services of care were conducted on single day shifts by experienced, senior nursing staff, in conjunction with a less experienced nurse or carer to test the processes, equipment and documentation
- After each visit:
 - documentation is updated and improved
 - staff and families are surveyed for feedback

The pilot will conduct 30 support sessions of in-home respite trialling night shifts, multiple shifts and split shifts utilising Registered Nurses and carers. If end-of-life care is needed our families will be offered inhome service and care. Ongoing discussions with Victorian Paediatric Palliative Care Program have been positive and we will continue to take a 360-feedback approach with ongoing post visit interviews with families and staff and all other stakeholder at conclusion of pilot. Once the pilot is completed it will be evaluated to determine if this is viable service to offer not only in the transition of our hospice rebuild but also as ongoing services for the families in our care.



Impact of pilot for families and staff

Each family and staff member that participates in the pilot is invited to share their experiences and feedback from the respite session.

Feedback from families about the benefits of receiving in-home care

- The nurses built a genuine rapport with me and my child so that I felt at ease and confident in their capacity to care for my child
- Providing me with a break knowing my child was being well cared for by experienced VSK staff
- Seeing how much my child enjoyed the attention and one on one engagement with the staff
- Not having to pack up and transport my child and equipment to the hospice

“

Our family lives in crisis day to day. Very Special Kids coming and giving respite even for a few hours let our family feel like we're not a family in crisis and stuck in our home for the next few years. And at the same time our child is not missing out on her care.”

– VSK Parent

Feedback from nurses and carers about the benefits of providing in-home care

- Getting to know the child, their care needs and family dynamic in their own environment which helps provide better individualised care for future hospice admissions
- Having time to provide comprehensive nursing care and one on one attention for a child in a way that cannot always be done at the hospice
- Feeling rewarded to assist parents/guardians to have a break and seeing how grateful they were

“

The most significant impact for my child was that she was safe and comfortable at home while she was unwell, while still receiving all the extra attention that she needed and getting chest physio from qualified staff.”

- VSK Parent

Honouring Lily



The Lily Calvert Foundation

After Lily died on 22 July 2017, Priyanka and Will established The Lily Calvert Foundation in honour of their daughter Lily. Priyanka and Will organise and run fundraising events to raise money for the Foundation with the help of family, friends and their broader networks. Many small businesses contribute, including major supporter, Tasmanian catering company Rhubarb Catering; Prahara Pilates Studio Sum of Us and Sofi Spritz.

The Lily Calvert Foundation will be funding a new music therapy-informed program at Very Special Kids, called the Lily Calvert Musical Care Program in honor of Lily and her love for music. The benefits of music and supportive care are seen in our current Very Special Kids Hospice Music Program. The Lily Calvert Musical Care program will now allow all children opportunities for music throughout their stay with us. Through this program, all children in the hospice will have access to music everyday. Previously budget restraints meant that the children only had access to music therapy two days a week.

Will and I were like any first-time parents, we eagerly waited for the birth of our baby girl. We had decorated the nursery and I couldn't wait to hold her in my arms. But at 36 weeks, after a routine sizing scan, we were given the news we never could have imagined. The doctor told us there was a problem with our baby's brain development, and at best, she wouldn't live past 2 years of age.

Nothing can prepare you for being told that your child is going to die. Shock, grief, love, fear, despair, helplessness, and deep sadness. It was completely overwhelming.

Lily was diagnosed with Miller-Dieker syndrome. An extremely rare genetic disease and there are only two cases per year in Australia. We just wanted to make every second count with Lily, we wanted her to be with us at home for as long as possible.

That's when we were connected to Very Special Kids. It was comforting to know we had options and we could get respite and support from Very Special Kids if we needed it. In such an unknown time, knowing where you can turn to for support, means so much.

Lily died when she 10-and-a-half-months young.

In the end, Lily stayed with us the entire time, she died at home in our arms and didn't go to Very Special Kids until the day after she died. Words can't describe this heartbreaking time, the hospice team helped to make things a little easier. They gave us use of a special room and cuddle cot where Lily stayed until it was time for her funeral.

We could stay overnight too or visit her at any time. This was a precious gift, the gift

of some extra time to say goodbye and allowed our family to come and say their goodbyes too.

Since then, we continue to be supported by their family support and counselling services. Very Special Kids role in the health system is vital for families going through the trauma of parenting a terminally-sick child and ultimately losing a child. They provide a calm and caring environment, free-of-charge, for families who already have so many medical expenses and challenges.

Their ongoing bereavement support is also critical in helping families cope with the loss and to manage their mental health in the days, and years, after experiencing child loss. It is so comforting for me to know I have a counsellor, who specialises in grief and child loss, whenever I need it.

— Priyanka Saha



'Music therapy sessions were our favourite time of every week. Lily just lit up to the music, it really helped her engage with us. Music therapy has the power to tap into all areas of the brain and it was an amazing communication and engagement tool for our whole family. We really wanted to be able to share that joy with other families'

— Priyanka and Will – Lily's Parents

The funding will enable our music program to grow, by providing resources and training to staff and volunteers to share music with children and families in the hospice. We anticipate that the experiences of children in the hospice will be enhanced through daily opportunities for music and supportive musical interactions



Very Special Kids Volunteer Training

In 2019, 89 individuals completed a nine week training course to be a qualified Very Special Kids Family Volunteer.

This training course is designed to equip individuals with the skills and knowledge needed to provide support for families who have a child with a life-threatening condition. The program supports everyone involved, from the parents, siblings, to the very special child and also the volunteer.

The training focuses on

- communication and listening skills
- loss and grief
- interacting with children
- how Very special Kids helps families access the supports programs and services that are available to them

All content is reviewed annually by the Family Support Team to ensure that the training continues to evolve with the needs of the children and families we care for. Whilst also empowering the volunteers to feel comfortable in either the home, hospice or hospital environment. The training sessions are run by qualified Family Support Practitioners with special guest from families, children and other volunteers to provide first - hand stories and experiences with potential new volunteers. Each training class is capped to ensure that lessons are interactive engaging and allow for the team to truly get to know each potential volunteer to determine their potential for placement with families we care for.

Our volunteers are a crucial part of the Very Special Kids team provide invaluable

service to families with children who have a life-threatening condition.

Upon successful completion of the course volunteers can choose to support families in the home, hospice or at the hospital.

In-home Volunteers

Home volunteers assist families by offering practical and emotional support to family members. A family may request a volunteer to spend time with the registered Very Special Kids child, their siblings or with the parents.

A careful matching process aims to ensure that the volunteer placed with a family is most suited to fulfilling the family's needs. Volunteers receive ongoing support and supervision from a member of the Family Support Team, and families who have a volunteer placed in their home are required to have ongoing contact with a Family Support Practitioner to monitor the placement.

Hospital Volunteers

At The Royal Children's Hospital and Monash Children's Hospital, a team of trained volunteers is rostered to visit children registered with Very Special Kids. Hospital volunteers visit on request of the families and may spend time with the unwell child, siblings or parents. Volunteers can also spend time with the unwell child while the family have a break from the hospital.

Very Special Kids Family Services Volunteer

Very Special Kids Hospice provides respite and end-of-life care to children registered with Very Special Kids. The role of hospice volunteers is crucial in supporting children, their families and the hospice staff and they may spend time with children playing, taking them for a walk or supporting the hospice staff.

Very Special Kids provides a range of services for families, including trained volunteer support. Trained volunteers aim to support families with the practical and emotional demands of caring for a child with a life-threatening condition, as well as families who would like support after the death of their child.

Trained Very Special Kids volunteers support families with the practical and emotional demands of caring for their child.

To learn more about becoming a family or friends volunteer please visit vsk.org.au

Meet our Volunteers



Alan Hall,
12 years volunteering with VSK

My life has provided me with many blessings and times of great joy and happiness.

In a hackneyed phase I jumped at the opportunity to give something back to community.

Very Special Kids not only cares for children with life threatening conditions but it gives their whole family so much. I wanted to be part of that.

I am 81 years old. My professional work was banking, investments and superannuation. I retired in 2007. My working life was in service industries and learning to serve people was a skill that has helped me in my volunteering experiences. People related skills are essential in any role I undertake at VSK and my working life provided the opportunity to develop these skills.

As a trained Family Support Volunteer, I have participated in family home visitations engaging with all the family members. In school holidays I participate in Sibling Day activities. I also work at the annual Family Christmas Party each year.

The volunteer training programs are outstanding. They not only prepare volunteers for effective service, they contribute to worthwhile personal growth and development.

The volunteering opportunities at VSK are many and varied, providing a wide range of duties from. The team are professional, welcoming, friendly, warm and inclusive. A wonderful working atmosphere has been created in its charming heritage listed property for the Families, staff and volunteer army.



Lucy Nicholson,
5 years volunteering with VSK

Very Special Kids is an organisation that has deep connections with the people it helps. It's a roll of the dice as to whether life puts you in the position of needing Very Special Kids' services, it's very rewarding to be able to help those families that do.

I'm a Friends volunteer which focusses on the fundraising events that support Very Special Kids. Though it may conjure images of rattling tins or sausage sizzles, this role has brought me so many new experiences. I learnt how to tow the giant pig trailers, have been on regional trails across Victoria, painted walls, put on the pig suit, stuffed envelopes, visited a school, tracked kilometres for the 24hr Treadmill challenge... always alongside incredible people. The program is unique and enables you to choose your own adventure!

Before volunteering with Very Special Kids I was not as confident as I am now and dreaded public speaking. However, after spending some time talking with people in the community through volunteering VSK has helped build my confidence.

My grandfather joined the VSK committee in the late 1990s barely 10 years after it had been established. He loved working with founder Sister Margaret Noone in those early years, helping to secure VSK's future. Today, my sisters and I all volunteer with Very Special Kids - I like to think of being actively involved with VSK as carrying on an important family tradition.



Margaret Jackson,
10 years volunteering with VSK

I am so lucky!!! I have a husband who supports me and two wonderful sons who work incredibly hard to achieve their goals. When I look at all the things our family has achieved I feel blessed. It was for this reason I decided to become a volunteer. It was time to give back.

Very Special Kids had so many opportunities, in so many different areas I could become involved with, maintenance, fundraising, family support, hospital visits, sibling days and the hospice just to list a few.

I have dabbled in so many areas but my true love is the Very Special Kids Hospice. Each week is different, I get to let my inner child out and there is nothing better than hearing a child laugh.

The children and the staff are wonderful, it would be a rare day when I don't leave feeling inspired or joyful. The love and the support from the girls makes my heart sing.

Anyone who walks through the door has something to offer and I have been privileged to learn from not only the staff, other volunteers but most of all from the children.

Volunteering helps to give my life perspective, the people I work with make me feel respected, loved, and valued. The children make my heart sing and remind me that I should not let life become too serious.

How to get involved

There are many ways that you can support Very Special Kids so we can continue to provide our invaluable services to families free-of-charge.



Make a regular tax deductible gift

Monthly, quarterly or yearly



Collect donations in a piggy bank

Work, school or home



Leave a gift in your will

Ensure your legacy lives on



Ask for donations in lieu of gifts

Birthday, wedding, bar/bat mitzvah or any other celebration



Volunteer

In the hospice, hospitals, with families or help with fundraising and administration as a Friends Volunteer



Develop a corporate partnership

Sponsorship, cause-related marketing, workplace giving, volunteering or in-kind support



Organise your own fundraising event

A fun run, trivia night, food and wine function, movie night, concert or fashion show



Attend or support one of our fundraising events

Piggy Bank Appeal, 24 Hour Treadmill Challenge, Footy Fever Debate, Golf Day, Ladies Lunch, Annual Fair and Fashion Sale



Make a donation

- @ www.vsk.org.au
- ✉ Mail a cheque or money order payable to **Very Special Kids**, 321 Glenferrie Road, Malvern, Victoria, 3144.
- ☎ Call 03 9804 6222